

**Disquieting disconnection: Finding meaning and purpose in life
when journeying with a partner who lived and died with
Semantic Younger Onset Dementia.**

by

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Thesis

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Abstract

This research explored the phenomenon of disquieting disconnection as experienced within a lifelong relationship as a consequence of the impact upon personhood when journeying with a partner who lived and died with Semantic Younger Onset Dementia (S-YOD). This study was informed by a heuristic approach to enquiry using Moustakas' (1994) method, providing congruence when addressing the lived experience of the spouse, the lone subject, who was experiencing disquieting disconnections.

Three major themes were identified during this research journey of finding meaning and purpose in life: 'Feeling Abandoned', 'There Are No Words' and 'Running in the Opposite Direction'. Constant immersion in the heuristic process led to the acquisition of new realisations. The main themes along with associated sub-themes and/or paradoxes were integrated and the accompanying creative synthesis of the experience evolved. This provided a depiction of a process of grieving, expressed within a thematic conceptualisation entitled 'Seasons of Grief'.

Paradoxically, the strength of this research can be viewed as its limitation. In essence, it is one person's journey, providing intensity and detail, however it is one person's perspective. It is the recommendation there be further studies highlighting the experience of others. The more lenses we are provided to look through, the richer our understanding will become. More studies on spousal experiences of living, loving and grieving a partner who lives and dies with YOD are required, in particular from those who represent minority groups.

Key words: disquieting disconnections, younger onset dementia, heuristic, grief, lesbian

Acknowledgements

Acknowledgements usually begin by thanking the participants for their valued contributions to the research. A heuristic journey, with the researcher as the one and only participant breaks from this tradition. This has been a pattern throughout this research, an unconventional and differing approach was taken, from what can be viewed by many as from left of field. I would like to begin in-light of this disclosure to acknowledge the people from the research department from CQU for taking the risk, supporting research from a lesser known, non-traditional approach. As I am the one participant, the one researcher and lone traveller thank you for your faith in me and enabling my journey.

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Arohanui

This journey was taken with and in memory of my darling Olga. There are no words...

§

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Declaration of Authorship and Originality

This thesis documents the author's personal perspective on a series of life events. The frame of the research is therefore related to personal recollections, the author's first-hand experience of events and of her interpretation of the behaviours and actions of others, and therefore are not necessarily statements of fact. Family and friends who are referred to in the thesis were aware of the research project but are not represented as research participants, and their appearance in the work is limited only to the author's interpretation of her own lived experience.

I, the undersigned author, declare that all of the research and discussion presented in this thesis is original work performed by the author. No content of this thesis has been submitted or considered either in whole or in part, at any tertiary institute or university for a degree or any other category of award. I also declare that any material presented in this thesis performed by another person or institute has been referenced and listed in the reference section.

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Patricia M. Awty

Date

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Preface

Once upon a time...

Once upon a time there were two women who felt alone and sad in a world where they felt rejected, different and misunderstood. One was very tall and slim with blond hair, big sea blue-green eyes and a smile that lit up the sky like a blazing summer sun. She read lots of books, was very clever and spoke in lots of different languages. Despite being so tall and handsome she felt no one saw her. Despite being so eloquent she felt no one heard what she was saying.

The other woman was short and round with dark brown hair, smiley 'pop-out' blue-grey eyes and was always laughing. She appeared to be a jolly and a 'larger than life' person, who made people laugh, told jokes and sang songs. Despite being a 'larger than life' person, bouncy and round she felt small and dead inside. She felt no one saw her. Despite joking and singing she felt no one heard what she was saying.

In their search to find connection with the world, to be seen and heard, they left their homelands and travelled to the land of the long white cloud in pursuit of happiness. They met and fell deeply in love with one another, even though they were so different. They seemed opposite in appearance and personality. It seemed the more things were different the more they were the same and like magnets they attracted each other. The pull drew them together, they stuck tight and connected. One plus one became one as they realised they were both the missing half of the other. They felt accepted, the same and understood by each other. They felt as one, complete. They thought they would grow old together and live happily ever after.

This is the story of my journey in finding meaning and purpose in life when my life partner Olga lived and died with Younger Onset Dementia.

CHAPTER ONE
BACKGROUND TO THE STUDY
SETTING THE SCENE

1.1 INTRODUCTION

This chapter sets the scene for the study. It begins by providing a background for the research journey. Contextualising and anchoring the beginnings of this enquiry helps provide justification and clarifies the roads taken in exploring the phenomenon - disquieting disconnection and finding meaning and purpose in life when a life partner lives and dies with Younger Onset Dementia (YOD). The chapter continues with a description of how this heuristic journey unfolded, signposted by the impact of losing connections, the impact of change, the traumas of past life experiences, medical interventions pathologised and objectified, loss and abandonment, entrenched heterosexism and misogyny, contemplating ways to maintain personal integrity, union and spiritual safety, and the decision to acknowledge dying as a part of living in the context of limited cognitively informed choices.

The chapter concludes with the researcher's expressed desire to shine light into the dark areas of the inadequacies within the current culture and system of care. A desire to increase the understanding and awareness of the disquieting disconnections experienced by people living with a partner who lives and dies with YOD is made in order to bring about changes. Changes are needed which can improve the care and support provided to people who are searching for meaning and purpose in life when loving a partner who lives and dies with YOD. The final component of this chapter outlines the structure of the thesis.

1.2 BACKGROUND

The change of focus with the development of a new direction for a Doctor of Philosophy (PhD) thesis was the first identifiable step to discovering a way forward through the tears and desolating silence which encompassed my life. The previous PhD thesis topic followed on from an earlier, successful completion, of a Master's degree. The exploratory, descriptive research study on psychiatric nurses' perceptions and perspectives on therapeutic relating became unimportant. What previously inspired and motivated study, faded into the distance and was no longer visible in my life. The repositioning of the research onto a heuristic study was for the researcher more relevant and poignant. My love of Olga was all that mattered to me. Staying connected with her was my only goal.

1.3 ORIGINS OF LOVE

The Greek philosopher Aristophanes (c.446 – c.386 BC) in his account of the origins of love mythically describes how in the beginning human beings had four legs and feet, four arms and hands, two faces and two lots of genitals (Kodera, 2005). There were three genders, males, who originated from the sun, females who originated from the earth and androgynous, male and female mixed gender humans who originated from the moon. Round in shape, strong and formidable the human beings threatened the Gods. Rather than destroy these pretty amazing creatures, the Gods decided to disempower them by splitting them in half.

This was catastrophically traumatic for human beings. So, with a few modifications, tweaks and updates, the Gods recreated people as we see them today (Kodera, 2005). Incomplete, half of a whole, in need to search for their soul mate, their other half, so they can feel connected and complete again. This myth poetically incorporates the concept of

homosexuality as a normal variation of human sexual diversity as well as giving an account of the origins for the most essential human need, to love and be loved.

This ancient mythical story symbolically summed up my life experience of being with Olga. Olga was a child of the moon and was the sun in my life, she connected me to this earth. All those clichés you read in tabloids magazines and airport paperbacks were in many ways applicable to how I perceived our relationship. My world, however, was being shaken.

1.4 CHANGES

Changes had been occurring in the behaviour of Olga, my life partner. Insidiously, over several years, the emotional and cognitive changes Olga battled with, and had managed to conceal, began to reveal themselves, and noticeably, had an impact upon our relationship. Olga was struggling to contain her anxiety and it was spilling over and flooding our world. The adaptations to maintain our connectedness and our loving relationship were increasing. Extra time was needed to prepare for appointments and meetings. Olga's ability to organise herself, and us, was rapidly diminishing and her calm gentle nature was fraying at the edges. The stress and pressure created was starting to overwhelm us. Drawing closer together, we hung on to each other for fear of drowning.

1.4.1 Lost for Words

Olga began to experience night terrors. She would wake up screaming in the middle of the night, fearful and crying inconsolably. She was unable to find the words to express what was happening for her and then she lost words altogether. After one terrible night-terror, Olga became mute and unable to make any sound. She stood shaking, tears streaming down

her face, clenching herself. She was oblivious to my words and fearful of my approach. I needed just to be there. As Olga regained her control, she would fall sobbing into my arms.

1.4.2 Post-Traumatic Stress Disorder (PTSD)

Following the loss of her ability to speak, we sought the help of a Psychologist. The Psychologist diagnosed Olga with Post-Traumatic Stress Disorder (PTSD). A previously unknown history of trauma slowly came to light as Olga's voice returned. It dated back to Olga's arrival in Australia, from the Netherlands, when she was five years of age. Olga's vulnerability, at this period of her life, throughout her primary, secondary and tertiary education was exploited and only ended when Olga migrated to Aotearoa New Zealand, at the age of thirty-two.

1.4.3 Mirroring Childhood

Further events, held secret within Olga's family occurring from when she was ten years of age added to the complexity of her development and affected her ability to contain grief and loss. I focused on supporting Olga in every way I could. The main thing was to do what appeared simple; to cook and prepare her favourite meals, create safe spaces, spend time and just be with her. These simple tasks became intricate and emotionally draining because the situation began to mirror my childhood experiences with my mother.

1.4.4 Abandonment

My mother's traumatic childhood, though not acknowledged until late in her life, contributed to her inability to attach or connect with me. The youngest of six children, my care fell, initially, to my father, and increasingly, to my siblings, as I grew up. The carer role was reversed in my childhood and I needed to be the adult caring for my mother. Her

loss of control, anger and anxiety needed to be contained by me. My mother, whose inability to nurture and demonstrate love to anyone other than my father, contributed to my difficulty in trusting people, especially women. There was never any chaos with Olga. She was so contained, ordered and calm. Her unconditional love and care had enabled me to trust, connect, feel safe and to love and be loved in return. Now the childhood chaos was returning, Olga was becoming out of control. It felt as though I was alone again.

1.4.5 Same-Sex Couple

These feelings of aloneness were magnified when I was given limited information about Olga and her care, by all her caregivers and support workers. Although I understood the need for Olga's autonomy to be respected, I wondered if the alienation I experienced was related to the fact that Olga and I were in a same sex relationship. Various health professionals asked me, on several occasions, "who is Olga's next of kin?" and they told me it needed to be a family member, and connected to Olga, as 'I didn't count'. I had explained we had entered into a civil partnership in England. I stated I was lawfully Olga's partner and her Next Of Kin (NOK). I also had documentation of Power Of Attorney (POA) from our solicitor. There was purely a willful lack of recognition of our relationship and my status. Olga tried to discuss with me what had happened in her meetings with health professionals. She became tearful and frustrated at her own inability to express her thoughts and feelings.

1.4.6 Together Alone

Usually, we would just lie together on her return home from consultations and meetings. I would hold her in my arms and try to comfort her by caressing her softly and quietly singing her favourite songs. She would fall asleep in my embrace. I would follow, drifting off into

a peaceful sleep. Lying together, all seemed as it had always been, as we slept. However, increasingly, we were becoming, together alone.

1.5 MEDICAL INTERVENTION

This pattern continued for several months. Early one evening, I received a telephone call from Olga's Psychologist saying she had referred Olga to a Psychiatrist. Despite trying to discuss the Psychologist's concerns, I was given no further information. Following the assessment by the Psychiatrist, Olga was referred to the 'Memory Clinic' (the 'Memory Clinic' is the name given to avoid the words 'Dementia Clinic'), for numerous investigative tests including various brain scans. Early one morning, with me by her side Olga received the medical diagnosis of 'Frontotemporal Lobe Degeneration (FTLD)'. The consultant with the nurse specialist present discussed in full with Olga and me the diagnosis, outlining the disorder's progression, the prognosis (two years approximately) and the implications for Olga and me in terms of our relationship. We left in silence, drove home and retired to the safety of our bedroom and sat on the edge of our bed. We began discussing some of the repercussions of the pending life changes.

1.5.1 Autonomy

We talked about how the changes impacted upon our relationship. Olga was concerned with her increasing dependency upon me and her loss of control. I was focused on Olga's wellbeing and did not consider the future impact these changes would have upon my personhood. Olga articulated her concerns at being unable to cope and the pending inevitable cognitive, emotional and physical losses. She facilitated an intellectual debate, with me, about the ethical concepts of self-determination and autonomy. We discussed the meaning of our relationship, our responsibilities to both ourselves and each other

1.5.2 ‘To Be or Not To Be?’

We discussed how we could cope and adapt to these new circumstances and dramatic changes in our lives. We talked about how we could, take control of our circumstances, and our daily lives, in order to move forward in this life united, as a couple; life partners in adversity. Would we rather take control together as a couple while we could, rather than lose our relationship and be alone? The accompanying guilt and shame of not being able to protect and care for Olga was overwhelming. I had made a sacred vow ‘till death do us part’, and I felt I was letting her down at the point where her life was concluding.

1.5.3 Tacit Understanding

We sat and discussed the ethico-legal considerations of this course of action. We sat and talked for the remaining hours of the day. Both exhausted, as the sun went down, we got back into bed and embraced, falling asleep in each other’s arms. We never discussed or alluded to this conversation or the disquiet it had caused again. We shared a tacit understanding and we both knew we had reached the same outcome, to continue on our journey together, wherever it was to take us. This was to be our last in-depth philosophical and overt, spoken, spiritual sharing, and although unspoken, we came to the same conclusion, to live the future together and continue our journey. Little did I anticipate the enormity of the challenges of the road which lay before us. Little did I appreciate the attacks on our personhoods, individually, and as a couple.

1.6 FINDING SELF

Caught in the harsh winds of change, it was difficult to see “self” in the whirlpool of our relationship, so the thought of saving self was never contemplated, as self appeared not to exist outside the union of our partnership, Patricia and Olga, ‘P&O’ as friends and family

called us. It was, and remained, unimaginable to anticipate the tsunami of personal loneliness and sorrow which followed. Finding self, without losing connection with Olga, and facing the loneliness encountered when having to make ‘life and death’ decisions for your loved one was nearly a fatal journey.

1.6.1 Takotsubo Syndrome

Late evening on the 23rd December 2007, whilst visiting family in England, I experienced my first heart attack. A second followed in May 2008 and I was experiencing numerous episodes of angina. It was not until 2017 a diagnosis of Takotsubo Syndrome, commonly referred to as Broken Heart Syndrome, was made. Whilst no significant disease was evident in my coronary arteries, the anxiety generated by loss and grief eventuated in constriction of a coronary artery, sufficient to stop blood flow to a part of the myocardium, causing it to die. I was living with the emotional trauma, the disquieting disconnections in my life. The pending loss of Olga precipitated the angina attacks and partial coronary artery constrictions I was experiencing. My heart was breaking...

1.6.2 Loneliness

From my first memories as a child, growing into adolescence and adulthood, I always felt ‘alone’. I went on to never feeling alone in this world once Olga was in my life. I felt complete as an independent individual, as one half of a loving couple. Living with Olga gave me direction and I felt there was meaning and purpose to my life. Whilst journeying with Olga, a partner who had Younger Onset Dementia (YOD), all focus was on staying connected. With the challenge of each disconnection came the creation of new ways to stay connected. When Olga died, I would be physically alone once more. How would my life with Olga continue once her body was no longer?

1.6.3 Confined to the Past

The future was something I did not consider at this stage of my journey. The adage ‘if you live in the future, you experience anxiety’ certainly summed up my situation. Olga had become unable to consider or discuss the concept of future because of the increasing Frontotemporal Lobe Degeneration (FTLD). We had started living mainly in the past. As the adage goes on to say, ‘if you continually live in the past you experience depression’ and this was becoming the situation. I do not believe we achieved peace but, more and more, to cope we began to live in the here and now. The idea of illuminating our experience in relation to the phenomenon – disquieting disconnection and contributing to extant knowledge about the phenomenon, so it can inform and help others, provided a light in the darkness. The cloud of helplessness we both felt about our future had an optimistic silver lining.

1.6.4 The Phenomenon Disquieting Disconnection

Our experience could be used to help other people in similar situations to ours. We knew from our own informal review of research and literature there was little out there which addressed our circumstances. Following lengthy consultation with my academic research supervisor, I was to engage in a process of inquiry concerning the phenomenon disquieting disconnection: my experience of loving and living with a partner who developed, and subsequently died from, Younger Onset Dementia (YOD). This became my new research journey.

1.7 FOCUS OF THE STUDY

This research will explore the phenomenon of disquieting disconnection as experienced by the partner within a lifelong relationship as a consequence of the impact upon personhood of Semantic Younger Onset Dementia (S-YOD). This study will be informed by a heuristic approach to inquiry using Moustakas' (1994) method. Illuminations of the heuristic journey of the researcher in relation to the phenomenon – disquieting disconnection – has the potential to throw light on the essential nature of the phenomenon.

1.7.1 The Research Question

The research question that guided this study was:

What is the lived experience of disquieting disconnections as the life partner of Olga who lived with and subsequently died from Semantic Younger Onset Dementia (S-YOD)?

1.7.2 The Research Objectives

The objectives for this study were:

- To engage in a process of heuristic inquiry concerning the phenomenon disquieting disconnection as experienced by the researcher whose partner developed and subsequently died from Semantic Younger Onset Dementia
- To illuminate the experience of the researcher in relation to the phenomenon – disquieting disconnection
- To contribute to extant knowledge about the phenomenon of disquieting disconnection

1.7.3 The Heuristic Journey

Within the very limited research on Younger Onset Dementia (YOD) there is a predominance of biomedical quantitative research. When specifically exploring the impact of YOD upon carers and spouses, quantitative research is rendered redundant. The very nature of understanding the lived experience clearly indicated a phenomenological methodology needed to be adopted. The research method chosen was heuristic in order to address the experience of the spouse, the lone subject, who was searching for meaning and purpose in life. Utilising Moustakas's methodology specifically engineered for such a research venture. It will explore the phenomenon of disquieting disconnection, as experienced by the partner within a lifelong relationship, as a consequence of the impact upon personhood of journeying with a spouse living with Semantic Younger Onset Dementia (S-YOD). Illuminations of the heuristic journey of the researcher in relation to the phenomenon – disquieting disconnection – has the potential to not only throw light on the essential nature of the phenomenon, but also to contribute to a greater understanding of the impact of this experience on the partner within the couple, who journey together, along a pathway which includes Semantic Younger Onset Dementia (S-YOD). Moustakas' (1994) heuristic approach to inquiry is clearly the best method to meet the needs of this study.

1.7.4 Reflection and Exploration

The reflective and explorative nature of heurist inquiry affirms imagination and creative processes (Moustakas & Douglass, 1985). Affirming the validity through reflection and exploration (Moustakas & Douglass, 1985) leads to a greater understanding of the impact of this experience on the partner within the couple who journey together along a pathway which includes Semantic Younger Onset Dementia (S-YOD). This contributes to the

collective knowledge and development of a greater understanding of a growing contemporary socio-cultural issue requiring urgent focus.

1.8 FRONTOTEMPORAL LOBE DEGENERATION

Frontotemporal lobe brain changes are prevalent in people diagnosed with Younger Onset Dementia (YOD) (Warren, Rohrer & Rossor, 2013). These changes include the inability to contain anger and problem solve, analyse thoughts and select corresponding actions (James & Jackman, 2017). The pathophysiological changes to this region of the brain amplify the psycho-sociocultural complexity for the person living with YOD (James & Jackman, 2017). Expressive and behavioural changes in their partner related to the FTLD aspect of YOD are absorbed by the spouse. Love and empathy charges the partner with contending with the implications of a spouse who is 'different', whose behaviours often presents as socially inappropriate when attributed to what seems a healthy adult.

In private, often alone, the spouse is bearing the fear and frustration of unpredictable violence and relationship uncertainty inherent in those with FTLD. This is further exacerbated by the social isolation which ensues due to being part of a couple whereby one has lost their grasp of sociocultural graces and communication. Therefore, the intensity and increased psycho-sociocultural distress is experienced, albeit differently, by both the person living with dementia and their spouse. Both the impact of changes contributing significantly to the complexity of the experience and stress, are exacerbated by the challenges to connectedness which FTLD changes embed in the relationship. Whilst there are no brain changes related to dementia occurring in the brain of the partners, the complexity of their reaction is relative to their partner's brain changes. The tacit awareness that this connectedness which develops between two people in a love relationship is a

physical, emotional and spiritual union, informs this research. In order to understand the experience of disquieting disconnection, a holistic, heuristic journey needs to be journaled.

1.8.1 Younger Onset Dementia (YOD)

The degree of stress experienced by spouses, is stated to be significantly higher in spouses of people with YOD than those occurring in partners of people diagnosed with other types of dementia (Kaiser & Panegyres, 2007). Older people are said, by Erikson, to be at a stage of development referred to as ‘Integrity versus Despair’, where they are reflecting on a life approaching its conclusion. Life expectations are very different for an adult in mid-life. Erikson describes this developmental stage as ‘Generativity versus Stagnation’. Life’s focus is on the development and growth of career, relationship and family.

The abrupt socio-cultural and developmental disruption of YOD has a catastrophic impact upon the personhood and the ability to integrate self. This is experienced by the carer as well as the index patient diagnosed with YOD. The disruptions to career, finances and adult life style expectations, in addition to the aforementioned interpersonal and relationship changes, contribute to the disquieting disconnections experienced by spouses. These phenomena need to be further understood if we are to illuminate the path of a partner’s experience. The disquieting disconnection experienced by the researcher, as a consequence of the impact upon personhood of her partner who has Semantic Younger Onset Dementia (S-YOD), is greatly influenced by the symptomatology and idiosyncratic aspect of a non-existent future.

1.9 DISCOVERING NEW DIRECTIONS

In 2020 a leading cause of death in the western world is Dementia. In Australia dementia was reported to be the second leading cause of death in 2019 and is predicted to become the leading cause of death within the next few years (Australian Bureau of Statistics Australia, 2019). In England and Wales it was reported to be the main cause of death since 2017 (Office for National Statistics UK, 2019). Similar statistics can be seen throughout most of Europe and the majority of the States of America where dementia is seen as being a significant mortality and morbidity issue going into the future (Dementia Australia, 2020). The impact of dementia within Western society and culture has been given little consideration, given the sociocultural significance and implications. The personal repercussions of dementia on the lives of people is easily lost in a Western world obsessed with youth and beauty, given the false perception that dementia is ugly, and only experienced by old people.

Dementia is unique from other leading causes of death in that there is no effective treatment. In the absence of a cure and limited treatment, the medical model offers little for those living with dementia, or their loved ones. Medications are of little assistance. Whilst caring institutions make a valid difference, the people who make the most impact are the loved ones, the spouses; those who validate the personhood of the person living with dementia. These relationships provide a continual reinforcement of identity for those lost in the fog of dementia. Loved ones can only be supported and validated in this vital role by the broader health care system if there is insight into the significant role they play.

Robust, honest dialogue is necessary to raise awareness, ensuring a sound knowledge base, and understanding generates the best quality care. Whilst there is research undertaken in

relation to dementia, when taking into consideration it is soon predicted to be the leading cause of death in the Western World, the enormity of the impact of dementia appears to warrant far more research and attention than it is currently generating. Younger Onset Dementia (YOD) accounts for approximately ten percent of dementia diagnoses (Craig & Strivens, 2016). High suicide rates and missed diagnoses skew and limit the reliability of figures because of society's widely held perception that dementia lives in the realm of the elderly and therefore, is expected or does not matter. YOD occurs in people in the midst of adulthood (Craig & Strivens, 2016), adding additional complexity to the needs of the people with the diagnosis and their loved ones. Additional gaps and discontinuity in the meeting of needs, is experienced by people in same sex couples, in particular, by women loving women, lesbian couples, who are further marginalised (Platzer, 2017) by these absences and shortfalls. These factors, along with the frequently accompanying economic disadvantage in these groups, further contribute to the inequalities in dementia health care.

The economic savings made by the government and taxpayers, by supporting carers in their own home, though an incidental factor within this study, is worthy of consideration, albeit in a 'sugar coating of the pill' philosophical approach. Whilst home care contributes greatly in improving the health economics of a system under financial stress (Livingston et al., 2017), care in the home provides, a healing, culturally appropriate milieu, protecting and promoting the personhoods of people living in a world disrupted by the changes imposed by YOD. Meeting personal needs such as these are beyond objective measures.

It is the intention of this thesis to contribute to a person-centred knowledge base of dementia, especially YOD. To care for the loved one contributes to not only a supported journey for the carer, but leads to better care for the person living with dementia. An

understanding and awareness of the impacts of loss of autonomy and cognition upon personhood and relationships for people living with dementia and their loved ones is needed. Quality of life and care for people living with dementia is disproportionately reliant on their loved ones. All the people caught in the dementia web rely and live, solely within the realm of care. The richness of findings from this research provides valued insights into caring for people living and dying with dementia.

1.10 STRUCTURE OF THE THESIS

This thesis consists of six chapters. Following on from the first chapter which sets the scene, providing a background and introduction to the study, is chapter two, the initial dynamic literature review. The rigor and limitations of current literature is critiqued and discussed. The dearth of research and literature in the focus area of this study, validates the journey. Chapter three presents the method and methodology guiding the study. Within the qualitative paradigm, Clark Moustakas's heuristic approach to inquiry is outlined and applied to exploring the phenomenon - disquieting disconnection and finding meaning and purpose in life when a life partner lives and dies with Younger Onset Dementia (YOD). Chapter four, 'the story' provides the major data base for the study and chapter five outlines and reviews the finding. The four major themes which have been identified, are explored and discussed in chapter six and critically analysed within chapter seven. In the final chapter, the meaning and purpose of life found whilst journeying with a life partner who lives and subsequently died with Semantic Younger Onset Dementia (S-YOD), is provided. The chapter concludes with redefining the journey of grief and outlining a grief process experienced.

The societal response, with palliative conditions, is to defer to the medical model for direction. A change in direction is required in order to help people living with dementia, and their loved ones, to stay connected to each other, within a cultural context, on their difficult journey. This holistic approach of care is currently lacking and thus the generation of further knowledge and awareness is not only warranted, but is greatly needed. The need to discover new directions in the journey towards a more considered just world, advancing humanity and refocusing on people is clear, however arduous.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter provides a literature review to explore the phenomenon of disquieting disconnection as experienced by a lesbian spouse, within a lifelong relationship, as a consequence of the impact of Semantic Younger Onset Dementia (S-YOD). Whilst no research could be found on all the specific concepts at hand, the literature review focused upon the topic of living with a partner diagnosed with YOD. This provided a context for the research question and a starting point for this study. The literature review undertaken provided a valuable background to begin the investigation on the issues pertaining to ‘disquieting disconnections, finding meaning and purpose in life, when journeying with a life partner who lives and dies with YOD’.

Dementia is becoming the main cause of death within the western world. This progressive, degenerative brain disorder has in the main, no active treatment and care is palliative. Whilst the focus within medical research is on ‘finding a cure’ to rid society of this new plague, people remain living and dying with Dementia. Fuelled by fear within the ageing population and their families, research has kept the spotlight on cure and treatment of Late Onset Dementia (LOD) and the diagnosed patient, the person living with Dementia. Socio-cultural expectations are limited by a lack of knowledge and understanding of Dementia and this ignorance obscures the lesser known and unacknowledged factor, of age of onset of the disorder. Younger Onset Dementia (YOD) adds further complexity to an already fragmented mosaic of understanding, symptomatology and care.

The nature of YOD requires a different perspective and approach than LOD. The symbiotic relationship between people living and dying with YOD and their primary carer, who is often their spouse or partner, impacts more profoundly because the couple are in the prime of their lives, mid-life. With life being in full swing, the effect of YOD upon personhood of both people in the relationship and upon their couple-hood is intense. There is very limited research on living with and loving someone with Dementia, even less when we scrutinise the lived experience of living with and loving someone with YOD. If we add the socio-cultural and spiritual dimensions of a life-long partnership between two women, a lesbian couple, journeying with YOD, nothing was to be found.

2.2 THE LITERATURE REVIEW

The literature review was undertaken to provide a critique and introduction of current research relevant to this study. The review presents current understandings of the experiences of the spousal caregivers of partners living and dying with YOD. Beginning by outlining the search strategies employed to locate the most recent and relevant data, the prominent themes throughout the literature are discussed. From the summary of the review five main areas of interest were identified. Current understandings of Dementia are outlined, along with the significance of the age of onset. The manifestations and impacts of Dementia upon the individual are reviewed in relation to the psychosocial stage of development being experienced at the age of the onset of Dementia.

Younger Onset Dementia (YOD), the significant Dementia in this study is then discussed. YOD's various presentations, the differing diagnoses, most significantly, Frontotemporal Lobe dementia (FTLD) with its sub-type Semantic Younger Onset Dementia (S -YOD) is then reviewed. The care and needs of the person living with YOD are explored, along with

the idiosyncrasies and challenges they bring. The spouses' experience of caring for a partner who is living and dying with YOD and their adaptations to many life changes such as, their partner's behaviour, sexual intimacy and connectedness are discussed. The role of the spouse and expectations within the socio-cultural context are addressed.

Stigma, as it invades the journey of the couple, the impact upon support, social isolation and discrimination in relation to access to care is examined in the penultimate section of the review. Finally, this literature review outlines the resounding silence on the topic of lesbian, or same-sex couples in the literature around YOD.

2.3 SEARCH STRATEGIES

The aim of the database search was to identify relevant literature pertaining to the research question 'What is the lived experience of disquieting disconnection as the life partner of Olga who lived with and subsequently died from Semantic Younger Onset Dementia (S-YOD)?' The literature searches were undertaken with the employment of four databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, Medline and PsychINFO. In an endeavour to examine a comprehensive range of literature pertinent to the topic at hand, the databases were chosen for their relevance to health and/or healthcare fields including, Nursing, Allied Health, Life Science and Psychology.

Key words searched for in this literature review to identify relevant material were 'younger onset dementia' AND 'partner OR spouse', along with the specific terms, 'frontotemporal dementia' 'semantic dementia' and 'lesbian'. The search for 'frontotemporal dementia' generated only three articles and no articles were forthcoming in the searches for 'semantic dementia' and 'lesbian'. Broadening the database search with the terms, 'partner' OR

‘spouse’ being combined with ‘younger onset dementia’ generated 77 citations over four databases. Titles and abstracts were scrutinised, with 59 being excluded due to duplication or tenuous relevance to the research topic.

Given the low number of articles generated overall, no time parameters were put in place for the database searches. The database searches revealed qualitative research, quantitative research, and research that employed mixed methods (qualitative and quantitative), as well as literature reviews and doctoral theses. Only those studies published in English were included. From this process the seventeen articles selected were reduced to fifteen as on further scrutiny two lacked relevance and suitability. The fifteen articles identified from the database search as relevant and suitable for inclusion were reviewed and critically analysed.

A tabulated summary of the database searches is indicated below in Table 2-1. A flowchart depicting the phases of identifying, screening and selecting articles for inclusion is provided below in Figure 2-1. The flowchart depicts a Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) process.

