A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease:
The collective reality from onset to end of life and beyond.

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Diploma Professional Counselling
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A thesis submitted to the Faculty of Arts, Business, and Law

University of the Sunshine Coast
Queensland, Australia

In fulfilment of the requirements for the degree of Doctor of Philosophy

March 31, 2018
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Judith R Boyland

For my mother, Sheila Veronica Ryan-McLachlan (1909-1987),

Who bequeathed me with the task,

“Take care of ‘Snookie’: he’s getting a little forgetful”.

For my father, Leslie Joseph McLachlan (1905-1992),

Who allowed me the honour to journey with him:

Through the cloud of our unknowing.

The collective reality from onset to end of life and beyond.  

Judith R Boyland.
we must let go of the life we have so as to accept the one that is waiting for us

Declaration of originality

I, Judith Rose Mclachlan-Boyland, declare that this thesis is my own account of research undertaken by me and has been wholly completed during candidature. I also declare that it does not contain any material that has been submitted by me in any form for a University degree or other similar qualification at this or other higher education institution.

Information derived from the published and unpublished work of others has been cited and acknowledged throughout the text. A list of references is tabled in the Reference List.

I certify that any help received in preparing this thesis, and all sources used, have been acknowledged.

The Australian Government’s Research Training Program Scholarship is also acknowledged in the list of acknowledgments.

Judith R Boyland

March 31, 2018

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Acknowledgements

I most sincerely thank Dr Ann Moir-Bussy, Adjunct Senior Lecturer and former Head of the Department of Counselling at University of Sunshine Coast, Queensland. Ann, as my principal supervisor, you provided insight, encouragement, and guidance. You also gave to me of your patience, friendship, and support as you kept me going when the going got tough.

I thank my co-supervisors, Dr Peter Innes and Associate Professor, Dr Mathew Summers. Peter, your knowledge of all things philosophy is boundless. Your feedback has been challenging and the sharing of your wisdom is highly valued. Mathew, I am most appreciative of your sharing with me of your knowledge and experience relating to Alzheimer’s and dementia.

Thank you sincerely to the amazing men, women, and children who, so willingly, welcomed me into their world and entrusted me with their stories to hold and to give away so that the lives of others might be enriched. Without my story tellers, there would be no narrative and no thesis. You are the people who own the knowledge and the wisdom. Each of you is an inspiration. Each of you breathes life into the words, “unconditional love”.

To those who sought out participants for referral, my most sincere thanks. Without your time, support, and connections, I would never have found such a wonderful and diverse group of story tellers to share their personal narratives about the world of caregiving, as they know it to be.

I acknowledge the Australian Government’s Research Training Program Scholarship in enabling me to fulfil a dream.

I acknowledge University of Sunshine Coast Faculty of Arts Business and Law Higher Degrees by Research Funding Scheme. The support of this scheme is greatly appreciated.

I acknowledge Jane Todd for professional copy editing and proofreading advice as covered in the *Australian Standards for Editing Practice*, Standards D and E. Jane, thank you for your guidance and for answering my many “how to” questions.
Library, HDR, and Faculty personnel – particularly Sue Svensen, Elizabeth Feeney, Sally Routledge, Francesca Shepard, and Dr Marcus Bussey: Thank you for your support and for always having that magic touch in being able to source the exact material I was seeking or to assist in problem solving around administrative procedures.

Thank you to my parents for teaching me the importance of caring for the disempowered and instilling in me a passion for working for the emancipation of the oppressed. I thank my mother for entrusting to me the care of my father. I thank my father for allowing me to share his journey through the Alzheimer’s maze.

Des, Megan, and Jason, my thanks for holding me up as, together, we traversed our caregiving trajectory. Those were the darkest of hours as we journeyed through transitions and witnessed the degenerative transformation of our “Special Someone” – my father, your father-in-law, and your grandfather. Jason, you were my rock and my soft place to fall. As a young man, you carried me with the wisdom and strength of ages as we investigated formal care facilities and hospitals whose specialisation was palliative care. An additional and current “Thank you” for being my sounding-board and my off-site keeper of “document-in-progress”: as we moved through multiple edits.

My precious grandchildren: Angelique and Lachlan, your Arma says “Thank You” for your interest and words of encouragement all through this journey. Rose, your Mumma Jude says “Thank You” for your gentle push at times when I wanted to give up and for your search for snippets of wisdom to head my chapters. Maximillian, Judith says “Thank You” for the hours of company, as you lay on the floor beside me, doing your “research”. I am truly blessed to have four very special grandchildren to share my life and keep me grounded.

My daughter-in-law, Claire, my thanks for translating Greek definitions and for allowing me the honour of incorporating a photograph of Παππού Βαγγέλη (Pappou Vangelis) into my figure that illustrates Caregiving: A process of dynamic transformation.

I thank Dr Philip Armstrong PhD for his mentoring and professional supervision across these last eighteen+ years. Philip, without your on-going professional support, encouragement, challenges, and guidance, this would all be but an elusive dream.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: iv

My friends, Shirley Graham and Wendy Watego-Ittensohn: my thanks for sharing your incredible illustrative designs for inclusion within the text – Shirley for Warped and twisted (image used to illustrate reconceptualisation of the lived reality) and Wendy for Knowing (image used in figure that illustrates Caregiving: A process of dynamic transformation). Your symbolic images breathe life into static descriptions of concepts.

Patrick Coughlan, my thanks and appreciation for sharing your knowledge and wisdom with the translation of Virgil and for being there when I was searching for just that right word.

My friends since school days, Veronica Cruise-Coughlan and Maree Scott-Ganley, my thanks for allowing me to vent, for reading passages of script, and for walking with me. Maree, we have both waited many years to come to this stage in our academic pursuits. May we both know the sweet sound of success – just a whisper away for each of us.

Dr Susan Scott, thank you for your guidance with incorporation of medical terminology.

Janelle Devery and Brendan Farthing: my thanks for your computing savvy and for your help when the technology gremlins of processing blocked my moving forward.

My amazing supervisees and colleagues, your encouragement is so appreciated.

Damien and Rima Jones: my thanks for reading chapters and offering opinions.

Miriam Elkin, thank you. My fingers would not have survived the cold winter mornings at the keyboard without my hand spun and lovingly knitted peep-tip gloves.

Last, and far from least, my thanks go to my husband, Des. You encouraged me to pursue my dream and during these four years, you have sustained our home. You have fed me and brought me water and coffee from dawn into the depths of the night. Without your support, this journey would all be beyond the realm of possibility.

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Abstract

Alzheimer’s is a ubiquitous disease. Referred to in terms of “a global epidemic”, the current estimate of people living with Alzheimer’s disease is 32.76 million. In Australia, alone, there is a current estimate of 289,177 care receivers and the co-related projection is that by 2025 there will be 255,800 informal caregivers caring for loved ones with the condition. This thesis focuses on investigating the question, What is the holistic and collective reality of caregivers’ conceptions and understandings about the impact of caring for a loved one who has Alzheimer’s disease when the trajectory of caregiving spans from onset to end-of-life and beyond?

Under the overarching umbrella of a qualitative paradigm, design, data collection, and analysis strategies were implemented within a framework of social constructivism. A hybrid methodology was believed to be the most effective tool to achieve the aim and to answer the research question.

Thirty-four participants, aged between 10 years and 90 years, shared their stories. Numbers included 23 primary caregivers or caregiving partnerships, four significant support persons, and five persons touched by vicarious connection. At the time of dialogue, primary caregivers and primary co-caregiving teams had collectively given 201 years of care, underpinned by unconditional love.

Participants were initially sourced by purposive selection through referral by a third party. Subsequently, some participants self-referred. Stories were gathered till the thematic data contained in the data set reached saturation. The demographic catchment spans the south-east corner of Queensland – from Sunshine Coast in the north to Gold Coast in the south; the islands of Moreton Bay in the east to Toowoomba in the west.

Using a process termed as bricolage, data extracts from individual stories were woven across the warp of a methodological hybrid; producing a broad and holistic conceptual landscape of lived experience that features seven themes – four issuing from the reconceptualisation of experiential reality and three from the synthesised reframing of reflection. The resulting collective narrative profiles the impact when caring for a loved one who has Alzheimer’s and identifies that impact as a process of dynamic transformation.
Discussion focuses on how repositioning previously conceived perceptions of the intrapersonal relationship with *Self* and the interpersonal relationships shared with *Other* embody that transforming process and lead to identity shifts within the imaginal space that Jones and Hermans (2011) define as the landscape of the mind. Implications from this study are futures oriented and signal a call for action. The focus of that action is on caregivers and caregiver need in a multifaceted arena that embraces community awareness, modification to training packages for professional practitioners, service delivery, formal care provision, and enlightened awareness in the professional practice of counselling clinicians, psychotherapists, and professional supervisors. Potential for in-futures research opportunity is also considered.

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Glossary of terms

**Acute stress reaction:** A transient disorder that develops without any other apparent mental disorder in response to exceptional physical and mental stress – usually subsides within hours or days. Individual vulnerability and coping capacity play a role in the occurrence and severity of acute stress reactions. Symptoms show a typically mixed and changing picture and include an initial state of “daze” with some constriction of the field of consciousness and narrowing of attention, inability to comprehend stimuli, and disorientation. This state may be followed either by further withdrawal (to the extent of a dissociative stupor), or by agitation and over-activity (flight reaction). Autonomic signs of panic anxiety are commonly present (for example, abnormally rapid heart rate, sweating, flushing). Symptoms usually appear within minutes of the impact of the stressful stimulus or event, and disappear within two to three days; often within hours. Partial or complete amnesia may be present (American Psychiatric Association, 2013).

**Alzheimer’s disease:** A progressive degenerative disease, commencing with mild and relatively circumscribed deficits that gradually worsen to become a severe dementia with widespread and marked impairments to cognitive, social, and behavioural functioning. The speed of progression of impairment is variable from individual to individual, with death occurring between two and 20 years post-onset, on average within 10 years (Summers, 2014). There is a possibility that the ravages of early onset Alzheimer’s disease may be subtly attacking the brain up to 20 years before a pattern of behavioural change is observed (Gupta, 2015).

**Analytic bracketing:** Moving from one train of thought to another while setting aside one reality for another (Holstein & Gubrium, 2005). The process is about attempting to remove biases while seeking to provide a channel of interpretation that is free from impeding and interfering preconceptions (Braud, 1998).

**Anti-foundational:** Denotes a refusal to adopt any permanent standard by which truth can be known (Lincoln & Guba, 2000).

**Axiology:** A way of acting and doing. As the philosophical study of value, it is underpinned by a transitional knowing. It has an ethical dimension and an
aesthetic dimension. As a collective term for ethics (what I “should” do or why I do what I do), it has come to be used to designate a values differentiation between right and wrong, and good and bad. From an aesthetic property perspective (how I actually act and what I actually do), it is about attitude, judgement, and defining experience with no reference to right and wrong, or good and bad (Kubát, 1958; Lewis, 1946/1950/1962; Wittgenstein, 1922/1955/1999/2017).

**Biological processes:** Processes vital for a living organism to live. They are made up of chemical reactions or events that result in chemical transformation: for example, “metabolism” – the process by which some substances are broken down to yield energy for the efficient function of vital organs while other substances are synthesised to sustain life. Another example of a biological process is “homeostasis” – the ability of the body or a cell to seek and maintain a condition of equilibrium or stability of vital organ function when dealing with external changes (Humpath.com - Human pathology, 2016).

**Bricolage:** Weaving multiple images and multiple threads of information into a collective whole; creating the profile of a broad conceptual landscape (Denzin & Lincoln, 2005).

**Bricoleur:** One who weaves multiple single images and multiple single threads of information into a collective whole so as to create the profile of a broad conceptual landscape (Denzin & Lincoln, 2005).

**Caritas:** Service administered with care, compassion, respect, and loving kindness: the model of caregiving proposed by Watson (1979/2008).

**Choice/Control Theory:** Built on the principles of Perceptual Control Theory (PCT) developed by Powers (1973/2005, 1998), Choice/Control Theory proposes that the human brain functions as a control system with the purpose of seeking needs gratification, determined by a balancing of perceptions. The underlying premise is that the human being pursues needs gratification through behaviour. In turn, behaviour has five functional goals of needs gratification. First and foremost, there is an innate biological need for survival. When survival is not at risk, there are four psychological needs that we strive to gratify: (1) the need for love,
belonging, and connection, (2) the need to know, learn, create, and have fun or experience pleasure, (3) the need for freedom and autonomy, (4) the need for achievement, purpose, and meaning. When survival and psychological needs are not at risk, the human condition seeks gratification of higher order need: that is, the spiritual need for inner peace and harmony (Glasser, 1984, 1989, 1999).

**Collective narrative:** A story that brings together multiple individual stories and creates a new whole by interweaving one with the other (Denzin & Lincoln, 2011).

**Comorbidity:** The presence of one or more diseases or disorders co-occurring with a primary disease or disorder: for example, Alzheimer’s disease + Parkinson’s disease + a vascular disorder such as heart disease + diabetes (Summers, 2015).

**Conception:** The formation and development of an idea (Bernard, 1989).

**Constructivist methodology:** A methodology that elucidates local rather than universal meanings and practices; focusses on provisional rather than essential patterns of meaning construction; considers knowledge to be the production of social and personal processes of making meaning; and is more concerned with the pragmatic utility of validity of application rather than with validity per se (Neimeyer & Levitt, 2001).

**Crystalline validity:** A non-authoritative or anti-foundational truth or validity. Like a metaphoric solid rock, it can be turned many ways; reflecting and refracting light through which can be seen “chunks” of truth, feeling, and connection (Lincoln & Guba, 2000; Richardson, 1997).

**Dementia:** A group of degenerative disorders that produce a condition of cognitive decline and functional impairment. Dementia can be irreversible, static, or reversible. However, the term *clinical dementia* is most commonly reserved for progressive and irreversible forms of decline associated with neurodegeneration of brain tissue (Summers, 2014). Most dementias are mixed dementias and it is estimated that between 50% and 80% have an Alzheimer’s related component. Estimates differ according to the source as referenced within the body of the text.
Dialectical process: A dialogue, conversation, or discussion between two persons for the purpose of creating new syntheses as the psychic system of one person enters into reciprocal reaction with the psychic system of another (Jung, 1935/1985).

Dialogic interchange: Creating an “interpersonal oneness” through dialogue where the focus is reflection on experience in the process of defining reality (Badenoch, 2011; Marcus & Fischer, 1986).

Dialogic relationship: Coming together with another in a spirit of understanding, recognition, and acceptance of the other’s subjectivity while also valuing the growth that emerges from this relationship (Yontef & Schulz, 2013).

Dialogical self/Dialogical Self Theory (DST): A dynamic multiplicity of I-positions in the society of the mind; intrinsically bound to particular positions in time and space, positioning and repositioning, and interacting like characters in a story (Hermans, 2012).

DSM: Diagnostic and Statistical Manual of Mental Disorders (DSM) that codifies psychiatric disorders (American Psychiatric Association, 2013).

Emotional anorexia: Reference to the social dynamic associated with processes of interaction and engagement that are not empathic, not respectful, and not sensitive (Fineman, 1993). The presence or absence of “emotional anorexia” is of particular significance in situations defined by power inequality such as doctor with patient, therapist with client, or service provider with consumer.

Emotional labour: The empathic component of organisational culture that underpins engagement of personnel with the consumer (Hochschild, 1983/2003).

Empirical data: Findings that are based on, concerned with, or verifiable by observation or experience. Tools for gathering empirical data include personal experience, life story, introspection, interview, interaction, and observation (Liamputtong & Serry, 2013).
Empirical Self: The position where I meets Me (James, 1890). The self that is known to the self or the I that is known to me through conscious experience and that consists of the social and the spiritual dimensions of Self (Nugent, 2013).

Epidemiology: The study of the distribution and determinants of health-related states or events and includes the incidence, distribution, and possible control of diseases and other factors relating to health (World Health Organisation, 2017).

Epiphanic knowing: A flash of recognition in which something is seen in a new light (Nordquist, 2014).

Epistemology: About a way of knowing. Epistemology is a branch of philosophy that investigates the origin, nature, methods, and limits of human knowledge. It asks the question, “How do we know what we know?” (Dictionary.com, n.d.).

Essential variables: Term coined by Ashby (1952) to refer to vital functions such as blood pressure, heart rate, body temperature, triglyceride levels, cortisol and dopamine levels.

Formal care: Care provided by person/persons who is/are paid for service (Lai, 2003).

Formal caregiver: One who is paid to care for another; including but not exclusive to staff in respite centres, nursing homes, or hospice centres (Lai, 2003).

Heuristic approach: Inquiry that is aimed at discovering or finding out. Within this context, the heuristic element of the inquiry honours the internal search through which both participant and researcher discover the nature and meaning of the experience and adopt and adapt methods and procedures that best give voice to investigation and analysis of data (Moustakas, 1990).

Hybrid methodology: The intertwining of different methodological approaches incorporating the strengths of each approach (Denzin & Lincoln, 2005).

Informal care: Voluntary caregiving, usually provided by family or friend (Lai, 2003).

Informal caregiver: One who cares for another in a voluntary, unpaid capacity: usually a family member or a friend (Lai, 2003).
Intelligentsia Alzheimer’s Dementia: A diagnosis of advanced Alzheimer’s disease: term used by a specialist geriatrician.

Intrinsic variables: Negative feedback control system relating to the essential nature of function of vital organs and measured by vital signs; such as heart rate, blood pressure, body temperature, and triglyceride levels. Term introduced by Powers (1973/2005).

Intuitive approach: Relating to the direct perception of knowledge (Anderson, 2011): also positioned as an irrational or unconscious function, in the sense that intuitive insights often elude attempts to understand their character or their origin (Jung, 1933/2001).

Major depressive disorder: Depressed mood must be present for most of the day, in addition to being present nearly every day during a two-week period while representing a change from previous functioning as indicated by either subjective report (e.g., feels sad, empty, hopeless) or observation (e.g., appears tearful). Sadness may be denied at first but may be elicited through interview or inferred from facial expression and demeanour. Fatigue and sleep disturbance are present in a high proportion of cases. Symptoms may also include unexplained weight change and suicidal ideation. Psychomotor disturbances (either agitation or retardation) are much less common but are indicative of greater overall severity, as is the presence of delusional or near-delusional guilt. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning and the episode is not attributable to the physiological effects of a substance or to another medical condition (American Psychiatric Association, 2013).

Multivoicedness: Multiple voices contribute different perspectives relating to a subject with each voice presenting a unique and personal snapshot of conception. Collectively, many verbal snapshots create a collective landscape. Multivoicedness also incorporates the bringing together of the multiple voices within the Self (Jones & Hermans, 2011).
Neural pathway: A bundle of neurons that make connection between relatively distant areas of the brain or nervous system. Collectively, neural pathways are known as white matter (Alzheimer’s Association, 2015a).

Neuron: A nerve cell that is the basic building block of the nervous system. Neurons are specialised to transmit information throughout the body and are responsible for communicating information in both chemical and electrical forms. Sensory neurons carry information from the sensory receptor cells throughout the body to the brain. Motor neurons transmit information from the brain to the muscles of the body. Interneurons are responsible for communicating information between different neurons in the body (Cherry, 2017). Electrical transmissions occur via specialised connections called synapses.

Obsessive-compulsive disorder (OCD): A condition characterised by the presence of obsessions and/or compulsions. Obsessions are recurrent and persistent thoughts, urges, or images that are experienced as intrusive and unwanted. Compulsions are repetitive behaviours or mental acts that one feels driven to perform in response to an obsession or according to rules that must be applied rigidly. Some obsessive-compulsive and related disorders are characterised by preoccupations and by repetitive behaviours or mental acts in response to the preoccupations. Others are characterised by recurrent body-focused repetitive behaviours: for example, hair pulling, skin picking, tapping, pacing, banging, etc. (American Psychiatric Association, 2013).

OK: “OKness” is the sense of knowing that I am an acceptable human being and that I have a right to live and to have my needs met. You, also, are an acceptable human being and you have a right to live and to have your needs met. One’s sense of OKness is akin to one’s sense of worth (Berne, 1966). The quest for a state of OKness correlates with the basic spiritual need for inner peace and harmony.

Ontology: Has to do with a way of “Being”, “Being-there”, “Being-in-the-world”, or “Being-present-in-the-world”. It is about transparency in interpreting that domain of Being in which the area of subject matter is itself confined (Heidegger, 1927/1962): for example, the impact of caring for a loved one who has Alzheimer’s.
**Pathogenesis/Pathogenic processes:** Pathogenic processes are biological mechanisms that lead to a diseased state. They include development of a disease and the chain of events leading to the development of that disease. The term can also describe the origin of a disease and whether it is acute, chronic, or recurrent. In the case of a condition such as Alzheimer’s disease, it defines the stages of functional degeneration. The term derives from Greek origin, πάθος (pathos meaning "disease") and γένεσις (genesis meaning "creation") (Medical dictionary, n.d.).

**Perception:** An immediate or instinctive recognition that leads to the gaining of knowledge or information (Bernard, 1989).

**Perceptual Control Theory (PCT):** A theory of behaviour, the basic idea of which is that people (and other organisms) act on their surroundings so as to manager and control the effects that the happenings within the environment are having on them. What is controlled is the perception of those variables and according to the catchphrase of the field, behaviour is the control of perception (Powers, 1973/2005, 1998).

**Polyvagal response:** All about “fight”, “flight”, “freeze”, and “faint” physiological responses to stress and trauma. Polyvagal theory specifies two functional and evolutionary branches of the vagus nerve: the more primitive elicits immobilisation behaviours (e.g., feigning death, or freezing) whereas the more evolved is linked to social communication and self-soothing behaviours. Functions follow a hierarchy of evolution, whereby the most primitive systems are activated only when the more evolved functions fail. Neural pathways regulate the non-conscious autonomic state and the conscious expression of emotional and social behaviour (Porges, 2014, 2015).

**Post-traumatic stress:** The essential feature is development of characteristic symptoms following exposure to or witnessing traumatic events. Fear-based emotional, re-experiencing, and behavioural symptoms may present. Mood states and negative cognitions may also be distressing. Symptoms may include flashbacks, nightmares, severe anxiety, and uncontrollable thoughts about the event. When post-traumatic stress is on-going, it could develop into post-traumatic stress disorder (PTSD) (American Psychiatric Association, 2013; Mayo Clinic, 2017).
Primary caregiver: The person who takes responsibility for someone who cannot care for themselves. It may be a family member, a trained professional, a friend, or another individual. Depending on culture, tradition, and filial expectation, there may be various members of the family engaged in care (Lai, 2003).

Qualitative paradigm: A field of inquiry that is about contextualising meaning from people’s beliefs and practices, actioning the imagination and looking for patterns of ideas or themes across a data set (Denzin & Lincoln, 2011; Gergen, 1999/2009; Liamputtong & Serry, 2013).

Secondary trauma: Emotional duress that results when one hears about or witnesses the traumatic experiences of another. It is often linked with care related roles and is also known as “compassion fatigue” or “vicarious traumatisation” (Wyder & Bland, 2014).

Sense of worthiness: A coined term referring to a self-perceived measure of one’s worth or the opinion of Self as an expression of worthiness.

Spiritual identity/Spiritual Self: The personal measure of “OKness” (Berne 1966) that is defined by one’s core beliefs and values and which, in turn, defines the essence of a sense of Self that addresses the ultimate questions about the nature, purpose, and meaning of life.

Sundowners/Sundowing behaviours: A group of symptoms that occur at a specific time of the day, usually late afternoon towards sundown. Sundowning can elicit a variety of behaviours such as distress, confusion, anxiety, aggression, ignoring directions, pacing, and/or wandering (Dementia Australia, n.d.).

Synapses: Tiny gaps between brain cells where the tips almost touch so as to transmit electronic signals passing between neurons (Alzheimer’s Association, 2015a).

The relational Self/Self in relationship: Knowledge about the Self is linked with knowledge about significant others and each linkage embodies a Self-Other relationship (Anderson & Chen, 2002; Hermans, 2004/2016). There is also the dimension of intra-relatedness between the many I positions and images that one has of Self (Hermans, 2012).
Transpersonal approach: The objectives of transpersonal inquiry are identified as including elements of wisdom and knowledge with a focus on transformation as well as information. There is an intertwining of the minds of story teller and researcher creating an interpersonal oneness. What happens and what is learned from one story is fed by other stories, with every story influencing and being influenced by all other stories (Badenoch, 2011; Braud & Anderson, 1998).

Triangulation: Reference in qualitative research to the use of multiple approaches to develop a comprehensive understanding of the research subject and to test validity through the convergence of information from different sources (Denzin & Lincoln, 2005).

Vicarious connection: One step removed from the direct impact of primary caregiving for a loved one who has Alzheimer’s: for example, the relationship with the primary caregiver could be that of spouse, partner, child, step-child, grandchild, sibling, other member of the caregiver’s extended family, or a close friend. Impact on the primary caregiver plays a significant role in determining vicarious impact. The impact on those who are one step removed also has a reciprocal, compounding, and indirect influence on the direct impact of caregiving as experienced by the primary caregiver. This is an example of a “ripple effect”.

Wayi: In Jandai Aboriginal languages, Wayi (pronounced “way-ya”) means “to let go” and refers to the sacred journey and the letting go of all bodily attachments – physical and emotional. It is the beginning of the journey of re-entering into the spiritual world from which we came (Ephesea).

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# TABLE OF CONTENTS

Declaration of originality ......................................................................................................................................... i
Acknowledgements ......................................................................................................................................................... ii
Abstract ........................................................................................................................................................................... iii
Glossary of terms ........................................................................................................................................................... v

## CHAPTER ONE – CONTEXT ........................................................................................................................................ 1

1.1 Introduction to Context ............................................................................................................................................. 1
   1.1.1 – Aim ..................................................................................................................................................................... 1
   1.1.2 – Relevance .......................................................................................................................................................... 2
   1.1.3 – Research Question ......................................................................................................................................... 3
   1.1.4 – Motivation ........................................................................................................................................................ 3
1.2 Structure ..................................................................................................................................................................... 5
1.3 Professional Journey .................................................................................................................................................. 8
1.4 A Personal Journey .................................................................................................................................................... 9
1.5 The Research Journey ............................................................................................................................................... 16
1.6 A Project Under Construction .................................................................................................................................. 18
1.7 The Dialog .................................................................................................................................................................. 18
1.8 About Alzheimer’s and Dementia ................................................................................................................................ 20
   1.8.1 – Alzheimer’s disease: What is it? .......................................................................................................................... 21
   1.8.2 – Alzheimer’s disease: Where does it all begin? ..................................................................................................... 24
   1.8.3 – From Alzheimer’s to dementia .......................................................................................................................... 25
   1.8.4 – Alzheimer’s disease and dementia: Issues of diagnosis .................................................................................. 28
1.9 Incidence and Prevalence of Alzheimer’s Disease ..................................................................................................... 32
   1.9.1 – Incidence and prevalence of Alzheimer’s disease: A global perspective ......................................................... 34
   1.9.2 – Incidence and prevalence of Alzheimer’s disease: A futures projection ......................................................... 37
1.10 Cultural Context of Care and Facility of Care Provision ............................................................................................ 40
1.11 Conclusion ................................................................................................................................................................. 43

## CHAPTER TWO – LITERATURE REVIEW ............................................................................................................. 44

2.1 Introduction to Literature Review ............................................................................................................................ 44
2.2 Living with Alzheimer’s/Alzheimer’s Dementia: Transitioning .................................................................................. 45
2.3 Transitioning to the Role of Caregiver ....................................................................................................................... 48
2.4 Transitional Change ....................................................................................................................................................... 51
2.5 Aspects of Impact: Stress Response .......................................................................................................................... 53
2.6 Aspects of Impact: Loss and Grieving ....................................................................................................................... 56
2.7 The Ripple Effect ........................................................................................................................................................ 57
2.8 Support ........................................................................................................................................................................ 59
2.9 Barriers to Support ...................................................................................................................................................... 60
2.10 Coping Strategies ....................................................................................................................................................... 62
2.11 Coping with Abusive Behaviour ............................................................................................................................ 66
2.12 Maintaining Dignity in the Midst of Chaos ............................................................................................................... 67
2.13 When it is Time ........................................................................................................................................................ 69
2.14 End of Life ................................................................................................................................................................ 72
2.15 Conclusion ................................................................................................................................................................. 75

## CHAPTER THREE – METHOD AND METHODOLOGY ....................................................................................... 76

3.1 Introduction to Method and Methodology ................................................................................................................. 76
3.2 A Qualitative Paradigm ............................................................................................................................................... 77
   3.2.1 – Design strategies ................................................................................................................................................. 79
   3.2.2 – Data collection and fieldwork strategies ......................................................................................................... 80
   3.2.3 – Analysis strategies .............................................................................................................................................. 80
3.3 Social Constructivism .................................................................................................................................................. 80
3.4 Participant Sampling .................................................................................................................................................. 86
CHAPTER FOUR – PARTICIPANT PROFILES IN CONTEXT .................115
4.1 Introduction to Participant Profiles in Context ...........................................115
4.2 Research Participants: As a Collective .........................................................115
4.3 The Storytellers ..........................................................................................117
  4.3.1 – Aemiel ........................................................................................................117
  4.3.2 – Aemelia .....................................................................................................118
  4.3.3 – Alex ...........................................................................................................119
  4.3.4 – Alice .........................................................................................................119
  4.3.5 – Aliena .......................................................................................................120
  4.3.6 – Angelica, Rosaline, Olivia, and Nym ......................................................121
  4.3.7 – Antony .....................................................................................................122
  4.3.8 – Audrey .....................................................................................................123
  4.3.9 – Edward, Emily, and Iach .......................................................................124
  4.3.10 – Elan .........................................................................................................125
  4.3.11 – Eleanor ..................................................................................................126
  4.3.12 – Elise .........................................................................................................127
  4.3.13 – Elizabeth ...............................................................................................127
  4.3.14 – Emilia ......................................................................................................128
  4.3.15 – Emma .....................................................................................................130
  4.3.16 – Ephesia ..................................................................................................130
  4.3.17 – Hal ..........................................................................................................131
  4.3.18 – Iris ..........................................................................................................132
  4.3.19 – Isabella .................................................................................................133
  4.3.20 – Jason and Megan .................................................................................134
  4.3.21 – Lavinia ..................................................................................................135
  4.3.22 – Nerissa ..................................................................................................136
  4.3.23 – Richard ..................................................................................................137
  4.3.24 – Rosalind ................................................................................................138
  4.3.25 – Rousillon and Lafe ..............................................................................139
  4.3.26 – Vince ......................................................................................................140
  4.3.27 – Yori .........................................................................................................141
4.4 Conclusion .....................................................................................................142

CHAPTER FIVE – FINDINGS: PART ONE ......................................................143
5.1 Introduction to the Collective Narrative ......................................................143
5.2 As Time Goes By: Transitions and the Trajectory of Care .........................144
  5.2.1 Transitions ...............................................................................................145
  5.2.2 The trajectory of care ...............................................................................152
    5.2.2.1 Emotional turmoil ............................................................................152
    5.2.2.2 Systemic impact on health and well-being of caregiver ..................156
    5.2.2.3 Relational impact ...............................................................................157
    5.2.2.4 Finance and reality checks ...............................................................159
CHAPTER SEVEN – DISCUSSION AND IMPLICATIONS ........................................ 223
7.1 Introduction to Discussion and Implications .............................................. 223
7.1.1 – Overview ......................................................................................... 223
7.1.2 – Caregiving: A construct of dynamic transformation ............................ 224
7.2 Epistemology of Caregiving ....................................................................... 226
7.2.1 – Caregivers’ accrual of knowledge ..................................................... 228
7.2.1.1 – Knowledge accrued through discovery and interpretation of lived experience ........................................ 229
7.2.1.2 – Knowledge accrued through testimony ...................................... 231
7.2.1.3 – Knowledge as the product of inductive reasoning ....................... 232
7.2.2 – Caregivers’ dissemination of accrued knowledge ............................... 233
7.3 Axiology of Caregiving ............................................................................. 234
7.3.1 Axiology of caregiving as an aesthetic perspective ................................. 236
7.3.2 Axiology of caregiving as a matter of values and principles, morals and ethics ...................................................... 237
7.3.3 Axiology of caregiving as a matter of opposing tensions ..................... 238
7.4 Ontology of Caregiving ............................................................................. 238
7.4.1 Ontology of caregiving as a repositioning of identity ............................... 239
7.4.2 Ontology of caregiving as impacting the relational self......................... 241
7.4.3 Ontology of caregiving as transformation ............................................ 243
7.5 Summary of Discussion ............................................................................ 244
7.6 Implications ............................................................................................. 245
7.6.1 – Implications for caregivers ................................................................. 246
7.6.2 – Community awareness ....................................................................... 247
7.6.3 – Professional training ......................................................................... 248
7.6.4 – Processes for accessing information and support ............................... 249
7.6.5 – Review of service delivery ................................................................. 250
7.6.6 – Review of formal care ....................................................................... 251
7.6.7 – Implications for counselling and professional supervision.................. 252
7.6.8 – Strengths, limitations, and potential for future research ..................... 253
7.7 A Journey Completed .............................................................................. 256
7.8 Conclusion ............................................................................................... 258

REFERENCES ......................................................................................... 261

APPENDICES
Appendix A – Reisberg’s Global Deterioration Scale ..................................... 299
Appendix B – Ten Signs of Early Detection .................................................... 315
Appendix C – Key Facts and Statistics ............................................................. 318
Appendix D – Queensland Health Statistics .................................................... 320
Appendix E – Information and Local Support Services and Providers ............. 322
Appendix F – The Self-fulfilling Choice to Cope ............................................. 325
Appendix G – A Qualitative Paradigm ............................................................. 327
Appendix H – Participant Documents .............................................................. 329
Appendix I – Ethical Considerations ............................................................... 349
Appendix J – Participant Profiles in Context .................................................. 350
Appendix K – Residential Care: The Village Alternative ................................. 352

The collective reality from onset to end of life and beyond. Judith R Boyland
LIST OF FIGURES

Figure 1  - The world of my reality ................................................................. 4
Figure 2  - Changes in the architectural structure of the brain ........................................ 26
Figure 3  - Methodological hybrid ........................................................................... 77
Figure 4  - The unfolding story .................................................................................. 96
Figure 5  - Data ........................................................................................................... 104
Figure 6  - The developing narrative .......................................................................... 107
Figure 7  - Warped and twisted .................................................................................. 143
Figure 8  - My knowledge development ..................................................................... 153
Figure 9  - Caregiver impact ........................................................................................ 154
Figure 10 - The process of reframing ......................................................................... 195
Figure 11 - A maze of metaphor and a simile or two ..................................................... 199
Figure 12 - Flying through the darkness ...................................................................... 205
Figure 13 - Wisdom won of pain: The voice of experience .......................................... 207
Figure 14 - From here to infinity: It’s OK to dream ...................................................... 215
Figure 15 - Caregiving: A construct of dynamic transformation .................................. 224

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A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: 

The collective reality from onset to end of life and beyond.

Judith R Boyland
CHAPTER ONE – CONTEXT

Let yourself be silently drawn
By the strange pull of what you really love.

Rumi (Power of Positivity®, 2015)

1.1 Introduction to Context

The title of the research project is A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Within the context of this project, “a loved one” is defined in terms of a “Special Someone”1 for whom one has unconditional positive regard: a significant other, kin or colleague, who holds a special place in the heart and the history of the caregiver. The research investigation seeks to gain insight and understanding about the nature of the truths embodied in a world of the lived experience of informal caregivers. It is about the relationship between the caregiver and the experience of caregiving. It is about the impact when caring for another human being whose personal, every-day world is marked by the reality of disempowerment associated with a life-changing condition of Alzheimer’s disease.

1.1.1 – Aim

Assuming a starting point of “normal”,2 the intention is to present a collective profile of the impact of caring for a loved one who has Alzheimer’s disease.3 Investigative discussion is focussed on the relationship between caregiver and the lived experience of caregiving, and the trajectory of care is from onset to post end-of-life.

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1 A term of endearment used by Lavinia (participant story teller) in referring to the relationship she shared with her husband: 5.5.5.3, The business of dying. What Lavinia misses is “being Someone Special to a Special Someone”.

2 Referenced as Stage One of Reisberg’s Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982/2007). Also referenced in the Seven Stages of Alzheimer’s Disease (Alzheimer’s Association, 2015a; Sheehan, 2015), and Reisberg’s Clinical Stages of Alzheimer’s (Fisher Center for Alzheimer’s Research Foundation, 2015). Characteristics of the Global Deterioration Scale are presented in Appendix A.

3 General references to Reisberg’s Global Deterioration Scale are discussed in 1.8 – About Alzheimer’s and Dementia. Ten Signs of Early Detection are profiled in Appendix B (Alzheimer’s Association, 2009/2016; Alzheimer’s Association, 2015b).
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: 2

The overarching aim of the investigative project is to give voice to those who care for loved ones who have Alzheimer’s disease. It is about giving informal caregivers opportunity to tell the whole of their story (the good, the bad and the ugly) and it is about giving those multiple voices opportunity to be heard and acknowledged. Each participant has a personal story to tell and while there are elements of similarity and difference, each story brings individuality and uniqueness. No single story is complete in knowledge or truth and it is within a framework of multivoiced dialogue that new understandings and new meanings are construed and conceptualised as one voice is heard by the other, one brain resonates with the other, and one mind intertwines with the other (Jones & Hermans, 2011). The threads of emergent stories are woven together as conceptions of “yesterday” are re-flected, re-lived, re-conceptualised, and re-framed in the time and space of “to-day”.

From the portfolio of stories shared by participants, themes are extracted and a collective profile that defines the landscape of caregiving is developed. The depth of understanding that emerges from a synthesis of stories presented by multiple voices has potential to create a new narrative. Weaving the stories into a collective breathes life into a dynamic evolution, impacted by dichotomies that profile the landscape of caregiving. It is the “big picture” of the collective landscape that is filled with an embodied richness of diverse reality. It is the diversity of this reality that profiles a landscape of lived experience, when someone I love has Alzheimer’s.

1.1.2 – Relevance

Reviewed literature relating to a contextual framework of the trajectory of degeneration, from observable onset to end-of-life, references data that is disease specific. This literature is discussed in 1.8, About Alzheimer’s and Dementia, and 1.9 Incidence and Prevalence of Alzheimer’s Disease. Reviewed literature relating to a conceptual framework of carer impact is referenced in themes that portray snapshots of lived experience and is presented in Chapter Two, Literature Review. While the concept related literature addressed a broad spectrum of impact related aspects, no empirical literature was found that described the collective landscape of the impact of caregiving for a loved one who has Alzheimer’s from onset, through pre-diagnosis, through diagnosis, to end-of-life, and beyond.

The collective reality from onset to end of life and beyond. Judith R Boyland
Of particular relevance to this project, minimal empirical literature was found with reference to an Australian demographic and there was no identified literature that explored this specific topic. This suggested a gap in the literature base. The specific gap profiled in this research project focuses on the collective landscape of impact as it relates to informal caregiving when the profile of the caregiving journey is described from onset to post end-of-life. The participant demographic is representative of the greater Brisbane region and surrounding constituencies bounded by Sunshine Coast in the north, Gold Coast in the south, islands of Moreton Bay in the east, and Toowoomba in the west. Statistical data relating to the global incidence and prevalence of Alzheimer’s disease and Alzheimer’s related dementias identify the importance of research that investigates carer impact (Alzheimer Europe, 2014a; Alzheimer’s Association, 2014; Alzheimer’s Australia, 2014a, 2015a, 2016, 2017; Summers, 2014).\(^4\) Statistics relating to an Australian demographic (Alzheimer’s Australia, 2014a, 2015a, 2016, 2017) confirm the importance of research that investigates carer impact.\(^5\) Additional confirmation is reflected in state trends which project rising numbers related to local incidence (Queensland Department of Health, 2015).\(^6\)

1.1.3 – Research Question

Whatever time period frames the snapshot of individual journeys, the relationship between caregiver and lived experience is universally marked by progressive disempowerment embodied in cognitive degeneration, physical debilitation, and loss of function. Thus it is that the research question is posed in terms of, What is the holistic and collective reality of caregivers’ conceptions and understandings about the impact of caring for a loved one who has Alzheimer’s disease when the trajectory of caregiving spans from onset to end-of-life and beyond?

1.1.4 – Motivation

Motivation in undertaking this research project is grounded in the lived reality

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\(^4\) Discussed in 1.9, *The Incidence and Prevalence of Alzheimer’s Disease*.

\(^5\) 2017 data are presented in *Appendix C*.

\(^6\) Profiled in 1.9.1, *Incidence and prevalence of Alzheimer’s disease: A global perspective*, and attached as *Appendix D*. 
embodied in my own experience of caring for my father who had Alzheimer’s disease. Actualising the research project begins with a professional curiosity in search for understanding and insight as it relates to a collective reality when the care receiver is not only a loved one, but is also a significant other in a dialogic relationship: a Special Someone with whom I share my life.

I have “walked the walk”. It is now my time to “talk the talk”, while also giving others opportunity to talk their talk and for their voices to be heard and acknowledged. As I walked my journey, it never occurred to me to seek help or to tell my story as I witnessed the disempowerment of a man in the throes of cognitive, physical, and functional degeneration. I was also experiencing my own sense of disempowerment in being unable to make “OK” the maze of transitions that consumed my world as caregiver and my father’s world as care receiver. Help was never offered from doctors. I was unaware of any organisation where I could turn for help, and the world of Google was not to be born for another decade. It seemed to me that whenever I did pose a question, I was met with a “brick wall” or a “closed door”.

My support came from my family, friends, work colleagues, clergy, and my bank manager. I found support from medical professionals only during the last weeks of a five and one-half year journey. I found information relating to the existence of an Alzheimer’s support group (Alzheimer’s Queensland), only when my personal journey was over. I was operating in a cloud of unknowing and that was the world of my reality.

![THE WORLD OF MY REALITY](image)

**Figure 1 - The world of my reality**: The world of my reality reflects the concepts of *the world that was* prior to caregiving and *the world that is* during the years of caregiving. My *pathway to the future* is shrouded in the cloud of my unknowing. Conceptual constructs of *world that was*, *world that is*, *pathway to the future* were developed by Professor Judith Murray (Murray, 2005, 2016).
Professor Judith Murray (2005, 2016) coined the terms of the *world that was*, *world that is*, and *pathway to the future* as foundation for a model of loss and grieving. Upon reflection, my *world that was* pre-Alzheimer’s seemed as if it had been a kaleidoscope of security, colour, adventure, and freedom. My primary focus was my family and I was enjoying the labours of a successful and fulfilling career. My *world that is* throughout the caregiving trajectory was in stark monotone: taking me deeper and deeper into the abyss of disempowerment. My *pathway to the future* was shrouded in the cloud of my unknowing. My time was no longer my own. My energies were stretched to the limits. I was no longer in control and I had no idea of what may lie ahead. I was confused and frustrated, angry and fearful.

Over a quarter of a century has passed since my caregiving journey and it seems that, suddenly, my path is being crossed by diverse reminders of that disempowerment and what it was like for me, when my father was stricken with that life-changing condition known as Alzheimer’s disease. The diagnosis is one of advancing degeneration, debilitation, and dysfunction; and the prognosis is terminal. In the best-case scenario, it is confronting. In the worst-case scenario, a sense of fear and hopelessness pervades.

1.2 Structure

This thesis comprises seven chapters.

**Chapter One** sets the scene and defines the context. It tells my story, which serves to demonstrate how my background and training enable me to engage in research that is both close to my heart and is much needed in enhancing everyday empathic support for so many who are shrouded in the complex robe of primary caregiving or the shadow robe of loving vicariously. Chapter One also profiles the changes underpinning diagnosis and prognosis, the characteristics and social impact of the disease, and the socio-cultural context of care embedded in the reality of lived experience.

In **Chapter Two**, literature related to the impact of caring for a loved one who has Alzheimer’s disease is reviewed. Focus is on the culture of care and on nuances that are particular to the universal demographic of caregiving and that influence the *I-Thou/Self-Other* position in the caring and the coping. This review of literature provides a
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.

Judith R Boyland

conceptual framework for considering similarities and differences between global carer impact and local carer impact when synthesising the data and profiling the themes that emerge from the stories told by research participants. Key concepts reviewed in the literature focus on how participants interpret their role as caregiver and how they conceptualise the I-Self relationship they experience within the role of caregiving. The I-Thou/Self-Other relationship shared with the care receiver is also profiled. These concepts provide a foundation from which to explore the notion of “the dialogic self” as embodied in the role of caregiver. With reference to Dialogical Self Theory (DST), Hermans (2012) explains the notion of the dialogic self in terms of:

A dynamic multiplicity of I-positions in the society of the mind, . . . intrinsically bound to particular positions in time and space . . . positioning and repositioning . . . interact[ing] like characters in a story . . . involved in processes of question and answer, agreement and disagreement, conflict and struggle, negotiation and integration . . . evoked by ever-changing situations. (pp. 8-9)

I-positions across an extended environment of care are reviewed from both the internal position of Self as I/me and the external position of Self as my: for example, I as in “I the caregiver” or “me the researcher” and my as in “my loved one” who is the care receiver or “my participant” who shares a story of lived experience. As explained by Hermans (2012), linking the internal I and the external I is about seeing the Other as part of an extended Self. Considered from this perspective, the I of the Self is seen as more than an isolated entity. Rather, as an extended I, the Self is contextualised in relationship with the Other and with reference to subsequent chapters, it is the internal I of me, the researcher, who links with the external I in relationship with each one of my participants.

In Chapter Three, focus is on method and methodology, presenting aspects of qualitative methodologies believed to best serve the aim of the research project and elicit a comprehensive answer to the research question. Underpinned by the philosophy of a hermeneutic approach, it outlines theoretical orientations that constitute a methodological hybrid that sits under the overarching umbrella of a qualitative paradigm and is supported by an epistemology of social constructivism.

The method features the process of bricolage in data collection, analysis,
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: synthesis, and development of the collective narrative. Focus is on process, ethical considerations, and empirical validity.

**Chapter Four** presents profiles of participants, introducing them in a sub-cultural orientation of relationship and relationship transformation. It also contextualises and grounds participants’ stories in the reality of lived experience, wherein *I-Thou/Self-Other* relationships are contextualised and re-contextualised; positioned and re-positioned; formed and transformed; framed and re-framed.

In **Chapter Five**, the stories of individual participants are woven together in reconceptualisation and a broad, holistic landscape of informal caregiving is profiled. Encapsulating the environment of care as a collective entity, Chapter Five embraces the multivoicedness that defines the imaginal space of abstract intrapersonal and interpersonal domains, wherein *Self-Other* relationships are construed and re-construed (Jones & Hermans, 2011). Chapter Five also highlights transitions as a dynamic multiplicity of *I*-positions that support what Jones and Hermans define as “the landscape of the mind” (p. 12). Intertwining the mind of *Self* with the mind of the *Other* is premised from a platform of the internal “I, the caregiver” in relationship with the external *I* embodied in the position of “my loved one who has Alzheimer’s”.

When intertwining the threads of experience, there is also acknowledgment of the internal position of *I*, the researcher with “inside knowledge” (Pedersen, 1997, p. 6), in relationship with the external position of *I* as embodied in my participants: the key holders of inside knowledge. The internal position of *I-Self* is repositioned in the shifting sands of time; as is the external position of *I-Self* in relationship with *Thou-Other*.

When viewed through a lens that focuses on change in the *I-Thou/Self–Other* relationship, transformation is pervaded by the environment of care. Readers are invited to both hear the voices and see the landscape as the stories of participants are reflected through a lens of reflexivity, while the researcher reflects critically of self and becomes the instrument through which the threads of multiple stories are interwoven.

Development of the reconceptualisation is defined in four themes that emerge through analysis of similarities and differences embodied in the stories as shared by
participants. Findings from the developing narrative profile stories by weaving a holistic landscape of participants’ conceptions and understandings of the impact of caring for a loved one who has Alzheimer’s disease.

In Chapter Six the findings of the collective narrative are presented in a synthesised reframing of the lived experience as it impacted the lives of participants. The reframing is woven across three themes that culminate with participants looking beyond the trajectory of care to a future free from all that has defined the role of informal caregiver for a loved one who has Alzheimer’s.

Findings and implications are addressed in Chapter Seven. Discussion focuses on how repositioning previously conceived perceptions of the intrapersonal relationship with Self and the interpersonal relationships shared with Other embody a process of dynamic transformation.

1.3 Professional Journey

In the early sixties, I left Teachers College with a passion in my gut; and in my heart, I had a dream. Like that of so many of my generation, my dream was to bring freedom and empowerment to MY world. My dream was for women and children to believe in what was right and just, to use their voice in a quest for emancipation from all forms of domestic and political oppression, to seek harmony of spirit, and to live with freedom and dignity. I was in the world of education for forty years, always using my voice to speak out against oppression and injustice as it related to disempowerment of women and children: not always a politically wise move!

While my focused field in education began in the primary sector, my area of interest and speciality soon gravitated towards behaviour. My passion for the emancipation of the oppressed was grounded in Ashby’s notion of maintenance of essential variables (Ashby, 1952), Powers’ theory of control and maintenance of intrinsic variables (Powers, 1973/2005, 1998), Glasser’s focus on needs gratification, control, and choice (Glasser, 1969, 1984, 1985, 1999; Glasser & Glasser, 1989), and Berne’s model of OKness (Berne, 1966). I spent most of my years in education serving in low socio-economic demographic constituencies: working in schools designated as “disadvantaged”.
During all of those years, my passion for the empowerment of the oppressed never wavered. I held leadership roles as Deputy Principal and Principal of Catholic Systemic Primary Schools (1988-2000): all disadvantaged schools and all led with a personal mission and a professional vision grounded in empowerment and embodying the notions of choice, control, and personal responsibility (Glasser, 1969, 1985), and OKness (Berne, 1966). As a consultant, I developed personalised and school-based behaviour programs across all sectors of schooling (Early Childhood to Upper Secondary) and I shared of my experiences with education and leadership students in the tertiary arena. I specialised in programs focused on engagement of disenfranchised students and I was one of the co-writers of the first National Curriculum documents for Studies of Society and Environment (1990-1997). Those principles underpinning the quest for freedom and empowerment, and born of the sixties, have never been far from my sights.

As well as following a career path in education, I have also diversified and expanded my knowledge and skills base. I have been engaged in counselling for some thirty years: initially in the context of the primary and secondary school while serving in leadership and consultancy roles. Subsequently, I have established my own private counselling practice where I now specialise in professional supervision while maintaining a small component of clinical clientele. Still, to this day, the principles of freedom and empowerment underpin my practice. The quest for freedom to seek harmony of spirit and to live with dignity of person is still my passion. Witnessing oppression of the disempowered is still abhorrent to me and is my trigger to act in support of those who seek empowerment amid the complexities of everyday life.

1.4 A Personal Journey

The youngest of three siblings, I always knew the love of two parents and two older brothers. Our parents were active in supporting families who had little; and from my earliest years, I remember sharing what little we had with those who had less. It was always assumed that we all looked out for each other and as a young woman and a young mother, I supported my mother as she cared for her mother and for her step-father; both of whom were living with degeneration, debilitation, loss of function, and disempowerment following strokes. My mother cared for her loved ones till the time
came when full-time nursing care was required, as the physical demands were beyond what could be managed in the home environment.

Twenty years had passed. Much had changed. Yet nothing had changed. It was January of the summer of 1987 and in the weeks before her death, my mother had said to me, “Take care of ‘Snookie’; he’s getting a little forgetful”. My mother died within a few hours of our having the last of these conversations and little did I realise that this was to be the beginning of a journey that would span five and one-half years of transition, turmoil, and redefining of roles, relationships, and responsibilities. My world that was would become consumed by my world that is (Murray, 2005, 2016).

It would be a time of re-positioning, re-conceptualisation, and re-framing; as the imaginal space of my intrapersonal domain was transformed by the dynamic multiplicity of I-positions that traversed the landscape of my mind (concepts defined by Jones & Hermans, 2011; Hermans, 2012). The journey that awaited me would prove to be a roller coaster of conflicting emotions and dynamic opposites, simultaneously fighting for supremacy (concepts of conflict posited by Jones & Hermans, 2011, p. 12).

It was an ever-present dichotomy of love and hate, empathy and resentment, compassion and impatience, respect and disgust, anger and resignation, confusion and frustration, chaos and calm, fear and embarrassment. There were times when all I wanted was to run away and hide or for someone to wave a magic wand. My world that is would vaporise and be gone and my world that was would materialise and return.

There were times when all was “OK” (Berne, 1966), times when I was super energised, and times when I was totally withdrawn: lost in the abstraction of my intrapersonal domain (Jones & Hermans, 2011). There were times when I felt that I was merely an observer, looking through a window into the reality of somebody else’s story. There were times when I would simply become frozen in time and space; oblivious to all that was going on around me: a situation that I now recognise as a “polyvagal response” (Porges, 2014, 2015) to “secondary trauma” (Wyder & Bland, 2014) as my body kept the score (van der Kolk, 2014).

In that January of the summer of 1987, as I recall it, my father could have been in
what I now understand to be stage two of Alzheimer’s disease. I did not know this then and it was to be quite some considerable time before I was even to hear the terms, *Alzheimer’s disease* or *dementia*. I was ignorant in the purest sense of my unknowing. I knew nothing more than our father was becoming more forgetful while also becoming more difficult to communicate with. All of this I attributed to the fact that he was grieving the death of his “Snookie”. He was eighty-two years old and had been with my mother for fifty-nine of those eighty-two years.

As the months passed, it was becoming obvious that the forgetfulness was becoming more regular. I was now the signatory to my father’s banking and I was making decisions regarding his health care and his general well-being. It was this stage, as I recall, that was one of the most difficult to deal with. Identified as stage four of advancing Alzheimer’s disease, it was the stage when my father knew that something was wrong and he was aware that his memory was failing him. He could not remember aspects and happenings significant to his daily life and he knew he could not remember. He was repeating himself and he knew he was repeating himself. He was also beginning to avoid social or mentally challenging situations, such as going to the TAB – a long-favoured Saturday afternoon activity where he would have his “little flutter” and bring the winnings home to his Snookie. This was very stressful for him and it was very sad to witness his distress and not be able to make it OK.

This stage transitioned and my father began to live in his own world of the past – forty, fifty, sixty, seventy years in the past. His memory of the present was questionable, even in relation to the most basic routines of time to eat and time to sleep. He was beginning to need help with day-to-day activities. Stage five was emerging and his executive domain and his spatial domain were also becoming noticeably impaired.

His recognition of family became dimmed: sometimes knowing his children and grand-children; sometimes not. Time came when I was my mother. However, in the midst of this identity confusion, the one person he always knew was my son, Jason: his “mate” and “buddy” – alias “Jimmy Johnson”. Time also came when he could no longer see, for his eyes were blinded with glaucoma and with advancing Alzheimer’s

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7 Stage references as per Alzheimer’s Association (2014) and Fisher Center for Alzheimer’s Research Foundation (2015).
dementia. Symptoms of stage six were presenting. He lost his ability to hear and began to have difficulty with incontinence. He was in constant pain. Stage six had arrived.

While he could not see and could not hear, he could speak. He became verbally abusive and it was at this stage of our journey that my polyvagal system (though neither known nor diagnosed at the time) began to send messages for “time out”. As is now known, my body was going into “freeze” response (Porges, 2014, 2015), and with reference to Powers’ notions, as conceptualised in his Perceptual Control Theory (Powers, 1973/2005, 1998), my “intrinsic variables” were showing signs of operating at near-lethal levels.

My roles were changing. My I-positions in the landscape of my mind were not only intertwining, they were becoming tangled and unrecognisable. My whole life experience was being re-construed and re-positioned. My sense of Self was being reconceptualised and reframed. I was in a process of dynamic transformation. I would never return to my world that was. The exterior defined role functions that I shared with my inner Self impacted upon my identity as I lived out the reality of my experience and as the role of caregiver consumed my being. Conflict reigned supreme.

I felt totally disempowered as I witnessed the progressive disempowerment of my father. My thoughts seemed to be out of my control as I wallowed under “the cloud of my unknowing” and with reference to the work of the unknown mystic of the fourteenth century, it was as if his words echoed around me. However, rather than being focused through the mystic’s vision of a spiritual relationship with his God, the cloud of my unknowing presented as a foreboding darkness that overshadowed my vision of a mortal relationship with my father:

But now thou askest me and sayest, “How shall I think on Himself, and what is He?” And to this I cannot answer thee but this: “I wot not.”

For thou hast brought me with my question into that same darkness, and into that same cloud of unknowing, that I would thou wert in thyself. . . . And thou shalt step above it stalwartly, but lustily, with a devout and a pleasing stirring of love, and try for to pierce that darkness above thee. And smile upon that thick cloud of unknowing with a sharp dart of longing love; and go not thence for thing that befalleth. (Underhill [Ed.], 2003, p. 14)
My father was a man trapped in time and in a body and a mind that could not serve his needs. He was not OK. No longer did he have any control over functioning in a manner that could serve to maintain his intrinsic variables within non-lethal limits. Nor did he have any control in being able to gratify his basic human need for survival (Glasser, 1984, 1999). Questions needed to be addressed.

We could no longer provide the care that our loved one needed. Our only option was to seek full-time formal and professional care for him in a care facility that specialised in geriatric care: a process which was almost unbearable. Stage seven had arrived. It was now a process of my owning that I could no longer cope. My internal I-position was that I was totally not OK and my external I-position as it related to my father was totally and completely transformed.

The very nature of this acknowledgement became an onerous burden for me to bear: I was totally disempowered. It was a process filled with mixed and conflicting feelings of failure. I could no longer take care of Snookie. I was abandoning him and in abandoning the fulfilment of my mother’s request, I was abandoning my mother. I was consumed with overwhelming guilt, sadness, fear, and anger. It was not fair. This was not what I had planned for my life. How could my parents have done this to me? Another dichotomy presented. I was filled with a sense of overwhelming relief in that I could relinquish my role as caregiver. I was also filled with an overwhelming sense of guilt. How could I dare feel relief and freedom in this most horrible of scenarios?

My father was transferred to a hospital that specialised in palliative care. As his body began to close down, he slipped into a comatose state. It was the day after his eighty-seventh birthday, in the spring of 1992. His body began to decompose before our eyes and the sweet smell of death was in the air. Some eight days later, my father died. Not only did his life end, but the timing and the terms of his end-of-life transition were totally controlled by his lost rational Self. It seemed that somewhere in that demented state, a rational moment was lingering and waiting to make one final statement in real time – “I am OK. I am in control”.

I had sat at my father’s bedside for those eight long days as family came and went. The only person we could not contact was Jason, who was away at University, in Armidale. Messages had been left and no response had been forthcoming. As it
eventuated, Jason had received our message and he was needing to have his own time and space to make his own peace, to evaluate his choices, and to make his own decisions. The only time I left my father’s side was when another family member was present. Family came and went: doing what needed to be done, saying what needed to be said, and giving permission for father and grandfather to leave this mortal coil. The nursing staff had prepared a bed for me and periodically insisted that I sleep whilst quieting my objections that “he might slip away while no one was with him”. They assured me that they were with him and insisted that he intended to go nowhere till Jason arrived. To my protestations that we didn’t know if Jason knew, the response was simply, “Jason knows. Your father is with him.”

**IT IS NOW 8:00am ON WEDNESDAY MORNING, SEPTEMBER 02 OF 1992:**
The attending doctor advises that the condition of our Special Someone is stable. Following consultation with the medical staff, my family choose to go to work and to deal with the business of the day. For, while death is steadily approaching, it is not deemed to be imminent. The sun is shining and there is a gentle hum of morning traffic as the rest of the world carries on with the normal business of a normal day.

**AND SO IT IS:** Jason walks into the room. After he hugs me and dries my tears, he sits with his grandfather – his Pa: his mate, alias Jo. Jo and Jimmy Johnson; sharing a lifetime of love and connection that can only be shared between grandfather and grandson: mate with mate: man with man. Although the years are dimmed by the distance of time, these intimate identities linger on. They have forged a special place in the heart and the history of each man’s journey.

I go for a walk. I return at about 10:00am and together, Jason and I sit in silence. Together, we hold the hands of this man we both love. We stroke his forehead and we brush his hair: an act of nurturing that he always loved. We reset the music we have been playing through headphones during these last eight days, in the belief that somewhere in whatever world he is in, this very special person who holds an intimate place in our hearts may be able to feel the music and know a sense of calm and tranquillity.

Time is ticking: never missing a beat as the day unfolds. It is 10:30am and the nurses need to roll my father and to bathe him. Jason and I leave them in privacy and
go for a cup of tea. Jason returns. I, for no particular reason, linger for a moment.

Jason is alone with his Pa: as it is meant to be.

This is Jason’s story and it is his to tell:

It was obvious his soul was strong and growing in peace but the body was failing and gone. After a few hours, I was alone with him. We were together, holding hands, his limp and cold in mine. His time was near and done as his hand warmed in mine and squeezed my hand. I looked at Pa, kissed him on the forehead, never letting go of our hands.

We looked at each other as his eyes opened: at first lifeless then filling with his soul and his love. For some time, at a guess I’d say somewhere between five seconds and eternity, we looked into each other’s eyes: breathing together, heart beats together. Then his eyes growing stronger, his breathing and heart grow weaker. His warmth and grip on my hand and sharpness in his eyes only increasing as our last time together here passed. Pa’s eyes showed peace and eternal love as his last breath left his body and his heart beat its last stroke. I felt them both heavy, yet full of his freedom and release through my body, my breath, and my heart. We held each other to Pa’s last. I closed Pa’s eyes, kissed him on his lips, and said a final, “Goodbye, for now”. Then I just held him.

I don’t recall if I went out or if someone came in. Nor do I know what period of time passed. At last, however, his suffering was over. He had lived his life. The final years of turmoil, pain, confusion, and loss of the person were now over and Pa was at rest and peace.

As I enter the room, Jason looks at me with tears in his eyes and says:

He’s gone, Ma. He opened his eyes, he looked at me, and he smiled; and I saw a bright light in his eyes. I know that he saw me; and he knew me; and I know that he knew I was here, with him. I held him. I kissed him. And his pain was gone.

The nurse keeping watch through the glass panel behind my father’s bed had pulled the curtain to give Jason his private space with his Pa: his mate, Jo. At the exact moment of my father’s death, she moved the curtain aside to check on my father. What
she witnessed was exactly what Jason had described and she spoke of a mystical light that had radiated around these two men, as my father breathed his last breath: something she had never before seen.

Not only had my father waited for Jason to arrive, he had waited till he and Jason had time together in the quiet and stillness of the morning. He then continued the waiting till he was, once again, alone with Jason: as it was meant to be. He was OK. He was in control.

There was no longer a sense of pain or distress in his demeanour. His skin was as clear and as smooth as that of a young man and for the first time in a long time, it was in death that he radiated life. The decomposition had ceased and there was a freshness enveloping him that I could not understand. It made no sense. I was witnessing the ultimate dichotomy. In life there had been death: in death there now was life. There was a calmness that had no place in the space of rational consciousness. Lesley Joseph McLachlan was free of all that had haunted him for all those demented years, and so was I. He was at peace, and so was I.

1.5 The Research Journey

It could be said that the research journey began as a dormant seed somewhere between 1992 and 2001. Since 2001, when I began my journey as a professional counsellor in private practice, the seed has begun to germinate. My curiosity and interest have nurtured the seed in its embryonic state as I have journeyed with clients who present with self-identified somatic indicators, consistent with those identified in the DSM-5™ (American Psychiatric Association, 2013) as being indicators for Acute Stress Reaction. I have also journeyed with clients referred by their general practitioners for support in managing diagnoses of Major Depressive Disorder and Post Traumatic Stress. Upon exploring lifestyle factors that could be contributing to their current distress, it is often found that they are caring for a loved one who has a life-changing condition.

Since 2003, in addition to journeying with my own clinical clients, I have also journeyed with clinicians, as their professional supervisor. Some are caring for their own loved one who has a life-changing condition. Some are supporting clinical clients
presenting with somatic indicators of secondary trauma associated with a stress response to circumstances brought about as they assume the role of caregiver for kin or colleague with a life-changing diagnosis.

It was in October of 2014 that I decided the time had come to explore presenting situations in a more structured manner. Given my own personal journey in caring for my father, I decided that exploring the impact of caring for a loved one who has Alzheimer’s disease was the avenue along which my formalised research journey would begin. My focus would be on telling the caregiver’s story: as it is lived in the reality of every-day experience.

With reference back to 1.2, Structure, initial searches on Google Scholar, Google Books, and EBSCO were for articles, papers, and documentation related to key words associated with both context and concept; for example, Alzheimer’s disease, dementia, family carers, carer stress, carer support, carer impact, and caring – family impact. While results yielded a myriad of relevant and subject specific information, most was in relation to the United States of America (US), Canada, and the United Kingdom (UK). A few originated in European countries other than the UK. There were also some originating in Latin America, The Middle East, and Asia. Information, sourced from Australian researchers focussed primarily on data relating to Alzheimer’s disease and dementias per se. Little information focussed directly on carer impact. None presented a holistic snapshot of the impact on the caregiver from onset through diagnosis to end-of-life and beyond. None presented as empirical data describing the collective reality as observed through the conceptions of caregivers.

This indicated to me that there was a gap in the literature base in reference to the impact of caring for a loved one who has Alzheimer’s disease: as situated across an Australian demographic. In addition to there being a recognisable gap in the literature base, statistical data (as discussed in 1.1.2, Relevance) identified the importance of research which investigates the subject of carer impact. Circumstances influencing impact include:

a) The care recipient is a loved one;

b) The onset to death trajectory spans a time frame which can be in excess of twenty years (Alzheimer’s Association, 2014; Gupta, 2015; Summers, 2014);
c) Whatever the time frame, the lived experience is marked by progressive cognitive, physical, and behavioural degeneration, and progressive loss of function (Alzheimer’s Association, 2015a; Fisher Center for Alzheimer’s Research Foundation, 2015; Reisberg et al., 1982/2007; Sheehan, 2015);

d) At this point in time, Alzheimer’s disease is a terminal disease for which there are no widely acknowledged existing treatments to delay or prevent disease progression (Refer to 1.9, Incidence and Prevalence of Alzheimer’s Disease);

e) End of the trajectory of care is withdrawal from the role of caregiver or the end-of-life of caregiver or a loved one who is care receiver.

1.6 A Project Under Construction

The research project is a story of impact. It opens a window to reality that defines the day-to-day world of informal primary care when the care receiver is a loved one who has Alzheimer’s disease and who also holds a special place in the heart and history of the caregiver. Empirical data were collected by way of person-to-person discourse, inviting response that tells a story of individual conceptions and understandings and that when shared, profile a collective landscape of relationship between caregiver and the lived experience of caregiving. Literature related to each evolving phase of investigation and thesis development was reviewed across a continuous linear progression, from inception of idea to conclusion of project.

It is my belief that if, as a clinical counsellor and a professional supervisor, I am to support caregivers in their journey, it is vital for me to understand their needs in the here and now of this time and in this place. It is also vital that I understand the reality of lived experience when caring for one whose life-changing condition is defined by a prognosis of progressive disempowerment from which, as yet, there is no turning back. Given the sensitivity of the experience being investigated, the process of dialogic interchange was a vital aspect of communication between researcher and participant.

1.7 The Dialogic Interchange

Considering care for a loved one who has Alzheimer’s disease, it was important to identify particular cultural anomalies that define the world that is and it was the participants’ identification of the personal and the specific that was to define the
collective of thematic attributes in data analysis and synthesis. I determined that the best way to achieve this goal was to engage in a dialectical process, defined by Jung (1935/1985) as being “a dialogue or discussion between two persons . . . the art of conversation . . . for the process of creating new syntheses . . . as the psychic system of one person enters into reciprocal reaction with another psychic system” (p. 3). Marcus and Fischer (1986) argued that dialogue creates space for multiple voices to be presented: a notion to be portrayed a quarter of a century later in terms of “multivoicedness” (Jones & Hermans, 2011, p. 12). In addition, dialogue is about creating what Badenoch (2011) referred to as, “interpersonal oneness . . . where the state of my brain is resonating with your brain” (YouTube). This would be a further example of the internal position of I linking with the external position of I: the I of researcher, linking with the I embodied in the position of my participant: as previously discussed in 1.2, Structure.

In this research project, both researcher and participant shared an understanding of the dialogic nature of intertwining one’s mind with the mind of the other (Jones & Hermans, 2011), as each had inside knowledge. The cultural anomalies of the context of care were familiar to both and as we engaged in the process of dialogue, a new synthesis was created. The depth of understanding that emerged from the synthesis of stories shared by multiple voices had the potential to create a holistic landscape that encapsulates the dynamic richness embodied in a collective narrative of lived experience. For, while no single story is complete in knowledge or truth, it is within the framework of dialogue that new conceptions and new understandings are construed and conceptualised: as one voice is heard by the other, as one brain resonates with the other, and as one mind intertwines with the other.

For both researcher and participant, it was through inter-personal dialogue as Self listened to Other and as Other was heard by Self, that on-going intra-personal dialogue was enriched. As Self-Other relations were construed and re-construed and as knowledge and meaning were reconceptualised and reframed, opportunity for empowerment was enriched. As truths were laid bare, invitation was issued for a space to be opened to processes of re-positioning and transformation: the essence of which is named by Krishnamurti (1973) in terms of relationship based on the image of self as brought about by memory which, of itself, is seeing and naming what is; as it is imaged
through knowledge and experience. Cartright (1997) draws on Krishnamurti in profiling a model of transpersonal transformation which reflects the therapeutic power of Being-with what is. What needed to be present for this synthesis to occur was ethical consideration of what Draguns (1996) described as “a respect for the other and a willingness to learn from the other” (p. 6). In a later reference to interpersonal dialogue, Draguns (2004) speaks of both the importance and the challenge of communicating empathy which he refers to as being a “pivotal operation” in interview dialogue (p. 752). It came to be about what Rowan (2010) refers to as the “intuitive self . . . where the Self has fully digested the Otherness . . . identified with it [and] entered into a concrete unity with it” (p. 15).

As an aid to enhancing the dialogic interchange and empowering the participant, it seemed wise to follow Draguns’ advice and draw from the adage, “know thyself” (2004, p. 751). Only by being open to self-discovery could I, as researcher, recognise the need to acknowledge implicit and internalised conceptions held by my Self and only by knowing my Self, could I, researcher, transcend my Self and be fully present in dialogue with the Other, my participant. Reviewing the work of Sommers-Flanagan and Sommers-Flanagan (2003), Draguns references their view of the need for interviewer to proceed from a recognition of “the affective reactions” that dialogue might evoke in the participant (p. 751). This reinforced the need to know my Self prior to engagement with the Other: particularly when the dialogue was of a sensitive and evocative nature.

1.8 About Alzheimer’s and Dementia

Initially identified as an unusual disease of the cerebral cortex, it was in 1906 that Dr Alois Alzheimer presented a conference paper addressing both the symptoms experienced by a patient across the last five years of her life and the autopsy findings relating to the condition of the patient’s brain following her death (Alzheimer’s Disease International, n.d.). George, Whitehouse, and Ballenger (2011) advise that it is now over 100 years since the condition that was to become known by the name of its “discoverer” was formally established as a distinct disease and described in the German psychiatry textbook (Kraepelin, Emil, 1910. Psychiatrie, [eighth edition]). George et al. also explain that since that time, the condition as initially described has undergone various permutations. They further state that ongoing evolution carries important
implications for the clinical treatment and cultural placement of persons who are given the diagnosis. For, while researchers in the field of neuroscience have made huge strides in understanding Alzheimer’s disease, it is still generally recognised as being both irreversible and progressive: culminating in severe dementia and death.

Global research continues and is supported by multinational infrastructure networks. As recently as July of 2016, researchers at Flinders University’s School of Medicine in South Australia, working in collaboration with US researchers from the Institute for Molecular Medicine and University of California, reported they had developed a vaccine that is said to target the abnormal proteins that trigger Alzheimer’s. It is believed that the drug could be used to prevent the disease as well as to treat millions of people already diagnosed and is scheduled for clinical trials to begin 2019-2021 (Petrovsky, 2016). A significant breakthrough was also acknowledged just eight months earlier when, on November 13, 2015, Dr Dale Bredesen (Bredesen, 2017) busted what he termed “the myth of non-reversibility of Alzheimer’s”. At the 56th Annual Conference Transitional Nutrition: Optimizing Brain Health, Dr Bredesen was awarded recognition for his ground-breaking research in the field of integrative and functional medicine. Bringing together the best of Eastern and Western medicine to develop The Bredesen Protocol™, Dr Bredesen has pre-empted what he terms as “the dawn of the era of treatable Alzheimer’s”. Focussing intervention on the balancing of synaptic signalling through metabolic enhancement for neurodegeneration (MEND), Dr Bredesen has demonstrated reversal of Alzheimer’s disease, with the intervention of personalised treatment for patients in the early stages of onset and diagnostic assessment.

1.8.1 – Alzheimer’s disease: What is it?

Summers (2014) states that typically, the earliest recognisable stages of Alzheimer’s disease are marked by memory impairment related to recent and current events. Impairment to memory may also be accompanied by subtle functional decline to a second cognitive domain such as language (presenting as difficulty in finding words or in explaining things to others). He advises that other domains that also become recognisably impacted are the spatial domain (presenting in behaviours such as becoming lost in familiar locations) and the executive domain (presenting as difficulty...
in coping with unfamiliar surroundings or with new or different tasks). Further claim is made that while memory impairment has traditionally been the first recognisable domain of change, recent research indicates that atypical presentations occur in which memory impairment presents later than impairment to non-memory domains. These variables would point to recommendation for revision to diagnostic criteria.

Definitions of Alzheimer’s disease are many and varied, with each definition giving a snapshot of the complex landscape:

a) Alzheimer Europe (2014a) defines Alzheimer’s disease as a progressive, neurodegenerative disease that causes gradual deterioration of tissue of the nervous system. It is characterised by death of nerve cells in several areas of the brain, leading to loss of mental functions such as memory and learning.

b) For the Fisher Center for Alzheimer’s Research Foundation (2008/2010/2014), Alzheimer’s disease is identified as “a fatal brain disorder” and “a disease of the aging” (p.5, 2014).

c) According to Medical Dictionary (n.d.), Alzheimer’s disease is a neurologic disease that is characterised by loss of mental ability enough to interfere with normal activities of daily living. It is not present from birth, usually occurs in old age, and is marked by a decline in cognitive functions such as remembering, reasoning, and planning.

d) Referring to the condition in terms of a progressive disease that destroys memory and other important mental functions, Mayo Clinic (n.d.) claims that in Alzheimer’s disease, the brain cells degenerate and die: causing a steady decline in memory and mental function. The authors of the report explain that while current medications and management strategies help persons with Alzheimer’s disease to maximise function and to maintain independence, symptom minimisation and relief is only temporary.

e) Perhaps the most comprehensive definition of Alzheimer’s disease is presented by Summers (2014) who, with reference to Alzheimer’s Association (2009), states that:

Alzheimer’s disease is a progressive disease, commencing with mild and relatively circumscribed deficits that gradually worsen to become a severe dementia with widespread and marked impairments to cognitive, social and behavioural functioning. The speed of progression of impairment is
variable from individual to individual, with death occurring between two and 20 years post-onset, on average within 10 years. (p. 250)

Alzheimer’s disease is described by Simank and Strickland (1986) as “a family disease” (p. 50). The reason given is that as the onset of cognitive degeneration and physical debilitation advance, the caregiver, who is usually a family member, is involved in a progressively more active role in caring for the loved one who has Alzheimer’s disease. Characteristics of the condition as outlined by Alzheimer Europe (2014b) include memory loss and inability to carry out voluntary and purposeful movements (for example, tie shoe laces, fasten a button, turn on a tap, turn on the television). There is also loss of ability to speak or to understand spoken, written, or sign language, and loss of ability to recognise what objects are and what they are used for. Personality and mood changes are characteristic of the epidemiology: for example, a person who has always been quiet, polite, and friendly can become loud and ill-mannered; or a dominant and controlling person could mellow and become placid and warm. Wandering, incontinence, disorientation, aggression, weight loss, inability to chew and swallow, wasting of muscle, and increased vulnerability to infection characterise advanced progression into dementia. While dementia is now named as cause of death,8 comorbidity resulting from breakdown in immunity often accelerates death by increasing a patient’s vulnerability to infections such as pneumonia.

According to George et al. (2011), a critical engagement of the history of Alzheimer’s disease and associated disease related terminology has evolved in relation to concepts such as dementia. Such evolution raises a number of questions about how labels and emergent diagnoses such as Neurocognitive Disorders and Mild Cognitive Impairment might continue to evolve and be identified in future editions of Diagnostic and Statistical Manuals of Mental Disorders (DSM).

In relation to DSM references, it is interesting to note the research results of Summers (2014) and Summers and Saunders (2012) who proposed that not all patients diagnosed with Mild Cognitive Impairment progress to Alzheimer’s disease and that “episodic memory impairments are not unique to AD” (Summers & Saunders, p. 502). In citing the work of Brooks, Iverson, Holdnack, and Feldman (2008) and Brooks,

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8 Refer to 1.8.4, Alzheimer’s disease and dementia: Issues of diagnosis.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: Iverson, and White (2007), Summers and Saunders also note that “subclinical impairments (mild form of condition with no detectable symptoms) to single cognitive functions are not uncommon in the normal adult population” (p. 502).

1.8.2 – Alzheimer’s disease: Where does it all begin?

The course of the disease, from onset to death, does not span a definitive time-frame and varying estimates are reported by different researchers. Alzheimer’s Association (2014) suggests a time frame that can span from five years to in excess of 20 years, with death occurring on average from four to eight years from diagnosis. Summers (2014) poses a time-frame spanning two to 20 years from onset to death: death occurring on an average of four to 10 years from diagnosis. Gupta (2015) claims that Alzheimer’s may start 20 to 30 years before lapses in memory begin to become problematic. These figures present a possible scenario whereby seeds of cognitive degeneration could be sprouting before cognitive development has completed.

Based on Gupta’s estimates of pre-problematic or pre-observable onset symptom recognition partnered with Summers’ onset to death estimates, it is possible that an extended time-frame for long-term support and care for a loved one, from a pre-observable stage of onset to end of life, could span 50 years. Such is reality and such is the relationship with a lived experience where the only definitive end factors for a caregiver are abandoning the role of primary caregiver or death: death of a very special person who is the care receiver or death of self, the primary caregiver.

According to Fisher Center for Alzheimer’s Research Foundation (2008/2010), multiple factors, both inherited and environmental, interact to cause the disease. However, this statement is claimed by Summers (personal communication, July 1, 2015) to be both supposition and conjecture. For, as he explains, while the actual cause of Alzheimer’s disease remains unknown, the single largest risk factor is age. The notion of advanced age being the greatest risk factor is also acknowledged by other researchers in the field of Alzheimer’s disease and the broader field of dementia research: for example, Access Economics (2009); Alzheimer’s Association (2014); Mayeux and Stern (2012); Neuroscience Research Australia (n.d.); Prince, Albanese, Guerchet, and Prina (2014); Summers (2014); World Health Organisation (2015).
In contrast to the dominant significance of age factor, recent research out of Flinders University School of Medicine South Australia identifies diabetes (particularly type 2) as being a major risk factor for Alzheimer’s disease (Petrovsky, 2016). Other contributing risk factors listed by these researchers include family history, Down Syndrome, stroke, obesity, hypertension, depression, head trauma, exposure to environmental toxins, gender (males, vascular related; females, age related), smoking, and heavy alcohol consumption. Positive protective relationships (also listed by the above cited researchers) have been found to include high level of education and high intelligence quotient, intellectually demanding occupations, increased physical activity, social integration, cognitive activity, engagement in leisure activities, and mild to moderate alcohol consumption. Inconclusive protective relationships (also noted by the above cited researchers) include caffeine consumption, cholesterol lowering medications, non-steroidal anti-inflammatory drugs (such as aspirin), omega-3 fatty acids, race and regional variation, hormone replacement therapy, and moderate weight gain.

Together with causal and protective factors, major challenges identified by World Health Organisation (2015) include stigmatisation, lack of access to treatment, delays in diagnosis, insufficient support for caregivers, and absence of cure. Help for both caregivers and care receivers is deemed to lie in early diagnosis (discussed below), keeping active both physically and mentally, appropriate treatment for physical illness and psychological distress, information and support, research to improve care and to find a cure, and laws to protect human rights.

1.8.3 – From Alzheimer’s to dementia

With a functional meaning defined in terms of losing the ability to remember, to think, and to perform, Alzheimer’s disease is also said to be the most common form of dementia (Access Economics, 2009; Alzheimer’s Association, 2014, 2015a; Alzheimer’s Australia, 2015c, 2016; Alzheimer’s Foundation of America, 2015; Mayo Clinic, n.d.; Mebane-Sims, 2009; Neuroscience Research Australia, n.d.; Prince et al., 2014; Reitz, Brayne, & Mayeux, 2011; Summers, 2014; World Health Organisation, 2015). In addition, Alzheimer’s disease is further recognised as being significant in the diagnosis of mixed dementia: the most common combination of contributing factors
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease:

being Alzheimer’s disease and vascular dementia (Alzheimer’s Association, 2014; Prince et al., 2014; Summers, 2014).

Considering this broader landscape, Summers (2014) speaks of progressive development of neurofibrillary tangles and senile/neuritic plaques that develop in the brain, marking the progressive death of the neuronal cells and the gradual shrinkage of the brain. He defines dementia as referring to “a group of degenerative disorders that produce a condition of cognitive decline and functional impairment” (p. 249) and states that while dementias can be irreversible, static, or reversible, the term clinical dementia is most commonly reserved for “the progressive irreversible forms of cognitive and functional decline associated with neurodegeneration of brain tissue” (p. 249).

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<thead>
<tr>
<th>CHANGES IN THE ARCHITECTURAL STRUCTURE OF THE BRAIN</th>
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<tr>
<td><strong>UNDER THE MICROSCOPE</strong></td>
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<tr>
<td><img src="image1.png" alt="Alzheimer cells" /></td>
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<tr>
<td><img src="image2.png" alt="healthy cells" /></td>
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<tr>
<td>Effects of Alzheimer's disease:</td>
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<tr>
<td>• Alzheimer’s tissue has many fewer nerve cells and synapses than a healthy brain: synapses being tiny gaps between cells where the tips almost touch so as to transmit electronic signals.</td>
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<tr>
<td>• Plaques that are described as abnormal clusters of protein fragments, build up between nerve cells.</td>
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<tr>
<td>• Dead and dying nerve cells contain tangles, which are made up of twisted strands of protein.</td>
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<tr>
<td>Scientists are not absolutely sure what causes cell death and tissue loss in the Alzheimer's brain. However, plaques and tangles are considered to be the prime suspects.</td>
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<tr>
<td><strong>MORE BRAIN CHANGES</strong></td>
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<td><img src="image3.png" alt="healthy brain" /></td>
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<td><img src="image4.png" alt="advanced alzheimer's" /></td>
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<tr>
<td>Massive cell loss changes the whole brain in advanced Alzheimer’s disease. This slide shows a crosswise “slice” through the middle of the brain between the ears.</td>
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<td>In the Alzheimer's brain:</td>
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<tr>
<td>• The cortex, which is the outer covering of the brain, shrivels up and damages areas involved in thinking, planning and remembering.</td>
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<tr>
<td>• Shrinkage is especially severe in the hippocampus, an area of the cortex that plays a key role in formation of new memories.</td>
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<tr>
<td>• Ventricles, which are fluid-filled spaces within the brain, grow larger.</td>
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Figure 2 - Changes in the architectural structure of the brain: Changes in the architectural structure of the brain are noted during microscopic examination of tissue. Adapted from “Inside the brain: An interactive tour”. Alzheimer’s Association (2015/2018a).
Summers also states that dementias can be either “cortical”\textsuperscript{9} or “subcortical”\textsuperscript{10}. The distinction, claims Summers, reflects a “difference in the resulting deficits to cognitive function, emotional and behavioural regulation” (p. 249). Summers further states that Alzheimer’s dementia is a cortical dementia, “commencing with mild and relatively circumscribed deficits that gradually worsen to become a severe dementia with widespread and marked impairments to cognitive, social and behavioural functioning” (p. 250).

While the significance of Alzheimer’s disease is widely acknowledged in diagnoses of dementia, estimates of the degree of significance differ according to different sources; with variation ranging between 50%-80% on a global scale. In acknowledgment of these current findings, best estimate, suggests Summers (personal communication, July 1, 2015), is that “the majority” of dementia cases are so-called “mixed dementia”, usually vascular plus Alzheimer’s.\textsuperscript{11}

Tracing the history of Alzheimer’s disease, George et al. (2011) noted that the phenomenology of dementia was first recorded in various genres of ancient Egyptian writing. They also cited a number of publications crediting the ancient Greeks with having recognised and formulated the concept of dementia: a term said to have been coined by Celsus, in the first century of the Christian Era. The term dementia has also long carried social implications for those diagnosed: having association with reduced civilian and legal competencies and with elevated entitlement to support and protection. According to Alzheimer’s Society (2008), one of the most prominent characteristics of dementia discourse is the pivotal role that stigma plays in defining the experience of the condition.

\textsuperscript{9}“cortical” – arising from pathological changes in the outer grey matter regions of the cerebral hemispheres.

\textsuperscript{10}“subcortical” – resulting from neuropathological changes in the white matter and deep grey matter regions of the cerebellum and cerebral hemispheres.

While recognising that stigma against people with dementia is widespread with far reaching consequences, World Health Organisation (2015) acknowledges that stigma also accentuates and deepens distress experienced by both persons with dementia and their families. As Alzheimer’s disease advances and as the architectural structure of the brain changes, patients become increasingly dependent on others for every aspect of their care with direct correlation between level of care and stage of progression.

1.8.4 – Alzheimer’s disease and dementia: Issues of diagnosis

As an alternative to Reisberg’s Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982/2007), Alzheimer’s Association (2014) speaks of a new three stage criteria guidelines model, developed in 2011 and proposed for clinical reference. It is noted that, as yet, the guidelines do not establish diagnostic criteria that doctors can use for purposes of diagnosis and additional studies are needed before the revised criteria and guidelines are ready for use in the physician’s office. However, upon scrutiny of the three stage model, while stage three appears to acknowledge some alignment with Reisberg’s traditional seven stage model, there also appears to be little in the first two stages that would reconcile this proposed model of diagnostic criteria guidelines with Reisberg’s Global Deterioration Scale. The criteria guidelines are outlined as follows:

1) **Stage one: Preclinical Alzheimer’s disease** – No evidence of outward symptoms but evidence of early brain changes detected by brain imaging or biomarker tests that show brain activity and distinguish Alzheimer’s from other forms of dementia. However, as explained by Summers (personal communication, July 1, 2015), evidence for this as a diagnosis is very patchy and inconsistent; to the point that it reflects a potential development in the distant future, as opposed to something that can be done now.

2) **Stage two: Mild Cognitive Impairment (MCI) due to Alzheimer’s disease** – Evidence of mild symptoms but can still perform everyday tasks. As explained by Summers (2014, 2015), there is significant debate about the validity of MCI as a diagnosis. Referencing the Tasmanian MCI study, which comprised two independent longitudinal studies (2006-2010 and 2011-2014), Summers noted outcomes indicating that MCI has low predictive value for developing dementia and therefore, is deemed to be “a rare and unstable classification” (2014, p. 254).
3) **Stage three: Dementia due to Alzheimer’s disease** – Symptoms are more pronounced and interfere with the carrying out of everyday tasks. It is in this third stage of the three stage criteria guidelines model that there appears to be scope for reconciliation with Reisberg’s Global Deterioration Scale. It is only this stage that focuses on the emergence and development of cognitive, physical, social, and behavioural, symptoms. All aspects of symptomology directly impact patient and caregiver experience. All clearly reference the progressive worsening of function and the spread across different cognitive domains, with appearance of deficits to previously unaffected cognitive functions not due to another medical condition: for example, a psychological disorder such as depression (Summers, 2015).

World Health Organisation (2015) also proposes a three stage model that collapses Reisberg’s seven stage model and links symptoms with stage of progression:

1) **Early Stage (may need some gentle reminders):** forgetfulness, losing track of time and becoming lost in familiar places;

2) **Middle Stage (needs organisational support and prompts):** becoming forgetful of recent events and people’s names; becoming lost at home; having increased difficulty with communication; needing help with personal care; experiencing behaviour changes, including wandering and repeated questioning;

3) **Late Stage (total dependence):** becoming unaware of the time and place; having difficulty recognising relatives and friends; having an increasing need for assisted self-care; having difficulty walking; experiencing behaviour changes that may escalate and may include sexual inappropriateness and aggression.

Perhaps a fourth stage could be added to the above three stages and that would be the **Final Stage (need for palliative care):** characterised by total loss of function, followed by transition through death.

The most common cause of death for persons with Alzheimer’s disease and associated dementias is reported by Fisher Center for Alzheimer’s Research Foundation (2008/2010/2014) as being a co-occurring infectious illness, such as pneumonia. However, while this may represent the situation beyond Australian shores, Summers (personal communication, July 1, 2015) explains that, technically, this is incorrect and inconsistent with the current Australian situation. Advising that Death Certificates in Australia now list dementia as cause of death, Summers also explained that before 2000,
dementia could not be listed as cause of death. Therefore, conditions such as respiratory failure, pneumonia, and heart failure were often reported as cause of death, whereby misrepresenting the statistical data with reference to death from Alzheimer’s related dementia. Consequently, stated Summers, only since the turn of the century (2000), are there accurate mortality rate data for dementia available from the Australian Bureau of Statistics webpage which substantiates the statistics listed above in 1.5, The Research Journey.

Considering diagnosis, Bunn et al. (2012) suggest that there is evidence that many patients who meet the criteria for dementia never receive a formal diagnosis or may receive a diagnosis late in the disease trajectory. Alzheimer’s Association (2015c) states that, in the US, only 45% of people with Alzheimer’s disease or Alzheimer’s related dementia (or their caregivers) report being told of their diagnosis. A figure of 45% is also noted by World Health Organisation (2015) as reflecting the global estimate of diagnosis. Reports from Alzheimer’s Disease International (2015a) show that most people currently living with dementia have not received a formal diagnosis. It is also claimed by these same sources that in high-income countries, only 20%-50% of dementia cases are recognised and documented in primary care. It is further stated that the treatment gap is much greater in low and middle-income countries, with one study in India suggesting that 90% of people with dementia remain unidentified. The implications of these statistics suggest that, if extrapolated to cover a world-wide context, 78% of people living with dementia have not received a diagnosis and therefore, have no access to treatment, care, or support other than what can be provided by family. Support available to the primary caregiver could be exponentially difficult to access. For people who have Alzheimer’s disease and who are without family support, the prognosis is a future lived out in destitution.

As noted by Summers (personal communication, July 1, 2015), this diagnostic summary reflects access or lack of access to appropriate diagnostic and or support services, even in industrialised countries. Summers also stated that diagnosis is based on symptoms, not on biomarkers that objectively measure and evaluate the biological or pathogenic processes. Summers further advised that symptom profile is variable and that in addition to the variability factor a lot of people just do not want to know and avoid seeking appropriate diagnosis. As a final point in considering diagnosis,
Summers explained that general practitioners are the first port of call when symptoms begin to present and Australian research indicates that general practitioners are less than 50% accurate in detecting and diagnosing Alzheimer’s disease and Alzheimer’s related dementias. This, Summers claimed, is partly because in a single year, the average general practitioner would come across only two or three new cases of Alzheimer’s disease. Therefore, it seems reasonable to infer that Alzheimer’s disease and dementia are not front and foremost in the clinician’s mind when assessing older patients and that other conditions take precedence as a far more prevalent diagnostic consideration.

In further acknowledgment of the study report of Bunn et al. (2012), it is noted that a wide variability in practice and attitude to diagnostic disclosure is referenced: with some professionals being worried about the possible harm of early diagnosis associated with a condition that is widely seen as being untreatable, irreversible, and life-changing. In opposition to advocates of delayed diagnosis, Bunn et al. merge their voice with researchers who advocate growing support for early diagnosis, including Alzheimer’s Association (2015c); Alzheimer’s Australia (2015b); Aminzadeh, Molnar, Dalziel, and Ayotte (2012); Beard (2004); Cooper, D., (2014); Dauwels, Vialatte, Musha, and Cichocki (2010); Hydén and Örulv (2009); Morris et al. (2001); Summers (2014); Tierney et al. (1996). Those advocating accurate and early diagnosis speak to research outcomes that support a range of benefits:

a) Deemed to be the most important of all considerations, is the right of the individual to know what is happening to them. As explained by Summers, there are overriding ethical codes that would not support withholding a diagnosis unless provision of that diagnosis would put the person at risk of harm (for example, suicide) or if the person lacks capacity (M. Summers, personal communication, July 1, 2015);

b) Minimisation of identity related distress associated with not knowing why significant cognitive and behavioural changes are happening;

c) Enhanced opportunity for improvement in quality of life through knowledge and through development of management and coping skills;

d) Enhanced possibility of early interventions delaying onset of dementia, resulting in prolonging quality of life while also decreasing health care expenditure;

e) Enhanced opportunity for gaining appropriate information and for accessing support in relation to managing for both present and future life planning;
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland

f) Enhanced opportunity to make sense of changes in life and in identity thus alleviating uncertainty by patients and families as to the true cause of perceived cognitive decline;
g) Enhanced opportunity for early access to dementia therapy with a goal of maximising a period of relatively good function;
h) Enhanced opportunity for patients to participate in planning for their future and in-futures planning for directives in relation to palliative care and end-of-life arrangements at a stage when decision-making capacity is minimally affected;
i) Maximising probability of success with focus being on a multidisciplinary approach to development of the most relevant and effective therapeutic strategies in support of both patient and caregiver;
j) With knowledge, patients and caregivers are empowered in life planning, end-of-life planning, and in delaying admissions to care facilities.

Neuropsychological assessment and good classification results that focus on early diagnosis are also recognised as being especially important in enabling access to appropriate medications that can alleviate stressful symptoms. For example, as discussed by Fletcher (2015) and Herper (2015), pharmaceutical agents are currently being developed for intervention in arresting the progression of the disease and in helping lessen or delay symptoms such as memory loss and confusion; even if for a limited time. Much in relation to cutting-edge research was also addressed at the Alzheimer’s Association International Conference, July 2015 (Alzheimer’s Association, 2015d) and successive conferences convened in 2016, 2017, and 2018 (electronic communication with Alzheimer’s Association).

1.9 Incidence and Prevalence of Alzheimer’s Disease

In 1982, Beck, Benson, Scheibel, Spar, and Rubenstein proffered the notion of “the silent epidemic”, predicting that “the graying of America will be accompanied by an epidemic of major proportions (dementia or intellectual impairment) that will have an impact on all aspects of the health care system” (p. 231, brackets included in original text). Beck et al. also predicted the world-wide need for health professionals, health planners, families, and the whole of society, to recognise that many curable physical and emotional diseases in the elderly are associated with intellectual impairment that may be
difficult to distinguish from irreversible brain disease of the Alzheimer type. It was also noted that even with normal onset of the aging process, muscle systems become stiffer, motor acts are performed more slowly, and chronic lower extremity pain may result from activity continued against muscle tone; adding to the difficulty of differentiating between that which is normal and that which is not.

Considering the notion of “Strategizing about Alzheimer’s”, Hodgson (2011) refers to Alzheimer’s disease as the disease of the 21st century and she also presents a phenomenological viewpoint of the “Alzheimerization” of our culture (p. 876). Speaking in a similar vein to that expressed by Beck et al. (1982), Hodgson cites Alzheimer’s disease as being one of the two most feared of all diseases by adult men and women: second only to cancer and ahead of heart disease and stroke. In support of her argument, Hodgson cites the proliferation of cultural and academic attention given to the concept of Alzheimer’s disease in literature (fiction and non-fiction), film, television, social media, newspaper, and magazine. She also speaks of how the terminology of Alzheimer’s and dementia has “crept into the vernacular and the popular psyche” (p. 876). As an additional factor, Hodgson suggests that because Alzheimer’s is an age-related disease, the longer we live the more likely we are to develop this particular type of dementia. Contributing factors are said to include demographic statistics related to increasing longevity, aging of the “Baby Boomers”, and the prospect that life expectancies at birth are increasing. However, the good news is that there is hope: not only for those with clinically normal age degeneration as identified in Stage One of Reisberg’s Global Deterioration Scale (Reisberg et al., 1982/2007, p. 1136), but also for those with degenerative symptoms associated with the earliest clear-cut clinical deficits as might appear in Stage Three: the stage of early diagnosis of Alzheimer’s disease or Alzheimer’s related dementia (Reisberg et al., 1982/2007, p. 1136).

As Beck et al. (1982) explain, along with the natural progression of degeneration, “a persistent residual capacity for regrowth seems also to characterize the aging nervous system” (p.235). They advise that this capacity of nerve cells to increase their size and surface area, even as they fail with age or disease, attests to the remarkable longevity and tenacity of brain tissue. Testimony to the validity of this concept features in the studies of Doidge (2010), particularly in relation to stories about “Building herself a better brain” (pp. 27-44), “Redesigning the brain” (pp. 45-92), “Turning our ghosts into...
ancestors” (pp. 215-244), and “Rejuvenation” (pp. 245-257). Kulkarni and Firestein (2012) and Liu, Pasini, Shelanski, and Greene (2014) also speak of the breakthrough discovery that regrowth of nerve cells occurs in the adult mammalian brain. They see these discoveries as opening new avenues for therapeutic possibility in treating central nervous system diseases by repairing damage through cell transplantation and inducing regeneration of neurons from within cell tissue.

1.9.1 – Incidence and prevalence of Alzheimer’s disease: A global perspective

Even in the light of hope in an age where the miracles associated with research into brain neuroplasticity are becoming increasingly prevalent, the enormity of impact from the silent epidemic cannot be dismissed. According to Alzheimer’s Disease International (2015b), the devastating reality is that, globally, the number of people living with dementia is estimated to be in excess of 46.8 million; with world-wide projection set to skyrocket to 76 million by 2030 and 131.5 million by 2050. The global estimated cost of dementia for 2015 is said to have been in the vicinity of US$818 billion; an estimated US$572.6 billion being Alzheimer’s related expenditure, based on a 70% incidence factor. The projected budget requirement by 2050 is estimated to be US$4 trillion. The estimate of people living with dementia in America in 2015 was reported to be in excess of five million (Alzheimer's Association International Conference, 2015). In March of 2018, this figure is now reported to be 5.7 million people living with Alzheimer’s (Alzheimer’s Association, 2018b). Transferring incidence into caregiving, the 2018 American figures report that 16.1 million persons are providing unpaid care of 8.4 billion hours at a cash value of US$232 trillion dollars. The estimate of people living with dementia in Australia is reported to be in excess of 413,106 (Alzheimer’s Australia, 2017).

World Health Organisation (2015) defines dementia as being one of the major causes of disability and dependency among older people worldwide; having physical, psychological, social, and economic impact on caregivers, families, and society. With 7.7 million new cases reported every year, the estimated proportion of the general population aged 60 and over who have dementia is stated as being five to eight persons

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12 Key facts and statistics related to the Australian profile are reported by Alzheimer’s Australia (2017) and attached as Appendix D.
in every 100, at any given point in time. The global incidental profile is reported by Alzheimer’s Disease International (2015b) to be one new case every three seconds.

Milne (2010) advises that at the time of her study in the UK, over 700,000 people were living with dementia at a cost to the economy exceeding £17 billion per annum: this cost being borne primarily by family caregivers who provided intensive support to over three quarters of the people living with dementia and residing in their own homes. At the time of her study, the projected figure for incidence of people living with Alzheimer’s related dementia was estimated to rise to over 1.7 million by 2015. However, updated facts issued by Alzheimer’s Society (2015) put that figure at 850,000 and soaring to 2 million by 2051. Referencing results of an earlier study conducted in partnership with Dening (cited by Milne as Dening & Milne, 2008), Milne estimated that one in three people will die from conditions such as pneumonia, resulting from functional complications associated with Alzheimer’s related dementia.

In Switzerland it is reported that approximately 100,000 people are living with dementia; with the number expected to increase to almost 300,000 by 2060 (Alzheimer Europe, 2014c; and 2014d, PO 158. National Dementia Strategy, 2014-2017). In Italy, 5.3% of men and 7.2% of women over the age of 65 have a diagnosis of dementia (Varela, Varona, Anderson, & Sansoni, 2011). In Singapore, it is anticipated that by 2020, there will be 53,000 people living with dementia; expected to expand to 187,000 by 2050 (Alzheimer Europe, 2014d, PO 175. Ethical Concerns in Institutionalized Care Settings). Research studies undertaken across France, Germany, Spain, Poland, Sweden, and the US (Blendon et al., 2012; Lindholm, Gustavsson, Jönsson, & Wimo, 2013; Mura, Dartigues, & Berr, 2010) report that few people recognise the severity of Alzheimer’s disease, even though it is the seventh leading cause of death in high income countries and the only cause of death across the top 10 that, at the time of writing, can be neither prevented nor cured.

It is worthy of note that in Australia, while in 2015 dementia was reported by Alzheimer’s Australia (2015a) to be the third leading cause of death for men and the second leading cause of death for women, in the space of two years (2015-2017) it was reported that dementia had become the second leading cause of death across both genders: a contributing factor in 5.4% of male deaths and 10.6% of female deaths, per
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: 36

The collective reality from onset to end of life and beyond.  

Judith R Boyland

annum (Alzheimer’s Australia, 2017). One needs also to be mindful of the fact that 50%-80% of those deaths are Alzheimer’s related. It is also reported that a large proportion of the public has had some experience with Alzheimer’s disease and that fear of Alzheimer’s gets worse with age: a reasonable concern considering that age and type 2 diabetes are named as being the most prevalent risk factors.

Alzheimer’s Australia (2014a) profiled a notable rise in the incidence of younger onset Alzheimer’s. With care receivers in their forties being diagnosed, the incidence of early onset Alzheimer’s has potential for a huge impact on families; particularly single parent families with no extended family and limited support networks. As previously discussed, figures of the situation in Australia as released by Alzheimer’s Australia (2017) indicate that 413,106 people are living with dementia. This figure represents a rise of 81,106 in a three-year projection, given that a figure of 332,000 was the estimate from 2014 (Alzheimer’s Australian, 2014a). However, while the projection of care receiver numbers escalates, the figure of 1.2 million Australians involved in care of people with dementia remains constant across 2014-2016 (Alzheimer’s Australia, 2016), indicating a significant increase in carer load and carer stress burden.

The global perspective as reported by Alzheimer’s Disease International (2015b) reveals that the prevalence of dementia increases exponentially with age across all regions. Prevalence is also reported to double with every 5.5 years of age in North America, 5.7 years in the Asia Pacific, 6.5 years in West and Central Europe, 6.9 years in Australasia, 7.2 years in the Caribbean and sub-Saharan Africa, and 10.6 years in Southeast Asia. According to 2015 estimates, East Asia is the world region with the most people living with dementia (9.8 million), followed by Western Europe (7.4 million). Closely following are South Asia (5.1 million) and North America (4.8 million). The country having the largest number (9.5 million) is China. It is estimated that 58% of all people with dementia live in countries currently classified by the World Bank as low or middle-income countries. The proportion of people with dementia living in these same countries is estimated to increase to 63% in 2030 and 68% in 2050. Future projections suggest that between 2015 and 2050, the number of people living with dementia in what are now high-income countries will increase by 116%. This is said to compare with a 227% increase in upper-middle-income countries, 223% in lower-middle-income countries, and 264% in low-income countries.
Profiling Queensland incidence, with reference to admitted patient episodes of care for Alzheimer’s disease and dementia with Alzheimer’s, in both public and private hospitals, figures for the period July 2014/June 2015 present as being 828 in total; with 629 of those episodes occurring in the region bounded by Sunshine Coast, Metro North, Metro South and Gold Coast. Compared with figures recorded July 2009/June 2010, there is a significant increase, where episodes of admission report 440 across the State of Queensland with 318 being the reported figure across the regions of Sunshine Coast, Metro North, Metro South and Gold Coast. To add Darling Downs into the regional mix shows an increase to 657 for July 2014/June 2015 and an increase to 355 for July 2009/June 2010. While Sunshine Coast, Metro North, Metro South, and Gold Coast record an increase in incidence of admission, Darling Downs records a drop in incidence of admission from 37 in 2009/2010 to 28 in 2014/2015 (Statistical Reporting and Coordination, Health Statistics Unit, Department of Health, August 13, 2015). While this statistical profile is interesting, investigation of contributing factors in relation to the drop in incidence in admission across the Darling Downs is beyond the scope of this project. However, one possibility could be that patients who may have been admitted to Darling Downs regional centres in the fiscal year of 2009/2010 are now being transported to centralised hospitals, due to closures and reductions in hospital facility in the regions.

1.9.2 – Incidence and prevalence of Alzheimer’s disease: A futures projection

Reflecting on the incidence and prevalence of Alzheimer’s disease and Alzheimer’s related dementia as discussed above, it is interesting to note the statement of Cirillo (2013) that dementia is not only a global public crisis but is also a global public priority. The statistics, he suggests, are compelling. Considering his observation in light of updated information released in 2014, 2015, 2016 and 2017 (as discussed above), one might suggest that statistical evidence is becoming more compelling and projecting heightened urgency for accelerated research focused on stabilisation, reversal, and prevention of Alzheimer’s disease.

The flow-on implication for heightened caregiver support also needs to be considered under the overarching umbrella of “urgency”. In looking to future

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13 Data profile attached as Appendix D.
development, Blendon et al. (2012) acknowledged that much could change in coming years, should a single reliable test be developed, an effective form of treatment be found, or certain lifestyle changes be scientifically recognised as being effective. Given the Petrovsky report (July 13, 2016) and development of The Bredesen Protocol™ (Bredesen, 2017), fulfilment of just such a dream may be within the realm of possibility.

Ground-breaking research was also reported by Alzheimer’s Association (2015d). During the course of the Alzheimer’s Association International Conference (July, 2015), world-renowned researchers addressed the introduction of cutting-edge breakthroughs in Alzheimer’s science. Further breakthroughs have been reported at the conferences of 2016, 2017, 2018 (Alzheimer's Association, email communication).

These breakthroughs, it is reported, have the potential to change the field in relation to acceleration in methods of treatment, prevention, care, and hopefully, one day, a cure. Some of the most promising new studies reported at the 2015 Alzheimer’s Association International Conference include:

a) Emerging roles for imaging and fluid biomarkers in early detection of Alzheimer’s;
b) Risk factors for Alzheimer’s, dementia, and cognitive decline; and possible risk reduction techniques;
c) Advances in determining the causes of Alzheimer’s and other dementias, including genetics and lifestyle;
d) Exciting early results from a new treatment approach that targets common components of all the Alzheimer’s proteins. It is suggested that this approach could eventually have benefits not just for Alzheimer’s, but for other neurodegenerative diseases as well;
e) A new series of tests to help predict Alzheimer’s disease: thus enabling help for patients, caregivers, and medical practitioners in planning for the inevitable while also bringing hope that experimental treatments might work better the earlier they are used;
f) Development of an experimental drug (solanezumab) that may go beyond treating symptoms to changing the course of progressive degeneration and functional decline that are the key components of Alzheimer’s disease – study in progress;
g) The latest in Alzheimer’s drug trials at all stages of development;
h) Developments in therapies and tools to aid management of progressive
debilitation – such as the tool for balance and gait for persons with dementia;
i) New methods of testing that could help predict the development of Alzheimer’s,
years before people ever get symptoms and among those who do not yet have the
memory and thinking problems associated with the onset of symptoms;
j) A new pipeline of experimental therapies that have the potential to delay the onset
of Alzheimer’s disease.

Reflecting back to Beck et al. (1982), it is interesting to note that these researchers
predicted “important new developments” occurring in the “next decade” (the 1990s
leading into the new century). Future development, they suggested, would address the
cause, the pathogenesis, further refinement of laboratory investigation, and specific
therapeutic interventions in dementia. The coming of age of these predictions is noted
in the work of researchers and practitioners in the field of neuroscience, such as Chen
(2015); Doidge (2010); Esiri, Nagy, Smith, Bametson, and Smith (1999); Fletcher
(2015); Guzmán-Vélez and Tranel (2015); Herper (2015); Karren (2015); Liu et al.
(2014); Petrovsky (2016); Porges (2014, 2015); Siegel (2012); Summers (2014);
Summers and Saunders (2012).

It is also interesting to note that since the Reisberg et al. publication of “The
Global Deterioration Scale for assessment of primary degenerative dementia” (1982),
Reisberg has been sole author or co-author of numerous publications that reference
research development in relation to the treatment, management, and prevention of
Alzheimer’s disease. The latest publication is reported to be as co-author of the paper,
“Evidence for affective symptoms as an early manifestation of cognitive change”
(Guillo-Benarous et al., 2015). Prompted to investigate the premise that persons with
Subjective Cognitive Impairment have the subjective belief that memory is impaired
while they also demonstrate normal performance in testing situations, the aim of the
Guillo-Benarous et al. study is reported to be assessment of the nature of cognitive and
affective symptoms so as to develop tools for identifying early predictors of cognitive
decline in the evolution towards Alzheimer’s disease. The good news is that outcomes
of the study are reported to indicate that “affective symptoms might be early indicators
of cognitive and associated physiologic brain changes and could point to prevention
strategies” (p. 1072).
Repositioning the same thought process as that posited by Beck et al. (1982), one can but dream, hope, and trust that in the approaching “next decade” (the 2020s), researchers will have developed both a prevention and a cure for the degenerative, disempowering, and life-changing condition that we know as Alzheimer’s disease. This most debilitating and destructive disease could become the scourge of generations past.

1.10  Cultural Context of Care and Facility of Care Provision

The notion of “care” is defined by The pocket Macquarie dictionary (Bernard, 1989) as including aspects of worry, anxiety, concern; giving serious attention, solicitude, or caution; to heed; protection or charge; an object of concern or attention; to have a liking, or a taste, or a fondness for; to be inclined towards, or to look after. The notion of “carer” is defined as a person who looks after another person or people, especially aged or disabled relatives (p. 154).

A more comprehensive definition of care in the context of “caregiving” is posited by Schulz and Martire (2004) who vision caregiving in terms of:

The provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting. (p. 1 of download text)

Alzheimer’s Association (2014), refers to “caregiving” as “attending to another individual’s health needs … [and] often includes assistance with one or more activities of daily living such as bathing and dressing” (p. 30). Based on this definition of caregiving, Alzheimer’s Association reports that more than 15 million Americans provide unpaid care for people with Alzheimer’s disease and other dementias, totalling 17.7 billion hours of informal, unpaid care. This represents an average of 21.9 hours of care per caregiver per week or 1,139 hours of care per caregiver per year. With care valued at US$12.45 per hour at 2013 rates, the estimated economic value of care provided by family and other unpaid caregivers of people with dementia was reported to be US$220.2 billion in 2013 and was equated to eight times the total revenue of McDonalds for the year of 2012 (US$27.6 billion).
Alzheimer’s Association (2014) also reports that the value of informal care is nearly equal to the direct medical and long-term care costs of dementia. They further report that 85% of care provided is from family members. Given that 60%-80% of all diagnosed dementia cases involve solely an Alzheimer’s pathology, it is estimated that up to 12.75 million Americans are providing unpaid care at a cost of $187.17 billion per year: 85% of which is the contribution of family members who are caring for a loved one who has Alzheimer’s disease. While these statistics profile the landscape of Alzheimer’s care in the US, it is well within the realm of feasibility to consider that on a proportional population base and a similar socio-cultural profile, the Australian situation would be statistically similar to that of the US. As previously discussed, the Australian profile, as referenced by Alzheimer’s Australia (2017), is presented in Appendix C.

In exploring literature for the purpose of creating an historical perspective of care, it is found that the story begins in the era of 4000 BCE where “hospitals” were places of healing and hospitality associated with gods and deities in Greek and Roman empires and where there was a linking of religion and medicine in the ancient cultures of Egypt, Greece, and Rome. It is also stated that “institutionalised” care in hospitals stretches over 2,500 years. The earliest surviving text that describes the building of a hospital and the earliest accounts of a civic hospital system are said to be dated from the period between 100BCE and CE150. (Risse, 1999; Science Museum. Brought to Life, (n.d.). Expansion into the Medieval Islamic World (early 700s), Medieval Europe (late 700s–1,500s), Spanish Americas (early–mid 1,500s), Early Modern Europe (mid 1,500s–mid 1,600s) and Age of Enlightenment (late 1,600s–early 1,800s) has led to the development of modern hospitals across Europe (mid 1,700s–early 1,900s) and Church-sponsored hospitals and nursing services (mid 1,600s–current time).

John Hopkins University Press Blog (2012) advises that it was not until the late 1970s that Alzheimer’s disease began becoming increasingly known and it is interesting to note that the timing coincides with Reisberg’s research and his subsequent development of the Global Deterioration Scale (Reisberg et al., 1982/2007). Managing the condition medically within psychiatry and geriatric departments was becoming more common and it is said that the psychiatry department at the John Hopkins Hospital was one of the first hospitals, world-wide, to establish a special unit for patients with dementia. The blog also explains that, even at that time, Alzheimer’s disease remained
barely understood among the general public as the primary cause of dementia and memory loss in older patients.

In Australia, one of the first organisations reported to have established special facility for integrated aged care is said to be Hammondville, initially established in the Liverpool region of New South Wales in the 1940s, under the leadership of Anglican Archdeacon, R. B. S. Hammond. Today, operating as an independent Christian charity, HammondCare offers a wide variety of services in New South Wales and Victoria, including specialised aged and dementia care, palliative care, older person’s mental health, younger onset dementia, and carer support. They also undertake research programs in dementia and aged care, restorative care, palliative care, and pain management (HammondCare, 2015).

In contrast to hospital care or specialised facility integrated care, a search for information on the history of non-institutionalised care or family care elicits only one report, which traces the history of Family-Centered Care across four decades (Johnson, 2000). With specific reference to care as represented in the US, Johnson traces the development of family-centred health care, beginning with the conceptualisation of family-centred care (1960s), changes in the healthcare system (1970s), collaboration between family and health providers (1980s), healthcare reform (1990s) and directions of the Institute of Family-Centered Care non-profit organisation (1990s). Papers referencing “family care” have a general focus on contexts such as paediatrics, cardiac care, palliative care, cancer, and diabetic care. There is minimal reference to caring for family where the diagnosis is Alzheimer’s disease. There are also papers that report on individual stories across a variety of locations and across a variety of demographic and socio-cultural contexts: for example, Iran, Mexico, Italy; parent, in-law, step. No like-referenced history has been located regarding development of family care in Australia: a topic worthy of research but outside the scope of this project. There is no evidence of a collective narrative that represents multiple voices telling a story of the lived experience of family care in Queensland. Nor is there evidence that represents a multivoiced profiling of a landscape of lived experience when the loved one who is being cared for

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14 As referenced across Chapter 2, Literature Review, and as portrayed in the findings, Chapters 5 and 6 (particularly 5.4, Breadcrumbs in the Forest: Survival and Support), it is interesting to note similarities across the stories told by the sampled demographic when compared with those that profile the broader global demographic.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease. It is proposed that this project brings insight to the lived experience within the social construct of family care in Queensland: the socio-cultural construct being caregiving for a loved one who has Alzheimer’s disease.

Thus it is that the specific focus of this research project is situated in constituencies across South-East Queensland spanning the Sunshine Coast in the north to the Gold Coast in the south, the islands of Moreton Bay in the east to Toowoomba in the west. The demographic is the informal caregiver and the cultural context is reflected in the title of the project – *A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.*

1.11 Conclusion

Chapter One sets the context within which the research investigation takes place. It describes professional and personal journeys that have prepared and equipped the researcher, bringing the dialogic Self to this space and this time where “the dynamic multiplicity of I-positions in the landscape of the mind” is ready to intertwine through dialogic interchange: where I meet Thou. A cultural background to informal care has been discussed in conjunction with characteristics, prevalence, incidence, and socio-economic impact of Alzheimer’s disease, from both a global and an Australian perspective. Statistics portrayed in the literature relating to prevalence, incidence, and impact of Alzheimer’s disease and Alzheimer’s related dementias serve to illustrate the importance of research which investigates the construct of carer impact.

Chapter Two reviews the literature related to the construct of carer impact when the care receiver is a loved one who has Alzheimer’s disease: kin or colleague who holds a special place in the heart and the history of the caregiver. The initial point of impact in the caregiver’s journey presents a snapshot of transitioning from wellness to diagnosis, as seen through the eyes of both the caregiver and the care receiver. The final point of impact for the caregiver is transitioning to a life post Alzheimer’s.

…000…

The collective reality from onset to end of life and beyond.  
Judith R Boyland
CHAPTER TWO – LITERATURE REVIEW

What matters in today’s world
Is not the difference between those who believe and those who do not believe;
But the difference between those who care and those who don’t.

Abbe Pire (M-Auwal Gene III, 2015)

2.1 Introduction to Literature Review

Chapter One set the context within which the research investigation takes place. It laid the foundation upon which to create A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease and to profile The collective reality from onset to end of life and beyond.

Chapter Two discusses literature related to caring for a loved one who has Alzheimer’s disease. The Literature review began when I made the decision to pursue my doctorate and to do this through a qualitative investigation of a topic that was close to my heart on a personal level and highly relevant to me on a professional level. The review was conducted continuously throughout the investigation: beginning pre enrolment and concluding upon submission of the thesis. The major portals through which the review took place were on-line search, library access, and personal communication. Initial search strategies were built around key words related to specific aspects such as context, concept, process, and philosophical approaches. Information was manually collated and thematised. As the investigation evolved, searches and inquiry became more refined and focused.

The conceptual review is focused through a framework that encompasses 13 key constructs: (1) Living With Alzheimer’s/Alzheimer’s Dementia: Transitioning; (2) Transitioning to the Role of Caregiver; (3) Transitional Change; (4) Aspects of Impact: Stress Response; (5) Aspects of Impact: Loss and Grieving; (6) The Ripple Effect; (7) Support; (8) Barriers to Support; (9) Coping Strategies; (10) Coping With Abusive Behaviour; (11) Maintaining Dignity in the Midst of Chaos; (12) When it is Time; and (13) End of life.

Assuming a starting point of “normal”, as referenced in Reisberg’s Global Deterioration Scale (Reisberg et al., 1982/2007), literature in relation to the onset to
end-of-life trajectory, as experienced by both care receiver and caregiver, is reviewed. Discussion focuses on the impact of lived experience and culminates with the promise from the medical world to patients and families, that they will not be abandoned.

2.2 Living with Alzheimer’s/Alzheimer’s Dementia: Transitioning

When reading reports that deal with aspects of living with Alzheimer’s disease and Alzheimer’s related dementias, similarities are noted across different cultural contexts. While the focus of this project is on the caregiver, it needs to be acknowledged that the person who is the care receiver is also transitioning from “a life that was”, through “a life that is”, to a life destined to be functionally degenerative and shrouded in a cloud of unknowing.

Milne (2010) of Great Britain identified dementia as constituting one of the most serious challenges facing families and health and social services in the developed world. She also stated that loss of independence, role function, and identity, together with feelings of low self-esteem, low sense of value, and low sense of worth were widely evidenced during the early transition periods. Also from the UK, Trigg, Watts, Jones, and Tod (2011) commented on the impact that awareness of loss of memory function can have on the quality of life of the one who has Alzheimer’s disease. With reference to the rate of cognitive decline, the Romanian study of Solomon, Dobranici, Kåreholt, Tudose, and Lâzărescu (2011) found comorbidity to be a significant predictor of faster cognitive degeneration, particularly in relation to cardiovascular and cerebrovascular conditions.

Following synthesis and analysis of an extensive body of heterogeneous Western literature published in the 1990s, Canadian researchers, Aminzadeh et al. (2012), suggested that despite variations in systems of care, there seemed to be substantial consistency in core recommendations of most Western contemporary clinical practice guidelines. These, they explained, indicated that primary care of persons with Alzheimer’s should begin with “a recognition of the signs and symptoms of dementia, followed by a thorough multidimensional evaluation, sensitive diagnosis disclosure,

15 As previously referenced in Chapter One, notions of “life that was” and “life that is” are based on concepts of world that was and world that is developed by Dr Judith Murray (2005, 2016) as a model of loss and grieving.
collaborative care planning, and ongoing monitoring and management of evolving needs of caregivers” (p. 86). The recommendations of Aminzadeh et al. are reflected in the Clinical Practice Guidelines for Dementia in Australia: Recommendations (National Health and Medical Research Counsel [NHMRC] Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People, 2016/2017).

Significance of family observations of behavioural changes was noted by Williams, Klein, Little, and Haban (1986) who, following studies conducted in the UK, stated that the observations made by family members serve an important role in the description of dementia-related illnesses, such as Alzheimer’s disease. Williams et al. explained that a common clinical practice was to interview family and to informally gather information about the severity and the history of intellectual impairment, such as memory disorder and loss of language and speech ability due to damage to the central nervous system. They reported the results of their study as revealing that family members made reliable judgments of everyday cognitive impairment and that observer ratings significantly enhanced diagnostic efforts: especially when used in conjunction with neuropsychological tests and also in cases in which the patient could not participate in a full neuropsychological evaluation.

More recent reports relating to psychosocial factors as researched in Britain also reflect the significance of family observations, with Bunn et al. (2012) having found that family members often recognise that something is wrong; even before the patient with dementia does. Such was the situation faced by Marcell (2005) from the US who, in recounting her struggles in dealing with a father in the early stages of Alzheimer’s related dementia, stated that she found it inexplicable that her father was suffering from a disease over which he had no control and which had remained undiagnosed for at least 11 years; until she sought the care of a physician who was sympathetic to her plight.

A local example of the significance of family observation was presented in the story of Gierck (2015) who, in discussion with her family doctor, spoke of her observations:

I think Mum has lost a little edge too, in a good way. She’s not so independent, so stoic that she has to battle on and do everything herself. She’s allowing herself to depend on others. She’s softening a little and it becomes her. (p. 16)
Gil et al. (2001) directed a Scandinavian research project ascertaining the correlation between onset of dementia and the impact on a reflexive sense of self-consciousness. Here, impact was presented as being the object of the person’s own awareness and in this situation, focused on the sensitivity of transition from what might be identified as being “normal” to the progressive onset of dementia.

Speaking of the importance of storytelling as a significant resource in communicating and negotiating identity, Swedish researchers Hydén (2009) and Hydén and Örulv (2009) referenced alteration in a person’s ability to tell identity related stories about the past; creating what Hydén referred to as a “void that is never to be filled again” (p. 3). Storytelling is also referenced by Aitkens (2005/2015) in the context of an Alzheimer’s related incident in an episode of Midsomer Murders, where the “void” is referred to in terms that state, “Yesterday is another country. Borders are now closed”. According to the research findings of Hydén and Örulv, the decline in ability to tell identity related stories was less problematic for those persons who had an early diagnosis of Alzheimer’s disease than it was for those who had a late diagnosis or no diagnosis. Similar thoughts were expressed by participants in a study undertaken in the UK by Benbow and Kingston (2014), who suggested that producing a narrative that described the feelings of care receivers as they transitioned through Alzheimer’s disease was both valuable and engaging and had the potential to contribute to future advancements in dementia care.

In a study focused through the responses of participants in urban Iran, Mazaheri et al. (2013) consulted with six women and nine men who also made reference to the impact on family members. As they reflected on the transitions, all participants were able to give concrete examples of their experiences of living with the progressive debilitation associated with Alzheimer’s. All participants also reported the emergence of five common themes:

1) Struggling with a changing life which included participants’ feelings about how they were perceived in the eyes of others;
2) The irritation of forgetfulness and the increasing inability to undertake simple tasks;
3) Increasing dependence on others and being a burden on loved ones;
4) Feelings of embarrassment, incompetence, shame, confusion, and loneliness;
5) Longing to be valued and finding strategies to deal with and mask progressive debilitation, even prior to diagnosis.

Cognitive and functional degeneration were said to be challenging to the participants’ understanding of themselves as competent people and they spoke of feeling deeply unfulfilled, with the reactions of others making them feel as if they were no longer themselves, but some other person. Also reported by British researchers Ablitt, Jones, and Muers (2010) as having a stress impact on care receivers, was their awareness of the psychological health of the family member who was their primary caregiver.

In a report out of the US on “Aging, memory loss, dementia and Alzheimer’s disease”, Pinson, Register, and Roberts-Lewis (2010) expressed the need to resist societal pressure to determine a person’s value based on economic and cognitive autonomy and productivity. In affirming the need to honour worth of older persons and persons with age-related dementia, the authors cite the work of Swinton (2000), whose words encapsulate the essence of the struggle for dignity:

To have Alzheimer’s disease, or any other form of dementia, is to have a form of neurological malfunction that stands in stark contrast to cultural assumptions that define the very nature of human personhood. People with dementia are particularly vulnerable within a society that worships the very thing that they are losing. In a society that prizes reason and autonomy and assumes the primacy of the ‘self-made individual’ and economic productivity, those who are lacking and challenged within these areas are particularly vulnerable to the types of depersonalizing forces that push them into social status of nonpersons. (Swinton, 2000, p. 117, cited in Pinson et al., 2010, pp. 191-192)

2.3 Transitioning to the Role of Caregiver

Recognising and acknowledging that a loved one has Alzheimer’s disease can be a distressing and emotional time. While preparing for a diagnosis, support is needed by both caregiver and care receiver. However, all too often, this support is lacking. Emotions can run high and, as reported by Varela et al. (2011), can range from shock to anger to grief; and in many instances there can also be stress, anxiety, and depression.
According to Varela et al., the first step in transitioning to the role of caregiver is to recognise the stage symptomatology being demonstrated by the care receiver. The next step is to seek formal diagnosis, as the decline in ability to function is co-related with the progression of debilitation. It was also reported that significant aspects to be considered when taking on the role of caregiver are to determine who is to be in control of decision making, how needs are to be met, and where the one who is now in need of care is to live after diagnosis.

Black et al. (2010) focused investigation on “Baby-Boomers” and the burden of care. They reported that participants identified several areas of burden of care, including negative effects on emotional health: demonstrated through increased incidence of depression, more stress, and greater fatigue. Financial costs were also noted as being a significant factor in magnifying the burden of care.

In a study of spouse and adult child caregivers, Ott, Sanders, and Kelber (2007) reported on the co-existence of grief and personal growth while transitioning to the role of caregiver. They explained that while grief was found to increase as the severity of the disease increased, the majority of caregivers who participated in the study also reported experiencing personal growth. Earlier research by Sanders (2005) had explored caregiver strains and gains with findings identified in this study revealing that while 81% of caregiver participants testified to both strain and gain, only 19% testified to experiencing strain with no experience of gain.

Calasanti and Bowen (2006) and Russell (2007) investigated the role of the male as caregiver: spouse, partner, and son. Focusing on the way gender might influence caregiving, it was suggested that while both female and male caregivers crossed traditional and stereotypical boundaries, different challenges were confronted by each gender. The experiences of the men who participated in the studies of Calasanti and Bowen, and Russell refuted any contention that male caregivers merely mow the lawn, fix the car, wash the dog, and pay the bills. Theirs are stories of adaptation, commitment, love, and transition; as illustrated in the words of ‘Ron’ who spoke of the “mixed blessing of having no sense of smell” (p. 13) and of ‘Roman’ who stated that six months of attending his wife’s personal hygiene needs, “cured [him] of biting [his] nails” (p. 14).
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease:

Speaking from the perspective of a Queensland demographic, O’Rourke (2008) wrote an autobiographical account of his journey with his wife and explained that his hope in translating his journals to narrative was that, through the recording of their journey with Alzheimer’s, other carers may find that they are not alone in their journey. They may also find that help is at hand, that knowledge about the progression of the disease may help in facing and planning for each new challenge, and that deep and abiding love will give them the strength to cope with whatever life throws at them. It is also O’Rourke’s hope that his and his wife’s story may bring to others who engage with care receivers and caregivers, insight and understanding of the need that both have for support and acceptance. Those who may find a deeper appreciation of the impact of living with Alzheimer’s may include doctors, nurses, and nursing home staff; as well as friends and relatives of those who suffer and those who care.\(^{16}\)

Investigating the situation of young wives married to elderly husbands, the term of “married widows” was posited by Baxter, Braithwaite, Golish, and Olson (2002) who referenced primary contradictions between the husbands’ physical presence and their cognitive and emotional absence. At the opposite end of the spectrum of care, Manthorpe (2005) profiled child or young carers as “those providing instrumental and emotional support to co-resident relatives” (p. 308). Research undertaken by Abel (1993) reported on the situation of adult daughters taking on the role of primary caregiver for a parent with Alzheimer’s disease. In this study, specific reference was made with reference to daughters’ expressed concerns regarding preservation of their parents’ dignity. Abel commented on how this concern impacted on interaction with the medical health care providers who dispensed advice. Also of concern was interaction with aides and attendants who delivered direct care. The report disclosed that as the dementia progressed, daughters found it more difficult to view their parents as self-governing and were reluctant to leave major decisions in their parents’ hands. Many daughters also expressed their belief that they needed to prevent their parents from engaging in activities traditionally considered basic to adulthood: for example, driving or managing money. A significant finding of Abel’s study was identifying that parents resented their daughters’ assertions of authority, while daughters feared that by taking control, they could be wounding their parents further.

\(^{16}\) O’Rourke is also a participant in this research investigation.
Minority related aspects found to influence stories of caregiver transitions, included ethnic identity and associated cultural resources. In a multicultural study undertaken by Hinton and Levkoff (1999), the authors noted that African-American, Irish-American, and Chinese-American caregivers focused their stories through a “what is at stake” lens (p. 468). From this perspective, Alzheimer’s is seen as a disease that erodes the core identity of a loved one, deteriorates their minds, and results in a loss of identity. The researchers also noted that for Chinese caregivers, the focus on transition emphasised how families might manage confusion and disability: changes ultimately construed as an anticipated and expected aspect of growing old. Further outcomes of the same study revealed that Puerto Rican and Dominican families perceived their elder’s illness in a context of tragic loss, separation, loneliness, and family responsibility; and their transition was considered to have a loss and grief focus.

Finally, in considering the transitional impact from different cultural perceptions, the study of Navab, Negarandeh, and Peyrovi (2012) reported on the lived experiences of Iranian families. Introducing a theme of “captivity in the whirlpool of time” (p. 1080), the focus of family stories revolved around reminiscence of a past defined by sorrows, regrets, and fear of the future. There was no speaking of the “now” time: implying that there was no acknowledging the pervading circumstances of the currency of experience.

2.4 Transitional Change

Change in a caregiver’s life is significant. As illustrated in research outcomes reported by Varela et al. (2011), participants expressed that they had little time to themselves and felt that their own social life was being impacted. It was also noted that participants expressed feeling emotionally drained; with the general consequences of impact being associated with physical health and subjective psychosocial well-being. Caregivers also shared a feeling that they were at risk of not receiving support from others, while exposing themselves to depression and physical vulnerability. This was highlighted by Varela et al. to be of particular significance as cognitive and physical deterioration of the care receiver progressed and as associated behaviour became increasingly stressful for both caregiver and care receiver.

Further findings of the study of Varela et al. (2011) identified that transitional
changes associated with moving into the role of caregiver included significant increase in depressive symptoms, along with decreased immune function, decreased wound healing capacity, and autonomic and neuroendocrine dysregulation: all worsening with increased stress. Sleep quality was also reported to be inadequate or insufficient, as caregivers were often wakened through the night by their care receivers – a finding also referenced in the research of Flaserud (2000). This resulted in the caregivers experiencing sleeping issues that continued well after the Alzheimer’s patient had moved out of home or had died. Caregivers also advised that they found themselves sleeping better when they were able to take breaks and it was reported that the weaker the social support for the caregiver, the worse the sleep quality: the corollary being that the stronger the social support for the caregiver, the better the sleep quality and the subsequent ability to cope with the presenting challenges of each day.

Drawing attention to the triad of sleep initiation, sleep maintenance, and frequent sleep disturbances, Flasuerud (2000) made specific reference to care-receiver needs for assistance with pain control throughout the night. Also discussed was the need for vigilance in attending to care-receiver behaviours: for example, wandering and associated risk of fall. Fall risk was also discussed by Härlein, Dassen, Halfens, and Heinze (2009) who suggested that possible risk factors of fall related to disease-specific motor impairments, impaired vision, severity of the onset of dementia, behavioural disturbances, functional impairments, fall history, neuroleptics, and low bone mineral density. Härlein et al. also suggested that with the onset of dementia, advancing motor impairment and behavioural disturbances would seem to be major contributors to the risk of falls.

From a more affective perspective, Large and Slinger (2013) referenced themes of losses associated with changes in the relationship and grieving for the loss of a loved one’s cognitive and physical function, while observing their striving to carry on despite the progressive debilitation of dementia. In addition, Large and Slinger presented the notion of caregivers perceiving death as the ultimate relief from caregiving: an aspect of caregiving impact also featured in local studies led by O’Dwyer and referenced in the following section, 2.5, Aspects of Impact: Stress Response. (O’Dwyer, Moyle, & van Wyk, 2013; O’Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2016)
From the perspective of changes in relationship, Daly, McCarron, Higgins, and McCallion (2013) posed the notion that what evolves for the caregiver is a battle to sustain place in the socio-cultural dimension of living in society while at the same time, living apart from society. In exploring the socially situated experiences and processes integral to caring, Daly et al. conceptualised the issue of “living on the fringes” (p. 503) as being of major significance. Participants spoke of experiencing a sense of displacement, stimulated by dementia-related stigma and by their living in a time and a space referred to as being an “unsettled place” (p. 504) and a “threatened place” (p. 505). Alterations in social interactions as the person with Alzheimer’s disease crossed social boundaries and transgressed socially accepted limits and tolerances were also discussed.

Reflecting the concept of living on the fringes as cited above, a recent report from Carers Queensland (Walbank, 2016), referenced the constant battle that caregivers have with a wider community that does not understand illness, disability, or the responsibilities associated with caring. Highlighting the impact of dealing with social stigma, it is noted that having constantly to deal with those who do not understand has the potential to push the caregiver to the point of breakdown.

2.5 Aspects of Impact: Stress Response

Stressors have the potential to be multi-dimensional and significant, particularly when the care receiver develops high levels of psychosis, including delusions, hallucinations, mood disturbances, and cognitive fluctuations. According to Flascherud (2000) and Lee, McKeith, Mosimann, Ghosh-Nodyal, and Thomas (2013), caring incurs significant levels of stress that may affect emotional, mental, and physical well-being. In both studies, aspects of impact were reported in terms of changes to lifestyle and role functioning abilities, through disruption of interpersonal relationships, social life, and work life. It was also noted in both studies that stress presented as having a flow on impact associated with increasing financial strain and loneliness that stems from loss of mutuality and reciprocity in the relationship with the care receiver due to the onset of functional dependence, cognitive decline, and general weakness and pain.

Earlier studies conducted by Williamson, Shaffer, and Schulz (1998) pre-empted current trends when they spoke in terms of memory deficits, inability to communicate,
and general decline in the functionality of the loved one who is a spouse. As the authors noted, if the relationship had been characterised by mutual concern and responsiveness to one another’s needs, it was the loss of intimacy and affection that was the greatest predictor to a depressed affect. However, in cases where the severity of patient symptoms (rather than loss of relationship) was promoted as the greatest stress response, the predicted stress response was characterised more by resentment towards the care receiver and the imposition of caregiver role.

Flaskerud (2000), Rongve, Boeve, and Aarsland (2010), and Simpson and Carter (2014) highlighted the correlation between sleep quality and depressive mood, depression, and anxiety: a factor also referenced in the studies of Varela et al. (2011) as discussed above. Rongve et al. also reported that in addition to depression, caregivers to Alzheimer’s patients, particularly when the progress of debilitation had advanced to dementia, were found to have a 63% greater mortality risk than caregivers without stress or non-caregivers with stress.

Goodman, Zarit, and Steiner (1997) proffered the notion that pre-existing personal orientation variables were key predictors of caregiver stress. Exploring elements of prior experience that influence pre-determined caregiver perceptions in relation to obligations and expectations, their research highlighted the importance of the social context of care-giving. Reflecting findings also noted by Goodman et al., Leblanc, Driscoll, and Pearlin (2004) indicated that the day-to-day manifestation of personal reflection in meditation, the social support from a religious community, and the outward expression of fears, worries, and frustrations in prayer, could be of significant help in coping with stress burden. Also referenced by Leblanc et al. was the correlation between depression and stress burden associated with fundamental stressors of the role of caregiver.

Czekanski (2007) found that family caregivers of loved ones with Alzheimer’s disease suffered from more depression and emotional burden than any other group of caregivers. Lee et al. (2013) also regarded depression as a “proxy marker” for carer stress (p. 135), advising that depression was reported in 24% of dementia caregivers in a study undertaken in 1997 and replicated in 21% of dementia caregivers in a study undertaken in 2008.
Leblanc et al. (2004) approached the correlation between stress and depression among caregivers from a perspective focused discussion on understanding association between religiosity and health. They also explored various dimensions of religiosity and spirituality in relation to positive and negative effects on stress and well-being. Findings suggested that more objectively understood burdens of care appeared to act as a “casual lever that begins the progression of stress towards depression, by engendering subjective feelings of overload and entrapment in the caregiver role” (p. 418).

Wang (2013) drew particular attention to the notion of chronic stress associated with caring for a loved one who has Alzheimer’s related dementia. Viewed in conjunction with the high risk of chronic disease among caregivers, it was expressed that caregivers in poor health were more likely to stop caring. Key supports were reported to be rest, sleep, relaxation, exercise, nutrition, and socialisation.

When comparing the burden of stress differentiation between caregivers who care for a loved one with dementia and caregivers who care for a loved one with depression, Leinonen, Korpisammari, Pulkkinen, and Pukuri (2001) reported significant connection between low functioning capacity of the care receiver and stress burden of the caregiver. Leinonen et al. also made reference to tolerance levels and reported that caregivers, who identified their own mental health as being poor, also identified as having higher levels of stress burden.

Flaskerud (2000) referred to loneliness as having a complex relationship in the process of caregiving and she highlighted one aspect of loneliness as being associated with social isolation stemming from the constancy of care: especially as the duration and intensity of care became greater. Intensity of care and constancy of contact associated with co-residing were aspects reported by Yan and Kwok (2011) as being significant factors in stress burden; with these latter findings being identified as predictors in initiating both verbal and physical abuse towards the care recipient. Intensity and constancy were factors also addressed by Lee et al. (2013), who suggested that stress could be related to the number of hours per week engaged in providing care, severity of cognitive impairment, relationship with the patient, demonstrated behaviours of the patient, and support received. A local perspective of time engaged in the tasks associated with caregiving is also referenced by Walbank (2016) who reported that
carers of a person who has Alzheimer’s disease put in approximately three times more hours of care per week than they would put into a full-time job.

The most significant impacts of stress response were evidenced in studies led by Dr Siobhan O’Dwyer from Griffith University Menzies Health Institute situated in Brisbane, Queensland. In a pilot study of nine participants (O’Dwyer et al., 2013), four reported having experienced suicidal thoughts and two reported having made preparations for a suicidal act. Follow-up studies (O’Dwyer et al., 2016) confirmed that 16% of family carers of persons with dementia had contemplated suicide on more than one occasion in the 12 months prior to participating in a survey conducted with 566 primary caregivers. Subsequent to the studies focused on suicidal ideation, a study investigating thoughts of homicide in family carers of people with dementia was undertaken (O’Dwyer, Moyle, Taylor, Creese, and Zimmer-Gembeck, 2016). Of 21 participants, two had actively contemplated the homicide of their care recipient, four expressed a passive desire for the care receiver to die, and four reported having physically and verbally abused the care receiver.

2.6 Aspects of Impact: Loss and Grieving

Considering the notion of a “grief response”, Ott et al. (2007) presented a definition in terms of “reaction to the perception of loss with normative symptoms including yearning, sadness, anger, guilt, regret, anxiety, loneliness, fatigue, shock, numbness, positive feelings, and a variety of physical symptoms that are unique to the individual” (p. 799). According to Ott et al., grief occurs when the safety and security that a person feels within a relationship become threatened. These same researchers also posited the notion that despite the stress and strain that occurred between a caregiver and a care receiver, a bond existed that created an intense form of attachment and as the attachment changed as a result of disease progression, grief was the natural by-product. Findings from follow-up studies by Sanders, Ott, Kelber, and Noonan (2008) identified six themes relating to loss and grieving. These they identified as yearning for the past, regret and guilt, isolation, restricted freedom, systemic issues, and life stressors and coping strategies.

Silverberg (2007) introduced a “3-A” grief intervention model for dementia caregivers and proposed that the model, “Acknowledge, Assess, Assist”, enfranchised
the caregiver’s grief experience through acknowledging, assessing, and assisting in grief management. Silverberg explained that from the time symptoms began to insidiously emerge, it could take well over 10 years for Alzheimer’s disease to run its course. This timeline was supported by Summers (2014) who, as discussed in Chapter One, proposed a time frame of four to 10 years from diagnosis to end of life. Silverberg also made reference to the impact on the primary caregiver in terms of emotional and physiological experience. In addition to the crippling effect for those inflicted with Alzheimer’s disease and Alzheimer’s related dementias, this lengthy time frame could have a debilitating impact on family, who were grieving the loss of the person of the loved one they knew, pre-Alzheimer’s.

In profiling the general experience of caregiver grief, Large and Slinger (2013) identified six emergent themes: challenges of caregiving, losses and changes in the relationship, the role of dementia in grief, striving despite dementia, utilising social support, and death as a relief from caregiving. Constancy of expressions of loss was also referenced in the studies conducted by Sanders, Morano, and Corley (2002): particularly evidenced in statements of male caregivers. Findings of Sanders et al. concurred with outcomes previously cited by Loos and Bowd (1997). Implications of loss and grief were expressed by participants in themes of loss associated with social and recreational activities, loss of personal freedom and control over life events, loss of well-being, and loss of occupation. Participants also expressed feelings of deep guilt accompanied by an increased sense of loss when their loved one was transferred to institutionalised care. Also reported were feelings of concern that the well-being of their loved one was at risk.

Reflecting the sentiment expressed by Hogan and Schmidt (2002) that “growth can emerge following difficult life events” (p. 617), the loss-grief paradigm presents as having the potential to enhance processes of becoming more caring and connected to others. This appears to be in stark contrast with the stress-burden paradigm which presents as having less scope for evaluating what is really meaningful in life and reassigning priorities.

2.7 The Ripple Effect

When speaking of the impact of caring for a loved one who has Alzheimer’s
disease, it is important to consider just how far the “ripple effect” is felt. Investigating the impact on extended family, Celdrán, Triadó, and Villar (2011) reported that adolescents experienced a frequency of 15 varying emotions as their relationship with a grandparent who had dementia began to change. According to Celdrán et al., in general, the dementia process was seen as having a negative impact on relationships, eliciting fear and confusion. However, in some cases, there was seen to be potential for positive changes that were mainly related to the adolescent’s ability to keep emotional contact, to express emotions, and to be heard. In follow up studies to those of 2011, Celdrán, Villar, and Triadó (2012) discovered that in situations where the grandparent moved into the grandchildren’s home, the adolescents reported experiencing changes in their daily activities and identified mainly positive changes in the relationship they shared with their parents. Similar impacts were reported by Hamill (2012) who advised that in her study, the trend seemed to be that the greater the affection adolescent grandchildren had towards their grandparent, the more they were inclined to offer help and the less concerned they seemed to be about the amount of time their parents gave in caring for their grandparents.

Younger children also encounter Alzheimer’s disease and Alzheimer’s related dementia, particularly among grandparents and great-grandparents and in multi-generational households and Manthorpe (2005) warned that the needs of children may be easily overlooked. The advice was that younger children also needed information, needed to be encouraged to ask questions, needed to be reassured, needed to help to a level and scale with which they felt comfortable and, above all, needed not to be overlooked and neglected.

Other scenarios where a ripple effect may be evidenced include blended families and in-law relationships. Sherman (2012) studied the situation from the perspective of the blended family and noted that while the majority of caregivers reported receiving support from their own family (including adult children, grandchildren, and siblings), there was a significant absence of support or assistance from stepfamily members: that is, the biological family of the care receiver. Globerman (1996) wrote of the complexities that may arise in families when an adult child is the primary caregiver for a parent and the impact of caregiving is experienced by both the caregiver and the caregiver’s spouse or partner. Globerman also referred to the scenario wherein it was
the adult child’s spouse who filled the role of primary caregiver. In these situations, she suggested that emerging issues are likely to be different and may entail inquiry into family and marital relationships, may warrant support for the in-law in managing caregiving tasks, may require the in-law to have access to his/her own support groups (separate from “blood-tied kin”, p. 45), and may require interventions of couple support as well as individual support.