Table 2-1 Literature review search strategy and results for YOD partner/spouse

Keywords	CINAHL	PubMed	Medline	PsychINFO	No for Review
Younger Onset Dementia AND Partner OR Spouse	10	17	33	14	17
Younger Onset Dementia AND Partner OR Spouse AND Frontotemporal Dementia	NIL	NIL	5	2	3
Younger Onset Dementia AND Partner OR Spouse AND Semantic Dementia	NIL	NIL	NIL	NIL	NA
Younger Onset Dementia AND Partner OR Spouse AND Lesbian	NIL	NIL	NIL	NIL	NA
Younger onset Dementia AND Partner OR Spouse AND Frontotemporal Dementia AND Lesbian	NIL	NIL	NIL	NIL	NA
Younger onset Dementia AND Partner OR Spouse AND Semantic Dementia AND Lesbian	NIL	NIL	NIL	NIL	NA
Total	17				

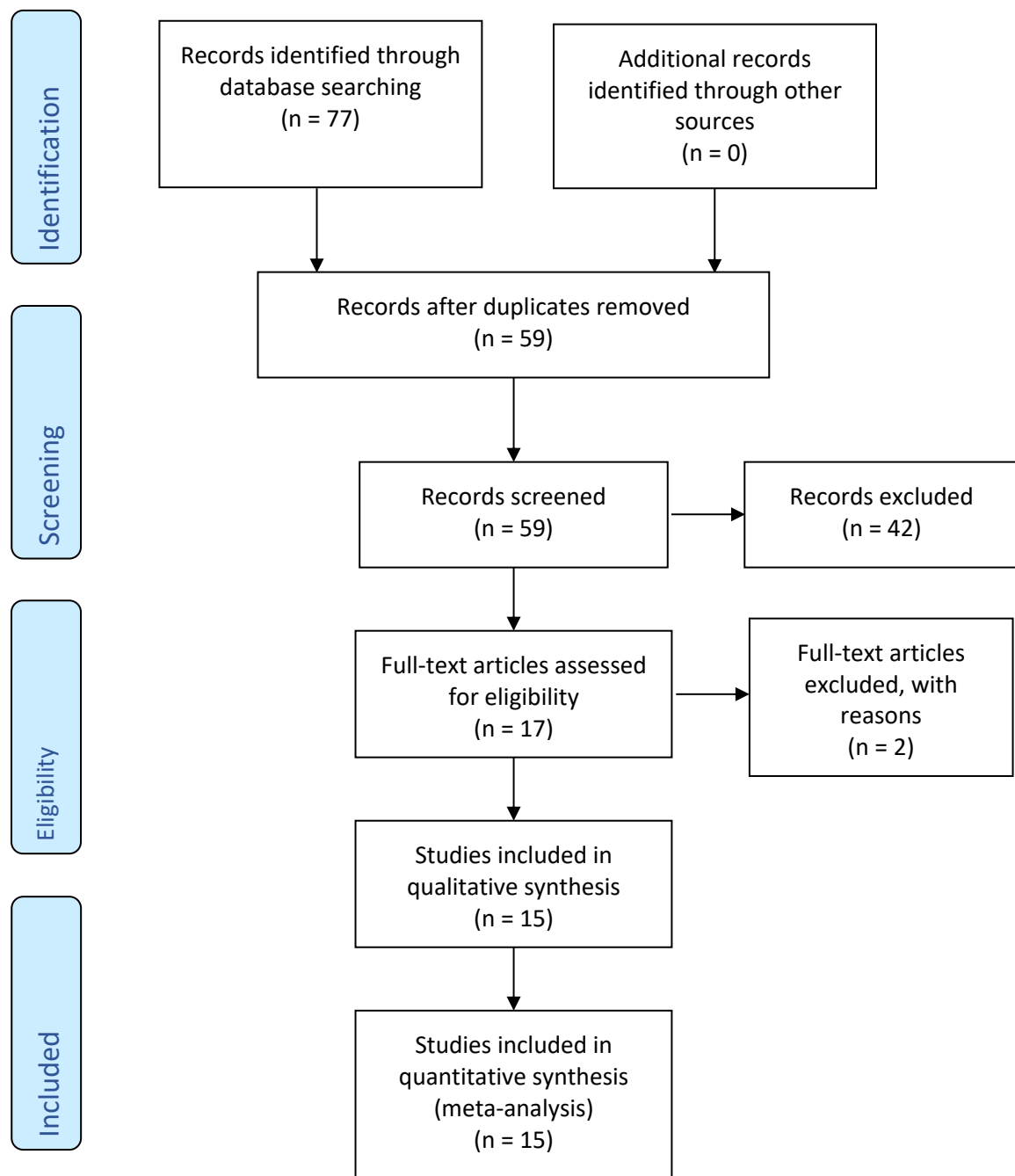


Figure 2-1 PRISMA flow diagram of literature selection and exclusion: YOD partner/spouse

2.3.1 Summary of Review

Of the fifteen papers included, five identified the utilisation of a qualitative research approach, four mixed methods and three identified as quantitative studies. Two literature reviews and a psychiatric summary were also included in the literature reviewed. The quality of the research was at times questionable when analysed. Methodological concerns revealed themselves on the application and the interpretation of data. Their inclusion in the review was in part warranted by the limited material available on the topic of investigation and the desire ‘not to throw the baby out with the bath water’. However, a clear picture emerged of the increased interest in the person living with YOD and their spouse since 2012, with the oldest article sourced being from 2007.

The first article of significance identified was the 2007 Australian quantitative study by Kaiser and Panegyres exploring the psychological impact on the spouse when their partner received a diagnosis of YOD. The following five years were barren and no suitable material was discovered in the data base search. It was not until the year 2012 writings began to emerge of increasing significance for this study. Following the article by Armari, Jarmolowicz and Panegyres (2012) there was an increase in publications within the literature, 2017 being the most fruitful year with four valuable articles identified. The initial call by Armari et al. (2012) for further research to be undertaken urgently into the impact of YOD on the spouse was echoed in all subsequent writings. This reflects the recognition and acknowledgement of the growing need within Western society to understand the impact of YOD on the spouse of people living with YOD.

The trend of increasing numbers of articles published in recent years is a noteworthy observation from the process of undertaking the database search. Consequently, as a relatively new research area, only recently gaining currency, the available literature was embryonic and general in nature, forming a foundation for further more in-depth studies. A tabulated summary of the fifteen articles found via the data bases searches included in this literature review is provided in the table below. Table 2-2 indicates, the author/s, year of publication and country of origin. The aim and chosen method/s of the study and/or research is provided along with the results and the conclusions made.

Table 2-2 Review of selected articles YOD partner/spouse

AUTHOR YEAR COUNTRY	AIM	METHOD	RESULTS	CONCLUSION
Armari et al. 2012 Australia	To elicit the experiences & perspectives of people living with YOD & their carers to inform best practice.	Mixed Methods Voluntary questionnaire Statistical & thematic analysis 18 People living with YOD 39 Carers of people with YOD 20 Spouses 8 Children 2 Carers 2 Health professionals	The principle area of improvement identified by dyads was early recognition of YOD & referral. Patients identified diagnosis whilst carers identified treatment as areas of most need.	Continual consumer involvement was considered essential. This ensured a 'tailored approach' to younger people living with dementia was developed.
Bakker et al. 2013 Netherlands	Two main aims identified:- 1.) To explore the amount of formal & informal care received by YOD dyad prior to institutionalisation 2.) To identify patient & care-giver factors that are related to the use of formal & informal care	Mixed Methods Community-based longitudinal study, 2 Year follow-up Questionnaire, Semi-structured interviews. Quantitative analysis of covariance. Qualitative theme analysis 215 Patient care-giver dyads Patient gender (Women = 95; Men = 114), Caregiver gender (Women = 125; Men = 84), Carers relationship (Spouse = 191; Children = 13; Other = 5).	All patients received informal care. 80% received formal care. 3:1 Ratio informal to formal. The amount of formal care received was related to:- 1.) Patient disease severity 2.) Behavioural problems 3.) ADL initiative 50% People living with YOD only had one caregiver	The spouse & family provided most care. Spouses identified as having the double burden of work & care. Aged related differences in the experiences of caregivers and patients living with YOD & LOD identified.
Draper & Withall 2016 Australia	To examine & explore the challenges & key issues in the assessment, diagnosis & management of people living with YOD	A psychiatric summary of the clinical information & practice related to people living with YOD Participants not applicable	YOD dyad have unique needs compared LOD dyad Clinicians need to have updated knowledge & skills to meet special needs YOD dyad	Early referral to specialised YOD health care workers needs to occur promptly following diagnosis to facilitate early psychological support, management plan development community engagement

AUTHOR YEAR COUNTRY	AIM	METHOD	RESULTS	CONCLUSION
Ducharme et al. 2013 <i>Canada</i>	To record the experiences of spouses of people living with YOD in order to inform the development of professional support tailored to YOD spouses' reality	Qualitative Phenomenological study of the lived experience of spouse care-givers 12 Spouses who were self-defined primary carers of people living with YOD Caregiver gender 8 Women 4 Men	Six themes identified:- 1.) Difficulty in managing behaviour 2.) Long quest for diagnosis 3.) Non-disclosure to others 4.) Denial of diagnosis 5.) Grief including loss of spouse 6.) Difficulty juggling unexpected role	The research opened up innovative avenues for development of interventions to assist YOD spouse caregivers
Holdsworth & McCabe 2017 <i>Australia</i>	To analyse the impact of YOD on relationships, intimacy & sexuality in mid-life couples	Systematic literature search utilising 5 databases:- 1.) Web of Science 2.) PsycINFO 3.) MedLine 4.) Scopus 5.) CINHAL Participants not applicable	Eleven articles utilised Main themes identified:- 1.) Shifts in roles and responsibly 2.) Decline in relationship quality 3.) Changes in identify and self-esteem 4.) Increase in social isolation and loneliness 5.) Shifts in intimacy and changes in sexual activity	Those studies that were undertaken were found to have a number of methodological issues Insufficient studies had been undertaken Research needed on YOD, relationships, individuals with YOD & the dyad over a longer time period.
Hutchinson et al. 2018 <i>Australia</i>	To increase the understanding of the experiences of families affected by YOD in order to inform & advise best practice, support & services	Qualitative Semi-structured interviews Thematic analysis applying a social & family systems model 26 People living with YOD & family members of people living with YOD 5 People living with YOD 6 Spouses/caregivers 17 Children (Aged 9-33 years) 7 Health care providers	Two themes identified:- 1.) Understanding the social demands on the family life cycle and the challenges living with YOD from social & family context 2.) Interactions of health & social care providers with families living with YOD	The ability of the spouse & family to cope with daily challenges of living with a person with YOD relied upon four main factors:- 1.) Quality of relationships 2.) Openness in communication 3.) Emotional connectedness 4.) Level of understanding of YOD

AUTHOR YEAR COUNTRY	AIM	METHOD	RESULTS	CONCLUSION
Johannessen et al. 2017 Norway	To discuss & analyse the experiences & daily life needs of spouse partners of people living with Younger Onset Frontotemporal Lobe Dementia (YO-FTLD).	Qualitative Grounded Theory Interview 16 Spouse primary carers of people living with YO-FTLD Caregiver gender 9 Wives 6 Husbands 1 Male co-habitant	Three themes identified:- 1.) Sneaking signs 2.) Other relations 3.) Need for assistance through all stages of the dementia processes.	Spouse partners of people living with YO-FTLD need interdisciplinary, individualised & specialised support throughout the progression of the disorder. More knowledge & understanding about YO-FTLD from a holistic perspective is needed amongst health care professionals.
Kaiser & Panegyres 2007 Australia	To assess the psychological impacts on the spouse of their partner receiving a YOD diagnosis.	Quantitative Cross sectional cohort analysis Questionnaires & interviews 100 Spouses of people diagnosed with YOD 54 Women 46 Men	Receiving the diagnosis of YOD has a significant impact on the spouse The main concerns were:- dependency, fear and depression.	A greater knowledge, understanding & awareness of YOD is needed in the community. Specialised YOD clinics are needed for support of both the patient & spouse.
Kobiske & Bekhet 2018 USA	Explore & understand resilience as it relates to caregiver.	Literature review A systematic review of 5 data bases Participants not applicable	Flexibility, positive thinking, self-efficacy, resourcefulness, social support & spirituality were the defining attributes of a caregiver.	The response of the caregiver to the challenges of YOD has implications for their wellbeing Interventions should be geared towards supporting caregivers in maximising resilience.
Kobiske et al. 2018 USA	Moderating effects of personal & social resourcefulness on dyad relationship were examined. Concepts of pre-death grief & resilience explored & applied to ability of spouse to cope.	Quantitative A cross sectional correlational design Study utilises the theoretical framework of resilience theory Descriptive statistics in data analysis 104 Partner caregivers of people living with YOD	There is a high positive correlation between predeath grief (PDG) & perceived stress (PS).	Future longitudinal studies are required to evaluate change over time.

AUTHOR YEAR COUNTRY	AIM	METHOD	RESULTS	CONCLUSION
Larochette et al. 2019 <i>France</i>	To explore how a home-based support program for spouses of people living with YOD perceived & appraised the impact of different care approaches.	Qualitative Semi-directed interviews 23 Caregiver spouses of people living with YOD 16 Women 7 Men	Five themes highlighting caregivers ability to overcome emotional struggle & control partner behaviour New ways to support partner & maintain the quality of dyad relationships were identified.	Findings represented preliminary evidence of the program's efficiency for caregivers.
Peyser 2017 <i>USA</i>	To explore & highlight issues of concern for spouses caring for partners living with YOD.	Qualitative Phenomenological study Parse's method of dialogical engagement utilised in face-to-face interview style 9 Spouse caregivers of people living with YOD 9 Women	Seven themes identified 1.) The way it was before dementia 2.) Maze of uncertainty 3.) Kaleidoscope of feelings 4.) Shattered dreams / expectations 5.) Solitary journey 6.) Struggle to survive 7.) Navigating day-today	The USA was found to be ill-prepared to manage the challenges posed by families of people living with YOD The study provides impetus for future research of spouses caring for a partner living with YOD.
Shnall 2014 <i>Canada</i>	To understand the experiences of spouses of people who have YOD.	Qualitative Grounded theory study Semi-structured interviews 30 Spouses of people living with YOD Type of dementia were:- 17 People living with FTLD 13 People living with Alzheimer's disease	Three initial themes:- 1.) Life stage 2.) Disease invisibility 3.) Living with continuous uncertainty Two final themes:- 1.) Caregivers felt they were "falling through the cracks of support systems" 2.) Surviving chronic crisis	Survival depended upon utilising coping strategies including:- <ul style="list-style-type: none"> • Advocacy • Reframing • Self-care • Spirituality

AUTHOR YEAR COUNTRY	AIM	METHOD	RESULTS	CONCLUSION
Wawrziczny et al. 2017 <i>France</i>	Explore the needs of spouse, caregivers of people with dementia. Compare need based on age at onset of person with dementia.	Mixed Methods Semi-structured interviews Quantitative Two-step analysis Qualitative Thematic analysis. comparative analysis 38 Spouses of partner living with LOD 40 Spouses of partner living with YOD	The majority of needs between spouses of people living with LOD and people living with YOD were identified as being the same Some differences did emerge. Carers of people living with YOD were seen to have a greater number of needs than carers of people living with LOD.	There was a need to develop a support group to improve spouse's well-being using common framework There was a need to develop specific modules depending upon the age of the person living with dementia within the common support group framework.
Werner et al. 2019 <i>Israel</i>	To explore the stigma experienced by family members considered informal caregivers of people living with YOD. Explore stigma experienced by professionals seen as formal caregivers. To gain an understanding of stigma formation process & its impact upon these populations.	Qualitative Focus groups Thematic analysis of transcripts from focus groups 16 Voluntary participants Three focus groups One group 6 spouses 4 Women 2 Men Two groups of 10 professionals 10 Women	Indicated both family members, including spouses, & professionals experienced stigma associated with people living with YOD. Lack of knowledge of YOD was seen as the reason for stigma. Emotional burden was identified as the main consequence of stigma.	Stigma experiences emerged as pervasive and complex phenomenon among formal and informal caregivers of people living with YOD. A need to develop a comprehensive and integrated approach was identified as being required at an individual, professional and societal level.

2.4 DEMENTIA

Holdsworth and McCabe (2017) in defining Dementia describe how it encompasses a wide range of diseases and degenerative brain disorders, all of which are characterised by changes in behaviour, cognitive ability and the loss of independence. Ultimately, the person living with Dementia's ability to endure in the world alone is lost and the terminal progression of Dementia concludes their life's journey (Johannessen, Helvik, Engedal & Thorsen, 2017). The vast majority of people living with Dementia are diagnosed with Alzheimer's Disease and/or Vascular Dementia (Holdsworth & McCabe, 2017). However, there are numerous other brain disorders, contributing to the ever-growing Dementia group of disorders, all with the same destination and final outcome, albeit differing trajectories, and presenting with various idiosyncratic and distinctive features (Peyser, 2017). These include Frontotemporal Lobe Dementia (FTLD) (Johannessen et al., 2017), Semantic Frontotemporal Lobe Dementia (S-FTLD) (Johannessen et al., 2017), Dementia's associated with autoimmune disorders, and Dementia's associated with genetic factors (Draper & Withall, 2016).

2.4.1 Age and Dementia

Wawrziczny, Pasquier, Ducharme, Kergoat and Antoine (2017) describe how Dementia is more frequently seen in people over sixty-five years of age, where it is referred to as Late Onset Dementia (LOD). Dementia's close association with aging, contributes to the anonymity of the lesser known and understood, Younger Onset Dementia (YOD), (Ducharme, Kergoat, Antonine, Pasquier & Coulombe, 2013). YOD is often referred to in literature as Early Onset Dementia (EOD) (Ducharme et al., 2013). In this study the term YOD is used, as employing the name Early Onset Dementia (EOD), can cause confusion

and misunderstanding, as it is also frequently used to describe the early stages of LOD (Kobiske, Bekhet, Garnier-Villarreal & Frenn, 2018). The terms Young Onset Dementia (YOD), (Draper & Withall, 2016) and ‘Working Age Dementia’ (Peyser, 2017) are also used in writings to refer to Younger Onset Dementia (YOD).

2.4.2 Psychosocial Development

Peyser (2017) identified the importance of applying Erikson’s psychosocial theory of development to the lived experience of YOD. It provides a useful tool to assess and comprehend the usual psychosocial developmental tasks faced at different stages in a life time which then can be applied to the dyad living and dying with YOD. According to Erikson, the older adult needs to successfully transition through a stage titled ‘Integrity vs. Despair’, reflecting back on life finding either contentment or disappointment. This undertaking affords significant challenges to the older person living with Late Onset Dementia (LOD), as alterations in cognition and perception hinder reflection. And therefore, the hurdles faced by the older adult are significantly different from the psychosocial fences to be climbed by the adult in middle years (Peyser, 2017).

2.4.3 Younger Onset Dementia (YOD) and Erikson

Peyser (2017) in discussing Erikson’s psychosocial theory applied the psychosocial stage of adults aged 25 to 40 years, ‘Intimacy vs. Isolation’ to the experiences of a person living with YOD. Whilst there was some relevance in applying this stage of development, as YOD occurs most readily between the ages of 45 – 55 years, Erikson’s stage of ‘Generativity vs. Stagnation’ clearly holds more significance. In order to find a ‘sense of coherence and wholeness’ for the adult in middle years, successful completion of the stage, ‘Generativity vs. Stagnation’ needs to be transitioned. The loss of meaning and/or purpose in life

experienced if this stage is not transcended, is as significant for the spouse journeying with a partner living and dying with YOD, as it is for the person living with YOD.

In order to move forward and meet a person's individual unique potential, Peyser (2017) acknowledges the importance of successfully transitioning developmental stages. The developmental stage 'Generativity vs. Stagnation' is to find a 'sense of coherence and wholeness'. This is difficult to find in a relationship affected by disorder and disconnection, when your partner is living with YOD. The feelings of 'usefulness and accomplishment' gained in meeting this stage are superseded by a sense of 'isolation and disengagement' if this stage is not transcended. Failure here can bring a sense of isolation and disengagement from the world, thus having a heavy impact upon personhood and couplehood. The existential question of Erikson's psychosocial developmental stages in middle adulthood is, 'Can I make life count?'. This becomes difficult to answer when living with YOD (Peyser, 2017).

2.5 YOUNGER ONSET DEMENTIA

Younger Onset Dementia (YOD) occurs in people under the age of sixty-five years, with the age of onset usually occurring between 45 and 65 years (Draper & Withall, 2016). However, the occurrence of YOD, has been documented to have been diagnosed in people in their twenties and thirties (Kobiske et al., 2018). People living with YOD, often go undiagnosed and are frequently misdiagnosed (Armari et al., 2012). It is not unexpected that clinicians using diagnostic criteria, developed to assess Dementia in the older adult, fail to identify dementia in people in the middle years of life (Armari et al., 2012).

It is with no surprise therefore, when a healthy-looking adult in middle years presents to the General Practitioner (GP), with mild neuropsychiatric symptoms and no obvious cognitive deficits, a dementia diagnosis is not identified and/or considered (Draper & Withall, 2016). Early misdiagnosis and inaccuracy and delays in initial diagnosis contribute to an underrepresentation of YOD in the statistics available (Kobiske & Bekhet, 2018). There are numerous irregularities and inconsistencies contributing to difficulties in achieving an accurate measure of the prevalence of YOD (Kobiske et al., 2018). GPs' lack of knowledge and awareness of YOD (Johannessen et al., 2017) and their disinclination to diagnose middle aged adults (Draper & Withall, 2016), only contribute to greater underlying problems.

2.5.1 YOD Assessment and Diagnosis

Draper and Withall (2016) point out there are numerous challenges and complex issues in the assessment and diagnosis of YOD. Diagnosis of YOD is said to be difficult and problematic. The range of differing types of YOD contribute to the intricacy of diagnosis (Draper & Withall, 2016) and the anxiety and depression which ensue stir the pot and add further ingredients to the neurotransmitter stew already boiling over. Armari et al. (2012), attributes further complexity to identifying YOD if the person has a history of other psychiatric disorders. However, this statement itself is contentious, as it is often impossible to know whether the psychiatric disorder is a misdiagnosis of YOD and/or a result of the bio-psycho-sociocultural impact of the brain disorder itself (Draper & Withall, 2016).

2.5.2 YOD Statistical Data

Armari et al. (2012), identified misdiagnosis had occurred in 30% to 50% of people living with YOD. The reluctance of GPs to diagnose Dementia in the adult, for fear of being incorrect (Draper & Withall 2016), further contribute to anomalies in the recognition of the prevalence of YOD. The best estimates suggest there are approximately 13,500 people diagnosed with YOD Australia wide (Draper & Withall, 2016). Of those diagnosed, 75% were diagnosed when they were over the age of 50 years (Draper & Withall, 2016). Synthesis of the available material provided an estimate that YOD accounted for approximately 8% of people at the time of their Dementia diagnosis (Draper & Withall, 2016). The substantial inaccuracies in scant statistical data limit the precision of any objective measure of the prevalence of YOD. The occurrence of YOD is clearly under reported (Kobiske & Bekhet, 2018).

2.5.3 Aetiology of YOD

Dementia titled ‘Younger Onset Dementia’ varies from Late Onset Dementia (LOD) in more noteworthy ways than the age of onset of the disorder (Ducharme et al., 2013). The simplistic and obvious diagnostic label and point of differentiation is only a chronological marker and does not adequately represent the vast differences between these two groups of Dementia (Ducharme et al., 2013). Ducharme et al. (2013), outlines the aetiologies of YOD are characteristically more varied than those of LOD. YOD presents with more diverse clinical profiles, incorporating more of the atypical Dementias, such as Frontotemporal Lobe Degeneration (FTLD), Lewy body Dementia, Mixed Dementia, Stroke, Brain Tumour, Traumatic Brain Injury and Parkinson’s Disease Dementia. Autoimmune Dementia (Draper & Withall, 2016) and genetic Dementia’s such as Picks Disease and

Huntington's Disease (Ducharme et al., 2013). Genetic Dementia's are more common in the YOD group and concerns about the heritability of Dementia may also add to the distress for the YOD dyad (Draper & Withall, 2016).

2.5.4 YOD and Memory Loss

Holdsworth and McCabe (2017) describe the typical picture of a person living with LOD, as gradual deterioration in memory, with the initial short-term memory loss being experienced, progressing to deteriorating long term memory. The most recognisable symptom of Alzheimer's Disease (AD), the impairment of anterograde episodic memory is the stereotype applied to all people living with Dementia (Peyser, 2017). Often with little or no memory loss, people living with YOD may experience speech difficulties or convulsive paraparesis, which differs greatly from the usual clinical picture presented by people living with LOD (Armari et al., 2012). More frequently manifesting in the mid-life adult, Semantic Dementia (SD), a disorder associated with Frontotemporal Lobe Degeneration (FTLD) transpires (Johannessen et al., 2017). A reverse pattern of memory impairment ensues. The short-term memory remains intact and there is retention of episodic memory. In Semantic Frontotemporal Lobe Dementia (S-FTLD) the future is lost and the past and the present are retained (Johannessen et al., 2017).

2.5.5 YOD and Neuropsychiatric Symptoms

Readily observed in people living with YOD are the neuropsychiatric symptoms which arise disproportionately to the cognitive deficits, reflecting the 'broader spectrum of expression' of Dementia (Ducharme et al., 2013; Draper & Withall 2016; Holdsworth &

McCabe, 2017). The Mild Cognitive Impairment (MCI) associated with YOD, experienced by a high functioning adult, can be masked and go unnoticed (Draper & Withall, 2016). Easily misinterpreted as depression, the early signs of YOD may be overlooked for a number of years (Draper & Withall, 2016).

2.5.6 Human Experiences of YOD

Depression, Anxiety Disorders, behavioural changes and common physical changes, such as increased clumsiness and tripping over, are all early signs and symptoms of the broad range of dementia's experienced more commonly by the YOD group (Draper & Withall, 2016). These are also signs and symptoms of depression and the accompanying anxiety may be attributed to loss of control. These human experiences and the young age of onset of Dementia and differing clinical presentations from LOD, contribute to delayed referral (Armari et al., 2012). Lack of awareness, knowledge and understanding about YOD, along with misconceptions about YOD by health care professionals are seen as major contributing factors to faults in diagnosing YOD (Shnall, 2014; Werner, Shpigelman, & Raviv Turgeman, 2019).

2.5.7 YOD and Alzheimer's Disease (YO-AD)

Alzheimer's Disease (AD) is the most common Dementia in LOD and YOD (Holdsworth & McCabe, 2017). However, the prevalence of atypical AD, with non-memory presentations, spatial orientation problems, speech and language difficulties, are reported to be up to five times greater in people diagnosed with Younger Onset Alzheimer's Disease (YO-AD) (Peyser, 2017). These distinct differences in AD presentation contribute to delays

and misdiagnosis of YO-AD (Peyser, 2017). Genetic forms and familial factors associated with AD are more prevalent in YOD (Draper & Withall, 2016).

2.5.8 YOD and Frontotemporal Lobe Dementia (YO-FTLD)

Frontotemporal Lobe Dementia (FTLD) is the second leading cause of YOD (Peyser, 2017), and presents with equal distribution among genders (Johannessen et al., 2017). Occurring more frequently in YOD than in LOD (Kaiser & Panegyres, 2007), Frontotemporal Lobe Dementia (FTLD) is also referred to as Frontotemporal Lobe Degeneration (FTLD). Genetic and familial factors have a great impact on the development of FTLD, 50% of people diagnosed having an affirmative family history of the disorder (Johannessen et al., 2017). There is also an association between FTLD and Autoimmune Disorders (Draper & Withall, 2016).

Johannessen et al. (2017) outlines Semantic Dementia (SD) as a distinctive syndrome associated with Frontotemporal Lobe Degeneration (FTLD). The degeneration affects the memory system which facilitates the knowledge and understanding of language. Typified by the gradual and pervasive loss of the meanings of words, a person's ability to comprehend language deteriorates whilst their ability to speak fluently remains intact. As the degenerative process progresses, the loss of meaning of objects and concepts is incorporated within the clinical picture (Johannessen et al., 2017). Semantic Dementia differs from the majority of other Dementias as a reverse pattern of impairment occurs and there is retention of episodic memory (Peyser, 2017). In Semantic Dementia, although the idea of future self is lost, the concept of self as in the past and as it is in the present, is

retained (Johannessen et al., 2017). The scarcity of studies on Semantic Dementia, in particular the lived experience for the dyad, further validates this study.

2.5.9 Caring for the Person Living with YOD

People living with YOD are more likely to be cared for informally rather than formally (Ducharme et al., 2013). The role of informal caregiver is usually adopted by the family, with the partner becoming the primary carer (Kobiske & Bekhet, 2018). In 80% of instances, people living with YOD are cared for at home, by their spouse (Larochette, Wawrziczny, Papo, Pasquier & Antoine 2019). Whilst it has been reported that health professionals' involvement, respite and community services, would be both beneficial to the person living with YOD and their spouse and family caregiver/s, formal care is minimal (Bakker et al., 2013). The benefit of respite for informal carers is evident, however the difficulty in finding age and need appropriate care services makes the patronage prohibitive (Draper & Withall, 2016). Often it is the high instance of FTLD and the behavioural changes in YOD, along with the accompanying carer stress, that eventually lead to formal interventions and institutionalisation (Bakker et al., 2013). Formal care is used when losing hope and as a containment crisis intervention, rather than supporting the desired informal care and the needs of the couple in their home.

People living with YOD have differing needs from those people living with LOD (Holdworth & McCabe, 2017). There are numerous physical, psychological and social age-related differences in care needs (Bakker et al., 2013). People living with YOD are physically more active, generally healthier and fitter than their senior counterparts. Usually working and/or in full-time employment with active financial responsibilities, relationships

with spouses, children and parents are at the forefront of life, differing in priorities and focus from the older adult (Holdworth & McCabe, 2017).

Especially pertinent is the recognition that people living with YOD have greater need to interact and maintain contact and engage with other people (Wawrziczny et al., 2017). Developmental intimacy needs are greater and relationships more dynamic (Peyser, 2017). More age appropriate care-services, designed and structured to meet developmental needs of people living with YOD set within age-related sociocultural contexts are needed (Wawrziczny et al., 2017). Forcing younger adults, into older adult care services, as nothing else is available, is like trying to make the head fit the hat and is clearly unacceptable and detrimental.

2.5.9.1 YOD prompt and appropriate care

Family accountabilities and psychosocial developmental differences mean at the time of onset a very different picture of a person living with Dementia, from those of an older adult is presented. Accordingly the needs of people living with YOD differ from those of people living with LOD (Holdworth & McCabe, 2017). Acknowledging and identifying the needs of the person living with YOD and their caregiver is urgently required (Armari et al., 2012). Prompt and appropriate care following early diagnosis positively affects the quality and effectiveness of ongoing interventions and support (Draper & Withall, 2016). The formal care system at present focuses on diagnosis and treatment of LOD, managing and treating patients. This inadequately addresses the need to support both the younger person with Dementia, their spouse and their families (Hutchinson, Roberts, Roach & Kurrle, 2018).

2.5.9.2 YOD formal care

Suitable residential care and health care staff with updated knowledge of assessment and care to meet the intricate needs of people living with YOD, their family and spouses needs to be available (Draper & Withall, 2016). Identifying and offering education however would be ineffective as the resources to provide appropriate care and support are inadequate (Armari et al., 2012). The services available are limited and designed for the older population living with Dementia. As already acknowledged, they are not geared to meet the needs of younger people living with Dementia (Hutchinson et al., 2018). Health care professionals express frustration with their medical training focus on diagnosing, managing and treating patients, and how this approach fails to equip them with the skills to care for people living with YOD and their spouses (Hutchinson et al., 2018). Few age-appropriate services catering for the complex and diverse needs of families living with YOD exist (Hutchinson et al., 2018).

2.6 THE SPOUSE

The inability to reach or connect with their loved one, along with the desire to protect their progressively more vulnerable partner are concerns expressed by spouses (Holdsworth & McCabe, 2017). Spouses often reported a changing role in their relationship, from an adult loving partner to a more parental caring role (Kobiske & Bekhet, 2018; Holdsworth & McCabe, 2017). The role transferred from being the spouse to being the parent occurs insidiously and the need at all costs to stay connected, love and care for their partner holds precedence over role identity.

The incongruity of the spousal identity arises as the role of partner in life and lover, becomes internalised and the parental role grows in importance (Ducharme et al., 2013). Spouses experience changes in physical intimacy and sexual activity, as roles change and the balance in interdependency in relating as a couple alters (Holdsworth & McCabe, 2017). The irony of being aware of needing your life partner at this time when it is the life partner creating the overwhelming need, adds to the pain.

2.6.1 Spousal Awareness

For the spouse knowing and understanding why the changes in behaviour are occurring in their partner and why the talking and sharing has stopped is extremely beneficial (Bakker et al., 2013). Receiving the diagnosis of YOD to explain and help to understand that behavioural changes are as a result of degenerative brain changes and not the loss of love for each other, provides an opportunity to grieve (Ducharme et al., 2013). Anger is transferred from the partner to the world. Spouses often on the cusp of leaving their partner redirect their rage, energise into caring and advocating for their loved one (Bakker et al., 2013). The loss of what was, their relationship, the loss of the future and growing old together is given a voice if the health professionals listen and the system hears the appeal (Bakker et al., 2013).

2.6.2 Sexual Intimacy

The nature and frequency of sexual activity for many couples is an essential and necessary part of their relationship, of staying connected. The health and emotional well-being of couplehood is disrupted by the disease progression of YOD (Peyser, 2017). This loss of

intimacy adds to the dynamic of the changing roles. The relationship roles and responsibilities continually shift from the early onset of YOD and throughout its progression (Holdsworth & McCabe, 2017). The loss of intimacy results mainly in a pervasive feeling of loneliness for the spouse (Shnall, 2014). The paradox of being alone together, yet closer than ever is experienced.

2.6.3 Connectedness

The disconnections and distances recounted by many were couched with feelings of new connections and new intimacy (Larochette et al., 2019), to fill the lonely void. Whilst Holdsworth and McCabe (2017) in their literature review, focused on identifying a theme of perceived decline in the ‘quality of the relationship’, as a result of YOD, the lived experiences of spouses manifested differently. With the dawn of YOD, couples often experienced a feeling of reunion and reconnection (Larochette et al., 2019). Often the insidious changes that had gently, silently and pervasively distanced a couple, were replaced with adaptations, endings and new beginnings, disconnections and new connections.