2.8 Support

Central to the role of caregiving is the need for support. Who cares for the caregiver and how does the caregiver access support? Support can be accessed in many places and according to Hogan and Schmidt (2002), social support is shown to facilitate healing as people transition, reconstruct their lives, and find new meaning in life when major life events impact on the world that is, turning it upside down and inside out. In information provided by Alzheimer Europe (2014e), it was noted that as dementia progressively develops, so too do the needs of the person with the dementia and, in turn, the needs of the caregiver. It was explained that while a particular solution may be helpful for a time, there is eventually a need to try different approaches. It was also explained that the caregiver can often feel alone and can tend to worry about coping. In support for the caregiver, it was suggested that it could be helpful to talk with others in a similar situation. The concept was posed that, often, personal accounts of others living with a care receiver who has dementia could be an invaluable support, normalising what is of the now and providing insight to what the future lived experience might entail. It is advised that contact can be made through Alzheimer’s Associations located throughout the world, with the mode of contact being by way of direct personal link with a local group or through social media crossing national and international boundaries.

Burns (2000) cited assistance available through primary health care providers in relation to dealing with patient behaviours and managing caregiver burden. Burns also suggested that caregivers need to be given written information on patient behaviour management, skills training, and behaviour modification strategies to decrease stress burden. In addition, Burns referenced the lack of support provided by primary health care providers, attributing this deficit to lack of knowledge and associated time and
resource constraints. In the study of Wackerbarth and Johnson (2002), caregivers identified the need for information concerning diagnosis and treatment and also information concerning legal and financial issues. Specific information about health plan coverage was also listed as being important.

Pinson et al. (2010) identified physical, emotional, financial, and spiritual challenges of living with behaviours that are symptomatic of the degeneration associated with Alzheimer’s disease. The authors referred to the general strains and stresses associated with caregiving and they emphasised the need for local communities to understand the diverse needs of older adults with dementia related debilitation. In addition, these researchers emphasised the need for community groups to learn tangible ways for best providing support to the caregiver, the care receiver, and the whole family.

For the local demographic featured in this investigation, community support can be accessed for in-home services, respite, self-care, skills training, and knowledge development related to key issues such as management of the home environment, financial concerns, legal matters, and future planning. A comprehensive list of information sources and local support services and service providers is attached as Appendix E.

2.9 Barriers to Support

Just as some caregivers experience personal growth in the midst of life changing events associated with the progressive debilitation of their loved one who has Alzheimer’s disease, others can traverse an alternative pathway. Some caregivers become stuck in what Hogan and Schmidt (2002) referred to as “a crisis of meaning” (p. 616). There are also those who experience a loss of self-confidence, become shrouded in a sense of unknowing, and confused about who they are in the midst of what is perceived as being “both interpersonal and intrapersonal crises” (p. 629). Etters, Goodall, and Harrison (2008) reported that appropriately tailored interventions can improve the health and well-being of both caregiver and care receiver. Etters et al. also suggested that individually developed and multicomponent interventions that included a

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17 The efficiency and effectiveness of available services is discussed in 7.6, Implications.
diversity of services, tended to decrease burden, improve quality of life, and enable caregivers to provide at-home care for longer periods prior to institutionalisation.

However, while multicomponent interventions might be recommended, services are not readily accessible to all caregivers. According to data published by Varela et al. (2011), the Italian Health Care System provided little support for caregivers. Barriers to using support services that were provided were said to include the attitude of health care professionals or health care assistants, as well as out of pocket expenses that the caregiver had to pay. Similar barriers were reported for caregivers in Canada with Strain and Blanford (2002) advising that while quite a range of services were available for Canadian residents (for example, day centres, cleaning services, personal care services, in-home nursing services, home delivered meals, respite in hospitals or nursing homes), caregivers chose to not use the services for reasons that included reluctance to leave their loved one with a stranger; personal and/or cultural attitudes about care giving; lack of knowledge of available services; perceptions that services were too expensive; and perceptions that their loved one presented with too many behavioural and emotional problems.

Cheung (2005) identified a different picture of carer support in Hong Kong where it was reported that home care services were more likely to facilitate the functional ability of both caregiver and care receiver. Cheung also reported that, in Hong Kong, nurses were good collaborators in health care services and this was seen as having a strengthening impact on service provision. A significant factor influencing whether or not a caregiver is able to access support services is geographic location. With specific reference to older carers in regional Australia, Winterton and Warburton (2010) cited a range of social barriers reported to inhibit participation and also said to be exacerbated by residing in a rural area. Additional factors reported by Winterton and Warburton to be of significance in rural communities, were the highly valued virtues of stoicism and resilience. Coming from a more personal perspective, Daly et al. (2013) made reference to caregivers experiencing feelings of abandonment. Findings of the Daly et al. study revealed that in the midst of social marginalisation and the implications associated with progressing dementia, aspects of what might be identified as being of the “normal life-world”, were frequently thrown away.
2.10 Coping Strategies

According to Ross, Holliman, and Dixon (2003), coping is about identifying the most difficult aspects of caregiving, dealing with them, and celebrating the benefits and growth opportunities. Coping is also said to be about resilience which is all about discovering and engaging methods of successfully managing the demands of caring for a loved one who has Alzheimer’s disease or Alzheimer’s related dementia.

As explained in the report of Daly et al. (2013), coping is about “sustaining our place”: moving from experiencing and interpreting threats to place, to developing and implementing actions that are aimed at sustaining place, and overcoming risk of loss of social contact and marginalisation. It was suggested by Daly et al. that this is done through developing a toolkit of enabling factors that comprise protective, defensive, and inter-relational strategies, conceptualised as “nurturative protecting” and “inter-relational labouring” (p. 505). Strategies employed included confirmation and upholding respect for personhood; claiming place rather than becoming dependent on others to grant or bestow; prioritising needs of both care receiver and caregiver; working to preserve dignity; nurturing Self and nurturing Other; acknowledging limitations; and recognising that at times, there is the need to prioritise I over You. Participants in the Daly et al. study also addressed the benefits of holding hope, developing strategies to manage emotions, respite, contingency plans, constructing a support network inclusive of other caregivers who could identify with similar emotions and challenges, and learning as much as possible about Alzheimer’s disease and dementia.

A key aspect to coping was identified by Fortinsky, Kercher, and Burant (2002), Gallagher et al. (2011), and Semiatin and O’Connor (2011) as “self-efficacy”: a notion that reflects the work of Bandura (1977) and is often referred to in every-day conversation as the “self-fulfilling prophecy”. Fortinsky et al. proffered the notion that higher levels of self-efficacy are expected to lead to health-promoting behaviours and improved measures of physical and mental well-being for family caregivers of persons with Alzheimer’s disease. For Gallagher et al., self-efficacy is about prediction of carer burden and carer depression in relation to symptom management, emotion-focused coping, dysfunctional coping levels, patient function, and/or neuroticism in relation to
anxiety, obsessive compulsive disorder (OCD), or perceived somatic complaints without any real evidence of disease or ailment.

For Semiatin and O’Connor (2011), self-efficacy is about influencing “the development of affective filters that influence whether life events are cognitively construed, represented and retrieved in an affectively benign or distressing manner” (p. 686). Self-efficacy could also be a significant factor in the functioning of what Donovan and Corcoran (2010) defined as “uplifted caregivers” (p. 592) who were identified as being less likely to live alone with the care receiver, as experiencing fewer symptoms of depression, and as having lower levels of both objective (related to self) and subjective (related to significant others) stress burden factors. Donovan and Corcoran also referred to the key coping strategies deployed by the uplifted, which included engagement in positive behaviours and making adjustments to attitudes. With specific reference to engagement in positive activities, Sixsmith and Gibson (2007) recommended music. The suggestion was that as well as being enjoyed in its own right, music could enable people to participate in activities that are both enjoyable and meaningful while having potential to stimulate social contact and social cohesion.

A key aspect to coping could also lie within the “intuitive self”, being about what Rowan (2010) described as “approaching the problem in the spirit of seeing that there is no problem” (p. 15). This, suggested Rowan, may sometimes enable one to see the whole thing quite differently and then to act more constructively.

In reviewing an edited volume of essays, titled Stress, coping and health in families: Sense of coherence and resiliency, Stanton (2000) linked coping with the “sense of coherence” construct developed by Antonovsky and Sourani (1988) in relation to family stress and resiliency in the context of medical health. Stanton suggested that the authors presented an individual usense of coherence that focussed on the resources that help an individual to stay healthy in the face of life challenges. In addition to ideas presented by Antonovsky and Sourani, Stanton further considered the importance of noting that a sense of coherence denotes certain core commonalities of resistance resources and presents “a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence evidenced in comprehensibility, manageability and meaningfulness” (p. 350).
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.

Judith R Boyland

Siegel (2012) also spoke of a sense of coherence in reference to the harmony that ensues when there is balance between Complexity that embraces the differentiation between chaos and the rigidity in self-organisational movement towards well-being. In defining the characteristics of coherence, Siegel chose to posit the notion of linking differentiated aspects of complexity through the linguistic structure of an acronym that denotes the very essence of being “Connected, Open, Harmonious, Engaged, Receptive, Emergent (arising in new and ever-changing ways), Noetic (a sense of knowing), Compassionate and Empathic” (p. 16-5. Note: pagination reference formatted as per original text).

Based on Bandura’s notion of self-efficacy (Bandura, 1977) and linking this with Power’s Perceptual Control Theory (Powers, 1973/2005) and Glasser’s Control/Choice Theory (Glasser, 1984, 1999), it would seem that coping could be viewed as being a choice. Interpreting the findings of the study of de Vugt et al. (2004) through a lens of self-efficacy, the self-fulfilling choice to cope can be identified within structural frameworks. These structures are based on management strategies that emanate from a premise where the focus is on attitude and whether or not caregivers accept the caregiving situation and dementia related problems associated with the diagnosis of Alzheimer’s disease. Structural frameworks are identified by de Vugt et al. (2004) as (a) “non-adapting”, (b) “nurturing”, and (c) “supporting” (p. 88).  

In a study undertaken by Sommerlad, Manela, Cooper, Rapaport, and Livingston (2014), it was reported that following a comprehensive intervention program, caregivers identified several components as being of major importance in helping to cope. These they referenced as relaxation techniques, education about dementia, and strategies to help manage the behaviour of the person with dementia. Interaction with a therapist was also recognised as being an important activity in supporting caregivers’ ability to cope. Within these sessions, caregivers could share their concerns with an independent person who showed them empathy and helped them to reframe negative automatic thoughts, while also helping them to learn strategies for changing unhelpful thoughts.

At the time of a two year follow up study undertaken by Sommerlad et al. (2014),

18 For an abridged description of the de Vugt et al. (2004) structural frameworks, refer to Appendix F.
two-thirds of the participants reported that they continued to use the intervention techniques on a regular basis. Some also reported that they sought to engage in similar activities through voluntary organisations while also sharing the techniques they learned and teaching these techniques to friends and relatives. Key outcomes identified by participants included a greater acceptance of the diagnosis and of the situation in which they found themselves, greater tolerance towards the loved one with Alzheimer’s, and validation of their own personal feelings.

Similar coping strategies had previously been found to be effective in the study of Williamson, Shaffer, and Schulz (1998). These researchers reported direct action and stoicism as helpful strategies in managing a more depressed affect in coping with memory deficit and loss of the person who no longer resided within the shell of the one whose debilitation had transitioned to a stage of Alzheimer’s related dementia. Relaxation, acceptance, and social support were also reported as being of significant benefit for a less depressed affect response. A further point discussed by Williamson et al. was the reoccurrence of “acceptance” as being a personal characteristic conducive to coping: reported as being mentioned in different studies across a time frame spanning in excess of 20 years.

Suggesting that communication about health has become increasingly interactive and dynamic, Robillard, Johnson, Hennessey, Beattie, and Illes (2013) identified the expanding use of online and social media applications by adults who are seeking health information and support. It was also noted that online health information has the potential to significantly impact public health; especially as the population ages and the prevalence of dementia increases. Perhaps the key outcome of the research conducted by Robillard et al. was that across both health and illness, social media was identified as reshaping health care by acting as a powerful new way for stakeholders to interact and share information.

While on the one hand social media may be seen as stifling interpersonal communication, on the other hand and for those feeling the pressures of isolation, social media could be their life-line. As a tool to alleviate stress associated with the burden of care, social media may be the only means by which a caregiver is able to stay connected with a world outside their personal world that is and a world free of the burden of care.
2.11 Coping with Abusive Behaviour

Reporting the results of a survey conducted in 2010, Alzheimer Europe (2014f) noted that 220 family carers of people with dementia identified as follows:

- Over one-third reported experiencing significant abuse from the people they cared for;
- Those who reported abuse also reported a greater deterioration in the relationship;
- Dysfunctional coping strategies partially explained deterioration in relationship.

Similar findings emerged from a study conducted by Cooper, Selwood, Blanchard, and Livingston (2010), who reported that over one-third of their family caregiver participants identified with significant abuse from the care recipient who had dementia. Abusive behaviours were noted as being a mix of verbal, psychological, and physical orientations; and in concert with the above cited report (Alzheimer Europe, 2014f), it was stated that caregivers who testified to more abuse also testified to a greater deterioration in their relationship with the person who had dementia. It was suggested that the extent to which caregivers used dysfunctional coping strategies could partially explain this incidence of abusive behaviour. Cooper et al. also claimed that some abusive behaviours may be indicators of neuropsychiatric symptoms, which are part of the dementia.

In keeping with this line of thought, VandeWeerd, Paveza, Walsh, and Corvin (2013) observed that as Alzheimer’s disease progresses, the risk of abuse by both care receiver and caregiver increases. The authors also claimed that with advancing progression the care receiver is more likely to become more verbally and physically combative as s/he fails to recognise loved ones, loses social filters, and becomes functionally more impaired. Considering risk factors from a perspective of caregiver burden, poor functional and psychological health, and difficulties in coping with higher levels of functional impairment, VandeWeerd et al. suggested that avenues for abuse prevention may lie in increased physical, occupational, and assistive device therapies for both caregiver and care receiver: a notion supported by Australian researchers, McInerney and King (2015). The rationale underpinning such intervention was said to have emerged from studies showing that many older adults were acting significantly below their functional capacity, with or without any contributing impairment.
Abbey (2015) and Ahn and Horgas (2013) referred to the notion that incidence of abusive behaviours could be in direct correlation with pain frequency, pain intensity, and the increasing inability for the person with Alzheimer’s or Alzheimer’s related dementia to verbally express that s/he is in pain. It was explained by both sources that with advancing dementia, the care receiver gradually loses the ability to process information. As a result, the presence of pain may be expressed through agitated, aggressive, disruptive, and abusive behaviours. Considering the context of support through progressive increase in pain intensity and frequency, Watson (1979/2008) proposed use of a transpersonal model of care which incorporates the practice of calming and comforting the patient through episodes of distress. This model embodies the practice of caregiving imbued with a spirit of *caritas* or “loving kindness”.

### 2.12 Maintaining Dignity in the Midst of Chaos

According to *The pocket Macquarie dictionary* (Bernard, 1989), dignity has to do with the notion of worthiness. In considering the wants expressed by participants in the studies reviewed above (2.2, *Living with dementia: Transitioning*) and reflecting on these through a lens of basic needs gratification as defined by Glasser (1984, 1999), it could be said that dignity has to do with a sense of “worthness”. It is about being seen as important, being valued, contributing, and having a sense of worth (basic psychological need for personal power). It is about being trusted to offer advice and opinion and to make decisions (basic psychological need for freedom). It is about being cognitively and physically able to learn and to engage in pleasurable activities and creative pursuits (basic psychological need for learning and fun). It is about being respected rather than ridiculed, loved rather than pitied, treated with empathy rather than with sympathy (basic psychological need for connection, love, and belonging). This sense of worthiness could also be seen in correlation with the notion of “personhood”, as discussed by Smebye and Kirkevold (2013) when they spoke of personhood as being “the right of every human being regardless of capacity” (p. 1). The work of Smebye and Kirkevold reflected ideas posited by Buber (1958) who is cited as postulating that “all real living” is about meeting with mutual acknowledgement of the uniqueness of the other. Thus, the dignity of personhood can be seen as a product of relationships with others and as such, has the capacity to be nurtured and strengthened or diminished and weakened.
Personhood is also the focus of care in the person-centred approach as espoused by Kitwood (1997) who defined personhood as “a standing or a status that is bestowed on one human being, by another in the context of relationship and social being” (p. 8). With specific reference to the needs of one who has Alzheimer’s disease, Kitwood (1990) drew attention to the dialectical interplay between neurological and social-psychological factors that mark the degenerative transitioning. Giving special emphasis to the latter, he signposts these factors as depriving the neurologically impaired care receiver of his/her personhood and sense of worth.

Looking at the notion of worthness through the lens of a transpersonal caring relationship as proffered by Watson (1979/2008), it is about caregiving that conveys concern for the inner life world of the care-receiver. It is about being fully present, in the moment, in a spirit that invites full loving-kindness and equanimity. It is about being able to read the moment and it is about a Self that is open, responsive, and sensitive to what is happening and to what is emerging for the Other. It is about understanding and appreciating that a significant caring moment can be a turning point that affects both caregiver and care-receiver and that, in the words of Watson:

Radiates out beyond the moment, connecting with the universal field of infinity to which we all belong and in which we all dwell. Thus the moment lives on.

Such an authentic spirit-to-spirit connection in a given moment transcends the personal ego level . . . and opens the [caregiver’s] intelligent heart and head to what is really emerging and presenting in the moment. (p. 79)

Such is also the essence of what Heidegger (1927/1962) refers to as being “concernfully absorbed” (p. 247) or concernfully present: being present in the world, becoming aware of the world that is, and interpreting that awareness in the light of lived experience (addressed further in 7.4, Ontology of Caregiving).

In their paper on ethical issues in dementia care, Streh, Mertz, Knüppel, Neitzke, and Schmidhuber (2013) referenced The Nuffield Council on Bioethics (2009). The cited report tabled factors that needed to be taken into account when weighing up conflicting ethical principles: with particular reference to well-being versus respect for autonomy. Considering the overall well-being and dignity of the patient, it was stated that ethical questions need to take priority in decision making processes.
In total contrast to focussing on the rights and advocacy on behalf of older care receivers in domestic settings, Rabold and Georgen (2013) reported on abuse and neglect experienced when professional caregivers (as opposed to informal caregivers) were the ones responsible for care provision. Unspecified psychological abuse, verbal aggression, and neglect were the most common incidents reported. The most common triggers were reported as serious aggressive behaviour by care receivers, use of alcohol as a means of alleviating work-related stress, and general judgments of quality of care delivered by respective home-care agencies.

In a similar vein, Yan and Kwok (2011) reported on older abuse of Chinese dementia patients by family caregivers. All participants were of a demographic identified as being of high income and most accessed community services including domestic help, home help with care receiver, respite care, and day care services. It was noted that the majority of care receivers had other chronic comorbid conditions in addition to dementia. Of 122 family caregivers interviewed, 62 reported having verbally or physically abused the care recipient in the past month. Intensity of care and constancy of contact were identified as being significant predictors in incidence of verbal abuse from caregiver towards care receiver. This was particularly evidenced when associated with lack of assistance from domestic helpers, agitated behaviours of the care receiver, and the collective magnitude of stress burden.

Addressing the situation of abuse from informal caregivers in the US, VandeWeerd et al. (2013) identified that mistreatment was prompted by behavioural aspects associated with advancing levels of functional impairment demonstrated by the care receiver, alcohol problems, use of violence as a general conflict resolution strategy, and low self-esteem. Impact was presented in terms of emotional difficulties such as feelings of inadequacy, feelings of self-contempt, decreased self-esteem, and depression. The investigation also linked caregiver abuse to survival and health problems such as increased rates of mortality and immunological dysfunction.

2.13 When it is Time

As much as family want to care for their loved one at home and through all the stages of degeneration and transitional phases of change, this is not always possible. Ultimately, the decision may be influenced by risk factors such as safety, physical
capability, or emotional/psychological resilience. There is a strong probability\(^{19}\) that the
time will come when admission to institutionalised care is what is needed to best serve
the needs of both the care receiver whose debilitation has progressed to advanced
dementia, and the caregiver who is unable to facilitate the means by which those needs
might be gratified. This may be due to social isolation; impact of caregiving on
caregivers’ health; dementia related behaviours worsening with progression of cognitive
impairment and loss of functionality; accelerated increase in daily care burden; need for
more skilled and/or specialised care; or a general need for more assistance linked with
availability of support resources (Buhr, Kuchibhatla, & Clipp, 2006; Sansoni, Anderson,
Varolna, & Varela, 2013; Simard, 2014; Sun et al., 2013).

It is noted that each of these factors, considered either singly or in combination,
has the potential to escalate risk factored impact on caregivers’ well-being, as well as
risk potentiality for caregivers to demonstrate harmful behaviours towards care
receivers. However, the research shows that whatever the circumstance, admission to a
care facility can have significant impact on the caregiver who, either temporally or
permanently, relinquishes to professionals the provision of control and care that has
been a major part of their Being and their doing for some considerable period of time.

Tornatore and Grant (2002, 2004) reported in relation to the subjective stressors
associated with transition to institutionalised care and Bloomer, Digby, Tan, Crawford,
and Williams (2014) addressed the need for good communication between clinicians
and caregivers and the need for the caregiver to be respected as the expert in the care of
their loved one. Bloomer et al. also referenced the need for the caregiver to be included
in decision-making processes and to be given emotional support throughout the period
of time their loved one is a patient in the professional care facility; whether that be for
respite, medical attention, residential transition, or palliative care.

However, unfortunately, the hospital/institutional experience does not always
conform to the ideal, as recorded by Gierck (2015) who stated that “Some days caring
and niceness seem mutually exclusive” (p. 217). As also reported in the studies of
Jurgens, Clissett, Gladman, and Harwood (2012) and Spencer, Foster, Whittamore,

\(^{19}\) Based on descriptors referenced in Alzheimer’s Association, 2015a; Fisher Center for
Goldberg, and Harwood (2013), experience of care was often negative, with key themes in the cycle of discontent being focussed through events, expectations, and relationships with staff.

Dissatisfaction is a concern of global significance. Experiences discussed by Jurgens et al. (2012) were cited as tending to lead to caregivers becoming uncertain and suspicious which, in turn, led to periods of “hyper vigilant monitoring” (p. 1). Implications from studies spanning in excess of a decade stated that patients with dementia and family caregivers needed support from professional staff, needed information to reduce stress burden and to support caregiver health and well-being, and needed to be considered as a unit (Bloomer et al., 2014; Buhr et al., 2006; Jurgens et al., 2012; Sansoni et al., 2013; Sun et al., 2013; Tornatore and Grant, 2002, 2004). David Cooper (2014) referred to such considerations in terms of compassion, respect, and dignity: “being with the person and family . . . – one human being to another – seeing through the other person’s eyes and empathising with that person’s pain, fear, joy, loss, and sadness” (p. 11).

In speaking of the importance of sensitive, appropriate, and evidence-based family involvement, Davidson and Anderson (2014) referenced the point that professionals sometimes reported feeling too busy to speak with the family. It was also said that professionals reported feeling resentful that family discussions could take longer than actual interactions with the patient who was being cared for. Davidson and Anderson noted the importance for a correct balance to be struck, as it was family who could provide insight into their loved one’s interests and previously expressed wishes. They also expressed concern in relation to what they termed as “pre-loss family variables” (p. 48). It was further suggested that aspects such as relationship quality, attachment style, premorbid depression, caregiver burden, and pessimistic life orientation may predict risk of psychological morbidity and/or related post loss mental health problems. While the well-being of all family members was considered, the concern for Davidson and Anderson was expressed mainly on behalf of the primary caregiver.

Reporting specific instances of conflict over care, Alzheimer’s Australia (2014b) referenced the inappropriate use of chemical and physical restraints. This aspect of care was of significant concern for people with dementia and for their families. It was also
an aspect of care that was reported as being particularly prevalent within residential care. Alzheimer’s Australia further reported that while people with dementia are high users of acute care hospital facilities, they have unacceptably worse clinical outcomes. These are stated to include longer stays in hospital and higher readmission rates compared with people who do not have dementia. In addition, patients with dementia are said to be twice as likely to experience adverse events such as falls, sepsis, or pressure ulcers during their stay in hospital.

### 2.14 End of Life

Relevant understanding of Alzheimer’s disease, together with an awareness and acceptance of the progressive onset of dementia related degeneration and debilitation is integral to appreciating aspects of impact when caring for a loved one who has Alzheimer’s disease. Simard (2014) noted that one of the biggest challenges facing professionals who counsel families whose loved one is living with advanced Alzheimer’s related dementia, is that the condition is irreversible, is terminal, and decisions and goals of care need to change as the disease progresses. Simard named three key aspects that need to be considered as the end of life is approaching: “prolongation of life”, “maintenance of function”, and “comfort” (p. 169).

Awareness, understanding, and acceptance also demand that appropriate management of the stage of advanced dementia requires it to be recognised as a terminal condition that needs palliative care: the concept of which was born in the 1950s when, based on careful observation of terminally ill and dying patients, Dr Cicely Saunders (nurse, social worker, physician, philanthropist, and writer) articulated her ideas about focusing on the care of the dying. Promoting the principle of dying with dignity and advocating that only an interdisciplinary team could relieve the total pain of a dying person in the context of family, Dame Cicely Saunders founded the first modern hospice (Saint Christopher’s, located in London, UK) in 1967. Her aim was to provide palliative care to those in need (ASH Education, 2008; Biography.com Editors, 2006).

Kumar and Kuriakose (2013) claimed that interventions during the palliative stage need to be carefully chosen to ensure maintenance of the quality of life of the care

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20 Order of Dame of the British Empire was conferred by Queen Elizabeth II in 1980.
receiver. They addressed the importance of advanced care planning whereby the individual’s wishes are made clear in relation to the care they would like to receive at a time when they may no longer be able to make such decisions nor be able to make their wishes known. These authors suggested that caregivers and other family members need to be educated and encouraged to actively participate in discussions related to aspects such as artificial nutrition, cardiopulmonary resuscitation, and other medical interventions. They also noted that critical aspects to consider include how invasive interventions can be when it is doubtful as to the amount of benefit compared with the amount of associated discomfort. The key question to be considered is, “If able to make the decision, would this be what the patient would want?” Kumar and Kuriakose refined these concepts when they addressed the differences in end-of-life care for patients with dementia and for those who are still cognitively aware; explaining that in a condition like advanced dementia, it is beyond the skill of doctors to give an accurate estimation of how long the patient is going to live. Kumar and Kuriakose and McInerney (2015) also explained that good person-centred care responds to the needs of the individual patient; and as the end of life draws closer, it is still possible to help the person have a good quality of life and a dignified death.

Van Der Steen, van Soest-Poortvliet, Achterberg, Ribbe, and de Vet (2011) assessed family perceptions of the preferences of dementia patients regarding end-of-life wishes about death and dying. Two specific areas purported to be most relevant were “treatment preferences” and “preparation for end of life” (p. 219). These elements of care were named as being the most significant conditions associated with a “good death”. Treatment preferences also focussed on maintaining dignity and freedom from pain, with particular reference made to bladder and bowel control.

In discussing end-of-life, Jo Cooper (2014) stated that a good death means different things to different people and can embrace such aspects as:

- Choosing the place of death and being spiritually at peace;
- Availability of resources such as appropriate and timely medication, practical aids to enhance comfort, good pain and symptom management, and competent and compassionate human support;
- Mending of relationships that may have been difficult or may have been broken;
- Effective communication between intra and inter disciplinary team members;
Compassionate and respectful communication with patient; particularly if the patient is conscious.

Cooper also spoke of the emotional and physical shock to family, even in the situation when death was expected. She advocated ongoing and intensive professional support to smooth the way forward for the family who undergo mounting pressures before, during, and after the death of their loved one. This support, or lack of support, suggested Cooper, has an immense impact on family (particularly on the primary caregiver), and has the potential to remain with them for the rest of their lives, as a memory associated with the death of their loved one.

End of life preparation covers a diversity of aspects, including costs, means to end life, talking about feelings, and spiritual counselling. In the study of van der Steen et al. (2011), findings flagged the importance of spending time with family. In situations where pets hold a significant place in the family, it was also considered to be important for the dying patient to be able to spend time with a much-loved pet. Spiritual caregiving was reported as being relatively unimportant in the overall priorities presented in the study.

In responses from approximately half the participants in the study of van der Steen et al. (2011), family reported being generally unfamiliar with their loved one’s feelings about fear of dying and preference for dying when conscious or unconscious: a condition of major relevance for palliative care sedation. This sense of unknowing was not part of Michele Gierck’s story as she shared of her experience with her mother:

For weeks I’ve been worried about how Mum can die when she’s so fearful of it. But today, she’s making that transition. My mother certainly has pain in her head, and there are moments of wanting to hang on, but there’s also a peacefulness. There is no longer fear of what beckons. She’s slowly slipping into the next stage of her journey which each of us must take alone. (Gierck, 2015, p. 231)

Reflecting on the thoughts proffered by Kumar and Kuriakose (2013) and referring to Simard’s (2014) notation of the concept that often, patient care is more about prolonging death than it is about prolonging life, it seems appropriate to conclude this literature review with words taken from the ASH Education Book (2008):

Palliative medicine is the continuation of the long struggle to accept life on its
own terms, honestly and openly. Taking its place in academic medicine, this new subspecialty will enable future generations of physicians to gain generalist-level palliative medicine skills while advancing knowledge in the field and fulfilling our promise to patients and their families that we will not abandon them when our treatments fail and that, at all times, we will do all we can to relieve their suffering. (p. 465)

2.15 Conclusion

Chapter Two presented a review of the literature tracing the pre-diagnosis to death journey in relation to caregivers’ conceptions and understandings about the impact of caring for a loved one who has Alzheimer’s disease. The review of literature was focused through a conceptual framework that encompassed 13 key themes portraying the trajectory of care across a global demographic.

What was evidenced in the Literature Review was the need for a collective narrative that profiled a multivoiced interpretation of caregiver conceptions from the perspective of a local demographic, while also embracing the full gamut of the trajectory of care – from onset to post end-of-life of the care receiver.

In Chapter Three, theoretical orientations that inform the method of investigation and the methodology underpinning participant selection, data collection, data analysis and data synthesis are discussed.
CHAPTER THREE – METHOD AND METHODOLOGY

The only thing that keeps us from floating off with the wind,
Is our stories.
They give us a name and put us in a place.
They allow us to keep on touching.

Tom Spanbauer (Kundtz, 2000, p. 283)

3.1 Introduction to Method and Methodology

Chapter Two presented a review of literature tracing the pre-diagnosis to death trajectory in relation to the subject of caregiving impact. Chapter Three introduces theoretical orientations that informed methods used for design, data collection, and data analysis and the chapter is structured in a way that moves between the method used and the supporting methodology. The philosophy behind the choice of methodology reflects a hermeneutic approach as represented in the work of Hermans (2001; 2012; 2016) – notably Dialogical Self Theory. As noted by Romanishyn (2010), the hermeneutic approach to research includes the researcher in an intimate way whereby the one who seeks to know and that which is to be known “embrace each other” (p. 317).

Underpinned by the construct of qualitative paradigm, a model of research defined in terms of a “methodological hybrid” (Holstein & Gubrium, 2005, p. 497) was chosen to explore and describe the everyday world of informal caregiving as situated in the natural setting of lived experience, when Someone I love has Alzheimer’s. Under the overarching umbrella of qualitative paradigm, design, data collection, and analysis strategies were implemented within a framework of social constructivism which, according to Lincoln and Guba (2000), embodies an epistemology whereby the truth of related knowledge lies in created findings that are both transactional and subjectivist.

As a hybrid methodology was believed to be the most effective tool to achieve the aim and to answer the research question, the action model chosen incorporated processes of intuitive and narrative inquiry intertwined with elements of transpersonal and heuristic approaches. The triangulation of methodologies enabled the research question to be explored from multiple perspectives, increasing the credibility and validity of the results, while explaining more fully the complexity of human behaviour.

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21 Introduced into the architecture of the thesis in 1.7, The Dialogic Interchange.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: and honouring the richness, diversity, and sensitivity of experience (Cohen, Manion, & Morrison, 2005; Holstein & Gubrium, 2005).

**METHODOLOGICAL HYBRID**

![Methodological Hybrid Diagram]

**Figure 3 - Methodological hybrid**: Blending a range of methodological practices through a triangulation of inquiry approaches honours the richness, the diversity, and the sensitivity of experience that is shared by multiple voices.

Incorporating strategies of dialogic interchange, multiple voices shared stories incorporating use of verbal and visual modalities. Adopting the position of *Bricoleur*, (Denzin & Lincoln, 2005, pp. 4-6), I, as researcher, wove the threads of experience to construct a narrative landscape; piecing together multiple positions according to how each story frame was re-visited, re-viewed, re-conceptualised, re-framed, and re-reported by participants. Thus, when the final word was processed, not only had stories been told, voices heard, and the research question answered, but what Denzin and Lincoln (2005) described as “a clearly defined sense of complexity” also emerged as “a meaningful emotional whole” (p. 5).

### 3.2 A Qualitative Paradigm

Qualitative inquiry is defined by Gergen (1999/2009) as “imagination in action” (p. 71). For Liamputtong and Serry (2013), it is about “looking for patterns of ideas or themes” (p. 366). Primarily, research that engages the tools of qualitative inquiry involves the use and collection of empirical materials such as personal experience,
introspection, life story, interview, interaction, and observation. However, as suggested by Marton and Booth (1997), alternative sources of engagement can also include drawings, written responses, and historical documents: modalities that were chosen by participants to augment verbal dialogue. Incorporating use of visual modes of expression as advocated by Prosser (2011), a variety of visually expressive modalities was also chosen by participants to illustrate particular aspects of their stories: for example, picture making, graphic illustration, photographs, and videos. What participants were expressing was their reality and as stated by Denzin and Lincoln (2011), by describing “routine and problematic moments and meanings in individuals’ lives . . . each practice makes the world visible in a different way . . . hoping always to get a better understanding of the subject matter at hand” (pp. 3-4). It was the weaving of independent realities as expressed, that promoted development of understanding in relation to the context and the meaning that participants ascribed to what they experienced as the lived reality of their known world.

Black (1994) identifies qualitative research as seeking out the what rather than the how often. By taking a holistic perspective that preserves the complexities of human behaviour, research incorporates processes of observation and interpretation of events and focusses on understanding the nature, strengths, and interactions of variables. This differentiation between the what and the how often is also referenced by Baskarada (2014), whose emphasis is on understanding the nature of the research problem and collecting the most relevant data in the most effective and efficient manner. A similar frame of reference is highlighted by Holstein and Gubrium (2005) and Marton and Booth (1997) who speak in terms of the “what” and the “how” (as opposed to the “how often”) that is embodied in the research question.

According to Patton (2002), it is a qualitative paradigm that facilitates open, deep, and detailed study, without the constraint of predetermined categories or hypotheses. Cohen et al. (2005) also reference this sense of openness by speaking to how qualitative inquiry reflects conceptions of reality that project a philosophical basis of subjective idealism, acknowledging that while the world exists, it is construed and contextualised in different ways by different people. That is, as people interpret the world in which they live, they define their own reality.
For Yin (2009), focus is on “within a real-life context” (p. 3); and for Sin (2010), it is about understanding the meaning of something to a person: the conception of which is assumed to be relational, in that it is internally constituted between the person and the world. Description from Jackson (2011) is that the data sought invite reflection on personal experience while also inviting a description of behaviours which embrace subjectivist dimensions.

Denzin and Lincoln (2005) explain that qualitative researchers study things in their natural settings. Locating the researcher in that world of lived experience, the authors also suggest that qualitative research consists of a set of interpretative practices that make the world visible: transforming the world and turning it into a series of representations or interconnected images. They further posited the notion that the researcher becomes the “Bricoleur” (pp. 4-6) who weaves the threads and constructs a narrative landscape that brings together the pieces that define multiple positions. It is these positions that are embodied in the voiced reconceptions of participants who share the stories of their lived reality: as it appears to them and as it is interpreted and identified by them. In the process of bricolage, it was the interconnection or the weaving together of the threads of data that presented as thematic images and collectively, created the broad, holistic landscape: the big picture of lived experience that defines the collective impact of caring for a loved one who has Alzheimer’s.

Considering themes by which to define implementation of the investigative process in keeping with principles that underpin the qualitative paradigm, a model developed by Patton (2002, pp. 37-73) was chosen. Within this model aspects of strategy are outlined as “design strategies”, “data collection and fieldwork strategies” and “analysis strategies”.22

3.2.1 – Design strategies

Inquiry occurred in the participants’ natural and real-world setting where no predetermined course of inquiry was established and where participants were simply invited to share their story, as was the reality of their lived experience. The approach to inquiry was flexible and open-ended with the focus of importance being on attention to

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22 Aspects of strategy outlined in Appendix G.
the realities and the truths as perceived and profiled by the participants. Within this context, participants were selected because of the richness and depth of information they could bring to the investigation.

### 3.2.2 – Data collection and fieldwork strategies

Data were gathered through observations, conversations, quotations, and documentation; and collectively, the data corpus told a story that gave insight into the nature of reality as it is lived. Through personal engagement, a closeness was created that promoted openness in process while stimulating depth in outcome. Working within a flexible framework, system dynamics were open to change as might be necessitated by emerging need. In addition, each participant was approached from a professional position of inquiry that portrayed empathy, sensitivity, and respect.

### 3.2.3 – Analysis strategies

Processes of analysis acknowledged that each participant brought his/her own unique story which in turn, presented with its own particular orientation. With a focus on exploration, discovery, and the evidence base of inductive logic, immersion in the specifics of the data items proved to have the capacity to induce discovery of description; whereby creating connection and relationship between and across stories. The subject under investigation (the impact of caregiving) was understood as being a complex system: more than the mere sum of individual stories. As multiple perspectives came together in the reconceptualisation and reframing of conceptions, a holistic snapshot of the collective landscape was profiled. Sensitivity to the context was expressed through authenticity: bringing balance, trust, and genuine positive regard to the I-Thou relationship between researcher and participant while also acknowledging the humanness of the Self-Other perspective and opening the way for genuine reflexivity in the dialogic interchange.

### 3.3 Social Constructivism

According to Schwandt (2003), a construction can be viewed as knowledge and truth being created by the mind in correspondence with something real in the world. This would seem to be consistent with the ideas expressed by Berger and Luckmann.
(1966/1975/1991), who postulated the notion that knowledge is created by the interaction of individuals, and the influence that one individual has upon another individual. It would also seem to be in agreement with the ideas of Hammersley (1990) who claimed that while reality is socially defined, it also refers to the subjective experience of everyday life and is about how the world is understood rather than about the objective reality of the natural world. Drawing on conceptions developed by Gergen (1991, [as cited by Cottone, 2001]) and Ginter et al. (1996, [as cited by Cottone, 2001]), Cottone (2001) argued that social constructivism highlights the notion that what is real is not objective fact. Rather, social constructivism allows for a biosocial interpretation of what is real. His claim is that the reality of the individual gives way to relational reality where all that is known is known through biological and social relationships, is grounded in the biology of cognition, and evolves through interpersonal interaction and agreement about what is fact.

In debating the notion of social reality, Finn (2002) argued that the whole issue of constructivism versus realism arises only in the context where the metaphysics of the freedom of will is accepted. In defence of his argument, Finn posed the following rhetorical questions for consideration – Is not reality constructed by our own activity? Is not social convention constructed out of individual beliefs? Do we not collectively invent the world rather than discover it?

According to Lincoln and Guba (2000), the belief is that knowledge encapsulates local and specific constructed realities and varies in accordance with the individual and the situation. In considering epistemological practicalities, the authors define the aim of constructivist inquiry as being about understanding and reconstruction; where the nature of the knowledge to be understood relates to individual reconstructions coming together around consensus. Knowledge is accumulated through informed and sophisticated reconstructions and vicarious experience, while the quality of the criteria relies on trustworthiness and authenticity. From an axiological perspective, Lincoln and Guba claim that knowledge is propositional, in that it is underpinned by a transactional knowing, deemed to be instrumentally valuable as a means to social emancipation. General values are formative in that they are inherent in the developing nature of the research, with the specific values of altruism and empowerment being promoted and with there being an intrinsic ethical tilt towards revelation. It is the expressed view of
the authors that as the constructivist researcher moves towards a praxis of participation, the focus of concern is on “liberation from oppression and freeing of the human spirit” (p. 169). Action is intertwined with validity: that is, it is purposeful and the means is justified by the end.

Profiling a constructivist perspective on the link between knowledge, action, and the impact on the relational Self, Lincoln and Guba (2000) propose that the ontology is grounded in principles of relativism. Therefore, from a platform of constructivism, absolute truth is unattainable. Methodology incorporates both hermeneutics and logic, where principles of interpretation are suspended in the common language that is shared and understood by both researcher and participant. Neimeyer and Levitt (2001) propose that constructivist methodology elucidates local (rather than universal) meanings and practices; focusses on provisional (rather than essential) patterns of meaning construction; considers knowledge to be the production of social and personal processes of making meaning; and is more concerned with the pragmatic utility of validity of application than with validity per se. The authors postulated that it is the focus on distinctive patterns or processes of constructing meaning in a given personal or social context without the presumption of universality that differentiates constructivist methodology from traditional knowledge claims. They also claimed that it is these very distinctive patterns that set constructivist methods apart from constructionist methods, where attention is shifted to broader systems that characterise cultural contexts.

From an alternative perspective, similarities with constructionism reflect Owen’s hypothesis that the inherited and developmental aspects of human nature and all other aspects of humanity are created, maintained, and destroyed in interactions with others (Owen, 1995). Such a hypothesis could give rise to the notion of a “social construct” as defining meaning or connection assigned to objects, situations, and happenings in the environment. Owen also referenced the notion of defining meaning to people’s conceptions of their relationships to and interactions with these objects and events. Therefore, it could be suggested that while a specific social construct might be an idea or notion that appears to be natural and obvious to the people who accept it, it may or may not represent reality as a statement of fact or as something that exists independently of ideas or perceptions that are universally held about it.
In further consideration of the social context, Kukla (2000) proposed the notion that social facts are the clearest example we have to constructed facts, with social convention being constructed out of individual beliefs and intentions. He also claimed that for this to be so, a certain kind of constructive activity needs to have taken place. In support of his argument, Kukla introduced the notion of a “quark”, maintaining that constructions are fashioned out of social episodes whereby constructive activities constitute the fact. In this project, the “constructive activity” embodies caring for a loved one who has Alzheimer’s.

While analysing social constructivism according to the aims of science, Khalifa (2010) identified social constructivists as holding to the notion that things taken for granted are actually products of social contingencies. He identified a philosophical pull between strong constructivism (the thesis being that facts are constructed) and weak constructivism (which claims that if scientific practices were different, hypotheticals would not be postulated as fact). Suggesting a middle path, Khalifa’s claim was simply that if social conditions were different, conceptions about reality would be different. Therefore, according to Khalifa, the short explanation of constructivism postulates that the aim must have something to do with social conditions while also satisfying some plausibility condition. In this investigation, the “social condition” is the impact of caregiving and the “plausibility condition” is that each story fashions part of the big picture that is profiled in the collective narrative. In turn, the collective narrative profiles a holistic snapshot of the landscape that encapsulates a world of lived experience – which may or may not represent “reality” as a statement of fact.

Piecing together the conditions postulated by Khalifa (2010), Kukla (2000), Neimeyer and Levitt (2001), and Owen (1995) as applicable to this research investigation, the context is inclusive of individuals, families, and small groups, without the presumption of universality. Concern lies with the pragmatic utility of validity of application and the specific social construct appears to be natural and obvious to the people who accept it. The collective narrative profiles a landscape that encapsulates this world of lived experience which, as well as not representing reality as a statement of fact, acknowledges that lived reality is something that exists independently of ideas or perceptions that are universally held about it.

23 A hypothetical postulated as a fact (Kukla, 2000, pp. 60-62).
Marton and Booth (1997) put forward a constructivist position when they expressed that “conceptions of reality are aspects of an individual’s awareness that exist in some latent form and can be brought to a reflected or thematisised state through the researcher’s interventions during the course of interview” (pp. 130-131). Thus it is that the authors posited the notion of seeing individuals as “the bearers of different ways of experiencing” (p. 114) which, for Prosser (2011), is contextualised through the visual when stated as “how humans ‘see’ is part nature and part nurture: being governed by perception that, like other sensory modes, is mediated by physiology, culture and history” (p. 479, internal quotation marks included in original text). Berger and Luckmann (1966/1975/1991) referred to the notion of everyday life presenting as a reality, interpreted by individuals as being subjectively meaningful as a coherent world organised around the “here” of the body and the “now” of the present (pp. 19-22). They identified thought processes as being shaped by conditions in the social setting within which they occur. These same authors also emphasised that all social facts were defined as including elements of human thought, understanding, and meaning: whereby constructing multiple realities.

Owen (1995) suggested that “the tool of knowing” (p. 162) is inevitably the subjectivity of the people themselves and while acknowledging that each human being is an individual, it also needs to be acknowledged that humans are part of a shared collective of aims, values, and experiences. As Owen argued, just because we can each say, “I” and because we each have a separate body, does not mean that thoughts and emotions are located solely within the individual. Rather, thoughts and emotions exist between individual human beings who can be said to construct a shared social reality: such as may reflect Siegel’s notion of the neurobiology of “we” (Siegel, 2008). Referencing the conventions of “individualism” and “groupism”, Owen maintained that it is only through the integration of both arguments, that contextual thinking can be produced: whereby “individual qualities and social forces are seen in parallel as a co-construction of the individual in community” (p. 162).

24 According to Owen, “Individualism” regards human behaviour as the result of personal choices, grounded in the individual’s values and unique personal characteristics.

25 According to Owen, “Groupism” holds the view that human behaviour can only be understood within its overall social context wherein individuals are influenced by the people around them much more than by their own trait.
The approach of human beings constructing a shared social reality was also posited by Berger and Luckmann (1966/1975/1991), who suggested that much of the individual’s personal space is intimately influenced by others who are around. In particular, are those with whom the individual interacts on a daily basis, sharing the world of everyday intersubjective immediate experience and using both verbal and non-verbal communication to influence the dialectics of social reality. Encountered social facts affect and condition human beliefs and conversely, human beliefs affect the social facts of the lived experience. Berger and Luckmann also claimed that the influence of others with whom the individual is intimately connected can impact to such a degree, that any clear boundary of “what is mine” or “who I am” can become blurred. They further argued that as individuals are interdependent with others, when the boundaries become blurred an individual can become dependent on others in sustaining personal well-being.

The notion of an integrated construct was also explored by Ashby (1952) and Powers (1973/2005, 1998) who referred to human beings as being essentially intricate control systems who behave as a means of defending essential variables (Ashby) and intrinsic variables (Powers) against external disturbance. As previously stated in Chapter One, these variables are said to include basic physiological fluctuations in body temperature, blood pressure, and/or blood glucose levels. Also included are higher order disturbances to the firing of cortical neurons and synaptic integration that influences perception, cognition, and action that is crucial to the holistic well-being of the human control system. Ashby and Powers claimed that these essential/intrinsic variables need to be maintained at optimum levels – or at least, maintained within non-lethal limits required for efficient operation and survival.

Critics of social construction have claimed that it rejects criticism, is too subjective, and avoids conflict (Ratner, 2005). However, in addressing such criticism, Gergen (1999/2009) postulated the notion that the major question within a framework of construction is not one of objectivity; but one of utility. Gergen also referenced the need for the researcher to take a critical stance towards “taken-for-granted” knowledge in favour of generating understanding of people’s lives, and appreciating the challenges that people confront. Through the sharing of first-hand experience, people “are encouraged to ‘tell their story’ in their own terms” (Gergen, 1999/2009, p. 66).
Throughout collection, analysis, and synthesis of data, Gergen’s critical stance on the taken-for-granted was actualised through incorporation of processes of analytic bracketing as referenced by Holstein and Gubrium (2005, pp. 495-497) and discussed in Data Analysis, 3.7. All bracketing recognised the philosophical platforms established by Husserl (1929/1960/1982) and Heidegger (1927/1962); discussed in 1.10, Validity: Rigor, Authenticity, Trustworthiness.

In keeping within the principles that underpin a constructivist epistemology, the target demographic for this project spanned a region that encompassed local constituencies with a focus on individuals and families. With the locus of inquiry being to profile distinctive patterns of constructing meaning within the social context of caregiving, participant sampling was oriented towards enabling the most comprehensive and valid profiling of relevant data, while portraying a holistic snapshot of local rather than universal reality.

3.4 Participant Sampling

Choice of participants was purposive, selective, and subjective; and as suggested by Cohen et al. (2005) and Patton (2002), was characterised by a deliberate intention to gain a broad representative sample of appropriate individuals to contribute to the development of the collective narrative. The only criteria for selection were (a) the prospective participant was currently, or had been the primary, informal caregiver for a loved one who has/had Alzheimer’s disease; and (b) the prospective participant was a constituent of the defined demographic location.26

As this was to be a holistic inquiry, there was no differentiation of participation according to any other factor – for example, social, racial, cultural, religious, gender, age, lifestyle orientation, relationship, duration of care, profession, career path. Therefore, considering the nature of the subject under investigation, the aim of the research, the research question, and the persons who could contribute relevant data, participant selection was based on the professional judgement of the researcher with the only consideration being that the prospective participant met the criteria for selection.

26 As stated in 1.1.2, Relevance, the designated boundaries captured Sunshine Coast to the north, Gold Coast to the south, islands of Moreton Bay to the east and Toowoomba to the west.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: 87

To ensure selection across the full region, as per criteria above, participants were initially sourced through referrals from nursing staff, hospice centres, medical practitioners and allied health clinicians, friends, associates, fellow counsellors, and other professional practitioners and community service providers (for example: hairdressers, clergy, meals-on-wheels co-ordinators, craft and interest group co-ordinators) whose practise and professional relationships placed them in contact with potential participants. Third party referees spoke with the person/s they believed might have relevant lived experience and sought their consent (in writing) to pass contact details on to the principal researcher. Contact was made and those referrals who met the criteria were given full explanation of the project and invited to participate.

During the course of the investigation, other participants self-referred to speak of their reflections and to tell the stories of their experiences of caregiving or of vicarious impact in concert with the caregiving relationship. Stories of vicarious impact added an unexpected dimension to the body corpus of data and so the invitation extended to me to listen, to share, to hold, and to give away stories that profiled a broader landscape of the impact of caregiving than was initially intended, was accepted with pleasure and appreciation.

Once referred, prospective participants were contacted by the principal researcher and were given comprehensive verbal and written information relating to the research project (documentation appended, Appendix H). Those who chose to participate were given choice of venue and mode of engagement and were also given the opportunity to have a support person present with them, should this be of their choosing. A mutually convenient time was arranged for dialogue. Written consent for the principal researcher to engage with the participant in dialogic exchange was signed prior to interview. There was no predetermination of how many participants would be interviewed. Selection of participants was complete when a point of data saturation had been reached: that is, when no new data was presenting.

At the completion of inquiry, 34 participants, aged between 10 years and 90 years, had shared their stories across a time frame spanning 10 months (October 2015 to August 2016). Included were 23 primary caregivers or caregiving partnerships, four significant support persons, and five persons touched by vicarious connection. At the
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: time of dialogue, primary caregivers and primary co-caregiving teams had collectively given 201 years of care, underpinned by love and unconditional positive regard.

3.5 Data Collection

The primary method for gathering data was by way of dialogic interchange actioned through interactive interviews that were verbal, in-depth, and semi-structured. As suggested by Moir-Bussy (2006), “the notion of dialogical dialogue or dialogical exchange links closely with the process of counselling and psychotherapy in which the participants are engaged in a reflective dialogic encounter” (p. 73). Respecting the notion expressed by Smith (2003) that “oral history interviews tap into a continuous outpouring of words that provide matrices defining identity” (p. 203), participants were invited to choose aspects of impact upon which they wished to focus, while also delving into what Jung (1961/1983), in a letter to his wife, Emma, (dated September 06, 1909), described as “the fruitful bottomlands of our own psyches, where we confront and re-create ourselves” (p. 402). Participants were invited to recall and to reflect on the realities of their lived experiences and it was in re-call and re-flection that they shared a story of re-conceptualised experience and re-framed awareness. It was through allowing the Self freedom to journey to these “bottomlands” of a personal psyche that richness and diversity of experience emerged.

With reference to translating what is known into what is told, Fuks, Kreiswirth, Boudeau, and Sparks (2011) spoke of the openness with which participants bring holistic perspective to the telling of their story: an openness that takes into account an idiosyncratic, anecdotal contribution in the construction of meaning. The authors also referred to the power of experiential and conceptual metaphor in helping to mediate communication by providing a rich vocabulary to describe that which may be difficult to verbalise, while also transcending the barriers between the story teller and those who hear the story. In keeping with the model of interactive interviewing outlined by Ellis and Berger (2003), participants were encouraged to tell their story as they recalled and reflected on their lived experience: as it was for them. From a constructivist perspective that reflects Adams’ (2006) notions of learning and knowing, interviews sought to elicit an understanding of how participants created their knowledge constructs and what these constructs meant for understanding influences and thought processes.
According to principles espoused by Adams (2006), the fluid nature of constructivist interviewing required for me to adopt a view that each participant constructed his/her reality differently. These differences stemmed from the various ways the individual participant acquired, selected, interpreted, and organised the information that s/he was willing to share in the telling of his/her story that identified as his/her life world of reality. As a social constructivist oriented researcher and in accordance with Adams’ claims, I (as the chief investigative researcher) positioned the dialogical self of I, the researcher, so as to provide each participant with opportunity to construct, to understand, and to make meaning of the reality of lived experience. Such was the position that best served the need of the individual participant to capture what Shotter and Gergen (1994) described as a “knowing from within” expressed as “conversational knowing” (pp. 4-5). By intertwining speaking, listening, and hearing reflexively within a process of dialogic interchange, “living dialogue” (pp. 4-5) emerged into conscious awareness. There was also acknowledgment that emotion was integral to the process and that Self states were dynamically organised and reorganised from moment to moment in a unified sense of Being and presence (Whelton & Greenberg, 2004).

Prior to consenting to participate in the research project, prospective participants were not only provided with information relating to the nature of the research project, they were also advised that, like themselves, the researcher had an “inside story” of the impact of caring for a loved one with Alzheimer’s. In concert with ideas expressed by Ellis and Berger (2003) and based on statements made by participants (referenced in Chapters Five and Six), it is believed that this self-disclosure helped participants to feel more comfortable as they reflected upon “the good, the bad, and the ugly” that defined the essence of their lived reality. It is also believed that the comfort factor was enhanced by interviews being guided by open-ended questions or prompts, aimed at what Ellis and Berger referred to as “promoting dialogue rather than interrogation” (p. 159). Openness also allowed for participants to have choice in the dimensions of lived experience they were willing to explore, in relation to the questions they chose to answer and/or the prompts they chose to follow.

Considering this notion of openness in interviewing strategy, Rosenblatt (2003) wrote of “blurring the boundary between fact and fiction” (p. 226). In committing to openness, I, the researcher, accepted that what was learned had potential to create, highlight, limit, and obscure what might be considered to be fact and truth, in favour of experiential diversity. Working within this frame of reference, what was given by participants was acknowledged as being more than mere stories which, while they may not have been unambiguous, invariant, or immutable truths, provided opportunity to learn about what was real and true to those who were telling the story: that is, those impacted by the informal caregiving for a loved one who has Alzheimer’s.

After general introduction, greeting, settling, recording of basic personal data, and assurance that in the telling of their story there was no right, no wrong, no good, no bad, only what is, the initial prompt was phrased in terms of, “Talk with me about what it is/was like for you, caring for ……..”. Subsequent prompts and questions followed on from statements of response made by the participant: for example, “Tell me a little bit more about ………” or “How do/did you feel when ……..?” or “What do/did you do when ……..?” or “What is/was that like?” or “How often do/did you have those feelings?” or “What prompted you to do that?” or “What is/was your motivation to keep going and not give in or give up?”

Employing processes that initiated introspection, recollection, and reflection, participants first reconceptualised their personal lived experience then reframed that reconceptualisation in a synthesis of all that defined the impact of caregiving as was their reality. As stories began to flow, participants were also invited to engage not only from a surface level of recall, but also from a deeper, inside space; where impact was identified with an experience that encompassed all of their senses, intuition, emotion, and imagination. At the conclusion of the dialogue and as a token of appreciation, each

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28 During the settling period, it was confirmed with participants that this was a research conversation and not a therapy session and should emotionally charged and unresolved issues emerge that required counselling intervention, I would support them in seeking appropriate therapy as per information previously provided. I placed a box of tissues and a selection of expressive tools on the table and ensured that we each had water.

29 Personal data collected included aspects such as relationship with the care receiver, ages, cultural background, duration of care, and key dates as may be relevant to the participant’s story – for example, realisation relating to observable signs of onset, diagnosis, progressive degeneration, admission to formal care, death. Refer Appendix J.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: 91

The collective reality from onset to end of life and beyond. Judith R Boyland

participant was given (1) a “thank you” card, (2) a bookmark with the quote, “When all else fails, hug your Teddy”, and (3) in concert with processes of an eclectic, expressive interviewing modality, either a feather upon which to place their worries and watch them fly away or a bottle of bubble blow for them to use to blow their stresses away.

An eclectic interviewing approach also incorporated Prosser’s (2011) notion of a “visual methodology” (previously cited in 3.2, A Qualitative Paradigm) which implied that how participants “saw” the reflection on experience, was part nature and part nurture: governed by perception, conception, and sensory engagement with the inner Self. It was acknowledged that sharing such an intimate and personal story had the potential to be emotionally charged: emotionally wrenching on the one hand or emotionally therapeutic and cathartic on the other hand. Therefore, in the process of telling his/her story, if a participant had need to speak about aspects of his/her life experience that were perceived as beyond or outside the focused orientation of the impact of caregiving, professional judgement of the researcher was used to ascertain when to bring discussion back in focus. When it seemed appropriate to the needs of the participant interviewee, the option to allow the story to veer off on a tangent was embraced: thus promoting a continuous and uninterrupted outpouring of reflection, emotion, memory, and dialogic expression.

An additional factor of consideration when in dialogue with participants was respect for the sensitivity of the topic under investigation and the potential vulnerability of participants as they relived situations and shared their stories. Therefore, the time-frame of each interview was guided by the perceived need of the individual participant. Follow-up conversation was welcomed by the researcher as additional thoughts surfaced for the participant in the light of our initial dialogic encounter. These

30 Reference beyond or outside the focussed orientation of the impact of caregiving, included aspects of relationship history with loved one, extended family history, anecdotal memories, or simply what emerged in the moment of reflection.

31 A lifetime and professional skills developed across 55 years of teaching, educational leadership, management, parenting, counselling, life-coaching, consultancy, and professional supervision.

32 The least time spent in initial dialogue was one and one-half hours and the greatest time spent in initial dialogue was six hours, which included lunch and a walk in a near-by park.
unsolicited “follow-ups” were by way of telephone conversation, Skype, or email communication and were initiated by participants. As explained by Anderson (1998), studying rich human experiences warrants comprehensive methods of inquiry that engage logic and analysis, as well as capacity for imagination and intuition. It might well be added that “studying rich human experiences” also warrants compassion accompanied with intuition and transpersonal engagement of Self with Other. Or, as Hermans (2012) might say, engagement of the internal I of the researcher with the external I as embodied in the person of my participant. If deviation, or time, or a tissue was ascertained to be what was needed at that point in time, then this need was acknowledged with empathy, sensitivity, respect, understanding, and appreciation of processes of participant-centred engagement: as was post-interview contact.

When gathering data, it was also important to be aware that this was a research scenario and not a therapy session. With reference to Denzin and Lincoln (2003), it could be said that when doing qualitative research the researcher becomes the instrument through which the participant tells his/her story: an image similarly reflected in the writings of Austin and Sutton (2015) and Sage Publications (n. 2017 [chapter reference]). Be this so, it was critical that I, the researcher, stay true to the role and when gathering, analysing, and synthesising data allow the participant’s story to be the hero: untarnished by any biases or assumptions that may have interfered with the resonance, clarity, and richness of the story as both a personal portrayal of a singular lived reality and as a contributory thread in the tapestry of the collective narrative.

In dealing with what one might refer to as the unconscious intruder to the reflexive Self, before engaging with either research participant or clinical client, one would be wise to take a moment to reflect and to action what Romanyszyn (2010) refers to “making the unconscious as conscious as possible” (p. 317). It is by being consciously aware of specific role function that one minimises risk of work related transference: be that “work” research or therapy.

While there are similarities between the roles and responsibilities of researcher and therapist, the key orientation of difference lies in the hermeneutics associated with

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33 Adhering to the ethical dimensions of non-maleficence and beneficence, participant contact was welcomed in a spirit underpinned by the principles of empathy, sensitivity, and respect. At no time was post-interview contact solicited nor did unsolicited contact become problematic.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland

Data analysis and the processing of the resultant image. What is significant is the differentiation between holding (therapeutic confidentiality) and giving away (research profiling and dissemination) and between focusing on the individual story (therapy) and focusing on the collective narrative (research). When one is consciously aware of these defining characteristics, the tasks of reflexive practice, maintaining clarity of purpose, and not blurring the lines between the two disciplines becomes easier to accomplish.

In considering expanded views of research, Braud and Anderson (1998) emphasised the importance of the use of words as the researcher moves, goes round, and circles the object of inquiry, again and again. What is ultimately provided, they suggest, is “a fine metaphor for the research enterprise” (p. 25). In accord with the position as explained by Braud and Anderson, and also by Holstein and Gubrium (2005) and Marton and Booth (1997) in relation to gathering qualitative, empirical information that relates to everyday life, focus of attention was on personal concepts and understandings, as they related to situations and constructs that informed the development of perception. Focus of attention was also on reflecting differentiation between the real, the ideal, and the perceived; embracing the reality embodied in living the experience rather than embracing the cause underpinning the experience. With intent to give the participant total freedom to engage, attention was drawn to the expression of the participant as s/he reflected and built his/her story. What does it look like? What does it sound like? What does it feel like? What other sensorial engagement is experienced? What emotional, physical, and functional reactions and/or responses are elicited? Ultimately, it is the merging of the what with the how that brings depth and richness to both the individual story and the collective narrative.

3.6 Developing the Hybrid

According to van Manen (1990/1997/2006), the research method and the approach used is only a way of investigating the question. His claim is that it is the question itself and the way one understands the question that is the important starting point. As the research question focused on gaining insight and understanding about the diverse nature of truths embodied in the impact of a lived experience, as previously

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34 For example, engaging with empathy, sensitivity and respect and adhering to the ethical principles of non-maleficence, beneficence, autonomy, justice, equity, and fidelity (Australian Counselling Association, 2015; Morrel, 2015)
stated, the most appropriate process of investigation was that embodied in a hybrid methodology. A key point for consideration throughout all processes of inquiry was to hold tightly to the position that the investigation was about lived experience within the broad arena of human science. Investigation also sought to delve deeply into expressions of transformation: referred to by Anderson (1998) as being “profound and inexplicable aspects of human experience” (p. 68).

Regarding this specific inquiry, it was important to keep in mind that the focus was on the impact associated with caregiving and about giving voice to those impacted in their caregiving for loved ones who have Alzheimer’s disease. Impact of the disease on the care receiver was of secondary significance within this designated context; and relevance of individual scenarios was considered only in relationship with the impact of caregiving. As stated above (3.1, Introduction to Method and Methodology), in acknowledgment of influencing factors, a qualitative hybrid paradigm incorporating the intertwining of heuristic and transpersonal approaches within the fields of intuitive and narrative inquiry, presented as being the most appropriate method for investigating the question of the impact of caregiving. Such hybridisation was believed to be well situated within the social construct of caregiving while also considering what Braud and Anderson (1998) referred to in terms of diversity as pertaining to adaptation of a hybrid approach in serving the individuality and uniqueness of each participant and the story that each had to tell.

3.6.1 - Narrative inquiry

According to Clandinin (2006) and Clandinin and Connelly (2000), narrative inquiry draws on a Deweyan view which sees experience as being personal and social, with both elements always present. Dewey (1938) argued that while all persons are individuals and need to be understood in terms of individual experience, individuality cannot stand alone. For Dewey, individuality is always in relationship within a social context. Drawing an analogy with the interpretation offered by Clandinin and Connelly, the term “experience” helped the researcher to think through the matter of “the impact of caregiving” as it pertained to an individual participant. Also understood is that the impact of caregiving takes place in relationship with other people in a social context which is inclusive of (but not exclusive to) the loved one who is the care receiver. The
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.

Judith R Boyland

relational domain also includes other persons such as family, friends, work colleagues; medical practitioners and allied health professionals; respite personnel, hospital and nursing care staff; palliative care staff, government agencies, and the wider community.

Dewey (1938) also claimed that a significant criterion of the lived experience is continuity, in so far as experience does not occur in isolation: for example, the experience of “now” grows from previous experience while also leading to an experiential future. It is this very process that was referenced by Clandinin (2007) as being “a profoundly relational form of inquiry” (p. xv) demanding that ethics play a central role both throughout and beyond the actual process of the investigative research. As I, the researcher, and my participant worked relationally, the stories of both shifted. Clandinin also claimed that while researcher and participant are in the midst of living and telling our own stories, we are also in the midst of larger cultural, social, and institutional narratives.

According to Pinnegar and Daynes (2007), the narrative relationship embodies stories lived and told. It is only through the interactive quality of relationship within and across these stories that we can call ourselves narrative inquirers. The narrative also serves to offer what Brownlie (2009) identified as crucial insight into the nature of a reckoning of relationships and emotional legacy. For Clandinin and Connelly (2000), the issue is about coming to terms with the values brought to bear on the situation whereby the relationship forms the link between story and storyteller as the narrative inquirer brings all the stories together:

Narrative inquiry is the study of experience, and experience, as John Dewey taught, is a matter of people in relation contextually and temporally. Participants are in relation, and we as researchers are in relation to participants. Narrative inquiry is an experience of the experience. It is people in relation studying with people in relation. (p. 189)

As explained by Gergen (1999/2009), narrative inquiry is about giving voice to those who are the subjects of the study, featuring first-hand accounts of the people themselves. It is about giving voice to the unheard and treating their voices with respect. Empathy and sensitivity are also considered to be significant elements that permeate inquiry, bringing compassion and understanding of an authentic self, while
also bringing a first-hand appreciation that comes with having a “from the inside” lived experience accompanied by the authenticity embodied in a listening heart.

For the caregiver, the impact of caregiving cannot be defined as an isolated moment of experience. It is an unfolding story where each incident, as it occurs in each moment, has a compounding history following from that which has gone before and influencing that which will surely follow. In a similar vein, when weaving the collective profile of the narrative, the thread of each individual story intertwines with threads of similarity and difference that have gone before; while also connecting with the threads of stories that follow.

**Figure 4 - The unfolding story:** (1) Advancing the story entails reflection on the what and the how that defines the impact of the caregiving experience. (2) Reflections on the lived experience are reported as subjective descriptions of how the events of “yesterday” are reconceptualised in “now” time. (3) For the story to be complete, that which has been reconceptualised is now reframed in the light of reflection as the story teller moves forward embracing the potential to create new events in awareness while bringing to the evolving narrative a vision of possibility that extends beyond the present.

Considering the knowledge that people acquire through the living of their stories and the knowledge they disseminate in the telling of their stories, Denzin and Lincoln...
(2011) state that knowledge claims about the world of day-to-day reality enable the threads of multiple voices to be interwoven. As expressed by Coles (1997) and cited in Craig and Huber (2007):

The point of personal stories . . . is not self-accusation. . . . The point is to summon one’s frail side so as to enable a more forthright sharing of experiences on the part of all of us: that guy has stumbled, and he’s not making too much of it, but he is putting it on the table, and thereby I’m enabled to put some of myself, my remembrances, my story, on the table, whether explicitly, by speaking up or, in the way many of us do, by also remembering—another’s memories trigger our own. (p. 265)

Fuks et al. (2011) speak of contextualising stories when a healthy life is interrupted by the unexpected. The somewhat coherent life story that one has “written” for oneself loses its explanatory power as one now faces a moment in which the causal link to the past and implications for the future are unknown. Fuks et al. also refer to the therapeutic effect of story-telling. Linking Dewey’s notions of continuity and relationship with a third dimension of situation, Clandinin and Connelly (2000) created what they termed as being “a metaphorical three dimensional narrative inquiry space” (p. 50, italics included in original text). Within this space of inquiry, the temporality of past, present, and future define one dimension. Conceptual elements of the personal and the social constitute a second dimension. The contextual aspect of place completes the triadic balance. Thus it is that the rituals, routines, metaphors, and everyday actions of lived experience as storied by participants, bring structure to the narrative inquiry: “people live stories, and in the telling of these stories, reaffirm them, modify them, and create new ones” (p. xxvi).

Transferring the premise of Fuks et al. (2011) from a clinical context to a research context, it could be suggested that when participant and researcher come together in “compassionate solidarity” (p. 310), there is potential to experience an act of healing. Such is the openness of narrative inquiry and such is the sensitivity, empathy, and respect embodied in the intuitive, the transpersonal, and the heuristic as brought together and entwined within the narrative through the process of bricolage. As extracted threads were interwoven, the emerging landscape pieced together multiple positions embodied in conceptions of participants who shared stories of lived
experience. Such was the essence of reality as it appeared to them, as it was seen by them, and as it was re-viewed by them in processes of reconceptualisation and reframing.

3.6.2 – Intuitive inquiry

With consideration to the derivation of that which is “intuitive”, Anderson (2011) referenced the Latin origin (intuitus) which she positioned as relating to “the direct perception of knowledge” (p. 246). Jung (1933/2001) presented intuition as being “of nature” and defining it as “a perception by way of unconscious contents and connections”, he determined intuition to be a non-rational function (pp. 93-94). In this sense, Jung claimed that intuitive insights often elude attempts to understand their character or their origin. This “yearning to understand”, Anderson described in terms of “love in pure form, because the intuitive inquirer wants to know her beloved topic fully” (pp. 243-244). To this end, she states:

Details matter. Secrets matter. The ordinary is extraordinary. The particular is favoured. Everything related to the topic has meaning and significance, drawing her closer to understanding. She yearns to know more. Named or unnamed, conscious or unconscious, an intuitive inquiry has begun. (p. 244)

The yearning in this investigation was to know more of the caregiver’s story and was about providing opportunity for caregivers to tell their stories – the good, the bad, and the ugly; the details and the secrets; the ordinary, the extraordinary, and the particular. It was about giving these multiple voices opportunity to be heard and acknowledged with empathy, sensitivity, and respect. It was about weaving a landscape of similarity and difference that honoured the named and the unnamed and the conscious and the unconscious that constituted collective perceptions, understandings, conceptions, re-conceptions, and re- framings of participants’ lived experience.

In expanding and connecting views inherent within intuitive inquiry as defined by Braud and Anderson (1998) and in explaining how the researcher “connects, circles and looks again and again” (pp. 25-26), the overarching intuitive connection was encapsulated within a framework of re-spect. Maintaining focus on a bilateral interpretation, associated with the duality as expressed in the notions of “re-spect” and “respect”, I, as bricoleur, connected with participants and their stories on a conscious
level of inquiry; while also bringing to the dialogic process “a fullness of attention [imbued with] minimal distortion, minimal filtering, minimal projection, minimal denial, and minimal preferences and biases” (p. 26).

Focussing on these same elements through processes of “intuition”, Petitmengin-Peugeot (1999) described the content of intuitive insight as incorporating the gestures of letting go and slowing down. Also discussed was connection with person, object, problem, and situation. An additional element alluded to was the significance of “listening” with all of the senses and with awareness that is open and attentive. Petitmengin-Peugeot spoke of a basic surge of pure intuition that presents in many forms: such as an image or a feeling, a sound or a word, a taste or a smell, or a simultaneous succession of sensory experiences. Also noted was the importance of “interior preparation” (p. 246) that consists of emptying out, casting off, and giving up old habits such as representation, categorisation, and abstraction. It is this preparation, states Petitmengin-Peugeot, that enables the researcher to find spontaneity: defined by Anderson (2011) as “the real immediacy of our relation to the world” (p. 247).

Within a framework of intuitive dialogue, new understandings and new perceptions were reconceptualised and reframed. Brains resonated, minds intertwined, and voices were released, projected, and heard. In describing the caregiving journey through a trajectory from onset to end-of-life and beyond, it was the intuitive elements of inquiry that breathed life into the diversity of conceptions embodied in multiple stories. Each profiled a lived experience, underpinned by the knowledge of a reality that is unique to the world of caregiving, when someone I love has Alzheimer’s.