Spending increased time being together and working together, solving problems and adapting to changes, resulted in the couple reuniting, rekindling intimacy and making new connections in an adult couple-hood (Larochette et al., 2019). However, as a couple there is a need to navigate the world, society, health care systems and health care professions. Armari (2012) recognises over time the spouses’ efforts to maintain couplehood with their loved one becomes increasingly challenging. The sense of relief experienced when the

partner living with YOD moves into a nursing home allowing the spouse to focus on their own needs, is conflicted by loneliness, guilt and loss (Johannessen et al., 2017). If respite and support are provided prior to the collapse of the spouse under the additional weight of socio-cultural pressure two questions arise. Firstly, would there be a need to go into a nursing home and/or if it was needed, would there be the accompanying guilt, shame, loss and loneliness?

2.6.4 The ‘Good Spouse’

Within the context of the impact and challenges of a spouse caring for a person living with YOD and the partner’s care management the troubling theme of the ‘good spouse’ presented itself. This narrative was exemplified in the article by Kobiske and Bekhet (2018), “She is able to see humour in life as she is able to laugh at things that do not go as planned” (p.417). Even though this diagnosis was not in the couple’s life plans, the spouse was able to alter their thinking to reframe situations to be viewed positively. A spouse needs to be able to find inner resources and not only cope with the devastating changes in their partner, but find positivity in the situation. This narrative of the ‘good spouse’ was juxtaposed against the spouse who had failed to meet these purist standards. It is implied if you are unable to meet these standards you’re a ‘bad spouse’.

2.6.4.1 Resilience

Kobiske and Bekhet (2018) explore the concept of resilience in caregivers of YOD and argue that resilience is a crucial factor which differentiates those spouses who manage, cope and succeed and those who do not make the grade collapse and fail. The conclusion of this study was that maximising resilience of caregivers can be beneficial for both the

person living with YOD and their caregiver. The article however, presents no strategies or solutions for how resilience can be acquired, rather it appears to present a standard for spouses be held to. The pursuit to find strategies to cope is honourable, however it is problematic when narratives place the onus on the spouse and place the cart before the horse. This pursuit of unrealistic coping expectations adds to the array of stressors already being experienced by the spouse who requires empathy and support not judgement and more burden.

2.6.4.2 Expectations placed upon the spouse

In presenting a review of a short-course for carers to acquire skills necessary for successful caregiving, Larochette et al., (2019) apply the concept of the ‘good spouse’ narrative framed in a sincere attempt to assist. Whilst this paper differs from Kobiske and Bekhet (2018) in that it puts forth the means, a short-course, to acquire necessary skills to be a good carer, the inference is the solution to caring for a person with YOD lies with the spouse and the narrative of the ‘good spouse’ is again promoted. Larochette et al. (2019) employs phrases such as, ‘psychological flexibility’, ‘acceptance approach’ and ‘engaging with the positive aspects of caregiving’. This contributes to the creation of the myth of the spouse who does not cope as one who is focused on negativity, is psychologically inflexible and unable to accept their partner’s illness.

Shnall (2014) also presented her model of coping with seemingly good intent. Sympathetically describing the devastation felt by the spouse caregiver, Shnall (2014) still placed unrealistic expectations onto the spouse to find means of coping. For example, Shnall (2014) presented ‘reframing’ as a coping mechanism and proceeded to cite examples of these mechanisms, including a subject who ‘reframed’ their situation by comparing their

experience to external tragedies "I look at the children dying all over the world and the wars and my friend's niece, 13 years old, just died." (p.168). These comparisons are unhelpful and generalise, seemingly trivialising a relative and personal experience.

Along with 'reframing' Shnall (2014) presents 'advocacy' as crucial, presenting examples such as "writing to the Minister of Health to get support" (p.166). The author has located the responsibility onto the spouse to not only succeed in 'reframing' and 'advocacy', but to achieve in coping. Employing cognitive approaches amidst frequent unpredictable acute crises to accompany the chronicity of the overall situation is not of assistance and the realism of the approach is questionable. The advantages of the neutrality and openness provided by applying grounded theory method was in part negated. Within grounded theory the researchers' immersion in a wealth of data obscures the view, creating a methodological paradox. The irony of the researchers' involvement impeding critical analysis and interpretation of the data is evident in Shnall (2014).

2.6.4.3 Working together

In notable contrast, other authors critique the suitability of healthcare provided, and call upon care services to align with the needs of the spousal caregiver. Hutchinson et al. (2018) called upon healthcare providers to address family-specific issues and needs. The authors challenge providers to adapt and ensure their preconceptions of dementia are managed (Huchinson et al., 2018), firmly placing responsibility on the professionals. A pragmatic approach, by Wawrziczny et al. (2017), place the focus on preventing exhaustion and isolation. The premise being, if the concerns of the spouse are addressed then coping is enabled by the lessening of burdens. The mixed method study, utilising semi structured

interviews took great care to ask the spouses what they needed and consequently wrote their recommendations based upon the responses.

The goal of spouses acquiring inner resources to cope, along with provision of practical services do not have to be mutually exclusive. Ducharme et al. (2013) differs in providing a voice of middle ground and practical strategies. Advocating for the acquisition of helpful skills whilst clearly identifying barriers a spouse may have to developing and finding inner-resources, provides helpful solutions. Ideally, the formation of coping strategies rests on the nexus of putting in place the foundations of basic supports along with appropriate care services. A dialogue regarding the acquisition of required individualised skills for spouses must occur within an appropriate cultural context. Assisting the spouse in a non-judgemental milieu, nurturing and supporting them, rather than placing further burdens and expectations upon the person experiencing trauma at such a vulnerable time would be preferable.

2.6.5 Disquiet and Disconnection

The uneasiness of the knowing the not knowing, relating to the unrelatable and living in the dying defined the disquiet and disconnection. Trying to balance all the ever changing and competing needs of a partner, who gradually but surely lost their independence, despite all of the couples' efforts, sealed the overwhelming feelings of concern, and this promulgated both the disquiet and the disconnection in the relationship (Holdsworth & McCabe, 2017).

The high levels of caregiver stress have a detrimental impact upon the physical and emotional wellbeing of the spouse (Shnall, 2014). A high risk of “psychological and physical morbidity, as well as social isolation and financial strain” (Kaiser & Panegyres 2007, p.398) for the caregiver/partner resulted. The caregiver stress cannot be taken in isolation. The symbiotic nature of relating cannot be viewed in a bubble. It is the couple’s concern, experienced by both members, and the couple’s forced separation that causes the disquiet and disconnection.

2.6.6 Together Alone

Johannessen et al. (2017), discusses the challenges of connecting with a partner living with YOD. These challenges are exemplified in the situation of those experiencing FTLD, in particular Semantic Dementia. The symptomatology and idiosyncratic aspect of a non-existent future present in a person living with Semantic Frontotemporal Lobe Dementia (S-FTLD), has a great impact on the spouse. The past and present of the relationship remain with no concept of the future in the person living with S-FTLD (Johannessen et al., 2017). This magnifies the guilt and shame experienced by the spouse for not being able to protect and care for a partner who is oblivious to the terminal progressive nature of their condition. The sacred vow made between two people ‘til death do us part’, now sits with the spouse, who lives alone with this understanding.

2.7 STIGMA

Fundamentally, stigma is felt by the spousal caregiver of YOD on many levels, some of which is generated by and occurs within the healthcare system and society in general. Werner et al. (2019) framed the experience of stigma which permeates all levels of society

as ‘structural stigma’. This structural stigma is pervasive, with consequences infiltrating practicalities of life, such as finances and the spirit of life such as emotional security (Werner et al., 2019). Accessing formal support services was fraught with difficulty as health professionals viewed Dementia as an ‘old age disease’ and thus excluded the person living with YOD from care (Werner et al., 2019). Hutchinson et al. (2018) describes how a spouse in the study had to educate healthcare professionals in order to access assistance, taking away some of their valuable energy to meet the deficits of the formal carer. This lack of knowledge and misinformation held by health care professionals was viewed by Werner et al. (2019) as a major source of emotional burden for the spouse.

2.7.1 Visibility

The lack of visibility of YOD is a consequence of stigma and perpetuates stigma in the same breath, clouding and obscuring. Spousal caregivers often described how they faced judgemental attitudes and experienced isolation because people do not see the frailty and incapacity of their spouse, who presents as a healthy adult (Shnall, 2014; Peyser, 2017). Shnall (2014) identified and described the respondents frustration experienced when they were receiving care in emergency departments. Their spouses looked healthy and thus, they were not offered appropriate assistance. A spouse sardonically recounted an experience when the development of visible and physical disabilities enabled her partner to receive support and understanding (Shnall, 2014). The unique presentation of YOD adds to the hiddenness and its inconspicuous nature which veils the despair. Peyser (2017) described how people in her study experienced disbelief when they disclosed the YOD diagnosis. This was due to their spouse being able to do things such as remember names which was inconsistent with popular understanding of Dementia. Misconceptions formed from

peoples exposure to LOD and it's presentation. The double-edged sword of the invisibility of YOD created by stigma, perpetuates stigma's blow.

2.7.2 Service Provision

Inappropriate care options and service provision are a consequence of structural stigma (Werner et al., 2019). Channelling those living with YOD into services for elderly people with LOD had a negative impact upon the spouse. With the limited options available spouses were less likely to pursue formal care (Bakker et al., 2013). Hutchinson et al. (2018), advanced the view further, incorporating the provision of age inappropriate services as not only due to stigma, but to discrimination. Spouses reported lack of age appropriate services made them feel as though they had fallen through the cracks in the health care system (Shnall, 2014). The lack of appropriate services and the associated stigma meant delays in seeking help. In some cases, formal care was only sought when physical disability presented (Bakker et al., 2013), resulting in an inability to cope. Draper and Whithall (2016) stated that due to stigma being encapsulated in the term 'Dementia', the term was avoided and other terms such as 'acquired brain injury' were employed by some clinicians and advocacy groups. The authors argued that avoiding the term 'Dementia' hindered the provision of appropriate services (Draper & Whithall, 2016), reinforcing misconceptions of its meaning.

2.7.3 Social Isolation

Spousal caregivers also experienced stigma in the form of social isolation. Holdsworth and McCabe (2017) described that for the spouse, decreased social activities and social circles arose as a consequence of their partners' diagnosis. Participants in Peyser's 2017 study were explicit in their belief that if their spouse had a disease which elicited sympathy, such

as cancer, they would have received a lot of support. Instead, on hearing the word Dementia, people looked the other way and avoided contact. Self-imposed social isolation was described by Hutchinson et al. (2018) who discussed a research participant who chose not to share the diagnosis of YOD with family in an attempt not to burden them. This was chosen by the subject due to an awareness of negative attitudes in relation to Dementia. Being more specific in describing this experience, Werner et al. (2019) purports the stigma attributed to the person living with YOD was projected onto and extended to the spouse 'by association'.

2.8 LESBIAN COUPLES AND YOD

The lived experience of lesbians, or people within same-sex relationships was not found to be represented within any of the literature examined in this literature review. The absence in the literature further contributes to the experience of lesbians and same-sex couples as invisible, and insidiously adds to the experience of marginalisation. In the main, this exclusion of same-sex couples was subtle and not explicit, perhaps suggesting the exclusion mostly occurred unwittingly. This notion is reflected in the absence of any inclusion or investigation of diverse marginalised groups. Studies on the whole were homogenous in regards to ethnicity, class and other diversities.

Hutchinson et al. (2018) offer hope by making reference to diversity and mentioning sexual orientation in the introduction, challenging the traditional family paradigm. In a sincere attempt to represent diverse family structures, a divorced couple with the ex-wife as the main caregiver is included in the study. However, the promise of including diverse sexualities made in the introduction was not followed and empty when examining the

research. The hopeful assumption that the exclusion of same-sex couples was consistently an inadvertent oversight is placed into dispute by Holdsworth and McCabe (2017) who are explicit in their inclusion criteria that couples had to be in a heterosexual relationship. No justification or explanation was provided for this insertion. This action affirms the status quo, simply promoting this exclusion as totally acceptable, along with other obvious criteria such as being under 65 years of age and having a diagnosis of Dementia.

2.8.1 Heterosexism

Within the majority of the studies, heterosexist references were abound, with statements which frequently encapsulated traditional gendered heterosexual assumptions. For example, Shnall (2014) purports that in the case of violence occurring as a consequence of YOD it is more distressing for wives than husbands because husbands have more physical strength. In a similar vein, Johannessen et al. (2017) explains that wives feel more strain than husbands when taking on economic responsibilities of the household and conversely husbands struggled more than wives taking on the role of caregiver. Such findings do not in themselves suggest a deliberate attempt at exclusion of the same-sex experience however, the studies are ingrained with the premise of traditional heterosexual roles and thereby add to the marginalisation of institutionalised homophobia.

2.8.2 Future Directions of Inclusivity

Some optimism was provided by Peyser in 2017 who acknowledged the homogeneity of her subjects as a limitation of her study (Peyser, 2017). She explicitly stated, the recruitment of only heterosexual couples was problematic and called for further studies to

include those within same-sex couples, which redeemed the exclusion. The absence of same-sex couples and diversity amongst study subjects may be a reflection of the embryonic stage of research into this area. As more researchers heed the call for more inclusivity, truly reflecting humanity, progress will capture the true experience of diversity, including same-sex couples and lesbians. Studies which interrogate the assumption of homogenised relationships, backgrounds and experiences are a starting point for a much-needed enquiry which enables an honest and accurate depiction of the experience of the spouse.

2.9 Conclusion

This literature review provided discussion and analysis of the relevant research and studies to enable an exploration of the phenomenon of disquieting disconnection, as experienced by the lesbian spouse, within a lifelong relationship, as a consequence of the impact of S-YOD. The search strategies employed four databases, the most fruitful and productive being Medline. Fifteen articles of mixed quality and methodologies were identified and utilised in discussion and analysis, inclusion of all fifteen warranted in-part by the limitations of material available.

Foundations for this study were laid by reviewing current literature to provide relevant information on YOD, with comparisons and impacts of variants integrated into the human experience of personhood, relationship, life and death. Age and developmental considerations were analysed within socio-cultural contexts and the spiritual dimensions of a life-long partnership of two women, a lesbian couple, journeying with YOD creatively synthesised within the process of reviewing the literature to inform this research.

There was no research to be found on the lived experience of a lesbian spouse whose partner lived and died with YOD. All the articles identified and reviewed as relevant for this study loudly concluded further research was urgently required in this area. Calls for studies to be conducted over longer periods of time were made. More qualitative, more quantitative and more mixed method studies were urged. The limited number of studies acknowledging the existence of Semantic Dementia, validating same sex couples and the lesbian experience validates this study.

CHAPTER THREE

METHODOLOGY AND METHOD

3.1 INTRODUCTION

The methodology and method guiding the study is presented in this chapter. The qualitative domain of research was identified as the preferred paradigm for this research journey as it is congruent in exploring the subjective nature of the human experience. Phenomenology, the lived experience of both the experiences (content) and the research journey (process), provided a wealth of descriptive information on which to base this research journey and the trajectory of data itself. In particular a Heuristic approach to inquiry was selected as the most suitable research pathway for exploring the phenomenon - disquieting disconnection and finding meaning and purpose in life when a life partner lives and dies with Younger Onset Dementia.

The chapter provides a preamble for the justification of the use of a heuristic approach to inquiry adopted to underpin this study. The relationship of phenomenology to heuristic inquiry progresses the discussion and this is followed by the provision of an overview of Clarke Moustakas (1923-2012) the creator of the heuristic method utilised in this work. The emergence of the heuristic method of inquiry as developed by Moustakas and the central tenets underpinning this approach are discussed and explored. Moustakas makes unique links between life experience and the finding of meaning. Within this process the potential for meaning and growth the life experience might provide is identified. The chapter concludes with a description of the processes used in Moustakas' heuristic method to research and the importance of spirituality within the context of this study.

3.2 PREAMBLE: THE USE OF A HEURISTIC APPROACH

Moustakas' heuristic approach has been identified and applied as the most appropriate methodology to meet the need to understand the phenomenon disquieting disconnection; finding meaning and purpose in life when your partner lives and dies with Younger Onset Dementia (YOD). The phenomenon 'disquieting disconnection' raises fundamental human life questions as to what is the meaning of 'being' and 'love'. The nebulous nature of the questions asked within this research require sensitive containment to direct and not block the creative flow of growth. The new growth generates new meanings and these combine to provide valued understanding and insights. Heuristic research generates clarification of complex ideas by utilising art forms. Art forms such as photography, drawings, paintings and sculptures, music, lyrics, film, video, poetry and prose. These art forms all contribute in their creation and interpretation to expressing people's feelings. The creation, interpretation and sharing of art forms in the process of expressing the subjective human experience, provide a creative conceptual depiction (Moustakas, 1990) and facilitate the discovery of the nature and meaning of significant human experience (Patton, 2014).

The significant human experience of lived grief and bereavement; the 'disconnecting' with a soul-mate when journeying through life, and death is a spiritual encounter into uncharted waters. As sole researcher and participant it is a solitary unique encounter. As a Registered Nurse, specialising and working within mental health care and nurse education, a professional dimension contributes to the experience of the phenomenon. As a lesbian woman, the diversity of the relationship with partner had a great impact upon the socio-cultural and personal aspects of experience. The unique experience of lesbian and gay people is informed by the political and social landscape, which did not permit or acknowledge lesbian union (Barrett, Crameri, Lambourne, Latham & Whyte, 2015).

Lesbian and gay marriage was not legalised in Australia until November 2017. Homophobia and heterosexism intrinsically underpins societal and cultural norms which has an impact upon the lived experience of lesbian and gay relationships (McGovern, 2014). The importance of utilising a methodology to accommodate the breadth and width of this study was a major consideration. The heuristic approach is particularly relevant when researching intense human experience, as in this study.

3.3 HEURISTICS AS A MODE OF INQUIRY

The development of heuristics as a mode of inquiry is first viewed within the paradigm of qualitative research and its relevance in the contemporary world, then, more specifically, within the phenomenological approach to research.

3.3.1 Relevance of Qualitative Research

Moustakas (1961b), as long ago as the 1960s, posits a very sobering thought about the changing nature of society and the gradually increasing focus on the tangible world at the expense of the hidden world of human experience:

We live in an age of comfort, ready to receive and consume, where it is better to keep quiet and look away when there is a vibrant cry for justice and truth, when it is better to stay on the edges of a real relationship because a genuine meeting often brings suffering and grief as well as joy and happiness (p.27).

We live in interesting times. The political rise of the ‘Right wing’ throughout the Western world, especially within the United States of America (USA). with the election and subsequent presidency of Donald Trump. His presidency has highlighted race, gender and

other issues, for people who are seen, as living in the margins. Changes have already burnt and scolded many. Women responding with the creation of the 'Me Too' movement and African American people, leading the way in the formation of the 'Black Lives Matter' movement. Changes have already had a great impact upon people who are perceived as different. People who hold differing values and beliefs. People who do not conform to the identified acceptable behaviours and do not conform to dominant culture and/or social 'norms' of the time. The pending outcome of the 2020 USA elections have the potential to reignite the fires of fear still smouldering.

Alarming parallels in history are being made by historians and social commentators, comparing the socio-political situation in Germany in the 1930's and the rise of the dictator Adolf Hitler with the current changes in the political arena in America and the far-right-of-centre president and leader Donald Trump (Green, 2017). The world narrowly avoided a world of white supremacy, with the annihilation of Jewish, Lesbian, Homosexual people, and people living with mental illness. As Moustakas discussed four decades earlier, the steady movement towards the quantifiable and focus on the objective at the sacrifice of the subjective human experience, produces an unjust and inhumane society (Moustakas, 1961b).

Historians are expressing grave concerns about the social climate worldwide and the 'Western' socio-cultural divides accompanied by simplistic 'black and white' thinking. A valuing of a 'concrete' worldview, with no 'fake news', one recognised truth, one believed reality, is promoted. A one size fits all world view, which is measurable, generalised and the same for all (Beck, 2012) is the only actuality. This has a great impact upon Australian relations with its close South Pacific neighbours. Seen as a close ally of America and

Trump, it is placed in a precarious position with the tensions between Trump and Asia. Australia can be seen to be drifting right and to the west, away from Asia, towards true blue America (Tow, 2017) and so Australia is at risk of becoming like another state of America and losing her unique 'fare go' egalitarian identity.

Favoured by society in the current political climate, quantitative methodology fits well within the political scheme of the time (Murphy, 2017). There is no doubt the quantitative research paradigm answers many questions and is useful within the world of scientific pursuits. Whilst it is vital in providing answers to many important questions, it is poorly equipped to answer subjective matters of the unique human experience; issues of human difference, uniqueness, spirit, and love (Murphy, 2017). It could be argued in these times of conformity and the dominating values of finance, business and science, we need art to soften and balance a world in disharmony.

Moving beyond the notion of human difference Moustakas further posits: "... reasoning and logic are only pieces of man[sic] engaged in certain kinds of intercourse with the universe. What about the experience of pain, suffering and love and the stars and the mountains and the seas? What about faith and God?" (Moustakas, 1961b p. 21). In addition, for Moustakas, the inner chaos and turmoil of the individual can be reflected in the world around us, the exploration of which is at the heart of understanding what it is like to be human. In an exploration of human experience Moustakas first turned to the world of phenomenological thought.

3.3.2 The Emergence of Heuristic Inquiry

Are there not many, many human experiences beyond logic and reason in which it takes courage to live the meaning, to embrace the other, to share a journey before there is any understanding or insight or clarification, long before there is any separate knowledge and comprehension? (Moustakas 1961b p.21).

Born into the phenomenological family and nurtured within the humanistic psychology movement the heuristic method of research developed its own unique identity whilst remaining within the broader phenomenological framework (Patton, 2002). Heuristic enquiry is essentially a different vehicle from phenomenology. It travels a different route to the same destination and views the destination point from a different angle. However, it is still wanting to understand the “...essence of the lived experience of this phenomenon...” (Patton, 2014, p.104).

Patton (2014) identifies four key differences which set heuristic inquiry away from its parent phenomenology (Patton, 2014). The heuristic approach of pursuing intimacy in relating and connecting with a significant experience differs to the more distant analytical approach adopted within phenomenological enquiry. The personal significance and identification of essential meanings of experience required within heuristic enquiry varies from defining experiences using definitive descriptions and structures of experience (Kenny, 2012). The concluding process of ‘creative synthesis’ reliant on intuition and tacit knowledge of the researcher used in the heuristic approach, differs greatly from the concluding processes of phenomenology. Phenomenology takes a more systematic

approach by taking and identifying essential meanings through the use of organised structures of experience (Moustakas, 1986). Finally, the heart of heuristic enquiry is the focus on the person's living experience of the phenomenon whilst phenomenology's interest is on the lived experience. "Phenomenology ends with the essence of experience; heuristics retains the essence of the person in the experience" (Moustakas & Douglass, 1985, p.43) defining the heart of the heuristic approach.

3.4 CLARK MOUSTAKAS

Clark Moustakas was born in the state of Michigan in the United States of America (USA) on the 26th May 1923. Born to Aristotelis and Toula Moustakas, Clark had four siblings with whom he shared a Greek heritage. Throughout his life, family relationships and his connection to family members was of vital importance to Moustakas and the significance of these relationships are clearly reflected in the focus and direction of his work.

Moustakas qualified as a psychologist and spent most of his early career working with children. He married Betty, in 1950, and together they had four children and his relationships with them had a great impact on his research and the development of heuristic research methodology. His first publication, in 1953, was 'Children in Play Therapy'.

Moustakas lived all his life in Michigan, a Midwestern state of the USA, which borders the four Great Lakes. Moustakas co-founded the Centre for Humanistic Studies (CHS), later to be renamed the Michigan School of Professional Psychology in 2006. His work spanned seven decades from the 1950's to his death in 2012. Moustakas's life is highlighted by numerous academic achievements, his colleagues describing him as "Exceptionally academic yet delightfully playful" (Blau, Bach & Scott, 2013, p.98). The main focus of his work was relationships and the therapeutic potential for personal growth, awareness,

change and healing. His writings and discussions valued self and the inner self; he spoke of relationship, love and healing.

His relationships with colleagues reflected these values and their respect for the man as well as the psychologist, is apparent. Comments on how his presence was profound and inspiring, demonstrated the fond regard in which he was held as a leader, mentor and friend (Blau et al., 2013). Following the compilation of the book titled ‘The Self’, published in 1956 and meetings and dialogue with Abraham Maslow, Carl Rogers, Dorothy Lee and Marie Rasey, in Detroit in 1957 and 1958, led to the development of the Humanistic Psychology movement (Moustakas, 1986). Moustakas, as one of the founders of Humanistic Psychology, went on with other members of this pioneering group, to make significant contributions to the development of phenomenological research methods (Moustakas, 1986).

Moustakas launched his phenomenological heuristic research venture with the publication of his book titled *Loneliness* (Moustakas, 1961a), where he reflected on his personal journey of struggling with the serious illness and potential death of his young daughter. He built upon the foundational work with further personal explorations of *Loneliness and Love* (Moustakas, 1972), and *The Touch of Loneliness* (Moustakas, 1974). He continued to refine his heuristic approach and in 1990 produced his text *Heuristic Research, Design, Methodology and Applications* (Moustakas, 1990). Moustakas continued to contribute to academia and research until his death on the 10th October 2012. He died in his home state Michigan where he had lived and loved throughout his life.

Moustakas dedicated his lifetime to understanding relationships, love and healing. The core themes of his writings were acknowledging the relational dimensions of people and the therapeutic potential for growth, change and healing between them. His heuristic research methodology is a tool to facilitate these processes and is an ideal guide when journeying to find meaning and purpose in life when grieving and being lost in a sea of despair. Moustakas (1923-2012) was placed in the position of having to make life and death decisions on his daughters behalf. This was a profound and an 'intense human experience' (Moustakas, 1961a). His journey, of what he identified as 'Loneliness', led to the creation of his design and methodology of heuristic research.

This brief biography lends insight into both Moustakas and the dynamism of the heuristic approach, which demonstrates the relevance and utilisation of his research method and framework in this study.

3.5 THE CHOICE OF HEURISTIC DESIGN

The term heuristic is derived from the Greek word 'heuriskein', which means to discover or find and 'eureka' the sense of joy when discovering something new (Moustakas, 1994, p.17). These linguistic origins aptly represent the creative and joyful findings follow the heuristic path which is a journey of discovery of an intense experience of a phenomenon. The significance of discovery within the context of intense personal experience is articulated by Moustakas in positing:

What about the tears I shed and the ecstasy I share with those I
love?...my loneliness and sense of being apart...Are there not
many, many human experiences in which it takes courage to live

the meaning, to embrace the other, to share a journey, long
before there is any understanding or insight or clarification, long
before there is any separate knowledge and comprehension?
(Moustakas, 1961b, p.21).

The creative self-processes and self-discoveries incorporated within the heuristic research journey as described by Moustakas (1990) make this methodology ideal for the nature of the challenging voyage undertaken in this present study. The dynamic process by which the researcher is in “constant appraisal of the significance” (Moustakas, 1990, p.33) of the authentic lived experience and where there is constant “checking and judging” (Moustakas, 1990, p.33) by the researcher, ensures a valid depiction of the experience being investigated.

3.5.1 Underpinning Processes ‘Immersion’, ‘Acquisition’, and ‘Realisation’

The autobiographical nature of the dynamic heuristic research process encompasses a continual process of ‘immersion’ in the question and an ongoing collection of information and data, which Moustakas & Douglass (1985) entitled ‘acquisition’. The synthesis and ‘realisation’ of these processes is also ongoing and these three underpinning processes are often occurring simultaneously (Moustakas & Douglass, 1985) reflecting the dynamic nature of this methodology (Figure 3-1). This facilitates a ‘strange’ encounter of a deeply personal kind, unique and creative, an implied heuristic way of knowing (Hiles, 2002).

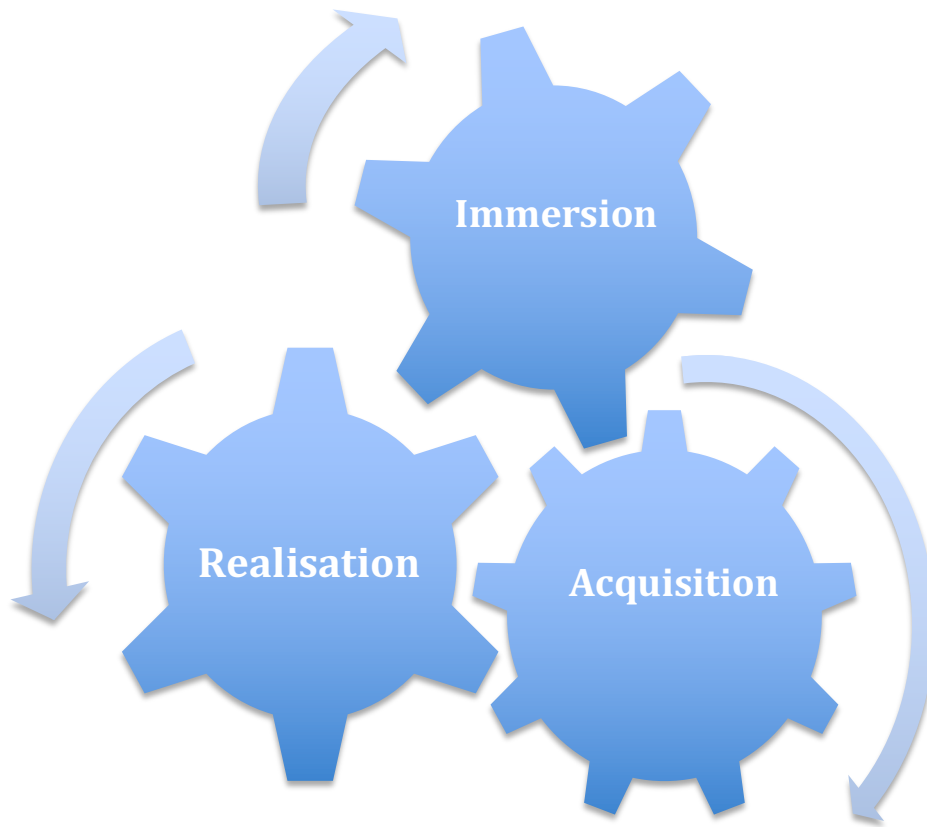


Figure 3-1 The dynamic heuristic process

3.5.2 Concepts and Processes

There are several dynamic driving forces and conceptual underpinnings focusing on and ensuring rigour in the heuristic process (Figure 3-2). The concept of ‘self-dialogue’ (Hiles, 2002), with continued reflection and exploration, is encouraged, in order to identify and inform the focus of the inquiry. The vital feature of the heuristic process is the concept of ‘tacit knowledge’ (Moustakas & Douglass, 1985).

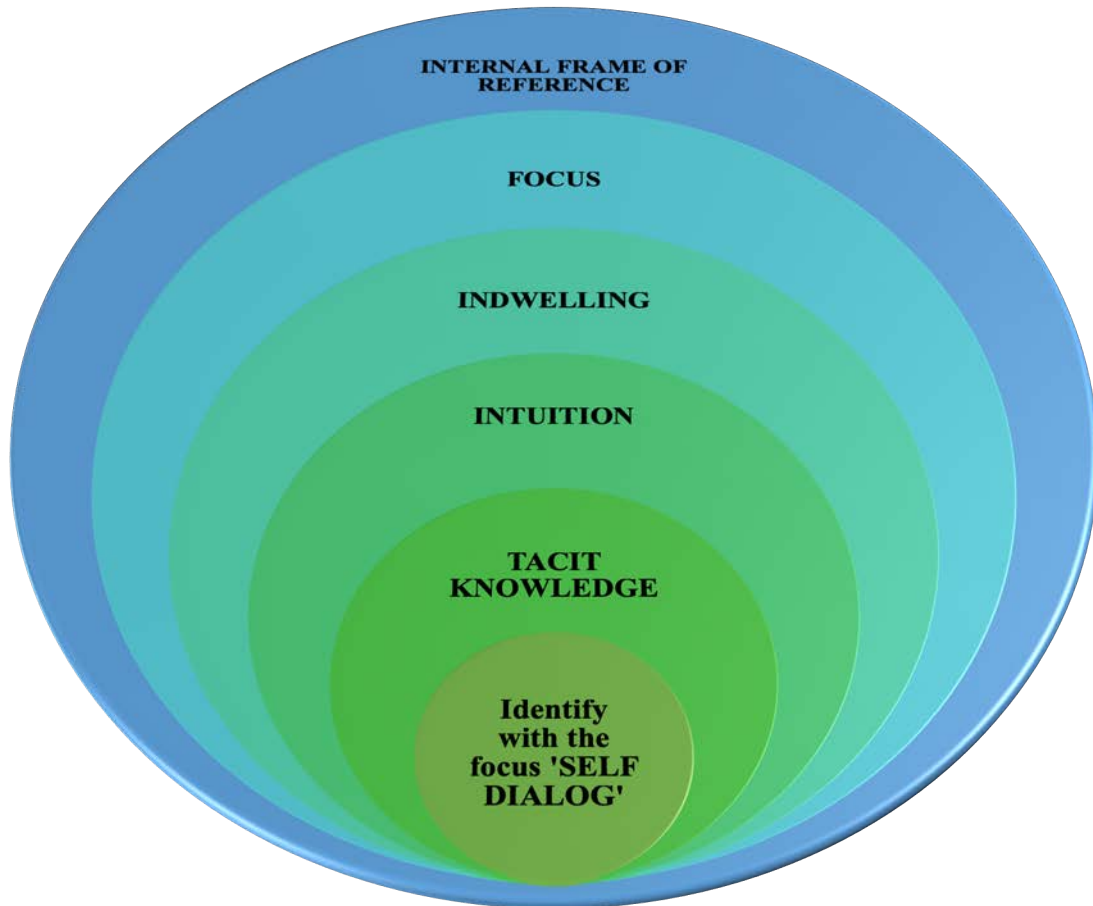


Figure 3-2 Heuristic process: The driving forces and conceptual underpinnings

3.5.3 Self-Processes and Self-Discoveries

The creative self-processes and self-discoveries incorporated within the heuristic research journey, as described by Moustakas (1990), made this methodology ideal for the nature of the challenging voyage undertaken. For the researcher journeying with a life partner who was living and dying with YOD involved constant adaptation to new ways of being to

accommodate the constant changes in relationship. The increasing vulnerability of the life partner placed increased emphasis on the researcher/participant need to utilise 'self-processes' and 'self-discoveries' to maintain connection with self, partner and life.