3.6.3 – The transpersonal

The objectives of transpersonal inquiry are identified by Braud and Anderson (1998) as including elements of wisdom and knowledge with a focus on transformation as well as information. The authors also claimed that it is the dynamic interplay between the researched stories, the practical application of weaving the threads of each story into a collective narrative, and the personal development that occurs during the research process that have the potential to loosen and dissolve boundaries. According to Laughlin (2013), engagement occurs within a social context where emphasis is upon integration of individual experiences within a social process. With a focus on
integration and drawing from the position as defined by Braud and Anderson, processes of inquiry in this project were aimed at expanding, enlarging, enriching, opening, integrating, unifying, awakening, transcending, enlightening, and interconnecting within and without. In considering a transpersonal approach to inquiry, association is also reflected back to Chapter One where, in discussion of the dialogic interchange, Badenoch (2011) speaks with reference to an “interpersonal oneness”: the position created when one brain resonates with another brain.

An intimate aspect of this transpersonal resonance is the notion of the “Spiritual Self”, defined by James (1890) as being concerned with the innermost centre of the “Empirical Me” (p. 659) constituted by the subjective interpretation of life as a whole. As the brain of the researcher resonated with the brain of the participant, the empirical self of I, the researcher, was invited to come to a position of knowing what was being studied as “subject rather than object” (Braud & Anderson, 1998, p. 51). With focus on “subject”, I was prompted to reflect on Hermans’ (2012) definition of the internal position of I linking with the external position of I: the I of researcher, linking with the I embodied in the position of my participant. As explained by Hermans, linking the internal I and the external I is about seeing the Other as part of an extended Self – particularly relevant where both participant and researcher share a story that is from the inside. Reflecting James’ embodiment of the Empirical Me, that empirical something in each of us which seems to go out to meet the qualities and contents that define life could also be seen to embrace elements of a spiritual something that defines purpose and meaning. These same qualities and contents come in to be received within the central nucleus of the Self: “the ultimate one of all the selves” (p. 674). For Steiner (1918/1923), this concept of the Spiritual Self presents as a “naïve consciousness” (p. 83) which regards as real only that which is perceptible and wherein only ideal facts are to be recognised in the making or the imagining of connections.

According to Braud and Anderson (1998), in bringing preparedness, sensitivity, and being to what is learned from the stories as told by participants, the researcher is changed and transformed through personal growth and spiritual development. Learning that occurs in one area allows particular types of knowing to occur in other areas: a transformational process defined by Braud and Anderson in terms of how “sensitivities mold being and being molds sensitivities in an endless cocreative, dialogical dance” (p.
It might also be said that in the re-visiting, the re-living, and the re-telling of stories, participants could also be changed and transformed. As stated above (3.6.1, *Narrative inquiry*), what happens and what is learned from one story is fed by other stories and the stories of others, with every story influencing and being influenced by all other stories. Elements of discourse are influenced by an expanded sense of inquiry that moves beyond the external and taps what was on the inside. As conceptualised by Steiner (1918/1923), “one must be able to confront the idea in living experience, or else fall into bondage to it” (p. 131).

In the process of dialogic interchange, elements of discourse were influenced by an expanded sense of inquiry that moved beyond the external and tapped what was on the inside. As claimed by Braud and Anderson (1998), it is the dynamic interplay between the researched stories, the practical application of weaving the threads of each story into a collective narrative, and the personal development that occurs during the research process that have the potential to loosen and dissolve boundaries. From a holistic perspective that embraces finding meaning and purpose, Kavar (2015), identifies movement within and across relationships, engagement, understanding, and finding an overall sense of happiness, joy, and fulfilment. For Berne (1966) it is about seeking the state of OKness; for Glasser (1984, 1999), it is the quest for internal spiritual gratification; for Jung (1961/1983), it is the interconnectedness of the psyches.

In gathering and analysing data, what was of significance in the making of connections were references to bodily reactions and sensory impressions; words, thoughts, and actions; imagery and imagination; memory and prior experience; feelings and emotions; realisations in altered states of consciousness and awareness; perceptions, intuitions, and direct knowing. In seeking to gain insight and understanding about the nature of truth embodied in the world of lived experience, no single story was complete in knowledge or truth.

The journey towards completeness is embodied in the collective narrative. Elements of shared experience expose a process of evolving personal and functional transformation (Being and doing – the ontology and the axiology of caregiving), while also revealing wisdom and knowledge (knowing – the epistemology of caregiving) that projects potentiality for further transformation.
3.6.4 – The heuristic

Defining that which is heuristic, Moustakas (1990) makes reference to the Greek root of origin, *(heuriskein)*, which means to discover or to find. Within this context, the heuristic element of the inquiry honours the internal search through which both participant and researcher discover the nature and meaning of the experience and adopt and adapt methods and procedures that best give voice to investigation and analysis.

The heuristic approach, as explained by Braud and Anderson (1998), relates to describing, understanding, and appreciating which, according to Moustakas (1990), embodies emphasis in a plurality of voices. This multi-voiced embodiment is portrayed by Moustakas as being inclusive of voices that belong to participants, researcher, and other contributors from various fields of human science and from wider disciplines such as humanities, the arts, and spiritual and wisdom-based traditions. Moustakas also links heuristic methodology with Patton’s observations that qualitative research attends to the uniqueness and individualisation of each case (Patton, 1990: cited in Moustakas, 1990). Such a link could also be seen to exist between Moustakas’ reference to heuristic psychotherapy and the heuristic approach as applied in research.

Considering the notion of “a dance creation” (Moustakas, 1990, p. 106) and linking Moustakas’ abstraction with the notion of “dialogical dance” (Braud & Anderson, 1998, p. 22, referenced above in 3.6.3, *The transpersonal*), it could be said that heuristic inquiry is choreographed through a combination of expressive modalities that reach a significant level of “mutuality and communion” (Moustakas, p. 106) between researcher and participant. As explained by Moustakas, “A mutuality of identities, compassion, and empathy facilitates the heuristic process” (p. 106). Reflecting Heidegger’s notion of being “concernfully absorbed” within the presence of the Other (1927/1962 – discussed in 7.4, *Ontology of Caregiving*), Moustakas explains the creativity embodied in processes of discovery as he states:

> From the opening moments with this other person, I immerse myself in his or her world. I become totally absorbed, curious, alert, and open, ready to enter into each expression. I want to understand what this person is expressing, not only

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35 The notion portrayed in terms of “multivoicedness” as referenced by Jones and Hermans (2011, p. 12) and discussed in Chapter One, *Context*. 

The collective reality from onset to end of life and beyond. 

Judith R Boyland
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.

Judith R Boyland

from his or her frame of reference, but from the vantage point of my own experience. Eventually what is expressed by the other person mingles with my own knowledge and experience. The meaning that is derived is intersubjective. My understanding of the experience is not an exact copy, but there is a mutuality of meaning that connects us in our awareness and understanding. I steep myself in his or her words, silence, actions, and creations, and understand his or her meanings. My energy, thoughts, and feelings, my self is centered in the other person’s life. Gradually, but definitely, we connect in knowledge, understanding and experience. Through heuristic methods, I come to know the other person’s world within the context of my own life. (pp. 106-107)

3.7 Data Analysis

Across the warp of a heuristic, transpersonal, intuitive, and narrative hybrid, multiple threads of data were woven together through an eclectic amalgamation of processes that encouraged dialogic interchange to be actioned through linguistic expression. Guided by the principles outlined by Anderson (1998) and Moustakas (1990), integration of the diversity embodied in collated stories created a landscape that could readily be appropriated into the development of a descriptive narrative, profiling a collective reality.

Preparation for data analysis began with scribing notes during the course of the interview36 followed by manual transcribing and processing of the recorded interviews. Given the sensitivity and the emotional vulnerability that underpinned the dialogic interchange, and also given that participants had not been kept to rigid adherence in discussing only that which related directly to the subject of the research question, the impact of caring, only data that was directly related to the construct under investigation was transcribed and identified as the data set.

Based on the model defined by Clandinin (2007), the collected stories of participants provided the narrative data which was manually analysed for common themes, metaphors, and plotlines in order to identify and extract general themes. Using terminology referenced by Braun and Clarke (2006) as a “tool” to define and

36 Hand scribed notes were subsequently processed and stored as text files.
differentiate elements of data in the process of thematic analysis, all data collected was referenced as the “data corpus”. That which was transcribed (the “data set”) was transcribed in full and as spoken, with no attempt to interpret, alter, correct, fill-in or elaborate. Analysis of data moved back and forth between the individual transcript (the “data item”) and the collective data set. As the weft of individual threads (the “data extracts”) was woven through the warp of a triangulated hybrid methodology, an evolving collective narrative began to flow, a tapestry was fashioned, and a holistic snapshot blossomed into focus. The emerging landscape began to profile the collective relationship between participant and the reality of lived experience: reconceptualised and reframed as expression of introspection, memory, perception, and projection to a future beyond caregiving.

**Figure 5 - Data:** All data collected is the “data corpus”. That which was transcribed is the “data set”. The individual transcript is the “data item” and individual expressions that profile lived experiences are the “data extracts”. Model reflects terminology developed by Braun and Clarke (2006).

As explained by Denzin and Lincoln (2005), qualitative research is inherently multi-method in focus. Therefore, not being wedded to any pre-existing theoretical framework, thematic analysis was an ideal tool to use in a research method defined in terms of a methodological hybrid. Using multiple voices, different textual formats, and various verbal and visual modalities, a complex text was woven as the threads of each
frame, as portrayed by each participant, were woven into a collective landscape. As argued by Smith (2003), “in the context of narrative analysis, the ‘data’ of interviews are first and foremost the ways in which a person has reconstructed the past to negotiate an ever-fluid process of identity construction” (p. 206, quotation marks as per in original text). Also, as stated by Smith:

Narrative analysis allows for . . . interpretation of . . . source material that is not dependent upon the ultimate veracity of the accounts provided [and] even if only tacitly expressed, explanatory assumptions affect every aspect of the interview, from the organisation of the story line . . . to the presentation of personalities and events, to patterns of factual errors, omissions, and contradictions. (p. 204)

Reflecting principles posed by Gergen (1999/2009), importance was focused through a process of listening twice – once to the content of what was being said by the participant and secondly to what the content implied for actions that might follow. As multiple story frames were brought together, the data set was established and the process of integration created what Denzin and Lincoln (2005) described as a pattern of “psychological and emotional unity” defined by “interpretive experience” (p. 5). A process of analytic bracketing, as described by Holstein & Gubrium (2005, pp. 495-497), was used to maintain a clear and unobstructed focus on the what and the how identified by coded “chunks” of data. Each extracted chunk comprised an episode of experience as described by a participant and identified both within and across individual stories. According to Holstein and Gubrium, simply having knowledge of the principle of bracketing, made it possible to move from one train of thought to another, setting aside one reality as another was introduced. Such was also the process of moving across data extracts and data items in the search for certain themes that might present across the data set. Thus it was that in concert with the views on thematic analysis as discussed by Braun and Clarke (2006), analytic bracketing was both “substantively temporary” and “enduringly empirical” (p. 497).

Setting aside the need for an indisputable resolution to prioritise, the process of analysis was firmly focussed on the interplay within interpretive practice which required movement back and forth between the various facets as presented in the data, while also defining the immediacy of relationship to the world of informal caregiving (Anderson, 2011; Holstein & Gubrium, 2005). Subsequent generation of theory came from the data
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: the collective reality from onset to end of life and beyond.

which, as Green (2014) suggested, projected a specific philosophical construct of knowledge as it related to the impact that is “my” lived experience, when someone “I” love has Alzheimer’s.

3.8 Doing the Analysis and Developing the Narrative

Doing the analysis was about identifying collective variations of conceptions that profiled the diversity of lived reality compiled in the data set. This diversity presented as statements (data extracts) in the shared stories (data items) of those with inside experience. Weaving of threads extracted from the data corpus profiled the diversity embodied in the collective narrative. Diversity defines the collective reality and it is the collective reality that brings depth and richness to the woven tapestry that profiles the landscape of lived experience and creates a holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease.

Through the lens of a qualitative paradigm, stories embedded in the dimensions of multiple truths were integrated and as the collective landscape emerged, the story board was set for what Sonnemann (1954) described as “a descriptive recording of subjective experience as reported” (p. 344). Underpinned by processes of exploration, explanation, and interpretation, narrative development sought to bring insight and understanding to the complexities of human experience which, reflecting the premise posed by Richardson (1999), relied on participants’ discursive accounts of experience. Also presented was what Sin (2010) described as the “collective variations of conception . . . rather than the conceptions of the individual participants” (p. 306).

As explained by Braud and Anderson (1998), narratives form the core and nuances of personal identity. They are responsive to context, audience, and events; and as the stories unfold in each telling, new elements emerge and are joined together in the “advancing saga” (p. 23) of telling the important stories that are lived out in different social constructs. In concert with the model of narrative development presented by Braud and Anderson, as each story was told, the past was remembered and light was shed on the present, while implicating the future in terms of epiphanic knowing; described by Nordquist (2014) as “a flash of recognition . . . in which something is seen in a new light” (p. 1). Such is the process identified in Figure 4, The unfolding story (3.6.1, Narrative inquiry).
According to Braun and Clark (2006), writing is an integral part of analysis and therefore, needs to begin in phase one with the jotting of potential coding schemes and continue right through the analysis process. Braun and Clarke also noted that analysis is not a linear process. Rather, it is more of a recursive process that involves a constant moving backward and forward between the entire data corpus (primarily the data set, the data items, and the data extracts) throughout all phases of analysis in development of the narrative. In Josselson’s terms (2011), it is Schleiermacher’s idea of the “hermeneutic circle” that fashions a position in which an understanding of the whole illuminates the parts which, in turn, create the whole (p. 226). Hence the focus of the developing narrative was to discover and understand the impact of lived experience, as reported from the subjective stance of participant story tellers. In turn, understanding the impact of lived experience became the focus of the developing narrative.

**THE DEVELOPING NARRATIVE**

**Figure 6 - The developing narrative:** A recursive process that involves a constant moving backward and forward across the entire data set, throughout all phases of analysis, incorporating Schleiermacher’s idea of the “hermeneutic circle” (Braun & Clarke, 2006; Josselson, 2011).
In terms of doing the analysis so as to develop the collective narrative of lived experience, Braun and Clarke (2006) proposed a step-by-step guided process starting when the researcher begins to observe patterns of meaning during data collection. The end point, they claim, is reporting of the content of these patterns or themes: themes being considered as abstract constructs identified before, during, and after analysis.

For McGettigan (1998), narrative development is about the individual’s capacity to redefine the multi-dimensional nature of empirical reality. For Kien (2013), in reflecting Denzin’s notion of epiphany, it is about “emotional urgency” that highlights the need to re-turn, re-explore, re-examine, re-conceptualise, and re-frame those “life-altering” moments of lived experience that “can identify as a turning point in one’s understanding of oneself and one’s relationship to the world” (p. 578). As the past was transported into the present through reflection that involved memory, introspection, and imagination, the telling of the story implicitly cycled from present to past back to present and in a line with processes of narrative development, the future was both implicated and illuminated. As claimed by Braud and Anderson (1998):

The sweep of the narrative seems to bring the future more luminously present and possible because narratives inevitably point forward. Fuelled by the dynamic of narrative, they inherently move forward bearing insight on present and future. The unknown terrain of the future seems more knowable and also more vivid, imaginable, and likely. In this way, like threads pulling us into the possibilities of the future, we live our stories, not in a deterministic manner, but imaginatively. This movement, the projecory of the narrative, may even create new events in awareness – possibilities and realities scarcely imagined without the stories’ thrust. (p. 23)

3.9 Ethical Considerations

Ethical approval was granted by University of the Sunshine Coast Ethics Committee (ethics approval number HREC: S/15/809). Commitment to adhere to all aspects of relevant codes of professional conduct was acknowledged by the chief investigating researcher, other research team members, and third party support persons. Referees who engaged in sourcing prospective participants were familiarised with principles of ethical practice. In respect of the participant and the participant’s story, a
professional code of conduct was developed and followed implicitly throughout the course of research.37 In keeping with thoughts expressed by Lincoln and Guba (2000) as relating to the position representative of a constructivist paradigm (previously noted above: 3.3, Social Constructivism), ethical considerations involved a process tilt towards revelation specific to the special nature of problems relevant to the investigation. Ethical considerations also embodied an axiological perspective where transactional knowing was acknowledged as being instrumentally valuable as a means to social emancipation which, as an end in itself, was believed to be intrinsically valuable.

In reference to the relationship shared with individual participants whose stories were being shared, held, and given away, Wilson (2001) spoke of the need for the researcher to come from a fundamental belief that knowledge is relational, needs to be shared, and therefore, cannot be owned. Wilson’s paradigm of relationality in a socio cultural context carries the potential to move beyond assuming an exclusive perspective. Therefore, in choosing to adopt Wilson’s paradigm of sharing, holding, and giving away participants’ stories, certain ethical questions needed to be considered:

a. How do I fulfil my role in this relationship with the participant?
b. What are my responsibilities in this relationship?
c. How do I share with others the stories that are shared with me?

Keeping with principles underpinning a constructivist paradigm as positioned by Lincoln and Guba (2000), ethical consideration respected the intrinsically valuable nature of the dialogic interchange. Processes of inquiry were tilted towards revelation of subjective, local, and specific constructed realities, and special problems encountered by individual players. At all times, participants and their stories were treated with empathy, sensitivity, and respect. In preparing a multivoiced reconstruction of the findings that profiled the landscape of lived experience, data were coded and de-identified with empathy, sensitivity, and respect. In representing the voice of the “passionate participant” (p. 166), the collective narrative was developed with empathy, sensitivity, and respect.

37 Ethical Code appended – Appendix I. This Code was developed with reference to The code of ethics and practice of the association for counsellors in Australia (Australian Counselling Association, 2015, [Version 12]).
In the frame of reference posited by Ely (2007), broader and more nuanced understandings of what had been studied were written in a form that honoured their complexity. The collective narrative bears a “signature” or “persona” that, according to Ely, “fuses a distinct, consistent authorial presence with a distinct, consistent professionalism and ethical stance” (p. 596). “This ethic,” said Ely, “does not speak its name. It is inherent” (p. 596). Further claim is that, “In the final say, it is not the fragments that move us but a wholeness that speaks to the mind and heart” (p. 596).

In considering ethical obligations for the researcher, Lopez (1990/2013) referenced the importance of respecting other people and giving thanks. He also noted that holding people’s stories is both an honour and a deep responsibility and he explained the need to care for the stories and to give them away when needed. As Lopez suggested, in order to stay alive, sometimes a person needs a story more than s/he needs food. In reflecting Lopez’ wisdom, it might also be said that, “Sometimes, in order to stay alive, a person needs to tell his/her story”.

3.10 Validity: Rigor, Authenticity, Trustworthiness

As heuristic researcher abiding by principles espoused by Moustakas (1990), I was committed to the rigour of “authentic self-dialogue, self-honesty, and unwavering diligence to an understanding of both obvious and subtle elements of meaning and essence inherent in human issues, problems, questions, and concerns” (p. 37). Questioning and checking was a constant, so as to ensure full explication of experience in the quest for validity.

From the transpersonal platform, risks in relation to reliability and trustworthiness were overcome by strict adherence to a framework of openness that recognised what Braud (1998) defined as “the various filters or resistances that might exist in the research participant, researcher, or reader and might interfere with the faithful reception, processing, or expression of the essence of an experience” (p. 227). Focus on validation also incorporated principles of the transpersonal as postulated by Anderson (1998), who proposed the bringing of a compassionate heart to the research inquiry:

Research informed by compassion is qualitatively different from emotionally detached research because our values and intentions frame the manner of our thinking and actions. . . . Compassion allows us to ask the most significant
questions and guides our hypotheses and speculations towards rich and expansive theories regarding the nature of human experience. Compassionate listening allows our research participants to speak to us freely and honestly about the depth and value of their human experiences. And, finally, as we report our findings, compassionate writing is heartfelt, a vessel for others to hear ideas and theories formed of compassionate listening, analysis, and synthesis of findings. (p. 71)

In considering foundations to truth and knowledge, constructivism is claimed by Lincoln and Guba (2000) to be “antifoundational”: denoting a refusal to adopt any permanent standard by which truth can be known. Rather, as stated by the authors with reference to Lincoln (1995), “truth – and any agreement regarding what is valid knowledge – arises from the relationship between members of some stake-holding community” (p. 177). Reflecting Lincoln’s position, inquiry was concerned with singular experience, individual crisis, the epiphany moment of discovery, and feeling and emotion. Criteria for determining validity are located in the processes and the outcomes. As stated by Lincoln and Guba, herein lay the hallmarks of authentic, trustworthy, and rigorous inquiry. These hallmarks they named as “fairness”, “ontological and educative authenticity”, and “interpretive rigour” (pp. 180-181).

Throughout the research process, where focus was on participants’ conceptions of the subject under investigation, reliability and trustworthiness were reliant on the anatomy of the researcher’s interpretative awareness, as postulated by Marton and Svensson (1979). That is, the researcher’s being aware and recognising how one’s own interpretations can influence the research, while acknowledging and explicitly dealing with personal subjectivity throughout the investigative process. How one deals with personal interpretation and acknowledges and deals with personal subjectivity is essentially determined by which philosophical approach best suits the specific research project; promotes the most rigorous, authentic, and trustworthy interpretation of the data; and produces the most valid interpretation of how participants conceptualise their world of lived reality.

If dealing with the data from a descriptive point of reference as postulated by Husserl (1929/1960/1982), one comes with a view that the object of investigation is an intentional structure that is understood in terms of the context. What one brings to this
particular context is a plethora of prior experience and assumption which must be purged or bracketed in order to attend to the actual phenomenon that is the focus of both attention and intention. If dealing with the data from an interpretative point of reference as postulated by Heidegger (1927/1962), one comes with a view that the subject of investigation is about one’s presence in the world that is defined by the context. According to Heidegger, above all else, we are “beings in the world” (p. 83) and it is how we Be in the world that defines our lived reality. In essence, from a platform of description, the focus is on the epistemology of the object and from an interpretative platform, the focus is on the ontology of the subject. From the hermeneutic position, as stated by Romanyszyn (2010, p. 317):

There is no way to step outside the work of interpretation, no way to stand apart from it.

The researcher is an encircled researcher . . . [and] enters into the circle with his or her prejudices. . . . [which] are the way into the text where they are challenged, transformed and lead to a different understanding of the text, a circular process that is on-going within an infinite horizon of possibilities.

Within the context of this investigation, my focus was on the ontology of the impact of caregiving: that is, how the construct of caregiving impacted participants’ Being in the world of their lived reality. Remaining true to my intent, I chose a pathway of “bracketing” that bridged middle ground between the descriptive and the interpretative: neither totally descriptive nor totally interpretative. As contextualised by Marton and Booth (1997) and Sandberg (1996), it is interpretative awareness that is embodied in a bracketed reduction of personal experience, enabling the researcher to avoid generation of description that is beyond evidence generated by participants.

For Braud (1998), the bracketing process is about attempting to remove biases while seeking “to provide as clear and pure a channel as possible” (p.227): one that is free from “impeding and interfering preconceptions about the research topic” (p. 227). Braud also claimed that employing strategies to quiet the interference of bias and to allow access to the embodied truths of impact as described by participants enhances the validity of empirical evidence that constitutes raw data. In concert with the position presented by Marton and Booth (1997) and Sandberg (1996), belief is that truth
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: embodied in experience brings strength to the trustworthiness of the collective narrative rather than posing risk to reliability. It is my belief that given my professional experience as teacher, educator, school principal, parent, counsellor, life coach, and professional supervisor, I have learned, practised, and developed skills to enable me to reflect and to become consciously aware of my own beliefs, assumptions, prejudices, and biases. I have learned to acknowledge and appreciate difference, thus minimising confusion and the harmful effects of transference and countertransference for both Self and Other – as may be within or outside what Covey (1989) refers to as my circle of control. I am open to learning and I welcome the transitional impact of filtering information, accruing knowledge, and allowing that knowledge to challenge both my beliefs and practices where the ultimate impact is on my Being – transforming how I Be in the world of my reality, while acknowledging that how others Be, may be different.

Referring to the collaborative nature of profiling the collective narrative, Craig and Huber (2007) cite Connelly and Clandinin (1990) and state that “the thing finally written on paper (or, perhaps on film, tape, or canvas), . . . is a collaborative document: a mutually constructed story created out of the lives of both researcher and participant” (p. 268, brackets included in original text). As suggested by Lincoln and Guba (2000), action is intertwined with validity and control is shared between researcher and participants. Voices are mixed and while sometimes it is the voice of the inquirer that is dominant, at other times the voices of the participants are dominant. Throughout the research process, I was conscious that as the research inquirer, it was my task to enable the reader to “hear” the voices of participants – their words and their paralinguistic cues, their lapses and their pauses, their stops and their starts and their tears. There was also a conscious awareness that reflexivity had potential to be problematic in so far as the action being reported was also the action of the person who was doing the reporting.

As suggested by Lincoln and Guba (2000), given that both inquirer and participant are located within the text, dealing with risk of problems arising from reflexivity demands interrogating each of our selves regarding ways in which the research is shaped and staged around the “binaries, contradictions, and paradoxes that form our own lives” (p. 183). Reflecting on the statement of Denzin and Lincoln (2005) that in qualitative research “objective reality can never be captured” (p. 5), there was also a conscious awareness of the potential to interweave viewpoints in a heuristic
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: the collective reality from onset to end of life and beyond.

Judith R Boyland

114

...to enhance richness, to secure in-depth understanding, and to bring insight to the research question. Melding processes of bricolage and triangulation to integrate a variety of empirical source materials added rigor, breadth, complexity, richness, and depth to inquiry. Resonating through the position of inquirer posture, the voice of the story teller is that of a multivoiced reconstruction, combining what Hertz (1997) defined in terms of multiple dimensions encompassing the voice of the author and the voices of participants within the text. This position relating to the multiple dimensions of voice is also referenced by Jones and Hermans as “multivoicedness” within the context of dialogic interchange (2011, p. 12): a notion that also incorporates the bringing together of the multiple voices within the Self of the researcher. When integrated through processes of narrative inquiry, concepts and contexts can be explained and understood; and as claimed by Pinnegar and Daynes (2007), “as a result, true beliefs about the social world can become valid and sure knowledge . . . and researchers have a secure base from which, with surety, they can assert knowledge” (p. 10).

3.11 Conclusion

In Chapter Three the theoretical orientations to method and methodology were discussed. Under the overarching umbrella of a qualitative paradigm, design, data collection, and analysis strategies have been addressed within a framework of social constructivist theory. Triangulation of methodologies created a warp through which the weft of data extracts could be woven, enabling the research question to be explored from multiple perspectives: whereby increasing credibility and validity.

Chapter Four introduces profiles in context as related to the storytellers. Collectively, participants present as a comprehensive representation of biological and interpersonal relationships with loved ones who have Alzheimer’s disease. As individual storytellers, each presents as a multivoiced Self in relationship with Other.

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[38] Reflecting Jones’ and Hermans’ concept of multivoicedness with reference to that which defines the imaginal space of abstract intrapersonal domains (Jones and Hermans, 2011) – previously referenced in Chapter One: 1.2, Structure.
CHAPTER FOUR – PARTICIPANT PROFILES IN CONTEXT

*The prettiest smile hides the deepest secrets;*
*The prettiest eyes have cried the most tears;*
*And the kindest hearts have felt the most pain.*

(Pinterest, 2017)

4.1 Introduction to Participant Profiles in Context

Chapter Three introduced theoretical orientations that inform the method used for design, data collection, and data analysis when investigating the research question. Chapter Four presents profiles of participant story tellers – inclusive of family clusters where caregiving tasks are shared and where family members are touched by vicarious impact.

Participants are introduced in relationship and social contexts. Most have been assigned a pseudonym. Where a pseudonym is not used, this is noted in the profile. Profiles also introduce participants as a multivoiced and introspective “Self” in preparation for sharing what Hermans and Dimaggio (2004/2016) refer to as “self-narratives” of the everyday realities of lived experience when caring for a loved one who has Alzheimer’s disease. The introduction of participants also presents each as a multivoiced *Other* in the dialogic interchange between the internal *I* of researcher and the external *I* as embodied in my participant (Hermans 2012). As stated by Morrow (2005), “contextual grounding is essential for understanding the meanings that participants make of their experiences” (p.253).

4.2 Research Participants: As a Collective

Participants in the research investigation present as a comprehensive representation of biological and interpersonal relationship with a loved one who has Alzheimer’s. They also present as a cross section of age, gender, experience relating to

39 Pseudonyms were not used for three participants. Two were my own children (Jason and Megan) who chose for their stories to be identified in the text as reflections of their lived experience as we journeyed together, as family, in the caring for my father, their grand-father. The third identified participant has published his story of the journey shared by himself and his wife. In publishing the story of his and Margaret’s journey, Vince hopes to raise awareness, to support, and to be a voice for those who care. Vince also chose to be identified in this narrative.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: care giving, and duration of care. There is diversity in education, work/career profiles, and lifestyle orientation. Caregivers and their co-related care receivers also reflect a comprehensive representation of socio-cultural and socio-economic background, ethnic origin, and religious/faith belief. There are sibling co-carers of a parent, a mother and son co-caring team for a mother/Nan, and there is a sister in a religious community who is “volunteer carer” for a fellow sister. Care receiving loved ones are mothers, fathers, parents-in-law, and grandparents; wives and husbands; life partner; and friend.

Most participants chose to share their stories by way of conversational dialogue. Some chose to incorporate complementary expressive tools to enhance their stories through visual, poetic, or journalistic modalities. One participant chose an initial conversation followed by giving me a copy of his published diary, which tells the story of “one couple’s struggle with fear, faith and Alzheimer’s” (O’Rourke, 2008).

Other participants chose to share their stories through written expression: for example, preparing a reflexive piece of writing prior to interview, forwarding a written script via email, or following initial conversation with emails or telephone calls as further reflections came to mind. While most dialogue was face-to-face, there were also Skype and telephone conversations: modalities chosen by participants who needed to schedule time for telling their stories around routines and sleep times of their care receiving loved one or other family restrictions. For some, the preferred venue for dialogue was their home or their office. For others, their choice was to come to my office.

Most conversations were voice recorded and hand scribed during conversation. I also chose to personally transcribe recorded interviews for, in self-processing the transcripts, I had opportunity to re-turn, re-explore, re-examine, and re-engage with the story in a eureka of discovery as new images and meanings emerged in epiphanic moments of knowing and learning.

It was in this personalised revisiting and re-engagement that common themes began to evolve and to crystallise. As with recorded conversations, those conversations not voice recorded because of situational circumstances were hand scribed as spoken and subsequently transcribed electronically. Personal data related to profiles in context are referenced as Appendix J.
4.3  The Storytellers

Storytellers represent male and female gender aged between 10 years and 90 years. They are primary caregiver, one of a primary caregiving partnership, significant support of the primary caregiver, or one impacted vicariously. They are son, daughter, son-in-law, grandchild, spouse, partner, or friend of the care receiver. What they share is that they are all impacted by the construct of caregiving for a loved one who has Alzheimer’s.

4.3.1 – Aemiel

I interviewed Aemiel by telephone in May of 2016. Aemiel is female, aged 52 years at time of interview and primary caregiver for her mother, Lena, aged 77 years. Lena resided with Aemiel and her friend, Osra, for a period of two years prior to her entry to a low care formal nursing facility in June of 2015. Aemiel is a palliative care nurse and described her socio-economic situation as “professional”. Lena was also a nurse: her specialty being midwifery. While Aemiel is her mother’s primary caregiver, her brother holds Power of Attorney. Lena has no formal diagnosis of Alzheimer’s. However, all 10 early detection signs are present – to a greater or lesser degree.

Aemiel explained that Lena had been demonstrating behaviours indicative of a gradual degeneration associated with the onset of Alzheimer’s for about 16 years. The first domain to show degenerative signs was the executive: observable in changes to mood and personality and in expression of fearfulness if called to make a decision. Disruption to executive dysfunction was followed by a demonstrated insecurity in executing spatial judgements relating to both time and place and accompanied by the onset of Sundowners: which was evidenced in her becoming agitated and demanding as daylight diminished. Also symptomatic of Sundowners, was Lena’s readiness to “roost” for the day as the sun began to set. This resulted in her being awake and wandering aimlessly around the house through the night and the early morning hours, causing concern in relation to safety and risk of falls. The last domain to begin to show signs of degeneration has been Lena’s cognitive domain with her still being able to write letters to her friends; even though she needs considerable prompting and help with words.

Lena is also still able to do her own banking and handle her own money, with
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease:

1. The collective reality from onset to end of life and beyond.

Judith R Boyland

some help from Aemiel. Aemiel has daily contact with her Mum and sees her as often as her working shifts permit. The girls regularly take her for drives, which Lena really enjoys. Aemiel still takes Lena to Melbourne for an annual trip to visit with her sister: a trip that both Lena and her sister really look forward to.  

4.3.2 – Aemelia

I interviewed Aemelia at her counselling rooms in April of 2016. Aemelia was aged 67 years at time of interview and has been a sister in a religious congregation for 45 years. Currently, Aemelia is a “volunteer companion” caregiver for a fellow sister, Anne, who is aged 83 years and who has been in the Order for 53 years. Aemelia has known Anne for 40 years although, as she stated, while she did co-reside with Anne for one year in the mid-eighties, she got to know her better from about 2009, when both sisters lived independently in the same unit complex. Aemelia advised that she had supported Anne for about six years and had been her official volunteer companion for three years, following Anne’s admission to nursing care, subsequent to hospitalisation and rehabilitation due to a fall where she broke her leg. Aemelia explained how it is the custom within the Order for every sister in nursing care to have a primary carer who is the formal “primary care companion”. Each sister in care also has and a supporting companion who is the “volunteer” and “special friend”. This is Aemelia’s role.

Aemelia is unsure if Anne has ever had an actual diagnosis of Alzheimer’s disease. However, she suggested that during their period of co-residence in the mid-eighties, Anne had started to demonstrate some “unusual” behaviours; like withdrawing to her room and sometimes seeming to forget dates. Aemelia explained that in more recent years, Anne would demonstrate episodes of paranoia and “getting suspicious”. Then, one of the other sisters would be in her “bad books”; and they would have to work with her to resolve the problem. Anne is now demonstrating all 10 signs of onset.

Aemelia also told of how, during the last six to 12 months prior to Anne’s admission to care, she was always “sorting out” her papers; and in the sorting out, she

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40 In communication received from Aemiel in January of 2018, I am advised that the girls are no longer enjoying their annual trip to Melbourne as Lena is “sundowning badly”, and is at the stage when disruptions to her daily routine and being away from her familiar environment are becoming stressful for her. Aemiel believes that her Mum is no longer strong enough to manage the travel.
would make a mess and paper would be everywhere. As Aemelia explained, it was obvious that Anne really did not know what to do with them. Aemelia continued to describe how, when the sisters cleaned out her unit following her entry to care, Anne had multiple bottles of various cleaners, shampoo, and other personal and household products. It was clear to them that Anne had forgotten what she had previously bought. Aemelia expressed the thought that perhaps for the last two years, Anne had a lot of difficulty solving problems and would often come to Aemelia to do something she could not do for herself or to solve a problem for her.

4.3.3 – Alex

I interviewed Alex in the family home in November of 2015, just one month following his 20th birthday. Alex has been co-caring for his Nan, Helen, since he was aged 18, sharing the round-the-clock caregiving role with his mother, Alice (4.3.4). Alex has been co-residing with Helen for a period of six years and has been formally registered as her carer for a period of two years. Alex has completed secondary schooling and defined his occupation as “carer” and his socio-economic situation as “blue collar”. He advised that Helen used to be an actor and he considered her to be, financially and socially, “quite well off”.

From Alex’ point of view, Helen was “always funny and a bit not your normal Nan”. As he recalled, Alex’ conception of his Nan’s onset was when she started to forget things, would become confused, and didn’t seem to be able to find the words she wanted to say. She would “cover up” by making comments like, “You know what I mean”. Alex observed that “it then just progressed from there and she started to do strange things and got kind of weird”.

4.3.4 – Alice

I interviewed Alice in her family home in November of 2015. Alice was aged 54 years and is caring for her mother, Helen, aged 87 years. Alice’s co-caregiving partner is her son, Alex (4.3.3). Alice has been caring for her mother for about nine years. Prior to retiring from the workforce to care for her mother, Alice was a geriatric nurse and Supervisor of Geriatric Nursing Care in a major hospital. She defined her socio-economic position as “professional”.

Helen is currently co-residing with Alice and her family: a big extended family all
living on a multi-acre property. Helen has been co-residing for the last six years and as Alice explained, “We work together as a total family: the whole household. Together we enjoy lots of things and [Helen] still has lots of fun”.

Alice explained that they have got to know Helen’s triggers and are “on the ball for new triggers all the time”. They know when she is hungry; when she is uncomfortable; when she is bored; when she is in pain. Alice advised that while her mother has had no definitive diagnosis, in 2011 a geriatrician hinted that she could have Alzheimer’s. However, despite having no definitive diagnosis, Alice stated that she has no doubt that her mother does have Alzheimer’s disease which first presented in interruptions to cognitive function, demonstrated as her memory started to wander. Alice added that now it is her mother who is the wanderer.

Alice also stated that, at the same time, Helen was having difficulty with words: like finding the right word to say what she wanted to say. In addition, it was becoming obvious that Helen’s emotions were “shot to pieces and all over the place”. Degeneration in the executive and spatial domains became evident as Helen began to have difficulties with complicated tasks like driving around roundabouts. Alice explained that it was at this time that she began to think, “There’s a process going on here”. Before too long, episodes of paranoia began to occur and by this time, all 10 signs of detection were being well and truly evidenced.

4.3.5 – Aliena

I interviewed Aliena in her home in April of 2016. Aliena was aged 83 years and had been primary caregiver for Oberon, her second husband, to whom she had been married for 37 years. After matriculation, Aliena worked as a comptometer operator with an insurance company and after leaving her first husband, she worked as a domestic aide in a hospital.

Aliena explained that several years before meeting Oberon, she had taken her four children and with $250 in child endowment, had sought a new life for her children and for herself – one free from beatings, verbal abuse, and violence: “an environment”, she states, “that no child should have to put up with”. She described her socio-economic situation as “a happy and satisfied pensioner”. Aliena was also Oberon’s second wife.
During his active working life, Oberon was an engineer; designing and making spas and masts for tall ships. He was diagnosed with Alzheimer’s disease in 2000, following his demonstrating obvious early detection behaviours for at least two years prior to diagnosis. Aliena stated that it was difficult to say in which order degenerative dysfunction occurred: as for quite a few years, he was saying and doing “weird things”.

For the 15 years Aliena cared for Oberon post diagnosis, five were at home and 10 were in a high care, secure unit within a formal care nursing facility. Oberon died from dementia in August of 2015: a mixed dementia being primarily Alzheimer’s and Parkinson’s. During his final days, Oberon was also succumbing to infection related to pneumonia.

4.3.6 – Angelica, Rosaline, Olivia, and Nym

I dialogued with Angelica in her home in February of 2016. Angelica was aged 72 years and was primary caregiver for her husband of 47 years, Earl. Prior to her recent retirement, Angelica was a registered nurse and she described her socio-economic situation as “professional and comfortable”. During his working life, Earl had owned and managed a range of businesses.

Angelica stated that while her husband had a diagnosis for just over four years, she had been caring and covering for him for a period of at least 10 years and she is of a professional opinion that early indicators were presenting long before this time frame. Angelica advised that prior to 2011 Earl had refused to believe anything was wrong with him. She stated that, as far as he was concerned, it was everyone else who was “doing crazy things and getting him annoyed with their stupidity”.

Following a hospital admission in February of 2012, Earl went straight from hospital to a “high care” nursing facility. He had now been in high care for a period of close to four years. Reflecting upon observable behaviours that could be linked to onset, Angelica stated that it was her husband’s executive domain that first showed signs of degeneration: demonstrated in his behaviours and interactions within the home and the workplace, as well as in general public and social situations. According to Angelica, Earl’s spatial domain was the next to present signs of degeneration as he began to lean to the left side; and when he was driving, he would “side-swipe posts, gutters, gates etc. – all on the left side”. Angelica suggested that the final domain to
show degeneration was the cognitive, as memory function was the last to go. By the time Earl was admitted to care, all 10 detection indicators had been observable for many years.

During the afternoon, I also chatted with one of Angelica’s granddaughters. Olivia was aged 12 years and lives next door to Angelica. Both Olivia and her younger sister, Nym, aged 10 years, wrote short statements of their reflections of their Papa and of how “all of this” makes them feel. Rosaline, Angelica’s daughter, also wrote a statement of her reflections.

Subsequent to interview, Earl died in July of 2016.

4.3.7 – Antony

Antony self-referred, following a conversation with Emilia (4.3.14). I interviewed Antony in his home in October of 2015. Antony was aged 88 years and had been primary caregiver for his wife, Eva, to whom he had been married for 49 years. Antony stated that, while being married to his beloved Eva for only 49 years, he had loved this woman since he first met her when they were at school, in 1943. Although Eva had married, had a child and was subsequently divorced, Antony had never loved another woman. As he explained, he just wasn’t interested. In addition, he was “difficult and headstrong and needed to be calmed down”; and Eva was the one person who was able to do that.

Anthony advised that upon marrying Eva, he also took on parental responsibility for her daughter who, he claimed, was an amazing support for him during the period of his caring for her mother through her years of degeneration. Eva died in March of 2015. The cause of death was documented as Alzheimer’s related dementia. Upon reflection, Antony suggested that while all 10 signs of detection were present at the time of Eva’s diagnosis of Alzheimer’s disease in 2008, perhaps it was in about 2005 that he first noticed “something not quite right”.

From Antony’s description, it would seem that Eva’s spatial domain showed the first signs of degeneration. She was bumping into things and couldn’t work out where the car would fit. She bumped gates and posts driving in under the house, bumped the posts in shopping centres, and was always scraping the car. The next domain to show
signs of degenerative dysfunction seemed to present in Eva’s cognitive capacity. For, while she was bumping into things and scraping the car, she could not remember that she had done it, nor how she had done it, nor where she had done it. In addition, she started losing keys and jewellery and money and she was becoming withdrawn. The final domain where change was observed was Eva’s executive functioning: demonstrated in her diminishing ability to make decisions and her inappropriate social behaviours. As point of illustration, Antony shares, “[Eva] was a very beautiful woman and was starting to let herself go. For one who was always impeccably dressed, she becomes a hell of a mess compared to what she always was.”

Prior to his marrying Eve, Antony had cared for his mother and his father, both of whom had journeyed through Alzheimer’s. Antony advised that his career before retirement had been in insurance and he described his own socio-economic situation as being “professional and comfortable”. Eva’s professional career was in the arts where she worked as an actor, singer, and artist. Financially and socially she was said to be “quite well off”.

Antony stated that he is gradually picking himself up from his beloved Eva’s death and he will get by. While he misses his Eva “dreadfully”, he talks to her every day as he tends to her garden. Antony is intending to “downsize” and states that he has his eye on a little villa just around the road. He has no wish to change his life: “just get on with it”. To this end, Antony is involved with his old surf club, footy club, and RSPCA (Happy Paws Happy Hearts). He also volunteers at the nursing home where Eva had resided.

4.3.8 – Audrey

I interviewed Audrey in her home in October of 2015. Audrey was aged 76 years at the time of dialogue and is primary caregiver for her husband, Ratcliffe, aged 80 years. The mode of dialogue between me the researcher, and my participant Audrey, was semi-structured verbal interview, with the support of photographs and reference to

41Happy Paws Happy Hearts (HPHH) creates positive social experiences, connecting members of the community who are at risk of social isolation, with rescue animals at RSPCA QLD. HPHH delivers group sessions for older Australians, facilitating meaningful animal interactions and engaging participants in conversation. The aim of HPHH is to help participants strengthen existing and create new connections, lessen the occurrence or risk of social isolation, and increase knowledge of animal care and welfare.
journal entries to illustrate key points in discussion. Audrey and Ratcliffe have been married for over 50 years. Prior to retirement, both Audrey and Ratcliffe had professional careers in education. Audrey described her socio-economic situation as “professional and comfortable”.

Ratcliffe was diagnosed with Alzheimer’s disease in 2008 at the age of 73 and entered a high care nursing unit mid 2015: seven years following diagnosis. Audrey stated that, while Ratcliffe is now presenting with all 10 signs of detection, upon reflection, she would say that it was his executive domain that showed initial signs of degeneration when he stopped doing things that he loved to do. It is Audrey’s perception that this was because he was having difficulty in making decisions and judgements. According to Audrey’s recollections, degeneration of Ratcliffe’s spatial domain followed, with obvious difficulties presenting in his finding his way around and in his easily getting lost. The final domain to show degenerative impact was identified as being in relation to his cognitive function which, Audrey claimed, “was so gradual”. Audrey also stated that it was hard to put a time line on things like memory and conversation and she suggested that the more she thought about it, it had probably been just the last two years, and that Ratcliffe was functioning quite well before that.

4.3.9 – Edward, Emily, and, Iach

I interviewed Emily and Iach at their home in March of 2016. Edward had chosen for his story to be relayed through his daughter (Emily) and son-in-law (Iach) and had stated that he was happy for his story to be told, even though he chose to not speak for himself. At the time of sharing his story, Edward was aged 90 years. Edward is legally blind and has extreme difficulty in hearing. While his children have legal Power of Attorney for their parents, Edward is still the official primary caregiver for his wife, Ophelia, aged 88 years. Edward and Ophelia live independently in their family home, just five minutes away from Emily and Iach. Emily was aged 64 years at time of interview and Iach was aged 65 years at time of interview.

Emily and Iach advised that they have been supporting Edward in his care of Ophelia for four years, when signs of onset became observable to family although they were denied by Edward who, even after diagnosis in February of 2015, was still in denial. Emily and Iach suggested that, according to their observations, it would have
been Ophelia’s executive function that first began to deteriorate, followed by her cognitive and finally her spatial. By the time their general practitioner referred Ophelia to the geriatrician, all 10 detection signs were observable.

As Emily recalled, Ophelia has always been “away with the fairies”, but it became obvious to the family in 2012 that there was significant decline in her ability to function: for example, she would take two hours to make a sandwich. Emily explained that it is only recently that Edward has begun to accept that Ophelia has Alzheimer’s. During their working lives, Emily and Iach, and Edward and Ophelia all followed professional career pathways. Emily and Iach describe the socio-economic situations of themselves and Emily’s parents as being “retired professionals who are quite comfortable”.

### 4.3.10 – Elan

Elan self-referred and chose to write her story and forward it to me by way of email. Elan, aged in her early sixties, supported her mother, Alexas, in caring for her father, Edgar, who was aged 85 years at the time of his death in 1990. Although Elan did not co-reside with her parents during their Alzheimer’s journey, she spoke with both parents almost on a daily basis and she visited regularly. Upon reflection, Elan recalls indicative signs of onset about five years prior to her father’s death, with earliest indicators relating to interruptions within her father’s cognitive domain. Degenerative signs began to escalate in the last couple of years of his life and included disruptions to spatial and executive function.

Elan believes that her father completed primary schooling, then worked on a farm, and subsequently owned his own green grocery store, “delivering good quality groceries directly to the kitchen table”. Elán’s Mum is reported to be number 13 of 14 children and following the death of her mother when she was still quite young, Alexas cared for the home while completing her primary schooling. After leaving home, Alexas worked as a shoe maker, dress maker, and retail shop keeper. She also worked as a nanny and her duties included cleaning and cooking. After marrying Edgar, Alexas became a home maker and helped at the family shop.

Alexas and Edgar were married for 48 years and Alexas was aged 68 years at the time of her husband’s death. Edgar was a religious man and kept a copy of the bible
beside his bed. Elan explained that he would be comforted by the words of the bible that had been part of his life for many years, “soothing his soul and encouraging his spirit: strengthening his heart with the love of the Lord”. Elan described her parents’ economic situation as “pensioners who saved”. Elan holds tertiary qualifications and works in the field of allied health.

4.3.11 – Eleanor

I interviewed Eleanor in my office in November of 2015. Eleanor was aged 64 years and is primary caregiver for her partner, Rod, who is aged 68 years. Eleanor, stated that she and Rod had been together “for years and years” and she suggested that the initial signs identifying an awareness of the onset of Alzheimer’s would have been in 2011, just one year before Rod’s own doctor made a comment about his “losing the plot”. It was in February of 2015, just nine months prior to our dialogue, that Eleanor’s doctor made a positive diagnosis of Alzheimer’s disease. Eleanor explained that, at this point in time, while nine of the 10 signs of detection are presenting, Rod is demonstrating no change to mood or personality. Rod is also using this time to learn as much as he can about what is ahead of him and how he can maintain maximum function for as long as possible.

Eleanor suggested that from her observations, it would have been Rod’s executive function that began to show the first signs of degeneration: demonstrated in his beginning to have difficulties in concentrating and making decisions and judgement calls. Degeneration to Rod’s cognitive domain followed as he began to become non-fluent in his speaking, particularly with finding his words. As far as Eleanor considered, Rod’s spatial domain is still functioning quite well. He is still driving and seems to have no difficulty in getting to where he wants to go or in knowing where the car fits and knowing his left from his right. However, to be safe, Eleanor always accompanies Rod when he is driving anywhere.

Eleanor and Rod both hold tertiary qualifications and both held professional positions. Eleanor retired to support Rod, who still does a “little bit” of consultancy work. Eleanor’s professional field is administration and Rod is in environmental science. Eleanor described their socio-economic position as “professional”.

The collective reality from onset to end of life and beyond.  
Judith R Boyland
4.3.12 – Elise

I interviewed Elise in August of 2016. The mode of dialogue chosen by Elise was by way of semi-structured interview conducted at my office. Elise had prepared an extensive written statement of reflection prior to our dialogue and she referred to this statement as the pivot around which she based her spoken story. Elise, aged 78 years at time of interview, was the primary caregiver for her mother, Alexandra. During her working life, following very little formal schooling, Alexandra completed a Certificate in Dressmaking and later worked with her husband in the family business. Alexandra, who celebrated her 104th birthday on September 30, 2016, was diagnosed with Alzheimer’s disease in 2005 at the age of 93 years. Behaviours indicative of cognitive decline were observable for about 12 years before formal diagnosis.

Alexandra entered a formal nursing care facility in January of 2013. She had three subsequent moves and at the time of interview, was in her fourth residential placement in what is designated as a “high, high, high” care unit in a nursing home. Alexandra had her own room with ensuite and was just a 10 minute drive from Elise’s home: the home Elise built for herself and Alexandra and situated on a lot next door to Elise’s brother. Elise could also access this new nursing home with public transport. This is an important consideration as Elise has macular degeneration and also has a pacemaker: either of which could mean that her driving days are numbered.

Prior to resigning from the work force to care for her mother, Elise held a full-time professional position as a social worker. She described the socio-economic position of both her mother and herself as being “comfortable, due to frugal saving”. Elise advised that she has lived with her mother for all but 11 years of her life. During these 11 years, she was working interstate: a position she left in order to return to Queensland to support and care for her mother.

Alexandra died in June of 2017: three months before her 105th birthday.

4.3.13 – Elizabeth

Elizabeth is the sister of Richard (4.3.23), was 45 years of age at time of interview, and resides with her family – her husband, Robert, and their four children. Elizabeth, who was primary co-carer for her father, Aaron, chose to come to my office for our dialogue in April of 2016. Elizabeth had supported her mother in caring for her
father in the early stages of his Alzheimer’s journey from observable onset, which was some years prior to diagnosis in 2007. Elizabeth’s and Richard’s mother had a stroke in the evening of Mother’s Day, May 2012. She was in a coma till the following Tuesday, when a family decision was made to turn off the life support. She died shortly thereafter.

Following an initial period of Richard’s co-residing with their father and as their father’s condition deteriorated quite rapidly, it became increasingly obvious that Aaron could not live alone. By December of 2012, while Richard had the luxury of flexibility in his work schedule and had spent some time residing with their father, the time came when he could no longer provide the full-time care that the siblings’ father was beginning to need. It was at this time that Robert, Elizabeth’s husband, suggested that they bring Aaron to live with their family. As Elizabeth explains, her Dad would listen to Robert more than to her; and it is Elizabeth’s expressed thought that this was because Robert was “more casual and laid back and relaxed”. Robert could also “take a little step back, as it wasn’t his father and he wasn’t there 24 hours a day”. At this point in time, the children were aged 16 years, 12 years, seven years, and four years.

Elizabeth and Robert renovated their home and sold it. Aaron’s home was also sold and with the combined finances from both sales, a larger home was purchased to accommodate Elizabeth’s and Robert’s family and Aaron. Aaron resided with Elizabeth and Robert and the children till it became necessary for him to be placed in a high care, secure nursing facility in August of 2014. As stated above, Aaron died in December of 2015. The cause of death was recorded as advanced Alzheimer’s related dementia. Elizabeth described her socio-economic situation as “worker”. She also described her father’s socio-economic situation as “worker”.

4.3.14 – Emilia

I interviewed Emilia in her home in October of 2015. Emilia is female, aged 62 years at time of our conversation and is primary caregiver for her mother, Elga. The mode of dialogue was by way of semi-structured interview conducted at Emilia’s home. Prior to resigning from the work force to care for her mother, Emilia held a full-time professional position as a teacher. During her working life, Elga was engaged in office work and Emilia described her mother’s socio-economic status as “working class”.
Emilia advised that she has been her mother’s primary caregiver for a period of about five years: initially living independently followed by a period where she co-resided with her parents. Subsequently, Elga co-resided with Emilia for two years prior to transition to a secure nursing unit. In the early stages of her caregiving, Emilia was juggling work, living at home, and having episodes of living with her Mum and Dad. Her sister, who had multiple sclerosis, lived independently. Emilia’s father, also, was reported to be “quite unwell” during this phase.

Emilia stated that her life was in chaos: the primary trigger for associated distress being when the phone would ring and she would become “sick in the stomach”. Emilia also explained that it was sometime during 2012 when she began to know that she would need to make serious plans for living and for work: plans that accommodated provision for her mother’s increasing need for care. The time had come when Emilia would need to give up full-time work and assume the role of full-time caregiver. In the intervening period between realisation that her mother was presenting with very definite signs of Alzheimer’s disease and bringing her mother to co-reside, both Emilia’s sister and her father died. This meant that for Emilia, there was no immediate family for support: physically or emotionally.

Emilia advised that while there had been “mixed suggestions” from doctors, Elga had no definitive diagnosis, even though all 10 signs of early detection had been presenting for some years. Upon reflection, Emilia stated that she would consider that behaviours associated with her mother’s cognitive domain flagged the initial signs of degeneration. This judgement is based on observing Elga’s difficulties with short-term memory and with her declining ability to find the right words to say what it was that she wanted to say. The next domain to show degeneration was spatial, followed by diminishing ability to execute executive function.

Emilia claimed that the closest her mother came to having a definite diagnosis was following a hospital admission in February of 2014 when it was suggested that Elga had a mixed dementia, Alzheimer’s and vascular. Emilia also reported that it was the social worker who said to her that she “couldn’t do it any more”. The fact that the call regarding the necessity for Elga to be placed in a “secure-care” unit was made by the hospital medical team, was a blessing for Emilia: somewhat easing the onus of guilt.
4.3.15 – Emma

Emma is self-referred and her story is of vicarious impact. Emma, who was aged 63 years at the time of our conversation, is the oldest of six siblings whose mother, Roberta, died of Alzheimer’s related dementia close to three years prior to our dialogue. Emma shared a perspective of impact that focussed on the strengthening of relationships across States and countries as siblings supported each other and their co-caring father and sister, Ely and Rebecca.

Roberta transitioned through the Alzheimer’s journey for a period of about seven years pre-diagnosis. Changes to mood and behaviour became clearly observable at about 73 years of age. This was followed by diagnosis at age 80 and death at age 86. Roberta resided in a nursing home for the last four years of her life. Admission to formal care became a necessary move as her tendency to wander and related incidence of psychotic episodes increased in frequency and intensity, to the point where her safety and the safety of others was at risk. It was during the period of Roberta’s residency in formal care that Emma’s father died, two years before the death of her mother. Emma and the elder of her brothers held Enduring Power of Attorney and were co-executors of their parents’ affairs.

Emma, her parents, and three siblings all followed professional career paths. Two siblings work in administrative roles. Ely was a medical practitioner. Roberta resigned from her profession in nursing when she married Ely in 1952. Her career from that time forward, was to be a full-time, “stay-at-home” wife to Ely and mother to her six children.

4.3.16 – Ephesea

Ephesea, who was aged 48 years at time of interview, is a Goenpil, Nughie, Noonuccal Goord woman whose mother, Ursula, is an elder of the Aboriginal Nation of Quandamooka. Ursula is the primary caregiver for her husband, Ira, who is an elder of both the Aboriginal Nation of Bundjalung and the South Sea Island of Mare. Ephesea is the major support for her mother, who is the primary caregiver for Ira.

I initially interviewed Ephesea by telephone in May of 2016: telephone being the most convenient mode of dialogue for Ephesea. Ephesea advised that, in retrospect, her father, aged 71 years, had been showing soft signs of Alzheimer’s for about 10 years.
and particularly in the last three to five years, when loss of short-term memory and some distortion in long-term memory were becoming quite evident. She also advised that over the last six months she had observed that her father’s frustration levels are raised and tolerance levels are lowered. He has also started to show signs of aggressive behaviours while beginning to isolate himself from family gatherings: “becoming somewhat introspective and living in his own little world”. Furthermore, Ira has started an obsessive tapping of his fingers – “just tap, tap, tap, tap, tap, ……..”.

Ephesea further reported that Ira was also starting to wander more than just his normal walkabout. As Ephesea explained, “He is going more often and when he goes, he just goes: telling no one where he is going and not letting anyone know that he is going.” Also, when driving, Ira is starting to forget where he is. In general, Ira is wanting to stay very close to Ursula and as Ephesea suggested, “It is as though he needs to have an anchor or needs something secure to hang on to.”

Discussing the impact that her father’s behaviours are having on Ursula, Ephesea explained that her Mum relies a lot on both herself, Ephesea, and her younger sister, Imogen, for support. Ephesea stated that her parents aren’t really open to the possibility of Alzheimer’s, although her father did have brain scans done and was told by his doctor that “all is good”. This diagnosis does not ring true to Ephesea if one is to take into account the degenerative changes in Ira’s behaviour and his demonstrated inability to function independently. For Ephesea and her siblings, the presenting evidence is that “all is definitely NOT good”.

Ephesea is the Co-founder and National Director of a national leadership program with First Nation Communities. Prior to retirement, Ursula was Director of a respite centre and Ira was a professional painter. Ephesea described her socio-economic situation as “financially secure”. She described her parents’ socio-economic situation as “retired professionals, depending on CentreLink to top up finances”.

4.3.17 – Hal

I interviewed Hal at his place of business in April of 2016. Hal is one of four siblings. He is a single male and is primary caregiver for his mother, Viola, who resides with him. At the time of interview, Hal was aged 52 years and Viola was aged 88 years. Hal has been caring for Viola for five years and stated that while she was given a
diagnosis of Alzheimer’s disease in 2014, there had been obvious degeneration for probably in excess of five years, with all 10 detection indicators gradually presenting over time. Hal explained that his mother’s spatial awareness was the first domain to be impacted, closely followed by the cognitive as demonstrated in her beginning to have memory lapses and language difficulties. The last domain to show gradual loss of function was Viola’s executive capacity to make decisions. Hal believes that if his mother was to be faced with a situation where she needed to make a decision, it would most certainly be a major stress for her: even if she still had the ability to make a judgement call.

Both Hal and Viola hold tertiary qualifications. Hal currently owns and runs his own restaurant and during her working career, Viola held a professional position in nursing. Hal described their socio-economic situation as being “not flash but probably somewhere in the middle”. So as to be able to care for his mother and continue to run his business, Hal bought a home about a kilometre from his restaurant so that he has the flexibility to continue to run his business, while also caring for his mother and being just a moment away if he is needed while he is at work.

Subsequent to interview, Viola died in October of 2016.

4.3.18 – Iris

Iris was 59 years old at the time of interview and had been the primary caregiver for her mother, Adriana, for a period of eight years prior to her death from Alzheimer’s related dementia, in 2008, at an age of 88 years. I interviewed Iris by telephone in November of 2015. The mode of telephone was chosen by Iris as she did not want for her husband to know what she was doing and we spoke while he was at work. Iris resides with her husband, a high profiled professional man who is said to “not like dealing with unpleasantness”. Iris stated that during her working life, she had been an administrative assistant and she described her socio-economic situation in terms of being “quite well off”.

At no time during the course of the Alzheimer’s journey did Adriana reside with Iris. Iris advised that her mother had lived in Melbourne, in an independent living unit. It was around the time of her 80th birthday that her behaviour was becoming “obviously uncharacteristic even though she had always been somewhat eccentric”.

Iris continued to explain that it was about this time that her mother started getting lost in familiar environments, $2000 just disappeared out of her bank account, and she took herself off on a cruise with no recollection of having received flowers and champagne sent to her for her birthday. Adriana had been an actor and musician. Socially and financially, she had also been “quite well off”.

Following Adriana’s return from her birthday cruise, Iris brought her to Brisbane and with the help of a friend, was able to get a diagnosis for her mother and was also able to settle her into an independent living unit in Brisbane. Adriana entered the dementia high care unit within the complex in 2006, where she resided until her death just two years later. As Iris recalled, at the time of her entry to care, Adriana was demonstrating all 10 signs of detection.

4.3.19 – Isabella

I interviewed Isabella in her home in October of 2015. Isabella is female, aged 66 years at time of interview and is primary caregiver for her father, Orsino, aged 92 years. The mode of dialogue between us was by way of semi-structured verbal interview accompanied, as we dialogued, by Isabella’s painting of a visual expression of her conceptions of her father’s journey as care receiver and her own journey as caregiver. Both prior to and subsequent of our conversation, Isabella had also expressed in poetry aspects of her own journey as caregiver and observations of her father’s journey as care receiver. Isabella resides with her husband in their family home in Brisbane. Prior to retirement, Isabella held a professional career role in administration and she described her socio-economic position as “professional”. Isabella’s father lives alone in the family home in Sydney. Isabella commutes between Brisbane and Sydney, spending one week in four with her father. During this time, she takes care of household, medical, organisational, and business matters that need attention. She speaks with her father by telephone at least once per day and has support and respite structures in place to ensure her father’s safety and comfort between her sojourns to Sydney.

Isabella stated that she first noticed things were not going well for her father in 2010. As she recalled, it was his spatial domain that initially began to present as his having very much confusion with time and place. Then came obvious signs of degeneration within the cognitive domain, as Orsino began repeating “stuff” and he also
began to lose his memory. The final domain to begin to show degeneration was the executive, presenting in poor judgement and inability to make decisions. Isabella reported that her father was given a diagnosis of Alzheimer’s disease in 2012, when all 10 signs of detection were easily observed.

Isabella stated that while her father had little formal education, he was a very intelligent man who taught himself to read and educated himself with reading. She also advised that Orsino was most adamant that Isabella and her sister had a good education. Orsino, who worked from the age of seven years as a farm labourer, was a market gardener. Isabella described her father’s socio-economic position as “a worker” and explained:

You’re a product of how you are raised and as the oldest of 12, he was raised as an employee in somebody else’s house. His family never had a home and his first “home” was the home he built for my mother: the home he still lives in.

Although Isabella’s sister lives in Sydney, she is unwell and unable to assume the role of primary caregiver. Her sister’s husband visits with his father-in-law on a regular basis. Isabella explained that her main support is her husband and that without his support and understanding, she would not be able to be the long-distance primary caregiver for her father.

Orsino transitioned to formal nursing respite, July of 2018. Isabella still commutes.

4.3.20 – Jason and Megan

Jason and Megan are my children and with their permission, I do not use pseudonyms. Jason, was aged 43 years and Megan was aged 49 years at the time they shared their conceptions, introspections, and memories. At the time of the death of our loved one, Jason was aged 19 years and Megan was aged 25 years. Jason, Megan, and my husband, Des, were the structural supports that kept me vertical during my years as primary caregiver for my father, our Special Someone: the man who held a special place in the heart and the history of each of us.

Jason was my “rock” during the last horrific months of my caregiving journey. Data extracts from his story serve as thematic illustrations across the woven tapestry of the narrative landscape. Part of Jason’s story is also shared in Chapter One, Context,
where the most intimate reflections of my father’s death, in Jason’s arms, serve to reveal something of my passion to give voice to those who have a story that needs to be told. Megan’s reflections are woven into the sub-theme that addresses vicarious impact and serve to reinforce the importance of giving voice to those who are impacted by the ripple effect of informal caregiving.

4.3.21 – Lavinia

I interviewed Lavinia in her home in November of 2015. Lavinia was aged 72 years at that time and was primary caregiver for her husband, Oswald, who had died 12 months prior to our dialogue, at the age of 87 years. While Lavinia holds professional qualifications, she never held a position in the work force: for, as she stated, she married her professor and never had a need to work outside the home. She described her socio-economic situation as being “quite well off”.

Lavinia stated that, upon reflection, she would estimate that her journey as caregiver for her husband began about six years prior to our dialogue: about two years before his diagnosis of Alzheimer’s disease, which was in 2010. The progression of Oswald’s condition is claimed by Lavinia to have been “a really stepped decline and was just so unexpected” as Oswald began to withdraw and to isolate himself. Lavinia recalled that first signs of degeneration would have been demonstrated in his spatial domain as he began losing direction. She then noticed that he did not want to drive, making just little statements like, “You drive, today”. Lavinia suggested that cognitive dysfunction closely followed with evidence of forgetfulness.

While all 10 signs of detection were presenting prior to diagnosis, the last area to begin to show obvious loss of function was reported by Lavinia to be Oswald’s executive domain, at which time Lavinia recalled that from a man who was so independent and so driven, his whole nature began to change and he became so dependent: which was so different. In addition, Lavinia explained that Oswald would take a lot longer to do things and seemed to be having difficulty in completing familiar tasks and in explaining what the problem was. Lavinia tells of how this inability to complete familiar tasks and then to not be able to explain what the problem was, worried Oswald. He entered a high care nursing facility just five months prior to his death.
4.3.22 – Nerissa

I interviewed Nerissa in her home in October of 2015. Aged 62 years at time of interview, Nerissa was primary caregiver for her mother, Octavia, for a period of 15 years. Nerissa advised that Octavia had co-resided with her for approximately seven years: coming to live with her following a fall which resulted in her breaking her collar bone and two fingers. About three years prior to Octavia’s death, Nerissa took leave from work. When that leave expired, she chose to retire: nine months before her mother died. Prior to retirement, Nerissa held a professional position as a teacher. During her working life, Octavia had worked as a telephonist supervisor and then as housekeeper for a priest. Nerissa described her mother’s socio-economic position as “working class” and her own as “professional”.

Nerissa explained that all 10 indicators of detection were presenting gradually in the beginning stages of Octavia’s functional degeneration. Upon further reflection, Nerissa stated that onset of cognitive dysfunction began with obvious loss of short-term memory and gradual degeneration in verbal and maths skills which, she says “were shot to pieces”. Loss of function in the spatial domain then became observable, presenting as loss of all sense of direction. With reference to her journal, Nerissa noted that from a slow progression across a 20 year span, there was acceleration from 2010. The last domain to show degeneration was reported as being Octavia’s executive function, with diminishing ability to organise herself and to make rational decisions. This, stated Nerissa, coincided with an increasing ability “to wreak more havoc”.

Nerissa recalled that “crunch time” came when it became hard to leave Octavia at home and she (Nerissa) needed to arrange for Octavia to go to a day care centre while she was at work, as she was fearful that Octavia would wander off and fall. Nerissa explained how her fears were somewhat allayed with her being able to access day respite for five days per week between 2004 and 2011, with the addition of some respite on some weekends, which enabled Nerissa to also have time to re-energise between work and caring for her mother. With reference to this support, Nerissa claimed that:

The centres were wonderful and I knew she would be well looked after so I had no sense of guilt that I needed to take her to respite while I was at school. However, there were lots of frustrations for me with her being with someone else and I would often wonder just what this person or that person was doing.
Nerissa advised that Octavia was given a diagnosis of Alzheimer’s disease in 2001, entered a high care nursing home 11 years after diagnosis and died, at 97½ years of age, three years and seven months following entry to the care facility. For the telling of her story, I met with Nerissa at her home on the weekend following her mother’s death. The timing of our dialogue was of Nerissa’s choosing as she felt that being able to share her story, at that point in time, had the potential to be a cathartic experience for herself as well as a help in her grieving the loss of her mother: a loss that she claimed had been a long and drawn-out process that spanned so many years. Nerissa also expressed her feeling that in sharing her story in the immediacy of her mother’s death and in the quiet intimacy of time shared with me, the counsellor and the researcher with my own inside story, she was giving herself a very personal moment. This was a time to celebrate the story of her mother’s life and her release from the horrors of Alzheimer’s and all that it entailed in what Nerissa described as “the slow progression to loss of identity”.

4.3.23 – Richard

I interviewed Richard at his home office in April of 2016. Richard was aged 49 years at that time. Following the death of his mother in May of 2012, Richard and his sister, Elizabeth (4.3.13), had shared caregiving responsibilities for their father, Aaron, who died from Alzheimer’s related dementia in December of 2015.

Aaron was diagnosed with Alzheimer’s disease in 2007, at the age of 64. As explained by Richard, at the time of diagnosis his father was showing signs of all 10 diagnostic detection indicators. Richard stated that the first domain to show degenerative characteristics was that related to his father’s cognitive function. Spatial disorientation followed and then loss of executive function. Richard explained that he knew that Aaron’s memory was fading but didn’t realise how much until he spent a lot of time with his Dad. Richard also suggested that, when anyone was around, his father “did a good job of disguise”. Following the death of his mother, Richard co-resided with his father, in his father’s home, for eight months (May 2012 to December 2012). Richard advised that he was able to spend this time with his father as he had the flexibility of being a single man, running his own business, and could modify his working hours to accommodate his father’s needs. However, as it became increasingly difficult to run his business and care for his father, a family decision was made for their
father to move in with Elizabeth (4.3.13) and her family: the suggestion being posed by Elizabeth’s husband. While Richard would continue to support his father and his sister, he would return to live in his own home. Richard has tertiary qualifications and runs a professional business as a chartered accountant. Aaron, who did not finish primary school, was a farm worker from the age of 12 years. Later, Aaron drove trucks for 35 years and, subsequent to his time on the road, he ended his career working in the office of the trucking company for whom he had been driving. Richard described his own socio-economic position as “comfortable”. He described his father’s socio-economic position as having “started with nothing and ended up financially comfortable”.

### 4.3.24 – Rosalind

I interviewed Rosalind in October of 2015. Rosalind was aged 77 years at the time of our conversation and was primary caregiver for her husband, Owen, to whom she has been married for some 30 years. The mode of dialogue between me the researcher and my participant Rosalind, was by way of semi-structured interview, conducted at my office: as Rosalind did not want her husband to know what she was doing. Rosalind advised that her current husband and care receiver, Owen, is her second husband. She explained that she left her first husband when the youngest of her three sons was little: the reason being that “he found religion and went to live a life of drugs and promiscuity”.

Owen was diagnosed with Alzheimer’s disease in 2008. Rosalind stated that, upon reflection, she would say that it was Owen’s spatial domain that showed initial signs of degeneration as he was having difficulty reading road maps and telling his left from his right. Degeneration of his cognitive domain followed, with difficulties presenting in short-term memory. The final domain to “go” was his executive function which Rosalind believes was first demonstrated in inappropriate social behaviours. Rosalind stated that it was approaching eight years since diagnosis and that having a diagnosis was really helpful. Prior to diagnosis, Rosalind had thought that Owen “was just getting old, and moody, and dependent”. Rosalind advised that she had also been primary caregiver for her mother, Beatrice, who died with Alzheimer’s related dementia, 15 years ago. She claimed that caring for her mother was so different from the experience with her husband. By way of distinction, Rosalind described her mother as always having been “a bit dotty and just getting dottier as time passed”.
Rosalind explained that she left Owen 15 years ago and came to live in Brisbane. Upon reflection, she stated that perhaps the behaviours that caused her to leave were possibly behaviours associated with the onset of Alzheimer’s: cranky, impatient, demanding, and bordering on abusive. Owen followed Rosalind to Brisbane and she agreed to try to rebuild the marriage. Reflecting on her current situation, Rosalind stated that there are times when she wishes that she hadn’t taken Owen back and she adds, “I didn’t envisage spending the last days of my life looking after a man I don’t really have any love for. But I do feel it is my duty.” Prior to retirement, Rosalind worked as an administration officer and Owen was a self-employed marine engineer. Rosalind described her socio-economic situation as being “quite comfortable”.

4.3.25 – Rousillon and Lafe

Rousillon and her husband, Lafe, co-care for Rousillon’s mother, Helena. Lafe had previously been primary caregiver for his mother who, prior to her death, resided in a nursing home and is said to have been a “happy dementia patient”: a totally different scenario from that which is now being experienced with Helena. Helena celebrated her 100th birthday in September of 2017.

I interviewed Rousillon by telephone in July of 2016. Rousillon self-referred following Helena’s diagnosis, just one week previously: her diagnosis was defined by a consultant geriatrician as “Intelligentsia Alzheimer’s Dementia”. Helena’s condition presents as atypical in that observable signs of changes in behaviour had been present for only six weeks prior to diagnosis. Behaviours of concern began presenting as psychotic episodes including paranoia, physical and verbal abuse, and extreme fearfulness. Helena was also starting to crawl on her hands and knees and to move through the house by sliding on her bottom. Rousillon stated that Helena’s changes in behaviour coincided with the death of her much-loved labradoodle. Rousillon also reported that while Helena was beginning to not want to leave the house, she still enjoyed company popping in to visit. At the time of our conversation, Helena was beginning to demonstrate spasmodic periods of poor judgement, was experiencing confusion, and was just starting to have difficulty in completing familiar tasks such as dressing. Helena was also refusing to shower and was becoming physically and verbally more abusive. There appeared to be no disruption to Helena’s memory, to the point of her being able to converse fluently and with time appropriateness relating to
current and recent events. In her lucid moments, Helena could remember that she had been abusive just a short while ago. She couldn’t understand why she was behaving like she was and the fact that she had behaved in an abusive manner distressed her.

Rousillon and Lafe both have tertiary education degrees and prior to retirement, both had professional careers. Helena, who had left school at the end of her primary education, started work in a housekeeping position and later worked as manager of a well-known café/restaurant by the Bay. The socio-economic status of Rousillon, Lafe, and Helena is said to be “comfortable”. Helena has co-resided with Rousillon and Lafe for a period of 40 years when Helena and her husband, Lewis (deceased), initially moved in with Rousillon and Lafe and resided in an attached independent living unit. When building a new home in 1988, it was designed with a duel independent living arrangement. Rousillon and Lafe are adamant that they will continue to care for Helena at home: “there will be no nursing home care for [Helena].”

Helena’s suffering ended September, 2018; three days before her 101\textsuperscript{st} birthday.

4.3.26 – Vince

For Vince, I do not use a pseudonym. Nor do I use a pseudonym for his beloved wife, Margaret. Vince, aged 76 years, was primary caregiver for Margaret: his “greatest friend, lover, wife and mother to [his] children”. Vince recalled recognising growing signs of early onset in 1996–1997 with Margaret’s demonstrated behaviours indicating that all was not right. Subsequently, Margaret was given a diagnosis of Alzheimer’s disease in 1999, at the age of 59 years. Margaret was in her mid-fifties when early onset began to be evidenced. The observable signs of detection began with impact on Margaret’s spatial domain, followed by the cognitive, and finally the executive. Vince was to be her primary caregiver for the next and last nine years of her life. Margaret entered a formal nursing facility, ‘Nandeebie’, on July 20, 2005. With Vince by her side, her life ended on the afternoon of October 10, 2006: a moment Vince claims will be with him, always.

Vince has published a book that tells the story of his and Margaret’s journey through the Alzheimer’s maze. His book, published in 2008, is titled \textit{I wish I were a leper: The diary of one couple’s struggle with fear, faith and Alzheimer’s} (O’Rourke, 2008). Recording his reflections and his journal entries in book form began as what
Vince described as his own personal way of dealing with the nine years of watching the most precious gift of his life being, ever so gradually, taken from him. In choosing to publish his diary and share his story with others caught in the Alzheimer’s net, Vince stated that reliving the journey and being open to the messages it contained, gave him a reason to wake up each day.

I knew Vince before his and Margaret’s Alzheimer’s journey. This was during my early Principalship days. At that point in time, Vince was Director of Brisbane Catholic Education. Following retirement, Vince established a consultancy practice which gave him flexibility in the early stages of Margaret’s degenerative journey. Vince married Lorrae Martin in 2010 and together, Vince and Lorrae have established “Carers Outlook”: a respite and retreat centre for those caring for a loved one who has Alzheimer’s disease or an Alzheimer’s related dementia. Carers Outlook is situated in the Sunshine Coast Hinterland.

4.3.27 – Yori

I dialogued with Yori, by telephone in April of 2016. Telephone was the preferred mode as chosen by Yori, due to the high care needs of her husband, Adam, who, Yori stated, was not safe to be left alone and who also became terribly confused if there were strangers in the home. For us to engage by telephone meant that Yori was able to chat, undisturbed, during a period when Adam was sleeping. Yori was aged 48 years at the time of our conversation and she is primary caregiver for her husband of 30 years, Adam, aged 72 years. Yori is “wife number three” and she and Adam have two adult children. Adam also has two children from a previous marriage and while Yori raised these older boys as her own, she stated that “they have both just turned” and have nothing to do with herself or their father: a disappointment to both Adam and Yori.

Prior to retirement, Adam was a plumber by trade, then a civic councillor, then Mayor of a remote town in the Northern Territory before moving to the south east corner of Queensland. A hairdresser by profession, Yori has now retired from work as she is no longer able to work and care for Adam: even though she used to have a salon at home and for a long time, had the flexibility in not needing to leave the home. Yori

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42 The large home located on 3 acres overlooks across Bli Bli Valley to the Pacific Ocean. It is a peaceful retreat, allowing guests to rest, socialize, or recreate. For contact details refer to Appendix E, Information and Local Support Services and Providers.
also has rheumatoid arthritis which is impacting on the flexibility in her hands and her skills in manipulating the tools of her trade. Yori described the socio-economic situation of herself and Adam as “comfortably cautious pensioners”.

Yori stated that Adam has had a diagnosis for just over five years. However, things have been happening for about 20 years – “mild in manner and nothing really showing its ugly head till about 2010”. Upon reflection, Yori identified disruption to spatial awareness as being the first domain to show degenerative signs. Next domain to show signs of degeneration was in relation to Adam’s executive functioning as he started to be disorganised and quite “laid back” for someone who had always been a very organised man. Finally, Adam’s short-term memory started to go. Yori also advised that Adam’s Alzheimer’s is merely one aspect of comorbidity for he also has diabetes and lung problems and has recently been diagnosed with Parkinson’s disease.

4.4 Conclusion

Chapter Four has presented the profile of participants, each of whom shared a personal story that contextualises the impact of caring for a person who holds a special place in their hearts and their histories: A Special Someone who has Alzheimer’s disease. For some, the life journey with their loved one has ended. For some, the journey is just beginning. Data extracts selected from the data set create the dialogical threads that form the weft to be woven across the structural warp threads of a methodological hybrid as discussed in Chapter Three, Method and Methodology.

Chapters Five and Six present the findings as shared in the data items that identify as self-narratives shared by participants. Using thematic analysis, the weft of intertwined data extracts that identify every-day reality serves to create a holistic snapshot of a landscape that is embedded in the genre of collective narrative. Findings in Chapter Five profile the reconceptualisation of accrued knowledge, lived experience, and impact that define caregiving for a loved one who has Alzheimer’s disease.

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CHAPTER FIVE – FINDINGS: PART ONE

It is a journey we will talk about for many winters to come.
The wisdom they have brought home is now our wisdom.
This pipe and this bundle are in the right hands.

Barry Lopez (1990/2013, p. 76)

Weaving the Narrative Landscape:
Impact of Caregiving Reconceptualised

5.1 Introduction to the Collective Narrative

Chapter Four presented profiles in context of participants who chose to share their self-narrative about the impact of caring for a loved one who has Alzheimer’s disease. In Chapter Five, the process of weaving the threads of individual stories begins development of the collective narrative. In keeping with the ontology of a hybrid methodology underpinned by a process of bricolage, the weft of every-day reality is woven across a heuristic, intuitive, and transpersonal hybrid warp. The emerging landscape of the collective narrative profiles a rich thematic description and interpretation of the data set.

WEAVING THE NARRATIVE LANDSCAPE: WARPED AND TWISTED

Figure 7 - Warped and twisted: Visual interpretation of the process of bricolage. Image designed by and used with permission of Shirley Graham, 2017.
Data profiled in the findings are the product of introspection, memory, recall, interpretation, and inductive reasoning as tapped through processes of dialogic interchange. As discussed by Josselson (2011), it is through a narrative epistemology that the relativity and multiplicity of truth is respected. The understanding of that truth involves an account of experience that is constructed through human discourse. The lived experience of informal caregiving is conceptualised in the journey of “yesterday”, each step being impacted by realities of day-to-day living. It is in reflection, that yesterday’s lived experience is reconceptualised in the “now” moment of “today”, as the story is shared with the researcher.

Reconceptualisation profiles a landscape of lived experience across four themes – (1) As Time Goes By: Transitions and the Trajectory of Care; (2) The Good, The Bad, and The Ugly; (3) Breadcrumbs in the Forest: Survival and Support; and (4) Formal Caregiving: The Last Bastion of Support. Participants translate knowing into telling through what Fuks et al. (2011) refer to in terms of an “oral transmission of internal experience” (p. 301); and as participants share their reconceptions, multiple voices speak as one.

So as to be true to the collective nature of the narrative, and in keeping with the purpose statement of “understanding a person through narrative” as referenced by Hall and Powell (2011), in most instances personal names are removed and identification is represented through the use of pseudonym, as discussed and profiled in Chapter Four. This is particularly evident in the following chapter, Chapter Six, where what has been reconceptualised is reframed in the light of reflection and introspection.

In referencing data extracts that expose a high level of emotional vulnerability, all identification is removed so as to add an additional layer of protection in respecting the anonymity of participants. Comments that are of a controversial nature in relation to expressed dissatisfaction and criticism of organisational and institutional structures are also de-identified. There is no differential value judgement between data items and all are deemed to be equal in enriching development as the collective landscape is woven.

5.2 As Time Goes By: Transitions and the Trajectory of Care

Christensen’s and Wagoner’s (2015) reference to the use of metaphor in narrative
development presents an ideal platform from which to project that very process of transposing an inside or an internal experience to an external repositioning:

Who is it who has destroyed me, pitiable one, . . . ?
What madness was this? . . . Behold again the cruel fates that call me back
As sleep closes my fading eyes.
And now farewell, I am carried away surrounded by immense night,
Holding up to you my feeble hands, but alas no longer yours.
She spoke and swiftly fled away from his sight, like smoke dissolved into thin
t.

The poetic analogy from Virgil could very well describe the passage of time that marks the Alzheimer’s journey. It could be during the onset stage that Eurydice sees herself as a “pitiable one”, experiencing those moments when she is aware that her cognitive capacity is failing her and her physical ability to function independently is rapidly deteriorating.

Yet, as the degeneration progresses, and even as the end-times are approaching, Eurydice has moments when she senses that there is something calling her back, right to the point when “sleep closes [her] fading eyes”. As she surrenders to the “immense night” of death, she holds out her feeble hands as a final gesture in acknowledging that she is entering a journey that must be traversed alone. She swiftly flees to a life beyond that which is bound by her mortal coil and it is to Orpheus as if she is fleeing “away from his sight, like smoke dissolved into thin air”. Eurydice passes to a life beyond and Orpheus is left “snatching vainly at shadows and longing to see so many things” that might bring meaning to the experiences that defined their journey: the journey that has impacted him, the lover and the caregiver; and the journey as it was for his loved one.

5.2.1 – Transitions

It is in retrospect that participants realise that the Alzheimer’s journey began long before there was conscious realisation that degeneration had begun. Something has
been happening gradually and unobtrusively; perhaps for a period in excess of 15-20 years. Incidents of behavioural changes have passed unrecognised until an occurrence is observed and identified as a snapshot in an evolving pattern: a “Where did that come from?” moment.

Only then is there recognition of subtle changes where, upon reflection, it becomes obvious that these changes have been happening quite discretely. As explained by Rosalind, “Looking back 15 years, when he started dozing and following me around, it could have been onset and he could have been not coping and covering up.”

Participants speak of observing initial changes in relation to cognitive function presenting as lapses in short-term memory and increasing difficulties with literacy functions of reading, writing, or finding the right word to express a thought. As a point of illustration, Nerissa tells of how, in retrospect, it became obvious that Octavia was showing “little signs” 25 years ago – “like she would forget words and couldn’t find the right word”. The “big turn” came for Octavia in 2003, when she couldn’t remember where the bus stop was to come home from the city. Gradual forgetfulness is also the first sign observed by Eleanor as Rod began “losing the plot and getting a bit muddled during presentations and he started to become non-fluent when he had always been a very sharp presenter”.

In other situations, changes in behaviours relating to the spatial domain are identified as the first indicators of onset. Yori reflects on the fear that both she and Adam felt when he started to drive on the wrong side of the road. As Yori recalls, “As soon as he realised what he was doing, he stopped the car, got out, gave me the keys; and that was it: no more driving.” Antony recalls the first signs for Eva’s decline as her becoming vague, bumping into things, scraping the car and then she started losing herself and not knowing where she was. Aliena used to have to watch Oberon all the time; otherwise he would wander off or fall.

The third significant domain identified as showing first signs of degenerative dysfunction is the executive domain, demonstrated in behavioural changes involving judgment and decision making, closely related with unpredictable mood swings and changes in personality. Angelica recalls how for Earl:
The business was the biggest problem. He had been avoiding making decisions or making terrible decisions and he was getting slower and slower. He was rude to staff and fired staff for no reason and he was always changing his mind and getting more and more inappropriate in his social behaviour.

For Helena, the first indicator of a transitioning was just about five-six weeks before diagnosis when, as Rousillon advises, she started pulling at the blinds, tearing at the curtains, becoming verbally abusive and slapped Rousillon across the face: something Helena had never done and an incident described by Rousillon as being “such a shock and so out of character”. Helena’s transition is extreme and is deemed by her attending geriatrician to have been triggered as a reaction to shock. Rousillon was advised by Helena’s geriatrician that, while an instantaneous, unprecedented, and unpredicted behavioural anomaly can flag an advanced stage of Alzheimer’s degenerative progression, such a rapid transition is uncommon.

The first transition from “normal” behaviour to behaviour that is significantly different in presentation has occurred. It has been observed by both the person with the condition that has yet to be named in diagnosis and by persons with whom the one in transition has regular contact. Family, friends, and work colleagues are all impacted.

At this phase of awareness, loved ones are reported as presenting with some level of confusion and as participants share their stories in a multi-voiced description compiled from collective data extracts, they explain that their loved ones become very good at covering up. For both caregiver and care receiver it becomes all about social survival and saving face. Some care receivers tend to lay blame for their behaviours elsewhere, while others pretend that all is “OK” and put on a good act. Some also try to hide lapses by making excuses when losing or misplacing things, having difficulties in finding the right words to express what they want to say, losing direction, or having increasing difficulties in making decisions. There is also incidence of denial: self-denial in failing to acknowledge functional difficulties, protective denial in relation to not seeing or “turning a blind eye” towards what is going on, or simply a failure to acknowledge that something is happening.

As Emily considers Edward’s reaction to Ophelia’s onset behaviours and her subsequent diagnosis she shares:
As [Ophelia] deteriorates, it is becoming more and more full-on for Dad and he tries to deny it and to hide it, as he is so very protective of her. There was big-time denial in the family and to some extent, there still is. We have to learn to deal with this. We’re all part of it and as a family we all have to work through what is happening. It’s a slow process and it’s not always easy.

Degeneration advances as all three domains (cognitive, spatial, and executive) begin to show observable signs of deterioration. The primary caregiver needs to be available for support and assistance with self-care tasks such as dressing, bathing, food preparation, and eating. It is also becoming apparent that assistance is required with walking: initially the support of a hand to hold, and followed by use of a walker for added support and protection from risk of fall. Finally, a wheelchair is required: initially when away from home, with a gradual increase in frequency of use on a daily basis; and then in all ambulation. As mobility continues to degenerate, falls become frequent, and often result in hospitalisation for generalised injury or breaks to bones.

Functional skills begin to slip away and, in an attempt to “save face”, loved ones begin to withdraw or become aggressive in an act of self-justification. There are mood swings and noticeable changes in personality. Episodes of delirium, paranoia, and phobia become increasingly evidenced. Participants share experiences of their loved ones being convinced that someone is coming in and eating all the ice-cream (Owen), or stealing their money and jewellery (Roberta), or rearranging everything (Elga). Obsessive behaviours begin to intrude as Octavia irons, Margaret checks the doors and washes her hands, and Orsino cleans his teeth with his biro. They hide things, lose things, and try to cover up mistakes and lapses. They are reported to need increasing support with managing business and social affairs. They become increasingly forgetful of names and may begin to not recognise familiar faces – even their own. A new transition is presenting; and while help and assistance are required, there may be no need for care receiver and caregiver to co-reside, providing there is access to regular in-home support and assistance as is the situation of Isabella’s caregiving for Orsino.

Degeneration continues to advance and transitions become more noticeable. Behavioural, personality, and mood changes become more noticeable and the level of dependency increases, as do the embarrassing moments. A once placid and calm loved
one may become aggressive to the point of being at risk of harm to self or at risk of harming others, particularly the caregiver or co-residing children. Alternatively, the one-time dominant personality may withdraw and become placid, submissive, loving, appreciative, and calm. Hallucinations and obsessive behaviours become more frequent and more intense; as do difficulties in identifying with time and place. Agitation and wandering behaviours may begin to escalate, particularly in the afternoon and as sundown settles in. As Alice explains:

[Helen] has become so shrewd. She waits till she knows there is no one watching her and she’s off. She walks for miles and she’s so damn sneaky and there are times when I think about doing a “Granny dump” at the nearest nursing home. There is a total lack of frontal lobe action.

As participants reflect on scenarios that bring transitional evolution into the spotlight, they recall and reconceptualise extensive diversity in demonstrated degenerative behaviours. Ratcliffe began to demonstrate behaviour that was sometimes quite embarrassing (Audrey). Aaron kept repeating himself, constantly: would get angry, shout, and swear, and the little ones would become frightened that their Poppy had changed so much (Elizabeth). From appearing to be nervous and rudderless and prone to mood swings, Lena morphed into a sweet little old lady who has quiet moods (Aemiel). Elga was constantly giving orders, telling Emilia to get to her bed and treating her like a child. There are times when Isabella feels like she is betraying her mother because of how “awful” Orsino used to be. She feels torn as she asks, “Why? Why were you like that then and like this now?” Adam tells everyone that Yori is taking his money and Yori just humours him, saying, “You tell me where you’re hiding it so I can take it.”

Inappropriate sexual behaviours also present, to the point where respite has been revoked. Loss of personal identity is documented, as loved ones initially forget their own name and then begin to lose their sense of spatial identity. Loss of recognition of loved ones becomes the norm. Another transition is occurring. Dependency on the caregiver is increasing and additional support is needed. Periodic respite, either in the home or within a formal care facility is found to be helpful and the need for full-time formal care is being contemplated as a real possibility for the not too distant future, particularly for the caregiver who is alone.
Cognitive, social, and functional degeneration continues and the pace of transitional change appears to escalate. Muscular control weakens. Incontinence sets in. Sleeping is disturbed. Obsessive and repetitive behaviours escalate. Wandering escalates, and anxiety and agitation intensify. Escape, obsession, and aggression become so difficult to manage that formal care within a secure unit becomes the only option for sustaining security of care receiver and safety of caregiver. All sense of time and space dissipates, even to the extreme of not being able to differentiate between night and day.

Further degenerative transition is accompanied by deeper and more intense physical and emotional impact upon the caregiver. “Round-the-clock” care is required and can only be sustained in homes where there is a co-caring partnership. From one who does have that support, it is Rousillon who says that without her husband, Lafe, who is “so patient and strong and supportive”, she could not physically care for Helena. In contrast, as a lone caregiver, Vince shares his story through this transition phase:

I am freely committed to vows freely taken. I will care for the personal needs of this precious gift. The thought of not caring scares me. Yet, I know in the depths of my being that the day will come when I cannot give my Margaret what she needs to keep her safe and to keep her comfortable.

There are times when I feel powerless to fill the void and stretched to the limit beyond bouncing back. I feel as if every part of my being is cut up on the inside. I am so desperate for assistance. I think that finally the penny is dropping. I am not Superman and 24-hour care is not possible for one person over a long period, in which lack of sleep is the norm.

Degeneration spirals towards a climax of total and complete disempowerment for the care receiver. This loved one is fast losing all capacity. The caregiver is losing emotional and physical resilience. Aggression and abuse, where demonstrated, may diminish as loss of facility, loss of function, and loss of awareness escalate. Physical abuse may be replaced with yelling, screaming, and cursing. Generalised verbal abuse may escalate to incorporate physical abuse as the loved one lashes out. As Emilia tells her story of journeying with Elga, she shares:

There are times of absolute chaos and times of somewhat calm. She was becoming more and more psychotic and verbally and physically abusive. There
were times when it was just awful and I was afraid. I even had to telephone in secret. Then she attacked me with her walking stick and pinned me to the wall. It took all of my strength to stop her from choking me. The whole thing was so surreal.

As the transitioning continues, accelerated degeneration begins to include breakdown of vital organ function. The care receiver is extremely vulnerable to infection. For some, multiple diagnoses contribute to the complexity of caregiving in a circumstance complicated by complex comorbidity. Heart, lung, and kidney function weakens. Diabetes, Parkinson’s disease, or vascular problems are diagnosed in a comorbid alliance with the diagnosis of Alzheimer’s disease or what has now developed into an Alzheimer’s related dementia.

As the final stages of transitioning begin to emerge, muscle collapse increases to the point where the loved one cannot sit without support and the head can no longer be supported in an upright position without the addition of external props. The ability to chew and to swallow is gradually lost, and intravenous feeding is suggested. It is at this point that Vince knew in his heart that he would not force his Margaret through that ordeal. The caregiver needs to make the decision as to whether the time has come to prolong life; or to prolong death through forced interventions. Sight and hearing fail. Muscle contractures develop, resulting in immobilisation of joint movement. The skeletal body begins to curl into foetal position. Legs begin to curl up at the knees and toes curl up. For those who love, there is fear, anxiety, and trepidation as they witness this final transitional stage. Aliena asks the question, “How will they ever fit this curled up skeletal frame in a coffin?” And to her horror she is told, “They will just break his bones.”

For some, palliative care is initiated. Others do not have access to palliative care. While all communication and recognition seem beyond reach, it is felt by those who have transitioned with their loved one through the passage of death that somewhere, deep within this mortal shell, the essence of the one they love is still present. Right up to the end, there occasionally seems to be “a moment of total rationality amidst the chaos” (Richard). “It is,” as Richard suggests, “All still there: just all jumbled up and missing for most of the time.” Antony speaks of “the ever so occasional glimpse of
momentary lucidity, coming and going in a fleeting second”. Vince recalls a discernible expression, “when those eyes have a look of one who has been abandoned to a fate worse than death”: and in that look, explains Vince, “in some weird sense she is communicating”.

Transition into the final stage has begun. Yet, be this the final transition for the care receiver, it is not the final transition for the caregiver. For those who love, the journey goes on. Further transitions confront the caregiver. As stated by Lavinia, there is “the business of death”. Time does not stand still and as Vince explains, there are “tasks to be completed”.

5.2.2 – The trajectory of care

As the condition of the care receiver progresses, the intensity of care increases exponentially. While some have just begun their journey, others have endured the pain of witnessing their loved one’s transition through the full trajectory of degenerative disempowerment. The persona that defined a loved one in the full bloom of life has gradually disappeared, “like smoke dissolved into thin air” (Virgil, as quoted above in the introduction to this theme). It becomes a matter of learning to appreciate and celebrate the good times as personalities change dramatically and quickly. Multiple voices express feeling sad and happy all at the same time. There are also multivoiced expressions of regret at getting upset over things that now seem so trivial; or of not enjoying the “now” times and doing things earlier while having time and ability before “life” is taken away. What is found to be helpful is captured in the combined statements of Hal, Isabella, Richard, and Vince; the essence of which is encapsulated in their multivoiced expression:

It is remembering that first and above all else, this person is a human being. Who she is now becoming in the shifting moments or each passing day, and who he is now compared with who he was then, is all part of the journey. It is a story of constant change and it is so important to be open to opportunities that each change brings as we move from moment to moment and from day to day.

As participants reflect on the “what” and the “how” of lived experience that impact so intimately on the internal position of I, the caregiver, thoughts turn towards their own mortality and vulnerability in being “targeted” by the Alzheimer’s gene. The
deeper questions of “why”, “where”, and “when” begin to be contemplated and it is Elise who captures the essence of that which is stated by multiple voices, as she speaks in terms of “knowledge development” as accrued and processed in a world of unmasked reality: “As I do what I do and as I learn more about myself with each passing day, I ask myself, ‘Where did I come from?’ ‘What is my purpose?’ ‘Where am I going?’ ”

**Figure 8 - My knowledge development:** Reconceptualisation of the reality of lived experience visually interpreted by Elise, 2016.

In the early stages following diagnosis, some caregivers have had discussions with the care receiver with a view to setting systems in train and to discussing future legal, financial, healthcare, and end-of-life plans. Others are not ready to face the reality of the end times. As participants tell their stories, it becomes evident that impact extends beyond onset to end-of-life, and embraces post-death experience. All that has been lived for has died and particularly in the dying of a spouse, participants express feeling stripped of their identity and their purpose.

There are moments of feeling that “life is on a plateau and is going nowhere” (Rosalind) and there are wonderings, “Where is this going to end?” (Hal) and “How much longer can I do this for?” (Eleanor, Hal, Isabella, and Vince). Yet, while
caregivers have learned to “push it off at a surface level” (Richard), “deep down, there is grief and distress” (Aemelia) that invades the emotional, physical, and behavioural domains. Financial concerns and issues relating to vicarious connection are also significant components of impact.

**Figure 9 - Caregiver impact:** When caring for a loved one who has a diagnosis of Alzheimer’s disease, there is emotional impact, systemic physical-behavioural impact and relational impact. Financial issues become a critical factor and a ripple effect impacts vicariously across the connection of immediate and extended family.

As the Alzheimer’s journey lengthens in duration, the impact of caring becomes both a multi-layered and a multi-lateral experience that touches every aspect of life and living. There is a total restructuring of lifestyle (Hal and Richard) and the time comes when caregivers intrinsically know that they “need to get over it and get on with it” (Iris); “toughen up or go under” (Aliena). There are moments of “living on the edge” (Elizabeth) and moments of resentment as caregivers ask the questions, “Why me?”, “Why her?”, “Why him?”, “Why us?”

Following the death of a loved one, reactions include feeling a sense of relief and release for a loved one no longer in pain, while at the core of the caregiver’s own being, there is deep and abiding sadness. There are also feelings of relief and release for self in regaining lost freedom. This personal sense of freedom is sometimes said to be
accompanied by feelings of guilt that relate to owning and valuing the very real fact that a loved one needed to die, so that the burden of care could be lifted.

For others, the loss is so intense that the thought of living without one so loved is beyond comprehension. Suicide is contemplated and death is considered as a very attractive option to living without one who has been so loved. The lingering agony that accompanies his loss is expressed by Antony as being “so inconceivably immense”: and in the midst of his own pain, there is also acknowledgement that death was a relief for his beloved Eva as he shares, “She wouldn’t have liked to have seen her the way she was.”

Some participants who have passed through this period of darkness and some for whom the journey is still in process speak of how they are involved in volunteering services that demand high levels of compassion and empathy. This, they say, brings them solace while providing a momentary distraction from their own grieving for the “life that was” (Aemelia, Aemiel, Aliena, Antony, Elise, Isabella, Nerissa, and Vince). The shared sentiment is that in giving to others, their own burden is lightened.

5.2.2.1 – Emotional turmoil

What a cocktail of emotions is expressed by participants. There is fear, frustration, and anger; guilt, regret, and remorse; embarrassment, shame, and anxiety; and there is jealousy towards those who are free to come and go as they please. Many factors that are stress-inducing revolve around security, worry over what will happen if the caregiver gets sick or is outlived by the care receiver, failing mobility, increasing responsibility, and the burden of making decisions. There is a surreal appreciation that while the care receiver may be disengaging more, becoming less stressed, and living in another time and space, the caregiver is engaging more, becoming more stressed, and living in the growing chaos of now; while looking into a future that is unknown territory: other than in the fact that “things are going to get a whole lot worse” (Rosalind).

Tears are an emotional release for all participants: shed alone and often, in a quiet moment, an adjacent room, or in the depths of the night. There are tears that flow from a chaos of emotions or from overwhelming tiredness; and there are tears that emanate
from an all abiding sense of dissolution in response to frustrations so intense that the
caregiver begins to disassociate with all social contacts and with the real world.

There are those who express that they are becoming socially isolated. All sense of
freedom is gone and a sense of oppression is so intense that with eyes closed, a plea is
made that all will go away and the hope is that when eyes are opened, the world that is
will have morphed back to normality (Lavinia). For Audrey, the desire is simply to be
able to bury her head in the sand with the illusion that if she cannot see it, it will
disappear.

Collectively, there are emotionally charged expressions related to the loss of
personal space and security and to a future marked by ever increasing restrictions on
freedom. As time takes its toll on the caregiver, there are also observations from those
in supporting roles that the caregiver is noticeably developing loss of empathy
accompanied by projection of negative energy. There are also observations of
resentfulness accompanied by what appears to be a decline in self-worth amid
accelerated feelings that one should be able to cope (Ephesea). Caregivers become
fearful about the growing need to make decisions alone and to take ownership for “stuff
that wasn’t on the radar, before” (Eleanor).

5.2.2.2 – Systemic impact on health and well-being of caregiver

As well as everyday emotional turmoil, the body is also subject to somatic stress
responses related to what is defined by Wyder and Bland (2014) as secondary trauma.
Collectively, these are reflected in tearfulness, exhaustion, and depression; back aches,
headaches, and joint pain. Immune systems become fragile resulting in increased
susceptibility to being generally “run down” and prone to all form of bacterial, viral,
and fungal infections.

There are reported breakdowns in vital organ function presenting as bowel,
stomach, kidney, liver, gall, or spleen problems. Heart palpitations and chest pains are
accompanied by erratic heart rate and blood pressure readings. There are reports of skin
irritations and outbreaks of eczema and psoriasis; and there are fluctuations in body
temperature.
Cortisol levels escalate and thyroid function and triglyceride levels become irregular, resulting in extreme weight changes or the onset of diabetes. There are reports of fainting, heart attack, and stroke. There is one report of the early onset of menopause.

Psychosomatic events present as hyperventilation and fearfulness when driving. There is expressed sense of suffocation, related to feeling an overwhelming oppression that accompanies total loss of freedom. Richard speaks of physical sensations commensurate with “being pulled in so many different directions all at the one time”; and both Richard and Emilia express feeling intense anxiety when the phone rings. Both also report a somatic sensation of their brains turning to “mush”. As explained by Richard:

There were times when I felt that my brain is just mush and it hurts to think. It physically hurts and it’s different from a headache. It’s just mush and I even feel that I could touch it and it would squelch in my fingers.

Nights become a time of increasing restlessness. Sleep becomes erratic, non-existent, or plagued with nightmares: leaving the caregiver with a lingering sensation of exhaustion. Tiredness and crankiness walk hand-in-hand for those who feel that they are living on adrenalin. Eating patterns become as erratic as sleeping patterns. Life is planned around the needs of care receivers and their growing dependency. Amidst the stress and the strain, there is expression of a self-imposed need of having to “keep up a front” for the family, while finding the whole situation quite traumatic (Audrey). Ongoing medical problems, mobility, and aging issues also need to be considered and there is the occasional “time out” resulting from a need for surgical procedures or medical treatment for other conditions that require terms of hospitalisation for the caregiver. The need for self-care becomes critical while finding the time for self-care becomes more difficult and elusive with the passage of time.

5.2.2.3 – Relational impact

As families traverse the Alzheimer’s trajectory, relationships are also reported to be impacted. For some, support structures are established for the primary caregiver and bonds are forged as extended family work together. For others, family bonds are reported to be weakened and broken as relationships with siblings become a “battle
ground” of conflict over anticipated inheritances. While some families rally around the caregiver and collectively take on the added responsibility of caregiving, other families become resentful of time spent in caregiving or simply ignore the fact that the caregiver is carrying an additional burden of care, accompanied by accelerated rise in emotional and physical stress. In situations of second marriage and blended families, it is more the rule than the exception that biological children of the care receiver either refuse to own the fact that their parent has Alzheimer’s or they just do not want to know. However, while there are situations where the step-child is reported to support the non-biological parent caregiver, it is more often the children of the caregiver who rally to support their parent in the care of their step-parent.

Relationships between caregiver and care receiver change, as loved ones travel back in time. Veils on past life experiences are lifted for Isabella and Iris, as stories of parents’ traumatic childhood events, hitherto unknown, are revealed. Having gained these insights, both ladies express a sense of “eternal gratefulness” in finding a parent they had never known. Both also suggest that, if not for Alzheimer’s, they might never have come to know that parent and to understand why they did what they did as their daughters were growing up.

In the discovery of the parent, a light is said to be shone on their own life’s journey, as the relationship each lady felt towards her parent is said to have changed and softened. Tough or abusive parenting practices, while not condoned, begin to be understood. To Isabella, this understanding is perceived as a gift that has been given to her by nature, and she explains:

My childhood is not an injury any more. I am released from the fear and the resentment. I have stopped asking, “What?” and “Why?” I now have selective memory as every day I am growing in knowledge, understanding, and kindness.

Relationships between caregiver and care receiver also become strained as mothers and fathers become as children to the child who becomes as parent to the parent. Spouses and partners become as strangers to their lover and companion as they, in turn, become parent and minder to the “tantruming toddler” (term coined by Emily). The care receiving friend is reported to become dark and suspicious, leaving the caregiving companion feeling sad and confused (Aemelia).
Relationships move from equal partnerships to partnerships constricted by dependency. As care receivers grow to be more dependent by the hour, it is to caregivers as if they are looking after a child who is travelling in “a reversed time warp” (Hal) and they begin to mourn lost identity, lost relationships, and lost time.

5.2.2.4 – Finance and reality checks

Participants speak of financial stressors emanating from the need to retire from the work force so as to assume the role of full-time caregiver: a career move that equates to what Alice refers to as “costing big bucks”. There is also financial stress in trying to find fees for respite, brokerage, entry costs to formal nursing care, and on-going care expenses. Caregivers need to find this money “in a hurry” and many are forced to take out an “interest-only” loan, sell the family home, or sell property that has, for many years, been their only temporary escape from reality, or was to be their superannuation.

Also discussed is the need to assume control of finances, organisation of business affairs, and closing down of businesses: tasks that had always been the domain of the care receiver. Elevated stress levels are said to accompany the increasing need to become the organiser, the planner, the financial manager, the fixer, and the decision maker: alone and without support.

5.2.2.5 – Vicarious impact

Vicarious stress is expressed in relation to the impact on others and that becomes an additional source of worry for the caregiver. Impact on siblings and children of the caregiver is said to relate to a somatic sense of fear, distancing, or denial; or alternatively, there is an innate sense to step-up and support. There are memories of a grandparent going to hospital and not coming home. Instead, he was transferred directly to a “nursing home”: a term that Olivia needed to “Google” and a situation that she recalls caused her distress and confusion.

The real sadness relating to vicarious impact is reported for the children and grandchildren who were robbed of their parent/grandparent; losing this special person piece by piece, to the ravages of early onset Alzheimer’s. There is also sadness for the grandchildren who would never get to know their “real” grandparent, pre-Alzheimer’s.
Yet, instinctively, the children sense that there is a need to protect: so beautifully illustrated in the words of Angelica, who shares:

> Looking back, it now seems quite amazing. The children always took his hand when we went anywhere and it was as if they were protecting him rather than him protecting them. Kids and animals are so instinctive! I guess in hindsight, I went into protective mode, the dogs went into protective mode, and the kids went into protective mode.

There is also the ripple effect, expressed in terms of impact on family: especially children in a co-residing environment. Younger children are reported to be confused and frightened while older children find the whole scenario to be very sad as they watch a parent or grandparent change in mood and personality. There is also potential for social isolation, as children’s friends stop visiting and the household goes into “quiet mode” when a beloved grandparent starts becoming distressed and agitated by noise associated with having extra people around.

Then there is the grandchild who takes on the role of formally registered carer for a grandparent, who is said to have “her own private nursing facilities at home” (Alex). There is also the grandchild who assures her caregiver grandmother that she will never be alone or need to reside in a nursing home as she, Olivia, will get a unit and care for her “MaMa”.

As the dread of Alzheimer’s casts its net over a family, no one is spared. There are feelings of sadness for a grandparent who had a car crash, got lost when he went roaming the streets with the dogs, and who forgot his birthday (Nym). There is an expressed sense of desperation for a grandparent who was unable to communicate or to move, and who started to have seizures: becoming a person of whom his grandchildren were scared (Olivia).

For Megan, there was a sense of wanting to protect a grandparent whose incontinence caused him embarrassment. There are also reflected memories of fearfulness and worry related to falls as she recalls one fall being from a window as her Pa was trying to escape from some hallucinatory vision. Megan further recalls a memory of community connection ensuring the wanderer’s safe return to home when, as the sun began to sink, the daily trek of this loved one (Megan’s and Jason’s Pa) was
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland

monitored by neighbours, who set up a watch to ensure his safety by progressively calling out from house to house as the neighbourhood’s “Special Someone” set out on walkabout.

Adult children express that journeying with and supporting their caregiving parent was both enjoyable and rewarding. Feelings of sadness, shocked realisation, and fear are also expressed as children and grandchildren reflect and reconceptualise the moment when the serious side of the condition was really confronted for the first time. For Rosaline, it was the day her father referred to her mother as “that lady next door: oh, you know; what’s her name?” For Ephesia, it was her father’s forgetting the names of his grandchildren. These scenarios are said to have struck an awareness of the seriousness of a loved one’s degeneration; and for what was to be the first of many occasions, there was need to withdraw and to sob in the privacy of an emerging grief for the disappearance and loss of the person of one so loved.

Adult children also express that supporting their caregiving parent has been both a privilege and an honour. It has also been named as a special time to forgive and forget personality clashes and to enjoy this new time with a parent who is lost. For some, their parent’s declining health has forced them to think about their own mortality and what it is that really matters in life. There is universal expression that what is “really” important is relationship and connection with loved ones.

I conclude this section with words penned by my son who held his grandfather in his arms as he breathed his last demented breath. Reflecting on events 26 years gone, Jason recalls:

Looking at homes for him was hard in some ways and a relief in others. Knowing it would be a place of safety for Pa and others around him was the easy bit. Knowing that we had to let go was the hard bit. The stages of deepening dementia take a hard toll on loved ones and those closest.

Pa finally went to a hospital: a good caring hospital. But you know there is only one way patients leave that facility. Tough times for all of us were assisted by good care from allied medical staff and palliative care staff. The mourning of the man who once was, was now beginning. He fought a strong fight to the end.
5.3 The Good, The Bad, and The Ugly

The trajectory of care is dichotomous and unpredictable. Alzheimer’s is the master. The patient and all those who love are the slaves. There is nothing so valued as the forging of a relationship hitherto unknown. There is nothing more “pitiable” than watching the dehumanising of a loved one. There is nothing more soul destroying than witnessing transformation of identity, as the familiar persona of a loved one disappears, “like smoke dissolved into thin air”.

5.3.1 – The Good

In the midst of all that is horrific, there are miracles and moments to be forever treasured. There are also moments of realisation that life is but a flash in the passage of time. Yet, all it takes is a tiny spark to keep the embers burning and that spark is what fuels an innate sense of motivation underpinned by human kindness and framed by love. There are moments of deep and intimate connection. There are moments of pleasure and learning. There are actions freely chosen and decisions freely made. There is an intrinsic knowing that a task has been completed and a job has been well done.

5.3.1.1 – Connection

As participants share their stories relating to the tribal connection between the internal position of I, the caregiver, and the external position of I embodied in my care receiver, there is evidence in the data extracts of an “intangible something” that brings caregiver and care receiver together on so many levels and in so many ways. Love is encapsulated in the universality of transpersonal connection. Even death cannot sever a connection that is forged of love as a caregiving grandson confirms, “I know in my head that this will all end with Nan dying. But in my heart, she will never be gone” (Alex).

Shared expressions of attachment are couched in the plain and simple love of child for parent. That bond of connection is framed by an innate drive to protect, to fulfil family obligation, or to honour cultural and/or filial duty that translates into assuming the role of primary caregiver for a parent. A lifetime of love is infused in the words of Nerissa as she says, “She’s my mother; right up to the end of her life. I love her and will care for her no matter what”.
There is a sense of awakening and healing coming through words shared by Iris when she says, “As she spoke of her childhood, that threw some light on my own rebellious youth: and my relationship towards her changed and softened.” There is also an expressed sense of satisfaction in being able to give back something of the care and nurturing that has been bestowed by a parent and that spans a lifetime: “Why do I do it? I ask myself. It’s only normal to feel you owe your mother something and being with her family gives her continuity and a sense of safety and security” (Alice). Similar sentiment is expressed by Rousillon and Lafe who state, “She [Helena] will never see the inside of a nursing home as long as we draw breath.”

There is connection between spouses and partners in honouring vows freely taken, either formally or informally, in a space that seems to be a lifetime distanced by the passage of time. As Eleanor shares:

I have moments when I wish I had left years ago. He’s not the easiest man to live with and never has been. Now I feel obliged to stay and care for him right through however many years this journey takes. We are only just starting and I live with that decision and I know that I will live up to my responsibility. There’s nobody else and there’s such a long way to go.

Bonded connection is also forged within religious life and across community filial relationships spanning many years marked by respect, friendship, and an ethos of compassion. As explained by Aemelia with reference to her connection with Anne:

She knows me as a friendly face, even if she doesn’t know who I am. I sometimes wonder what is going on inside her brain and while I feel so sad for her, I also feel good that I am able to be with her. And I think she feels safe when I am here.

Caregiving also presents opportunity for a touching of hearts as families network and join together in the sharing of caregiving tasks. Doorways are opened for renewal and strengthening of relationships across extended family, as shared in the stories of Alice, Alex, Angelica, Antony, Audrey, Elan, Elizabeth, Emily and Iach, Emma, Ephesea, Hal, Jason and Megan, Lavinia, Richard, and Vince.

The essence of family connection is captured in the words of Emma as she reflects and shares:
We bonded to get things done. People found their strengths. For the first time in [Rebecca’s] life she truly felt needed by us all. This gave her great confidence in being the primary caregiver. Every single family member was affected and none of us would ever wish anybody to see a loved one lose their soul. This disease forced us, as a family, to work, talk, and finally to play together. It brought humanity together: and certainly for me, I learned patience. All of us learned and improved on delivering with more empathy towards Mum and each other.

As I dialogued with participants, I gained an awakening sense that translates in terms of connection. Be it love or be it duty that drives the bonding within a caregiving network, determination of spirit and respect for those in need of protection intertwine within the driving need to connect, as one journeys through progressive degeneration and disempowerment with another: one who holds a special place in heart and history. To get close to the child in the parent and to be given insight into a life before meeting a spouse, partner, or friend, is considered by participants to be an honour and a privilege: albeit, there are times of annoyance, anguish, and anger. Stories from the past are played out in the reality of the now as snippets of one story intertwine with snippets from another time and another place. Yet, in the magic that overrides the chaos, all comes together in some strange reality that is executed in present time.

Mundane and repetitive tasks take on new meaning in a spirit of connection. Suddenly, the frustration of a father’s obsession with pigeons is tempered with understanding and appreciation as Isabella expresses in “Landings”, written on August 14, 2015:

**LANDINGS**

Pigeons take off from the shed roof
Like many white gloves.
In handfuls they soar,
Opening and closing fists,
Clapping and not clapping
Against their bodies.
They land on a white gum tree
In the neighbour’s yard.
Branches are instantly decorated
With bright magnolia-like flowers
That move up and down
On short stalks.
Soon they take off again for no particular reason
In unison:
In an act of solidarity
To some other unknown location.
And my father lands
And sees them again:
For the very first time.

There is bonding between parent and child; grandparent and grandchild; spouses, partners, and friends. There is pride born of pain, and creativity born of necessity. There is the common bond of random human kindness that brings people together in the strangest of circumstances. Even when times are tough and are getting tougher, an ingrained sense of connection “kicks in”; and born of the love that underpins this relationship, the weary caregiver acknowledges never being able to bring the Self to a point of total acceptance in saying and carrying through on that momentary vagal prompt that says, “I can’t do this anymore”. With the passing of each day child, grandchild, spouse, partner, and friend watch hopelessly and helplessly as degenerative progression strips their loved one of identity. And, in the watching, there is bonded connection born of unconditional positive regard.

5.3.1.2 –Pleasure and learning: Fun and enjoyment: Calmness and contentment

As data extracts are woven across the hybrid methodological warp, there emerges a surreal sense of pleasure and learning, fun and enjoyment, calmness and contentment that blends seamlessly with frustration, tiredness, grief, and horror. As Yori explains:

I think that’s what saves me; my sense of humour. If anyone had us on CCTV, they’d think I was crazy. We have fun and we enjoy life. It works for me and it works for [Adam] and that’s all that matters.

Fun and enjoyment promote calmness and contentment in the care receiver and there is a reciprocal interchange. This interchange sets in motion a ripple effect that
projects through the household. It becomes about laughing “with” and not “at” the one who is becoming more the child as each day passes. Playing games and laughing become routine and as explained by Alex, transform difficult moments and break through the fear, disorientation, anxiety, and agitation experienced by the care receiver:

I’ve learned that afternoons and dusk are the worst times. That’s when she gets cranky, that’s when she’s most likely to try to escape and that’s when you get the most refusals. She’s a real “Sundowners” and we have to watch her like a hawk as the sun starts to set and the evening starts to come in.

She definitely does change personality and mood in the evening and sometimes it’s pretty hard to stay patient with her. So that’s when I need to keep coming up with games to keep her amused. I have a set routine and we cycle through the games; and then we start all over again when she can’t remember that we’ve played that one before. She is happy and that’s what it’s all about: keeping her happy, learning what sets her off, and doing things that amuse her and keep her calm. (Alex)

The need for calmness and contentment is confirmed by all caregivers who claim that being with family gives to the loved one a sense of continuity and security. Where there is security there is trust and when blended with a thread of creativity, fun and enjoyment can be found in the darkest of moments. Disempowering feelings are kept at bay. Sadness and grief are minimised for the caregiver as frustration and anxiety are minimised for the care receiver.

5.3.1.3 – A role freely chosen

Giving of Self and the innate satisfaction that accompanies a repeated bringing of Self to Other, is noted across a spectrum of statements shared by participants and collectively voiced as follows:

This I do because I love her (Vince). It’s important that they stay together and that’s why we choose to be their last line of defence: just to keep that eye on them (Emily and Iach). We do it because we can (Rousillon and Lafe). She’s my Nan and I wouldn’t want it any other way (Alex). It was really more about my need than about her need. I needed to be with her and nothing else counted. She was my wife (Antony).
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: 167

Just giving the Self permission “to go with the flow” (Yori), is expressed as bringing more of a sense of open mindedness and less of a sense of expectation and being judgemental. There are also expressions of developing a diminished sense of vulnerability to the opinions of others, whereby lifting a burden of oppression and allowing oneself freedom to own the reality of the situation within which one finds oneself:

I decided a long time ago that I didn’t have the luxury of getting frustrated or to be dictated to by others who think they know better and who wouldn’t have a clue. I’m logical and I’ve created ways of dealing with everything. My life runs on lists and I have labels on everything. That way I don’t have to think and it frees me up for the important stuff. I think that’s my survival. (Yori)

Freedom is expressed by participants as coming in the form of visiting a parent, sitting with “her” and simply being with her. Freedom comes in a partner’s taking time to just sit and be with “him”, in the moment. There is a sense of satisfaction and well-being that comes with a bonding of relationship as the caregiver gives unconditionally of Self: never questioning and never resenting – for longer than an instant. In a giving of Self, there is also a social component when information regarding transitional changes is freely shared with friends and neighbours and there is no longer the intangible oppression that accompanies secrecy hidden behind closed doors because of self-imposed expectations and fear of confronting the face of social stigma.

When confronted with the monumental task of caring for a loved one who has Alzheimer’s, what is identified as being “really” freeing, is when life can be visualised through a totally new lens of changed priorities and seeing things differently – as shared by Elizabeth when she states:

It’s just the little things, like the kids’ homework is not nearly as important as seeing them outside enjoying themselves and it doesn’t matter if the house doesn’t get tidied, today. Getting things right is not so important any more. I’m also not as sensitive and accommodating in complying to the expectations of others. And having the freedom to just say that and know that I am heard is so empowering.

5.3.1.4 – A sense of achievement

Finally, in looking for the good, there is expression of accomplishment. Thoughts
around gratification in the enduring quest for personal power and control are reflected in statements that reference achievement and personal growth. Keeping a loved one at home for as long as possible; or having a positive feeling of doing something worthwhile; or a sense of responsibility in not only doing a job, but doing it well; or simply “growing up”. As explained by Elizabeth, “I’ve grown up and I’m proud of who I have become.” A sense of satisfaction and achievement is expressed in knowing that one is contributing to the well-being of another while also bringing happiness, comfort, and security.

Speaking from the heart, participants express that they see their caregiving as a personal achievement and they know that they are doing the best they can. Unforeseen opportunity has also opened a door to action: a door that otherwise may never have been found, let alone opened. Walking through what Isabella refers to as “this door to opportunity”, participants speak of finding epiphanic discoveries and awakened feelings of surprise as tasks are undertaken and jobs are done that prior to entering this new reality, were never, as Yori suggests, “even on the radar”.43

Bonus impact is reflected in terms of being allowed to put into action true feelings about how we, as human beings, “should” all act towards each other in “a spirit of human kindness” (Aemelia, Elan, Hal, and Nerissa). Opportunity presents in letting go of stereotypic gender models; and speaking from open and authentic hearts, male participants unashamedly own that they have cried for months while putting on “a bravado” of keeping it all together before rationality took over and they allowed themselves to own their grieving (Antony and Vince). “That’s a blokey thing,” says Antony.

There is also the bonus of time where one is forced to stop, to listen to the voice of reason, and to take stock of the business that controls our lives. There are expressions of learning to see beauty in the smallest thing: like a flower blooming, or dew drops on the petals of a rose, or a butterfly settling on a leaf in the garden, or a stormy sky rising across “the [Moreton] Bay” (Antony, Emelia, Hal, and Yori). Learning has brought husbands, sons, and grandsons to a point of expertise in learning

43 An expression regularly used by participants in a variety of different contexts and with reference to different scenarios.
about “secret women’s business”, women’s bodies, and women’s personal needs (Alex, Antony, Hal, and Vince).

Caregivers have learned to tread wearily in discerning what hour, what day, what month, what year, or what century their loved is living in; as both time and place are forever changing. The sentiment of multiple voices is expressed in the words of Richard as he speaks of how learning has occurred in discovery of the profound truth that life is unpredictable and that one just cannot assume and take anything for granted: “not even life, itself”.

There is generalised expressed surprise in learning what one can do for someone who is loved; with the greatest learning being encompassed in a realisation of what one human being is capable of in the name of love, authenticity, and compassion. The role of the caregiver is described so clearly by Aemelia: “We don’t know what we have in us till we’re tested. And when we come with a compassionate heart, it’s amazing what one human being can do for another human being in the face of such suffering.” Herein lies the essence of unconditional love. Love is not about “warm fuzzys”. Love is about empathy, sensitivity, and respect: as embodied in unconditional positive regard.

There is also a learned awareness and developed sensitivity in relation to the importance of being able to read and interpret body language and instinctively be able to put strategies into place so that fear, pain, and discomfort might be eased. Such is a skill collectively identified by all participants as being a profound gift in the transformation of Self in relationship with Other.

Perhaps the achievement that stands above all else is the sense of accomplishment that accompanies development of an authentic and compassionate heart; expressed in words that say:

I guess the hardest thing is adapting to the advancing baby mode – clean his bottom, shower him, catch his dribble, wipe his nose, shave him, and dress him. Some days are very difficult and in finding the compassionate in the Self, one also learns to be very, very patient. It’s OK if it doesn’t get done today. Most importantly, I’ve learned the value of tolerance and understanding and appreciation and how helpful that is for both of us. (Yori)
5.3.2 – The Bad

Bad times are reconceptualised as having somewhat of a global impact for both the caregiver and the care receiver. There is expressed belief that the world has done wrongly to both. The caregiver has no time for Self and the Self of the care receiver is consumed and lost (Antony, Lavinia, and Vince). Bad is collectively conceptualised in notions of “awful”, “sad”, and “hard”.

5.3.2.1 – That which is awful

The Alzheimer’s is always there, and said to bring an awful shame to all that is embodied in the construct of “human life” when such beautiful human beings, who have wronged no one and brought so much pleasure to so many people are struck down. The awful state of humanness is reflected in circumstance when those who have always acted justly and fairly are stripped of their ability to function; and when those who have so much to live for are disempowered and disengaged from society in the prime of life (multivoiced expressed sentiment shared by Antony, Audrey, Emilia, Lavinia, Nerissa, Richard, and Vince).

The notion of “constancy”, embodied in round-the-clock vigilance, also carries an element of awfulness for many participants, resulting in the onset of excessive tiredness, escalating stress levels, diminishing tolerance levels, and “wear and tear” on the whole system: as previously discussed in 5.2.2, The trajectory of care. This is particularly so, for those whose loved one is at an advanced stage in the degenerative progression of the disease; and also for those who are alone in the job of caregiving. Finally, all quality of life is consumed by the condition and living comes down to a point of survival.

There is also a universally expressed link between the preservation of dignity and an overarching protective instinct to save a loved one from embarrassment as well as from harm. Participants speak of “awful and scary moments” relating to functional safety, mobility risk, wandering, and social engagement. Awfulness also embraces the caregiver’s trying to keep the care receiver calm, particularly as the “end times” are approaching and there is awareness that their loved one is so frightened of dying (Aliena, Richard, and Rousillon). However, as fearful as the caregiver might be, there is still that all-abiding need to protect the loved one for as long as is mortally possible.
Chaos also falls within the realm of all that is awful. For some, it is chaos embodied in simple everyday happenings when misbehaviours, akin to those of the naughty child, are repeated over and over in this strange world of unpredictable reality. The tantrums are real. The incontinence is real. The fear is real. The escapes are real. The frustration is real. As Alice so succinctly frames the notion of chaos, “It’s like having a toddler: only more dangerous.”

Awful is also about the “What ifs” and the “Whys”: presenting in terms of what Hal refers to as “a slippery slope” and collectively expressed in terms such as:

- What if I can’t provide financially? (Nerissa)
- What if he wanders off and I can’t find him? (Aliena)
- What if she takes too many pills and overdoses? (Vince)
- What if she goes to hospital and they won’t let her come home? (Hal)
- What if I get to a point where I can’t cope? (Rosalind)
- What will happen if I go first? (Elise)
- Why is human nature so unfair? (Antony)

Maybe the worst of the awful times is when there is denial or just a plain non-recognition of degenerative changes. This is a time when loved ones become embarrassed, frustrated, fearful, and depressed. They know that something is going on and that all is not OK. It is repeatedly expressed that this worst of times is when loved ones know that they don’t know and they begin to become “dark and gloomy”, “withdrawn and embarrassed”, or “bossy and dependent”. When they transition to the place where they “don’t know that they don’t know”, it seems to be easier for them; and in some strange yet real sense, that makes it easier for their caregivers.

5.3.2.2 – That which is sad

Witnessing the degenerative process is reported as being a sad time for the caregiver: particularly when the loved one is obviously struggling while trying to be what Eleanor terms as “so very stoic”. Sadness is also felt as loved ones forget who they are, who their spouses and partners are, who their children and grandchildren are, and who friends and colleagues are. It is said that while there may be signs of recognising a familiar or friendly face, capacity to identify is gone to that place where so much of the now time has already transitioned. A sad reality emerges while
watching a loved one chat with a new-found friend who lives in the mirror or any reflecting surface (Margaret) and the sadness becomes scary when that newly discovered person is seen as a house-breaking intruder and is warned to leave the loved one’s home immediately or risk being shot (Orsino).

Participants tell of feeling sad for their loved ones when they do not know who they are, who it is that they are talking with, or who it is that is trying to feed, bathe, or change them. “Strangers” are invading their personal space in all sorts of ways that are so obtrusive to their innate sense of privacy, modesty, and self-preservation: and I, the caregiver, am that invader of my loved one’s personal space.

Sadness is also said to equate with unfairness and life is deemed to be unfair to both caregiver and care receiver. Sentiments express unfairness in relation to observed changes in personality as caregivers speak of progressive sadness going hand-in-hand with progressive degenerative transitions that are totally impacting on the person of the Other.

To watch loved ones who were so vibrant and independent transition to a position of just dozing for 24 hours a day or following the caregiver around and shadowing like a little puppy, is just so overwhelmingly sad. Sadness is also felt for the loved one who is just sitting and staring into space, lost in a world of nothingness; or obsessively tapping, making noises, or sighing; rattling the blinds, pulling at the curtains, or shredding the pillow case; banging, mumbling, stomping, washing up, or ironing; hiding, hoarding, or pacing.

Expressions of sadness and unfairness turn into feelings of resentfulness and there are moments when caregivers begin to question their own sanity. This is particularly so in relationships where love has begun to dim and the primary motivator for caregiving is a sense of duty or responsibility. For those who have walked this journey before, there is the burning question around one’s ability to travel down this pathway, one more time.

Being an outsider to a life that is long gone also provokes a feeling of sadness. As time progresses, there is said to emerge an “all-consuming darkness” (Isabella) of “a sadness that is overwhelming” (expression used by multiple voices). There is a
compounding sense of loss and grieving which, for some, begins to emerge at the point of being confronted with the stark reality embodied in diagnosis. For others, it is being confronted with moments of total helplessness in the journey through time: as day becomes week and week becomes month and month becomes year, after year, after year. It is witnessing frustration and confusion, and wondering and worrying if a loved one is in pain, as a repetitive scenario is played out over and over and over again.

5.3.2.3 – That which is hard

An added layer of complexity enters the mix of that which is bad, when all emotion is stripped away and life is simply described as hard. Hard times are when the care receiver becomes depressed and suspicious and paranoia sets in. “Life goes into ‘on-hold’ mode, while also oscillating with the speed of a roller coaster when everything begins to happen all at once” (Emilia). Lack of communication is hard: no conversation and no discussion. Hard also embodies a sense of losing ability to cope in the midst of trying to juggle multiple roles. Hard is the sense of feeling “shut off and shut out” (Aliena) as memory fades and one so loved no longer recognises spouse, partner, or child; and it is from a position of being in this hard space that Yori states, “One simply learns to accept.”

Communication on an organisational scale is what some caregivers find hard, whether this be trying to negotiate the multiplicity of community services, or breaking through the barriers that seem to block access to specialised medical and allied health structures or hospital and formal nursing care facilities. Trying to communicate and co-ordinate how to work together can be so hard when phone calls are not returned, emails are not responded to, and appointments are constantly rescheduled. More than frustrating, this lack of communication is said to become so hard to deal with while trying to juggle escalating needs of a loved one who cannot be left unattended: even for the duration of trying to make a phone call.

Hard is also defined as being on one’s own: totally alone and having no support from family or friend. There are those outside the intimate space occupied by caregiver and care receiver, who simply do not like dealing with unpleasantness. Others are in denial and some just laugh off and excuse obsessive and childish behaviours as being “funny” or “eccentric”. Feelings of abandonment become all consuming. There are
also those caregivers who have no family upon whom to call. For these, the sense of social isolation in the midst of a bustling metropolis becomes overwhelmingly hard.

Participants speak of a sense of displacement for their loved one and suggest that, in some kind of way, it puts them in a position of confronting their own mortality: and this they find to be extremely hard (Aemelia, Alice, Isabella, and Richard). Also found to be hard and confronting is facing the fact that, someday, they too could be in the same position: and this brings forth a sense of fear at the “horribleness” of being in these dark places (both physically and metaphorically) as well as bringing an escalated sense of helplessness. Feelings of helplessness are also referred to with reference to a lack of ability to protect a loved one from his/her own fears: a sense of what Aliena refers to as “unableness” in the knowing that this person who holds a special place in one’s heart and history is suffering; and that one is powerless to make it better.

5.3.3 – The Ugly

What is ugly all about? According to The pocket Macquarie dictionary (Bernard, 1989), “ugly” has to do with that which is nasty or displeasing; troublesome or threatening; unpleasant or dangerously rough; ill-natured, quarrelsome or vicious. For those who care from a place of unconditional positive regard, the notion of “ugly” has a depth of meaning that is all encompassing and cuts to the very soul of one’s Being.

5.3.3.1 – Incontinence

When first reflecting on the “ugliness” of Alzheimer’s, it seems only logical to consider that it does not get much worse than dealing with double incontinence. This is acknowledged by some as being “as ugly as it gets”. However, while the ugliness of incontinence is acknowledged, for several participants it is deemed merely to be part of the condition and is dealt with as a matter of course. The projected sentiment is encapsulated in the attitude expressed by Nerissa, “One can choose to see the ugly or one can choose to make the most of reality.”

Incontinence is dealt with in a diversity of ways. There is simple acknowledgment with the loved one, “We’ve got a mess here and we’ve got to clean it up” (Yori). There is also the “gagging in the fight to change the nappy while also just
dealing with it” (Elizabeth). What can be upsetting to the caregiver is when there is a sense of embarrassment for the loved one who might try to deal with soiled nappies and pads themselves by hiding them in drawers and cupboards. This requires the caregiver to be aware of the pattern of behaviour and to be on the lookout: checking regular hiding spots before they get “smelly”.

In naming that incontinence is “not too bad” and in accepting that it is part of the condition, several participants express that the best way to deal with incontinence is simply to acknowledge and accept. As Alex, Elizabeth, Emily, and Yori suggest, “Just deal with it.” Such is the case for those caregivers who draw on their professional background and “simply go into nursing mode”, while also owning that there are times when they are not very compassionate nurses. These ladies are also very aware that dealing with a situation from the subjective perspective of a family construct is very different from having objective capacity to manage in the context of a workplace (Alice and Angelica).

On the other hand, there are those for whom the ugliness of incontinence is overwhelming: resulting in caregivers’ becoming frustrated and annoyed and yelling at the loved one in relation to the mess that is made. Then, following this outburst, there are feelings of self-disgust and remorse that they could react in such a way with one so loved, so helpless, and so dependent. As explained by Vince:

There is also the ugly side and that has to be incontinence: accepting incontinence as a normal part of daily living. It is the undignified part of reality and the first is the worst. When I am tired, I can react as if my darling wife is a naughty child. I become frustrated and annoyed and I yell at her.

There is blame and condemnation with the mess she makes with the incontinence and then I become disgusted with my own reactive behaviours and overwhelmed with guilt and feelings of inner turmoil that I am failing to love, while rationally knowing that I am doing my best. I pray for patience and I have come to know my own humanness: my strengths and my weaknesses.

5.3.3.2 – Lifestyle

The most frequently named conditions of ugliness are lifestyle related and these
positions are termed as isolation, the ever increasing dependency of the care receiver, and the stereotypical attitude of the general public and those once thought to be friends: an attitude of projected stigma expressed in rejection.

So often these social constructs are recognised as going “hand-in-hand” and “one with the other”. They also seem to happen unconsciously and slowly: bit by bit and over many years, as a process of gradual withdrawal and increasing overwhelm. While circumstances might vary, the outcome is the same as participants share their feelings on how they have become “socially isolated” from the perspective of a social construct, while also becoming a “social isolate” from a perspective of relational connection.

5.3.3.3 – Loss of freedom

Naming loss of freedom as the ugliest part of the Alzheimer’s caregiving journey, it is suggested by multiple voices that while being a really big thing in all sorts of ways, the biggest impact is feeling that you have lost that most basic right to freedom of speech. This is said to relate to the fact that you just can’t mention it to anyone and you just don’t talk about it. The overarching perception is that nobody wants to listen: not even those holding roles that engender an expectation of their providing professional support.

Participants express feeling as if they are prisoners in their own homes and many have made reference to the cathartic experience of being able to share their story with me. They also project perceptions of knowing that I am listening and I am interested; that I am not shocked by the story of their lived reality; that I am not judging them; and that I come to this dialogic interchange as an insider. It seems that having traversed my own caregiving journey, I am accepted and seen to be non-judgemental and trustworthy.

5.3.3.4 – Isolation

From a perspective that is all encompassing of both isolation and loss of freedom, caregivers repeatedly express feeling like an outcast. Friends are lost, or as is suggested by multiple voices, “at least they were thought to be friends”. Participants express

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44 Discussed further in Chapter Six, *Weaving the Narrative Landscape: Impact of Caregiving Reframed*. 

The collective reality from onset to end of life and beyond. 

Judith R Boyland
feeling so lonely and so desperately in need of someone to talk to and it was Margaret’s comment to Vince, reflecting the biblical notion of outcast, that inspired the title of his book, *I wish I were a leper: The diary of one couple’s struggle with fear, faith and Alzheimer’s* (O’Rourke, 2008).

In their stories, participants share how they have become wary of people and even of going to familiar places and doing familiar things. They describe the need for learning to deal with abandonment, while also learning to deal with the outward expressions and behaviours of people who treat the Alzheimer’s patient as if s/he is invisible, intellectually impaired, or hard of hearing. Neither is spared in these scenarios as both caregiver and care receiver are treated with equal contempt. In a poor reflection of the professional sector, similar behaviours of dismissal are reported to have been demonstrated: indicating lack of ethical adherence to duty of care and bringing into question the Hippocratic ethic embodied in the statement, “Do no harm”.

5.3.3.5 – Wandering

Wandering is also said to embrace elements of ugliness. All who have experience with the wanderer speak of the need to watch so carefully: not only so they do not get away but also to minimise the risk of their falling: as usually, by the time they start to wander, they are often quite unsteady and prone to falls. Protection becomes all about coming to know patterns in the timing and being able to pick up on the cues.

Often it will be found that agitation and wandering will both set in at sundown. This adds an additional layer of complexity to behaviour management and it is suggested by those experienced in dealing with the escapee, that this is the time when the wanderers need to be watched and where vigilance and distraction need to be high.

5.3.3.6 – Mood and personality changes

Mood and personality changes are also named as framing an ugly side of Alzheimer’s and quite often it is aggression, sexual impropriety, obsessive and/or destructive behaviours, verbal abuse, and physical violence that are identified as the “breaking point”. Whereupon, the caregiver feels that s/he is going insane or being tortured.
It is also found that once aggression and/or sexually inappropriate behaviours set in, any respite that may have been helpful in the caregiving support regime is withdrawn. Caregivers find that they are alone and left totally to their own devices in trying to manage the presenting problems of lived reality.

5.3.3.7 – Guilt

Guilt is also framed as a most confronting aspect amid all that is ugly; for in “guilting”, the caregiver comes face-to-face with the very essence of Self. There is guilt associated with becoming frustrated and cranky or tired and stressed. Guilt accompanies admission of a loved one to formal nursing care and even though, in the rational mind, the caregiver knows that s/he can no longer manage abusive and violent behaviours, wandering and paranoid behaviours, or the physical lifting as mobility declines, that overwhelming sense of guilt pervades the unconscious mind.

Once a loved one is admitted to formal care, there is guilting at not being able to spend more time with them and this is particularly significant for those whose loved one is in a nursing facility that lacks an ethos of caritas and leaves much to be desired. Then, as the end-times draw nigh, guilting is framed in a sense that one could have, and should have, done more.

5.4 Breadcrumbs in the Forest: Survival and Support

Support is found in many places and often in unexpected places. On the reverse side, so often support is not found where one might hope to find it. In weaving the threads that profile a focus on “survival and support”, a variety of aspects is considered, including informal support, formal support, professional support, and self-care.\footnote{The sub-theme of self-care is addressed in 6.4.2.2 under the overarching theme of 6.4, Wisdom Won of Pain: The Voice of Experience.}

5.4.1 – Informal support

Some participants share that support from adult children is “fantastic”. Other adult children find it just “too hard” to deal with their parent’s/grandparent’s incapacity to function. Children are said to provide support in many ways including casual conversation, a sounding board to share feelings and frustrations, or actively
participating in the care process. Giving the caregiving parent/step-parent a regular day’s respite, they sit with the care receiving parent/step-parent or take them out for the day while the primary caregiver has time to rest, socialise, shop, take in a movie, or enjoy time to engage in some form of more structured social or recreational activity.

Yori’s and Adam’s son sent his mother for a month’s holiday to Italy, flying business class, while he moved in to care for his father. Rosaline, Angelica’s daughter, “took over” one day each week so that her mother could escape. There is the adult child and her spouse (Emily and Iach) who, while “hovering in the background” without obvious intrusion on their parents’ privacy, see themselves as “the shadows and the last line of defence” for a 90-year-old father/father-in-law who so “lovingly and efficiently” cares for his wife. Always having been “free roammers”, these two precious people still reside alone in the family home while “the shadows” reside just five minutes away.

While step-children of the caregiver are often reported as being in denial of their parent’s condition or just do not want to know, there are also those who step up to help and support. Such was the situation with Antony’s step-daughter who willingly and lovingly supported Antony with the care of his Eva, her mother. There is also the daughter who sees herself as “the glue that connects with both the parents and the siblings”. As Ephesia sits on the sideline and observes her father’s denial, she says, “All us kids can see and are concerned and we need to note that the conversation needs to be had, sooner rather than later.”

In the partnerships of Rousillon and Lafe and Elizabeth and Robert, each daughter lovingly acknowledges that without the emotional and physical support of her husband, she would have long passed the point where she could physically care for her parent. The emotional and physical support offered by both husbands is greatly appreciated. Then there is the partnership of Alice and Alex. With some formal care respite, this mother and son co-caregiving structure has enabled both caregivers to work in shifts and take rest breaks across a 24-hour period, seven days a week. Alice also speaks lovingly of Alex’ friends, who “muck-in” and help to keep Helen occupied when she is “looking for action”. Co-residing extended family have also gradually come to share the care; and it is noted by Alice that as they give more “hands-on” support, the extended family has grown to be more empathic towards people who are broken.
Family becomes the support behind the one who takes on the role of primary caregiver and caregiving becomes a family affair. Siblings rally, “sticking like glue” with support that can be counted on at any time: day or night (Angelica and Vince). Siblings co-care for a parent (Richard and Elizabeth) and siblings support each other from a distance, providing “time out” by way of a periodic respite and taking responsibility for a care receiving sibling or parent while the caregiver has some freedom (Eleanor and Hal). Other siblings “fly in” on a periodic basis; bringing an ear, a shoulder, and an extra pair of hands for emotional and physical support (Emma and her siblings in support for Rebecca).

There are those who have the support of wonderful friends and neighbours: people who can be relied on for both emotional support and hands-on support when needed (Antony, Hal, Lavinia, and Rousillon and Lafe). Support is also found from friends of the care receiver: described as “amazing people who, although a little rough around the edges, are also good and kind people” (Iris speaking of the family of Adriana’s “boyfriend”).

However, for every child, sibling, spouse, friend, or neighbour who is always there to help and support, there are those who simply do not want to know, are in denial, or are too fearful to step up: leaving the primary caregiver feeling alone and isolated. Also, there are those primary caregivers who do not have extended family and they are the ones who, so intensely, know the pain and loneliness of social isolation, loss of freedom, and overwhelming tiredness.

5.4.2 – Formal support

In considering formal support structures, it is sad to say that some participants have found the behaviours of some staff of Alzheimer’s Australia to be “quite demeaning”. On the other hand, there are those participants who speak highly of the helpfulness of staff and the organisational support that is provided, especially by Carers Queensland. While, collectively, services and service providers are judged to range from “totally incompetent” to “amazing”, there are multiple expressions of appreciation that refer, with a sense of astonishment, to the fact that a complete stranger is so compassionate and kind to both care receiver and caregiver.
Respite is highly valued by caregivers: in home respite, day and/or overnight respite at care centres, and organised outings, activities, and socialisation opportunities. In the early stages of transition, participants have been able to access daily respite, thus enabling them to continue working for quite some time before it became necessary for them to give up their jobs so as to provide the full-time care that became necessary as transitions advanced. Participants also speak of respite services as giving them “breathing space” to attend to business, do the shopping, socialise a little, pick children up from school, sleep, or simply enjoy the luxury of undisturbed time to take a bath, to linger under a warm shower so as to wash the stress away, or to shampoo their hair: all without interruption.