3.5.4 Three Underpinning Processes

The dynamic process by which the researcher is in "constant appraisal of the significance" (Moustakas, 1990, p.33) of the authentic lived experience and where there is constant 'checking and judging' (Moustakas, 1990 p.33), by the researcher, ensures a valid depiction of the experience being investigated. In the present study the autobiographical nature of the dynamic heuristic research process encompasses a continual process of 'immersion' in the question and an ongoing collection of information and data, which Moustakas & Douglass (1985) entitled 'acquisition'.

Living the experience of loss, disconnection and ultimately death each minute of the day, each day of the week, each week of the month demonstrated a process of total 'immersion'. My relationship with Olga was everything, the most important, all-consuming experience of my life. The experience was magnified by the need to stay connected in a 'healthy' loving relationship at all cost. Nothing else mattered. I constantly reflected and analysed the situation as the winds of change shifted and abilities were lost and found. The dynamism of continually 'checking and judging' making sure nothing was overlooked, misunderstood, misinterpreted or forgotten was as vital as honesty and truth was implicit within our love and within our relationship. This ensured the validity of the 'acquisition' of the data being collected and a true reflection of the lived experience (Moustakas & Douglass, 1985).

3.5.5 Realisation

The synthesis and ‘realisation’ of these processes is ongoing and these three underpinning processes are often occurring simultaneously (Moustakas & Douglass, 1985) reflecting the dynamic nature of this methodology. As previously stated this facilitates a ‘strange’ encounter of a deeply personal kind, unique and creative, an implied heuristic way of knowing (Hiles, 2002).

3.6 TACIT KNOWLEDGE

Tacit knowledge was the brainchild of Michael Polanyi (Moustakas & Douglass, 1985). Polanyi’s ideas and work entitled *Personal Knowledge* (1958), introduced the concept of tacit knowledge, which is central to heuristic research (Hiles, 2002). ‘We can know more than we can tell...’(Moustakas, 1990, p.20). A picture can paint a thousand words, music can summon a tsunami of grief, we know these emotions, what is meant in each brush stroke and each note of a melody, yet we are unable to tell it; there are no words, we just know.

Tacit knowledge may be evoked when listening to music, which stirs deep emotion and understanding thereof, which the composer may not have consciously envisaged, or intended. The listener, however, hears and gains a tacit understanding of these emotions through the music without knowing how. The human experience of tacit knowledge transcends language and culture and in its very nature challenges objective structured definitions (Moustakas, 1990).

Duende is often referred to as the most difficult word and concept in the Spanish language and culture to translate and define in English. It can be described as an instinct, a mystical

force, a tacit way of knowing, the music taking and informing the movement transcending the dancer. Duende moves through the artist who is channelled and becomes a conduit for pure energy, to tacitly create a work of art without knowing how (Elkins, 2004)

The heuristic process beckons the tacit knowledge from within the researcher (Hiles, 2002). Hiles (2002) also emphasises the application of ‘intuition’ and ‘heuristic indwelling’ along with ‘focusing’ and ‘internal frame of reference’ outlined originally in Moustakas (1990).

3.6.1 Intuition

With one foot in the world of tacit knowledge and the other foot in the world of explicit knowing, intuition guides the heuristic process. “The bridge between the explicit and the tacit is the realm of the between.” (Moustakas, 1990, p.23). This is how Moustakas describes the realm of intuition, the linking of the subjective and objective worlds - the invisible merging life line to reality. Informing and supporting the researcher’s journey over rivers of pain and treacherous waters, intuition informs by connecting the researcher to the participant’s experience, identifying patterns, informing and deepening understanding.

3.6.2 Heuristic Indwelling

Heuristic indwelling is the ability to hang on to and focus intensely, ‘like a dog with a bone’. There needs to be ‘...a willingness to gaze with unwavering attention and concentration...’(Moustakas, 1990, p.24) in order to fully live every nuance of an experience. The dynamic process of ‘Indwelling’ allows sensory and cognitive processes the opportunity to capture every detail and ‘feel’ of the experience, to be a part of, to be at one with, and fully live the total milieu of the experience. According to Moustakas, this

vital and active process is essential within heuristic research in order to reveal and understand the nature and meaning of life, love and being.

3.6.3 Focusing

In order to provide clarity, there is a need to focus, ‘...to see something as it is...remove clutter and make contact with...awareness and insights into one’s experiences’ (Moustakas, 1990, p.25). The symbiotic nature of the concepts of clarity and focus are seen in the informal personal growth and awareness skills utilised in gaining insights and navigating changes in life’s journey. The duality of clarity and focus are also utilised as a formal therapeutic strategy employed within a more structured therapeutic framework. The process of focusing is seen as essential, within the heuristic framework, as it enables the identification of key themes connecting feelings and thoughts, clarifying and refining meanings and perceptions.

3.6.4 Internal Frame of Reference

To know and understand the nature, meanings, and essences of any human experience, one depends on the internal frame of reference of the person who has had, is having, or will have the experience

(Moustakas, 1990, p.26).

To find the meaning and purpose of life experienced by the researcher, the internal barometer is the measure of understanding. The researcher is informed by their connection to the world and their understanding of how they relate from their internal frame of reference. The unique perspective is reliant on the feelings and behaviour of the individual and the meaning they attach to their experience and reality.

The commonality in this process is the teasing out and facilitation of the lived experience of the researcher in this study. These conceptual underpinnings ensures the breadth and depth of work needed, by the researcher is achieved when applying this methodology of the six phases of heuristic research. This application and maintenance makes for an often arduous and challenging journey.

3.7 PHASES OF THE RESEARCH PROCESS

The six phases of research outlined in Moustakas' heuristic process is as follows:

- Initial Engagement
- Immersion
- Incubation
- Illumination
- Explication
- Creative synthesis

(Moustakas, 1990)

It needs to be emphasised that although the differing phases of the heuristic process are expressed in a linear fashion, the dynamic circular nature of the heuristic research process is implicit (Hiles, 2002). This process of achieving a valid continual, exclusive focus is achieved by the application of a dynamic six phase heuristic process described by Moustakas (1990). The dynamic nature of the six phases is best expressed in Figure 3-3. The constant movement one phase to the next around and around, growing and increasing understanding is reflected within this chart. The journey, like life, can be seen as never ending. This six-phase process was used to examine and explicate my journey (as researcher and participant) with Olga by exploring the personal experience of finding

meaning and purpose in life when journeying with a partner who is dying with younger onset dementia (YOD).

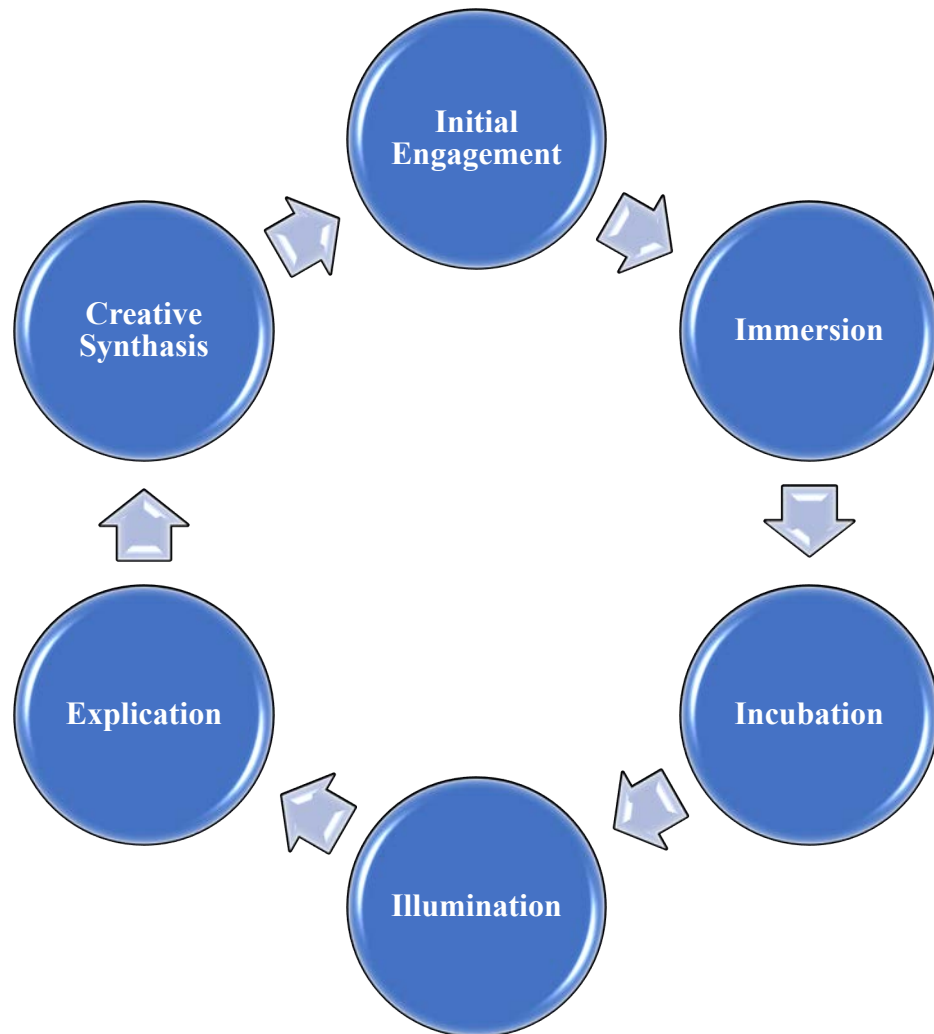


Figure 3-3 Dynamic nature of the phases of research

3.7.1 Initial Engagement

Moustakas (1990) describes the initial engagement as the arrival of the main question, a topic or question of critical interest to the researcher. Hiles (2002) states “The question chooses you!” (p. 76) an early demonstration of ‘tacit’ awareness and the free flow of the

researcher's intuition. With this in mind, the accompanying questions or issues the researcher seeks to answer are uncovered through engaging in a process of critical reflection.

3.7.2 Immersion

Immersion involves living the question. With energy and knowledge from the tacit dimension, life becomes crystallised around the question. Spontaneous self-dialogue, self-searching and following intuitive hunches draw the researcher from the mystery into enlightenment (Moustakas, 1990).

3.7.3 Incubation

Moustakas (1990) describes the incubation phase as a time when the researcher retreats from intensity of focus and immersion in the question. Whilst it may appear nothing is happening, the inner, tacit dimension is in operation, informing the researcher.

3.7.4 Illumination

Illumination is described by Moustakas (1990) as a naturally occurring phase. Although naturally occurring reflectiveness is essential in this phase. It is an awakening to new knowing and ways of seeing the situation, question or answer. It can also be a corrective process; a new way to seeing things; changes to old ways. Tacit knowing is occurring to uncover new and/or to clarify old mystical meanings.

3.7.5 Explication

Explication is when the new discoveries are fully examined Moustakas (1990). Awakenings are explored and key components are discovered in the knowing. It is like

identifying and discovering the seasoning, herbs and spices in the meal, which give different flavours and have an impact upon the contribution of the main ingredients to the meal.

3.7.6 Creative Synthesis

This final phase is the stage at which the researcher becomes fully familiar with data. The main themes are synthesised and integrated into the experience as a whole. The connectedness with self, others and the world are established and come to light (Moustakas, 1990). An integral part of this heuristic journey is a major focus on the notion of spirituality as part of this researcher's journey of the phenomenon under study.

3.8 SPIRITUALITY

“...spiritual life is not made up of portents; it is an obscure and constant endeavour.”

(Moustakas 1961b, p.26)

Within Heuristic research, the researcher learns and gains an understanding of the phenomenon through engagement in the research process, through the authentic lived experience; knowing through participation (Hiles, 2002). Two key heuristic philosophical perspectives underpin these processes. Firstly, the essence of spirituality is said to be the participation in life. Spirituality is connecting with living as well as dying. The second concept is that authenticity must be participatory (Hiles, 2002). It is not just the journey's end which is of significance, but the journey itself. The phenomenon of disquieting disconnection experienced in the duality of researcher/participant was, and continues to

be, a soul-searching quest, finding meaning and purpose in life when your soul-mate is ‘disconnecting’ and truly as I articulate my thoughts, I journey into uncharted waters.

“What is a mystery is a mystery; and life is a mystery and death is a mystery and creations of the self and of the universe are a mystery”

(Moustakas 1961b, p.26).

3.9 MAINTAINING RIGOUR

Rigour was primarily generated by the continual self-talk and listening to self and others. Within heuristics, the solitary researcher takes a sensory journey whereby they collect and analyse data, containing, relating with and living in the holistic experience (Guba & Lincoln, 1989). Exhaustive dialogue and deep discussion, both internal with self, and external, provide thorough and considered understandings (Moustakas, 1990). Music, lyrics, journaling, art, sculpture, paintings, poetry and literature are used as an avenue to facilitate, interpret and express self-dialogue; to inform and explicate the essential nature of experiences. “This creates consecutiveness as the researcher and core searchers collaborate to illuminate the nature, meaning, and essence of a significant human experience” (Patton, 2014, p.1080) and to generate a creative depiction of it (Moustakas, 1990). Placing self as central provides a richness of material, self-awareness enables rigour throughout the research process.

Maintaining rigour throughout the research process necessitated being constantly aware of self and applying self with a spirit of openness. Commitment to transparency and sincerity to each experience was fundamental, as was being mindful of the importance of in-depth dialogue with self and others. Upholding trustworthiness throughout the research process, exploiting art forms and journaling was central to sustaining rigour and staying true to

Moustakas's approach. "The researcher comes to understand the essence of the central phenomenon through openness to the experience, indwelling and intuition, and shared inquiry of and reflection on the experience" (Sultan, 2017, p.184). Trustworthiness in heuristic research is gained by rigorous self-searching involving inner processes such as tacit knowing and intuition and repeatedly returning to the data (Moustakas, 1990). Continually, remaining open and genuine to each experience and remaining true to the creative depiction of the phenomenon was critical to ensuring rigour.

3.9.1 Ethical Considerations

There was no doubt undertaking a heuristic journey of disquieting disconnection: finding meaning and purpose in life when journeying with a partner who lived and died with Semantic Younger Onset Dementia (S-YOD), was an enlightening and challenging road to travel. Essentially with considerable roads taken prior to the commencement of the formal research and the highways and byways ventured up until present time and ongoing, the expert guides who have accompanied and are accompanying me provide safety. Advising, providing expertise on the well-planned journey, anticipating the unexpected the weekly discussions and reflections with either of the supervisors ensured academic rigour and security. The supervisors are expert researchers and clinical mental health experts who have known and worked with me in the academic context for a number of years. In addition their understanding and appreciation of the researcher's cultural and spiritual perspectives ensure appropriate and well-grounded research processes are applied.

As discussed the issue of potential risk in undertaking this heuristic study was an intrinsic consideration throughout this research process. My two supervisors believed I was competent to undertake this study and additional support infrastructures were set in place

in case some level of discomfort was experienced during reflection on the experiences of the phenomenon. My family general practitioner (GP) of over a decade has been instrumental in providing counselling and mental health care support throughout my study and met with me on a regular and as needs required basis in offering ongoing support. The university through the student centre and counselling services are also resources, I had the opportunity to utilise if I had required.

Ethics approval was obtained for this research from the Human Research Ethics Committee. The ethics approval number is H16/01-014.

3.10 CONCLUSION

It is apparent after discussion of the methodological considerations and method for determining the most appropriate approach of inquiry for this thesis, it was not only apposite for describing and exploring the lived experience, but heuristic analysis was essential. The following chapter describes the research processes undertaken in the conduct of this study.

Moustakas (1995) discusses the importance of being truthful with yourself and your partner. Although honesty can be extremely difficult at times and cause a great deal of pain he asserts that failing to do so is destructive for the relationship and the individual. Deception is seen as manipulative, as the other party is denied access to honest thoughts and feelings, it is also self-destructive as it compromises personal integrity. Tacitly within our relationship Olga and I knew the importance of honesty. We tried to be truthful with ourselves and each other. The heuristic journey requires the same honesty and commitment.

CHAPTER FOUR

THE STORY

4.1 INTRODUCTION

From my first memories as a child, growing into adolescence and adulthood, my experience was one of always feeling alone. The inability of my mother to attach or connect with me from my time of birth and her inability to nurture and demonstrate love contributed to my difficulty in attaching and trusting people, especially women. As a lesbian, this added further complications when developing a healthy life long partnership. From always feeling alone I went on to never feel alone in this world once Olga was in my life. I felt complete as an independent individual as one half of a loving couple. Living with Olga gave direction and I felt there was meaning and purpose in my life.

Olga was contained, ordered and calm, her unconditional love and care enabled me to trust, connect, feel safe and be loved. Olga living with ‘Frontotemporal Lobe Degeneration’ (FTLD) had repercussions and had an impact upon our relationship. Olga’s increasing dependency upon me and her loss of control changed our relationship. I was unaware and naive as to how. Now my childhood chaos was returning; Olga was becoming out of control; it felt as though I was alone again. The disquieting disconnections occurring in our relationship dictated my behaviour, thoughts and feelings. The accompanying guilt and shame of not being able to protect and care for Olga was overwhelming.

We shared a tacit understanding we would continue our journey together wherever it was to take us. With no road map or guide I traversed uncharted waters. Who knew where the future would lead and where our continuing journey would take us. Little did I anticipate

the enormity of the challenges that lay before us. Little did I appreciate the attacks on our personhoods, individually and as a couple. Caught in the harsh winds of change, it was difficult to see self in the whirlpool of our relationship as self, appeared not to exist outside of the union of our partnership. We were Patricia and Olga, 'P&O' as friends and family called us.

It was unimaginable to anticipate the tsunami of personal loneliness and sorrow which followed. Finding self without losing connection with Olga and facing the loneliness encountered when having to make 'life and death' decisions for your loved one was paradoxically nearly a fatal journey for me. Developing new ways to stay connected became the meaning and purpose of my life. When Olga died, I was physically alone once more and finding new meaning and purpose in life was the challenge I faced.

In telling my story and journeying down the heuristic research river, my experience of navigating the twists and turns, prevailing currents and rapids, is told. Sharing my experiences about the phenomenon of disquieting disconnection, along with the insights and understandings as they unfolded may help other people in similar situations to ours. Disquieting disconnection: my experience of loving and living with a partner who developed and subsequently died from Semantic Younger Onset Dementia (S-YOD); the story begins...

4.2 PART ONE: BEGINNING OF A NEW LIFE

I arrived in New Zealand Wednesday 3 June 1987 and moved into Huia nursing accommodation at Auckland hospital on Saturday 13 June 1987. All I owned was contained in two suitcases, which were with me in the lift as I rose to the 9th floor. As the lift doors opened and I stepped out looking to my left, I saw a door room number 907, name Olga Glaubitz. Arriving from stage left was a woman, tall, very tall, with blond hair, plaited in a traditional Dutch style. She was wearing pink, white and dark red flowered fabric, harem pants.

Quite unique; I had never seen the like before. Coupled with a plain simple maroon t-shirt, her style was reflected in her motion, subtle yet striking. She appeared to be in slow motion as she turned and in deep husky tones said “Hello”. Her eyes scanned mine imprinting their gaze as she turned away to gracefully enter her bedroom. This was the first time I saw Olga. I am able to replay that scene and relive it at the drop of a hat. Tacitly I knew the significance of this moment. It was the beginning of my journey.

My journey to the land of the long white cloud had been twelve months in the making. I had decided to depart the place of my birth as my discomfort had increased incrementally with my ageing. The rise of Margaret Thatcher and the increase in homophobia had made an uncomfortable life intolerable. Aotearoa was a nuclear free country where not only homosexuality was legal, it was a country which accepted and embraced my lesbian presence. I was to join my partner of seven years who had departed a year before me to lay foundations for our new life together. Unfortunately, whilst the country was accepting as I had anticipated, my partner was not.

On arrival she informed me she had a new partner but did not tell me this prior to my arrival. She informed me that she was unsure whether the new relationship would work out and she wanted me there in case it didn't. I was very uncomfortable staying with my newly discovered ex-partner and her new lover. I knew I had to find work and a place to stay as soon as possible. It took me only ten days to secure accommodation and a new job working as a registered nurse (RN) within an acute psychiatric inpatient unit. I never considered returning to England and although devastated at the time by the abrupt knowledge of an ex-partner, on reflection, this allowed me to make a truly new beginning. I had fifty New Zealand dollars in cash and six hundred pounds of debt back in the United Kingdom, yet I felt empowered and wealthy. What more did I need? Work, accommodation and a vision of the woman who was to be my future.

My newly acquired work-place was on the tenth floor of Auckland hospital. The tenth floor was divided into two units, the acute psychiatric unit on which I worked permanent afternoon duties with, in the main, other lesbian registered nurses and the chronic pain and skin disorder unit, where Olga was a staff nurse. Quite a coincidence that I worked on the same floor of the major city public hospital and my accommodation was room 909, two doors down from her room. These wonderful coincidences, (or were they?) meant I would see Olga daily without arranging anything. I would see her each day, at least once and I would often share meal breaks at work together.

The advent of the Auckland film festival June 1987 made for daily visits to view the "art films". I had only ever seen mainstream movies to this point in my life, but when Olga invited me to attend these mainly foreign language, subtitled films with her, how could I refuse? It was a new experience, we would watch the films, go to her favourite local coffee

shop which had an unmistakable European milieu, drink strong coffee and discuss the films. Depending on the time and work commitments, we could sit for three or four hours analysing and discussing the movies themselves and concepts arising from the content viewed. I had fallen in love. Olga was living as a heterosexual and had only ever dated men. Why on earth was she devoting so much time to me and open to any arrangements to meet with me?

On 25 July 1987, my relationship with Olga changed. Independently we were invited by a gay male colleague to go to a 'straight' nightclub in the city. We both accepted without realising the friend in question was setting us up. Prior to going out I had consumed copious amounts of red wine. At the night club in question 'Club 21' I continued to bathe myself with gin. I was fearful Olga would identify that my attention and feelings were far more than platonic. I found it increasingly difficult to disguise my feelings. However, I managed to keep them in check and hidden. On return to the nurses' accommodation, Olga invited me to her room for a glass of port. How could I refuse?

It was very difficult for me to maintain a veneer of sophistication and calm when I was so intoxicated. When Olga offered me marijuana to smoke, as coolly as possible I replied in the affirmative. I had never partaken in smoking marijuana before, but the last thing I wanted to appear was 'uncool'. Despite containing enormous amounts of alcohol, I found it extremely difficult to interact with this amazing woman. Sexual overtures were certainly out of the question even though I strongly desired to play those tunes. Politely, I enquired if it was all right for me to ask if I could hold her hand. There seemed to be a silence that lasted forever. In a broad Australian accent, the reply came back "Fuck yeah, I thought you would at least ask me to go to bed! Do you want to go to bed with me?" Stunned, I nodded

in the affirmative. I refused to remove any of my clothes until the lights were turned off. Olga's sighs of disbelief were audible. We did however spend our first amazing night together. Falling asleep in the moon lit room, embraced in each other's arms, we had begun a new chapter in our lives.

4.2.1 PART TWO: PATRICIA AND OLGA: P&O

Blazing out of the loud speaker in the corridor opposite Olga's room, on the nurses accommodations intercom system, announced in the dulcet tones of the work supervisor came, "Patricia Awty you are late for duty", followed by "Olga Glaubitz you are late for duty". The work supervisor was working down the check list of oversleeping nurses alphabetically. We did not consider we were the only two nurses to be remiss and late for work that morning. We both immediately concluded "Everyone knows we have slept together!" Olga ran from the room with all but a towel wrapped around her. She made a beeline for the telephone to inform the ward that she would not be in that day and apologise. On returning to the bedroom and seeing me lying naked on the mattress, she ran back out of the room at twice the speed of the previous sprint to telephone her work place again. She explained she would be late for duty today but would definitely be there in fifteen minutes.

Whilst she went to shower, I fell into my clothes which were strewn across the floor where I had thrown them the previous night. I hurriedly left. Working within acute mental health area of nursing meant no uniform was required and smart casual wear was permitted. Overdressed, yet unkempt, I arrived on completion of the handover. Obviously unfit for duty, my nursing colleagues kindly directed me to return home to bed. Relieved I began to trundle back. On the way I made a brief diversion to the nearby florist and purchased a large bouquet of flowers for Olga. Returning to my own bedroom, I hid the flowers in the

wardrobe. I showered, fell into my bed and slept soundly. I awoke at mid-day, got dressed and lay in wait for Olga. At approximately four o'clock there was a knock on my door, it was Olga. On invitation she entered and sat awkwardly at my desk. The conversation was clumsy and stilted. As words stumbled about I felt the anxiety increase and I began to panic.

I tried to stay calm. I put myself in 'work mode' and spoke clearly. I explained I knew myself well and if Olga felt unable to spend the rest of her life with me then our friendship needed to end now. I knew my body language and manner was controlled whilst my heart rate exceeded 200 beats per minute. Olga's mouth dropped open slightly and her face paled. She calmly advised me I should be a patient on the ward that I was working on and that I needed my 'head read'. She gently rose from the chair to exit the room. I blurted "wait a minute", opened my wardrobe, grabbing the flowers and thrust them into her arms told her she may as well take these with her. She left with an astonished and somewhat perturbed expression sealed on her face.

The next three days I consoled myself with the wine from the cask on my bedroom window sill. On returning from work each evening I would consume the red nectar until I fell into an alcohol fuelled slumber. It all seemed like a bizarre dream and it began to feel as though I had lived out some self-manufactured fantasy. Somehow the usual regular contacts with Olga did not occur or were avoided; I didn't see Olga at work, or in the corridor, or anywhere. Then, out of the blue, mid-morning on Thursday 30 July, there was a knock on my bedroom door. It was Olga. She quietly and calmly came into my room and sat in the same chair as before at my desk. In her deep, rich voice she quietly told me how she couldn't stop thinking about me, the night we shared, the times we had spent together and how her initial reaction was a knee jerk reflex and, on reflection, she had reconsidered.

With tears gently falling on her cheek, her beautiful sea blue-green eyes focused on mine, she whispered to me, “Patricia the connection and love I have felt with you over the past two months, culminating in the night we spent together have been the happiest in my life”. She went on to say she had never felt so at ease, as comfortable and as safe. She didn’t want to lose these feeling. She asked me if I would consider spending the rest of my life with her; I of course said yes!

4.2.2 PART THREE: A NEW HOME

By October, Olga and I had moved into rental accommodation; a small one-storey brick house which we shared with the gay male colleague, who had set us up, and his partner. Within walking distance to the sea and close to city cafes and restaurants, it was a perfect first home. We were soon to be joined by Jess, a New Zealand Huntaway puppy, which I acquired from the local pet shop without any prior negotiation with Olga. As was always the case, Olga was accepting of my unilateral impulses. She positively reframed this major fault as creative spontaneity.

A part of my creative spontaneity was my overwhelming need to travel back to the UK to inform my family, and primarily my mother, I would not be returning to England and would be remaining in New Zealand to live my life with Olga. I had sent several letters to my mam explaining my sexuality and my relationship with Olga. The final letter I sent was to say that I was coming to visit and if she was unable to accept me as a lesbian then I wouldn’t visit her. I used the return part of my original ticket and Olga purchased a one-way ticket back from the UK to New Zealand for me. I stayed for only one week and it was purely to confront ‘me mam’.

I arrived at my mother's house on a Saturday afternoon, unannounced. I knocked on the back door and she told me to come in. I don't really know what I was expecting, but she was watching the television, the professional wrestling, as was her habit every Saturday afternoon. She didn't move her head and out of the corner of her eye she saw me and enquired as to whether I would like a cup of tea. I replied in the affirmative, and she replied, 'so would I, put the kettle on'. I went to the back kitchen and made two cups of tea. It was as though I had never moved from home and I received the same acknowledgement or lack of it, as always. The only reason to interact was to get me to perform a task. I returned to the kitchen, gave my mother a cup of tea and sat in silence for 45 minutes while she watched the television.

When the wrestling bouts had finished on the television and the teas were drunk, my mother turned to me. She casually asked "so how have you been keeping?" as if I had just popped in from across the street. I said, "Good Mam". This was followed by a long pause and both of us staring into space. The very uncomfortable silence was broken by my inquiring as to whether my mother had received my letters. To my great surprise she became very animated and jumped off her seat. Briskly she went over to the old wooden stool by the fireplace. On the top of the stool were a pile of randomly sized clippings taken from magazines and newspapers. She proceeded to go through each article that she had neatly cut out from various places proclaiming, "If it is ok for Rock Hudson to be a 'homo-sequal' then it was fine for my daughter to be one!".

Again, a long silence followed. It was broken by my mother asking, "So what is the weather like in New Zealand?" I then received a detailed weather review of the local area for the last three months. This was followed by predictions for the next three months. Then

comparisons were drawn between the changes which had occurred over the last fifty years and how this had a great impact upon important life events like “doing the washing, doing the shopping and going to Bingo!” This was the only occasion in my life, that I can recollect, when I had received a positive affirmation of acceptance from my mother. An acknowledgement of accepting me for who I was, no judgement, no put down. I had never received it before and I only ever received it on one further occasion, when nursing my mother three days prior to her death.

On returning to New Zealand Olga met me at the airport wearing a dress that she had made whilst I was away, specifically for my arrival. Her greeting could not have been any sharper contrast to the one I had received when I went to England. I felt I had arrived home. Olga who was a ‘carnivore’ also decided to join me in my vegetarianism; I had been a vegetarian since I was twenty years of age. It was a socio-political choice and was a strongly held part of my belief system. At the time it was an unusual position to hold and I was frequently criticised by friends and family, especially when I was vegan for three years. Olga accepted it with no comment except to say out of her respect for me she would no longer eat meat or fish. This was an amazing gift to me as it was never discussed or deliberated upon.

4.2.3 PART FOUR: GETTING TO KNOW ONE ANOTHER

Life was good. We lived together in great harmony, with no apparent difficulties despite being very different in the way we lived our everyday lives. Olga was organised, methodical and calm. I was a little chaotic; both practically and emotionally. I constantly tried to please and entertain Olga, assessing her needs and trying to meet them. Olga’s quiet relaxed presence was constant and as a result, my every day anxiety lessened. I was constantly moving about, agitated and fearful. I had learnt as a child, a moving target is

harder to hit. Keep your mind and body on full alert to stay safe. Nothing seemed to upset Olga and her gentle humorous demeanour enveloped my performance anxiety enabling me to be just myself. I loved to create in the kitchen, cook and bake. Olga loved to eat; she ate all I produced with gusto and sang my praises endlessly.

One day, in 1988, with a full stomach and face covered in cake crumbs, Olga voiced an idea she had been cooking for some time. She wanted us to finish work and travel Australia together, for a year. Olga said we needed to spend this time with one another to get to know one another; really get to know each other. I had never had more than two weeks off work in my life and had started working in part-time jobs from the age of ten. Work was my saviour and had always been my focus, my safe space. The idea of not working for a year put me into absolute panic; it was quite a leap of faith to resign my job and set off with Olga to hitch hike around Australia. For Olga, travel was her safe space, her way to feel free and independent and she wanted to share this with me. Olga wanted me to know her and have time to focus on keeping me still long enough for her to see me.