As much as respite services are helpful, there are reported gaps in efficiency and effectiveness. Inconsistencies are of particular concern: for example, different workers “turning up”, which results in agitation within the care receiver who does not cope with change. There are instances where the respite worker simply does not turn up; leaving the caregiver with a situation of needing to change scheduled medical or business appointments at the last minute. Inappropriate “matches” between a respite worker and the care receiver are also noted: for example, a young woman to sit with an aggressive older and stronger male patient or the patient who is beginning to behave in sexually inappropriate ways. There are respite workers who neither have fluent English nor speak the language of origin of the care receiver for whom English is a second language, no longer used or understood. There is the respite worker who sits and watches television and eats the lunch that was prepared for the care receiver while all the while the care receiver has been left unattended. On a similar vein there is the respite worker who locked the care receiver under the house, while she sat under a tree to bask in the sunshine, while reading a book.

In addition to respite services, participants value and speak with high regard for education programs offered by Alzheimer’s Australia, community centres, or church-based organisations. Being able to access free counselling sessions, funded through Carers Queensland, was also found to be helpful for caregivers as they were dealing with a diversity of stressors associated with transitioning through the stages of progressive degeneration.
5.4.3 – Professional support

Starting at the very beginning of the caregiving journey, participants acknowledge the benefits of having a diagnosis. This milestone is said to provide understanding of what is happening for their loved one and what it is that is giving rise to observable changes in behaviour. Having a diagnosis is also said to give insight into what that means for the times ahead and provides family with opportunity to work through a learning process in relation to what is happening. Families also have time to plan with their loved one while s/he still has capacity to participate in discussion about his/her future: particularly in relation to such things as Enduring Power of Attorney, living wills, and end-of life plans.

Being able to access information is reported to have been helpful, making it easier to cope and to appreciate that one’s loved one is not just getting old, “moody”, and dependent. Education programs and workshops such as Living with Memory Loss (Alzheimer’s Australia) have been informative, and while carer support groups have been found to be helpful for partners and spouses, they are reported to offer nothing by way of relevant information when the primary caregiver is neither a spouse nor partner. Nor are they considered to offer anything by way of social networking: leaving a non-spouse feeling “so totally out of it” (Elizabeth).

In addition, it is reported that as helpful as the content might be, support groups are considered to be of little practical help if a caregiver cannot access respite for a loved one who is beyond being able to accompany his/her caregiver to information sessions or who cannot be relied upon to behave appropriately during course sessions. An additional point regarding service provision is that there seems to be nothing for the patient who, while in the early stages of transition, would benefit from education programs and programs that would stimulate cognitive activity and creativity while helping to sustain function and social interaction (Eleanor).

There are varied feelings about support received from family doctors, general practitioners, and specialist geriatricians. Some are said to be “just amazing” and “always truthful”. Others are said to just prescribe medications that keep the patient “drugged up, drugged out, and zombie’d to the hilt”; while telling patient and family “absolutely nothing”.

For Isabella, volunteering at a local nursing home and learning how to support those in care has been extremely helpful in building a knowledge base related to caregiving. So too has undertaking formal studies in dementia care. Isabella states that what she has learned has been “informative and a fantastic support” in understanding the condition and in learning strategies to make life easier for both herself as caregiver and her father, the care receiver.

5.5 Formal Caregiving: The Last Bastion of Support

The day has arrived when the primary caregiver needs to surrender care of his/her loved one to the formal care of others. Feelings of guilt, sadness, and relief are said to vie for supremacy. There is a sense of joy as a spouse who had transitioned to “minder” or “mother” can now reverse that position and once again become lover and companion. Sons and daughters who had become parent to the parent can return to being son and daughter. Those whose professional career role of nurse had taken precedence over a simple and loving family relationship can now leave the professional care to others as they reclaim the role of spouse or daughter. There are also expressed feelings of freedom and control that accompany return to a life that has been placed on hold: life totally consumed with the responsibilities and tasks of caregiving.

5.5.1 – Decision

The decision to place a loved one into the hands of formal caregivers is a decision not taken lightly and one that is the absolute last resort. It is an admission that informal care can no longer be sustained and for some, this is seen as failure. Participants speak of reaching the point where one simply cannot carry the burden of care any longer without full-time professional and formalised support.

Timing for entry to formal care accommodation is often commensurate with escalated episodes of violence that involve ranting, raving, stomping, yelling, swearing, cursing, hitting, destruction, flailing, and abusive language. Episodes are reported to be so extreme, so scary, and so distressing that they become as “acts of torture” towards a

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46 For example, short based Massive Open Online Courses (MOOC), “Understanding Dementia” and “Preventing Dementia”, and AQF course, “Bachelor of Dementia Care” offered through The Wicking Dementia Research and Education Centre of the University of Tasmania, contact details listed in Appendix E, Information and Local Support Services and Providers.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland

caregiver who is approaching endurance saturation. Such behaviours warrant particular consideration when vicarious impact on co-residing children becomes the highest priority and the caregiver has no other choice but to say, “Enough! This behaviour is no longer acceptable” (Elizabeth).

In several instances, this “point of no-return” coincides with a period of hospitalisation. The decision to admit one’s loved one into the formal care of a nursing home comes as recommendation from doctors or allied health personnel, such as a social worker or a psychologist. This recommendation for admission to formal care is seen by caregivers to be “a real blessing” and “a great escape”.

What is significant about a professional recommendation is that it has relieved the caregiver of the guilt it is believed would have been felt had it been they, the caregivers, who had needed to initiate the making of this momentous decision. As Angelica explains, “I did never have the guts to make the call and the fact that it was made for me was just perfect”. However, whoever initiates the call for need of institutional care, the ultimate decision to act is for the caregiver and although the guilt factor is reduced at a rational level, it still hovers ominously in one’s emotions and permeates one’s whole being till the rational mind takes over from the relational heart.

There is also the circumstance where the care receiver initiates admission. Ratcliffe pre-empted his own entry into formal care when, during an 18-month period of rapid decline, he said to Audrey, “I think I should be in an old people’s home.” Audrey describes this incident as being “a sad day for both of us” and she shares that it was only a matter of months, till rapid decline in function, accompanied by rapid increase in deterioration, necessitated Ratcliffe’s admission to formal care. As Audrey recalls, “There was so much red tape and paper work to be completed”: a scenario reported to be “an anxious and sad time” by all who have prepared for admission of their loved one to formal care.

Frailty, tiredness, and stress become too burdensome for the caregiver who reaches a point of being no longer able to carry the physical and emotional burden of informal care. The option to seek admission to a formal care facility is the only viable choice. It is the next phase in the trajectory of care. No guilt and no regret.
5.5.2 – Admission

Whatever circumstances surround admission to a nursing home and whether admission is to a “low care”, “high care”, or “secure care” unit, transitions are universally claimed to be traumatising. As discussed above, caregivers experience feelings of guilt even though their rational minds acknowledge that there is no other option for the care of their loved one whose life and living has become totally disempowered and dysfunctional. Nor is there any other option for maintaining their own safety, guaranteeing safety for their children, or for sustaining their own mental, emotional, and physical well-being.

Preference in choice of nursing home, where choice is an option, is said to be for one that projects a warm and caring ethos, is competitively priced, is open and airy, and has competent staff who know how to care for patients who have Alzheimer’s disease and dementia. Preferably, staff are experienced in geriatric care, have a history of working with family, speak and understand English, and speak the patient’s first language if that is not English. There is also expressed preference for a facility that provides palliative care, so as to maintain continuity of care as one’s loved one approaches the final transition through death.

For some participants whose loved one has transferred to a formal nursing care facility, the need has included access to a high care and/or secure care unit where there is specialised care for residents who are demonstrating violent and aggressive behaviours, wandering behaviours, and/or destructive obsessive behaviours. There is also need for specialised care for those whose physical condition has degenerated to the point where behaviours of concern have been transitioned and are no longer demonstrated: for example, the wanderer who no longer has the mobility to wander has no need for security to prevent escape. As loved ones transition to the final stages when muscle collapse and vital organ failure have begun to set in, they, also, are beyond the need for secure care.

It is at this stage of transitioning that the need for a high level of nursing care escalates. The priority in care need is to keep the care receiver safe, comfortable, and pain free. Palliative care is what is needed. Yet, there are so many respite and hospice centres, formal care residences, and hospitals that do not have the facility of palliative
care for this very special loved one, as s/he transitions through this final stage. The inability to access palliative care for a loved one, serves to compound the grief of loss.

5.5.3 – General experience

Participants share stories of nursing homes where they experienced “a real family feeling” and “a real support network for one another”. It is universally stated that while there is a general lack of staff, caregivers and family all look out for other residents as well as their own loved one. There is connection as they assist where assistance is needed or simply talk and laugh with residents: reading to them, feeding them, and even shedding a tear with them. With a touch of humour in her voice, Aliena speaks of regularly being invited to put on her uniform when she arrived to care for Oberon as, while he was sleeping, it was her practice to talk with other residents and attend to their needs. Others speak of staff as being caring, dedicated and brilliant: going above and beyond in their care and explaining everything before they do anything, thus allaying fear and anxiety and avoiding situations that could lead to agitation and aggression.

There are nursing homes where regular care meetings with family are the norm, where a caregiver’s advocacy on behalf of his/her loved one is acknowledged and addressed, and where family histories are collected so as to enable staff to better understand and appreciate the times and places to which residents retreat in their moments of regression into the past. These are the facilities where caregivers know empowerment.

There are also complexes where there are assisted-living independent units, low care support access units, and a range of care facility from low care through to high care and secure care nursing. These are facilities where caregivers feel comfort in knowing that their loved one is safe. Having Lena in such a complex is considered by Aemiel as being “a real gift”. For not only is the standard of care considered to be excellent, the staff are also said to bring a deep kindness and compassion to their interactions with patients. The environment is also said to be “harmonious and well set up for stimulation of the thirsty brain”. An added bonus is that residents can move through stages of care commensurate with their transitions; and for caregivers, this infuses a sense of security. Residents retain friendships across the various complexes, visiting each other at their leisure while their mobility and spatial awareness enable them to do so.
Caregivers whose loved one is cared for in a place where loving kindness is demonstrated towards both resident and family express a deep sense of gratitude. However, even for those who are happy with the care that their loved one is receiving and for those who express sentiment in terms of the facility being very “homely” and the staff being “wonderful people who are so caring and quite amazing”, there are said to be moments of “melt down” as caregivers experience random bouts of guilt, abandonment, sadness, and loneliness.

As loved ones become more withdrawn, there are expressed feelings of loss for the person “who is just not there anymore”. There are also expressed feelings of regret that more opportunity was not taken to tell loved ones just how much they are loved, while channels of communication were still open. The simple and sad sentiment, expressed so aptly by Richard, is that “life just got in the way and the years just slipped by”.

When the rational mind has won the battle, there is no control over vagal systemic and somatic reactions. As Lavinia shares, 12 months after Oswald’s death she still experiences an olfactory sensation related to the smell of “bulk food” when she even thinks of the nursing home and she adds that there are times when her whole memory is just the smell of commercially prepared food. Other caregivers find that as they sit with their loved ones and simply take in the circumstances that surround them, they are confronted with a sense of their own mortality. They are also confronted with the fact that, maybe, Alzheimer’s has already taken its degenerative hold on themselves or their children and that someday, in the not too distant future, they could be care receiver in this same situation – a realisation that induces a sense of overwhelming fear, regret, and dread. Caregivers speak of the helplessness they feel in these moments and express that it is their hope, should Alzheimer’s be their fate, that there will be someone who will step up to be their primary informal caregiver at home: till the time comes for them to need residency in a formal care facility.

5.5.4 – Care found to be wanting

While even in the best of nursing homes there are suggestions of “little problems” arising, there are also stories relating to nursing home care that leaves much to be desired. As participants speak of the “horrible things” that they have experienced, there is the story of a mother’s being punished when her daughter made a complaint or
questioned a procedure. There were times when what were supposed to be “planning and care meetings”, are described by the caregiver as “attack meetings”. There are situations where there are faeces on the rails of the bed and of beds smelling of urine and faeces: and when a family member asks if they can clean the mess, change the bed, and make their loved one comfortable, it becomes a matter of “shoot, execute, and crucify the messenger”.

There is the incident when a daughter was gently stroking and massaging her mother’s hand with soothing hand cream and she was accused of “elder violence”. There are also reports of yelling and screaming from other residents: situations that cause concern for family to the point where they are fearful for the safety of their loved one in residence as well as being fearful of the impact these behaviours could have on children visiting with a loved one.

There is a general sense that nursing homes are greatly understaffed with the staff to patient ratio being perceived as a “massive issue” when there are two staff members to 20 patients in a high-care, secure unit: a situation expressed as being ineffective in the ability to handle patient need. Additional factors of concern are staff perceived as being unkind, untrained in aged and dementia care, and fearful of residents with dementia. The result is that patients become frustrated and fearful resulting in further confusion, distress, and anxiety. The quiet ones become verbally abusive and the timid ones become more withdrawn. Caregivers also become frustrated, fearful, distressed, and anxious. They express feeling that they have no place to turn for support and advocacy.

There are also expressed concerns that in many cases care staff can neither speak nor understand English and lack plain and simple communication skills in relating with patient and family. It is also suggested that if a nursing home chooses to admit residents whose first language is not English, there needs to be a staff member who does speak and understand the languages spoken by patients who are admitted to residency. A further suggestion is that it needs to be understood by management, that as residents regress, many who have spoken fluent English for many years will revert to speaking the language of their cultural origin – the language of their childhood. This inability to communicate is also reported as an additional source of escalating frustration, anxiety, and agitation as loved ones try to make their needs and their fears known to strangers.
A generalised conception is that there are few “real nurses” in nursing homes and that most staff members are “just paid carers”. It is an expressed concern that, in so many cases, nursing homes are really just boarding houses and if those in care need even the simplest medical attention, a doctor is called in or they are sent out to a hospital which, as described by Richard, is “another strange and unfamiliar environment with lots of strange noises and smells that just escalate confusion, anxiety, agitation, and aggression”. Reflecting the disenfranchised feelings that many caregivers experience, Nerissa speaks of her reality as she shares, “We all go into there, grieving; and instead of being supported in my grief, I was treated as an enemy.”

5.5.5 – Last days

The last days of that very special person who held a most significant place in the heart and the history of kin and colleague and for whom participants were primary caregiver, were all spent in nursing care facilities. Reflections on a loved one’s last days reveal feelings of guilt related to the fact that one could not be with their loved one for more hours in each day or that one so loved was even in a formal nursing care facility and not at home. Caregivers sat with their loved one for days on end, leaving their side only to attend to personal business.

Journeying through the final transition with their loved one was described by some as being “just awful” and “so terrible” and participants explain that they hated leaving their loved ones, even for a few hours. In other situations, where loved ones were assisted through their final transition with the compassion and loving kindness that defines palliative care, participants express feeling a sense of relief for their loved one’s release from pain. For the Self, the realisation that death was immanent filled them with a sense of loss so intense that the pain of living without one so loved was said to be indescribable.

5.5.5.1 – Waiting

Some caregivers sat by the bedside of their loved one day and night for days on end. For those traversing a longer transition, time away from their loved one was spent in activities that kept them close in spirit: for example, Antony tended Eva’s garden at home listening to her distant voice issuing direction: words which echoed in his mind as
clearly and as lucidly as if his precious Eva was but a pace away. Time away from the loved one is also spent in reminiscing: looking at old photos, going beyond the sad, and reliving happy times while shedding a quiet and private tear. These are activities that engender feelings of “usefulness” and “closeness” and “quiet acceptance”.

There are stories of loved ones who, in their passing, recalled the names of family right up to the end and would ask for or call for a mother, father, son, or daughter: some who were living and some who had died many years before. There were those who, right to their last breath, were demonstrating a spark of cognitive awareness. There were little moments of a shared smile and soft and gentle laughter. There were moments when signs of a life within were clearly witnessed as “some weird and mystical sense of communication” (Vince), described by Aliena as being “more felt than witnessed with the senses”. There were those who had passed through stages of confusion, agitation, and violent ramblings, and were now settled into a calmness – giving further credence to the question as to whether there needs to be a stage in formal care where a resident comes out of secure care and enters a unit that is high care without the security that is needed for those who are wanderers and those who are violent or obsessively destructive. It is suggested that maybe this is what is deemed to be the beginning stage where palliative care needs to be a “must have” intervention available to all patients at all nursing homes, all hospice and respite centres, and all hospitals.

Participants share stories of how they sat with their loved ones, talking to them, holding them, and just knowing that all that made this loved one their Special Someone was in there, somewhere. There are shared expressions of being frightened, exhausted, and sad in just knowing that it was merely a matter of time. For others, it was obvious that in their final transition, their loved one was suffering and in pain: and those who loved them suffered with them, sharing in their pain.

Some participants made reference to the setting in of “the death rattle” as life drew to a close. Some referred to “the sweet smell of death” that lingered in the days and hours preceding this final transition that was awaiting their loved one. Those who traversed this transition with their loved one tell of how they held them, stroked them ever so gently, massaged their arms and their foreheads, brushed their hair, sang to them, prayed with them, read to them, or simply played their favourite music for them:
anything at all, as they tried to make it better and tried to ease the suffering. In easing
the suffering for this beloved Other, there was also an easing of suffering for Self.

As participants journeyed with their loved ones through their last transition, they
recalled the loss of others who had gone before and there was a compounding of grief.
For some, there was also grief in realising that for so many years, life had simply
happened and there had been “no place for a living relationship with one who had always
been somewhat of a stranger and somewhat of a mystery” (Iris). There is an intense
sadness in seeing a father “so frail and so frightened: a man once so physically strong
and active” (Richard). There is also regret in the realisation that only in these last short
years or these last few months has one come to know and to love a parent who had
always seemed so distant, so unreachable, or so eccentric. Sitting in quiet reflection,
there is a feeling that if only this relationship could have been shared a long time ago,
maybe lives might have taken a different turn. For others, time simply ran out before
they got around to an intimacy that touched the depths of a veiled inner spirit: and as life
draws to a close, there is a determination to be protective of this loved one, who is so
very special. There is an intrinsic need to protect, right to the end.

5.5.5.2 – Passing

Some loved ones are reported to have been fully conscious and appeared glad to
see family; right to the end, as they drew their last breath. Some were in a state of semi-
consciousness for many days during which time family shared celebration of life, gave
their loved one permission to go, and prepared Self and Other for the final moment and
the last farewell: expressed as being a time so long and so lonely. Some had traversed
the full gamut of degeneration, their knees folding and their skeletal little bodies curling
into foetal position: their primary caregiver needing to make the final decision to
prolong death through intervention, or to allow this most special of persons to slip
quietly away in the knowing that this would be what their loved one would want. Some
were blessed with having the caritas of palliative care, while others simply died as they
lived, in distress and torment. Some transitioned through death as they slept.

While some were peaceful through this final transition, others were distressed:
and in their weakened physical state, there was fear. Aaron’s passing was filled with
pain and torment, expressed in agitation and escalated yelling, thrashing, and banging of
a fist on a pillow that had been placed so as to provide “a soft target” while protecting the frail and weakened body from injury. With the banging, there was calling for a parent long passed, “Daddy, Daddy, Daddy”. Or was it a voice in the subconscious? The voice of a child who had been tragically killed many years before, calling from beyond to this loved one, his “Daddy, Daddy, Daddy”, and inviting him to pass through to a life on the other side. The emptiness that filled Richard as he sat with his father was said to be all consuming. Sensing fear in a loved one brings forth an intense feeling of helplessness and sadness in the one who is caregiver, right to the end.

Speaking words of love and assurance, caregivers cradle their loved one and holding their hands so tightly yet so gently, they try to ease the emotional and the physical pain and they try to take away the fear and the torment. Most caregivers revealed having an awareness that this last transition for their loved one was in process. They knew that time was running out rapidly and that what time they did have to be together was going to be short. During these last moments, some loved ones are said to have deteriorated quickly. For others, there was simply a drifting away. Still for others, death came as if in answer to prayer. Their loved one appeared to be calm and at peace and as “hearts beat as one and as together [they] breathed as one, for somewhere between five seconds and eternity”, the last breath is taken and the loved one has journeyed through the last transition to whatever lies beyond. And with a kiss on the lips and closing of the eyes, it is, “Goodbye: for now”. (Jason, my son: as he cradled his grandfather, my father, in his arms; and sealed his closed eyes with a tear.)

5.5.5.3 – The business of dying

When the end comes, there is expression of reality that in their passing there is relief and release for a loved one who has suffered long. There is also a sense of relief and release for all who have witnessed the suffering and suffered with their Special Someone. Several participants worked through “end of life” plans prepared long before when loved ones, who have now passed through the final transition of death, were able to make their wishes known.

Lavinia tells of how “the business of death” was made easier in that Oswald had organised things financially and had procedures in place to action Power of Attorney, living will, and last will and testament. All participants who had end-of-life plans
explained that it made everything so much easier as family knew the wishes of their loved one and they followed them through. As for the Self of the caregiver, there is expressed a deep sense of “missing the love”. As Lavinia explains, there remains and there will always remain, “an absence of being Someone Special to a Special Someone” (term chosen as definition and referenced in 1.1, Introduction to Context).

Some speak of the beauty and peacefulness that shroud their loved one in death. Inner beauty shines through in a final defeat of the disease that had robbed them of their identity, their life, and their external beauty. For the person who is caregiver, there is expressed such a deep sense of loss: marked forever by the feeling that part of Self has gone with Other. And it has.

5.6 Conclusion

Chapter Five has profiled a collective reconceptualisation of the impact of caring for a loved one who has Alzheimer’s disease. Using the process of bricolage, threads extracted from individual stories have been woven across a hybrid methodological warp. What has emerged in these findings is the beginning of a narrative in which multiple voices speak as one in an outpouring of reality as reconceptualised in dialogic interchange. Reflections were reported as subjective descriptions and interpretations of how events of yesterday were “re-visioned” in now time and the narrative truth was encapsulated in a constructed account of lived experience, as knowing was translated into telling.

Chapter Six profiles a second tier of findings, as the re-visioned portrait is reframed in the light of conscious reflection.

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CHAPTER SIX – FINDINGS: PART TWO

Weaving the Narrative Landscape:
Impact of Caregiving Reframed

6.1 Introduction to Impact of Caregiving Reframed

Chapter Five profiled a reconceptualisation of the impact of caring for a loved one who has Alzheimer’s disease. Chapter Six presents a reframing of conceptions. After bringing the lived experience of “yesterday” into the reconceptualised temporal domain of “now”, it is as if participant storytellers stop, draw breath, and step back.

From this place, they re-vision, re-structure, and re-develop what they have spatially structured in a multivoiced, dialogical process. As explained by Hermans and Dimaggio (2004/2016), each voice functions as a “partly independent agency that generates specific memories, thoughts, and stories” (p. 2). These “self-narratives”47 are repositioned in the reframing, and emerge as a profile of the dominant character identified as I, the storyteller. In the stillness of that space, there seems to be a letting go and a catharsis: as expressed in the words of Antony:

[Emilia] was right when she said that I needed to talk to you. I so needed to talk to you. I have told you things today that I have never told another human being and I have revealed parts of myself that no person other than my beautiful [Eva] has ever seen. All that was going around in my head now looks different. It is as if I am seeing this whole thing with new eyes. And it feels so good.

In that reflexive and re-visioned space, there seems to be discernment that emerges in an epiphanic moment of awakening. A trajectory of care that collectively

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47 As structured from multivoiced positions in the dialogical interchange under the influence of what Hermans and Dimaggio (2004/2016) describe as “the polyphony of the mind” (p. 2).
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: spans 201 years of lived experience is collapsed into a synthesis and reframed in a deeper interpretation of what has been voiced in the dialogic interchange of reconceptualisation.

6.2 – The Process of Reframing

As participants reflect on what has surfaced for them in the process of reconceptualising their caregiving journey, the knowledge that emerges as a collective reframing is disseminated in three distinct themes. These themes move from a place of deep introspection, through an emergence into an external space that reaches beyond Self, to a place where the caregiver is able to “sprout wings and fly” (Angelica).

**THE PROCESS OF REFRAMING**

**A MAZE OF METAPHOR AND A SIMILE OR TWO** - Metaphor and simile portray the essence of impact as it is experienced in the depths of a personal, inside space: a place of deep introspective reflection, revision, and restructure.

**WISDOM WON OF PAIN: THE VOICE OF EXPERIENCE** - There is an emergence into a space that reaches beyond Self as participants share wisdom won through the pain of lived experience and as they disseminate knowledge that is the fruit of lived experience.

**FROM HERE TO INFINITY: IT'S OK TO DREAM** - Time comes when the caregiver can see beyond the world that is to a world where there is freedom to dream of life beyond the trajectory of care.

*Figure 10 - The process of reframing*: Lived experience is repositioned in words that portray the essence of impact as it is felt in the depths of a personal, inside space. From this space, participants look within and reflect, before reaching out in sharing the knowledge they have accrued across the trajectory of care. Finally, the caregiver is free to see beyond the world that is and contemplate a pathway to the future (terminology developed by Murray, 2005.2016).

In the first theme, *A Maze of Metaphor and a Simile or Two*, the impact of caregiving is described in symbolic abstraction, phrased in metaphor and simile. Words portray the abstracted essence of impact as it is felt in the depths of a personal, inner space. The second theme, *Wisdom Won of Pain: The Voice of Experience*, profiles movement beyond the intra-personal as participants reach out to others, disseminating

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48 Lived experience of primary caregiver and caregiving teams – does not include experience of primary support persons or experience of those touched by vicarious connection.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland

6.3 A Maze of Metaphor and a Simile or Two

From an expressive perspective, it is noted that as each participant reflects on the reconceptualisation of yesterday’s perceptions, years of lived experience are reframed into words of descriptive symbolism. Diversity of abstraction gives rise to the creation of a living maze as multiple statements connect, intertwine, and create new pathways of conception. Reframing brings forth expressions of symbolic abstraction that portray a long, arduous, and transforming journey.

Viewing metaphor through the context of symbol, Wagoner (2013) suggests that humans are able to distance the self from the here-and-now environment while creating contemplative knowledge about the lived experience; thus extending possibility for action. Metaphor and simile are linguistic elements chosen by participants to describe the spirit embodied in a reframing of the impact of caregiving as experienced from a multiplicity of I positions. They are expression of the ultimate “epiphantic” or “aha” moment of acknowledgement and acceptance, where I meets me – the empirical self as positioned by James (1890) – in that moment of absolute conscious awareness where I not only “know” what I know, I also “feel” what I know. It is the moment where the “outside” and the “inside” connect in unity.

Experience verbalised in abstraction implies a constant seeking, with the only predictive ending being the darkness of unknowing that pervades the trajectory of care. While each voice is that of either a caregiving story-teller or another who is impacted vicariously by the caregiving journey, it is the collective multivoicedness of participants that gives a profile of enlightenment to a “maze” of degenerative disempowerment. Comments that are woven into this theme speak of an introspective sense of being lost. They also reference difficulties that are encountered as participants try to negotiate their way through the symbolic darkness that shrouds unknown territory. Dilemma and confrontation are constantly present and just as the caregiver overcomes issues that present along one pathway, another crossroad is reached and new challenges emerge.

There is transition in the degenerative development of the disease and there is need to
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.

Judith R Boyland

find new ways of caring and of coping. What is shared by participants describes the maze that defines their journey: complex, dark, and surreal.

In the process of reframing, attention is focused through the unsaid aspects of the target source and portrays feeling and intuition from the internal position of I, the caregiver. As participants encapsulate the essence of lived experience in symbolic terms, the final threads from the data set begin to be tied off. Herein is created what Badenoch (2011) referred to as “interpersonal oneness” (previously discussed in 1.7, The Dialogic Interchange). It is in this state of unity that the brain of one interacts, resonates, and connects with the brain of another: participant with researcher, researcher with participant, and participant with participant. Through the researcher, the story of the impact of caregiving is also shared with any other person who chooses to engage with the collective narrative. From symbolic translation of all that has been reconceptualised, the woven landscape of the impact of caregiving now moves beyond the introspective personal self of the caregiver. This new space embodies a spirit of interpersonal connectedness with others and projects an image of evolving transformation.

In concert with thoughts expressed by Lakoff and Johnson (1980/2003), the language of metaphor used in the process of reframing promotes creation of new meaning and new reality within the lives of caregivers. A similar connection might also be applied to the use of simile. As referenced in Chapter Three (3.5, Data Collection), Fuks et al. (2011) also speak of the power of experiential and conceptual metaphor in helping to mediate communication. What is provided is openness to a rich vocabulary for describing what may be difficult to verbalise while also transcending the barriers between the storyteller and those who hear the story that is told. Christensen and Wagoner’s (2015) reference to the use of metaphor in narrative development presents an ideal platform from which to project that very process of telling what is known on the inside or of externalising the internal experience. With reference to the use of metaphor in telling the story of what is known, Christensen and Wagoner posit the notion that an “abstract target” is conceptualised in terms of a “more physically graspable source domain” (p. 516) and through the bodily experience of the source domain (caregiving), aspects of the target domain (impact) are highlighted. For Cornejo, Olivares, and Rojas (2013), use of metaphor reflects the spirit of the storyteller and captures the attention of
the audience, as a seemingly simple juxtaposition of ordinary words brings a new perspective to the world of experience. This asymmetry, Cornejo et al. explain, impinges on the stronger relevance of the unspoken aspects of metaphor. Its complexity resides in congruence with the non-cognitive implications that work through suggestion and insinuation rather than through statement of proposition. What the unspoken aspects of a metaphor suggest is more a matter of feeling and intuition than a matter of reflection and inference. It is through the use of metaphor and simile that participants create a new symbolic and abstracted reality that highlights what can only be felt as an overwhelming maze of confusion and contradiction.

The notion of maze encapsulates bilateral dimensions of this reframing process. The first dimension is experiential. The second is expressive. With reference to that which is experiential, focus is on a lived experience that is underpinned by a multiplicity of twists and turns. Pathways of transition are pitted with caverns of emotional turmoil, systemic impact on health and well-being, fractured relationships, strengthened relationships, finance and reality checks, and vicarious implications. Throughout the trajectory of care there are moments identified with all that is good, bad, and ugly. Some pathways lead to support and empowerment, while others lead to loneliness, isolation, and feelings of disempowerment, entrapment, or abandonment. Amid the twists and turns, informal care leads to formal care and the caregiving trajectory enters a totally new phase of transition: where the light at the end of the tunnel is shrouded in the darkness of death.

Reflecting on precepts expressed by Campbell (1988), Moir-Bussy (2006) notes that “metaphoric symbols deliver not simply an idea, but a sense of actual participation in something transcendent, infinite and abundant” (p. 130.). This creates a state of something being realisable within the Self. As Moir-Bussy explains, metaphors also serve to bridge a gap between two places with quite different philosophical underpinnings. In this process of reframing, the use of metaphor gives testimony to the realisable. It also serves to bridge the gap between the epistemology of knowing caregiving, the axiological value inherent in doing caregiving, and the ontological conception of “Being-there”. Adding the linguistic element of simile to assimilate the state of “likeness” with the metaphoric value of “aboutness” creates a further epiphanic and transpersonal dimension to that which issues from a static realisation within Self.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland

**Figure 11 - A maze of metaphor and a simile or two:** Symbolic abstraction profiles the essence of impact. Using linguistic elements of metaphor and simile, the maze of experiential impact is represented by a maze of expression and abstracted across four sub-themes – distancing, invisibility, truth, and reality.

In the process of a symbolic reframing of all that has been reconceptualised, four sub-themes emerge in a unified amalgamation of epiphanic awakenings. These sub-themes of *distancing, invisibility, truth,* and *reality* portray the pure essence of impact as experienced in the depths of a personal, realisable, inside space. Multiple voices speak as one; and it is in the collective voice that reconceptions of impact are subsequently synthesised and reframed. The bilateral dynamic of the maze metaphor\(^\text{49}\) has a broader conceptual and contextual application than the notion of maze discussed by Peel and Harding (2014), where the focus was singularly directed to the perceptions of British carers in relation to health and social care services available in support of people living with dementia. In the context of this study, the symbolism of maze presents as the framework for constructing a broad and holistic snapshot of the reality embodied in lived experience.

Collectively, interwoven perceptions and conceptions embrace a depth of authenticity that is as rich and meaningful to each individual participant as is the pain of

\(^{49}\) (a) That which profiles the impact of lived experience and (b) That which is symbolic expression of the impact of lived experience.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: a reality that spans undefined dimensions in time and space. It is all-consuming and gives rise to awakenings that can be verbalised only in intuitive dimensions of the symbolic. The first theme in reconceptualisation (Chapter Five, *As Time Goes By: Transitions and the Trajectory of Care*) was introduced with metaphoric abstraction. Metaphor is again used, as the spirit embodied in the impact of caregiving is collectively reframed in a process of deep internal synthesis.

### 6.3.1 – Distancing

Shared words express that Alzheimer’s disease is both “the long goodbye” (Elise and Emilia) and “the long farewell” (Vince), “embraced in an ever-deepening sadness” (Nerissa). “It is a distancing: like a kite that is flying away and you never know when the string will run out. Then the last little thread slips through your fingers and it is gone” (Nerissa). Caregiving becomes a journey of falling into a dark hole and trying to cope with all that comes from the depths of hell (Emilia, Isabella, and Vince) or stepping into “no man’s land” and just disappearing (Richard). It is “a balancing act” of emotional dilemmas that is smooth and bumpy all at the same time and it is extremely traumatic (Emilia). Like “a roller coaster ride” (Aliena, Elise, Hal, and Vince), it is “flashing down at blinding speed” (Hal): “downhill and out of control” (Aliena). Or as expressed by Vince, it is “a journey through a maze that is ever turning, never straight, and never still: a kaleidoscope of colour that alternates with shades of grey”.

For Aemiel, there is expression of a “blurring of clarity that, like a helicopter, hovers between the profound and the childlike”. And while Elizabeth claims that “any sense of clarity is blurred”, Emma suggests that it is the changing personality of one so loved that “blurs the edges between behaviour that is vitriolic and that which is apathetic”: leaving the caregiver in a constant state of confusion. For Angelica, the experience of living becomes “a dissociation with all social contacts and with the real world” and it is Audrey who has an image of “companionship that fades away, ever so gradually, as one’s lover, companion, and best friend drifts like a cloud into the distance: just like having a divorce”.

In multivoiced expression, the impact of caregiving is witnessing this distancing from a place where there is no refuge: a place described as being “so isolating” and “so lonely”: “overshadowed by the cloud of a loneliness that can’t be quantified and cannot
be described” (Antony). It is a spot to which one is tethered and as the end of the tether is reached, any sense of freedom is so far away in the distance that not only is it out of reach but it is also out of sight (Iris and Lavinia). For that Special Someone who is living with Alzheimer’s, “It is a life unremembered and a spirit lost as one so loved slowly becomes as the walking dead” (Emma). And for the caregiver, in that walk there is an all-pervading sense of unbearable grief for the person who is slipping away, “disappearing ever so slowly and ever so surely” (Vince). “It is the attacker of peace and harmony” (Emily); a mental and emotional trap in which both care receiver and caregiver are caught. There is no escape from the “slippery slope to nowhere” (Hal).

Impact of caring is also expressed as being “the long and winding road” (Elise) and as one travels that road, “the fuel tank moves from full to empty as the distance from that which is both home and known increases and as the gap widens” (Audrey). The one we know and love is not the same person any more (Aliena). “Life as we know it is gone and all that remains is a future of ever increasing restriction” (Alice) that is spiralling like a cone shell, in a diminishing circle of life: just getting tinier and tinier until it is about living in one room then in one bed. And both are trapped” (Yori). The progression of distancing may occur over a long period of time, yet in retrospect, it seems like a flash: “blinding and distorting all vision of the world as it used to be as one rides the roller coaster to hell and the train to nowhere” (Richard).

6.3.2 – Invisibility

Alzheimer’s is “like a thief in the night: it just creeps up on you and it’s got you before you know it is there” (Antony). It is “the extractor of hope” (Aemelia) and “the great unknown and stealer of freedom” (Eleanor). It is “a robber of the future and you don’t even know that it’s coming. When it arrives it is invisible and you still don’t know that it is present until it has staked its claim” (Richard). “It is the unexpected guest who arrives out of the blue and stays forever: never going away and just becoming more difficult to live with” (Lavinia). Framed within the context of a fairytale:

Alzheimer’s is ‘The Sleeping Beauty’. The real Beauty is sleeping and that which is awake is horrible and invading. Ever so slowly it is putting the Beauty into a deeper and deeper sleep with the passing of time: a sleep from which there is no awakening and there is no Prince Charming charging to the rescue. (Aemelia)
The “real and blinding cruelty” of the dementia that accompanies Alzheimer’s disease is something to be hated (Angelica). It is all about “a cruel jumble of crossed wires that are hidden and can’t be seen from the outside” (Richard). Caring for a loved one with the condition is “like navigating an unknown landscape” (Lavinia) or “like being attached to an anchor and being thrown into the bottomless depths of the ocean: visibility nil” (Rousillon). For Elise, the similarity is akin to “walking through a minefield” which she describes as “a hidden maze of explosive devices that cannot be seen: just buried beneath the surface and waiting to be triggered into explosion”.

Mixing that which is invisible with that which is known and familiar, there is also expression of an emerging element of transformation. What Iach sees, is a stripping away of the layers, “little bit by little bit”. “The isolator, whittler, and merciless stripper of functions-taken-for-granted strips away, and what emerges bears no resemblance to the original. Yet, there is a mysterious beauty to that which does emerge” (Emily). This transformation is also observed by Nerissa who describes it as “a beauty that is sometimes hidden and invisible in the darkness and is sometimes breaking through the darkness at the most unexpected moments”. In those “fleeting appearances” (Aemiel) and “momentary flashes” (Rosalind), “one draws breath, breaks through the haze, and carries on with kindness, determination, loyalty, and love: till the next time” (Richard).

6.3.3 – Truth

For both caregiver and the “disempowered loved one” (Elise), Alzheimer’s is “a slow descent into hell and a slow living death” (Emily): “death without the benefit of dying and grieving for a loved one while they are still alive” (Lavinia). One feels “entrapped” (Audrey, Eleanor, Isabella, and Rosalind): like being “sucked down into darkness” (Emilia): “drowning in quicksand and being buried alive” (Vince). There is an overwhelming sense of suffocation as the impact of caregiving “penetrates every pore of one’s being and every moment of one’s life” (Isabella). Like a dichotomous cocktail of “pleasure and pain” (Hal), the mix is one of memories and that which is forgotten: “suffering and happiness; separation and bonding; highs and lows; good times and bad” (Jason).

There is confusion as a “private and personal journey is played out in public . . . and there are moments of embarrassment, right up to the end” (Vince). Partnered with
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland

confusion, there is also wonder, “Are others travelling the same road?” and “What can this be like for my darling wife?” (Vince) “Where has he gone?” (Isabella and Yori) “Do others feel what I feel, think what I think, do what I do?” (Hal) “Where in the name of all that is hell do I belong?” (Elizabeth). Amidst the confusion and wonder, Vince speaks of “a living grief that grows stronger over time as opposed to grief that is fading over time” and it is Emily who states that this living grief is all about “learning to live with learning to die”.

The trajectory of care is equated with The Never Ending Story (Angelica) as “once it arrives, there is no turning back” (Iach). And as Elise expresses that the impact of caregiving is analogous with the concept of The Yellow Brick Road, she explains:

Just as Dorothy and her companions faced all kinds of challenges as they travelled to see the Wizard of Oz, so too does the caregiver face all kinds of challenges while travelling the trajectory of care. And just as they found courage, heart, and wisdom along the way, this opportunity is also open to the caregiver.

Multiple voices suggest that truth about the impact of caregiving for a loved one who has Alzheimer’s is that it is a cruel, topsy-turvy world of thoughts and emotions and in the midst of all that is real, there is the surreal. For Vince there is correlation with being on the production set of One Flew Over the Cookoo’s Nest. The essence of an experiential truth could also be likened to The Mad Hatter’s Tea Party where nothing makes sense and just when you think you know what to expect, you’re down in the darkness of the rabbit warren and the whole scene changes (Emilia). Truth is also defined as a reflection of “the ultimate adrenalin rush” (Angelica) and “the erosion of all that is good” (Vince).

While the jigsaw analogy is used by multiple voices, it is Richard who makes specific reference to “the jigsaw that can’t be put together because it’s just all jumbled up and missing lots of the bits most of the time and the more you fight it, the harder the fight becomes”. Yet, as the fight gets harder, it is Elan who acknowledges that, ultimately, “destiny is controlled by the Lord Jesus” and “with faith and hope in the grace of God”, it is Elan’s expressed belief that one day, “with the knowledge and intelligence given to medical science people, a cure will be found”. The ripples of impact spread far and wide and there is unity born of diversity. Amidst the
complexities of impact, the simple and most poignant abstraction of truth is expressed by the collective voices of Alex, Elise, Iris, Jason, Richard, Vince, and Yori, each of whom acknowledges and states, “The truth is, that it is what it is”.

6.3.4 – Reality

Caregiving for a loved one with Alzheimer’s is “raw honesty and is about awareness and owning of reality” (Alice). It is “time in reverse” (Alice) or “like taking a journey back through time” (Hal). It is also role reversal that “just swallows one up” (Richard). In Vince’s words:

It is like watching a movie being rolled backwards as the one you love fades into a shadow: only the shadow is real. The tantrums are real. The incontinence is real. The fear is real. The frustration is real. And the pain is real as one so loved regresses to childhood and then to infancy.

“Instead of a child growing up, it is a parent growing down” (Elizabeth). It is a “backwardy birth” (Emily) where “the reality of everyday living grows to be a step closer to the helplessness of infancy” (Iach). “It is teaching a little child new skills, on a daily basis” (Vince) or “like having a little puppy, only the mess is much worse” (Iris). As the degenerative nature of Alzheimer’s disease advances, the impact of caregiving becomes more intense. Uncertainty is the only element of certainty as every day becomes “like opening a can and being exposed to all manner of things that are just so different” (Iris).

Elizabeth speaks of “a horrible nightmare of deterioration” and Aliena shudders as she reflects on what she recalls as 20 years of caring for a husband who was living with “a most terrible and most hideous disease”. “Demanding and demeaning” are terms chosen by Aemiel. Yori speaks of the tragedy embodied in becoming a slave to “an innate boss”, while Vince reflects on the overwhelming sense of being consumed with a “constant, indescribable, insidious feeling”.

Expression that embodies the broader social, political, and economic scope of impact, is voiced in comments made by Elise, Elizabeth, Richard, Rousillon, and Vince who refer to the need for investigation of formal and professional support structures. In considering future projections of incidence and prevalence, it is Vince who predicts that
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: the collective reality from onset to end of life and beyond.

Alzheimer’s is shaping up to be “a Time-Bomb for governments”. Yet, what is the reality of degenerative impact if it is not “the flight into darkness?” (Isabella).

**Figure 12 - Flying through the darkness:** Visual reframing of the Alzheimer’s journey that impacts both care receiver and caregiver. Painted in acrylics on canvas by Isabella during our initial dialogic interchange – 23/10/2015.

Isabella continues to reflect as she paints. She stands back and looks at what she has put onto the canvas and her thoughts begin to focus on a different frame of reference as she suggests, “Maybe it’s not a flight into the darkness at all. Maybe it’s all about a flight through the darkness”. For Isabella, this image “summons up a world of contradictions” and she explains:

The dichotomy is that as I grow to understand more, I love him more. And because I love him more, I believe that I will be less distressed to know that he is out of the darkness that has enveloped his life. When I loved him less, I missed him more and now that I love him more, I miss him less: and that is something that I really need to think about.
I value that we both had to go through this darkness to get to the light. I’ve always had a father but we had to go through this for me to be able to get close to him and to have an understanding of him: where he came from and what he had to give up as such a little boy so that his family could survive. Maybe our journey has really been into the darkness and out again.

Running parallel with these thoughts expressed by Isabella, there is also a point of consideration that all may not be as it appears to be. Reflecting on the observed reality of behaviours defining that which is cognitively, physically, and functionally degenerative, Ephesea speaks from a transpersonal and spiritual space. She defines Alzheimer’s as Wayi, which in Jandai Aboriginal languages means “to let go”. From a position of Wayi, Alzheimer’s becomes “the sacred journey and the letting go of all bodily attachments, physical and emotional: beginning the journey of re-entering into the spiritual world from which we came” (Ephesea). For the caregiver, it is a repositioning of identity and a letting go of a familiar relationship and with a very Special Someone, who is so loved.

Entwining the epiphanic and transcendent descriptors of a flight through the darkness and Wayi, maybe it could be said that moving through the Alzheimer’s maze is the sacred journey through the darkness. In that space there is a letting go of all that holds one to that which is of the human experience while opening the door to transcendence into the spiritual realm where life began. It is going home. And when life has spun full circle, the journey for the care receiver is complete while the impact for the caregiver lingers on. For the caregiver, there is always a part of that journey through the trajectory of care that is never completed and even when the care receiver has transitioned through Wayi, there are fragments of impact that, for a lifetime, will lie embedded deep within the energy field of a moment in time.

6.4 Wisdom Won of Pain: The Voice of Experience

Intuition and creativity are deployed in action as participants devise a “how” when confronted with the challenge of a “what”. Drawing on that which has proved to be a helpful solution when faced with a confronting challenge, participants highlight significant milestones in managing impacting behaviours associated with the progressive degeneration in their loved one’s ability to function. That which is shared
by participants is wisdom that has been won while traversing the everyday reality that identifies and defines caregiving for a loved one who has Alzheimer’s disease. Those for whom the advice may be particularly relevant are novice caregivers embarking on the journey of caregiver for their own significant other who holds a special place in their heart and history. One caregiver’s solution to an everyday problem may also help the seasoned caregiver who may be searching for an elusive response to a confronting challenge. The focus of action is practicality, safety, and maintenance of dignity for the one who is transitioning, as degeneration reshapes and redefines life and identity.

The woven fabric of disseminated wisdom is profiled as “tips of advice” reflecting solutions that have served to ease the pain of impact associated with the burden of care. However, while the presenting circumstances may be similar, actions may differ according to individual need that pertains to the lived experience of each caregiver, who is in a unique caregiving relationship with his/her own loved one. With experience comes knowledge and in the process of growing in knowledge, caregivers have also grown in wisdom.

Knowledge has been gained through living the day-to-day reality and through accessing a diverse variety of formal and informal sources and resources.Accrued knowledge is filtered, stripped, and transformed into action; through the creative application of weaving a weft of intuition and discovery, across a warp of necessity and

**Figure 13 - Wisdom won of pain: The voice of experience**: Participants reach out beyond the self in a sharing of wisdom and a dissemination of knowledge about how to do caregiving: knowledge that is the fruit of experience.
the very essence of self. In weaving the threads of that which is known by the knower, it is the intent of participant caregivers to demystify the maze and to share tried and tested solutions for what might otherwise be mystifying challenges and burdensome tasks. For the reader, some personal presenting issues may be normalised and some emerging problems may be profiled. The reader may also find a possible and immediate solution to a presenting problem or may be inspired into developing a creative alternative to an impeding situation.

### 6.4.1 – Wisdom won

Whatever the scenario, it needs to be remembered that all the experience of all the caregivers who have ever journeyed with a care receiving loved one, will not equate in one-to-one correspondence with the unique experience and specific need that presents in the individual construct of caregiving. The reality is that while there are universal characteristics or properties that define the aesthetics of action across the trajectory of care, each caregiving situation is as individual as each caregiver, each care receiver, all that defines that unique relationship, and all that is shared in the reality of lived experience. With respect of difference and diversity, aspects of “how” to manage a presenting “what”, based on specific advice shared by a fellow caregiver, carries potential to resonate elements of truth, reality, and solution-oriented wisdom. That wisdom, when applied to one’s own position, may also serve to inspire.

The collective voice of wisdom is dichotomous in that it tells a story of victory and defeat, joy and sadness, reality and creativity, opportunity and growth, frustration and humour, description and interpretation, awareness and action. Above all, it is the willingness of one who has “walked the walk” to now “talk the talk”, honestly and empathically: so that navigating the caregiving maze may be a little easier for others.

### 6.4.2 – Wisdom shared

Considering the wisdom that is born of experience, perhaps the best advice for those embarking on their journey is to come with openness and willingness to learn: to listen to all, to reflect on all, and then to filter. As one filters, one takes only that which holds a common feel of shared identity and reality.
Words that carry the wisdom of experience are worthy of being listened to, not only from a space held by spoken truths, but also from the interactional space within which veteran and novice caregiver come together in a dialogic experience that resonates from the “inside”.

Given that action examples are regularly shared by multiple voices, snippets of wisdom that are conceptually similar are merged and presented as a singular statement. Collectively inspired sharings of what has been found to work, or what alternative approach could have potential to ease the burden of care, encapsulate the essence of circumstance. As singular examples serve to illustrate a concept, these are individually identified.

6.4.2.1 – Practical insights

Projecting a sense of purpose and connection is acknowledged as being essential in a loved one’s maintaining some sense of “worthness”. Caregivers are constantly clutching at the smallest straws to help their loved one to feel “OK”. Activities such as reading to them, telling stories, and encouraging them to tell their own stories are noted as being helpful activities. Participants also find that working out the cues, picking up on just where their loved one happens to be in the moment, and being able to tune in to time and place are critical skills to be developed in sustaining a sense of calm and in keeping anxiety at bay.

Drives have proved to be “sanity savers” for caregivers whose loved ones are obsessive noise makers, bangers, or tappers. It seems that the rhythm of the drive has a calming effect on whatever is at the core of their anxiety. Depending on the stage of transition and the mobility of both caregiver and care receiver, walking also seems to bring a sense of calm and is said to be an amazing distractor. It could be a simple walk out into the sunshine and around the garden or it could be a stroll through a shopping centre, along the river bank, around parklands, or through the bushland: maybe stopping at a quiet little coffee shop, should one have access to such facility.

A note of caution is shared by caregivers who suggest that holding the hand of the loved one when walking serves as both a mobility support and a restraint on a loved one’s escaping and wandering off. If mobility is becoming an issue, use of a wheelchair
is found to be a safety precaution while also helping the loved one to feel steady and safe. It is noted that funding can be accessed to purchase mobility aids: also said to be frequently found at second-hand stores, online, and op-shops. Alternatively, aids and accessories can be readily hired.

Devices and strategies used by caregivers include a laser beam set up at the end of the bed and when the loved one attempts to get out of bed through the night, the beam is broken and an alarm rings: waking the caregiver, Vince. There is also the “Escapee Nan”, Helen, with the GPS attached to her so as to aid locating her when she has “broken out” and walked for miles. Ophelia, has a little button she can press and it rings like a door bell, alerting Edward that she needs him when he might be taking a quiet moment in the garden. Being “legally blind”, Edward also has systems of knobs and buttons that enable him to “see” with his fingers and guide him when operating electrical switches. There is the bell attached to the bathroom door to alert Yori that Adam is trying to enter the shower when, actually, he is wanting to find the toilet: and just in case, there is the “pooper scooper” specifically designed and fashioned by Yori to deal with Adam’s “little accidents”.

There are support railings around the perimeters of rooms, in bathrooms, on stair cases, and in the garden. There are lists, and labels, and notes. There are double sets of keys and double sets of teeth so that when one set is lost or hidden, there is always a spare. As Aliena found, “it seems that just as the second set is lost or hidden, the first set turns up: so there are always enough to go around”. Hal has also found that two sets of “essentials” are sufficient to avoid disaster.

It is claimed that the trick is all about being alert: getting to know the signs and learning to “just deal with it” in whatever way might work. It is suggested by multiple voices that maintaining a sense of humour and being creative really helps. It would appear that there is no right, nor wrong: there is only what works.

Helpful hints when a loved one is acting in cantankerous or inappropriate ways include being blunt and assertive in giving direction; being shrewd and careful; telling a little white lie; agreeing with them when there is no risk of harm resulting from what is being agreed upon. Distraction has also been found to work wonders: for example, assigning little jobs that give a sense of helping while also enabling the care receiver to
feel important and valued and giving the caregiver a few moments to attend to something else. General distractors include making an album of specially selected photographs that cover the life history of the loved one. Gathering together a box of treasures that stimulate the memory and have association with a bygone era is also a great distractor and time filler. Making time to pick through these objects with one’s loved one has been found to give caregivers space to have some quiet time in simple communication: the result being that both share an enjoyable and peaceful moment that is rarely found amidst the chaos.

Dealing with boredom also requires introduction of “hands-on” distractors and caregivers find themselves constantly coming up with games to keep their loved ones amused. What gives them pleasure are key factors for the caregiver to know so as to avoid tantrums. Ophelia loves to sort and organise the “junk mail”: a task that can keep her occupied for hours. Ratcliffe likes to sort through photos. And turning an obsession into a fruitful task, Octavia could be kept occupied for hours while ironing. Taking Helen for a drive or a trip to the “op-shops” to spend $1.00 on a treat, or writing letters with her and then going to the post box to post the letter are activities that Alex finds to be helpful. And, when speaking of activities he shares with his Nan, Alex says, “Doing these little things with Nan and taking her on little outings makes her happy. And that makes me happy.”

Creative challenges are addressed by participants in creative ways and as Isabella suggests, a great deal of stress can be avoided when one views the glass as being “half full” rather than being “half empty”. For example, as with Octavia and her ironing, turning an obsession into a game rather than viewing it as a frustration is said to be helpful. Such is the situation where Helen likes to abscond with things and hide them. Be this as it is, Alex and Alice “plant” things for her to find and to hide. Then, every so often, having given her time to forget, they retrieve her “stash” and start all over again, switching around the hiding places. When Orsino is cleaning his teeth with his biro, Isabella discreetly just swaps the pen with a toothbrush or a toothpick and deals with removing the ink from his face and hands when an opportune moment presents. Nerissa also learned that rather than being frustrated or annoyed, it was easier to just laugh with Octavia while cleaning the lipstick off her eyebrows and replacing the lipstick tube with an eyebrow pencil so that Octavia could continue attending to her beauty regime.
In playing such games, it is suggested that a big part of coping, is knowing and acknowledging that the loved one has a “deficit function”, and that the deeper the retreat into childhood, the greater the need to keep them stimulated with child focused activities and to deal with aberrant behaviours with child focused responses. Filling the day with tasks, activities, and games is a survival strategy that works for both care receiver and caregiver. It is also noted that when the loved one is calm and occupied, this leads to a calm home and reduces stress levels for care receiver, caregiver, and all other members of the household.

Life like and real life activities are also found to be helpful in dealing with boredom. For example, giving a loved one a doll to nurture and care for and take for a walk, or having a little garden patch to dig in, or a sand pit to play in, could be helpful. Pets are also said to be an amazing source of company, safety, security, and pleasure – dogs, cats, fish, and birds. However, it is recommended that one keeps a watchful eye on a loved one if giving them a cuddly toy pet, for like Anne, they could become distressed when they realise that their “pet” is not real.

However, as noted by multiple participants, the caregiving is not always about fun and games and it needs to be remembered that there are times of incredible pain, fear, and discomfort. When these times occur, natural pain relief strategies can be helpful when used in conjunction with prescribed medication. Some suggestions include nursing and gently rocking the loved one, just as one would with a baby: “round the clock”, if necessary. Incorporating calming talk, talking about good times and happy memories, playing calming or favourite music, singing to them and with them, massage, or simply stroking the hand, arm, or forehead: all are suggested as helpful strategies for calming and soothing both care receiver and caregiver. In the midst of all the games and distractions and with the progression of time, degeneration, and disempowerment, it is noted that there is need for constant reminding of Self that one is caring for an adult with the brain of a child. In the caring, it is important to consider the words of multiple voices, all of whom have come to realise that quality of life needs to be sustained for caregiver so that quality of life can be sustained for care receiver.

6.4.2.2 – Self-care

Participants acknowledge that as time progresses and as the condition of their
loved one transitions to advanced stages of progressive degeneration, it becomes easier and easier to become frustrated with obsessive, paranoid, psychotic, and generally inappropriate behaviours. Tolerance levels are said to fluctuate and there are times when it is necessary to release pent-up emotions.

Reactionary emotional release behaviours are diverse and range from uncontrolled outbursts, followed by feelings of remorse, regret, and self-rerimination, to appealing to God as “whipping-boy, advocate, protector, and all-embracing merciful saviour” (Vince). Those with religious faith simply know that God is on their side and “will give guidance with a protective hand on the shoulder, while gently pushing in the right direction” (Emilia).

Developing routine responses is reported to be more helpful and less stressful in the longer term. There are those caregivers who escape to another room and bang their fists or scream into a pillow.

Some find their release in music: singing with a choir or playing a musical instrument. Others relish a moment “to veg out” in the quiet of the night, listening to music or watching something trivial on the television. Or there is simply allowing oneself the luxury of having a little cry or shedding a quiet tear in the privacy offered by the darkness, in a precious “time-out” moment for the Self, when a loved one is sleeping.

For those who endure obsessive noise-making behaviours during their loved one’s waking hours, just to have a moment to sit in the stillness and dream is time to be cherished. Having a jigsaw puzzle on the go is also said to help stimulate the mind while providing distraction from the ever present chaos.

Creative pursuits such as building, gardening, drawing, painting, and writing are recommended by caregivers; as are manipulative pursuits such as textile crafts, pottery and ceramics, wood carving, sculpture, and cooking. For those who have the support of family, friend, or formal respite, there is the luxury of an occasional holiday: be it a day off duty, a night away, a week-end break, a week alone, or a month in a foreign land. Some use their “respite” time to socialise, to read, or to catch up on all variety of hobbies. Those still in the workforce find that work becomes their escape.
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: For some, their “survival kit” is when they can have their own room. Others enjoy the ultimate luxury of having “time out” at a house in the mountains: a peaceful place to periodically be free from the dichotomous routine of chaos.

Physical activities are highly valued as a means of maintaining emotional, physical, and psychological well-being. Walking, weights, and exercise machines provide opportunity to work out the muscles and work off the stress. As Yori claims there is nothing better than walking the treadmill when one is “over-the-top mad”.

Considering a multi-lateral approach to support, it is suggested by Isabella that, “while it takes a village to raise a child, it also takes a village to care for that child: right up to the end of life”. Also considering the drive that underpins that caregiving, it is Ephesea who states that motivation is a cultural tradition encapsulated in the values that “sharing is caring” and “community is unity”. With a vision that is transpersonal, it is possible for all to share the burden of care with kindness, compassion, and understanding for the loved one, the primary caregiver, and each other – all of whom are touched by the impact of caregiving.

6.5 From Here to Infinity: It’s OK to Dream

The reframing process is completed as some participants allow themselves a moment to dream beyond responsibilities, boundaries, and limitations that define the trajectory of care. While this journey of multiple transitions is time bound, the period of transitioning is indefinite and the terrain is as individual as is each caregiver, each care receiver, and that bonded unit that is Self and Other.

Those who allow themselves the freedom to dream consider life beyond Alzheimer’s in terms that are simple and meaningful and acknowledge the transient nature of the journey. For other participants, the intensity of caregiving is still too raw to even consider giving to Self the permission to contemplate a pathway devoid of restriction and duty, where it is OK to dream. Freedom and friendship are dream themes repeated over and over again: themes that dispel feelings of oppression and isolation and reflect a “turning around” and a “flipping over” of those aspects of lived reality that have been reconceptualised as “bad” and “ugly” and reframed as “distancing”, “invisibility”, “truth” and “reality”.

The collective reality from onset to end of life and beyond. Judith R Boyland
FROM HERE TO INFINITY: IT’S OK TO DREAM

Figure 14 - From here to infinity: It’s OK to dream: The time comes when the caregiver can see beyond the world that is and is free to dream. Image of releasing butterfly retrieved from http://media.photobucket.com/user/jade_2010

Impact has encroached on life and lifestyle and on physical, psychological, and emotional well-being. It is from this place that caregivers dare to dream – or not.

6.5.1 – Primary caregiver providing informal care

For those participants who are still in “at home” caregiver mode, there are expressed thoughts that before life after Alzheimer’s can even be contemplated, their primary focus is on what the future holds for their loved one. There is a collective expressed dream that loved ones will not linger to the final awful stages of debilitation, disempowerment, and dehumanising; that their last days will be sooner rather than later; and that they will be pain free. There is also the shared dream that transition through death will be a simple drifting away as the loved one sleeps. The sentiment of many is expressed in the words of Isabella as she states:

I think about when he dies and I just hope he goes in a hurry and misses out on those last awful stages. It is going to be really sad and, hopefully, I will understand in my heart what I know rationally in my mind. It really scares the daylight out of me.
Participants acknowledge that with the death of their loved one, life will be filled with emptiness and a deep sadness. There is trusting that the emotional heart will understand what the rational mind knows: again expressed so poignantly by Isabella as she refers to a wish that her father is free of pain and torment. In that rational knowing, there is hope for an understanding of the relief and the release that death brings to one who is lost and suffering. As explained by Alex with reference to transitions shared with his beloved Nan:

Each day she becomes frailer and frailer and we deal with each day just one day at a time. What is important is that she is safe and happy and as comfortable as she can be for as long as she can be. We are carried by a determination to see it through to the end.

So intense is the caregiving that it has become the caregiver’s whole life, as exemplified in the experience of Alice:

Two years ago I had a bit of a breakdown. I was so tired, my emotions were shot to bits and I was on antidepressants. The impact on marriage and family began to take its toll. I took a redundancy package and finished work to care for her full-time. And I wouldn’t have it any other way.

There are those who cannot move past what Isabella metaphorically described as “a big dark hole” into which life is falling. All that can be seen is more of the same: “simply exchanging one set of problems with another set of problems” (Rosalind) as each transition emerges and with no end in sight. There is also an expressed combining of dream and determination: “dealing with solving each problem as it presents” (Alex). Acknowledging that “we have yet to face the worst”, Eleanor shares the multivoiced sentiment that what is of the utmost importance is that loved ones are safe and protected; that they are as happy and as comfortable as they can be; and that they are not stripped of their dignity.

For those who allow themselves to dream beyond the now, the dream is simply and succinctly embodied in the words of Hal as he states, “It would be so nice to have some freedom”. And when Yori allows herself a “luxurious moment to dream” it is

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50 Image of “a big dark hole” also used by Emilia, whose loved one has transitioned to formal nursing home care; and by Vince, whose loved one has transitioned through death.
that, one day, she will go back to Italy and live there for six months. For Ephesea, her dream is situated totally in the now time and it is that her mother will seek the support she needs in helping her to journey with Ira as he traverses Wayi.

6.5.2 – Loved one transitioned to formal nursing care

All loved ones who are currently in full formal care are in nursing homes that are considered to be friendly, co-operative with family, and “nice”. Nursing care is said to be grounded in compassion and loving kindness. Caregivers of these loved ones share in the expression of Emilia when she suggests that “the dream is already beginning to materialise” in her gaining some sense of reclaiming freedom.

However, as previously discussed, formal nursing care can be totally bereft of any sense of loving kindness: as has been the lot of the loved ones of Aemelia and Elise when they, Anne and Alexandra, had previously resided in different nursing care facilities.\(^{51}\) While Anne had previously endured the distress of changes in environment, care personnel, and routine, she has now moved to a care facility where she is comfortable and well cared for in a spirit of caritas: and that, for Aemelia, is “a dream already come true”. For Elise, her mother’s new residency is inspiring her to dream of what can be done to ensure a future where all those in care can live out their last days in a place where the spirit of caritas underpins all policy, all operation, and all interaction with residents and families.

At the time of dialogue, Elise’s dream extended beyond the now and was bounded only by what she referred to as “the limits of infinity”. And while she stated that she did not dare to dream too much about the future, she did dream of doing something significant in the area of aged care. Beyond the scope of that which is within her own power to control, Elise also dreams that researchers will not only find a cure for Alzheimer’s disease but will also focus on prevention rather than a pharmaceutical solution following diagnosis. In a broader context that extends beyond limits of aged care and research, Elise’s dream is that she might be an instrument of peace and love for the rest of her life.

\(^{51}\) At the time of dialogue, both Anne and Alexandra had endured multiple moves. Alexandra has since transitioned through death at age 104: 10 months following my initial dialogue with Elise.
When caregiving is shared with formal caregivers in a residential nursing facility, and when that facility projects an ethos of caritas, some informal caregivers begin to live the dream as they gain an element of freedom that enables them to engage in all variety of activities. House refurbishment projects, going to the “gym” on a regular basis, and undertaking some part-time work are bringing back a sense of freedom and empowerment. Independence is also found in enjoying short holiday breaks so that bodies and minds can be refreshed while being away for only a few days at a time so as not to bring distress to loved ones by long absences.

For all whose loved one has known full-time formal residential care, the expression of “a dream fulfilled” – as mooted in 5.5, Formal Caregiving: The Last Bastion of Support – is that daughters once again become daughters, sons become sons, and spouses, partners, and friends return to being lover, companion, partner, and sister. Caregivers express their new-found freedom to be almost an unbelievable concept to grasp, and as explained by Emilia:

Who would ever think that simply being able to go out with friends and have friends over, could be such an expression of freedom. It just goes to show how much we take our freedom for granted: a real eye-opener and makes you sit back and think about all the people in the world who know real oppression.

With the support of her children, Audrey is exiting the world of social isolation and re-entering a world of social connection. A similar scenario is also the experience for Angelica. There are also those whose dreams of future revolve around everything going along smoothly and stress free: being actioned in their gradual return to living “a very full life”, with some having already taken up a social, sporting, or group activity. There are palliative care and end-of-life plans in place and it is a living-dream that having these plans in place will make future transitions easier to deal with. From a perspective of vicarious impact, Rosaline shared that she was “beginning to desensitise from the roller coaster” as she visioned her father as “someone on life-support”. She knows “the steep decline” is still to come and by internalising her father’s situation as his being on life-support, she is preparing herself for “the inevitable”. 52

52 Presenting situation at time of dialogue. Earl has since transitioned through death at age 74: five months following Rosaline’s sharing of her story.
6.5.3 – Post death transitioning

Grieving the death of a loved one takes many forms. There are feelings of sorrow that relate to personal loss, mixed with feelings of joy that a loved one has been set free from this horrific and debilitating disease. Once the intense pain of the loss begins to diffuse, it is only then that caregivers allow themselves to dream, to plan, and to live. Reflecting on the expression of Jason, “Pa is just a day away”, as researcher and one who brings inside experience, I make reference to the words of the 13th century mystic Jalaluddin Rumi, and add, “Goodbyes are only for those who love with their eyes: because for those who love with heart and soul, there is no such thing as separation” (Erickson, 2015).

There have been expressions of intense grief accompanied by suicidal thoughts. However, with the passage of time has come a “picking-up” of Self, accompanied by an expressed dream to simply get on with life and to make the most of the time one has, doing what one wants to do, and being of service to others (Antony and Vince). While holidays are said to “look good”, expressed themes for recovery also emphasise physical exercise, friendship, reconnection with family, and structured activities to keep the brain active and to stave off one’s own Alzheimer’s journey for as long as possible.

There are plans to study family history, tracing links back through a mother’s culture of origin with a view to the possibility of using the research as a topic for further academic study (Nerissa). Nerissa also shares her intention to become involved in volunteering with Catholic Psychiatric Care. Antony speaks of working in voluntary care services and his organisation of choice is RSPCA – Happy Paws Happy Hearts (previously referenced in Chapter Four – 4.3.7, Antony). Participants envision doing things with friends, children, and siblings while looking forward to being actively involved in watching grandchildren grow up to become fine women and men. Lavinia summarises the collective diversity of sentiment as she emphasises the importance of “staying busy”.

However, while there are dreams of service, family, fun, freedom, and academic

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53 An email was received from Nerissa on the first anniversary of her mother’s death. In this email, Nerissa advised that she has nearly finished the course to become a psychiatric pastoral carer.
pursuit, there are also dreams born of worry and concern that relate to the genetic DNA link with Alzheimer’s. The dream that surpasses all others is that self, children, and grandchildren will be spared this genetic inheritance. As caregivers move beyond the now time, yet are still time bound by a foreseeable future, the universal expression of dreaming is that they, their siblings, their children, and their grandchildren are not carrying the Alzheimer’s gene.

In further consideration as to whether or not a participant might “do it again”, there are mixed feelings. There are “definitely yes” responses and there are “would need to think about it” responses. There are no definitive “No” responses. All expressed thoughts acknowledge that to assume the role of primary caregiver for another loved one who might be diagnosed with Alzheimer’s disease would be a decision to be made if and when that time comes around. It is further stated that should that happen, the decision will come from a place of love, compassion, and knowing something of what lies ahead. It will not be made in ignorance.

While acknowledging all that was “demanding”, “demeaning”, “frustrating”, “hard”, and “horrific”, every participant expressed that they had already fulfilled dreams that, pre-Alzheimer’s, were not within the realm of conscious awareness. There are expressions of being both glad and proud to have cared for this very special person who held such a significant place in their hearts – for whatever period of time measured their personal lived experience. In concert with sentiment expressed by Elizabeth and Richard, without the Alzheimer’s journey they would never have had opportunity to travel their own pathway through extraordinary experiences of personal growth. There are also those who expressed their gratitude in having had the opportunity to discover a parent they had no understanding of and a parent they came to know, to appreciate, and to love (Iris and Richard).

There are revelations that, in dementia, loved ones travelled back through time and space, sharing reflections that while often temporally disconnected, shone so much light on the unfolding story of their own childhood, youth, and parenting practices. These journeys are reported to have given caregivers the freedom to forgive that which they had never understood, while also helping the parent to make sense of so much from their past: an unprecedented dream and gift, presented by life’s circumstance.
There is expression that participants are living the dream: some comforted in the thought that, as their loved ones progressed through the end-time, they seemed not to suffer. For those whose loved one appeared to pass in pain and torment, the dream is that their own death will be peaceful. For those whose loved ones have transitioned through death in nursing homes deemed to be bereft of loving kindness, the dream is that lobbying by those who have inside knowledge will help to divert government funding so as to support families in keeping their loved ones at home, where they are in a familiar environment and are surrounded by love. As to a reality of what the future might hold, there is multivoiced acknowledgment that “it will be what it will be”.

Sharing a video of his father, distressed, tormented, and slapping at a pillow just a couple of days before his death, Richard expresses that he is wholly aware that this could well be himself in not too many years. Acknowledging that it is all about reality and mortality, Richard plans to find old photos and to put a pictorial family history together, before it is too late. His intention is to portray his father as the vibrant, strong, active, quiet, calm, and loving man that he was, pre-Alzheimer’s: the man his grandchildren never really knew. For Elizabeth, the pain is still too intense to even begin to dream beyond “just getting the family back to a normal way of living” and committing herself to saying “yes” more often. Her pain has many compounding layers beginning with the unresolved grief in her mother’s passing. Then there is transitioning through her father’s abusive and obsessive stages of progressive degeneration and grieving her loss of the identity of the father she knew and loved pre-Alzheimer’s. There is also the grief she felt for her children as she supported them through their trying to understand and rationalise the changes in the man who was their Poppy. For this caregiving daughter, the future is said to be “a closed door” that she will open when she is ready.

Peace, with a capital ‘P’, is the expressed dream of Aliena. Her dream for Peace is accompanied by a hope to last a few more years. In that time, she would like to enjoy freedom and independence following 20 years of caring for her husband as he slowly transitioned through the full gamut of progressive degeneration – from the subtle changes associated with pre-recognisable onset behaviours to his most horrible death.

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54 Having had no time to grieve the death of her mother, before beginning to care for her father.
It is Vince’s expressed dream that all carers come to know that they are not alone and that the only “normal” is what applies to each of them in relationship with their own loved one as together, they “struggle with fear, faith and Alzheimer’s”. Vince is living his dream as from his home, “Carers Outlook”, situated in the Sunshine Coast Hinterland, he and Lorrae facilitate respite and retreat for caregivers who are caring for a loved one who has Alzheimer’s.

There are expressions of walking with fear that is mixed with hope and dreaming. Fear relates to the possibility that self, child, or grandchild may already be incubating the as yet unobservable stages of onset that mark the arrival of Alzheimer’s (Angelica, Elizabeth, Hal, Lavinia, and Richard). Hope is the fuel of motivation. Elan’s ultimate dream is also voiced by Elise and Vince and shared by every person who has ever been touched by Alzheimer’s disease: and that is, that one day, both a cure and a preventative will be found.