Our friends were happy to look after our few possessions and our dog Jess. They encouraged and seemed to approve of our great adventure and things seemed to easily fall into place. We decided to begin our travels in Western Australia. On arrival in Perth we purchased a backpack each and a one-person tent. We found the local youth hostel to book in a comfortable night before we began our trip. They refused to give us the double room which was available as it was reserved for couples. Despite telling them we were a couple they refused. Reluctantly as we were so very tired, we realised we were getting nowhere and gave up. Settling for bunk beds in the shared women's dormitory we settled for a

sleepless night amidst drunken snoring women with flatulence. After one night in the youth hostel we were happy to hit the road and start hitch hiking.

After waiting for over an hour for a lift, it rapidly became apparent my smiling face and enthusiastic waving was not cutting the mustard. Olga requested I put aside my feminist politics and moral high ground. Directing me to hide in the bushes with the packs, Olga adorned her skimpy shorts, her briefest tight top and moved into action. With blond hair, blue-green eyes, bronzed body and extremely long legs, she positioned herself as close to the edge of the curb-side as possible, seductively reaching out her elegant arm with thumb in the air. The longest we waited for a lift was two minutes. The trucks would screech to a halt, the truckie would get out and offer Olga a lift. Once the lift was secured, Olga whistled me to come out of the bushes. I would appear stumbling and tumbling out of hiding with the two packs and grinning from ear to ear. The look of disappointment and displeasure on the truck drivers faces was apparent. I would immediately start chatting, using all the charm I could muster, to engage the driver in polite conversation. Usually after only a few moments, they engaged with me and would share their life stories. Olga would never speak another word until we were dropped off.

On one occasion whilst hitchhiking through Victoria, we were picked up by a truck driver. This guy was different. He did not engage with me and I could not initiate a conversation. Whilst Olga was sleeping, which was her usual pattern, he turned off the main road onto an unsealed road within thick forest. He started to talk to me. The content and process of the interaction was unsettling. With no eye contact he began to talk about other women who he had picked up. In particular he focused on two Swedish girls. I sensed sexual overtones and began to feel extremely vulnerable. When he stopped the truck, turned to me

and looking straight into my eyes and proclaimed, “this is where your trouble begins”, without thinking I pulled out a sheath knife from my boot. I pressed the knife firmly against his neck. I shouted to Olga to “get out, get out!” With this the driver changed his manner and with gentle protests said, “I was only joking, what’s the problem, what’s the problem?”

We remained in the cab and the knife remained indented against his throat. I told the driver to go to the nearest exit on a main road. As per instructions the driver dropped us off, my knife never left his throat until Olga was safely out of the cabin and I could quickly follow. I was very surprised at the instinctive way I reacted to defend Olga and myself. There was no conscious thought. My reaction was swift and I was totally focused; I wasn’t frightened and felt absolutely confident and in control of the situation. This incident occurred in February 1989. It was several years later, that I heard about and saw the picture of the truck driver on television and in the papers; it was Ivan Milat, a serial killer who murdered several backpackers in Australia between 1989 and 1992.

During the next nine months of hitch hiking, we visited every state and every state capital in Australia. I stopped panicking about not working after burning myself to a crisp, in forty-degree heat, grape picking, for the cost of a camp site. I realized, that my security and safety came from the relationship I had with a person, Olga. It was not a place, a job, or money. Our relationship blossomed and we felt secure, happy and very much in love.

4.2.4 PART FIVE: FOUNDATIONS FOR THE FUTURE

When we returned to New Zealand we initially house sat a property in the Auckland suburbs. Fully furnished with large manicured gardens, it was a beautiful place to consolidate our relationship. What was to be a year rental was suddenly brought to an end

as the owners returned after six months. The owner, Sean, had been diagnosed with Motor Neurone Disease (MND) and had taken early retirement prior to the trip. He and his wife believed a visit to family in Britain and Europe was a great idea and had no expectation of the rapid progress the disease was destined to make. The disease progressed so rapidly the owner died within three months of his return.

This affected Olga greatly as her father had died with MND in a very similar timeframe and at the same age as Sean. In the case of her father, the type of MND he developed was hereditary in nature. It is believed her paternal grandfather, uncle and cousin had died with MND. Olga stated at the time of Sean's death that she did not want to die of MND at sixty-two years of age like her father. She repeated this fear every few months, throughout our relationship, usually late at night before falling asleep in my arms. Olga stated she didn't care how else she died, but she did not want to die that way.

On reflection it seems ironic Olga's life and death reflected the fate she so feared. Olga died of MND at sixty-two years of age. As happened to her paternal cousin, it was to present with Younger Onset Dementia. However, Inhalation Pneumonia as a result of the muscle wastage and respiratory decline associated with MND was the cause of Olga's death. At the time of Olga's statements about MND, I thought her fears, though understandable, were somewhat neurotic and exaggerated. Looking back and reflecting on life events, I wondered whether intuitively she knew she had inherited the gene for MND. Why she was so fixed about sixty-two years of age, I am unable to reason or understand. Was this a tacit understanding Olga had of knowing when her life was to end?

Below the surface of happiness within our relationship I felt a dis-ease whenever the subject of MND was raised. I knew Olga's comments were significant. I had a tacit awareness that changes beyond my control would impact upon my life journey. The immediate impact of MND meant we had to leave our accommodation with very little notice. We had to find alternative accommodation very quickly. As our long term goal was to purchase a home of our own and we were saving to do so, we looked for the least expensive rental we could find at this short notice. Cheapest meant the property we were to find was in sharp contrast from where we had just come.

We moved from a large three bedroomed detached home on half an acre of land to an extremely small one bedroom flat attached to the back of an ex-Housing Commission weatherboard home. Our new accommodation was in a run down, low socio-economic area and Olga thought it ideal. I found living in the Otahuhu area and in a very small space depressing. I understood the need to save money and be frugal, however, the environment reminded me of my childhood: stray dogs, dirty kids playing on the street until midnight, domestic violence, alcohol intoxication and arguments in the street. It appeared not to affect Olga at all, even though she had grown up in a Housing Commission home in an Australian, working-class, migrant suburb.

Olga was very contented and happy there. I became very aware, I definitely was not. I felt heavily the negative impact of my living environment on my sense of well-being. It was a constant reminder of how I had lived in my past, a discordant echo of my childhood and adolescence experiences. I had suppressed many memories and in time it would become apparent many traumas had been repressed. Although the year or so spent living in this suburb was itself uncomfortable, it began to produce an awareness of the need to address

previous experiences in order to ensure future happiness for us both. Visiting the Netherlands and England for similar reasons needed to be at the least a yearly trip for both of us. As we stayed with family and friends, the expense was only the flights and we always managed to secure a very good deal.

Visiting our birth places and families enabled us to re-evaluate childhood experiences and relationships through the eyes of an adult with the safety and security of having each other by our sides. Supporting each other and growing in our understanding of each other, our lives were enriched in deeply personal ways as well with these experiences. We grew individually and as a couple, healing ourselves and growing healthier, wiser and stronger. We never shied away from conflicts and confronted issues which arose between us, family and friends. Nothing was off the table and we were brave and compassionate together, sharing our love when appropriate and addressing old hurts. Old relationships grew or ended with new understandings, and new relationships were established.

When we returned to Otahuhu from the Netherlands and England and sought work, there were no nursing positions available. I scanned the papers and found a cleaning job, filling and maintaining vending machines. It was hard work for little pay but I had work and we had an income. It was good to have hard physical work and to go to factories and work places I had never visited. My understanding of New Zealand life and culture grew and my perspectives broadened. Eventually, Olga found employment as a Night Supervisor in a nursing home. I recommenced my nursing career when I successfully gained employment teaching an Introduction to Nursing course for Samoan, Tongan and Maori women.

For the first time in my life, I was the smallest woman at my workplace. The warmth and friendliness bestowed upon me by the students was overwhelming. They all developed English accents, which was very amusing when they went shopping with their families and visited local cafes. This teaching position was extremely significant. Not only did I develop my own style of teaching based on the needs of the students, but it introduced me to local nurse lecturers who were to, later, provide references for me and assist me in acquiring a position as a Nurse Lecturer at a local Polytechnic.

4.3 PART SIX: LIVING OUR LIVES TOGETHER

I was the youngest member of staff in the School of Nursing and by far the least qualified. Whilst employed full time on a salaried position, the Polytechnic provided time for and financed my studies in education at the University. I worked as a Nurse Lecturer for nine years and my work life could not have been happier. My life with Olga also blossomed, she acquired a position in special education and returned to university studies successfully completing a further two higher degrees in special education and education of the deaf. Olga took up a position as a Teacher of the Deaf and subsequently was successful in being employed as Coordinator of Deaf Education for the North Island of New Zealand. We were financially secure, in a happy and loving relationship with a house full of cats and dogs and, therefore, all should have been well.

Towards the later stages of working in nurse education in New Zealand, I was unaware I had increasingly emotionally detached myself from everybody. I stopped contacting family and friends in England and overseas. I had stopped socialising with work colleagues and friends. One night following dinner at home I experienced my first panic attack. It was a dark night and the living room curtains were slightly open. There was a strip of black which

seemed to engulf my very being, I froze and started screaming. The next thing I recall is sitting on a chair with Olga's arms around me. I had no idea what was happening.

I was conscious of the increasing discomfort when seeing the colour black. I identified students' clothing, shoes, furniture, anything black and I diverted my eyes avoiding seeing that colour at all costs. No matter how hard I tried to avoid the colour black I continued to be aware of it looming in the shadows. I began to feel an overwhelming sense of doom internally. Deep inside me the black dog remained hidden, cohabiting with anxiety. They grew together inside me with insatiable appetites, feeding and thriving in the darkness together. I talked to no one. I could not fathom why I felt so unhappy; everything appeared to be perfect. My mother was correct, I had ruined her life and I was ruining Olga's life as well as those of the people I touched.

I reasoned, if I left, Olga could develop a relationship with someone who was worthy of her. Maybe I would please my mother; she may even love me. Maybe I would find some peace and escape the guilt of being. On Olga's birthday I took her for lunch to a favourite cafe and informed her, as we completed the dessert, the relationship was over. I wanted her to hate me, to feel free to be able to acknowledge the bad person I was and move on. Olga was devastated. She sobbed uncontrollably saying, "I don't understand? What is wrong?" I said nothing and left.

I had booked a room in the Nurses' Accommodation and headed straight there. As I had now discontinued relationships with all friends and family, I felt I could free myself of my past life with no impact on anyone. I would follow my mothers' script for me. She could

play the role of betrayed mother, getting support and sympathy from those who knew nothing of what was hidden behind closed doors and silenced in the distance of time.

I was sitting on the bed in my room in the nursing home. I questioned my right to ‘dump my shit’ onto people who were just living their lives, behaving and loving me. How autonomous was my life? I sat for a very long time not knowing what to do — a very long time. Eventually I reached out. I made a phone call to a friend. I’m not sure what I said, but the next thing I recall is being with them in their car being driven back to Olga.

Olga calmly welcomed us inside. She took me to my bedroom where it was warm, safe and welcoming. She helped me undress and tucked me into a soft cosy bed. I fell into a deep sleep. On awakening some time later Olga was sitting close to me, next to my bed. She smiled gently and in soft nurturing tones told me not to worry. She informed me, “No matter what, I will be there for you. There needs to be no commitment made to anything. Take time my Bubby and sort yourself out.”

For the next six to nine months Olga ensured I got up for work when needed. Each week day I went to work, ate, went to bed and slept. Weekends, Olga would drive me to the sea and we would walk with our dogs. We would walk all day only stopping to picnic and take in the views, the salt air and to hold hands. I visited a nurse colleague, a friend of a friend who had similar experiences to myself. I would visit twice a week for six months. I talked and we shared our childhood stories, feelings and hurts. Whilst reliving childhood as an adult, the unconditional love and care Olga provided me over this period of my life, further cemented our relationship.

Slowly but surely, I began to integrate the memories and events I had remembered, reflected upon and discussed. Light had been shone into the dark places and I could now see where I had been, and where I was going. I developed the confidence to venture down new roads and continue along a more appropriate path. I saw the genuineness and honesty of Olga's love for me and mine for her. The future looked bright and I now felt all the obstacles and past challenges had been met. However, unbeknown to me, out of the darkness, the biggest challenge to our relationship begun to emerge.

4.3.1 PART SEVEN: FAMILY

Olga's and my life continued and was enriched by the venture we took into fostering children from abusive families who had to be cared for in a safe environment. We became the first same-sex couple in New Zealand to be granted the right to become permanent guardians of foster children. Because we were pioneers in this area, there were continual obstacles which prevented the final stage of actually adopting a child. In retrospect, I often wonder whether the final hurdle was not jumped because of our intuitive awareness our role was to pave the way for others, and not to journey that path ourselves.

In what was to be my final year of teaching nursing in New Zealand, I was heavily involved in developing the Bachelor of Nursing degree. At the end of this process, I and a number of other teachers were asked to undertake the degree we had written. I felt extremely uncomfortable with this suggestion and believed it to be unethical. I requested a year's leave of absence in order to acquire a Degree in Nursing elsewhere. I was fortunate enough to be accepted by an Australian university to undertake a conversion course leading to a Bachelor of Nursing. Olga continued to work in New Zealand whilst I went to Melbourne, Australia. Whilst undertaking the degree, I was offered a senior position coordinating nurse

education for a mental health program within a health care network. As Olga's mother was ageing and Olga had expressed a desire to establish more meaningful relationships with her siblings, we decided, on successful completion of my degree, we would live in Australia.

On our first weekend in Australia we purchased a home and moved in thirty days later. My new job was extremely demanding and I found myself working from seven in the morning until seven at night, six days per week. Olga found employment in deaf education in Australia we were working hard and establishing ourselves in this new chapter of our lives. After twelve months or so we had decided on a suburb in Victoria that we would like to live in. Williamstown was where we wanted to live and we wanted to get a joint mortgage for our home. I had a limited work history in Australia and the bank required me to have a medical clearance for mortgage insurance. I was fine with this and found an appropriate doctor to carry out the examination.

I explained my medical history to the doctor. At the time nothing was out of the ordinary. Because I had been diagnosed previously with Polycystic Ovarian Disease (PCOD), to clarify and determine accurate diagnosis it was suggested I needed a few diagnostic tests. At first everything seemed to be normal. However, a positive result for Carcinoembryonic Antigen (CEA) was returned and further investigations ordered. Immediately following a dilation and curettage procedure, I was told everything looked absolutely normal. Histology results would be returned in ten days to confirm the surgeon's diagnosis. I returned to the consulting rooms with Olga ten days following the procedure.

I went into see the consultant gynaecologist alone whilst Olga waited outside. The gynaecologist began the dialogue with sincere apologies. It appeared the result from the

histology report indicated an aggressive adenocarcinoma of the endometrium. I was booked into the hospital for surgery the following day. I realised, whilst obviously surprised and concerned at the diagnosis I could contain the news and deal with the situation. I was concerned Olga would not. I discussed this with the doctor and Olga was invited in to the consulting room. When the consultant explained to her the findings from the investigation, she was inconsolable. On reflection this was so unlike her previous persona. Her ability to remain calm and totally cognisant of a situation and all relevant information was one of her greatest assets; her reaction that day was an early indication of the pathophysiological changes already occurring in Olga's brain.

In August 1997 I had a Total Abdominal Hysterectomy (TAH) having declined any chemotherapy or radiotherapy. I remember when I came around in the High Dependency Unit (HDU), I heard the nurses at the end of my bed laughing. In my dazed state, I asked "Why are you laughing at me?", they said "In all our time we have never seen anybody come around with such a broad smile on their face." They asked me what I was smiling about, I replied I was just so glad to be alive. Uncharacteristically, during my stay in hospital, Olga visited for forty-five minutes only each day. There was little depth or meaning in our interactions, which left me feeling extremely alone.

I was in the HDU for five days. The staff asked me "do you have no family?" "Is your mother dead?". I found myself making a hundred excuses to explain why my mother was absent. Silently and secretly, I was really surprised I wanted to hear from her so much. I had no contact from my mother at all, no phone call, no card, no flowers. I received flowers from my brothers and sisters with lovely words of love and support. My mother was fully aware of my situation. But nothing, no words. I thought perhaps she was hoping that I

would die enabling her to get sympathy from family and friends for the loss of her daughter. I didn't want to die, I was so glad to be alive. My mother was fully aware of my situation. But nothing, no words.

I was moved into a six-bedded dormitory with other women who all had a similar diagnosis and surgical procedure to mine. I had to wait a further five days for confirmation that the cancer had not spread to other organs; I remember waking each morning at two o'clock and listening to the sobs of the other women sleeping in the six bedded dormitory. I was the youngest by over twenty years and had the most aggressive form of cancer; I longed to have Olga with me, to comfort me and talk about my fears. For the first time in our relationship she was not present. I had to contain my own anxiety and the only person to connect with was myself.

I was discharged ten days following the surgery and gynaecological follow-up continued for five years. On return home from the hospital Olga had taken only one day off work, she returned to her job the following morning and left me to care for myself. Again this was so uncharacteristic of the woman I had come to know. I felt abandoned and unwanted. There was no intimacy between us partly because I was unable to initiate anything due to the post-surgical pain and discomfort.

The events of August 1997 had a greater socio-cultural impact upon my health than physical. I felt robbed of my femininity and womanhood. Olga's disinterest compounded these feelings and I found it hard to understand her disengagement with the process and growing disconnections with me. I lacked the energy to facilitate much needed discussion with Olga. I returned to full-time work two weeks following surgery and buried myself in

work. I tried to carry on as usual, cooking her favourite meals at weekends and whenever time permitted.

I would organise after work meals and get together. No matter how I tried my energy levels and motivation seemed to flag. When I returned home each night to Olga there was no time to talk, exchange ideas, discuss politics and philosophy as we had always done in the past. Our love life resumed, but the intimacy lessened and the times we would just lie in each other's arms diminished. In my growing sense of abandonment and detachment, old remedies to accommodate the pain took over. Spending many hours dissociated in time and space, I left my body to deal with the physiological aspects of anxiety whilst my soul floated in the cosmos.

4.3.2 PART EIGHT: ADAPTING TO CHANGES

Insidiously, other changes were creeping into our life. Olga, who usually read approximately six novels per week, had stopped reading. Her calm and laid-back persona started to diminish. There were days when she would become distressed about her relationships with her siblings. She could not understand their indifference and their reluctance to meet together on a regular basis for a meal and a chat discussing their childhood and building upon their previous foundation ties. Often, she would return home in tears, telling the story of how their meal had ended in arguments and disharmony rather than unity. Olga had stopped writing, sewing, knitting and creating. Her anxiety around everyday issues was increasing. However, so insidious were these changes that, at the time, I hardly noticed them.

There was no time or place for me in Olga's life. The balance in our relationship had slowly shifted. I was so focused on Olga's needs and distress; I gave no thought to self. I was languishing further and residing in my head and outer space. I was back under the table. As a child my earliest memories are of hiding from my mother under the kitchen table, at the furthest point, safe from her clutches. Here I was safe; and whenever I had to be physically present I would put myself, my mind, my being in that, warm, protected corner far away under the table.

Friends had begun to notice changes in Olga's behaviour and thinking. They thought this was the impact of the menopause, which Olga was now beginning to experience. They recommended a lesbian nurse-counsellor, Gill, whom they believed would help Olga explore and possibly resolve some of her personal conflicts. We arranged consultations with the counsellor and, initially, she found these one to one meetings helpful. It provided respite for me; I welcomed the physical space, alone in the car, whilst Olga was in consultation. This was the first time there was another person intervening in Olga's distress.

Olga discussed with Gill her need and desire to develop her family relationships. She attended weekly sessions for approximately one year. When I picked her up from, what was to be her final visit, she was distraught. She said Gill had informed her there was nothing more she could do for her. Olga was unable to clarify why her counsellor had terminated their relationship. I recall being surprised and unable to comprehend the situation fully. Once again, Olga and I were alone and there was no support for me in my quest to care for Olga's well-being.

I became aware of Olga's subtly deteriorating health in numerous ways. Her movement was slower and it took time in the morning for her to start functioning and for her to be her usual bright self. Her responses, both physiologically and mentally, were dull and delayed. Her hand eye coordination was less sharp. We often threw objects between each other, competing over who was the best catcher. Olga started dropping the oranges and apples I would playfully lob to her at breakfast time. During conversation her quick wit was failing and often responses were incongruous and clumsy. There were noticeable changes in Olga's ability to read.

Unconsciously, in an attempt to normalise and put changes down to 'common' things I concluded Olga's difficulty and misinterpreting of words was due to deteriorating eye sight. After seeing her Endocrinologist, a recommendation was made for Olga to see an Eye Specialist. The best available was engaged to assess Olga's eyes; we were informed he was a leading expert, especially in diagnosing and treating people living with diabetes. However, he lacked interpersonal skills and his direct delivery of information was brutal. At the time, we were focused on only wanting to know the condition of her eyes and getting the best treatment, so we went ahead with the referral.

On the day of Olga's appointment at the eye hospital I was working. I had asked Olga if she would like me to accompany her but she was insistent on going alone. I received a telephone call from her mid-afternoon. Olga was unable to explain to me what was happening. She was crying uncontrollably and all I could hear was "I could go blind tomorrow". I told her to sit in the waiting room and I would be with her as soon as I could be there. I left immediately and drove to the hospital. Olga was sitting quietly sobbing.

When I walked towards her, she ran, throwing her arms around my neck and she cried uncontrollably. Like a child, her anxiety and distress were uncontainable. I sat holding her until eventually she could put into words what had happened and what was distressing her so badly. The eye specialist had asked Olga if she was working. When Olga replied in the affirmative he told her to retire now as she could go blind tomorrow. A large aneurysm behind her left eye could rupture at any time, resulting in blindness. Macular degeneration had increased in the right eye and her vision had already been affected and vision from this eye was extremely limited.

I felt absolutely helpless. After the immediate impact of these diagnoses had subsided, it was several days later before we were able to talk. I asked Olga to list every place in the world she would like to visit and see. The list was confined to Europe and I planned and organised a three-month trip, for her to see all the places she had on her list. The tour of Europe was amazing for us both. The time spent one to one re-connected us. We got to see so many wonderful sites and experienced so many differing cultures. Olga still had the ability to understand the vast majority of the languages.

She would usually speak a sentence in the local language with poor accent and diction. I would repeat the sentence with excellent delivery, but no understanding of what I had said. This situation reflected the differences in our perceptions of the world. Olga was very much a visual person. Her written language skills and understanding of the structure, origins, grammar and use of language originated and was held within the visual domain. I am an auditory person. Sounds, music, diction and the paralinguistic domain of language and communication are what I hear. This difference was always an asset in our relationship, but became contentious.

With the changes taking place it was difficult to explain to Olga the need to get ready and meet appointments. Organising and keeping to a time schedule became a nightmare with her. She would rely on lists and the written word, she certainly did not respond to verbal prompts. I realised the degree of Olga's anxiety and her inability to contain it. She was no longer able to function at an independent level; this autonomy was lost. It was like caring for an out of control two year old with the cognitive functioning of a professor. Her rage, at times, was uncontrollable and I internalised my anxiety in order to deal with Olga's. Olga was deaf to any emotional content in voice. The changes in her frontotemporal and parietal lobes of her brain prevented interpretation, although at the time I had no energy to consider this.

It was not only emotional content Olga could not hear. On return from Europe a visit to the audiologist identified that Olga had otosclerosis; degenerative changes to the minute bones in the ear which conduct sound. This is a hereditary condition which Olga inherited from her mother. Olga needed to be fitted, initially, with a hearing aid to her left ear; she had profound hearing loss. The degree of sensory deprivation Olga was experiencing clouded the pathophysiological changes which were also contributing to her perceptual and cognitive functioning. I chose to focus on the changes I could accommodate, and with which I could cope. I unconsciously suppressed the understanding and knowledge of the degenerative changes which were so obviously occurring in Olga's brain.

4.3.3 PART NINE: SLIPPING AWAY

With the end of Olga's relationship with her counsellor, came the beginning of my developing role as being the ear for her concerns about her desire to establish closer relationships with her family members. I would listen to her each day and each conversation

usually concluded with Olga bursting into tears. She could not understand why her brothers and sister in her eyes seemed to have less motivation in establishing relationships with her than she did. At times her distress was uncontrollable and I felt unable to connect with Olga and comfort her in any way. At night she started becoming extremely restless.

Olga would often awake in the early hours of the morning. She was distressed and unable to communicate what was happening. The night time terrors increased and she began waking up yelling out “stop, no more”. The behaviours continued to escalate over a period of approximately six months until, one morning, in the early hours, Olga woke up screaming. She got out of bed and walked to the corner of the room then, as suddenly as the screaming started it stopped. Olga became mute. Over the next few weeks her voice gradually returned. It began with monosyllabic responses to questions followed by short limited sentences.

Olga started talking in simple terms about her childhood and how the experiences of migrating to Australia was detrimental to her in numerous ways. When Olga began to attend school from when she was five years of age the loss of the safety of the family home was devastating. The insecurities and trauma of attending school were life changing for Olga. The circumstances and events which began at this stage in her childhood development continued to haunt her throughout her life in Australia and was the catalyst for her leaving Australia and moving to New Zealand. The loss of control of her life and ability to be who she was further heightened when scholarships and support for Olga to accept a place offered, at Melbourne University to study the Arts, were withheld. The school priest who was involved heavily with Olga’s family, performing marriages, christenings and visiting Olga’s parents, persuaded Olga’s parents to forbid her from

accepting a place offered at Melbourne University to study the Arts. It was her duty to obey her parents and the socio-cultural norms of the time gave Olga no choice.

The priest steered them into sending Olga to a fully funded and supported place at a teachers training college to become a teacher. He was involved in the college and continued to be involved with Olga's life and future whilst she was there. When she successfully graduated he ensured she acquired a teaching position at her first school, continuing to attempt to assert control in her life. When, at twenty-eight years of age, Olga left teaching to become a nurse he found where she was living and visited her home, banging on the door until Olga reluctantly answered. Olga escaped Australia and went to New Zealand to give herself the distance and space to be herself; safe and free. The priest managed to trace her whereabouts and phoned her at the nurses' accommodation in Auckland.

Olga was able to confront the priest during the telephone call. As a result of the confidence and distance she had gained from establishing a life in New Zealand and forming a relationship with me, Olga ensured all contact was ended. From the age of ten, Olga was told to keep 'special secrets' with an older male family member. This dishonesty further contributed to her distress and belief that she was a bad person. As is often the case, when she did tell some of the family, they did not believe her. This contributed greatly to her distress. Visiting our general practitioner (GP), with whom we had established a trusting and supportive relationship, facilitated discussions to assist with the issues of disclosure.

I had known, when I first got together with Olga, she had experienced childhood traumas. She minimised it and we never discussed or explored the immense impact it had upon her. I didn't want to know details, as I knew this was irrelevant, so I respectfully refrained from

asking any questions and only spoke about these matters when raised by Olga. She never raised them again. I felt extremely guilty as I knew we were both sitting on a ticking time bomb. The discomfort created by Olga's disclosure, in part, was caused by my own history, some of which I kept hidden and some of which was locked away out of my own reach.

I felt rage towards the adults who had not nurtured Olga as they should have done when she was a child. I imagined her fear arriving in a new country having no words to explain what was happening and no ability to contain the immense anxiety caused by the many losses she had experienced. I wanted to rescue her, but it was too late to save her from people and a system, which protected and supported such behaviours. I recall seeing a lovely picture of Olga on the beach at Williamstown when she first arrived in Australia.

A happy innocent five year old waiting for a new, better life, sitting in the sunshine. This favourite picture of mine provoked uncontrollable grief when I looked at it, as a picture paints a thousand stories and the devil lay in the details of hearing her story. Guilt, helplessness and extreme sorrow overwhelmed me and I felt powerless to make any positive difference to the impact the terrible harms on the woman I loved and wanted to protect. The rescuer desires to save the victim often, with no awareness that it is themselves they are trying to save.

Olga began seeing a counsellor to support her with recalling past memories. We employed a therapist who specialised in caring for people with childhood traumas and Olga started seeing these specialists two or three times a week. Olga contacted a support group, an Australian non-profit organisation that supports and advocates for people with similar experiences to Olga. Olga asked me to help her write her story, and to assist her in

describing her childhood experiences; her language skills were becoming increasingly compromised in situations of acute anxiety such as this. Olga's support organisations and people would not share with me any information Olga had disclosed, despite Olga having given permission. We were informed that to do so was against policy. I had explained Olga's difficulties, that we were a couple and I appreciated the need for confidentiality and autonomy. However, there was no support or appreciation that Olga's emotional and psychological distress ought to supersede privacy concerns when she had indicated that she was unable to express herself clearly, nor was there sufficient recognition of the importance or nature of our relationship.

The situation was compounded further when the therapist refused to provide any information Olga had shared because of confidentiality concerns. I was not accepted as Olga's partner, and despite lengthy discussions with care organisations about the situation no support for me was offered or forthcoming. I felt discredited and unacknowledged by the people assigned to support Olga. The distance between Olga and I seemed to be reinforced by care organisations and people, it felt like they were pushing us apart and my sense of helplessness and isolation increased. I was desperate to comfort Olga and remain connected within our relationship.

All of these circumstances contributed to my inability to assist Olga with writing her story as she had asked me to do. She repeatedly begged me to write for her and the guilt and remorse I felt in not meeting her desire to be heard burdened my heart. I was overwhelmed with feelings of helplessness and felt totally unable to assist her. I was frustrated and disconsolate at not being acknowledged as Olga's life partner. Feelings of isolation and despair surfaced, which only served to fuel my anger at the injustice and rejection I was

experiencing. Olga's limited vocabulary and speech, along with the severe distress recounting and reliving her childhood experiences made the task of writing her story impossible.

I had let down Olga and was failing to support her as I would have liked. The desire to acknowledge Olga's experience and help her heal and grow motivated me into planning our future together with a new adventure. On reflection it was an escapist journey into a fantasy of what could have been, not of what was a reality. We would live between Europe, Australia and New Zealand dividing our time between the countries and people we loved. Olga desired to further develop her understanding of her mother-tongue. Already fluent in Dutch and able to speak in Frisian, she had discovered a course in the Netherlands where she could be totally immersed in the Dutch language, studying its history, development and literature. I was to study at a university in Northern England for a doctorate in nursing. We would meet at weekends in either the Netherlands or England, returning to Australia every six months.

4.4 PART TEN: ACKNOWLEDGEMENT

We were financially secure and this new direction would provide us both with the opportunity to explore and reclaim our cultural heritages. I felt I was losing self in the constant adjustments and changes needed to feel connected to Olga and remain a couple. This opportunity enabled me to consolidate and re-evaluate who I was and what I was about. Unfortunately, Olga's father had taken Australian citizenship for his family in the nineteen sixties losing Olga's right to Dutch citizenship and a Dutch passport. A civil partnership in England would enable Olga to acquire a British passport and live and work in Europe.

Although same-sex marriage had not been legalised in England, a civil ceremony to legitimise same-sex union was permissible. Olga never agreed with marriage as she informed me it was a patriarchal institution, another way for men to control women and for women to be owned by men. Gay marriage was a way to assimilate the lesbian community into a patriarchal society and the ‘well’ Olga would never have even considered the union. My romantic notions of acknowledgement of a union between two women, up until this point, had always been dismissed. I was aware my views were accepted because Olga was coping with more fundamental needs and identity issues. The need to see a future and find hope. I saw this as an opportunity to celebrate our lives together.

The carrot of a passport appeared to win Olga over to the idea of having a pseudo marriage and, though never spoken about, we knew there were more elusive and complex motivators at work for us both. Happy to continue with the process of acquiring a passport to a destination we had no hope of reaching, we journeyed on together growing closer, strengthening and adapting our relationship to meet changing needs. We both knew this was a fruitless path with regards the original desire to study and learn more of our mother cultures. Intuitively, this was a Trojan horse and not the true purpose of the civil partnership we were undertaking.

This was to be our last hoorah, an acknowledgement of our lives together and our love. We would continue to dream our dreams, even if it was all they would be. It was the sharing of ‘the dreams’, the closeness which grew from the trust and desire to grow and be together. Our planning began when we visited England in 2006 to fill-in the appropriate documentation and meet all the many legal requirements. Our civil ceremony was booked

for 25 July 2007. The date was significant as it was to be our twentieth anniversary of being together.

I had booked an old farm house in Alton, Staffordshire as a base for our celebrations. Alton was the village of my father's birth, and held great significance for me and had developed into an important safe haven for Olga. We would live together with family and friends who were joining us for the wedding week. This very large home contained us all, warming us with large open fires, music, reminiscences of childhood, shared memories and conversations of love and happiness. Each day we broke bread together, starting with hearty breakfasts, picnic lunches and dinner banquets.

Concluding with cheeses and wines, singing and dancing. During the days we walked the local lanes and hills and visited gardens. We took trips on canals and trains venturing and exploring Staffordshire. Sharing these stories and times together, enriched long standing relationships and created new understandings of each other. It was such a special time which climaxed in our wedding at Lichfield registry office. Lichfield registry office was previously the children's library where I had spent a great deal of time in the evenings and at weekends immersed in books and safe space.