6.6 Conclusion

Chapter Six has presented a synthesised reframing of perceptions, conceptions, introspections, and memories of lived experience as reconceptualised in Chapter Five. Stories already told were re-viewed, re-lived, re-structured, re-developed, and re-framed as if temporally and spatially re-visioned through a clearly focused lens. The process of reframing and the weaving of the synthesised findings bring the collective narrative to completion.

In Chapter Seven, discussion is focused through a philosophical framework that considers the epistemology, axiology, and ontology underpinning dynamic transformations as related to the impact of caring for a loved one who has Alzheimer’s.

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55 Extract taken from the title of Vince’s book, I wish I were a leper: The diary of one couple’s struggle with fear, faith and Alzheimer’s (O’Rourke, 2008).
CHAPTER SEVEN – DISCUSSION AND IMPLICATIONS

When we drop below our stories,
We are led back to the here and now.

Jack Kornfield (2008, p. 147)

7.1 Introduction to Discussion and Implications

This final chapter argues that the reconceptualisation and reframing that embody participants’ stories serve to identify all that has been shared in dialogic interchange as deep and dynamic internal transformation. Findings encapsulated in the collective narrative push through and go beyond the primary base level of description. Discussion of the research findings also considers the transformative power of the participatory approach taken in the investigation, as discussed in Chapter Three, Method and Methodology. An additional point of discussion addresses implications that emerge from analysis of the collective narrative.

7.1.1 – Overview

The journey of the caregiver is defined by the construct of caregiving and is impacted by the evolving needs of a loved one who has Alzheimer’s. How-I-Be in this new world (the ontology of caregiving), is impacted by and impacts what I do and why I do what I do (the axiology of caregiving) which, in turn, is impacted by and impacts what I learn and my accrual of knowledge (the epistemology of caregiving), which impacts and is impacted by what I do and why I do what I do. A cycle of dynamic transformation begins rotation.

Movement is directional, interactive, and constant, as illustrated in Figure 15, Caregiving: A construct of dynamic transformation. The model of a three cogged rotating machine serves to illustrate that the doing of caregiving is influenced from alternating directions: from one direction by what is known and from the other direction by what is experienced. While the doing is pivotal in the process of caregiving, it both influences and is influenced by movement in the caregiver’s knowledge base and movement in the caregiver’s emotional, spiritual, and somatic sense of Self as s/he is “Being-there”, totally immersed in the world that is. The cyclical model of the infinite loop is simple. The journey through the transitional rotations is complex.
7.1.2 – Caregiving: A construct of dynamic transformation

Considered as a philosophical construct, the knowledge that a caregiver accrues (epistemology of caregiving), influences and is influenced by the doing of caregiving (axiology of caregiving) which, in turn, influences and is influenced by the caregiver’s way of Being-there in the world of caregiving (ontology of caregiving). The cycle rotates in continuous movement and the process of dynamic transformation evolves.

**Figure 15 - Caregiving: A construct of dynamic transformation:** The infinite loop of dynamic transformation is set in motion as knowing activates doing activates Being-there activates doing activates knowing activates doing …….. Image for knowing is supplied by and used with permission of Wendy Watego-Ittensohn. Photos for doing and Being-there are supplied by and used with the permission of care receivers’ families.

The imbalance of teeth on the cogs shows that knowing and doing need to be in rotation before there is movement in Being-there and that a full rotation of knowing and doing must be completed to start the rotation of Being-there. I intuitively know that something is happening for my loved one (knowing). I question, I wonder, and I observe the behaviours of my loved one a little more vigilantly (doing). I learn more and accrue more knowledge (knowing). I record and continue to observe (doing). ……
I continue to accrue more knowledge (knowing). I make a decision that it would be helpful to discuss what I have been observing with my loved one and other family members (doing). My stomach churns in my unknowing, and based on prior knowledge of what could be going on, I may also feel anxious, fearful, and nauseous (Being-there).

The infinite loop is set in motion. The cycle starts to gain momentum and the steady rotation of Being-there leads doing and knowing to rotate at higher speeds. There is no turning back and the cycle will continue until it begins to slow progressively,\(^{56}\) or until it is stopped by catastrophic failure.\(^{57}\) A full rotation of Being-there denotes the pathway travelled by the caregiver through one stage of the care receiver’s degenerative transitioning.\(^{58}\) As the cogs that symbolise each cycle of rotation between knowing, doing, and Being-there continue to move, each phase in the process of dynamic transformation continues to evolve.

The individuality of each caregiving journey and each evolving story is expressed in words shared by Rosalind and Antony; each of whom had cared for a parent who had Alzheimer’s, before now caring for a spouse who has Alzheimer’s. As Rosalind explains, “No two patients are the same. [Owen] is so different from Mother. He is moody and anxious and cantankerous. With Mother, it just crept up and she just became more eccentric as the years passed by”. Antony simply states:

I thought I was beyond surprises. But my darling [Eva] was different again from both Father and Mother. I just kept learning and every day was a new day and every day I did what needed to be done. And that was my whole life. That was all I lived for.

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\(^{56}\) For example, a progressive slowing could occur as informal support structures are strengthened or the care receiver is admitted to a formal care facility.

\(^{57}\) In the scenario of caregiving for a loved one who has Alzheimer’s disease, catastrophic failure would be either the caregiver’s need to relinquish the role, or death: death of the caregiver or death of the care receiving loved one.

\(^{58}\) It is noted that the diagrammatic representation of momentary differential between knowing, doing and Being-there is abstracted symbolism. Therefore, mathematical accuracy in the number of teeth on each cog has no direct one-on-one correspondence with the cycling differential that defines the actual and individual transformative process. Any measure of accuracy is reflected in the same number of teeth on the cogs that represent knowing and doing and a greater number of teeth on the cog that represents Being-there.
7.2 Epistemology of Caregiving

Epistemology is about a way of knowing. What is it that caregivers know? How do they learn? How do they come to know what they know? How do they process what they know? How do they disseminate what they know? The caregiving journey is dynamic because, while caregivers instinctively know that the knowledge they accrue through lived experience is their reality, there are times when they can be undermined in a serious way by their own thoughts and actions or by the words and actions of others. They can also be undermined by their own expectations and/or by the expectations of others. (Examples cited in the construction of the collective narrative: Findings, Chapters Five and Six.) As discussed in Chapter Three, Method and Methodology, and reflecting the position posed by Lincoln and Guba (2000), knowledge accrued by caregivers encapsulates local and specific constructed realities and varies in accordance with the individual and the situation.

The very experience of caregiving for a loved one who has Alzheimer’s disease results in a turning upside down of all prior knowledge relating to caregiving. In the general circumstance, when caring for a loved one who is sick or injured, there is an unconscious assumption that the body is supposed to look or act wrong. There is also an expectation that it can be fixed or managed and there is a projected time-frame that is perceivable and can be accommodated within a knowledge base that is known and understood. However, when the condition is slowly and progressively impacting the cognitive, social, and functional capacity of the care receiver, all expectation about connections leaves the caregiver looking backwards and looking forwards while, at the same time, being lost in a maze of “now time” that is an ever-changing space: a space that is constantly shifting and clouded by the unknown. (Examples of transitioning experiences are as reconceptualised in the theme, As Time Goes By: Transitions and the Trajectory of Care, Chapter Five and as reframed in the theme, A Maze of Metaphor and a Simile or Two, Chapter Six.)

The undermining of all that is known presents as a problem of epistemology. It is not a problem of social constructions. It is a learning process and there is no simple and universal following of direction that relates to what one “should do” in the situation where the presenting symptomatology and corresponding issues line up with a defined
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease:

The collective reality from onset to end of life and beyond.

Judith R Boyland

medical model of pathogenic reality. In the early phase of onset, there is no variation to measured levels of intrinsic variables; no biomarkers against which subtle behavioural changes can be measured; no circulation problems; no breathing problems; and no bleeding. Nothing is broken and until the final stages of transition, there is no deformity. What is presenting externally and what is observed on the outside is in opposition with the inside experience. Therefore, there is potential for confusion and frustration in interactions with the care receiver and other family members as well as in broader social and professional encounters.

Any indication that something is wrong is invisible to one’s conscious awareness for a long time before observable behaviours begin to flag that “all is not as it used to be”. Nothing is as it seems to be in the shifting sands of time. The condition cannot be fixed. It does not go away and the loved one who has Alzheimer’s does not get better. As Aaron shared with Richard in the early stages following diagnosis, “I’m the one with the brain problem and your poor Mum has to live with it”. In Hal’s words, both caregiver and care receiver are on the “slippery slope to nowhere”.

From the position of caregiver, s/he is engaging with a loved one who outwardly appears to be the same person right up to the final stages of degeneration which, as discussed in Chapter One, could be a transitioning that spans in excess of 20 years. For a lifetime, or for much of a lifetime, this person has been mother, father, sibling, partner, lover, spouse, friend. In a circumstance of “early onset”, it could even be one’s child. However, the Self of this Other, who is known and loved, is not there in the same way. The presenting Self is becoming a stranger who has invaded the exterior shell of this very special person and the caregiver’s established sense of connection is gradually stripped away. As Lavinia reads from her journal, she shares:

Gradually, I moved from companion to minder and that was the sad bit. I was missing the person I loved as [Oswald] was getting frailer mentally and physically every week. What used to be so good isn’t good any more. The time comes when I have lost my relationship with my husband. I am now his “mother”. I am no longer his “wife”.

Yori tells of how expectations about how one cares are “rolled inside-out”. Elizabeth speaks of relationships being “turned upside-down” and Vince refers to the
“topsy-turvy” state of thoughts and emotions. It is about change that moves from the inside to the outside at a functional level and from the outside to the inside at a relational level.

One’s knowledge base is eroded as new learning takes precedence over old. Change is transitional and impact is transformative. Both are in a constant state of flux. In the lived experience of negotiating one’s way through the cycles of dynamic transformation, it is about distancing, invisibility, truth, and reality, as addressed in the theme, *A Maze of Metaphor and a Simile or Two*, Chapter Six. Impact as the caregiver accrues transformative knowledge and adjusts actions is defined in Eleanor’s disclosure of her innermost doubts and fears:

I don’t know who I am any more. I don’t know who [Rod] is. He is not who he used to be and who he is, is changing all the time.

He has a terminal disease but he’s not sick. He is dying but he looks the same: so alive and well, but just not so sharp. Nothing has changed but everything has changed. There are times I just look at him and I say to both of us, “I don’t know if I can do this.” I am so scared of what lies ahead and for what could be such a long, long time.

7.2.1 – Caregivers’ accrual of knowledge

Malinowski (1945) claimed that knowledge gives foresight and that with the gaining of foresight, comes empowerment. Anderson (2011) speaks of the power of intuition and highlights the concept of listening with the senses and with awareness that is open and attentive. While Malinowski and Anderson speak with reference to the researcher’s gathering of knowledge as a source of data, the positions they present apply equally to all knowledge, as may be gathered and applied in any circumstance.

The accrual of knowledge is, primarily, experiential and evidence-based. That is, the internalisation and evaluation of experience is based on the sensory and emotional response to what is presenting within the confines of the world in which we live and function. As the caregiving journey transitions, knowledge is gained through discovery and interpretation of lived experience. Knowledge is also gained through channels of testimony where information is context specific and is transferred through formal and
informal processes of communication. The caregiver’s ability to foresee and intuit is constantly strengthened with the accrual of knowledge.

7.2.1.1 – Knowledge accrued through discovery and interpretation of lived experience

The most fundamental source of experiential knowledge is daily interaction with the care receiver. Caregivers have witnessed and lived through the confusion and frustration that accompany onset and progression of degeneration associated with the executive, spatial, and cognitive functions of their loved one, as discussed in Findings, Chapter Five. There is abandonment by family and those thought to be “friends” and at the opposite end of polarity, fractured relationships are healed and there is support from the most unexpected sources: discussed in the theme, Breadcrumbs in the Forest: Survival and Support, Chapter Five.

There is reported evidence of subjection to avoidance, ridicule, or feigned invisibility by the general public. Stories are told that evoke grave ethical and professional concern as disclosures reveal how some doctors, allied health professionals, staff of nursing homes and respite centres, and staff linked with Alzheimer’s Australia have demonstrated what is described as abusive, condescending, demeaning, and belittling behaviours when communicating and engaging with caregivers and care receivers. An example of just such a scenario relates to the formal nursing care for Octavia; a time when Nerissa experienced “chaos, conflict, and confrontation”. Scenarios described by Nerissa identify incidence of institutional abuse and neglect. Sharing stories of experience that profile the “horrible things” that went on in the nursing home, Nerissa revisits “three-and-a-half traumatic years when [she] should have been able to enjoy [her] Mum’s final days with the help of the nursing home. Instead, it got to be a game of survival”. Stories expressing similar feelings of disempowerment were shared by Aemelia, Aliena, Elise, Elizabeth, and Richard.

Yet, amidst this exposure to behaviours devoid of respect for personhood, there is incidence of experience where caregiver and care receiver are greeted with recognition, respect, acknowledgement, sensitivity, and understanding from the compassionate stranger. Just such an incident is reported by Elise who, when in the midst of a period of traumatic events, was told by an attending nurse, “You are your mother’s rock”. This
experience left Elise feeling empowered; as compared with the disempowerment she had previously felt in scenarios wrought with conflict. Stories citing similar moments of empowering acknowledgement were shared by Alex, Antony, Audrey, Hal, Isabella, Lavinia, and Vince.

Other stories shared by participants reference a plethora of interactions with individual persons in the street, neighbours, family, and persons acting in professional roles in industry, medical, institutional, and organisational settings. Some experiences have been helpful, bringing warmth and encouragement to the tired soul. Some have been totally unhelpful. All of these encounters contribute to an accrual of experiential knowledge. What is learned from social and professional encounters is internalised and has ongoing consequences for influencing how caregivers identify with “a safe space” or “an emotionally unsafe space”.

What is missing in transactions that leave the caregiver feeling small, confused, insignificant, unimportant, protective, dissatisfied, sad, stressed, frustrated, and angry is the emotional component of empathy. On the other hand, transactions that acknowledge and inform leave the caregiver feeling confident and empowered. These latter experiences have capacity to introduce a relational dynamic that inspires trust, respect, confidence, and connection within the caregiver; with a flow-on benefit to the care receiver. Within organisational structures, this empathic component to professional transactions is defined by Hochschild (1983/2003) in terms of “emotional labour”. Behaviour demonstrated by one who is seen by the caregiver to be in a position of authority and power, 59 leaves the caregiver thinking and feeling that this person is either their strongest ally or their worst enemy. A connection is made. The implication is that here is a person (or a place) upon whom I can depend when in need of support and/or information. Alternatively, the learning is that here is a person, place, or organisation devoid of any sense of compassion and respect. For the well-being of myself and my loved one, this person, place, or organisation is to be avoided.

59 Reference is to people holding professional roles such as doctors, allied health professionals, staff of nursing homes and respite centres, and staff linked with support organisations, such as Alzheimer’s Australia or Carers Queensland.

60 In a more global sense, reference is to all persons who hold interactive roles in health services or allied health services.
Considered from a position that relates with a social dynamic of “emotional anorexia” (Fineman, 1993), when a caregiver is confronted with dismissive relational transactions, the transformation that is experienced resonates internally and has a negative polyvagal impact. What results is a burgeoning sense of distrust, disrespect, and disillusionment with the very people who are the holders of professional knowledge. Considered from a platform informed by the adage that “every dark cloud has a silver lining”, it could also be inferred that being the “victim” in a situation which may be interpreted as “emotionally anorexic”, has potential to bring one to a position of conscious awareness and realisation that one’s actions have enormous power to impact the well-being of another. What may emerge is a greater appreciation that the way one externalises frustrations, has capacity to impact the emotional and somatic well-being of the loved one who is the care receiver – maybe: maybe not.

For caregivers whose personal caregiving role reflects their professional career, vocational and disciplined learning bring an added dimension to the accrual of experiential learning, underpinning that which is individual and personal with a body of knowledge gleaned from diverse experience. Such is the position of Alice, Angelica, and Aemiel – all of whom have held senior positions in nursing, with Alice having held a supervisory and teaching role in geriatric care. There is also Elise, whose former profession was in social work.

However, all the professional knowledge and experience in the world cannot counterbalance the dynamic of a relational impact that triggers an involuntary internal transformation as Self engages with Other, across the passage of time:

There is a definitive change in dynamics. It’s not having a mother but at the same time having her there right in front of you and that’s the hardest part. Life is totally different. Sometimes I get really scared that I can’t connect and there are times when I feel a failure on a personal level. And that’s also when being a geriatric nurse is no help at all. This is me and my [Helen]. It is not nurse and patient. (Alice)

7.2.1.2 – Knowledge accrued through testimony

Knowledge accrued through testimony has been accessed from many sources and transferred by diverse means. This has been by way of the ordinary encounters of daily
life, such as conversation or regular interpersonal dialogue with the care-receiving loved one and engagements with family, friends, neighbours, other caregivers, and people who simply care. Also included are conversations with medical and allied health practitioners, personnel representing support agencies, and personnel servicing respite, nursing, and hospital facilities. It needs to be noted that while there is incidence of a presenting culture of emotional anorexia demonstrated at the front line of some professional and organisational interactions, there are also individual persons who approach consumers with a spirit of caritas, the essence of which is referenced by Watson (1979/2008) and introduced in 2.11, *Coping With Abusive Behaviour*.

Testimonial knowledge and information have been accessed through shared communication in social and business situations or interactions during volunteering activities in nursing homes. On a more structured basis, Isabella engaged in formal online study programs (*Understanding Dementia*, *Preventing Dementia* and *The Arts and Dementia Care* [University of Tasmania] and *Art for People Living with Dementia* [National Gallery of Australia]). Further to formalised academic studies, testimonial knowledge is tapped through a variety of technological applications: for example, Google and social media. Educative and informative television programs have been reported as helpful sources of knowledge: for example, programs such as *Four Corners*, *One Plus One*, *National Press Club Address* and *Insight*. Movies and literature have also served to portray reality as it is lived, for example, *Still Alice* and *Notebook* (movies) and Wilfrid Gordon McDonald Partridge (Fox, 1984), *Fraying: Mum, memory loss, the medical maze and me* (Gierck, 2015), and *I wish I were a leper: The diary of one couple’s struggle with fear, faith and Alzheimer’s* (O’Rourke, 2008). It is noted that all portals to knowledge referred to by participants are in concert with sources of knowledge and information referenced in the *Literature Review*, Chapter Two.

### 7.2.1.3 – Knowledge as the product of inductive reasoning

As participants acquire knowledge through lived experience and testimony, they “sift and sort” the information that presents to them. From this conglomerate of information, they differentiate that which they believe to be relevant for their own situation. They make their own choices and define their own rules, subject only to that which serves their unique need as caregiver for their own loved one.
In sharing their stories, participants have allowed this researcher to enter their world. In profiling the *Findings* (Chapters Five and Six), I, as “holder” and “giver-awayer”\(^{61}\) of the knowledge that is revealed, have honoured the trust of participants and respected the intimacy of stories shared. The scope of knowledge that profiles the collective narrative of impact as experienced in a local demographic has significant correspondence with knowledge representative of evidence-based global research: as referenced and discussed in the *Literature Review*, Chapter Two. Reflecting the writings of Owen (1995) and in congruence with discussion presented in *Method and Methodology*, Chapter Three, the findings of this research support the hypothesis that the tool of knowing is inevitably the inductive subjectivity of the people, themselves.

### 7.2.2 – Caregivers’ dissemination of accrued knowledge

Knowledge that is shared by participants is embedded in their internal world of thinking and feeling and expressed through their external world of action and linguistic expression. It derives its existence from the participants’ own perceived realities of lived experience and is subjective in determination. When presented as evidence-based knowledge, the authenticity and trustworthiness of internal experiences are recognisable as reflection that is actioned through processes associated with memory, recall, and introspection. There is no element of luck underpinning the disseminated knowledge that participants relate to caregiving and the impact of caregiving: it is pure and true expression of lived experience.

Accrued knowledge is disseminated through behaviours associated with the doing of caregiving and through dialogic interchange with others. In disseminating knowledge into an action base, caregivers react and respond to identified needs and demonstrated behaviours of a care-receiving loved one. Reactions and responses reflect levels of gratification relating to the fulfilment (or lack thereof) of their own intrinsic and basic needs as a human being whose life is immersed in a world of caregiving.

As caregivers accrue more knowledge and as they progressively discover and redefine their personal and individual self-sense of the caregiving journey, old knowledge is constantly enhanced, complemented, filtered, and replaced with new

\(^{61}\) Reference to Wilson (2001) and the paradigm of “sharing, holding, and giving away”: 3.9, *Ethical Considerations.*
knowledge. Old beliefs and expectations are transcended in the shifting sands of time and as the gap between the world that was and the world that is widens, so the dynamic transformation of Self and Other evolves. The cogs that denote knowing, doing, and Being-there continue to turn: keeping the infinite loop in motion.

7.3 Axiology of Caregiving

As a way of doing, axiology is underpinned by a transitional knowing. From a constructivist perspective, and reflecting the position of Lincoln and Guba (2000) as discussed in Chapter Three, Method and Methodology, “doing caregiving” from a place of love moves towards a praxis of participation where the focus of concern is on liberation from degenerative oppression and freeing of the human spirit from the torments of the degenerative process. Actions are purposeful, and the means is justified by the end.

When caring for a loved one in any circumstance of illness or injury, there is love, concern, consultation with professionals, and following of direction. There are moral and social constructions and in general circumstances, the expectation is that if one follows the rules, all will be “OK”. However, for the caregiver whose journey is with a loved one who has Alzheimer’s, there is an underlying mis-match between moral and social construction conventions. Because the experience of caring for a loved one who has Alzheimer’s disease is unlike any other experience of caregiving, expectations are also different. The sense of moral fabric is disoriented and the sense of Otherness in relationship with people is undermined, as voiced in the words of Angelica:

My motivation was my sense of duty and my sense of responsibility. I was always a little embarrassed and as time went on, my embarrassment became worse. I was frustrated and angry and tired and cranky and also a little bit frightened. And so, to protect him, I closed in and I tried to hide his behaviour from the community. I became isolated. But I could never bring myself to the point of being able to say, “I can’t do this anymore”. After all, I am a nurse.

With specific reference to transformation of the primary relationship between Self (caregiver) and Other (care receiver), impact is influenced by the linear progression of transitional change. As previously noted, that which is transitioning happens in a way that the outward appearance of the care receiver’s body does not seem to change in any
significant way until the final stages of progressive degeneration have been reached. It is all happening in the brain of the care receiver and it is the ability to function “normally”\textsuperscript{62} that is progressively impacted. As the stories shared by participants unfolded, what became evident was what Hermans and Hermans-Konopka (2010/2012) described as “an interplay of positions at the interface of the biological and the social” (p. 261). What also became evident, particularly throughout the process of reframing, was a repositioning of what these authors referred to as internal negotiations underpinned by implied social rules and expectations.

Positions internally constructed by caregivers are played out in action according to perceptions and interpretations – as exemplified in Isabella’s and Iris’ initial motivation to care for a parent in a self-sense of obedient compliance with cultural rule and social expectation to act in accordance with an implied sense of filial duty. With reference to Brentano’s (1889) emphasis on the role of a subject’s performing intentional acts, Kubát (1958) speaks to the notions of “aboutness” and “intentionality” as conceptions of axiological theory. Considering the depth and the richness of participants’ stories in relation to the doing of caregiving, it is evident that the focus of intention is about actions.

Caregiving actions not only define the construct of caregiving in aesthetic terms, they also reflect the values that underpin them – moral, spiritual, and ethical. Tension is created between these axiological dimensions, as a strong sense of duty underpins the action pathway through the maze of emotional and functional transitions and dynamic transformations. As the action component of the data set is woven into construction of the collective narrative, the landscape that emerges is highly internal, personal, and relational. Yet, emanating from the subjective, are elements of practicality that are external, objective, and foundational. As Kubát (1958) states:

The recognition of certain stable relations among men (as valuing subjects) and the intentional (or intended) objects require acceptance of certain “objective” values. These values, then, have a genuine existence in our physical acts (intentiones), and a spurious, transferred and inferred existence in the objects of intentions themselves. (pp. 134-135)

\textsuperscript{62} Scale of reference as profiled in Reisberg’s Global Deterioration Scale (Reisberg et al., 1982/2007). Progression profiled in Appendix A.
7.3.1 Axiology of caregiving as an aesthetic perspective

Referenced in an aesthetic sense, the “doing of caregiving” corresponds with properties or characteristic behaviours that identify with the “subject of caregiving” and define what caregivers do. There are foundational actions that emanate from expectation and there are anti-foundational actions that emanate from a simple response to need. As framed by Wittgenstein (1922/1955/1999/2017):

In order to know an object, I must know not its external but all its internal qualities . . . Objects contain the possibility of all states of affairs . . . The object is simple . . . Every statement about complexes can be analysed into a statement about their constituent parts, and into those propositions which completely describe the complexes. (pp. 30-31)

The picture can represent every reality whose form it has . . . The picture represents what it represents, independently of its truth or falsehood, through the form of representation . . . What the picture represents is its sense. (pp. 34-35)

In the doing of that which is done, there are consequences that impact the well-being of both care receiver and caregiver. The impact is multifaceted in that there are responsive factors that are external, objective, and foundational. There are also reactionary and intuitive factors that are internal, subjective, and non-foundational. For example, external impact is experienced through factors such as “finance and reality checks” (5.2.2.4, Findings) and internal impact is experienced through factors such as “emotional turmoil” (5.2.2.1, Findings).

Reflecting on the stories of Rosalind and Eleanor, it could be said that a foundational aesthetic dimension underpins statements relating to their not having anticipated that their later years “would look like this”. In their shared expressions, “this” references what they are now doing and what they expect to be doing as the condition of husband and partner advances in functional degeneration. Caring for a loved one who has Alzheimer’s and doing caregiving out of a sense of duty and commitment, is in stark contrast with travelling overseas or simply being free to do what one chooses. It also contrasts with the anti-foundational property dimension that underpins the actions of Alex, who “wouldn’t have it any other way”.

The collective reality from onset to end of life and beyond. Judith R Boyland
Reflecting on properties that caregivers have assigned to caregiving (as discussed in *Findings*, Chapter Five and Chapter Six – particularly 6.4, *Wisdom Won of Pain: The Voice of Experience*), there are necessity driven actions and there are actions triggered by emotional, psychological, and functional needs of both the caregiver and care receiver. These are transformative action properties that emerge and evolve as stages of transition are realised and transcended. There are action properties issuing from engagement and disengagement, from exposure to experiences of rejection associated with social stigma, or from experiences underpinned with compassion, sensitivity, and acknowledgment. There are demographic anomalies associated with isolation and loss of freedom. There and somatic anomalies consistent with fluctuating states of wellness and physical strength as the caregiver tires and ages.

Beyond actions associated with routine and functional activities, aesthetic action statements that are most frequently enunciated by participants relate to behaviours focused on maximising security and safety and minimising risk of harm for the care receiver, caregiver, and those touched by vicarious impact. One universally definitive property of caregiving, named by every participant as being of the most fundamental significance and concern, is action that poses risk to preservation of dignity for their loved one through and across the gradual loss of independence, identity, intellectual capacity, and functional control.

### 7.3.2 Axiology of caregiving as a matter of values and principles, morals and ethics

It is acknowledged that there are an inexhaustible number of predications about possible experiences that might identify with the construct that is “caregiving for a loved one who has Alzheimer’s”. However, this argument is concerned more with the intention that underpins the doing of caregiving.

It is about the intrinsic need of the caregiver to connect with the care receiver and it is about acting from a platform that is fortified by non-foundational elements such as personal beliefs, values, and principles; and also by foundational elements that underpin moral and ethical value dimensions. These are the motivating forces underpinning the knowledge base that drives the caregiver in the direction of action. The everyday reality that identifies the doing of caregiving is actively constructed, managed, and sustained in
response to need. That need is dictated by transitional changes that mark staged
milestones in the process of progressive degeneration. The care receiver has a need for
care. The caregiver has a need to care.

At the very foundation of personal, moral, and ethical motivators is a core that
comprises multiple dimensions of love – be that at a conscious or a subconscious level
or be that overtly or covertly recognised and acknowledged. As a point of illustration,
reference is again made to Rosalind who did not envisage spending the later years of her
life with a man she no longer loved and to Eleanor who shared that she had moments
when she wished she had left years ago. There are also Isabella and Iris who grew to
love, admire, and respect an estranged parent. Then there is Aemelia for whom the
bonds of sisterhood within a religious community carry special filial attachment.
Incidents, situations, circumstances, and behaviours that defined the action of
caregiving also defined reality for participants who were totally free to believe that what
they knew to be their reality was also their truth – Someone I love has Alzheimer’s.

7.3.3 Axiology of caregiving as a matter of opposing tensions

From the perspective of researcher and as discussed in Chapter Three, Method
and Methodology, and also with reference to Anderson (1998), it is our values and
intentions that allow us to ask the most significant questions while guiding our findings
towards rich and expansive theories regarding the nature of human experience. A
detailed analysis of the tensions between “esthetic” (Lewis, 1946/1950/1962) judgement
and moral/ethical contributory values is outside the parameters of this investigation and
is comprehensively addressed by Lewis and by Wittgenstein (1922/1955/1999/2017).

7.4 Ontology of Caregiving

Turning now to the ontology of caregiving which is about a way of Being, it is
helpful to reflect on Siegel’s notion of the neurobiology of “we” (Siegel, 2008) where
he explores the transformative power of “Being-in-the-world” and references the
concept of I as being more accurately expressed as a concept of We. As an expression
of relationship, We encompasses not only that which is of the singular Self but also that
which is of the world, including all those Others with whom one interacts.
For Heidegger (1927/1962), in “ontologico-Temporal terms”, Being is about “presence” (“Anwesenheit”) (p.47) – “Being-present-at-hand” or “Being-present-in-the-world” (p. 245). In that presence, Heidegger suggests that one is “concernfully absorbed” (p. 247) with that which may be akin to what Murray (2005, 2016) refers to as the world that is. It is “Being-there”, concernfully present with Other or consciously concerned about what is happening for Other: and as well as being another person (care receiver, medical or allied health professional, person in the street, or anyone at all), Other may very well be the unconscious Self. Whether it is about relationship with other persons or relationship with other self, “Being-there” is about impact and confirming the internal relation between “human being” and “world”. It is about caritas. It is about unconditional positive regard. It is about being present to Self while also being present with Other.

The emerging hypothesis suggests that the way of Being-in-the-world of caregiving is incomprehensible in isolation from knowing about caregiving and doing caregiving. In essence, Being is about Being-there. Thus, it is implied that understanding the way of Being-there or Being-in-the-world or Being-present-in-the world impacted by caring for a loved one who has Alzheimer’s, is also incomprehensible in isolation from an insight into the world where one is concernfully absorbed. Herein lies its transformative power, as reflected in words shared by Yori:

I never imagined that I would be looking after a grown-up baby. I had to learn and I did learn new skills. I always had him around to do the “blokey” stuff. Now I do everything. I change the washers in the taps and I do the house maintenance. I look at him as he stares and I wonder, “Who are you and where are you? Give me my husband back”. And as he changes with the coming and the going of each passing day, so do I.

7.4.1 Ontology of caregiving as a repositioning of identity

As the tapestry of the collective narrative grew, it became evident that as degenerative transitions merged and as the processes of everyday living shifted and changed, there was corresponding movement in conscious awareness. No longer was there a sense of security in knowing “who I am”, “who You are”, and “where We fit in the world”. Repositioning identity became inexorably linked with loss of freedom,
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: redefining of roles and relationships, social isolation, social stigma, and preservation of dignity. Gratification of higher order needs became secondary to the need for survival: on both an emotional and physiological level.

One can only begin to imagine the internal tensions when an adult child is asked by a parent, “When did you become my mother?” (Helen asking of Alice). One might also ask how Being-there presents for a wife of 40+ years when she is referred to as, “That lady next door – oh, you know, what’s her name?” (experience of Angelica, as reported by Rosaline), or the wife of 48 years when she is referred to as, “That young hussy who tried to climb into bed with me” (experience of Alexas, as reported by Elan). As caregivers’ journey with their loved ones, their position of knowing who they are in relation with self and in relation to others continues to cycle through an infinite loop of dynamic transformation. Friends become as strangers, as those who were thought to be friends withdraw. “What would be nice”, says Rousillon, “would be if some of my so-called friends could pick up the phone and just say, ‘How are you going?’ Just a minute or two slows the cycle and says that someone cares.”

What also emerged in the findings was a deepening of personal growth and appreciation of Self, as expressed by Elizabeth when she states, “I’ve become stronger and more vocal and speak out more often. I speak up and stand up for myself and my family and I’m happy about that.” In other circumstances, anonymity of being just another person in the crowd is replaced with moments of Being-there in the spotlight of embarrassment, as the social behaviours of the care-receiver transition to behaviours that are anti-social, attention seeking, and embarrassing. Such was the experience for Audrey when Ratcliffe said to a young mother pushing a toddler in a stroller, “That kid should be pushing you”.

Even for the care receiver the relationship with Self is transformed, as exemplified in scenarios when a “new best friend” or an “invading intruder” is found in the mirror or in reflection in a window. Transformation within the family is evidenced as filial relationships become strained and estranged relationships reconnect. Across the broader collective, social and professional relationships impact on the caregiver’s sense of self-worth, influencing a repositioning of identity associated with a self-sense of capability and competency. Given the changes in lived experience and the ways in which others treat both caregiver and care receiver – be that with empathy, sensitivity,
and respect or be that in ways that reinforce social stigma and a sense of isolation – perhaps the getting of wisdom could be said to come with building resilience and the development of a stronger sense of Self. Maybe the hypothesis is that for the caregiving journey (or any life-journey experience) to have a positive outcome, one needs to pass through a dying process or a shedding of one’s “old skin” in a process of dynamic transformation.

Acknowledging and accepting that life is what it is in any present moment in time, demonstrates that when love underpins all that is good, bad, or ugly, one can compose a sense of Self that rises above the transformative energies of degenerative transitions. The intrinsic power of the love through which caregivers identify with their loved one who has Alzheimer’s, needs to be acknowledged. For those whose stories are woven into this narrative, Being-there acquires a “meaning of reality” (Heidegger, 1927/1962, p. 245). In their presence, caregivers have demonstrated an inner strength that, even in the worst of times, and even when love is waning, surmounts all obstacles.

7.4.2 Ontology of caregiving as impacting the relational self

As stated by Moir-Bussy (2006), the “relational self” stands in contrast to the “individual self”. This position was evidenced as participants applied processes of introspective reasoning when reconceptualising and reframing perceptions and conceptions that defined the reality of lived experience. Presenting the notion of variations in one’s sense of self in terms of an interpersonal social-cognitive theory of the relational self, Anderson, Reznik, and Glassman (2005) posit the notion that what is assumed, is that significant others play a critical role in self-definition and self-regulation – the essence of the relational self. This notion of the relational self is what Being-there is all about. For the participants in this study, the relational self (or the self-in-relation), is central to the processes of reconceptualisation and reframing. Linking participants’ conceptions of Being-there, the importance of relationship permeates the parameters of each of the seven themes that profile the collective landscape of caregiving: as illustrated in the Findings, Chapters Five and Six.

From an empirical perspective, Whitehead (1929/1957/1978) postulates the notion that the relational aspects of the lived experience are about the internalisation of data. By way of clarification, he claims that “our datum is the actual world, including
ourselves” (p. 4): the “actual world” being that which is applicable and adequate in relation to the immediate “matter of fact”. In this instance, that actual world is defined by the construct of caregiving and the matter of fact is Being-there: fully present and concernfully absorbed. In this space, there is playing with inconsistency while throwing light on the consistent and persistent elements in experience. Such is the scenario as described by Rousillon when she shares:

Talking about it and living with it are totally different. I cope with what I’m coping with and what every other caregiver is coping with is different. It can’t be categorised and it’s not one hat fits all.

When reflecting on the notion of the relational self, Anderson and Chen (2002) speak of how knowledge about self is linked with knowledge about significant others, with each linkage embodying a Self–Other relationship. As a result of the entanglement of these ties that are defined by diverse and multiple relationships with significant others, one’s sense of self (or the relationship that one has with Self) is not static. Rather, as a function of relationships, one’s sense of self varies across time and across contextual scenarios. Values, principles, thoughts, feelings, motives, and self-regulatory strategies are impacted in both conscious and unconscious expression. How one acts according to these influences is also impacted which, in turn, impacts and initiates a momentary shift in the knowledge base.

In concert with identifying the internal and external positions of I as defined by Hermans (2012) and discussed in Chapter One, Context, there is also a space for conceptualisation of Self in terms of “a dynamic multiplicity of relatively autonomous I positions” (Hermans, 2001, p. 248). In this conception, Hermans (2001) claims that as the I fluctuates between different and opposing positions, it has the capacity to give voice to each position and so establish dialogical relationships between positions. Each voice has a story to tell and as stories are shared and interwoven, the result is a complex, multivoiced constructed image of the relational Self: the Self who is caregiver, daughter, son, spouse, partner, parent, brother, sister, colleague, neighbour, friend, citizen, …….

The relational Self is also the one who seeks information and has a right to empathic and respectful professional support. It is the Self who laughs and who weeps. There is the Self oppressed by the burden of stress, and the Self grieving the loss of the world that was and the loss of the loved one whose persona is dramatically transforming with the
passage of time. The embodiment of the relational is the *Self-Being-there in the world that is*. This is the *Self* who has a story to tell.

### 7.4.3 Ontology of caregiving as transformation

As stories unfolded, participants owned the roller coaster of emotions and the action tendencies produced by what Hermans and Hermans-Konopka (2010/2012) defined as “organismic positions” which permeated the collective narrative and became part of the interplay of positions at the interface of the biological and the social (as referenced above, 7.3, *Axiology of Caregiving*). What emerged from the collective narrative is that data items do not simply relay the events of “yesterday”. Rather, they reconceptualise and reframe events that denote milestones in transformation. Throughout the dialogic interchange, there is reflection, introspection, and dialogue: internal dialogue within the participant’s own conscious awakening; and external dialogue with the researcher, who came to the dialogic interchange with inside knowledge and understanding.

The essence of transformation has been captured in reconceptualisation and voiced in the sub-theme, *The Good* (Chapter Five, 5.3.1). While subconsciously incorporating philosophical underpinnings of traditions that inform the ways in which people behave, communicate, relate, and think about things, participants have delved into the essence of their *Being* to find the good in all that is bad and ugly and they have emerged victorious. Amazing transformations occurred in the interpersonal relationships between Isabella and Orsino and between Iris and Adriana. Parents who engendered fear (Orsino) and rebelliousness (Adriana) became gentle and loving in the state of advancing Alzheimer’s. Children who had been fearful (Isabella) and rebellious (Iris) came to love and understand. As a window opened, a previously unknown life story was revealed. Past becomes present and a veil of childhood trauma is lifted and removed to be replaced with understanding, compassion, and forgiveness.

Transformation also embraced a re-evaluation of priorities as exemplified in the stories of Elizabeth and Richard. Families bond (Alex, Alice, Angelica, Antony, Emily, Emma, Ephesea, Jason, and Vince) and families are torn apart (Elise). Personal transformations are expressed in terms of growth in resilience, patience, awareness, acceptance, and creativity. In addition, just as virtues have grown, vulnerabilities have
been transformed as a tendency to criticise is replaced with a search for understanding; as a potent need for control is tempered with curiosity; and as dependence on another falls away when the need to take control brings forth untapped strengths. Reflecting the symbolism embodied in Richardson’s image of a transgressive *crystalline* validity (Richardson, 1997), what is observed is that multiple layers of meaning are reflected, refracted, and seen as “human currents” carrying elements of truth, feeling, and connection (Lincoln & Guba, 2000, p. 182). These currents are revealed through processes of dialogic interchange and embrace sensory engagement, discovery, telling, storying, re-presenting, re-specting, and empathising. The symbolic essence of transformation is encapsulated in the theme *A Maze of Metaphor and a Simile or Two* (Findings, Chapter Six).

### 7.5 Summary of Discussion

What makes this research contribution significant is the uniqueness of Alzheimer’s disease combined with the co-related uniqueness of the caregiving role. Alzheimer’s is different from other diseases in its presenting symptomology, the progressive nature of cognitive and functional degenerative transitioning, changes in the architectural structure of the brain, and the duration of time spanning the trajectory of transitional changes and the trajectory of care. Also of significance are aspects of incidence and prevalence that identify Alzheimer’s disease as a modern-day epidemic impacting social and economic resources on a scale of concern that is unprecedented at global, national, and state levels: as discussed in Chapter One, *Context*.

While sharing many common elements with caregiving in many circumstances, caregiving and the impact of caring for a loved one who has Alzheimer’s disease is also different. When dealing with other conditions, maladies, and diseases, presenting signs and symptoms prompt a visit to a medical practitioner or other health care professional immediately or in the early stages of progression: for example, variation in states of consciousness, fainting, bleeding, pain, changes in body temperature, shifts in blood pressure or pulse rate, shifts in blood glucose levels, deformity, rash, skin irritation, nausea, or a general disruption to normal functionality and/or wellness status.

From a generalised perspective of diagnoses, professionals look at things from an outside, objective, and foundational frame of reference. They deal with the signs and
symptoms and the diagnosed condition is healed or regulated. Both patient and caregiver know what is happening and they know what to expect. Caregiving is time bound with a view to a foreseeable end. Impact is managed accordingly. With Alzheimer’s disease, observable change is subtle and caregiving need is unpredictable and inconsistent. Incremental changes are not registered until an incident occurs when, in retrospect and in metaphorical terms, “the dots are joined” and there is an epiphanic moment of recognition that, in the words of Alice, suggests, “There’s a process going on, here.” What is changing is the brain and changes are not measurable for a very long time. Diagnosis is generally made with reference to behavioural changes that can take decades to become consciously and consistently observable. For example, Adam’s diagnosis followed eight years of his undergoing various processes leading to confirmation. For Brian and Heather Fischer, Brian’s diagnosis was a process that spanned 11 years (personal communication given by the couple in an interview profiled on *Four Corners*, July 10, 2017).

### 7.6 Implications

The epistemology emerging from this investigation is that the impact of caregiving for a loved one who has Alzheimer’s is timeless, constant, intense, inconsistent in levels of intensity, isolating, lonely, oppressive, and internal. Dynamic transformation is a long, slow process that can be both empowering and disempowering. Finally, the point is reached when maintenance of well-being is at risk and intrinsic variables begin to approach near lethal levels. This discovery also demonstrates the power of the narrative to breathe life into experience and to bring an awakened awareness to that which has been buried in the depths of the subconscious.

As caregivers travel along the many pathways that define their journey, reality is exposed as it is lived. Understanding how individuals change in resonance with the internal dynamics of introspection and reflexive repositioning is facilitated. For participants in this research investigation, reconceptualising and reframing lived experience has been a unique, personal, and relational process that has awakened acknowledgment of the dynamic transformation that has been progressively evolving. The study also demonstrates that, for these caregivers who reside in South-East Queensland, there is “common ground” which makes the construct of caregiving a
collective experience, as unique in its entirety as is each caregiver, each care receiver, and the individual convention that profiles Being-there: in a world where one is concernfully absorbed in caring for a loved one who has Alzheimer’s. The findings reveal that there is also common ground across cultural background, gender, age, faith, lifestyle, education, career, relationship, and duration of care. Considered in relation to a global platform, elements of common ground are also shared with caregivers from beyond regional and national boundaries as profiled in Chapter Two, Literature Review.

Each caregiver sees Self as a relational being and as contextualised in Chapter One, Context, the relational self is a dialogical self which, according to Hermans (2004/2016), “can be seen as a theoretical effort to extend the self from a self-contained entity to a process that is extended to the other person” (p. 14). Beyond the person of Other, the relational Self is also extended to the wider community: a concept also embodied in Siegel’s thesis pertaining to the neurobiology of We (Siegel, 2008). In this space, there awaits a world where, in the words of Hermans (2001), “contrasts, oppositions, and negotiations are part of a distributed, multivoiced self” (p. 245). The process of dynamic transformation moves beyond the “foundational object of caregiving”63 when it becomes a consciously relational experience and emerges as the “anti-foundational subject of caregiving”64. Only then, can it begin to involve a dynamic evolution of personhood.

7.6.1 – Implications for caregivers

Throughout development of the collective narrative that profiles the findings, participants have told their stories of the impact of caring for a loved one who has Alzheimer’s disease. These are feet that have walked through the caregiving maze. These are voices that embody a constructed truth as they portray the stark reality of a lived experience that is like no other.

As lived reality was brought to conscious awareness in the telling of stories, the cycle of dynamic transformation was revealed. The conversation that is required for a

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63 Profile in concert with a Husserlian descriptive framework as discussed 3.10, Validity: Rigor, Authenticity, Trustworthiness

64 Profile in concert with a Heideggerian interpretive framework as discussed 3.10, Validity: Rigor, Authenticity, Trustworthiness
dynamic transformation in attitude across the broader social collective is one which takes place in dialogue where there is trust in revealing what is on the inside while engaging in multivoiced interchange. If there is to be change, caregivers will be the voice of change. Caregivers have the power to bring violations to personhood to the arena of public awareness. Each needs to Be-there: acting in a spirit of authentic caritas. By standing together and by continuing to testify from a multivoiced platform, caregivers have the power to make a difference. What is also required is that knowledge continues to be disseminated through multimodal representations that encompass educational, social, and political action; while engaging perceptual, sensory, cognitive, and testimonial facility.

Caregivers hold the knowledge that is at the very core of lived experience. Post caregiving, experienced caregivers also have the opportunity to light the pathway for novice caregivers so that their journey through the maze of transitional degeneration may be illuminated and hence, a little easier to negotiate. An example of just such a model of outreach is encapsulated in the work being undertaken by Vince and Lorrae O’Rourke (referenced in Chapter Four, Participant Profiles in Context). Other examples of outreach to the wider community are exemplified in the political action initiated by Elise, the pathway of psychiatric pastoral care being followed by Nerissa, and the voluntary support being given by Antony and Isabella.

7.6.2 – Community awareness

From a personal stance, Elise has demonstrated her preparedness to engage in ongoing dialogue with a view to bringing about the transformation of community attitudes. Vince is also disseminating knowledge through his consultancy practice. From an organisational stance, so much work is being done by Alzheimer’s Australia and the associated State branches. Yet, the message is not being received and not resonating in the consciousness of the wider community. Further steps need to be taken to address social stigma and to enhance public awareness.

The challenge for counsellors and all allied health professionals, nursing care managers, support associations, government gatekeepers and agencies, and medical practitioners, is to listen to the collective voice. It is the caregivers who have the lived experience. They are the holders of the knowledge and they can provide the empirical
data. They know the reality and it is only through the lived reality of Being-there, that wisdom is won and can be shared and that improprieties and injustices can be exposed.

7.6.3 – Professional training

While the importance of disease specific research that focusses on cure and prevention cannot be minimised, the place to initiate emancipation of those disempowered by the burden of care is in relevant and transpersonal training of all personnel who engage with caregivers and care-receivers on the front line of service delivery. What is needed to enhance this engagement is conscious awareness of the vulnerability of caregivers and care receivers and empathic engagement in dialogic encounters that are not, as Fineman (1993) would term, “emotionally anorexic”.

First and foremost, general practitioners, specialist gerontologists, allied health clinicians, respite agencies, formal nursing care agencies, hospital staff, information and service providers, funding agencies, and government agencies need to understand that the impact of caring for a loved one who has Alzheimer’s disease does not fall within the parameters of traditional care. As demonstrated by Bredesen (2017) and profiled in 1.8, About Alzheimer’s and Dementia, more than a medical model is needed. What is needed is a training model that incorporates components that inform and are designed to promote greater understanding of the impact of caregiving and greater appreciation that both the patient and the caregiver are persons with basic human rights, feelings, and emotions; and that they deserve and need to be acknowledged with respect, sensitivity, and compassion. Training packages for people on the front line of engagement with caregivers and care receivers need to be designed and developed so as to enhance knowledge and appreciation about the uniqueness of Alzheimer’s disease, the uniqueness of the degenerative process as it morphs into an Alzheimer’s related dementia, and the uniqueness of the impact of caregiving.

Modules that focus on inter-personal communication need to be included. Empathic engagement and development of an appropriate professional manner when representing a care related industry are not options. They need to be professionally embraced as ethical givens. Caregivers look to the medical fraternity for advice, guidance, and support. When the caregiving transitions to a full-time commitment, general practitioners are often the only “normal” persons with whom some caregivers
engage. All persons who hold professional roles need to know that, as reflected in the writings of Hochschild (1983/2003) and Fineman (1993), their work involves adopting an emotional attitude appropriate to their role, their job description, and their duty of care. Engagement that challenges the “taken-for-granted” and the “known-and-accepted” is not just desirable. It is essential – particularly if the promise to patients and families, that they will not be abandoned (ASH Education Book, 2008, quoted above 2.14, End of life), is to be taken seriously and applied to all facets of patient care.

7.6.4 – Processes for accessing information and support

With specific reference to the demographic represented in this research project, the primary portals for accessing information and support are Alzheimer’s Queensland, Carers Queensland, Queensland Health, and denominational support services such as Anglicare, Blue Care, and CentreCare. While a comprehensive list of agencies and local support services can be accessed on the websites of Alzheimer’s Queensland and Queensland Health, there is a pattern among caregivers of not accessing these services. Reasons given are many and diverse. Those most commonly expressed relate to the time taken to navigate a way through due process, tiredness, and the need to sleep when what might be considered as a “free moment” presents itself.

Inconsistency in support personnel who deliver home care and respite services is also cited as being a significant factor, as change can escalate agitation and anxiety for the care receiver and hence it is considered to be easier to forego respite than to try to implement “damage control” strategies. The presenting attitude of some staff poses a further issue associated with the choice to not access services as those caregivers who have been subjected to “hostile”, “demeaning”, and “belittling” encounters choose to protect their loved ones and themselves from risk of additional emotional distress.

A key point of significance is stated as being the lack of relevance to the unique needs of the individual care partnership of caregiver and care receiver. For example, support structures that are designed to meet the needs of a spousal or partnered caregiving relationship are said to be not relevant to the needs of a child/parent or friend/friend caregiving relationship.

An additional factor is organisational scheduling; for it is stated that times when
information sessions are scheduled tend to coincide with times when care receivers are at their most demanding and caregivers are at their busiest. It could be ascertained that there is a miss-match between support services that are available, caregiving needs, and caregivers’ facility to access support services. In simple and practical terms, the price to procure access to services is too high.

7.6.5 – Review of service delivery

While each story is unique, within the diversity of the collective there is reflected a sense of unity and oneness. The landscape of impact profiled in the collective narrative is in concert with the portrait of impact presented in the Literature Review. Common elements are shared in the stories of those whose journey has just begun, those in the midst of their journey, those whose cycle of impact has progressively slowed, and those whose infinite loop has ceased to revolve following the impact of catastrophic failure as the mortal life of the care receiving loved one ends. Many common elements are also shared across cultures, genders, duration of care, age, and relationship.

There are services available. Yet, as discussed above, there are many caregivers who choose to not access these services for diverse reasons. Service providers at local, national, and global levels need to ask the question, “If so much is being done to support informal caregivers, why are so many not accessing those supports?” The dialogue needs to continue, and the power needs to be transferred to those who need the support and the service. Of specific significance is the need for support structures where the focus is on empowerment for both caregiver and care receiver across all stages of transition and where there is a strength-based orientation towards what the one with the condition of Alzheimer’s disease is able to do, rather than a deficit-based emphasis on degeneration.65

What is also emerging is a widespread need for flexible service delivery. Electronic and mobile in-home skills training service is the way of the future. There is a growing need for mobile psychosocial therapy and in-home self-care packages for caregivers – inclusive of exercise equipment and/or access to services of an exercise physiologist, a personal trainer, masseur, hairdresser, and dietician or nutritionist.

65 Such programs could mirror the Dementia Without Walls Program undertaken in the UK, June 2012 – December 2015 (The University of Edinburgh, 2015. [Blog]).
Knowledge-enhancing and self-care services would also provide opportunity for social interaction while freeing the caregiver to access services of choice.

External services need flexible scheduling so that caregivers can access when loved ones are settled and when a “friendly face” can give respite in a “safe space” that is familiar to the care receiver. Reflecting on the reasons given above (7.6.4, Processes for accessing information and support), it is apparent that there needs to be a review of service delivery – inclusive of not only the what, but also of the how, when, where, and who – so that when they are at their most needy and most vulnerable, caregivers can access information, support, and/or service. A service that is not accessible is a service that is not provided and a service that does not get to where it is most needed, is a service not delivered.

7.6.6 – Review of formal care

Participants have shared stories of many incidents that identify need for review and for accountability processes to be actioned within the formal care sector. For participants whose loved ones have traversed the transition through death in nursing homes deemed to be bereft of loving kindness, the dream is that lobbying by those who have inside knowledge will help to divert government funding so as to support families in keeping their loved ones at home, where they are in a familiar environment and are surrounded by love. Such is the lack of trust in formal care provision. There is need for staff in nursing homes and in respite and hospice care centres to have knowledge and skills relevant to the care of persons with dementia, which includes engagement with families and with residents.

Residents are also entitled to expect that staff speak English. And if a care facility chooses to admit a resident whose language is other than English, caregivers have a right to expect that there are staff members, on all shifts, who can communicate with their loved one, in their first language.

Levels of cleanliness and hygiene present as a major concern. Standards need to be “policed”, sanctions need to be enforced, and penalties need to be applied. It would seem that Workplace Health and Safety infringements are common place, yet penalties are few and far between. With the national projected annual cost of dementia care being
predicted to reach to $18.7 billion by 2025 (Alzheimer’s Australia, 2017), there needs to be thorough investigation into how expenditure can best meet the needs of care receivers and caregivers.

Accountability measures need to be installed and enforced. If funding is to be allocated to residential facilities, these facilities need to be more than bricks and mortar. There needs to be a vision whereby the care culture is underpinned with the spirit of caritas; where medical care and palliative care are available to all residents; where residents know joy and have freedom to move about; where creativity underpins engagement; where staffing/resident ratios equate to care need; where family are welcomed as important members of the care team; and where dignity and respect for personhood are reflected in operation.66

7.6.7 – Implications for counselling and professional supervision

Considering implications that have emerged in relation to caregiver well-being and speaking from the position of Professional Supervisor, I see a need to challenge counsellors, psychotherapists, and those in mentoring positions. As allied health practitioners, we each have professional responsibility to be able to recognise, to appreciate, and to not minimise the potential scope of role-related impact. There is also ethical responsibility to validate approaches and techniques used in therapeutic practice focused through a diagnostic framework for working with suppressed or unidentified secondary trauma. I also see need for clinicians to be consciously aware of ethical guidelines and commit to maintaining professional standards in the delivery of service where empathy, sensitivity, respect, and appreciation of the uniqueness of the caregiving relationship are the defining tools of engagement. Professional responsibility also extends to developing training materials designed around the enhancement of knowledge and skills for clinicians who work with caregivers.

An indirect implication that emerges from the research findings is the need for professional supervisors and clinicians to develop a conscious awareness and an acute sense of discernment in relation to the diversity of presenting scenarios that could be triggered by change-related factors. An associated impact could be a cycling of

66 As exemplified in the village/neighbourhood model developed in the Netherlands and being replicated across Australia in Hobart, Bendigo, and the Sunshine Coast. Refer Appendix K.
dynamic transformation set in motion by a shift in the client’s values base, a violation of expectation, a disruption to lifestyle, or a polyvagal disturbance to maintenance of emotional well-being and balance of intrinsic variables.

When a client seeks our support, we each have an ethical responsibility couched in duty of care to always be conscious that, in a re-contextualising of Alice’s comment, “There’s a process going on here”. All may not be as it appears to be on the surface level of initial presentation. When engaging with clients, there is no place for diagnostic assumption or for apathy in taking implications of a presenting scenario for granted. The question always needs to be asked of the Self of the clinician, “Is what I see on presentation really what I am getting; or are there deeper unidentified and/or suppressed factors that need to be brought to the surface and released?”

Being in the world that is, (Murray, 2005, 2016) is what brings a client to the counselling room. And while the world that was (Murray, 2005, 2016) can never be reclaimed, it is our responsibility and our privilege to walk with our clients as, together, we discover a pathway to the future (Murray 2005) where, in the best-case scenario, the stepping stones to wellness are stamped with a footprint of resilience that denotes a balancing of needs gratification; and where the light at the end of the tunnel is not a big train. Rather, it is a ray of sunshine, breaking through the darkness to the dawn of a new day.

7.6.8 – Strengths, limitations, and potential for future research

This investigation has been a journey of engagement, employing a hybrid methodology comprising a triangulation of research approaches. The strength of the hybrid lies in its honouring the richness, diversity, and sensitivity of experience that is shared by the multiple voices of participant caregivers and those touched by vicarious connection. Under the overarching umbrella of a qualitative paradigm, design, data collection, and analysis strategies were implemented within a framework of social constructivism which, according to Lincoln and Guba (2000), embodies an epistemology whereby the truth of related knowledge lies in created findings that are both transactional and subjectivist.

A further strength relates to process – particularly within the structure of the
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland

dialogic interchange whereby participants were totally free to share as much or as little of their reflections on lived experience as they chose to disclose: without the distraction, encumbrance, predetermination of outcome, and external direction of invasive questions. Given the flexibility woven into the process, participants’ stories are imbued with a subjective truth that is born of spontaneity and the real immediacy inherent in the relational world as framed by Petitmengin-Peugeot (1999) and Anderson (2011). As stated above, for those who shared their stories, experience has been a unique, personal, and relational process that has awakened acknowledgment of the dynamic transformation that has been progressively evolving. From this experience, they have emerged stronger persons.

Additional strengths include participant-focussed dialogical engagement where accommodation of the participant’s choice of venue for dialogue and modality of expression was of paramount consideration. Abandonment of time limits and freedom to use multimedia resources to enhance the intimacy and the depth of the self-narrative was acknowledgment of the sensitivity of the subject and the vulnerability of the storyteller.

Perhaps the greatest strength was the researcher coming to the investigation with inside knowledge and lived experience. This, I believe, was a major contributing factor in strengthening trustworthiness. While inviting connection that touched what Jones and Hermans (2011) referred to in terms of the imaginal space of the intrapersonal domain, a dynamic multiplicity of what Hermans (2012) referred to as I-positions was revealed – all of which came together in dialogic interchange.

Strength of the participant demographic is represented in diversity. There is no differentiation between the positions of male and female gender as either care receiver or caregiver. There is a broad spectrum of age, relationship, socio-cultural/socio-economic background, and religious affiliation. Additional factors that reflect diversity include lifestyle orientation, education, career history, experience in the role of caregiver, position along the scale of stage transition and the trajectory of care, and duration of care. A limitation of the participant demographic is the localised constituency: the result being that the data corpus is not generalised to all parts of Australia nor to regions further afield and distributed across the world. However, this
localisation is counterbalanced by the strength of qualitative research being in-situ. Adopting a constructivist approach also brings insight to the subjective experience of every-day living for a specific and localised demographic, within the broader social construct of family care in Queensland: without the presumption of universality. While not representative to total populations and while also limiting the profile of participant contribution that constitutes the data set, there is advantage in generalising to the theory and laying a foundation for future research.

Future researchers are invited to use my localised qualitative findings to drive investigation that goes ahead and digs below the footings that underpin this foundational contribution to Alzheimer’s related research. Employing quantitative methodology, there is potential for future research to tap particular areas of need with a view to directing funding to where the need is greatest. Considering potential for further development, this seminal research might also be utilised as the basis for more positivist approaches in order to establish representative findings or to further develop relative strengths of each of the themes as in-future factors. By revisiting individual emergent themes or sub themes from a platform of critical theory, future research could focus on specific aspects such as the unequal distribution of power and the social forces that contribute to a proliferation of scenarios characterised by social stigma, professional apathy, and social isolation as experienced by both care receivers and caregivers.

Conflict as a concept within and across the various stratum of social status might also be investigated from a platform representative of conflict theory ideologies. Topics that present scope for consideration could include investigation of a social model of disability, the prevalent culture of wellness and productivity, gender differentials, socio-cultural and/or socio-economic inequities, division of labour, unequal distribution of resources, unequal access to support structures, and institutional internal politics. Herein lies potential to research related issues from positions of feminist theory, post-structural theory, or theories of globalisation and international systems as might be representative of a Marxist approach. Each of these approaches provides an ideal

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67 For example, development of measurement scales around constructs such as knowledge accrual; characteristic caregiving behaviours; motivational factors such as values, filial duty, cultural traditions and/or expectations; transitionary change; role division; and/or identity shifts.
platform from which to focus on the consumptive transformation of health and the health industries as might well illustrate “first-world” priorities being in contrast with “third-world” concerns.

From a platform of conflict theory, it might be argued that our natural site of caring has been eroded by the modern capitalist system which is individualistic and markets needs as consumptive on every level. The outcome is an emergence of labour or work systems which fracture traditional family structures and then require the health and caring systems to be contracted out and consumed like all other commodities that are sold. The authentic original sites of both production and consumption are torn apart, and consumption is rendered separate to production. The result is that consumption drives the outsourcing of so much that was once an integral part of family/village life – for example, care of a loved who has Alzheimer’s, or any other life-changing and degenerative condition (Adorno, 1991; Adorno & Horkheimer, 1944/1993/2002; Veblen, 1994).

A topic definitely worthy of future in-depth focused research is what Hochschild (1983/2003) refers to as “emotional labour” and Fineman (1993) references as “emotional anorexia”. Under an overarching umbrella of organisational theory, the broad spectrum of human relations and service delivery needs addressing. The impact of how support organisations, residential facilities, and specialist medical services interact with this thesis through reading the expressions of participants and choosing to evaluate and act on service delivery cannot be minimised. Processes of engagement with consumers need targeted review and intervention.

7.7 A Journey Completed

Findings profiled in the collective narrative have provided answers to the research question. Insight into the socio-cultural construct of caregiving was gained through participants’ sharing of personal and intimate stories: self-narratives that are

68 That is, the family as extended and inclusive of grandparents, parents, and children: all living together in a home or village.

69 For example, the model of care within the family and the village as referenced by Isabella in 6.4.4.2, Self care, - “…….. it also takes a village to care for that child: right up to the end of life”.

The collective reality from onset to end of life and beyond. Judith R Boyland
multidimensional in emotion, rationality, reality, conscious awareness, and functional response. Persons who were feeling lost, lonely, overwhelmed, and disempowered delved into the inner depths of their Being and, intertwining elements of the intuitive, heuristic, transpersonal, and spiritual Self, they stepped outside their own personally constructed “safe space” and came together in an authentic and multivoiced, dialogic interchange.

The collective narrative is more than a gaggle of voices or a collection of individual data items. It is a story of dynamic transformations that move from inside to outside, from outside to inside, and are in constant motion. It is a very private story played out in a very public arena. It is a story of frustration and fear, disillusionment and despair, faith and hope. It is a story of loss and grieving. It is a story of personal growth and wisdom in a world of degenerative functionality. Above all else, it is a love story: and the voices of the story tellers have been heard and acknowledged.

The journey goes beyond knowledge, aesthetics, values, and Being-there. The journey has the potential of enabling the caregiver to see and embrace complexity, to traverse unknown territory, to reconceptualise and reframe life experience, and to be open in allowing and acknowledging the dynamic transformation that occurs in the “aha” moment of epiphanic discovery. The participants in this study have engaged in these processes, have been challenged by them, and continue to search creatively for ways of moving forward to a life beyond Alzheimer’s. In the telling of their stories, caregivers have also opened the door to future research that has potential to build on this foundation and construct a future devoid of hopelessness, social stigma, professional apathy, and social isolation for those caring for loved ones who are living with debilitating and degenerative diseases.

While supporting participants as they delved into what Jung (1961/1983) described as “the fruitful bottomlands of [their] psyches” (p. 402, cited above, 3.5, Data collection), I, also, experienced a dynamic transformation as I found and lay to rest my own unresolved demons. My personal and professional journey has been deeply enriched by the dialogic interchange with others who traverse the trajectory of care. The insights that I have gained have the power to make me a more enlightened person, a more attuned clinical counsellor, and a more evocative professional supervisor.
Through processes of professional supervision, I am in a position to better monitor and promote the welfare of caregiving clients seen by supervisees. I am also in a more informed position to promote development of supervisees’ professional identity and competencies in supporting those who are caregivers for loved ones – whatever the context of care might be. While the specific context of caregiving in this project has been Alzheimer’s disease and Alzheimer’s related dementias, learnings have potential to be applied to a broader spectrum of caregiving: particularly when the condition of the care receiver has a pathogenesis of cognitive and/or functional degeneration.

7.8 Conclusion

I began the investigative journey in a quest to answer the question, What is the holistic and collective reality of caregivers’ conceptions and understandings about the impact of caring for a loved one who has Alzheimer’s disease when the trajectory of caregiving spans from onset to end-of-life and beyond?

Motivation in undertaking this research project was a professional curiosity in search for insight. The evolution of curiosity was fed by a desire to understand the impact embodied in a landscape that profiles the relationship between caregiver and the experience of caregiving. I wanted to discover and disclose the power of love by exploring the dimensions embraced by what one does in the name of love from the inside position of negotiating a social construct broader than my own lived experience.

This study has identified that for caregivers, the experience of caregiving is more than a task. It is an intensely personal and relational experience. It is an evolving journey of dynamic transformation, beginning with an intuitive knowing that something about the person of somebody who is special to me is different: and that which is different is not OK. Attitudes and behaviours are changing. This significant other for whom I hold unconditional positive regard is doing weird and strange things. Not only is something not OK: something is terribly wrong.

Values, principles, expectations, and obligations begin to be reconciled as caregiving activities replace the “normal” activities of daily life as I know it to be. The Self that is revealed is a reflection of realities embodied in the lived experience of caring for a loved one, who has Alzheimer’s. As “my participants” discovered and shared their
stories “I, the researcher”, was also led to discover images and meanings that were relevant not only to the investigation of the research question, but also to the realisation of an intrapersonal transformation related to my own inside experience as caregiver for my father who had Alzheimer’s disease.

In Chapter One, the context was set by sharing something of my own personal and professional journey and by reviewing literature related specifically to dialogic interchange, Alzheimer’s disease, and the historical development of informal caregiving. In Chapter Two, literature related to the social construct of informal caregiving was reviewed and presented a global perspective of the impact of caregiving. Chapter Three discussed the design and implementation of a hybrid methodology, considered to be the best modality for engaging in this anti-foundational and empirically driven research project. Chapter Four introduced participants, and Chapters Five and Six profiled the findings through the genre of collective narrative. The thesis is drawn to completion in Chapter Seven, where the impact of caring for a loved one who has Alzheimer’s disease is identified as a process of dynamic transformation.

Thus, when the last word has been processed, voice will have been given to those who care for loved ones who have Alzheimer’s. From the items distributed across the portfolio of stories that constitute the data set, individual threads have been drawn, intertwined, and woven across the warp of a hybrid methodology. As the collective narrative evolved, data extracts breathed life into a landscape that profiles the impact of caregiving. It is this multivoiced profile that illustrates and defines reality and using the reference of Denzin and Lincoln (2005) as cited in Chapter Three, *Method and Methodology*, not only does it portray a clearly defined sense of complexity but it also enables that complexity to emerge as a meaningful emotional whole. In dialogic interchange, application of intuitive, narrative, heuristic, and transpersonal processes led this investigator to discover, identify, and interpret new images and meanings while also framing new realisations relevant to my own experience and to my own personal and professional life.

In summation, I am now able to “talk the talk” and to use my voice to speak as one with every caregiver who cares for a loved one who has Alzheimer’s. In our darkest moments, we may be feeling as if set adrift in a surging sea or tumbling...
aimlessly amidst the shifting sands: having no control and no sense of direction. We may be feeling lost in a maze of emotional turmoil or overwhelmed by an enveloping cloud of unknowing. Yet, we carry on. We have climbed free from the depths of despair and have walked through the darkest forests of delusion.

Caregivers profiled in this narrative have tackled a task that is long, hard, awful, sad, scary, oppressive, and lonely. Yet, amidst all that is “bad” and “ugly”, there have been the most amazing breakthroughs in conscious awareness, personal growth, and relational healing. Whatever stages of transition their process of dynamic transformation has cycled through, they have survived. Through the journey, there has been growth in knowledge, understanding, and wisdom. There has been attitudinal, behavioural, and relational change.

Caregivers have been confronted by an authentic Self as they have cared for Other. They have faced their demons and owned their vulnerabilities and in the darkness of their souls, they have wept a million tears. Through it all, they have learned to ride this “roller coaster to hell and back” (Hal). They have learned to seek the beauty in that which is “horrific beyond imagination” (Richard). They have learned to conquer a loneliness that can be “neither described nor quantified” (Antony).

Wherever the journey leads those who care for a loved one who has Alzheimer’s, there is need for their enduring commitment to be acknowledged. Each and every caregiving storyteller has earned the right to stand tall and to step beyond the barriers of social stigma, emotional anorexia, and professional apathy. On the inside, it is their time to breathe with a deep sense of pride and claim victory in committing to live out a narrative that is born of unconditional love.

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Judith R Boyland


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Judith R Boyland


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Judith R Boyland


A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.


A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland


A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.


The collective reality from onset to end of life and beyond. Judith R Boyland


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Appendix A – Reisberg’s Global Deterioration Scale

“Global Deterioration Scale (GDS) for Primary Degenerative Dementia for conditions such as Alzheimer’s disease”

Scaling formula initially developed by Dr Barry Reisberg in mid 1970s, validated in research outcomes and FIRST published in Reisberg, Ferris, de Leon, and Crook (1982/2007).

All illustrations are from Fisher Center for Alzheimer’s Research Foundation (2015).

Descriptions are a blend of information cited in Fisher Center for Alzheimer’s Research Foundation (2015); Leonard (2014); Sheehan (2015).

STAGE 1: NO COGNITIVE DECLINE

Patients at Stage 1 appear clinically “normal”.

NORMAL: They have no complaints of memory deficit and a clinical interview elicits no evidence of memory deficit. At any age, persons may potentially be free of objective or subjective symptoms of cognition and functional decline and also free of associated behavioural and mood changes. There are no symptoms at all: no memory impairment: no visible sign of cognitive decline. These mentally healthy persons at any age are referred to as Stage 1 or normal.

Figure 1 - Stage 1

STAGE 2: VERY MILD COGNITIVE DECLINE

This is the stage of forgetfulness, with the patient complaining of memory deficit. Most frequently, patients in this phase complain of forgetting where familiar objects have been placed and of forgetting names that they formerly knew well. There is no objective evidence of memory deficit in the clinical interview and no objective deficits
in employment or social situations. The individual in this phase displays appropriate concern about the symptoms.

**NORMAL AGED FORGETFULNESS:** Half or more of the population of persons over the age of 65 experience subjective complaints of cognitive and/or functional difficulties. A person will notice some mild memory loss and will usually start misplacing objects and forgetting names of people whom s/he knows well. The nature of these subjective complaints is characteristic and will usually be blamed on aging. Elderly persons with these symptoms can begin to worry that they can no longer recall names as well as they could five or 10 years previously. They also frequently develop a deep concern regarding the fact that they can no longer recall where they have placed things as well as they previously could recall. Subjectively experienced difficulties in concentration and in finding the correct word when speaking are also common.

![Figure 2 - Stage 2](image)

*Why can’t I remember where I put those papers? I used to remember where everything that I put away was located.*

Various terms have been suggested for this condition but normal aged forgetfulness is probably the most satisfactory terminology. These symptoms which, by definition, are not notable to intimates or other external observers of the person with normal aged forgetfulness are generally benign. However, there is some evidence that persons with these symptoms do decline at greater rates than similarly aged persons and similarly healthy persons who are free of subjective complaints.

**STAGE 3: MILD COGNITIVE DECLINE**

The earliest clear-cut clinical deficits appear at this stage. However, objective evidence of memory deficit is obtained only through an intensive interview conducted
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: by a trained geriatric psychiatrist. Concentration deficit may be evident on clinical testing. Also, the patient may demonstrate decreased facility in remembering the names of people s/he has just been introduced to. The patient at this stage may read a passage in a book and retain relatively little information.

Decreased performance becomes manifest in demanding employment and social situations. Co-workers become aware of the patient’s relatively poor performance. Difficulties in finding words and names may become evident to intimates. The patient may lose or misplace an object of value. Frequently, for the first time, the patient may get seriously lost when travelling to an unfamiliar location.

The subtlety of the clinical symptoms may be increased by the denial that often begins to become manifest in patients. Mild to moderate anxiety also accompanies the symptoms. Anxiety is increased if these patients are forced to cope with employment and social demands that they have previously found to be challenging but which, in their present state, they are no longer capable of negotiating.

MILD COGNITIVE IMPAIRMENT (MCI): Persons at this stage manifest deficits which are subtle but which are noted by not only themselves but also by persons who are closely associated with them. The subtle deficits may become manifest in diverse ways. For example, the person with MILD COGNITIVE IMPAIRMENT (MCI) may noticeably repeat queries or may make a trip to the shops and forget how to get back home.

The capacity to perform executive functions also becomes compromised. Commonly, for persons who are still working, job performance may decline because they will forget important details of a project. They may need to think about what a particular object is called and the frequency of forgetting names of people well known to them increases. Reading can become a problem as the person may not remember what has just been read. Valuables may be lost or misplaced, with no memory of where they have been placed. MCI subjects who are not employed but who plan complex social events, such as dinner parties or work-related functions, may manifest declines in their ability to organise such events.

During this stage, most patients will go into denial and will begin to have problems with anxiety. While a substantial proportion of these persons will not decline
(even when followed over the course of many years), in a majority of persons with Stage 3 symptoms, overt decline will occur and clear symptoms of dementia will become manifest over intervals of approximately two to four years – for example, to be considered dementia, mental impairment must affect at least two brain functions such as memory, thinking, language, judgment, behaviour and may also begin to cause personality changes. Concentration becomes difficult and for those who need to master new job skills, decrements in these capacities may become evident. For example, a person with MCI may be unable to master new computer skills.

![Figure 3 - Stage 3](image)

In persons who are not called upon to perform complex occupational and/or social tasks, symptoms in this stage may not become evident to family members or friends of the MCI subject. Even when symptoms do become noticeable, MCI subjects are commonly midway or near the end of this stage before concerns result in clinical consultation. Consequently, although progression to the next stage in MCI subjects commonly occurs in two to three years, the true duration of this stage, when it is a precursor of subsequently manifest dementia, is probably approximately seven years. Management of persons in this stage may include counselling regarding the desirability of continuing in a complex and demanding occupational role. Sometimes, a strategic withdrawal in the form of retirement may alleviate psychological stress and reduce both subjective and overtly manifest anxiety.

**STAGE 4: MODERATE COGNITIVE DECLINE**

This is the late confusional phase and a clear-cut deficit is apparent in a careful clinical interview. Deficits are manifest in many areas. Concentration deficit is elicited if patients are requested to do serial subtractions. They display decreased knowledge of recent events in their own lives and of current events in the world around them. Upon careful questioning, patients may also display a deficit in memory of their personal
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.

Judith R Boyland

History. Ability to travel alone is notably curtailed and difficulties with managing personal finances may become apparent.

At this stage, patients can no longer perform complex tasks accurately and efficiently. However, certain abilities characteristically remain preserved. Patients remain well oriented to time and to person. Familiar persons and faces can still be readily distinguished from those of strangers. There is generally no deficit in patients’ ability to travel to familiar locations. Denial often becomes the dominant defence mechanism and evident decline in intellectual and cognitive capacities is too overwhelming a loss for full conscious acceptance and recognition. Flattening of affect and withdrawal from previously challenging situations are observed.

MILD ALZHEIMER’S DISEASE: Symptoms of impairment become evident in this stage and some long-term memory loss will be seen. When asked about news headlines or current events, the person may have difficulty in recalling what is happening. Seemingly major events, such as a recent holiday or a recent visit to a relative may or may not be recalled. Similarly, overt mistakes in recalling the day of the week, month or season of the year may occur. Travel becomes difficult because of the anxiety it causes.

The Stage 4 subject may no longer be able to handle finances because of the confusion it causes and s/he may begin to withdraw from anything that presents as a challenge. Denial is prominent. The diagnosis of Alzheimer’s disease can be made with considerable accuracy in this stage with the most common functioning deficit being a decreased ability to manage instrumental and complex activities of daily life. The most common deficits include decreased ability to manage finances, to prepare meals and to shop for food and groceries.

For the Stage 4 patient who is living independently, this may become evident in the form of difficulties in paying rent and other bills. For those not living independently, a spouse or partner may note difficulties in writing the correct date and the correct amount in paying cheques or in the ability to use a credit/debit card. Persons who previously prepared meals for family members and/or guests begin to manifest decreased performance in these skills. Similarly, the ability to order food from a menu in a restaurant setting begins to be compromised and frequently, this is manifest in the
patient handing the menu a person they are dining with and saying, ‘You order’. The Stage 4 patient shown has difficulty writing the correct date and the correct amount on the cheque (Figure 4). Consequently, her husband needs to supervise this activity. The mean duration of this stage is two years.

Despite the overt deficits in cognition and functional compromise in capacity to perform complex activities of daily life, persons at this stage can still potentially survive independently in community settings. They can still generally recall their correct current address, can also generally correctly recall the weather conditions outside and can generally recall very important current events, such as Christmas or the name of a prominent head of state.

![Figure 4 - Stage 4](image)

The dominant mood at this stage is frequently what psychiatrists term a ‘flattening of affect’. Withdrawal is common and the person often seems less emotionally responsive than what might be deemed to be a previous or usual pattern of response. This absence of emotional responsivity is probably intimately related to the patient’s denial of their deficit and to a foreboding sense of anxiety and fear, which is often also notable at this stage.

Although the patient is aware of their deficits, this awareness of decreased intellectual capacity is too painful for most persons to accept and hence the psychological defence mechanism known as denial becomes operative with the patient seeking to hide their deficit, even from themselves, where possible. In this context, the flattening of affect occurs because the patient is fearful of revealing their deficits.

Consequently, the patient withdraws from participation in activities such as
conversations. In the absence of complicating medical pathology, the diagnosis of Alzheimer’s disease (AD) can be made with considerable certainty from the beginning of this stage. Studies indicate that the duration of this stage of mild AD is a mean of approximately two years.

STAGE 5: MODERATELY SEVERE COGNITIVE DECLINE

This is the phase of early dementia. Patients in this stage can no longer survive without some assistance. During interviews, they are unable to recall a major relevant aspect of their current lives. For example, they may have difficulty recalling or give incorrect responses when queried about their address or telephone number, the names of close members of their family (such as grandchildren) or the name of the high school or college from which they graduated. Frequently, patients are somewhat disoriented to time (date, day of the week, season) or to counting backward from 40 by 4s or from 20 by 2s.

Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses’ and children’s names. They require no assistance with toileting or eating but may have some difficulty choosing the proper clothing to wear and may occasionally clothe themselves improperly: for example, they may put their shoes on the wrong feet.

MODERATE ALZHEIMER’S DISEASE: In this stage, deficits are of sufficient magnitude as to prevent catastrophe-free, independent community survival. Patients can still feed themselves and use the toilet without assistance. However, they may begin to have trouble remembering the names of family members and while they usually can still remember their own name and the names of spouse, partner, and children, they often cannot remember the names of grandchildren and siblings.

The characteristic functional change in this stage is the beginnings of observable deficits in basic activities of daily life and the person needs assistance with some activities of daily living. This is manifest in a decline in the ability to choose the proper clothes to wear for the weather conditions or for the circumstance of different occasions. Some patients begin to wear the same clothing day after day unless reminded to change and the caregiver begins to counsel regarding the choice of clothing. Behavioural problems, such as anger and suspiciousness, also begin to present.
Cognitively, persons at this stage frequently cannot recall such major events and aspects of their current lives as the name of the Head of State – for example, President, Prime Minister, Premier, Mayor, King, Queen. They may have difficulty recalling the weather conditions of the day or their correct current address. Characteristically, some of these important aspects of current life are recalled, but not others. Also, the information may be loosely held – for example, the patient may recall their correct address on certain days but not on other days. Patients can no longer manage on their own in the community and have difficulty recalling such things as their own telephone number. If they are ostensibly alone in the community, then there is need for someone to assist in providing adequate and proper food, as well as to ensure that the rent and utilities are paid and that the patient’s finances are taken care of.

Remote memory also suffers to the extent that persons may not recall the names of some of the schools which they attended for many years and from which they graduated. Orientation may be compromised to the extent that the correct year may not be recalled. Calculation deficits are of such magnitude that an educated person has difficulty counting backward from 20 by increments of 2.

![Figure 5 - Stage 5](image)

This stage lasts an average of approximately 1.5 – 2 years and for those who are not properly watched and/or supervised, predatory strangers may become a problem.

**STAGE 6: SEVERE COGNITIVE DECLINE**

This is the middle phase of dementia. These patients may occasionally forget the name of their spouse or of the loved one upon whom they depend entirely for survival. They are largely unaware of all recent events and experiences in their lives. They retain some knowledge of their past life but this is very sketchy. Patients are generally
unaware of their surroundings, the year or the season. They may have difficulty counting backwards from 10 and sometimes they may also have difficulty counting forwards. Patients at this stage will require substantial assistance with activities of daily living. For example, they may become incontinent. Also, they will require assistance in travelling but occasionally will display the ability to travel to familiar locations. Diurnal and circadian rhythms frequently become disturbed: that is, they may be unable to tell day from night and their sleeping patterns become erratic. However, patients almost always recall their own names. Frequently, they continue also to be able to distinguish familiar from unfamiliar persons in their environment.

Personality and emotional changes occur at this stage. These are quite variable and may include …

1) delusional behaviour – for example, accusing a loved one (particularly their primary caregiver) of being an imposter or talking to imaginary figures in the environment or to reflections in the mirror;

2) obsessive symptoms – for example, continual repetition of simple cleaning activities;

3) anxiety symptoms, agitation and even previously non-existent violent behaviour;

4) cognitive abulia – that is, loss of willpower or motivation that occurs because the person cannot carry a thought long enough to determine a purposeful course of action or to make even the simplest of decisions.

MODERATELY SEVERE ALZHEIMER’S DISEASE: At this stage, the cognitive deficits are of sufficient magnitude as to interfere with the ability to carry out basic activities of daily life and to compromise any capacity for independent living. They may become incontinent and will require help with most functioning activities – such as, bathing, toileting, dressing and eating.

The Alzheimer’s patient (now fully in the state of dementia) is disoriented in time and place. They may start forgetting the names of spouse, partner, children and usually cannot recall any recent events such as eating a meal or a friend’s / family member’s coming to visit just moments before. However, they may be able to recall happenings from the past (but usually without detail) but will probably be unable to count to 10. Cognitive deficits are generally so severe that persons will display little or no
knowledge when queried regarding such major aspects of their current life circumstances, such as their current address or the weather conditions of the day.

Delusions, obsessions, compulsions and paranoia may become a problem and difficult behaviour problems may begin to emerge – for example, the patient may believe s/he is the Prime Minister or Picasso; s/he may wipe hands continuously; may pace back and forward or constantly walk to the door to open it and then to close it and then to open it ...; or s/he may believe s/he is being held prisoner and be constantly screaming out for help to escape. Anxiety, agitation and violent / abusive behaviour may also occur. Functionally, five successive sub-stages are identifiable in the stage of moderately severe Alzheimer’s disease.

**Stage 6a:** Initially, in addition to having lost the ability to choose their clothing without assistance, patients begin to require assistance in putting on their clothing, properly. Unless supervised, patients may put their clothing on back-to-front, may have difficulty putting their arm in the correct sleeve or may dress themselves in the wrong sequence. They may also put their street clothes on over their night clothes or may want to go to an important function (for example, a family wedding) in their pyjamas.

![Figure 6 - Stage 6a](image)

**Stage 6b:** At approximately the same point in time but generally just a little later in the temporal sequence of the evolution of Alzheimer’s related dementia, patients lose the ability to bathe independently and require assistance in handling the mechanics of bathing. While difficulty adjusting the temperature of the bath water is the classical earliest deficit in bathing capacity, once the caregiver adjusts the temperature of the water, the patient can, potentially, bathe independently.
Subsequently, as this stage evolves, additional deficits in bathing independently, as well as in dressing independently, occur. Also in this 6b sub-stage, patients generally develop deficits in other modalities of daily hygiene, such as brushing their teeth.

**Stages 6c, 6d, 6e:** With the further evolution of Alzheimer’s related dementia, after Alzheimer's patients lose the ability to dress and bathe without assistance, they lose the ability to independently maintain cleanliness in toileting and they lose the ability to manage the mechanics of toileting correctly (stage 6c) – for example, patients may place the toilet tissue in the wrong place or will forget to flush the toilet properly.

As the disease evolves in this stage, patients subsequently become incontinent. Generally, urinary incontinence occurs first (Stage 6d) and then faecal incontinence occurs (Stage 6e). The incontinence can be treated or in many cases, can even be prevented entirely by frequent toileting – such as when toilet training a toddler.
In this stage, the patient’s cognitive deficits are generally of such magnitude that the patient may at times confuse their husband with their father or their daughter with their wife and they may misidentify or be uncertain of the identity of close family members. At the end of this stage, speech ability overtly breaks down.

In summary, recall of current events is generally deficient to the extent that the patient cannot name the current national head of state or other similarly prominent newsworthy figures. Persons at this sixth stage will most often not be able to recall the names of any of the schools which they attended. They may or may not recall such basic life events as the names of their parents, their former occupation and the country in which they were born. Usually, they still have some knowledge of their own names, although patients in this stage begin to confuse their spouse with their parent, their child with their spouse and otherwise mistake the identity of persons: even close family members in their own environment. Calculation ability is severely compromised, with difficulty counting to 10 – either forwards or backwards.

Emotional changes generally become most overt and disturbing in this sixth stage of Alzheimer’s disease. Although these emotional changes may, in part, have a neurochemical basis, they are also clearly related to the patient’s psychological reaction to their circumstances. For example, because of their cognitive deficits, patients can no longer channel their energies into productive activities. Consequently, unless appropriate direction is provided, patients begin to fidget, to pace, to move objects around and place items where they may not belong or to manifest other forms of purposeless or inappropriate activities.

Because of the patient’s fear and frustration regarding their circumstances, they frequently develop verbal outbursts and threatening or violent and abusive behaviour may occur. Patients can no longer survive independently and they commonly develop a fear of being left alone.

Treatment of these and other behavioural and psychological symptoms which occur at this stage, involves pharmacological interventions and counselling for both caregiver and patient. The priority focus of counselling in these circumstances needs to address appropriate activities for engagement and also the psychological impact of the illness upon both the patient and the caregiver.
The mean duration of this sixth stage of Alzheimer’s disease is approximately 2.3 – 2.5 years and as this stage comes to an end, the patient is doubly incontinent, needs assistance with dressing, bathing and toileting and functional hygiene. The patient also begins to manifest overt breakdown in the ability to articulate speech. Stuttering, inability to understand or use new words and an increased reluctance to speak become manifest.

**STAGE 7: VERY SEVERE COGNITIVE DECLINE**

Stage seven is late dementia. All verbal abilities are lost. Frequently there is no speech at all, only grunting. Generalised cortical and focal neurologic signs and symptoms are frequently present and present as a total loss of function. There is no presence, there may be no vision or no ability to hear. These patients are incontinent and require assistance in toileting and with eating. They also lose psychomotor skills, becoming unable to walk and then unable to even sit without props and supports. They lose the ability to swallow and need to be fed intravenously. The brain appears no longer to be able to tell the body what to do. Full time nursing and palliative care is required.

**SEVERE ALZHEIMER’S DISEASE:** With the advent of the seventh stage, certain physical and neurological changes become increasingly evident. At this stage, most communication skills are lost and speech is non-existent. The patient is incontinent and needs help with toileting. They are unable to feed themselves and require continuous assistance with basic activities of daily life. Physical rigidity becomes evident and upon examination of the passive range of motion of major joints (such as the elbow), rigidity is present in the great majority of patients.

![Figure 10 - Stage 7](image)
In the final stages of Alzheimer’s disease, increasing rigidity is evident to the examiner upon testing the passive range of joint motion. In many patients, this rigidity appears to be a precursor to the appearance of overt physical deformities in the form of contractures (joint deformities that make full range movement of a joint impossible without producing severe pain). These contractures are identified as irreversible deformities which prevent both passive and active range of motion of joints.

![Figure 11 - Stage 7](image)

Patients are becoming progressively less able to walk and to control other motor functions. They are unable to survive independently and it is usually during this stage that the Alzheimer’s patient becomes bed bound. Six consecutive functional sub-stages can be identified over the course of this final seventh stage:

**Stage 7a:** Early in this stage, speech has become so circumscribed as to be limited to approximately a half dozen intelligible words or fewer in the course of an intensive contact and any attempt at an interview with numerous queries.

**Stage 7b:** As Stage 7 progresses, speech becomes even more limited to, at most, utterance of a single intelligible word.

**Stage 7c:** Once speech is lost, ambulatory ability is readily compromised then lost and the patient requires assistance in walking. This can be due to onset of escalating physical disability, loss of muscle tone, poor care, medication side-effects or other factors. However, superb care provided in the early seventh stage and particularly in Stage 7b, can postpone the onset of loss of ambulation – potentially for many years. This stage can last approximately one year.

![Figure 12 - Stage 7c](image)
Stage 7d: Patients now lose the ability not only to ambulate independently but also to sit up independently. At this point the patient will fall over when seated unless supported. This sub-stage lasts approximately one year.

![Stage 7d](image)

Figure 13 – Stage 7d

Stage 7e: Patients who survive Stage 7d, subsequently lose the ability to smile. Only grimacing facial movements are observed in place of smiles and this sub-stage lasts a mean of approximately 1.5 years.

Stage 7f: Those who survive to this final stage are totally immobile and unless their neck becomes contracted and shrinks, they are unable to hold their head up, without bracing and support. While with appropriate care and life support, patients can survive in this final 7f sub-stage indefinitely (often for several years), most patients succumb during the earlier sub-stages of the course through stage 7.

In the early seventh stages (7a and 7b) approximately 40% of Alzheimer’s patients manifest physical deformities to the extent that they cannot move a major joint more than half way. Later in the seventh stage (7d to 7f), nearly all patients manifest contractures in multiple extremities and joints, particularly the elbows, wrists and fingers. In the immobile Alzheimer’s patient, approximately 95% of patients manifest these deformities which, by this time, are usually present in many joints.

Neurological reflex changes also become evident in the stage 7 patient. Capacity to see and capacity to hear can be compromised or completely lost. Particularly notable is the emergence of so-called ‘infantile’, ‘primitive’ or ‘developmental’ reflexes which are present in the infant but which disappear in the toddler. These reflexes include the grasp reflex or the sucking reflex (Figure 15) and the plantar extensor reflex which in the Alzheimer’s patient, is referred to as the Babinski plantar extensor reflex (Figure 16). This abnormal response to stimulation of the sole of the foot is marked by dorsiflexion (bending back) of the great toe and fanning of the other digits of the foot.
While often beginning to emerge in the latter part of the sixth stage, these reflexes are usually present by the later sub-stages of stage 7 and because of the much greater physical size and strength of the Alzheimer’s patient in comparison with an infant, these reflexes can be very strong and can impact both positively and negatively on the care provided to the patient.

Under ordinary circumstances, Stage 7a has a mean duration of approximately one year and Stage 7b has a mean duration of approximately 1.5 years. Each subsequent sub-stage of this final seventh stage lasts an average of 1-1.5 years. Patients with Alzheimer’s disease commonly die during the course of the seventh stage. The mean point of death is when patients lose the ability to ambulate and to sit up independently (stages 7c and 7d).

The most frequent proximate cause of death is pneumonia with aspiration (diminished ability to breathe out) being the most common cause of terminal pneumonia. Another common cause of death in the Alzheimer’s patient is infected decubital ulcerations (bed sores). Alzheimer’s patients in the seventh stage also appear to be more vulnerable to all of the common causes of mortality in the elderly including stroke, heart disease and cancer. Some patients in this final stage appear to succumb to no identifiable condition, other than the cognitive degeneration, physical debilitation and loss of function associated with Alzheimer’s disease.

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Appendix B – Ten Signs of Early Detection

Alzheimer’s Association (2009/2016); Alzheimer’s Association (2015b)

Over time, abnormal changes in the brain are said to worsen and eventually interfere with many aspects of brain function, resulting in cognitive and physical degeneration and loss of function. While a full description of progressive symptoms is presented in Appendix 1 (Reisberg’s Global Deterioration Scale), 10 signs of early detection are noted by Alzheimer’s Association (2009) and presented as …

1) Memory loss that disrupts daily life: One of the most common signs of Alzheimer’s, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aides (lists and notes or electronic devices such as timers) or family members to handle tasks they used to be able to handle on their own.

   Typical age-related change involves sometimes forgetting names or appointments but remembering them later.

2) Challenges in planning and solving problems: Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

   Typical age-related change may involve making occasional errors when balancing a chequebook.

3) Difficulty in completing familiar tasks at home, at work or at leisure: people with Alzheimer’s often find it hard to complete daily tasks. Sometimes they may have trouble driving to familiar locations, managing a budget at work or remembering the rules of a favourite game.

   Typical age-related change may involve occasional need for help with such things as using the settings on the microwave or recording a television show.

4) Confusion with time and place: People with Alzheimer’s can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.
Typical age-related change may involve getting confused about the day of the week but figuring it out later.

5) **Trouble understanding visual images and spatial relationships:** For some people, having vision problems is a sign of Alzheimer’s. They may have difficulty reading, judging distance or determining colour or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not realise that they are the person in the mirror.

Typical age-related change in vision is related to cataracts.

6) **New problems with words in speaking and writing:** People with Alzheimer’s may have trouble following or joining in a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name – for example, calling a watch a ‘hand clock’.

Typical age-related change involves sometimes having trouble finding the right word.

7) **Misplacing things and losing the ability to retrace steps:** A person with Alzheimer’s may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes they may accuse others of stealing and this may occur more frequently over time.

Typical age-related change involves misplacing things from time to time, such as a pair of glasses or the remote control.

8) **Decreased and poor judgment:** People with Alzheimer’s may experience changes in judgment or decision making. For example, they may use poor judgment when dealing with money like giving large amounts to telemarketers. They may also pay less attention to personal grooming and hygiene.

Typical age-related change involves making a bad decision every once in a while.

9) **Withdrawal from work or social activities:** A person with Alzheimer’s may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favourite sports team or remembering how to complete a favourite hobby. They may also avoid being social because of the changes they are experiencing.
Typical age-related change involves sometimes feeling weary of work, family and social obligations.

10) Changes in mood and personality: The mood and personalities of people with Alzheimer’s can change. They can become confused, suspicious, depressed, fearful and anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

Typical age-related change may involve developing very specific ways of doing things and becoming irritable when a routine is disrupted.
Appendix C – Key Facts and Statistics

Alzheimer’s Australia, 2016, 2017

(Alzheimer’s related dementias estimated on a reference of 70%)

A3.1 – The Story in Australia

- There are more than 413,106 Australians living with dementia (more than 289,175 Alzheimer’s related)
- This number is expected to increase to 536,164 by 2025 (375,315 Alzheimer’s related under current conditions)
- Without a medical breakthrough, the number of people with dementia is expected to be almost 1,100,890 by 2056 (770,624 Alzheimer’s related under current conditions)
- Each day, there are around 244 new cases of dementia in Australia (170 Alzheimer’s related). This is expected to grow to 318 new cases each week by 2025 and over 650 new cases per day by 2056
- There are approximately 25,939 people in Australia with Younger Onset Dementia (a diagnosis of dementia under the age of 65; including people as young as 30. An estimate of 18,158 would be Alzheimer’s related)
- Three in 10 people over the age of 85 (2.1 in 10 people Alzheimer’s related) and almost one in 10 people over 65 have dementia (one in 13 Alzheimer’s related)
- An estimated 1.2 million people are involved in the care of a person with dementia (1.19 million Alzheimer’s related)
- Projections suggest that by 2025, some 255,800 carers will be needed in the community and 122,100 carers working in the cared accommodation sector. These numbers are expected to double by 2056
- Dementia is the second leading cause of death in Australia and currently there is no cure. However, in a news release from Flinders University (July 13, 2016) Australian researchers, in collaboration with researchers in the United States of America, are on the brink of developing a vaccine formulation to successfully target abnormal proteins that trigger Alzheimer’s (Petrovsky, 2016)
- On average symptoms of dementia are noticed by families three years before a firm diagnosis is made
A3.2 – The Impact in Australia

- Dementia is the single greatest cause of disability in older Australians (aged 65 years or older) and the third leading cause of disability burden overall
- Australia faces a shortage of more than 150,000 paid and unpaid carers for people with dementia by 2029
- Total direct health and aged care system expenditure on people with dementia was at least $4.9 billion in 2009-10 ($3.43 billion Alzheimer’s related)
- Dementia will become the third greatest source of health and residential aged care spending within two decades. These costs alone will be around 1% of GDP (0.7% Alzheimer’s related, under current conditions)
- By the 2060s, spending on dementia is set to outstrip that of any other health condition. It is projected to be $83 billion in 2006-07 dollars ($58.1 billion Alzheimer’s related under current conditions) and will represent around 11% of health and residential aged care sector spending (7.7% Alzheimer’s related under current conditions)
- More than 50% of residents in Australian Government-subsidised aged care facilities have dementia (35% Alzheimer’s related) with 85,227 out of 164,116 (59,659 out of 164,116 Alzheimer’s related) permanent residents with an ACFI (Aged Care Funding Instrument assessment at 30 June, 2011)
- Almost half (44%) of permanent residents with dementia also had a diagnosis of a mental illness – approximately 70% have a diagnosis of Alzheimer’s

A3.3 – International Statistics

- Worldwide, there are more than 46.8 million people with dementia today (32.76 million with Alzheimer’s) and 135.5 million predicted by 2050 (94.85 million Alzheimer’s related under current conditions)
- In high income countries only 20-50% of people with dementia are recognised and documented in primary care
- The total estimated worldwide costs of dementia were US$818 billion in 2015 (US$572.6 billion Alzheimer’s related)
- If dementia were a country, it would be the world’s 18th largest economy

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Appendix D – Queensland Health Statistics

HOSPITALISATION

Admitted Patient Episodes of Care for Selected Principal Diagnoses (a),
Source: Queensland Hospital Admitted Patient Data Collection, Department of Health (Extracted Aug 13, 2015)
Prepared by: Statistical Reporting & Coordination, Health Statistics Unit, Department of Health (Aug 13, 2015) (DB 27,661)

p. Preliminary data, subject to change
Note: Excludes unqualified newborns; posthumous organ procurement and boarders

(a) Dementia in Alzheimer’s disease (ICD10AM F30)
Alzheimer’s disease (ICD10AM G30)

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g:\chris\requests\2015\boyland_aug13.rtxx Page 1 of 1
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.

Judith R Boyland
Appendix E – Information and Local Support Services and Providers

Advanced Care Planning Australia:  www.advancecareplanning.org.au

Aged and Disability Advocacy: telephone 07 3637 6000
www.adaaustralia.com.au

Alzheimer Europe http://www.alzheimer-europe.org/

Alzheimer’s Association (Chicago):  https://www.alz.org/

Alzheimer’s Association of Queensland: telephone 07 3857 4043

Alzheimer’s Australia, Queensland, Woolloongabba: telephone, 07 3895 8200
www.fightdementia.org.au

Alzheimer’s Disease International: https://www.alz.co.uk/

Alzheimer’s Queensland: telephone 1 800 639 331

Alzheimer’s Queensland, Darling Downs: telephone 07 4613 0052

Alzheimer’s Queensland, Gold Coast: telephone 07 5594 0270

Alzheimer’s Queensland, Gordon Park: telephone 07 3857 2191

Alzheimer’s Queensland, Ipswich: telephone 07 3812 2253

Alzheimer’s Queensland, Toowoomba: telephone 07 4635 2966

Alzheimer’s Queensland, Upper Mount Gravatt: telephone 07 3422 3000

Alzheimer’s Society: https://www.alzikers.org.uk/

ARAFMI: telephone 07 3254 1881

Beyond Blue:  www.beyondblue.org.au

Catholic HealthCare, Villa Maria Centre, Fortitude Valley: telephone 1800 551 834
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: 323

Judith R Boyland

Carers Australia: telephone 1800 242 636
www.carersaustralia.com.au

Carers’ Advisory Service: telephone 1800 242 636

Carers Outlook: telephone 07 5476 0642

Carers Queensland: telephone 07 5451 1882
telephone 1800 242 636
www.carersqld.asn.au

Centrelink (eligibility and entitlements for Carers): telephone 13 27 17

Council of the Aging, Queensland: telephone 07 3316 2999
telephone 1300 738 348

Dementia Behaviour Management Advisory Service (DBMAS): telephone 1800 699 799
www.dbmas.org.au

Department of Veterans’ Affairs (DVA): telephone 1300 555 727
www.dva.gov.au

Happy Paws Happy Hearts telephone 0422 045 666
07 4326 9926
www.hphhfoundation.org

Horseaccord: telephone 0411 710 780
www.horseaccord.com.au

Legal Aid Queensland: www.legalaid.qld.gov.au

My Aged Care (advocacy): telephone 1800 700 600

My Aged Care (respite services): telephone 1800 200 422
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: 

My Aged Care Service: telephone 1800 200 422
www.muagedcare.gov.au

National Dementia Helpline: telephone 1800 100 500
www.fightdementia.org.au/national/helpline

Queensland Aged and Disability Advocacy Inc.: telephone 07 3637 6000
1800 818 338

Queensland Civil and Administrative Tribunal: www.qcat.qld.gov.au

Queensland Community Care Services: telephone 1800 600 300
www.qld.gov.au/communitycare
www.serviceavailabilityregister.com.au

Queensland Young Onset Dementia Key Worker Program: telephone 1800 100 500

Sunshine Coast Hospital and Health Services: www.health.qld.au/sunshinecoast

Synapse (formerly Brain Injury Association of Queensland): telephone 07 3367 1049
telephone 1800 673 074

Queensland Art Gallery Of Modern Art (QAGOMA): telephone 07 3840 7255

University of Tasmania: https://mooc.utas.edu.au/courses

…o0o…
Appendix F – The Self-Fulfilling Choice to Cope

STRUCTURAL FRAMEWORKS:

Bays (2014); Berne (1966); De Vugt et al. (2004); Hooker, Frazier, & Monahan (1994)

A5.1 - Non-adapting Coping Strategies

‘Non-adapting’ strategies tend to be characterised by non-acceptance: with caregivers demonstrating a lack of understanding of the care receiver and/or a lack of acceptance of the situation. Their approach is tempered with impatience, irritation and anger and they tend to manage behavioural problems with confrontation, ignoring or walking away: patterns of behaviour defined by Bays (2014) as being unhealthy. Personality could also be considered as a contributing factor in whether a caregiver might be ‘adapting’ or ‘non-adapting’. As Hooker, Frazier, and Monahan (1994) noted, when measured on the ‘Ways of Coping Checklist’, personality traits explained 60% of the variance in emotion-focused coping, 30% of variance in problem-focused coping and 15% of variance associated with social-support coping. Given these outcomes, it may be helpful to consider personality type profiling when supporting caregivers in a therapeutic context. According to the study of De Vugt et al. (2004), caregivers who used non-adapting strategies reported a lower sense of competence, more depressive symptoms and higher levels of anxiety, OCD or hypochondria. They also reported more care receiver hyperactivity symptoms.

A5.2 - Nurturing Coping Strategies

‘Nurturing’ strategies tend to be characterised by acceptance: with the caregiver implementing a parent–child approach. The care recipient was no longer identified as being an equal in what Berne (1966) might term an adult–adult transactional relationship. Operating from within a ‘nurturing’ framework, caregivers tended to do most of the daily chores, protect the care receiver and focus on personal care tasks such as providing physical assistance with self-care and meal preparation. Caregivers who used a ‘nurturing’ strategy reported lower levels of patient hyperactivity.

A5.3 - Supporting Coping Strategies

‘Supporting’ strategies tended to be characterised by acceptance: whereby the situation was managed by adapting to the care receiver’s level of functioning and by stimulating his/her existing capabilities. The care receiver was encouraged to take the
lead with the caregiver supervising, assisting and supporting through discussion. Caregivers tended to exhibit patience, adopting a calm and curious manner and managing behavioural problems with compliance. They tended to stimulate the receiver into participating in physical, social or household activities and they engaged in fun and pleasurable activities together. It was noted that the majority of caregivers who used supporting strategies were highly educated.

…000…
Appendix G – A Qualitative Paradigm

ASPECTS OF STRATEGY


A6.1 – Design Strategies

Design strategies incorporate naturalistic inquiry, emergent design flexibility and purposeful sampling. According to Patton, inquiry design is ‘naturalistic’ in the sense that it takes place in the real world setting of the participants: no predetermined course is established and there is no attempt by the researcher to manipulate the phenomenon of interest. ‘Design flexibility’ stems from an open-ended approach to inquiry, placing importance on attention to facts and practicalities which, in turn, demands a high tolerance for ambiguity, uncertainty and trust in what the ultimate outcome will be and what the value of the ultimate outcome will be. ‘Purposeful sampling’ selects participants because of the richness and depth of information that they can bring to the investigation.

A6.2 – Data Collection and Fieldwork Strategies

Data collection and fieldwork strategies are focussed on qualitative data, personal experience and engagement, dynamic systems, empathic neutrality and mindfulness. ‘Qualitative data’ consist of observations, quotations and documentation. They describe and take the reader to the time and place of the phenomenon under study. They tell a story and give insight into the nature of the reality of the lived experience. Through ‘personal experience and engagement’, a closeness is created that promotes openness in process and stimulates depth in outcome. With attention to process, ‘systems are dynamic’ and open to change as the researcher stands on middle ground. The researcher is in a place of ‘empathic neutrality’ – between becoming too involved and remaining too distant. The researcher also brings a state of ‘mindful attention’ to systemic and situational sensitivities and dynamics.

A6.3 – Analysis Strategies

Analysis strategies are characterised by unique case orientation, inductive analysis and creative synthesis, holistic perspective, context sensitivity and voice, perspective and reflexivity. Assuming that each participant brings his/her own story, it
can be said that each ‘case’ has its own ‘uniqueness’ and its own particular ‘orientation’. Focussed through exploration, discovery and the evidence base of inductive logic, immersion in the specifics of the data has the ‘capacity to induce discovery of description’ that ‘creates connection and relationship’ between individual stories, by categorising characteristics according to either their sameness or difference. From a ‘holistic perspective’, the phenomenon under study is understood as a complex system that is more than merely a sum of its parts. As the researcher gathers data on multiple aspects, a comprehensive and complete picture is established: with each individual story representing a snapshot that portrays part of the broad landscape. Focus is on interrelatedness and complex interdependencies that cannot be reduced to discrete variables or linear cause/effect relationships. All perspectives or conceptions need to come together in order to get the full picture of what the phenomenon actually looks like, what it sounds like, what it smells like, what it tastes like and how it feels to the touch, to the emotions and to the physiology. Such is the nature of ‘context sensitivity’: elevating the context, the participant and the relationship between context and participant as critical to understanding. In the final analysis, the qualitative researcher is aware of, owns and is reflective about personal perspective, bias, prejudice or preconceived notions. A credible and authentic ‘voice’ conveys trustworthiness and a balanced focus. It brings a genuineness to the ‘I-Thou perspective’ and it acknowledges the humanity of the ‘Self-Other perspective’. It implies relationship and mutuality, opening the way for genuine ‘reflexivity’ in discourse.

…o0o…
Appendix H – PARTICIPANT DOCUMENTS

NOTE: It is noted that the title of the completed thesis has been modified to reflect the findings as profiled in the narrative landscape.

CONSENT TO SHARE CONTACT INFORMATION

(where relevant)

Someone I love has Alzheimer’s:

The impact of caring for a ‘Special Someone’ who has a diagnosis of Alzheimer’s disease.

(ethics approval number: HREC: S/15/809)

I, ……………………………………. give my consent for

……………………………………. to share my contact details with Judy Boyland.

SIGNATURE: ……………………….. DATE: ……………………….

NAME:
…………………………………………………………………………………………

PREFERRED CONTACT DETAILS:
…………………………………………………………………………………………

………………………………………………………………………………………………
CONSENT TO SUPPORT

(where relevant)

Someone I love has Alzheimer’s:

The impact of caring for a ‘Special Someone’ who has a diagnosis of Alzheimer’s disease.

(ethics approval number: HREC: S/15/809)

I, ..................................... give my consent for ........................................... to support me during my chat with Judy Boyland.

SIGNATURE: ............................. DATE:.................................

...00o...

I, ................................................................. give my consent to support ................................................................. during his/her chat with Judy Boyland. I fully appreciate that whatever is discussed during this chat is totally confidential and I agree to abide by total and complete confidentiality.

SIGNATURE: ............................. DATE: .................................

The collective reality from onset to end of life and beyond.

Judith R Boyland
RESEARCH PROJECT INFORMATION FOR THIRD PARTY

Ethics Approval Number HREC: S/15/809

PROJECT TITLE

Someone I love has Alzheimer’s: The impact of caring for a ‘Special Someone’ who has a diagnosis of Alzheimer’s disease.

INVESTIGATORS

Judith R Boyland (PhD Student), Dr Ann Moir-Bussy (Principal Supervisor), Dr Peter Innes (Co-Supervisor) and Associate Professor Mathew Summers (Associate Supervisor)

Chief Investigator – Judith Boyland

RESEARCH PURPOSE

The primary aim of the project is to provide caregivers, whose loved one has (or has had) Alzheimer’s, an opportunity to tell their story and to know that they are heard. By bringing together the threads of experience as defined in each story, it is proposed to develop a collective narrative that portrays the broad landscape of how participants view the reality of lived experience.

Research investigation seeks to gain insight into the many truths that lie embedded in the lived experience. It also seeks to understand the impact on a caregiver’s well-being when the one being cared for is a ‘Special Someone’ whose personal, every-day world embodies the reality of progressive disempowerment associated with the life changing diagnosis of Alzheimer’s disease.

PARTICIPANT EXPERIENCE

Participation in the research study is voluntary and participants may withdraw at any stage, without explanation and without judgment. Research will be conducted by way of in-depth interview between the caregiver and the chief investigator, Judith Boyland. It is expected that the duration of the interview will be approximately one hour. Participants will be invited to tell their stories, embracing the truth, the uniqueness and the richness of their individual experience as lived in the reality of their world that is.

Participants will be guided by use of open-ended prompts and questions and may choose to express elements of their stories with doodles, pictures or symbols; story, poetry or sculpture. Interviews will be voice recorded and transcribed for the purpose of analysis and organisation of stories into themes or categories of description. When
brought together, the woven threads of each story will be profiled in the collective narrative and frame the broad landscape that brings to life the impact of caring for a ‘Special Someone’ who has a diagnosis of Alzheimer’s disease. The story of each participant will be valued for the richness of experience that is the truth and reality of a world of individual experience.

DURATION

Participants will be asked to volunteer approximately 60 minutes of their time to participate in this study. It is anticipated that all stories will be collected within a timeframe of eighteen months from the date of ethics approval.

RISKS

The interview process is deemed to be benign in nature, designed to be conducted with empathy, sensitivity and respect to participant and to participant’s story. While all care is taken to ensure participant comfort, participants will be asked to not hesitate in letting me know if they feel uncomfortable during the interview process. At all times, participants and participants’ stories will be treated with empathy, sensitivity and respect and any participant is free to withdraw from this study at any stage.

RESULTS

Once the stories have been analysed and the narrative developed, implications for action will be considered. All participants will be given a copy of the final narrative – anticipated to be chapter six of the final document.

CONFIDENTIALITY

Participants will be identified by number, being assured that at the end of the research all identifying information will be destroyed and only non-identifying data will be stored at the University of the Sunshine Coast in secure systems, for the duration of five years, as required by legislation. During the course of the research investigation, all recordings and transcripts will be locked in secure filing systems and all processed data will be password protected. Data gathered throughout the study will be coded so that participants will be identifiable only by the number assigned to their story. The researcher is transcriber and is committed to confidentiality. No published findings will reveal the identity of any participant, without express written consent.

ETHICAL CONSIDERATIONS

At all times, professional ethics will be adhered to. Code of ethical considerations attached for your information.

COMPLAINTS

If you have any complaints about the way this research project is being conducted, you can raise them with the Principal Researcher or if you prefer an independent person,
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease:

contact the Chairperson of the Human Research Ethics Committee at the University of the Sunshine Coast: (c/- the Research Ethics Officer, Office of Research, University of the Sunshine Coast, Maroochydore DC 4558; telephone (07) 5459 4574; email humanethics@usc.edu.au).

CONTACTS

Judith Boyland (Chief Investigator and Principal Researcher)
Faculty of Arts and Business: School of Social Science: Department of Counselling
University of the Sunshine Coast
Phone: 0413 358 234
e-mail: Judith.boyland@research.usc.edu.au
preferred email: judyboyland1@bigpond.com

Dr Ann Moir-Bussy (Principal Supervisor and Senior Lecturer)
Faculty of Arts and Business: School of Social Science: Department of Counselling
University of the Sunshine Coast
Phone: 07 5456 5068
e-mail: AMoirbussy@usc.edu.au

Many thanks for your interest and support in this research project

Judith R Boyland

The Researchers and the University would like to thank you for your interest in this project and appreciate the effort involved in your participation.

…000…

ETHICAL CONSIDERATIONS

In considering the relationship shared with the individuals whose stories are being shared, held and given away, Wilson (2001) speaks of the need for the researcher to come from a fundamental belief that knowledge is relational. Knowledge needs to be shared and therefore, cannot be owned. Wilson’s paradigm carries the potential to move beyond assuming an exclusive perspective and should the researcher choose to
adopt his/her paradigm of relationality in a socio cultural context, then certain ethical questions need to be considered: such as …

d. How am I, the researcher, fulfilling my role in this relationship with the participant?

e. How am I, the researcher, fulfilling my role as ‘holder’ and ‘giver-awayer’ of the knowledge shared by the participant?

f. What are my responsibilities in this relationship?

Thus it is proposed that the practical implementation of a professional ethical code considers implementation of the following measures …

a) Participants are invited to participate voluntarily and without coercion

b) Participants are fully briefed about the purpose, process and boundaries of the research

c) Informed consent of each participant is gained in writing, prior to commencement of research interview

d) Individuality of the participant is honoured at all times

e) Participants are treated with empathy, sensitivity and respect at all times

f) Stories shared by participants are treated with empathy, sensitivity and respect at all times

g) Limits of Duty of Care are to take relevant and appropriate steps to ensure that the researcher does no harm

h) Confidentiality and anonymity of identity are assured with each participant being invited to take on a pseudonym or a codified identity of choice

i) Falsification, fabrication and misrepresentation of data is avoided at all times

j) Non-judgmental and non-offensive language is used in all written and verbal communication with participants

k) Participants are assured that in allowing the Self to speak, there is only truth: there is no judgement

l) Debriefing sessions can be accessed by any participant who chooses to avail him/herself of this facility

m) Data gathering proforma are designed to elicit information that is directly related to the research and invites reflection on personal reality, allows description of personal reality and tells the story of lived experience

n) Stories of participants and works of other researchers and authors are acknowledged and referenced appropriately

o) All communication in relation to the research is done with honesty and transparency

p) Any form or type of misleading information is avoided

q) Any biased representation of primary data is avoided

r) Autonomy of participant is respected at all times

s) There is no betrayal nor deception in representing information shared by participants

t) Codified data is securely stored both during analysis and following analysis for period of time in keeping with legislative requirements
RESEARCH PROJECT INFORMATION

ETHICS APPROVAL NUMBER HREC: S/15/809

PROJECT TITLE

Someone I love has Alzheimer’s: The impact of caring for a ‘Special Someone’ who has a diagnosis of Alzheimer’s disease.

INVESTIGATORS

Judith R Boyland (PhD Student), Dr Ann Moir-Bussy (Principal Supervisor), Dr Peter Innes (Co-Supervisor) and Associate Professor Mathew Summers (Associate Supervisor).

Chief Investigator and researcher – Judith Boyland

RESEARCH PURPOSE

The primary aim of the project is to provide caregivers, whose loved one has (or has had) Alzheimer’s, with an opportunity to tell your story and to know that you are heard and acknowledged. By bringing together the threads that define each story, it is proposed to develop a collective narrative that profiles the diverse landscape of real life experience as it is experienced by those who are living (or who have lived) the experience of caring for a loved one who has (or who has had) Alzheimer’s.

Research investigation seeks to gain insight into the many truths that lie embedded in the lived experience of caregiving. It also seeks to understand the impact of caregiving when the one being cared for is a ‘Special Someone’ whose personal, every-day world embodies the reality of progressive disempowerment associated with the life changing diagnosis of Alzheimer’s disease.

YOUR EXPERIENCE

At all times, you will be treated with empathy, sensitivity and respect and your story will be acknowledged with empathy, sensitivity and respect.

Your participation in the research study is voluntary and you may withdraw at any stage, without explanation and without judgment. Research will be conducted by way of in-depth interview between you (the caregiver) and me (the chief investigator, Judith [Judy] Boyland). It is expected that the duration of the interview will be approximately one hour. However, this time frame can be varied according to your needs and the needs of your story.
Ideally, interviews will occur at a mutually convenient venue where we can be assured of a warm, welcoming, quiet, empathic and safe environment. I could come to your home or we could meet at my office in Springwood. We could chat via distance mode, using Skype or we could chat over the telephone. We can discuss the most comfortable venue and mode for you when we have our initial chat, after you have read and digested the Research Information. In addition to chatting, you might also like to illustrate your story with drawing, painting, or doodling; sculpture; poetry; writing; or any other expressive mode of illustration.

The interview is all about your story. You will be invited to tell your story, embracing the truth, the uniqueness and the richness of your individual experience as lived in the reality of your world: just as it is or just as it was – the good, the bad and the ugly.

I shall initially ask you to share some general information such as your relationship to the loved one you are caring for or the loved one you cared for. Another example of general information will be how long you have been caring for your ‘Special Someone’ or how long you cared for your ‘Special Someone’, your relationship and some dates. Remembering that the focus is on your story more than on the story of your Loved One, I shall then invite you to share your story by beginning with a probe along the line of …

- Talk to me about what it is (was) like for you caring for ………………

My questions will then follow on from your answers and if we get stuck, I shall prompt you with other leads like …

- What is it that drives you to care for your ‘Special Someone’?

Or I shall give you a prompt like …

- Tell me about the good times or
- Talk to me about the awful times or
- Tell me about the scary times or
- The times when or
- Talk to me about the stressful times or
- Tell me about some of the things that have changed for you or
- How do you feel about that?

All the way through the interview, you will be guided by open-ended questions or probes and you may choose to illustrate your story with doodles, pictures or symbols and we shall discuss your needs for expressive aides, when we set up our time to chat. Interviews will be voice recorded and transcribed for the purpose of analysis and organisation of all the stories of all the caregivers into themes or categories of description. When brought together, the elements from all the stories will profile the broad landscape that brings to life the big picture of impact of lived reality that is the real experience when caring for a ‘Special Someone’ who has a diagnosis of
Alzheimer’s disease. Your story will be valued and respected for the richness of experience that is your truth and your reality in your world of individual experience.

If at any time during the course of the interview you become upset while telling your story, I shall support you. Should you require additional support, appropriate support services may be accessed should additional support intervention be needed – for example, you might like to contact LifeLine Support Counselling Services on 13 1114 or you might prefer to chat with a private Counsellor. A Counsellor in your area may be found through Australian Counselling Association Inc website (www.theaca.net.au find a counsellor), should this be a preferred option. Should such an incident arise, the interview will be terminated and you will be given the option to continue at a later date or withdraw from the project: the choice is entirely yours. As previously stated, at all times you will be treated with empathy, sensitivity and respect and in a totally professional manner.

DURATION

Also as previously stated, you will be asked to volunteer approximately 60 minutes of your time to participate in this study. However, if you feel that you would like more time or less time to tell your story, then that is fine and we can negotiate whatever time frame is best for you to tell your story. It is anticipated that all stories will be collected within a timeframe of eighteen months from the date of ethics approval.

RISKS

The interview process is deemed to be benign in nature, designed to be conducted with empathy, sensitivity and respect for you and for your story. While all care is taken to ensure your comfort, please do not hesitate to let me know if you feel uncomfortable during the interview process. If you are feeling uncomfortable or if emotions rise to the surface as you relive your story, this is OK and we can manage this together. I have walked the journey of caring for a loved one who had Alzheimer’s and I know something of the emotional roller coaster that can be experienced. We can talk about any worries you might have about telling your story during our initial chat over the telephone. Also, remember that you can withdraw from this study at any stage.

While all information you share in the telling of your story will be de-identified and coded, there is always the possibility that someone who reads the final document could recognise circumstances described and assume, through inference, that they know who the example or illustration relates to. However, this would be an assumption and there would be no way of positive identification other than that person asked you directly if that scenario was your story and you said, Yes to identifying yourself as the story teller who told of that particular circumstance.
RESULTS

Once the individual stories have been analysed and the collective narrative developed, implications for action will be considered. All who have shared your stories with me will be given a copy of the collective narrative, which is proposed to be Chapter Six of the final document.

CONFIDENTIALITY

During analysis and synthesis of shared information, your story will be identified only by pseudonym: I am the only person who will have knowledge of your personal identity. You are assured that when all stories have been analysed, when similarities and differences are categorised and when I am sure I have no further need to contact you for any point of clarification, all identifying information will be destroyed and only non-identifying information will be stored at the University of the Sunshine Coast in secure systems, for the duration of five years, as required by legislation. During the course of the research investigation, all recordings and transcripts will be locked in secure filing systems and all processed data will be password protected. Data gathered throughout the study will be coded so that your story will be identifiable only by number or by global descriptor. As researcher and transcriber I am committed to confidentiality. No published findings will reveal the identity of any person who chooses to share your story, without your express written consent. Such an example could be a person who chooses to write a book telling of your experience as caregiver for your ‘Special Someone’; a person who has written a book relating to your experience: in which case relevant quotes from you publication will be accurately and appropriately referenced; a person who paints a picture or writes a poem which may be interspersed at random intervals throughout the narrative with no specific identifiable reference to elements of the narrative – in the latter, the participant may choose to have his/her work identified by real name or by pseudonym.

COMPLAINTS

If you have any complaints about the way this research project is being conducted, you can raise them with the Principal Researcher or if you prefer an independent person, you could contact the Chairperson of the Human Research Ethics Committee at the University of the Sunshine Coast: c/- the Research Ethics Officer, Office of Research, University of the Sunshine Coast, Maroochydore DC 4558; telephone (07) 5459 4574; email humanethics@usc.edu.au

CONTACTS

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Dr Ann Moir-Bussy (Principal Supervisor and Senior Lecturer)
Faculty of Arts and Business: School of Social Science: Department of Counselling
University of the Sunshine Coast
Phone: 07 5456 5068
e-mail: AMoirbussy@usc.edu.au

Many thanks for your interest and support in this research project

Judith R Boyland

The Researchers and the University would like to thank you for your interest in this project and appreciate the effort involved in your participation.
CONSENT TO PARTICIPATE IN RESEARCH

Someone I love has Alzheimer’s:

The impact of caring for a ‘Special Someone’ who has a diagnosis of Alzheimer’s disease.

(ethics approval number: HREC: S/15/809)

- I have read, understood and kept a copy of the Research Project Information Document for the above research project.
- I realise that this research project will be carried out as described in the Research Project Information Document.
- I am comfortable that the information I share will be stored securely.
- I am comfortable that the information I share will be non-identifiable in the collective narrative.
- I give consent for the information I share to be used in a confidential manner for the purposes of this research project and in future research projects.
- I am also comfortable knowing that it is possible that a third party may infer my identity from illustrations used in the development of the collective narrative.
- Any questions I have about this research project and my participation in it have been answered to my satisfaction.

Name and contact details of the person I would like contacted should there be need.

NAME __________________________ CONTACT TELEPHONE _______________

I __________________________ agree to participate in the research project, Someone I love has Alzheimer’s: The impact of caring for a ‘Special Someone’ who has a diagnosis of Alzheimer’s disease.

________________________________________ ________________
Participant Date

________________________________________ ________________
Chief Investigative Researcher Date

The collective reality from onset to end of life and beyond. Judith R Boyland
Someone I love has Alzheimer’s:
The impact of caring for a ‘Special Someone’ who has a diagnosis of Alzheimer’s disease
(ethics approval number: HREC: S/15/809)

What are caregivers’ conceptions and understandings about the impact of caring for a loved one who is a ‘Special Someone’ and who has a diagnosis of Alzheimer’s disease?

PROFORMA FOR DIALOGUE – INTERVIEW AND OBSERVATIONS

How participants conceptualise their role as caregiver and how they reconceptualise previously conceived perceptions of the relationship they shared with their ‘Special Someone’ are key aspects to be considered in describing and evaluating I-positions that intertwine in the landscape of the mind, as the view of Self is transformed in the shifting sands of time and as the view of Self both pervades and is pervaded by the environment of care. Through responding to the invitation to reflect, conceptualise and evaluate the role of caregiver and the impact of this role, it is hoped to provide opportunity for participants to identify and own all that is the good, the bad and the ugly of their every-day reality of their lived experience.

Under the overarching umbrella of a qualitative paradigm, a model of research defined in terms of a “methodological hybrid” (Holstein and Gubrium, 2005, p. 497) is chosen to explore and describe the everyday world of the informal caregiver as situated in the natural setting of lived experience, when Someone I love has Alzheimer’s. Data collection is guided by the epistemology of social constructivism and within this construct, intuitive inquiry and narrative inquiry lay the foundation for heuristic design and application that incorporates a transpersonal approach: deemed to be the most appropriate approach to provide the most effective frame through which to develop a profile of the collective landscape embraced by the research question – What are caregivers’ conceptions and understandings about the impact of caring for a loved one who is a ‘Special Someone’ and who has a diagnosis of Alzheimer’s disease? By adopting the position of ‘Bricoleur’, as defined by Denzin and Lincoln (2005, pp .4-6), the researcher weaves the threads and constructs a narrative landscape that pieces together multiple positions embodied in conceptions of participants who share the stories of their lived reality, as it appears to them.

It is believed that a triangulation of multiple methods is the best way to honour the richness, the diversity and the sensitivity of experience that is shared by multiple voices through processes of dialogic interchange. The emerging landscape is woven into a collective whole, according to how each frame is seen and how it is reported by individual participants. When the final word is processed, not only will stories have
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland

been told, voices heard and the research question answered, but what Denzin and Lincoln describe as “a clearly defined sense of complexity” (p. 5) will also have emerged as “a meaningful emotional whole” (p. 5).

<table>
<thead>
<tr>
<th>DETAILS OF PARTICIPANT</th>
<th>DETAILS OF ‘SOMEONE SPECIAL’</th>
</tr>
</thead>
<tbody>
<tr>
<td>name</td>
<td>name</td>
</tr>
<tr>
<td>date of birth</td>
<td>date of birth</td>
</tr>
<tr>
<td>pseudonym</td>
<td>awareness of onset – domain progression</td>
</tr>
<tr>
<td>duration of care</td>
<td>Cognitive spatial executive</td>
</tr>
<tr>
<td>relationship</td>
<td>date of diagnosis date of entry to care type of care facility</td>
</tr>
<tr>
<td>cultural background</td>
<td>cultural background</td>
</tr>
<tr>
<td>socio-economic status</td>
<td>socio-economic status</td>
</tr>
<tr>
<td>highest level of education</td>
<td>highest level of education</td>
</tr>
<tr>
<td>occupation</td>
<td>occupation</td>
</tr>
<tr>
<td>locality</td>
<td>locality</td>
</tr>
<tr>
<td>currently co-residing</td>
<td>date of death – if relevant</td>
</tr>
<tr>
<td>period of co-residing</td>
<td></td>
</tr>
</tbody>
</table>

CONVERSATIONS
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond.  

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>general comment / need for special consideration</th>
</tr>
</thead>
</table>

ANY SPECIAL CONSIDERATIONS THAT MAY NEED ATTENTION DURING INTERVIEW

OTHER PERSONS INTERVIEWED / ENGAGED WITH – eg
- support person if requested by participant to be present during interview
- other persons in the home if interview is conducted in participant’s home
- other persons participants might wish to be interviewed – eg spouse, child/ren, GP

<table>
<thead>
<tr>
<th>name</th>
<th>relationship to caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

COMMENTS:

DOMAINS
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease:

The information presented in this summary tells a story of the reality of lived experience as told by one who is living or who has lived the role of caregiver when the care receiver is a loved one who has Alzheimer’s. The phenomenon under investigation is the impact of caring for that ‘Special Someone’ who has a diagnosis of Alzheimer’s disease.

Both researcher and participant share an understanding of the dialogic nature of ‘intertwining one’s mind with the mind of the other’ (Jones and Hermans, 2011) as each has what Pederson (1997 in Moir-Bussy, 2006) terms as “inside knowledge” (Pederson, p. 6). Each has a story to tell. The cultural anomalies of the context of care are familiar to both and as the minds of researcher and participant intertwine, individual stories are blended together as brains resonate through the process of dialogue. A new synthesis is created, from which evolves a categorisation of similarities and differences and profile the broad landscape. The depth of understanding that emerges from this synthesis of stories represents the multiple voices of participants and has the potential to create a collective narrative filled with a richness that embodies the diverse truths of lived experience.

While no single story is complete in knowledge or truth, it is within the framework of dialogue that new understandings and new meanings are construed and conceptualised as the mind of Self intertwines with the mind of Other, as the brain of Self resonates with the brain of Other and as the voice of Self is heard by the Other. Each story brings its own unique individuality and richness which, when blended with the stories of other participants, breathes life into that new and dynamic collective narrative. It is the evolving narrative that defines the ‘big picture’ as a broad landscape unfolds, encapsulating the essence of experience depicted in the frame of each individual snapshot.

OPENING STATEMENT:

Talk to me about what it is/was like for you, caring for ...............  

POSSIBLE PROMPTS:

- Talk with me a little more about ...............  
- What is it that drives you to care for your ‘Special Someone’ who has Alzheimer’s disease?  
- Where does your motivation come from?  
- What is it that enables you to carry on day after day, week after week, month after month, year after year?  
- What is it that is your greatest source of achievement?
What is it that is your greatest source of distress?
How do you manage your stress levels?

Summers states that, typically, the earliest recognisable stages are generally in the **cognitive domain** marked by memory impairment for recent and current events. Impairment to memory may also be accompanied by subtle impairment to a second cognitive domain such as language: presenting as difficulty in finding words or in explaining things to others. Summers also states that other domains that become recognisably impacted are the **spatial domain** (presenting in behaviours such as becoming lost in familiar locations) and the **executive domain** (presenting as difficulty in coping with unfamiliar surroundings or with new or different tasks). Summers further states that while memory impairment has traditionally been the first recognisable domain of change, recent research indicates that atypical presentations occur in which memory impairment presents later than impairment to non-memory domains. These variables, suggests Summers, would point to recommendation for revision to diagnostic criteria.

Over time, abnormal changes in the brain are said to worsen and eventually interfere with many aspects of brain function resulting in cognitive and physical degeneration and loss of function. While a full description of progressive symptoms is presented in Appendix 1 (Reisberg’s Global Deterioration Scale), ten signs of early detection are noted by Alzheimer’s Association (2009) and presented as …

1) Memory loss that disrupts daily life
2) Challenges in planning and solving problems
3) Difficulty in completing familiar tasks at home, at work or at leisure
4) Confusion with time and place
5) Trouble understanding visual images and spatial relationships
6) New problems with words in speaking and writing
7) Misplacing things and losing the ability to retrace steps
8) Decreased and poor judgment
9) Withdrawal from work or social activities
10) Changes in mood and personality

SUMMARY
EMERGING THEMES
TIPS FOR HELPING TO FOCUS ON …

The impact of caring for a ‘Special Someone’ who has a diagnosis of Alzheimer’s disease

accurate snapshots of every-day reality - the good, the bad and the ugly …

a) Focus on specific examples and describe specific events, happenings and particular experiences

b) Focus on an example of the experience which stands out for its vividness or as it was the first time it was experienced

c) The experience needs to be described as it is lived, avoiding causal explanations, generalisations or abstract interpretations

d) Describe the experience from the inside: including the feelings, the mood and the emotions

e) Attend to the senses – how the body feels, what the experience looks like, what it sounds like, how things smell, is there stimulation to the salivary glands that produces a sense of taste

f) Avoid trying to beautify the account with fancy phrases or flowery terminology.

I have a right to tell my story

There is nothing so awful that I can’t talk about it
MY WORLD ‘THAT WAS’ – pre Alzheimer’s

MY WORLD ‘THAT IS’ – during my caregiving journey

MY FUTURE – what does it look like
Appendix I – Ethical Considerations

Practical implementation of a professional ethical code considers the following measures:

a. Participants are invited to participate voluntarily and without coercion;
b. Participants are fully briefed about the purpose, process and boundaries of the research;
c. Informed consent of each participant is gained in writing, prior to commencement of research interview;
d. Individuality of the participant is honoured at all times with non-judgmental and non-offensive language being used in all written and verbal communication;
e. Participants are treated with empathy, sensitivity and respect at all times;
f. Limits of Duty of Care are to take relevant and appropriate steps to ensure that the researcher does no harm;
g. Confidentiality and anonymity of identity are assured with each participant being invited to take on a pseudonym or a codified identity of choice;
h. Falsification, fabrication and misrepresentation of data is avoided at all times;
i. Participants are assured that in allowing the Self to speak, there is only truth. There is no judgement and stories are treated with empathy, sensitivity, respect;
j. Data gathering proforma are designed to elicit information that is directly related to the research and invites reflection on personal reality, allows description of personal reality and tells the story of lived experience;
k. Stories of participants and works of other researchers and authors are acknowledged and referenced appropriately;
l. All communication related to the research is done with honesty and transparency;
m. Any form of misleading information is avoided; as is any biased representation of primary data, with autonomy of participant being respected at all times;
n. There is no betrayal nor deception in representing information shared by participants;
o. Codified data is securely stored both during analysis and following analysis for a period of time in keeping with legislative requirements;

…00o…
### Appendix J – Participant Profiles in Context

<table>
<thead>
<tr>
<th>CAREGIVER</th>
<th>DURATION OF CARE</th>
<th>AGE WHEN TAKING ON THE CAREGIVER ROLE</th>
<th>RELATIONSHIP TO CARE RECEIVER</th>
<th>AGE OF CARE RECEIVER AT OBSERVED ONSET</th>
<th>AGE OF CARE RECEIVER AT DIAGNOSIS</th>
<th>PERIOD IN CARE FACILITY</th>
<th>PERIOD SINCE DEATH OF LOVED ONE WHEN SHARING STORY – AGE OF LOVED ONE AT DEATH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aemiel</td>
<td>3-5 years</td>
<td>47</td>
<td>daughter (mother)</td>
<td>72</td>
<td>no formal diagnosis</td>
<td>1 year</td>
<td></td>
</tr>
<tr>
<td>Aemelia</td>
<td>6 years</td>
<td>50</td>
<td>volunteer sister and friend</td>
<td>77</td>
<td>not sure</td>
<td>3 years</td>
<td></td>
</tr>
<tr>
<td>Alex</td>
<td>2 years</td>
<td>18</td>
<td>grandson (grandmother)</td>
<td>78</td>
<td>83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alice</td>
<td>9 years</td>
<td>45</td>
<td>daughter (mother)</td>
<td>78</td>
<td>83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aliena</td>
<td>15 years</td>
<td>66</td>
<td>wife 2nd wife of 2nd husband</td>
<td>67</td>
<td>69</td>
<td>10 years</td>
<td>8 months (age 84)</td>
</tr>
<tr>
<td>Angelica</td>
<td>10 years</td>
<td>62</td>
<td>wife</td>
<td>63</td>
<td>69</td>
<td>4 years</td>
<td></td>
</tr>
<tr>
<td>Rosaline</td>
<td>10 years</td>
<td>62</td>
<td>wife</td>
<td>63</td>
<td>69</td>
<td>4 years</td>
<td></td>
</tr>
<tr>
<td>Olivia</td>
<td>10 years</td>
<td>62</td>
<td>wife</td>
<td>63</td>
<td>69</td>
<td>4 years</td>
<td></td>
</tr>
<tr>
<td>Nym</td>
<td>10 years</td>
<td>62</td>
<td>wife</td>
<td>63</td>
<td>69</td>
<td>4 years</td>
<td></td>
</tr>
<tr>
<td>Antony</td>
<td>9 years</td>
<td>78</td>
<td>husband 2nd husband of wife</td>
<td>79</td>
<td>81</td>
<td>8 months</td>
<td>8 months (age 87)</td>
</tr>
<tr>
<td>Audrey</td>
<td>7 years</td>
<td>69</td>
<td>wife</td>
<td>73</td>
<td>73</td>
<td>4 months</td>
<td></td>
</tr>
<tr>
<td>Edward</td>
<td>4 years</td>
<td>87</td>
<td>husband daughter (mother)</td>
<td>85</td>
<td>88</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emily</td>
<td>4 years</td>
<td>61</td>
<td>daughter son-in-law (mother-in-law)</td>
<td>85</td>
<td>88</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iach</td>
<td>5 years</td>
<td>about 55</td>
<td>daughter (father)</td>
<td>80</td>
<td>no formal diagnosis</td>
<td>16 years</td>
<td>16 years (age 85)</td>
</tr>
<tr>
<td>Elan</td>
<td>5 years</td>
<td>about 55</td>
<td>daughter (father)</td>
<td>80</td>
<td>93ish</td>
<td>3’ years</td>
<td></td>
</tr>
<tr>
<td>Eleanor</td>
<td>3 years</td>
<td>60</td>
<td>female partner (male partner)</td>
<td>64</td>
<td>65 geriatrician hinted that he could have Alzheimer’s</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emilia</td>
<td>3 years</td>
<td>58</td>
<td>daughter (mother)</td>
<td>83</td>
<td>mixed suggestions but no definitive diagnosis</td>
<td>20 months</td>
<td></td>
</tr>
<tr>
<td>Emma</td>
<td>13 years</td>
<td>48</td>
<td>daughter (mother)</td>
<td>73</td>
<td>80</td>
<td>4 years</td>
<td>3 years (age86)</td>
</tr>
</tbody>
</table>
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. 

Judith R Boyland

<table>
<thead>
<tr>
<th>CAREGIVER</th>
<th>DURATION OF CARE</th>
<th>AGE WHEN TAKING ON THE CAREGIVER ROLE</th>
<th>RELATIONSHIP TO CARE RECEIVER</th>
<th>AGE OF CARE RECEIVER AT OBSERVED ONSET</th>
<th>AGE OF CARE RECEIVER AT DIAGNOSIS</th>
<th>PERIOD IN CARE</th>
<th>PERIOD SINCE DEATH OF LOVED ONE WHEN SHARING STORY</th>
<th>AGE OF LOVED ONE AT DEATH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ephesea (support)</td>
<td>10 years – particularly last 3-5</td>
<td>37</td>
<td>daughter (father)</td>
<td>62</td>
<td>no formal diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hal</td>
<td>5 years</td>
<td>48</td>
<td>son (mother)</td>
<td>82</td>
<td>86</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iris</td>
<td>8 years</td>
<td>44</td>
<td>daughter (mother)</td>
<td>80</td>
<td>80</td>
<td>2 years</td>
<td>7 years (age 88)</td>
<td></td>
</tr>
<tr>
<td>Isabella</td>
<td>5 years</td>
<td>60</td>
<td>daughter (father)</td>
<td>87</td>
<td>90</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Jason (support) | 5½ years | Jason was 13  
Megan was 19  
I was 43 | grandson (grandfather)  
my emotional rock as I cared for my father granddaughter |
| | | | 80 | 6 months | 24 years (age 87) |
| Megan (support) | | | |
| Lavinia | 6 years | 65 | wife (husband) | 81 | 83 | 7 months | 1 year (age 87) |
| Nerissa | 15 years | 46 | daughter (mother) | 82 | 83 | 3½ years | 5 days- (age 97) |
| Richard | 4 years | 45 | son (father) | 64 | 64 | 16 months | 4 months (age 72) |
| Rosalind | 7 years | 69 | wife 2nd wife of 2nd husband | 80 | 80 |
| | | 5/6 years | daughter (mother) | 67 | no real diagnosis | 15 years (age 72) |
| Rousillon & Lafe | 18 months since fall – 8 weeks since observable signs of onset | 70 | 72 | daughter (mother)  
son-in-law (mother-in-law) | 98 | 98 |
| Vince | 9 years | 56 | husband (1st wife) | 57 | 59 | 1 year | 9 years (age 67) |
| Yori | 20 years of little changes – 7 years mild changes – really showed it’s “ugly head” about 2010 | 28 | Wife (husband) (third wife) | 52 | 66 |

...000...
Appendix K – Residential Care: The Village Alternative

In the small town of Weesp, in Holland, there is a neighbourhood that is known as “Dementiavillage”. Established in 1992, this very special living centre is called De Hogeweyk. The idea, as explained by Hogeweyk’s creators, was to design a world that values the person and maintains as much a resemblance to normal life as possible, without endangering the patients: a world where people with advanced Alzheimer’s disease and dementia could enjoy life and feel welcome here on this earth.

Hogeweyk is a secure complex of apartments and buildings with gates and security fences and provides residents with attention and support for 24 hours every day. Within the complex, there exists a unique, self-contained world of “normalcy”, where 152 residents are watched over and comforted and have free access to restaurants, cafes, a supermarket, gardens, a pedestrian boulevard, and much more.

Staff to resident ratio is two staff members to each resident and all staff are highly qualified in geriatric and specialised dementia care – for example, nurses, medical practitioners, or allied health professionals. Activities focus on physical and social stimulation and empirical evidence indicates that residents eat better, sleep better, and seem to have more joy than residents of “traditional” nursing homes. It has been observed that initially, the average duration of care for residents (time between entry and death) was two/two-and-one-half years. It is now three/three-and-one-half years.

The complex has been described by one caregiving husband as being “perfect – just so open and free”. Future development hopes to provide facility where partners of residents can also live with their loved one at Hogeweyk.

Information retrieved from https://www.youtube.com/watch?v=LwiOBlyWpko

In Aalborg, Denmark, there is a care centre for residents with advanced Alzheimer’s and dementia. With a vision similar to that which drives Hogeweyk in the Netherlands, the facility consists of 75 apartments, a medical and dental clinic, a fitness centre, several themed rooms, and a public restaurant. With a focus on utilising technology and public spaces to revolutionise the concept of an aged care facility, the
A holistic snapshot of the impact of caring for a loved one who has Alzheimer’s disease: The collective reality from onset to end of life and beyond. Judith R Boyland

Aalborg centre is reported to have a ‘living lab’ which provides a meeting place for residents, university researchers, and technology companies to trial new technology. Examples include a physical rehabilitation robot and a mobility monitoring system, which aims to prevent residents from developing pressure ulcers. Other technologies currently in use in the care centre include ceiling lift systems, adjustable bathroom sinks, and sensor floors that sound an alarm when a resident falls or has not returned to their bed.

Information retrieved from https://soundcloud.com/australian-ageing-agenda/the-nursing-home-of-the-future-thomas-noerkaer

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Closer to home, the notion of “the dementia village” as modelled in the De Hogeweyk village received approval in 2017 and will be constructed in Glenorchy, Tasmania. “Korongee” is Australia’s first dementia village. Mimicking the small-town setting of Hogeweyk, Korongee aims to create conditions so that residents are challenged by recognisable incentives to remain active in daily life.


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Also based on the successful Dutch model, there is a proposal for a dementia village to be built in Heathcote, 45 kilometres south-east of Bendigo, in the state of Victoria. This proposal has won the support of the state government, which contributed $150,000 towards a feasibility study. The aim of the developers is said to establish a facility that would not feel or look like an institution, but rather, mimic a tiny country town.


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Further north, on the Sunshine Coast in the state of Queensland, Synovum Care is preparing to open what they refer to as the world’s first inclusive village for residents.
with dementia and other complex needs. The award-winning design of the Bellmere facility seeks to provide residents with as normal a life as possible, where freedom of movement is deemed to be critical. The vision is to provide a safe, dignified, and familiar environment with individualised services that are underpinned by a wellness and empowerment approach.

The development consists of 17 houses where up to seven residents live in a domestic-style house, each of which has a fully functional kitchen, dining room, laundry and sitting rooms and where House Companions assist residents in their day to day activities such as cooking, cleaning, personal care, and medication management. The facility will be staffed by a team of registered nurses, physiotherapists, exercise physiologists, and dementia support specialists. Residents will also have access to a corner store, cafe, hair and beauty salon, barber, cinema, fitness centre, men’s shed, dental clinic, and an onsite GP medical office.


…00o…
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