Books and safe space held a shared value with Olga and this was a perfect venue to make our vows to one another. Several members of Olga's family who lived in the Netherlands joined with friends from Australia and New Zealand, my siblings and their families, for our wedding. It looked to be a perfect day and to all intents and purposes it was. To achieve this wonderful and fitting finale of our life to that point, behind smoke and mirrors the perfect illusion was created to protect integrity and pride lay, unspoken truths.

Behind the scenes events took place which I did not acknowledge until long after the event. The beautiful clothes and outfits Olga wore for our wedding day and the change into evening wear for night time celebrations which appeared as Olga always did, beautiful, graceful and faultless was, out of view, a hideous, awkward and traumatic battle. A sharp contrast to the appearance was the process of Olga adorning the garments. I needed to dress Olga in every item of clothing that she was wearing. The procedural difficulties of washing and dressing Olga so she looked her usual beautiful self was a nightmare we shared together.

Containing the ugliness of our anxieties in the beauty of adorning marital costumes was a stroke of genius and a testament to our love. Nobody had any awareness of what was occurring behind the scenes. We did and we shared this secret connecting together in our hour of need. I wrote our wedding vows. I did this together with Olga, however her ability to be her eloquent self and find her unique individual expression was absent. It was a joint effort with me as the conductor and pianist of the orchestra with a much depleted string woodwind and brass section. Olga could only manage percussion at this stage, banging her drum to a limited beat with erratic rhythm.

I was able to commandeer a close friend of Olga's from the Netherlands to translate a small speech into Dutch for Olga. I stated that Olga was too nervous and excited to be able to do it herself. For several weeks prior to the trip to England, I would practice each day the Dutch version with Olga in order for her to memorise it and say her speech at the reception. It worked.

This was the last time Olga was able to interact and behave as ‘her old self’ in the main. Family, friends and guests believed the excitement of the occasion, her disclosures of childhood abuse and the subsequent traumas were the causes of tears and uncontrolled distress which occasionally peppered the air. The overall feel of this time was joy and happiness. Our love and lives to this point had been shared and celebrated by our family and friends who acknowledged Olga and I, our love, our life and our journey together.

4.4.1 PART ELEVEN: CHANGE OF SEASONS

Insidiously and subtly our road together was narrowing. Olga’s steps were shortening and her energies depleting. Changes were occurring on many pathways and the seasons were changing. As each change either snuck or powered in, I would adapt and modify my behaviour and the environment to adjust to the inclement weather, trying to protect and keep us safe. My focus was maintaining connection with Olga, I feared we could become separated, detached and alone, lost in the stormy seas of our lives. Each day there were adjustments to our living together and staying as a couple. Some slight and gentle, others major and drastic. Like the ticking hands of a clock often that goes unnoticed time slips by, so it was with the changing hues of our union. As the falling rain fills the garden pond with water a drop at a time, going unnoticed until eventually the pond full to the brim overflows.

Olga’s tears became a constant stream of sorrow. The frequency increased in duration and intensity and a river of despair made it impossible to stay afloat. Olga had become clinically depressed. The treating psychiatrist felt Olga was experiencing a reactive depression as a result of recalling past traumatic memories. Reluctantly she agreed to take the prescribed medication. Selective Re-uptake Serotonin Inhibitors (SRSI) anti-depressant medications were prescribed to correct the biochemical imbalance in the brain caused by

the brain disease. These had little bearing on her mood and just caused a flattening of her affect. Her tears were dammed and unable to flow away. The waters flooded her heart, plunging her soul into the depths of despair. The sun vanished from the dial. Olga's beautiful smile was not seen for several months.

Olga's ability to control impulses and utilise her language skills also were changing. Whilst shopping at our local supermarket, standing in line to purchase our shopping, trolley full of cat food, towering above everyone else in the queue, Olga exclaimed in loud disgusted tones 'who has farted?' She proceeded to walk up the line smelling everybody's bottom. The people in the queue became noticeably disgruntled by Olga's continual interjections of disgust. Olga expressed to people they lacked manners and the ability to control their anal sphincter. At the time this provided no amusement to the growing crowd. Quietly and as inconspicuously as possible in the circumstances, I abandoned the shopping trolley. Gently taking Olga by the hand so as not to upset her further, I led her from the supermarket to her continual cries back to the crowd, 'Who farted!'. I never returned to that particular supermarket again.

As well as disinhibited and volatile behaviours becoming a pattern in living with Olga, language ability was deteriorating. Sentence structures and vocabulary was becoming more limited. Short sentences and correct English sentence structure was becoming replaced impart with 'Dutch' language sentence structures which were incorrect when used in English language. This compote of sentences and words were replacing the usual articulate conversation we would have together. When Olga could not recall words, she would creatively invent words. A kangaroo became a 'boing-a-boinger'; a step-ladder became a climbing stick; cups, mugs, glasses and saucepans were all referred to as containers.

I asked Olga one day why she referred to a number of vessels as containers. Most people say pass me the ‘thingy-me-gig’ or ‘what’s-a-ma-call-it’. Olga replied to me indignantly “I use the word container because it supports myself deluded belief that I have some control in containing these losses”. It was apparent whilst she had lost her ability to communicate, her cognitive functioning remained at a higher level than was manifested. She was creatively utilising her skills and learning processes to adapt to the changes occurring. The development of new neural pathways to replace those degenerating in her brain was apparent as was the awareness that the replacement was less rapid than degeneration.

I was in awe of Olga. Her tenacity and resilience creatively expressed with a limited palette allowed me to see the depth and complexity of the woman I loved. There was still paint for her to use to express herself. I feared the day when there was no colour left in her life and I would be plunged into her darkness with her. We both were terrified by loss of control and our vulnerability. Within our relationship we protected each other. We would shine daylight into the other’s night to show the way. Now we both relied on the gentle and fluctuating glow of the moon to see our connections.

It became clear Olga’s loss of ability to communicate had become the main issue in our relationship. As I was the partner with greater ability, it was my responsibility to ensure we endured these changes and our relationship continued to reflect our love for one another. Olga and I were educators and nurses, we both knew the importance of working together in continually assessing our needs, identifying our goals, meeting needs together and focusing on the here and now. The majority of our friends came from the education and nursing world so noticed changes in Olga and our relationship.

Friends and colleagues saw changes in Olga's behaviour and my mental state. They saw my increased protectiveness of Olga. They saw my anxiety and stress as direct responses to Olga's experience of PTSD, disclosed sexual abuse and depression. They constantly reassured me of the devastating effects upon personhood of the menopause, anxiety, and depression. Everybody consciously or unconsciously avoided what in our hindsight was blatantly obvious, Olga was living with dementia.

On several occasions I went to talk with one of my dearest friends and confidants who was a senior Gestalt therapist and health educator. She had worked within mental health for over twenty years and knew Olga and I very well. She was convinced the effects of the menopause, compounded and increased the anxiety symptoms Olga was experiencing. These factors were responsible for the changes in Olga's behaviour. The anxiety I was experiencing clouded my judgement and concerns about Olga having pathophysiological changes to her brain. My fears she believed were misguided. Later these discussions had a profound impact on the grief experienced by myself and our dear friend.

Olga's incredible intellect, personality and ability to be creative and adaptability maintained her autonomy, past all expectations. It masked the many changes which had occurred. These skills and talents were reflected in her ability to relate to the world and others and heavily disguised many issues and hid many other deficits. She developed strategies and paced herself in order to contain her own anxieties. It was a game of smokes and mirrors and she was an expert. Olga managed to maintain personal integrity; at a time when she needed assistance in washing and dressing, she was able to work effectively as a unit manager in an aged care assessment unit. My ability to ensure that Olga maintained as

much of her autonomy as possible, giving her choices and creating as therapeutic a milieu as possible ensured her safety and provided a mist of tears to cloud the view further.

This was my meaning and purpose in life. Staying connected to Olga at all costs for when there was disconnection, I felt abandonment and rejection. I was rescuing Olga to save myself.

4.4.2 PART TWELVE: A NAME FOR THE CHANGES

It was on one of the regular meetings with our general practitioner (GP) that she suggested a referral be made to see a consultant psychiatrist. Our GP who had been our traditional family doctor for well over ten years had a number of increasing concerns. She had noticed a number of changes in Olga's affect and cognition and had also noted an increase in my anxiety levels. My increase in anxiety could be directly correlated to Olga's behavioural changes and inability to cope with everyday life without increasing support. I felt overwhelmingly responsible for Olga's safety and well-being. I saw daily the increase in her vulnerability and I walked a tight rope each day between protecting her and facilitating her autonomy.

Our GP was extremely respectful of our relationship and cared for us as a couple. She discussed with us both the need to seek further help in assessing Olga's health and a referral was made to the neuropsychiatrist. The referral was addressed very quickly and within a few days Olga had been interviewed and received a comprehensive physical assessment. Numerous scans and investigations were carried out and results and findings steadily collated and analysed. A senior consultant, a former colleague of Olga's would be the

clinician assigned to her care. Olga had worked with him at the post-traumatic stress disorder unit for people diagnosed with dementia.

The consultant informed Olga and I of the results of her diagnostic tests and investigations together. The irony of the situation escaped none of those present when he informed her, she had PTSD and Semantic Younger Onset Dementia (S-YOD). The frontotemporal lobe degeneration evidenced in her brain scans was extensive, as was the degeneration seen in the parietal lobe. It wasn't a surprise to Olga, myself or the clinician present, but it put an end to any thoughts that our previous assessments and observations were flawed and misguided. It was the confirmation of our worst nightmare. Motor-Neurone disease had manifested upon Olga's brain before the rest of her body.

Overwhelmed and emotionally devastated by these confirmations I found the only place to escape to were my thoughts. I felt the crushing pain in my chest, my heart beat rapidly out of time with the situation. Being logical, objective, sensible and pragmatic was the only place to hide in the chaos of emotions and fears. I had to stay in control for both of us, now wasn't the time to abandon ship, I had to be the captain and the honourable captain always goes down with the ship. It was Olga this was happening to, and the focus needed to remain on her.

This was November 2008 and the doctor believed her life expectancy was approximately two years. Olga had hit the tip of the iceberg and I wasn't prepared to look at what laid below the cold deep sea. I had plenty of time to grieve and mourn and deal with the emotional aspects of the death of Olga and the end of our relationship. Our lost dreams, plans and future life. There would be no life without Olga. I wished I had received the

diagnosis, I wanted to bargain my way into being the one who would die and experience this one way no through road to dying with dementia.

On returning home and having received Olga's medical diagnosis, 'Frontotemporal Lobe Degeneration (FTLD)', Olga and I retired to the safety of our bedroom and sat on the edge of our bed. We discussed the repercussions of the pending life changes. A life prognosis of two years and we knew the changes which would occur to end life. Olga was concerned with her increasing dependency upon me and her loss of control. I was focused on Olga's wellbeing and did not consider the future impacts these changes would have upon my personhood.

Olga was able to articulate her concerns and fears about her loss of autonomy and our loss of control of our relationship. We debated the ethical concepts of self-determination and dependency ensuring we remained in the cognitive domain. We discussed our remaining options remaining in our heads and steering clear of our hearts. We talked about how we could perhaps take control of our life circumstances, and living requirements in order to jointly take control of our lives, to be united, as a couple; in charge of our fate as life partners until death.

This was Olga's way, control the things you can to reduce anxiety about the things you cannot control. How could we live our lives together with dementia and not lose ourselves and be alone? The accompanying guilt and shame of not being able to protect and care for Olga was overwhelming. I had made a sacred vow 'til death do us part' so what was the best viable solution? We sat and discussed the ethico-legal considerations of differing

courses of action. We sat and talked for the remaining hours of the day. Both exhausted as the sun went down, we fell into bed and embraced.

Falling asleep in each other's arms, exhausted, connected and contained, we never discussed or alluded to this conversation, or the disquiet it caused again. We shared a tacit understanding and we both knew we had reached the same outcome to continue on our journey together wherever it was to take us. This was to be our last in-depth philosophical discussion and the last overt spoken spiritual conversation. Although unspoken we came to the same conclusion, to live the future together and continue our journey. Little did I anticipate the enormity of the challenges of the road that lay before us. Little did I appreciate the attacks on our relationship, personhoods and individual identities that this decision would cause for both of us.

4.4.3 PART THIRTEEN: MONEY AND CONTAINMENT

Olga had always done the finances for our company and personal life. I had little interest and even less ability in money matters. She was extremely organised and great at financial management. I am not organised and as Olga would often quote... "You do not have a practical bone in your body!" This being true, the tasks imposed upon me by the changes in Olga meant I had to quickly grow skills and know how. I had noticed over several months Olga was struggling with the business book-keeping and finances. As I didn't have time or energy, I had employed a book-keeper to take over this task. The books when closely scrutinised by an expert were an absolute mess.

Over several weeks the book-keeper had made appropriate adjustments and amendments to books. These were done in pencil in order for the accountant to check and make further

changes if required. All this work was done by the bookkeeper in order for the accountant to make sense of the company's situation. One afternoon in the office I found Olga erasing all the figures from the books entered by the book-keeper. She was replacing them with her calculations which of course made no sense. I panicked and asked her to stop. I was aware of the high levels of anxiety that I was experiencing. Olga in the past was able to briefly contain my anxiety until I gained control. On this afternoon I was made acutely aware this was no longer the case.

I am unable to recall the actual events that took place and can only recall lying on the floor with Olga standing over me. She had a leg either side of my waist and was yelling and screaming a tirade of abuse, I was terrified. I thought she was going to kill me. I felt like a mouse being tormented by a cat. There was nothing I could do, I was at the mercy and will of a stronger creature who would decide my fate. My body was shaking and I was crying uncontrollably. This behaviour seemed to fuel Olga's anger and her aggression escalated further.

I am not sure how long this went on for, other than to say, eventually I found myself alone on the wooden floor, regressed and battered. I lay motionless for several hours with no energy, or mindfulness to care where Olga was, or what was happening. I fell asleep and when I awoke it was a brand new day. The new day brought with it feelings of guilt and shame. Olga had reasons for her vulnerability, she had organic brain disease. I needed to be responsible for our relationship and I strongly felt I had let her down. Allowing my anxiety to trigger and pass to Olga who had no ability to contain it, was inexcusable.

Olga was unable to contain impulses and control her fear and anger because of the degenerative changes to the front of her brain. Sometimes after experiencing these losses

of control she recalled her behaviours and some of the events that had occurred. This would cause her great distress, she was aware of my history and loved and cared for me. When she recalled behaviours where she had hit and shouted at me, she would become extremely remorseful and distressed. I tried to downplay and minimise these events, on this occasion however I was too traumatised and distressed. Her aggression and behaviour was escalating to the point where we were both losing control.

As a child I experienced my mother's loss of control. My half-sister was my main nurturer and carer until I was eighteen months of age. My father filled in gaps when home from work, with nappy changes and feeding. Being the youngest of six siblings I was fortunate enough to be loved and raised in their arms and hearts. Sadly, when left alone with my mother, a Monday to Friday occurrence, beginning at eight in the morning until four in the afternoon, things were not so harmonious but memorable. When alone with her as a child she would hit me and stand over me. The last beating I recall was when I was about seven years of age.

I recall her screaming and hitting me, totally out of control and raging. I recall saying to her, "You can hit me as hard and as long as you like but you can never touch me." At this she stopped, looked at me in amazement as I stood motionless. With only silent tears rolling down my cheeks and an expressionless face I took control on that day. Although the frequent 'clips' around the ears and head continued, I never received another thrashing. Olga was aware of this and knew the emotional toll it had upon my soul.

When Olga was standing over me, I flashed back to the experience of my mother beating me. It was no good saying to Olga "You can hit me as hard and as long as you like but you

can never touch me” because Olga was not cognisant of her behaviour. Somehow simultaneously I gained awareness that to a degree my mother was. As a child I gained autonomy and control something I was unable to achieve in this situation with Olga. I disconnected from my mother the day I stood up for myself. I was trying to stay connected with Olga at whatever costs.

Olga was also very aware of my first sexual experience which was with a woman and not an ideal encounter. She had always been mindful of my sensitivity to firm touch from others and voices raised in anger toward me. I had developed excellent skills professionally as a psychiatric nurse and when wearing the nursing hat had the ability to remain in a therapeutic role. On a personal level it was totally different. I was aware Olga had pathophysiological changes in her brain and had lost control due to this factor. At the time I was experiencing her rage. I found it impossible to stay in my cortex, to think as I would if working as a mental health nurse. I could not think, I was blinded by feeling, seeing only pain, feeling like a helpless child longing to be loved.

4.4.4 PART FOURTEEN: MORE MONEY PROBLEMS

There were a number of situations that occurred around this time indicating pathophysiological changes were taking place in Olga’s brain. Early one afternoon Olga presented me with an envelope from the tax department. She had been emptying the mail box, keeping some mail and disposing of others without me having any awareness of what we had received. The tax bill was for two hundred thousand dollars. She sobbed uncontrollably telling me that she couldn’t work out the tax anymore but didn’t want to let me know because I would worry. She was hoping that she could work it out and fix it without me ever finding out. She now realised that was not going to happen. She was

devastated and so traumatised by this event. We had purchased an investment property which fortunately I was able to sell and pay the tax bill. This was the last of our financial resources.

Midmorning on a usual day at home with Olga I received a telephone call from the local council rates department. The female official was informing me that the rates had not been met for eighteen months. I tried to explain that my partner had dementia and she had been throwing the mail away. I calmly attempted to explain I was totally unaware of the situation. In obvious disbelief I was asked when I would pay the bill. At the time of the phone call Olga was outside organising the rubbish bins. The rates department employee continued to inform me how much money was owing and demanding payment.

At this point Olga proceeded to walk through the opened French doors of the lounge room with the rubbish bin in tow. I asked the rates official to hold the line. I quietly and calmly requested Olga to take the bin around the outside of our home. Olga lost it. “This is my house and if I want to walk the bins through my house, I will walk the bin through my house.” Olga yelled with expletives and proceeded to pin me against the wall with the full rubbish bin. She told me in no uncertain terms where she was going to insert the rubbish if I didn’t get out of her way. I remained calm and quietly said “okay my darling, take the bins out.” Olga stormed passed with the rubbish bin slamming the front door loudly behind her. I then realised the woman from the rates department was still on the line waiting for a response from me. With quiet dulcet tones she apologised and said I would be receiving a rates rebate in the return mail.

A further loss for Olga was when she was considered no longer safe to drive. Acquiring the driving license off Olga was an enormously difficult task. I found it extremely hard to take away something more from Olga. She loved driving and the freedom it gave her. Clipping her wings was a further assault on her frail personhood. I started to feel like her jailer and rather than enriching her life, I felt I was diminishing it.

At this time, I also had to take away her bank key card. I had noticed large sums of money withdrawn from our account and yet no money found on Olga. She told me on one occasion that she met a nice young man whose birthday had gone unacknowledged by his family. She said she had withdrawn some money to give him for his birthday so he could celebrate. I think a number of similar events occurred each week as often between five hundred and one thousand dollars went missing from our account on a weekly basis. Our finances were already grossly depleted and further mortgaging our property was no longer an option. Olga had an enormous fear of 'being poor.' My poor financial management was putting her at risk and I began to feel extremely guilty. Olga always managed our financial affairs so well, and I had put us in a vulnerable position.

Caught in the harsh winds of change it was difficult to see self in the whirlpool of our relationship. The thought of saving self was never contemplated as self appeared not to exist outside of the union of our partnership, Patricia and Olga, 'P&O' as friends and family called us. It was and remained unimaginable to anticipate the tsunami of personal loneliness and sorrow that followed. Finding self without losing connection with Olga and facing the loneliness encountered when having to make 'life and death' decisions for my loved one, was nearly a fatal journey.

4.5 PART FIFTEEN: BREAKING HEART

My heart was breaking and I was drowning in a sea of sorrow. It was the same year as I had experienced the best days of my life, the year Olga and I were married on 25 July 2007 at my birthplace Lichfield, Staffordshire, England. It was twenty years on from the year Olga and I committed to sharing the rest of our lives together when we met in Aotearoa, New Zealand. Returning to Staffordshire after a civil partnership later that year to be with family for Christmas I did not realise it was to be the first and last time Olga and I would be together, acknowledged and accepted by all as family. This was also the first indication of the toll this would take upon my body.

We had returned late evening on 23 December from a hectic day visiting various kith and kin. We were both exhausted. Olga's energy was spent keeping it together and containing her anxiety. She was masking her increasing loss of language with neologisms and descriptive adaptations for lost nouns. Whilst my language was intact, I was doing much the same meeting slightly differing needs. Keeping sharp and focused I was performing linguistic gymnastics of a different nature to Olga. I was hurdling over the verbal fences Olga had created and dodging and blocking the 'fast ball' comments that frequently came flying from left field; Olga must not be caught out! I had to help her keep her integrity and dignity.

I followed in Olga's wake mopping up spillages and filling in gaps. I needed to protect her and ensure she stayed safe. By the time we arrived back at our bedroom and fell into our bed it was 24 December, the early hours of the morning of Christmas eve. Exhausted Olga quickly fell into a deep sleep. She was peaceful and safe next to me. I was profoundly aware of Olga's presence and her rested body. I reflected on her struggles of the day and my

inability despite all my efforts, to take away her mounting grief and pain. There was nothing I could do to stop the force of the water. Olga's tears were seeping through and the dyke would inevitably break.

A crushing pain in the center of my chest began to radiate down my arm and into my left shoulder blade. I stayed still, as still as I could be. I could not breathe. In a split-second numerous options filtered through my mind. I must not create a fuss. This was Christmas, everybody in my family, our family, had gone to a great deal of trouble and effort to ensure we felt accepted and welcomed. I needed to stay by Olga's side. I needed to breathe so I focused my mind and efforts on breathing. The 'elephant' sitting on my chest must be ignored. I must breathe and relax.

I repeated over and over in my head, I will sleep and wake up in the morning. If I am going to die, there is nothing I can do about it and panic will just make things worse. The next morning, I felt terrible but I was alive. Olga was still asleep and I could continue albeit at a very slow and laboured pace. On the 9 January 2008 when we returned to Australia I visited my General Practitioner (GP). Following blood tests and an Electro Cardio Graph (ECG) I discovered I had experienced a Myocardial Infarction (MI). Because I had delayed interventions until January, I experienced a cerebral vascular accident (CVA) on 18 February the same year. Another minor MI followed in May 2008 and I continued to experience Angina related to emotional distress following the initial heart attack. Takotsubo Syndrome commonly referred to as Broken Heart Syndrome was diagnosed in 2017. You can die of a broken heart; it is not a myth or a romantic fictionalised notion. My journey is to learn to live with a broken heart, to find a meaning and purpose in life, to find a happily ever after...

During the process of writing my story there came a point at which I needed to discuss something that I had not revisited before. It's not that telling the story was ever easy, but for reasons of intimacy and privacy this seemed to be the most challenging disclosure. Throughout our relationship up to this point physical intimacy, touch and sleeping together each night were fundamental aspects of our connectedness. Olga needed the comfort of being held and lovemaking as much as I did. With the progression of the degeneration of the frontal temporal lobe of her brain came the difficulty to contain emotion and for behaviours to reflect feelings accurately.

Navigating the minefield of sexual intimacy and accommodating vulnerability which could detonate at any time, a buried memory for Olga with compromised cognition and containment was alone difficult enough. My childhood experiences, along with initial harrowing relationships with women in adulthood added complexity to what was going to become an explosive period in our relationship. Olga's need to express her desire and love for me began to breach boundaries. Her inability to contain strong emotion would penetrate through the trust we had established over the years.

My inability to reject and push Olga away compounded the situation. Her realisation that her attempts to demonstrate desire had turned into mutual hurtful and dangerous indiscretions were devastating. I needed to take control of this situation as she was unable to. Dividing our home into two living areas, two bedrooms and two bathrooms tested Olga's sense of abandonment. It was for her safety and my own that I reluctantly ended our time sleeping together each night.

4.5.1 PART SIXTEEN: LIVING ON THE KNIFE'S EDGE

Not long after we had started sleeping in different beds, I awoke in the early hours of one morning, to find Olga standing over me. She had a bread knife clutched in both hands and was holding it above my abdomen. I looked up into her eyes and she was absent. I spoke gently to her “Are you all right Darling? Is everything okay?” She stood motionless looking down at me lost, absent. Olga was unresponsive and I was unable to connect with her. Slowly I slid my body to the edge of the bed and gently arose, moving extremely slowly I removed the knife from her hand and kissed her on the cheek. I led her back to her bedroom and laid with her until she drifted off to sleep.

The vigilance that I was experiencing with Olga had similarities to past experiences with my mother. When Olga was standing over me it was like my mother threatening to harm me. With my mother it was because I shouldn't have been born, I caused her pain and ruined her life. It didn't make sense because mothers are supposed to love their children. I must be a very bad person. My grandmother said, “The sins of the fathers are brought down upon their sons for seven generations”. She told me she was bad because she was illegitimate and I would inherit her sins. My grandmother was lovely and kind.

Olga was lovely and kind. She loved me, so why is she trying to harm me for no reason. Maybe she can see my badness. Maybe I deserve to die? I returned to my half of the house and was struck with terror at what might happen to Olga if I was not there to care for her. I kept saying to myself Olga has a brain disease this is not Olga. How on earth could I keep safe when Olga had no control? How could I stay in control to keep myself and Olga safe? From that day onwards sleep became difficult.

I listened for every movement and every sound in case Olga was in danger, in case I may be in danger. Thoughts raced through my mind; what was happening to Olga, what was happening to me and what was happening to us as a couple? No longer could I feel in control given the circumstances. The need for safety was manifested in a disquieting vigilance as I struggled with the need to protect Olga whilst also needing to protect myself. Continuous monitoring of Olga's behaviour without compromising her sense of autonomy and independence gradually gave way to physical and emotional exhaustion which surfaced doubts about my ability to continue to care for her - I needed help.

With great reluctance I contacted local government health authorities. Initially making such a decision gave me a sense of relief knowing that help was on its way however, a sense of relief was short lived as I was confronted with unforeseen barriers that led me up uncertain streets and blind alleys. Between thinking about Olga as well as my own safety, Olga would often get up in the middle of the night, empty cupboard drawers, take books off shelves and carry out numerous inexplicable and seemingly meaningless tasks. I would monitor from a distance trying to protect her autonomy and independence but keeping us safe. I became exhausted, it was apparent I needed some help.

Olga didn't fit into the usual categories, whilst she was diagnosed as living with dementia, she was not an elderly person. At fifty-five years of age her needs were very different to an elderly frail person who had a similar illness. Initially I was transferred from one department to another, each department telling me that it is not their responsibility and to contact someone else. My frustration was further increased each time I explained that I was Olga's partner. They would sometimes ask if Olga had any real family and who her next

of kin was. I would explain that we had been married in the United Kingdom and that I am Olga's family and her next of kin.

Eventually the psycho-geriatric aged-care assessment team (PGAT) made an appointment to come and assess Olga at home. Two Registered Nurses arrived at the house, I greeted them took them to the dining area, they sat down and I offered them a cup of tea and some biscuits. Olga was busying herself around the house. Briefly on one of her meanders past she introduced herself to the visitors only to carry on with her usual routine of tidying drawers, checking books and other domestic activities. I explained to the Registered Nurses that I was a Registered Nurse (RN) as was Olga. I received no acknowledgement for the information content or the process of supplying it. They clearly expressed a disinterest in interacting with me and wanted Olga to sit down so they could carry out a mental status examination, so they could allocate points in order to assess what assistance could be provided.

The continual lack of acknowledgement as Olga's life partner was compounded by the professional lack of respect offered by the nursing family. Continual feelings of rejection and non-acceptance fuelled the anger which bubbled through my life blood and drove my desire to bring about change.

It took quite a while before I managed to get Olga to join us at the table. Olga was extremely perceptive and could feel the tension in the air. The nurses just wanted to do the job, ask the required questions and get out. They proceeded to ask Olga questions; What time of day is it? Do you know what year we are in? Do you know where you are now? Their patronising tone, lack of eye contact with Olga or myself facilitated a tirade of abuse from

Olga. I would have liked to have joined in. At this point in the interview I was extremely grateful to be able to abdicate responsibly to Olga's frontal temple lobe degeneration.

Finally, although the process was distressing, I was allocated eight hours during the week for carers to assist. Olga's comments to the RN's that they possessed less intelligence than she had in her little finger and that they should go forth and multiply and not waste her time were dismissed by the interviewers as evidence of her brain disease. I asked them to leave, and they seemed very keen to do so. They parted and walked rapidly up the garden path to expletives and colourful gestures from Olga.

A week or so later I received notification that Olga had been allocated a carer to attend for four hours two days a week. This turned out to be a great assistance. Initially carer after carer came to leave hurriedly following Olga's emotional outbursts. She would assess each carer's ability, personality and their suitability to spend time with her. Olga's standards were high. She did not suffer fools gladly. She did not want to be patronised and certainly did not want to be domineered and instructed. Eventually she identified two people with whom she developed extremely close friendships which were to last until she died. I asked them if they would come and visit Olga when they were not working and they agreed. Olga would have carers visit her five days a week.

Olga was so happy with this arrangement and it made my life a lot less stressful. I had time to myself, to think, to reflect, to just be knowing Olga was safe. Despite the very positive outcome of these arrangements there was a degree of feeling guilty at not being able to care for Olga by myself. I felt in some way I had let her down and was not giving her enough.

Although Olga was pleased to go with carers and to the day centre she made it quite clear she would rather just be with me and not the ‘others’.

My nursing education and the skills I had developed as a unit manager were standing me in good stead at home. On a weekly basis I would organise Olga’s days for that week. I would write two versions, one version for Olga and one version for carers. Olga’s version was a list of times with pictures and cartoons and single words to explain her activity and who was with her. The other version was a detailed holistic care plan, for everybody caring for Olga to read and add to each day. This enabled me to modify, adjust and change her care according to her changing needs. Other practicalities of care were also accommodated.

4.5.2 PART SEVENTEEN: THE FOOD OF LOVE

Each Sunday I would set up small baskets of food for Olga. Breakfast, morning tea, afternoon tea, supper and an emergency/nibble basket. Five baskets for seven days a week would be organised filled with appropriate foods and lined up on my kitchen bench. At the appropriate time these would be transferred to Olga’s living area by mainly myself or sometimes carers. This ensured food of the correct type and quantity was available for Olga and her living with diabetes Type One was managed the best it could be. Olga was on an Insulin pump and I would support, and sometimes instruct her to administer the correct amount of insulin. I taught carers to also monitor and prompt Olga with regard to her administration of Insulin.

In the local cafes just down the road from our home I set up a ‘tab’. This meant that at any time, accompanied or alone, Olga could walk down the road and order coffee, snacks or anything she wanted. I also made the same arrangements with the local hairdresser and

beautician. If Olga wanted to, she could have her hair cut, styled, coloured, have a manicure, pedicure, or whatever other beauty treatment she desired. This in the main worked very well and maintained Olga's relationships with the people in the local community whom she had got to know over the years.

All of these practical strategies also served to give me meaning and purpose. Based on my relationship with Olga my role was to ensure her autonomy was maximised, she was safe and felt supported. Our relationship continued to reflect our love for each other, and my days and my life was full. My relationship with Olga intensified, the energy and love we both shared with each other became more focused and our world became more about each other and our needs. As her abilities faulted and her needs changed, I continually attempted to maintain as much independence for her as possible, ensuring her needs were fully met.

Any opportunity which arose that enhanced Olga's quality of life was embraced. This was usually of mutual benefit, I had more time to work knowing Olga was safe, was stimulated and was energised by people. When an opening for her to attend a local day care centre for people living with dementia and other cognitive disorders became available it was accepted gladly. This was a wonderful experience for Olga. The mini-bus would pick her up in the morning and drop her off at the end of the day. Olga would eagerly get ready and wait excitedly by the garden gate for the mini-bus, like a child waiting for the school bus. I would kiss her and wave her off and greet her on her return taking her inside for tea and biscuits while she told me about her day.

Olga firmly believed she was one of the staff at the day care centre, looking after people. Olga felt needed, useful and employed. The familiar routine of a workday, the environment,

along with her desire to work and have a purpose, made this a most helpful intervention. Her sleeping improved, her affect became congruent and happy and her smile returned. When the offer was made to attend two days a week, we accepted it gladly and were both very happy with the additional day. Her energy increased further. The chats on her return home were now even more full of life, telling me about her work day and stories of the friends and colleagues she had cared for and worked with that day.

The other five days in the week soon became full and organised around purposeful activities and interactions for Olga. The three week days were full with carers taking her shopping, to the movies, tenpin bowling, swimming, trips to museums, libraries, Olga always selected from the many choices she was given. I would usually take Olga out for the evening meal and sometimes we would go to see movies in the city or go to concerts or lectures. Old colleagues and friends continued to stay in-touch and became a great support for us both.

We would meet together at weekends for breakfast and lunches and our old social networks continued accommodating Olga's difference. Olga was oblivious to the changes in the dynamics and the interpersonal relationships as friends accommodated Olga's communication difficulties and at times inappropriate behaviours. Life was busy and full. Everything in my life revolved around meeting Olga's needs. I lost sense of time and the changing nature of our relationship. As long as Olga was happy and enjoying life, I felt content. When we would go on walks together hand in hand, our love for each other felt the same as ever. We would not talk for words could never express our love and connection.

It was my sister's sixtieth birthday that upset this secure routine and pattern of life which contained us both. In the past I wouldn't have given it a second thought, Olga and I would

have taken a four-week trip to England and spent the time with family and friends and joined in the celebrations. How on earth could I take Olga to England now? I couldn't do it. I also felt unable to let my sister and family down. In the last conversation I had with my father before he died, he asked me to "look after your Mam and your brothers and sisters". I was the youngest in the family but my father had handed down this responsibility and it was very important to me to meet this obligation. I had to be there for my big sister on this special day.

My sister Ann had died suddenly in England in 2003. It was impractical for me to attend the funeral and be with family at that time. Travelling between Australia and England, time differences and arrangements made it extremely difficult to arrange, so I did not attend. In retrospect I realised what a great mistake this was and the grief of not being there for such a significant event weighed heavily on my conscience. I wrote a heartfelt and poignant eulogy for my sister which was read at her funeral on my behalf. Despite receiving sincere acknowledgements from friends and family for the words they valued it made little difference to my feelings of guilt and letting the family down, breaking my promise to my father.

I looked at Olga's daily timetable and the carers and friends who were supporting me. I decided to travel to England alone for a week feeling confident and sure that I had planned for every possible eventuality for Olga and that she was safe. How wrong could I be?

4.5.3 PART EIGHTEEN: PARTING WAS NOT SUCH SWEET SORROW

On arrival in England I phoned home to see how Olga was and how the arrangements were panning out. I was informed by one of the carer friends who was looking after Olga that

Olga had been admitted to hospital due to hyperglycaemia. The carers were RNs as well as personal friends at the times when medications were due. They knew all the medications Olga was prescribed and how to administer them. Olga's independence was promoted and as I believed Olga always managed to give herself the required amount of insulin when I was caring for her, I did not foresee the difficulty. Prompts were given to Olga by the care team as discussed with them prior to my departure, as safety measures at meal times.

It appeared to the RN carer that Olga had been giving herself her insulin, her actions and behaviour were congruent with insulin pump management. She was entering data into her insulin pump and it seemed she was administering her insulin according to the amount of carbohydrates estimated in her meal. However, the data she was entering was invalid and she had not been giving herself insulin at all. The night of my departure from Australia Olga's blood glucose levels skyrocketed as she had eaten her evening meal and taken her supper with no insulin to enable her to metabolise the carbohydrates. Olga was vomiting profusely and was extremely confused. An ambulance was called and she was taken immediately to hospital and admitted.

I became extremely distressed on hearing this news. I really didn't know what to do. Olga was safe and the staff at the hospital assured me as far as her diabetes was concerned, they had no concerns. They did say however there were some important issues they wished to discuss with me. These were of a non-urgent nature and advised me to return home as planned at the end of the week. I spoke to Olga over the telephone and she sounded well in the circumstances. Olga made it sound like this was all a bit of an adventure and she was able to put the nursing staff right, and teach them a thing or two. After a number of hours

deliberation, I was reassured sufficiently by hospital staff, family and friends to keep to the original time table.

It was my sister's sixtieth birthday, I was in England and so I decided to stay for the family get together and then fly home. I phoned the hospital and Olga a couple of times each day and my stress subsided, as I believed when I returned home Olga and I could resume our lives together as we had been doing. I was curious as to the matters of non-urgent concerns the staff had expressed but thought these were to do with her insulin regime, or possibly the need for a new insulin pump as it was about time for an update. As soon as my plane touched down in Melbourne, I headed to the long-term car park to retrieve my car and speedily went to the hospital.

I arrived at the hospital expecting to bring Olga back to our home. The problem with her diabetes I believed had been resolved. However, it was not her diabetes that was the issue. The nurse in charge had a number of concerns, the main one being Olga's inability to care for herself independently and safely. I explained I was able to care for her and had a number of people, both professional carers and nursing friends which enabled me to keep Olga safe and well cared for. She asked me about Olga's insulin pump and I explained with prompts Olga had to this point managed it well. The nurse in charge said this was not the case. In order to demonstrate, the nurse asked for Olga's and my consent to make obvious her concerns. She felt strongly I had an inability to be clear about the situation.

I agreed and Olga joined us in the clinical room. The RN handed Olga an insulin pen and asked Olga to administer her insulin with it. Not only did Olga draw up the incorrect amount of insulin but she tried to inject the insulin into her foot. I was astounded. Gently I

intervened and took the pen from Olga. I thanked her and asked for some time to talk with the nurse alone. Olga graciously returned to her room and I was left bewildered and confused. The RN went on to inform me that the nurses on the ward had to support all cares for Olga; wash, dress, everything. Olga was incapable of doing any self-care without supervision.

The nurse in charge went on to advise me that it was the medical team's belief that I was incapable of caring for Olga at home. I am unable to recall the rest of her conversation fully as I became distressed. I pointed out to her that I had both medical and legal power of attorney. She responded by stating they had the ability to over-rule my authority. She went on to say the team believed that I did not have the capacity to make a rational decision and also that I was 'deluded' about Olga's situation. She told me I was in denial and incapable of caring for Olga; Olga's discharge was refused. Olga would not be allowed to come home with me. She was to be transferred to the neuro-psychiatric ward for a comprehensive assessment.

I was extremely angry and felt helpless. I was not acknowledged as Olga's life partner and was told I was incapable of caring for her. I had been caring for Olga for the last several years. This situation only occurred because I made an incorrect decision to go to England and was guilty of poor judgement, not neglect which is what I felt I was being accused of. I could not appreciate their position and the lack of compassion, understanding and overt homophobia enraged me. I felt they were abusing their power and in not discussing, or even consulting with me about my life partner, our life and our future that they were not helping Olga.

I left the ward distraught and alone. I visited Olga the next morning on the neuropsychiatric unit. The attitudes of the staff and the neuro-psych unit were little different from the previous endocrinology ward. I was not considered Olga's next of kin and needed to continually ask for information and direction with regards Olga's care. Olga was put through a plethora of tests and investigations, all of them medically based to find out what was wrong with her brain. On completion of all investigations I was told Olga had extensive degeneration of the parietal and frontotemporal lobe of her brain. A formal diagnosis was made of Semantic Frontal Temporal Lobe (S-FTL) Younger Onset Dementia (YOD). The doctors advised me in a clinical meeting that there was nothing that could be done and to find Olga accommodation in a dementia unit as soon as possible. The treating doctor's parting comment at the end of the meeting was to ask if they could have her brain after death as she was a very interesting case.

4.6 PART NINETEEN: FORCED DISCONNECTION

This case was the love of my life who begged me each day I visited, to take her home. Whilst Olga was in the neuropsychiatric unit I was not allowed to stay outside the visiting hours. I would have to ask several staff, several times each shift, to find out any information about Olga's nursing care and medical treatment. Interactions with me were avoided by all ward staff and there was a prevailing atmosphere of disengagement at best, and obvious avoidance at worst. Olga believed she was awaiting discharge home. Each day I explained to her that she was not coming home. This continual discussion was increasingly difficult as no support or reinforcement of what I was saying to Olga was provided by staff.

At this time, I received several minor driving infringements for violations of road traffic rules and regulations. I was experiencing several angina attacks a week, sometimes two or

three a day. I was unable to sleep and would find myself crying uncontrollably either sitting on the edge of my bed before going to bed and in the early hours of the morning or in my car, pulled over at the side of the road, leaning over the steering wheel. Work commitments combined with erratic eating and drinking compounded the situation. I was out of control and exhausted.

I visited several dementia units in order to try and find a place for Olga to live. Following each visit, I was devastated by even the thought of Olga being there. Whilst I appreciate the difficulties in caring for people with dementia, the thought of Olga being surrounded by men who were sexually disinhibited and inappropriate in their behaviour filled me with horror. How on earth could she be safe? How on earth would she cope? Of course, I knew the answers to some of these questions as my daily battles with staff on the neuropsychiatric unit about not using neuroleptic medications to sedate and modify Olga's behaviour told me how the dementia units would manage her case.

Olga was not a case, she was a beautiful woman experiencing profound losses and finding herself in an extremely vulnerable situation. It was my responsibility to keep her safe to care for her and to love her as she had always loved me. I was failing. Not only was I unable to protect and provide for Olga, but my body was not coping with the additional stress. There was a further increase in the frequency of angina attacks, and they were increasing in intensity. I felt I was existing in absolute chaos. Like an unanchored boat in a torrential storm out at sea. I was crashing against rocks, disorientated, out of control and just being taken by the wind whichever direction it chose to take me. I was unable to keep myself afloat, let alone Olga. Unexpectedly a life boat appeared in the form of an old nursing colleague to rescue me.

Olga's mother, who was referred to by all as Oma, resided in an aged care facility. Olga and I had found this accommodation for her mother, who was classified as elderly frail when her mum's physical health declined. The Director of Nursing (DON) who managed the facility was a lesbian nurse, who was a previous colleague of Olga's. Cognitively Olga's mother was highly functioning. Her thick Dutch accent, frank, direct opinionated comments flew readily from her lips as they had done throughout her life. She was a very strong character who hid her humanity and compassion from all who were oblivious of the depth of this woman's personality.

Oma was an active member of the Dutch resistance during the German occupation of the Netherlands. She had relayed to me many stories of horrific events that she had kept hidden from Olga and the family members in order to protect them from the horrors which haunted her daily. As a devout catholic the emotional turmoil my relationship with Olga created for her was immense. Over the years however I had established a very close relationship with Olga's mother. Olga told me that I was the only person she had ever seen make her mum cry. Oma respected and loved me despite all of the reasons not to. It was an act of desperation that I went to the nursing home where Oma resided.

I went to the office and I broke down in tears. The reception staff knew me as obviously I visited there frequently. They took me to an office and sat me down and gave me a glass of water. The Director Of Nursing (DON) came in and asked me why I was there and was it about Olga. I find it hard to recall what I said, but I explained the situation I was in, and the events of the last few months. I had spent all of our money, I was in debt and had no personal resources. The DON told me to remain in the room and that she would be back shortly.

On her return she replied Olga could stay in the facility in a low care area and there would be no charge, she would sort it all out and she would remain in the low-care area until her death. It was a perfect situation, it was in a low-care area that she was familiar with, that she had chosen herself for her mother and that she knew the people. I felt an enormous sense of relief. Now I had an opportunity to ensure that Olga was safe and cared for, and whilst the enormity of the guilt that I felt for not caring for Olga in our home remained, the practicalities of daily living were catered for.

A week after this meeting, quite suddenly, Olga's mum became gravely ill. She had cancer which was in multiple organs and she died within a few days. Olga was to have her mother's room. Olga visited her mother the day before she died. Oma was cognisant and engaged beautifully with Olga. Uncharacteristically, she was warm and gentle without being patronising in any way. She spoke and touched Olga like a mother nurturing a distressed child. Olga responded with smiles and frequent kisses to her mother's face, her resolution of the often disharmonious relationship was there for all to see and hear.

4.6.1 PART TWENTY: TOGETHER IN LIFE AND DEATH

Within a week on the 13 July 2009, we were attending the funeral of Olga's mother. Immediately following the funeral on the afternoon of 13 July 2009 at two o'clock Olga moved into her mother's room in the aged care facility. This day sat between Olga's birthday on the 3rd July and our wedding anniversary on the 25th July making the month of July a pivotal month in our lives and always to be emotionally loaded. July in Europe; the heart of summer, Olga's life began. Our wedding, times of connection, warm togetherness and birth. July in Australia, the heart of winter, Olga's mother's death and Olga moving away from our home, times of separation, cold aloneness and death.

The morning of 13 July 2009 began with Olga's discharge from hospital. I went to the hospital to be greeted by Olga. She was so pleased to see me and for me to be taking her back to be with me. She was so happy and unable to contain her delight at departing the hospital and her confinement. With her belongings packed away we hurriedly fled from the scene into the getaway car. Driving to a nearby cafe for cake and coffee made the morning for Olga. Like the old times, the two of us indulging in the joys of life, sharing good food, good company, good times together.

Olga had just had her morning insulin and I was aware the stress of the funeral and how it would impact upon her blood glucose levels. I needed to keep her physically safe and able to cope with the physiological impact of the morning's events. For Olga we were celebrating with delicious party food, cake, cream and coffee. I had told her of the day's happenings, last evening occurrences, and again the events of the morning. Should I remind her again or stay in the moment with her celebrating a reunion of pending departures?

Whether for ease of purpose or ease of mind I remained in each moment, reacting to the here and now staying with where Olga was at. Containing the forthcoming day's upheavals, I played along, feeling the tears of guilt and deceit flood my heart. I felt the pressure and the tightness in my chest gradually intensifying a drop at a time throughout the day. I contained and sidelined my experience. The priority was Olga. Staying focused on the practicalities of Olga's care, I escorted her to the toilet and ensured her bladder and bowels were in order as well as her hydration and nutrition. Continuing to ensure Olga was prepared for attending her mother's funeral I allowed her to chatter on, acknowledging her comments, nodding and affirming her feelings and thoughts whilst gently guiding her into the car and the forthcoming journey.

On arrival at the church Olga was so pleased to see her family and friends. She was excitedly exclaiming “There’s John, hey there’s Antoinette!” I stayed calm, softly holding Olga’s hand and quietly affirming her comments. As we walked into the church the realisation of the occasion collided with Olga’s sense of the day. Tears gently ran down her face as we slowly paraded down-the-isle with her siblings, passing family and friends whose eyes lifted to Olga as we passed. I could see written on their faces the grief of the death of Olga’s mother and of the passing of Olga. Like leading the condemned to the gallows, I felt like a reluctant assassin, viewed with a mix of pity and resentment by the crowds.

As we sat together with her immediate family on the front bench, I felt in her hand her growing distress. As her brother and sister spoke, I recall Olga’s recollections of her father’s funeral where her mother refused to allow Olga to speak at the funeral service. Olga would tell me the story with so much sadness and regret. “Mom said I would be too emotional and cry. Emotion should be contained and not expressed to others.” Olga raged at the rejection of her for who she was and what she felt. I tried to put my arm around her. I was trying to show her I was here for her, I understood. I wanted to comfort her, ease her pain. She took my arm and threw it down by my side releasing my hand and firmly pushing me away.

Olga’s feelings of rejection and non-acceptance transferred to my soul. The discord and incongruity of our actions towards each other sounded a disharmonious clash. I was standing alone in a house of strangers with nowhere to run to. I couldn’t reach Olga and worse still, Olga did not want me there; she did not want to connect with me. All I could

do was observe, a silent witness to the proceedings. Redundant, helpless and superfluous to needs, what was my purpose and what was the meaning of my relationship with Olga.

Olga sobbed uncontrollably throughout and I stood silent and invisible. As the service concluded Olga walked out of the church following her siblings. She walked in single file. I followed a few yards behind. I could feel my tears flowing generously down my expressionless blank face. I made little sound, my steps were light and slow my breathing shallow and soft. As we left the darkness of the church into the light, it was as if a switch had been flicked. Olga transversed into another reality and I was left standing in the void.

Like in remote control I switched onto automatic pilot flying with Olga, ensuring safety protocol was maintained. Joining family and friends at a local venue for shared food and drink people reflected on the life of Olga's mom, sharing stories and memories. The sharp contrast in Olga's affect astounded me. I was still rocking from the grief and emotional outpouring which had taken place. Olga was light and breezy telling anyone and everyone how delighted she was to have her mother's room now her Mom was dead.

4.6.2 PART TWENTY-ONE: LIVING WITH DYING

Olga saw moving into her mother's room as a rite of succession. She asked me if her niece who is also her god-daughter could move into this room when she died. Olga said this in all seriousness. I reflected on Olga's tacit knowledge about her father and Motor Neurone disease. I wondered whether she was sensing her niece having inherited the condition and I pondered the thought Olga would die at 62 years of age like her father as she had expressed this fear as if it was a forthcoming reality. I felt overwhelmed with sadness. I

believed we would stay and live as two old ladies in our home which we had created together. This isn't what we planned for and I felt cheated by fate.

In order to try and make sense of this nonsensical situation I found myself trying to find familiar philosophies and theories to explain the unexplainable. Room eight was the number of Olga's room, the room inherited from her mother. In astrology, a subject of interest for both Olga and me, the eighth house is ruled by Scorpio. The mysterious sign which governs birth, death and sex. This room where her mother who gave birth to her, died and where Olga would live until she dies. Sex, Olga's lesbianism was the main issue challenging Olga's relationship with her mother. Olga's sexual abuse history though underpinned by a far more complex socio-political concepts broadly fell into this domain. Her sexual abuse caused Olga to experience Complex Post Traumatic Stress Disorder (CPTSD) and recent poignant research findings clearly indicate a direct correlation between Post Traumatic Stress Disorder (PTSD) and the development of Younger Onset Dementia (YOD). The eighth house is said to rule property, real estate and inheritances. The connections with Olga's situation astrologically speaking is clear here.

These astrological understandings hurtled into my mind. In microseconds these thoughts rushed around my head attempting to create order from the chaos of a multitude of intense overwhelming emotions that drown my reality. I pushed all thoughts and feelings away. I repeated to myself "Stay in the moment, stay present, be in the here and now. Don't think, don't feel, just be." I did just that and looked at the room. It had been stripped of all of the majority of her mother's personal belongings and all that remained of the previous furnishing was a small fridge and an old tiny telephone table. I could not feel her mother's presence. It was an empty room, a blank canvas for Olga to paint herself in.

Taking directions from Olga, I assisted her in decorating and creating the room, her space. Olga's photographs, paintings and memorabilia were hung and placed with precision and care around the room. Totally transformed in Olga's unique and usual eclectic style and fashion, the area became her own. There was not a square inch of empty wall. She had transformed the room into her space and she was delighted with the outcome of our labours. Her television was installed with her collection of discs of her favourite films. Her music was stacked next to her player and she proceeded to select some Dusty Springfield classics to play at full volume to signal her arrival.

Her new room was now definitely her space, but she could not comprehend why I was not staying in her space with her. Her room contained things from our home, many of our treasures as well as her personal things. For Olga we were moving into the room, so why was I leaving? I was exhausted by the day's events and felt physically and emotionally spent. Olga's sense of abandonment and desertion overwhelmed her, she cried and begged for me to stay. I lay on the bed and we both fell asleep together, both unable to contend with any more of anything. All we were both able to do was hold onto one another and drift to sleep to escape into a dream world with each other as the real world had become too hard.

When I awoke, I slipped away like a thief in the night taking myself from Olga's side leaving her to wake alone. Unable to contain her grief, I left her to face her new life. I felt numb and empty yet unable to hold onto anything in the black void left by Olga's absence. I was overwhelmed with guilt at not being big enough to hold her and support her in her despair. I felt helpless to stop this train carrying a cargo of losses hurtling down the track of her life destined to fall off the end of the line into oblivion. I was powerless to do anything

but stand watching from the platform waving and acknowledging fond farewells. With no purpose or meaning, I faded like a shadow into the dark night.

I visited next morning. Olga ran to get me, throwing her arms around me, chatting about people she had met, other residents and staff. We went out to a cafe for coffee. We walked along the local beach, had lunch and returned to the nursing home for the afternoon. It was always traumatic to leave with Olga's tears and her pleas to stay or take her home with me. If new visitors arrived, it was easier for me to go, but this seldom happened. I visited six days a week, each time I would come to leave it was the same emotional turmoil. Olga's sense of abandonment and desertion overwhelmed her, she would cry and beg for me to stay.

Each day when I had left and was not present, my phone would ring on several occasions with Olga asking "Where are you? When will I see you? Why can't you come now?". It was overwhelming. Exhausted I could not sleep and would wake in the early hours unable to stop the racing thoughts of guilt and my betrayal of the most important person in my life. I had vowed to stay with, care for and honour; I was dishonouring and not caring for her in the way I had promised and always intended.

These dominant themes of feelings of abandonment, betrayal and guilt continued to occupy my world. My own ability to adapt and change was prevailing. I consoled myself with the faith and knowledge of Olga's ability to survive. Olga would walk each day for several kilometres, never getting lost and discovering new things. She found a ten-pin-bowling alley where she taught herself ten-pin-bowling and rapidly became extremely proficient. The staff at the ten-pin bowling identified that Olga was vulnerable cognitively and

pretended to take her money whilst allowing her to go there with no charge. There were days when I went with Olga. Olga always beat me easily in the games and the staff continued to refuse any form of payment.

The main cook at the facility was Dutch and often would bake traditional Dutch cakes and biscuits and foods which Olga adored. Olga formed a friendship with her, they spoke together in their mother tongue and shared cultural exchanges. I continued to hire private carers to visit Olga and take her to the movies, shopping and cafes for lunch, morning tea and afternoon tea. Olga only had breakfast in the nursing home, she was out most days for lunch. This enabled me to focus on work and pay off accumulated debts. I worked and then visited Olga. There was no time for anything other than work and Olga.

4.6.3 PART TWENTY-TWO: A COUPLE THAT EATS TOGETHER STAYS TOGETHER

Most evenings of the week we dined together. The regular exception was on Thursdays. Her brother John established a routine that provided me with great respite and practical support. He would visit every Thursday and take Olga out to a local cafe that Olga and I had frequented for several years. The manager was a dear friend of ours and he welcomed meeting Olga's brother and 'spoilt' Olga. He would greet her warmly with European kisses and hugs. The free coffee and delicious cake which concluded the generous evening meal main course always won Olga's favour. Following the meal John would take Olga to the movies.

The art deco theatre next door to the cafe had also been frequented by Olga and I since it had opened several years earlier, just after we had arrived in Australia. These familiar

places and their associated memories added to the process of Olga establishing a deeper and extremely important connection with her brother. John connected with his sister like never before and the relationship she had longed for earlier in life now blossomed.

The now obvious vulnerability of Olga and her cognitive decline made clear her need for him. Olga freely expressed the unconditional love she held for her brother. Their relationship became more genuine, honest and free of the debris which too often remains following the traumas of life. This collision litter of life, leaves obstacles on the pathway to the desired destination. All too often this means a delayed or missed connection and relationships never eventuate or are mis-conceived. Olga's experience of dementia provided John and myself with this ironic gift.

The Dutch word 'kinse' means child-like and is associated with the progress of cognitive changes that occur in dementia. Olga became extremely kinse and had the opportunity to experience a pseudo-childhood of joy and happiness within this stage of her life that was taken from her when she was an actual child. By proxy my exposure to these phenomena allowed me the same pleasure. It helped heal my childhood wounds of rejection and non-acceptance by bathing them in the warmth of relating in innocence.

This process was an endowment bestowed upon our relationship by the adaptations and effects of degenerative brain changes. Olga was able to experience me holding and caressing her with nothing but love and care. I was able to receive in the giving. There were never sexual overtones and there was a purity that neither of us had ever experienced before in our lives. We enjoyed simple pleasures of being in the world, sharing and connecting with everyday life. We cherished eating, cuddling, walking by the beach, through gardens

and simply being with each other. These experiences were acknowledged and felt because of the changes facilitated by Olga's experience of living with frontal temporal lobe degeneration. These changes impacted upon my perception of my relationship with Olga and my focus shifted. I began to develop a different understanding of life and love.

The relationship which developed with her brother John also provided me with acknowledgement and a sense of acceptance I had longed for. I often would meet him and Olga on their return from their excursion. John and I would then conclude the evening by leaving Olga as she retired to bed and go to debrief and exchange our thoughts and feelings at the MacDonald's Cafe next door to Olga's facility. Our love and care of Olga united us and gave us greater understanding of Olga, and of each other. Reflecting and empathising on Olga's lived experience facilitated shared childhood memories and life experiences. This created a new, stronger relationship between John and I, as we were building upon new understandings of Olga and each other, set upon more rigorous foundations.

Previously I had denied the sense of rejection I experienced from John and the family when not invited along with Olga to family functions. Often they would arrange separate get togethers devised to avoid confrontation with other homophobic relatives and freinds. Olga and I attended but I felt relegated and alienated from the main stream. These feeling which lay hidden lived and breathed in my being. These painful feelings were engulfed in the safety of the cultural confines of English and Dutch stoicism. These shared understandings, the joint anger of injustices, and the hypocrisies of non-acceptance, were a glue which bound Olga and I.

The echoes of a misunderstood childhood and feelings of rejection were the unspoken truths that held us together. They informed our current experience of living and dying with dementia and they also fed the pathophysiological processes which were devastating our physical bodies. As a same sex couple living with dementia, we felt a marginalised group within a marginalised group. The degenerative changes in Olga's brain fed my anxiety and triggered the angina and Takotsubo syndrome. My breaking heart made visible the secreted fears. The physical manifestation made visible the hidden emotional pains. I was becoming aware that painful feelings cannot be denied, and in connecting with them an awareness of love was growing.

4.7 PART TWENTY-THREE: DETERMINED NOT TO LOSE THE WOMAN I LOVE

Sometimes insidiously and sometimes dramatically, changes continued to challenge our adaptability. It seemed as soon as we had adjusted to a change there was another shift. It was noted that Olga was becoming incontinent of urine at night time, not every night, but at least once per week. Late one evening Olga was observed to suddenly lose consciousness and start convulsing. Due to the degenerative changes to the brain, Olga had started to experience grand mal seizures. It was more distressing to observe than I hope it was to her experiencing these episodes. The thing that I feared was her loss of control and falling.

I recalled our last trip to Britain where I believed Olga had inexplicably tripped whilst walking along the cobble streets of my home town. I recall at the time her falling like a mighty tree that had been felled, she landed on her face and bloodied her nose and got quite a nasty gash to her forehead. At the time she appeared unconscious only for a few seconds,

but it occurred to me on reflection, Olga had a seizure. The duration of the seizures not their commencement, had now been formalised and acknowledged.

My inability to identify Olga was experiencing seizures when I was witness to these events, added to my sense of guilt and inadequacy. I am an experienced RN who has witnessed on numerous occasions such events, yet I was unable to acknowledge and or see what was in front of me. If I had identified these seizures earlier Olga could have been protected and interventions could have been established to at least lessen and possibly prevent several injuries which had occurred to Olga as a result of loss of consciousness. The continual erosion of the sense of control fuelled my feelings of anxiety and helplessness. I began to feel like a mouse in a wheel; the faster I ran the more quickly I got nowhere.

Olga's seizures began to increase in duration, intensity and frequency. Medication was prescribed with only moderate effect, and striking the balance between reducing seizures whilst not over-sedating Olga was proving to be an extremely challenging exercise. Some days I would visit Olga and she was in a stuporous state related to the effects of her medication. I found it so distressing to see her fighting this fogged mental state. Her physical appearance declined and she would often have food spilt down the front of her t-shirt and saliva was spilling from the side of her mouth. Olga so proud and elegant was unable to be herself.

I was losing the woman I loved and unable to protect her and keep her safe. She was unable to maintain her dignity and self-respect and where was I to uphold them for her? The anger I held inside at my perceived injustices and cruelty of the world was turning into a silent rage. I felt unable to voice or at times identify the implosion of intense sorrow I was

experiencing at witnessing Olga's gradual demise and fall from grace. I wanted to catch her, rescue her from this suffering. I felt powerless and futile.

Early one morning I received a phone call from the nursing home. Olga had been found on the bathroom floor following a grand mal seizure. She had banged her head and although initially there was no alteration in her neurological status some inconsistencies had developed. An ambulance had been arranged to transfer her to the accident and emergency department of the local public hospital. I arrived at the nursing home and escorted Olga in the ambulance to the accident and emergency department. Assessments were made and investigations were carried out. Olga had developed a slow bleed below the linings of her brain, a sub-dural haematoma.

Whilst I was sitting next to Olga holding her hand it became apparent, she had begun to lose consciousness. There was a flurry of activity within the nursing and medical staff. Olga was to be transferred to a surgical, neurological unit at a major city hospital and then very quickly taken to theatre. I sat in this whirlpool of activity and felt like a rabbit caught in the headlights of a fast approaching car. Motionless I watched the advancing vehicles and secretly hoped I maybe run over.

I was waiting on the ward for Olga's return from theatre. A section of her skull had been removed to drain the blood (haematoma) which was causing pressure on Olga's already fragile brain. The medical staff advised me that due to the fact that she had dementia they had not put metal plate in place to protect the exposed section of her brain. They had a plastic surgical drain in-place in her head, draining the wound site, a urinary catheter was inset to prevent urinary incontinence and an intravenous infusion was inserted in her arm

so that medications could be administered intravenously and her hydration maintained. Wearing a white gown and clutching (Leo) her soft toy lion, she looked like a giant baby in her bed and was sleeping soundly.

Despite being told frequently to go home by nurses, doctors and other hospital staff I remained with Olga, holding her hand and softly telling her she was safe and back from the operating theatre. I was asked by the nurses who was the next of kin. I explained I was.

They told me they wanted to contact her brother John as he was Olga's family. They did not acknowledge that as Olga's life partner I was in any way significant. I explained I held power of attorney and legally could advocate for her. They phoned John. I felt no energy to oppose their will. I just sat with Olga gently stroking her hand and speaking softly to her. I sat in an invisible bubble with Olga. I heard and saw nothing outside that space at that time. As long as I was with Olga, I thought we were safe.

4.7.1 PART TWENTY-FOUR: KEEPING US BOTH SAFE IN ENEMY TERRITORY

Olga and I were extremely unsafe. I constructed an invisible bubble around Olga and myself. It provided us with an illusion of safety. Paradoxically the advantage of not being seen was outweighed by the disadvantage of the nursing and medical staff's inability to see us. This made the invisible bubble a totally ineffective defense. Although not always verbalised by carers the attitude of hostility towards me and our relationship was palpable. The tone and manner of the voices used to pass on instructions or information was always flat and when possible monosyllabic in nature. It was accompanied by the absence of eye contact and voiced from a distance that avoided the need to shout by a whisper, thus allowing for the idea one had misinterpreted or misunderstood their meaning. The lack of

eye contact, the sideward glances and other gestures and postures made it obvious our presence was not wanted.

I felt terrified. How on earth could I protect Olga and ensure she was cared for with respect and dignity when I was unable to negotiate and receive appropriate treatment for her. Prior to Olga returning to the ward from surgery I informed the staff about Olga's childhood experiences of vulnerability. I expressed to them this made it especially important she was to be cared for by female nurses only as she becomes distressed sometimes by men and regresses into a fearful childhood state. Her inability to contain and process information related to the frontotemporal lobe degeneration of her brain also contributed to her difficulty. Olga became fearful and relived her past childhood experiences. This response may be triggered when faced with male nurses.

Male nurses also maybe unsafe to care for Olga as she may become sexually inappropriate due to her regressed behaviour and altered perception. Confidentially I disclosed Olga's experiences and her relevant childhood history and her vulnerability to the nursing and medical staff in the hope it would translate into personalised appropriate nursing care. I ensured the information I provided was documented in her notes to ensure consistency and clarity. Instead an attitude that this request was related to our lesbianism and our dislike of men was voiced and expressed.

The unit manager informed me there was insufficient female staff to guarantee that Olga was always cared for by females. She would endeavour to try and meet this request, but felt it was not a very important consideration especially within an acute surgical setting. I seemed unable to make myself heard. A standardised 'clinical check list' approach was

adopted to Olga's care and treatment. Any deviation from this was seen as favouritism. From my professional stance I was horrified at the attitudes and lack of appropriate nursing ethics applied to Olga's care.

From the first evening I was ordered to leave Olga's bedside at ten o'clock. No matter how hard I tried to reason I was not permitted to stay past that hour and not allowed to return until nine o'clock the next morning. I felt angry that I was being prevented from caring for Olga, helpless to protect her and keep her safe. As Olga regained consciousness from the post-operative experience her anxiety increased. She was trying desperately to regain her independence and communicate with staff. Conflict occurred between myself and nursing staff when they came to administer Olanzapine. Their inability to contain Olga's anxiety using interpersonal skills was questioned by me and I was told this is a surgical ward not a psychiatric unit. I felt disrespected and discredited by my nursing family and frustrated having to take such a position.

Olanzapine is a major anti-psychotic used for people experiencing psychosis. I explained to the nursing staff this medication was contra-indicated in people with Type One Diabetes as it caused hyperglycaemia and in the literature it specially stated not to use Olanzapine in people with dementia as it increased confusion. As Olga not only had dementia but acute brain trauma it seemed not a good idea to administer it. As I was present from nine in the morning until ten at night, I thought I could keep Olga safe. On a couple of occasions, they had attempted to give Olga this medication and when I queried what the tablets were and identified that Olanzapine was present they did not administer it on my request.

I found these continual confrontations, questioning of my relationship to Olga and continual challenges exhausting. For me to maintain my position and be continually pushed to reconsider and change stance angered me. I tried to contain my anger as I believed if I didn't it could be used to their advantage. I could be removed from the ward and deemed unfit to advocate for Olga. I just wanted to take Olga home and care for her myself. I couldn't and felt I had let her down and betrayed her trust in me. I was determined to stay firm and try and ensure Olga got the best care for her. I felt compromised but was resolute in not leaving her totally alone.

Olga was recovering quite well. It was the third day post operatively. She still had the wound drain in situ in her head however the urinary catheter had been removed and the intravenous infusion discontinued. Despite my efforts to keep Olga calm her agitation increased. I realised that she was unaware that she needed to have her bowels opened. I explained this to staff and escorted Olga to the toilet where eventually she had her bowels opened. I returned her to her bed where she was settled and dropped off to sleep.

I had learnt to take advantage of these situations and took myself off for a cup of coffee and some late lunch in the hospital cafeteria. When I returned Olga was in bed and cot sides had been fixed on either side of her bed. She was shackled to the cot sides with bands around both wrists and fastened to the rails. I looked at her medication chart and saw that she had been administered Olanzapine. I asked to speak to the unit manager who asserted that this was an acute neurosurgical ward and this was the only way that Olga's disruptive behaviour could be managed. I felt I had been ambushed and Olga and I were unwilling participants in a power game.

The unit managers tone of voice and smug facial expression reflected her assertion of control. I was helpless to stop what she had done, I became more motivated than ever to stay with Olga and keep her safe.

4.7.2 PART TWENTY-FIVE: CRUEL WERE THE FOE

Despite my explanations as to why Olga was becoming agitated and that this behaviour had changed before I had left the ward, the unit manager insisted that their actions were appropriate and I was over-involved, irrational and over-emotive. Dismissed as a ‘difficult friend’ the unit manager said she had contacted Olga’s brother, the next of kin, to inform him of their actions as I was not present. John had informed her he would come in straight away and should be there within the hour.

I had great difficulty containing my rage. I felt guilty in that I had indirectly contributed to the mistreatment Olga had received. I was not present when needed. I had not protected her from the nursing team who I knew provided care to meet their needs, not to promote Olga’s health or healing. I could feel my heart racing and rapid breathing. I said to myself stay calm Olga will feel your distress. Stay calm. I felt my body calm and I sat by Olga’s bed, held her shackled hand comforting her and ensured the staff released and reapplied the restraints after fifteen minutes.

I am not sure how long had passed when Olga began to emerge from a deep sleep. As her sedation lessened her agitation and frustration increased. No matter how hard I tried I could not contain her anxiety and distress and she started thrashing around the bed trying to escape her prison bed. Olga’s legs were now restrained as well as her arms and a belt tied

around her waist. My protests fell on deaf ears, I tried to explain that restraining her was causing her more distress. I begged the staff please review Olga's file.

I felt sure if they knew Olga's childhood history, which was clearly documented in the files, they could perhaps understand why their interventions were causing escalation of Olga's distress and mine. Olga has Fronto-Temporal Lobe Degeneration this was not 'behavioural' she is frightened and frustrated. My pleas fell on deaf ears and Olga's terror increased further. I felt I was living in a horror movie. I was awake in a terrifying nightmare. Four male security guards arrived and begun to physically restrain Olga. Olga started screaming and crying, yelling at me "Mommy, why aren't you stopping these men raping me, please stop them Mommy!".

I had never felt such rage. My heart was pounding as I stood helpless and mortified. Olga's screams increased in intensity, as did my rage as it exploded sending my heart into overdrive. I stood transfixed as if in slow motion, tears streamed down my face. I suddenly felt a hand on my shoulder, my body jolted as if receiving an electric shock and I landed back into real time. It was John, he quietly said to me "it is okay I will take care of this". I heard him keep repeating this phrase over and over as I drifted back to another reality, time and space. It sounded like the needle on an old gramophone player had got stuck and the sound distant and distorted kept on going, the words becoming more and more incoherent. "Patricia go home and I will look after Olga".

John must have repeated this on several occasions. Time seemed to be suspended. I recall him gently leading me away and sitting me down in the corridor just outside the ward, firmly, but kindly, he told me everything would be alright, he would care for Olga. He told

me to go home. I am not sure how I got home, it felt like I was running on automatic pilot. As if guided by remote control I found myself back at my apartment. I stood outside my front door on the balcony. I recall my legs giving way as I fell to my knees sobbing uncontrollably.

My chest burnt and ached as I lay on the cold hard tiles. I was pleased at their harshness and how they pained my heavy bruised body. The iciness of the floor was the correct ensemble to accompany the occasion and like a pile of waste I lay dumped outside the door. I must have fallen asleep as I awoke some hours later cold and hungry. I let myself in, went upstairs, showered and changed my clothes. I went down stairs, went to the nearest cafe, hurriedly ate a meal and returned to the hospital.

I found Olga heavily sedated in bed, but with no cot sides, no restraints and no one there. I resumed my vigil. I sat in silence, talked to no one, no one spoke to me. I sat holding Olga's hand until she woke. On seeing me she burst into tears. I lay on the bed beside her, held her in my arms. I remained there for the next few hours oblivious to what was happening around me and not caring.

The devastation that I experienced that day I had never felt the like before and hope to never feel so again. Empty, powerless, insignificant and void of any will to live or be, I envisaged that day as a living hell. The memory of the feelings of that time were archived. They sat in a dark desolate corner until I felt able to slowly shine some light and warmth into the darkest of voids. As the heat melted the pain of recollection little by little, I was able to recall events. Collecting piece by piece.

4.7.3 PART TWENTY-SIX: WINNING THE BATTLE IF NOT THE WAR

Olga remained on the acute ward for a further four days before she was transferred to a rehabilitation hospital. My recollection of those days are of me sitting anchored to Olga's side. Interacting with people only when initiated by them, the exchange of words in response was always polite, courteous albeit minimal. I was vigilant and connected only to Olga, engaging only in things impacting upon her. There were no visible signs of the obvious sense of relief growing secretly below the surface as each day passed.

The crisis was over and Olga had won another battle with death and we were still together. The transfer to a rehabilitation facility did not provide the escape from the ignorance and prejudice and the medically focused system as we had hoped. As we had private health insurance, we were happy to pay into the public service for Olga's stay in the rehabilitation hospital. This act carried out with the socio-political belief system held by Olga and myself backfired and was viewed by the Charge Nurse of the unit as a payment made for privileged attention and care. She stated on several occasions during the rehabilitation stay there was "No special treatment just because you paid private". Socio-politically and culturally I couldn't have been more misunderstood. Personally, Olga and I felt unacknowledged, uncared for and unsafe.

Olga was placed in a four-bed dormitory. The woman opposite Olga's bed received frequent visits from a catholic priest who would perform mass and pray with her on a daily basis. Given Olga's unfavorable childhood within the Catholic education system and the detrimental relationship imposed by a priest with Olga from the age of six years until she left Australia at the age of twenty-eight years, the presence of a priest and accompanying rituals caused Olga great distress. I explained this situation to the unit manager. This history

was extensively documented by numerous health professionals in Olga's nursing and medical notes. There was also a very confused gentleman in the four-bed room next to hers who would wander into Olga's bed space and get into her bed. This further contributed to Olga's anxiety and inhibited her recovery.

In an attempt to facilitate Olga's rehabilitation, I approached the Unit Manager and requested a single room. I provided a detailed rationale for my request. The unit manager was quite indignant and her attitude bordered on hostile. "Just because you have paid privately it does not mean that Olga has priority for a single room". I again attempted to explain that it was based on Olga's needs and was in no way linked to any financial consideration. My explanation was not accepted by the Unit Manager and Olga remained in the dormitory throughout her stay, even when a single room was left empty.

I struggled with my continual inability to negotiate and advocate for Olga. The energy I held previously to fight against the system which wrongly discriminated against us was depleted and my self-esteem was plummeting. Helplessness and victimhood replaced the capable and competent self-image I previously held. My ability to contain my own stress when my reservoir was full with Olga's tears was straining the dam wall and I feared the cracks appearing would lead to the waters breaking. More gender politics and patriarchal hegemony poured into the flood of ignorance.

Despite informing the staff on several occasions and ensuring the information was documented and contained in Olga's nursing care plan that due to Olga's life experiences it was preferable that no male nurses were engaged in assisting her with her personal hygiene, male nurses continued to assist in her personal physical care. A competition came

into play between the male nurses as to who could ‘successfully’ shower and dress Olga. When I arrived on the ward, they would greet me to tell me how upset or not upset Olga was when they had assisted her in showering and dressing. Olga was receiving inappropriate care and I felt powerless to do anything. Was I an unwilling accomplice in all of this or a fellow victim? Either way the anger as if by osmosis, vicariously seeped into my veins.

If she hadn’t lashed out at them, they would brag to me about the fact expecting some acknowledgement from me as to how good they were as nurses. I pointed out this may be because Olga felt powerless and unable to object. This was dismissed immediately and their defensiveness was clear. I overheard comments between male nurses around the “men hating lesbians” and “demented dykes” and on a couple of occasions they saw me and continued with the homophobic misogynist comments. I felt so frustrated and worn down. Despite continual explanations as to why this was inappropriate things remained the same throughout Olga’s stay and I did nothing.

The energy I had I focused on connecting with Olga. One of the wonderful things about Olga’s time at the rehabilitation unit was the walks we would take together in the beautiful park lands that surrounded this hospital. Following lunch each day Olga and I would take a walk through the gardens and parklands and nature reserves which surrounded the hospital. Walking hand in hand, Olga became her old self. She would comment on the beauty of the sky, trees and flowers and the birds and feel so light and happy. We were as connected as ever. I was at peace, calm and so content just to be together.

There were no signs of a degenerative brain disorder and the anxieties and traumas of the world melted with each step we took along the pathway. We would walk for at least two hours hand in hand, heart in heart. I felt the connection between us more deeply than ever, like day and night, sunshine and moonlight. No longer caged within the public eye and free together alone. These daily walks, shared evening meals and special times together consolidated our relationship journey. Despite all of these superficial physical and environmental changes Olga and I were closer than ever.

There was no sexual intimacy, we did not share our bed at night together anymore, outward expressions of affection were contained within our entwined hands and the gentle kisses on each other's cheek, yet the power of love existed within each breath we took together. Olga adapted to the further brain damage and subsequent losses to her ability to communicate. She accommodated the frustration generated by her loss of ability to express her feelings and interpret the words of others with humour and good grace. As well as the difficulties with spoken language Olga began to misinterpret the function of different objects. I continually modified my behaviour developing and adopting new strategies to accommodate Olga's changes.

An example of Olga's misinterpretation of objects was when out at a cafe she would try to cut up the serviette and eat it as if it were a piece of food. I tried very hard to intervene without causing her embarrassment and to try and maintain her integrity so I would say 'Try this darling' and place a piece of cheese on her plate next to the serviette. There would be a pause and then a wry smile would creep onto Olga's face, she would pick up the piece of cheese and dab her mouth with it as if it were the serviette. We would both laugh and continue this playful facade defusing the grief and loss with humour and play. The

foundational mutual tacit awareness we both understood provided the firm foundation of love to secure and hold us together. I felt the meaning of our relationship and was clear about my purpose, I was the mutable one in this watery union.

Amidst all the frustration of the rehabilitation hospital there was the joy each day of spending one to one time with Olga and the creation of new ways of staying connected and loving each other. The long walks together holding hands and just being, the gentle caressing of each other's hands, the stillness in lying together and our bodies just melding as we focused on touch, not knowing where each other's body started and the other's ended. Her ability to adapt and heal astounded me. Within a few weeks we returned to the nursing home and initially life resumed much as it was before. I felt safe and connected more than ever with Olga. Our loving relationship endured and disquiet was still for the moment.

4.8 PART TWENTY-SEVEN: THE SETTING SUN

When Olga settled back into the nursing home and I resumed the old routine, her distress at my leaving her each visit returned. I was still visiting six days a week and was working full time and trying to study. I was not sleeping well and I was eating erratically. I was walking my two pet dogs each morning at around 5 o'clock and again before I went to bed when I got home from seeing Olga. I hired a dog walker to walk my dogs mid-day for an hour as I was feeling guilty at giving them less attention and I thought they were being neglected.

Oblivious to the impact this chaotic behaviour and activity was having upon me I berated myself continuously for not performing well and not meeting my responsibilities adequately. My General Practitioner Kay advised me to reduce the visits to Olga. Initially

I refused and then dropped my visits down to five days a week. I was greeted one afternoon when I arrived to see Olga running towards me and grabbing my hand frantically. She was almost incoherent, but I was able to decipher from her salad of words that she had been out and purchased a compact disc (CD). There was a song on it that she desperately wanted me to hear. She led me by the hand to her room saying, “this song is me and how I feel”. She sat me on the bed in her room and with tears running down her face she put the CD into her player and pushed the start button...

“Ain’t no sunshine when she’s gone

It's not warm when she's away

Ain't no sunshine when she's gone

And she's always gone too long

Anytime she goes away

Wonder this time where she's gone

Wonder if she's gone to stay

Ain't no sunshine when she's gone

And this house just ain't no home

Anytime she goes away”

Olga had found the words to express her feelings and I was lost for words on how to respond. In a number of the sketches I drew when I was in crisis earlier in our relationship, there was a sun shining on the right-hand side of the page. In the gloomiest and darkest of the depictions, though small there was this shining light in the corner of the page. Ever present, giving hope, guiding and showing the way forward on my life journey. As I

reflected and processed experiences I became aware that the sun was symbolically Olga. From then on, I use to refer to Olga as the sun in my life. The sun was now setting and there was little I could do about it. I could see the darkness approaching and I always feared the dark.

In search of finding some light I made contact with a friend and colleague, Heather, who was an expert in caring for people with dementia. Her specific area of specialty was movement. She utilised dance and movement in optimising the building of relationships with people experiencing degenerative changes to the brain. Heather was a tiny, nimble Scottish woman, with a warm melodic voice and gentle sensitive touch. I had received numerous complaints from staff about Olga's 'aggressive and uncooperative behaviour'. I had observed a number of interactions with staff where their focus was primarily on the performance of a task and Olga was treated and cared for as an inanimate object.

I felt helpless to protect Olga. I had numerous discussions with the Director of Nursing (DON) and the Registered Nurses (RN's), but the Personal Care Attendants (PCA's) behaviour continued. I could predict by looking at the staff on duty how Olga's care would be carried out. I was frustrated and fearful. Having a functioning brain allowed me to contain my rage only for the heat and energy generated to be relaid through my body systems, somatised and out of view. I didn't want to make things worse for Olga by staff disliking me more than some already did.

I perceived Olga's frustration and her fear. Her many losses were not being acknowledged and no changes were being made by the able people interacting with her. My intuitive suspicions were totally supported by the assessment made by Heather. She had been able

to assist Olga showering, dressing and living the day with no ‘aggressive and uncooperative behaviour’. Heather had noticed the issues with language and the misinterpretation of the function and use of various objects and tools. Heather had used a therapeutic approach and been guided by Olga’s needs and merely gently redirected when appropriate.

She produced a comprehensive report with guidelines for staff and the facility to follow to assist Olga. I presented this to the facility manager who ensured it was incorporated within Olga’s care notes and discussed fully in staff and multi-disciplinary team meetings. This proved to be of great help at this time in improving the quality and nature of the care Olga was receiving. It provided me with a sense of meaning. I had initiated the interventions and improved the quality of life for the person I loved. I was unable to stop the continual pathophysiological changes constantly overwhelming and threatening Olga’s integrity. I had the greater capacity to continue to adapt to these changes.

My actions were motivated by the need to stay connected to Olga, to cherish our being together. I knew our time together was limited by Olga’s dementia. Her physical resources were now extremely depleted and her body unable to endure the ravishes of the disease process. I needed to use this time together to enable us to share in our love for one another. The clock was ticking and would soon stop, ending our life together. Every minute now counted, every second was precious. I felt compelled to utilise every possible way to maintain our relationship, to stay connected with Olga. I spent as much time as possible with her. I utilised every sense I could to relate to Olga. Eating together our favourite foods, touching hands and faces, surrounding her with sweet smelling flowers and talking about them, singing songs from our past. Every sense, every potential doorway was entered to connect with Olga. All the time assessing and adapting to her mutable needs.

Olga loved to dance and the activities team utilised Olga's love of dance and Heather's guidelines in ensuring Olga was able to express and enjoy herself on several occasions during the week when they had arranged either concerts and dance events at the facility. I would be invited to these and it was a wonderful and meaningful way to connect with Olga. We would twirl around dancing together with me singing to her in her ear. I was hoping my voice, the music if not the lyrics would reach Olga and cradle her soul. Sadly, over the next eighteen months further degenerative changes made Heather's assessment redundant and dated. Olga was losing the ability to walk and coordinate her movement.

4.8.1 PART TWENTY-EIGHT: A SLOW WALTZ

Getting Olga out of the chair to dance became increasingly difficult. It became noticeable on our trips to cafes and restaurants transferring Olga from her reclining chair to standing and walking to my car was taking longer and longer. In cafes a new problem had emerged. For no apparent reason Olga was unable to stand sometimes. It would on occasions take up to two hours to get Olga to stand and walk back to the car. The frequency of the times when I could not get Olga out of the car when returning to the nursing home increased.

It would often take up to an hour to get Olga out of the facility to the car and back into the facility on return. I required the assistance of at least one staff member and this over time increased to two. This issue was compounded by Olga losing the ability to control her bladder and bowels. The delay in assisting Olga in moving meant she became incontinent. This caused her a great deal of distress. As her language losses were now at the point that she was unable to be coherent when anxiety was added to the advancing pathophysiological degenerative changes, Olga's frustration was vented by screams, flailing arms and hitting out at the world.

I remembered from my childhood what it was like to have no voice and be distressed, hungry, cold and in pain. I struggled to stay connected with the world. Even with a voice I felt I was a silent witness to Olga's pain and I wanted to escape, escape with Olga, but there was nowhere to go. Things were deteriorating and I felt powerless. I wanted to take on her pain and relieve her from her suffering. I could do nothing.

I started receiving frequent calls from the facility that Olga was incontinent of faeces and urine. She was walking and stumbling around the unit in this undignified state. Olga was noticeably embarrassed but unable to take any direction or allow any assistance in helping her. I would rapidly go to the facility and assist Olga in showering and changing her clothes. It became more and more difficult for me to communicate with and assist Olga. I had a number of skills and strategies that I had learnt in my nursing life. This was very different. Distressed and disinhibited Olga would shout abusive comments at me.

I had to contain her anxiety as well as my own. Olga had no capacity to hold this degree of pain and was clinging on to maintain her integrity. I needed to hold it all in, push my body to the limits in order to protect us both, protect our relationship. I couldn't face being abandoned by Olga but her ship was sinking so I needed to keep us afloat. I wasn't going to abandon ship though water was spurting through the bottom of my boat. I just kept plugging the holes with whatever I could find; bits of food, a handful of touch, a blanket of looks to mop up her tears. I had to save Olga to save myself.

Often deeply personal and sensitive in their nature I struggled to contain the content of the abuse which flew from Olga's lips. Out of control her slaps and punches hit my pride and whilst the bruises and redness from the contact faded, the pain of rejection lingered and

reminded me of childhood hurts. Despite my knowledge and understanding of Olga's inability to discern or control these impulses, it was becoming very difficult for me to remain detached when my aim was trying to connect. There were several occasions where the situation escalated and I was in fear of losing control.

One particular event epitomised my despair and inability to provide the care I so much wanted to provide for the person I loved. It was a usual situation of a call out from the facility where Olga had been incontinent of faeces and walking around the unit. As usual Olga came with me to her room and whilst she was distracted with various displacement activities, I prepared the shower and clothes readying myself to assist her in having a shower. At this stage I needed to totally undress also and take the shower with her in order for her to understand what was happening and to feel safe.

At first things went as usual and I found myself naked in the shower with Olga. She was fully dressed which was becoming more common place, but it was no problem removing her wet clothes, once the water and my naked body prompted her and informed her that she was in the shower. Today was different, the prompts didn't work and she lost control. She proceeded to physically lash out and scream. She removed faeces from her underclothes and threw it at me informing me that I was "shit, good for nothing".

I could not contain the distress her words and actions were causing me. I reverted back to my childhood and saw my mother, not Olga. I found myself curled in the corner of the shower crying uncontrollably whilst Olga continued to hurl faeces and words towards me. I am not sure how long I was in the shower, probably well over an hour before I was able

to focus and regain composure. The memory of what followed is a blur. I know eventually we both emerged from her room as if nothing had happened.

I was unable to discuss or share this experience with anyone as I felt I had totally let Olga down and been less of a person than the situation had called for. I had disconnected from Olga only to attempt to connect with an abusive mother and connect with the hurt child who was self. I felt an inadequate partner for a beautiful woman and an unwanted obstructive daughter for a distraught damaged mother. The anxiety of this experience and the many others that preceded and followed this, the most memorable traumatic event described, were internalised. They were archived in order for me to continue to function.

These traumas were not lost nor did they stay totally hidden. They re-appeared in the darkness of night. Creeping into my unconscious, causing sleepless nights and nightmare riddled power naps. These dreaming's were the fragile holders of personal fears and conflicts which imprisoned my soul and being. I needed to go one day at a time in an attempt to make each day better than the previous day for Olga. I knew our time together was fast approaching catastrophic changes and the tides were rapidly changing.

As time advances one grain of sand upon one grain of sand through an hourglass, Olga's ability to stay connected with the world and with me was falling away. With her total loss of language and her ability to walk, Olga's freedom and ability to express her needs and desires ceased. Olga was fading into the shadows of time. I was silently screaming as I ran on the spot, keeping time with the changes and hearing the sound of fate falling on my deaf ears.

4.8.2 PART TWENTY-NINE: BROTHERLY LOVE

Olga's brother John also bore witness to all of these changes in Olga. He was my one constant support and friend. One Thursday coincidentally following John and Olga's weekly excursion for dinner and the movies, I met up with them on their return to the nursing home. Upon settling Olga back and saying our farewells to her, John and I decided to go for coffee at the 'McDonalds' next door to the nursing home. John and I discussed our thoughts and feelings concerning Olga. We talked about the changes we had observed in Olga and how these changes had impacted upon Olga and our relationship with her.

Over the time Olga was living with dementia John gained a greater understanding of my partnership with her. He gained an appreciation of the love Olga and I had for each other. I gained a greater understanding of his brotherly love and the connection he had with Olga. Talking and spending time with John also gave me a greater insight into the family relationships and cultural complexities associated with a migrant family childhood originating in the Netherlands. There was a wonderful connection between John and I that had steadily grown with our mutual love for Olga. From the time of their mother's death and Olga's admission into the facility the rapport between John and I intensified further.

John and I explored how we felt and thought Olga's death would impact upon us and our family and friends. Acknowledging how our discussions were enjoyable and helpful John asked me if I would consider continuing to meet on a regular basis when Olga had passed. He felt we had an understanding of each other and shared in our loss of connection with Olga. I affirmed these comments. I believed we had already grown closer together. I echoed the sentiments expressed. I felt continuing our friendship would be mutually beneficial especially when we both faced Olga's death.

The idea of meeting with John on a regular basis when Olga had passed would be a great way to be reminded of her and share with someone who loved her. John looked like a male version of Olga, his personality, humour and general persona reminded me so much of her. It was a warm, lengthy conversation, so open and honest and the genuine regard for each other was apparent. I had no idea this would be the last conversation and the last time I would see John. As our conversation was drawing to an end John mentioned that he was going into hospital for a small surgical procedure but hoped to be fine to see Olga the following week.

Wishing him well I asked John to let me know how things went. We gave each other a hug and a peck on each cheek, the traditional Dutch European farewell. John went into hospital where the investigations discovered he had a huge malignant tumour in his liver which had grown around the hepatic artery and blood vessels. He received surgery and chemotherapy. Radiotherapy and further interventions did little. John rapidly became weak and was unable to visit Olga again. The final conversation with me was John's final contact with Olga. John died 12 December 2013.

John's death had a huge impact upon Olga and me. I had lost the most significant person who shared in and supported my relationship with Olga. He was a link, a constant reminder of the woman Olga had been, her history and her culture. A reliable, practical and constant support whose value I did not truly appreciate until he was no longer there. A gentle loving brother to Olga, we had become each other's confidante sharing our most personal thoughts and feelings with each other. His death was a prelude to the aloneness and sense of grief I would soon experience with Olga's death.

His funeral was to be held at his local parish where he was a much-loved teacher and member of the local community. I was determined to ensure Olga was able to farewell her much loved brother. I hired a special vehicle which would accommodate Olga's personalised wheelchair which I had organised be built for her. Her six foot two and a half inch stature didn't fit conventional wheelchairs and her wheelchair didn't fit conventional vehicles. I had told Olga at the time John was ill. I would give her updates each time I visited her. It was difficult to assess how much she understood. I operated from the stand point that she comprehended everything.

Sitting, holding her hand, talking softly and quietly I explained to Olga why John wasn't visiting any more on a Thursday. I softly told her John had died. A single tear rolled down Olga's face. There was no expression upon her face as the tear fell. At the time I wasn't sure whether the tear was a coincidental falling or an acknowledgement of her grief. All doubt was erased from my mind on the day of John's funeral. I had gone to the nursing home to help Olga get ready for the funeral.

I ensured Olga received analgesia prior to leaving to lessen the severe joint and bone pain she was now experiencing. I collected another dose of analgesia to give Olga for our return journey. Olga was silent during our forty-five minute drive to the family church. We arrived at the church and as I wheeled her in, she begun to quietly sob. We took our position in the front row next to family and I remained by her side holding her hand. As the service begun, uncontrollably Olga began to rock in her wheelchair. Lurching backwards and forwards, Olga let out a heartfelt cry of despair.

The sound of the wheelchair creaking and groaning seemed to fill the church, Olga was inconsolable. Her gut wrenching wailing was only punctuated by the rhythm of the wheelchair's strain. Again, I sat as a silent witness to Olga's pain. My sense of powerlessness and inadequacy left me static, feeling impotent and numb. As the service concluded I felt a relief at being able to flee and I swiftly wheeled Olga out of the church. Immediately on breathing the fresh sweet air outside the church Olga fell silent. I was looking for a quick escape as I felt unable to contain the grief and raw pain much more.

In the crowds of mourners outside the church a figure rushed towards us. It was a dear friend of Olga's from her childhood. Also, a Dutch immigrant, this man grew up with Olga,. A neighbor whose family was a part of the local Dutch community, who attended the same primary school and Catholic church youth group, who was connected with Olga throughout her life in Australia. His experience of the Catholic education system and his relationship with the priest was very similar to Olgas. He approached Olga and put his arms around her. They both embraced each other and began crying uncontrollably. No words were needed for what was happening between them. The crowd surrounding us fell silent as we all watched on with a sense of sorrow and despair. United in grief and trying to embrace the two lost children the crowd held firm. My hurt child wept silently in harmony at the discord of the unheard songs of tormented children muffled in the veil of time.

The return journey with Olga seemed to last forever, the analgesia that I had given to her prior to us leaving was no longer effective. I had given her additional pain killers prior to us leaving the funeral, but this seemed to be absolutely ineffective. Constant grimacing accompanied by physical contortions and sorrowful groaning emanated from Olga. Each bump on the road, sudden jolt of the vehicle was accompanied by a yelp from Olga. The

longest of days concluded. I assisted Olga in going to bed knowing this was the end of many things.

4.8.3 PART THIRTY: HAND IN HAND

It seemed as if the funeral of John was a landmark. It was a point in time where recollections and reflections highlighted significant events and changes. Being mindful of these increased my awareness of current changes and transitions. It seemed to me things were shifting. I felt a sense that I was entering into a new set of circumstances bringing profound and inevitable ends and new beginnings. The season was changing.

Sometimes if I put my face close to Olga, I would see a flicker of recognition in her eyes. In the main her affect remained flat and mask-like. My health was continuing to deteriorate. My diabetes mellitus was out of control, my blood glucose levels were elevated and I was getting minor infection after minor infection. My cardiac health was also poor and I was getting angina attacks quite regularly and not responding to them appropriately. Again, supported by my GP Kay I reduced my visits to four days a week. This increased my guilt two-fold and was counterproductive in that blood glucose levels, and angina frequency increased.

There was no John for me to talk to any more and I felt more and more isolated, detached and alone. When I visited Olga, my time was spent helping her eat favourite foods and drink her favourite beverages. I would talk to her, sharing my thoughts and feelings with her. Talking about our life together, travels and adventures we had shared. Time seemed to evaporate with the sharing of memories. I would sit holding her hand and would feel her

energy as she softly squeezed and stroked my hand. She would touch my fingers, running her index finger along each of mine slowly and surely, gently caressing them.

I would sit with her for three or four hours, often more, feeling content and at one with Olga. Often no words were exchanged and for random observers there appeared nothing to be passing between us. Yet this could not be further from the truth. These exchanges were intense and profound in nature to me. This was the only time I felt real, the rest of my day seemed like an endless meaningless television commercial. The mind numbing, superficial brain washing filler that interrupts the enjoyment of an interesting documentary or enjoyable movie. I wanted to fast-forward the advertisements and get to the reason I was participating. I just wanted to be with Olga.

The irony of someone who loved words and language developing, Semantic Younger Onset Dementia was never far from my mind. The cruelty and sadness of this occurrence weighed heavy on my heart. To lighten this burden, I continued to converse with Olga. I was the only audible voice, but I was sure we both felt the meaning. Now profoundly deaf and with very limited sight, touch and taste were the main senses unhindered in our interactions. So, food and caresses were taken full advantage of each time I was with Olga.

Olga would sit with her mouth open beckoning for food like a baby bird waiting for her mother to deliver the nourishment. I would drop a morsel into her open mouth and she would relish each mouthful, chewing and salivating joyfully. Her eyes would sparkle with delight as she swallowed and paused to ponder the delight, recover and make ready for the next mouth opening sensation. I would sit transfixed at her enjoyment of this simple act yet complex experience.

I was profoundly aware of an unseen and intangible connection that bound us together. The energy and communication which passed between us felt more meaningful than ever yet, nebulous and indefinable. When I recall first meeting Olga, her beauty and intellect were the initial characteristics I would have identified as being the magnetic attraction between us. Olga's ravished body was now a shadow of its former glory, her intellect was caged within a diseased mind and her graceful movement grounded. The beaming smile was now limited to just a faint grin and a squeeze of the hand was the remains of our embraces.

The stillness and silence which lay between us provided fertile ground for new, more profound connections which words fail to adequately describe; There are no words. Olga's beauty and being was more vivid than ever and our connection stronger. I found it increasingly difficult to leave her at night and my four day visits a week not the previous six were a blessing because I knew once I was there, the pain of leaving was unbearable. On numerous evenings I would sit in my car outside the nursing home after assisting Olga going to bed. I would fall asleep at the steering wheel, crying uncontrollably and wondering what was the point to all of this pain and suffering.

Christmas Day 2014 proved to be the birth of a new understanding of my journey. I had arrived at the nursing home early that morning, loaded with gifts. This was a change in the way traditionally Olga and I had celebrated this day. Following the Dutch tradition, we would share our presents late on Christmas Eve. This was the first year that we hadn't done that, I am not sure why. I sat with Olga chatting talking about each gift as I opened it for her. Unresponsive, Olga lay reclined in her chair motionless with a mask-like expression on her face. There appeared no way that I could reach her. I pushed all feeling down, deep

down, so deep I was able to continue with my cheery voice and exclamations when I would unwrap gift upon gift.

Lunch arrived for us to share as we had done so for every Christmas that we had been together. Waking Olga, it felt as though I was force feeding her and her robotic chewing and swallowing of food made it difficult for me to swallow. There was no joy or delight anymore in sharing food. Olga went into a deep sleep following the meal and I felt very alone. I felt there was no connection. I tidied the area around her chair, neatly folding her new clothes and placing them with her gifts next to her. I pondered for what seemed an endless time what to do. It felt like I didn't exist, more importantly, it felt like Olga was unaware of my existence. I decided to leave feeling emotionally exhausted and numb.

I was living in rural Victoria some two hours from the nursing home and the drive home was often a replenishing time. I had purchased a four-wheel drive vehicle so I could take back roads and unsealed tracks through bush land and the rural landscape. I was only about twenty minutes from home when I pulled over and stopped the car. It was like an epiphany; Olga was not going to get better. The profound realisation that Olga was not going to come running towards me on my arrival at the nursing home one day and say "everything is alright now, I am well, please take me home", dawned on me. It was like a bolt from the blue. How could I have not realised this?

When I talked about Olga to family, friends, colleagues and clinicians I appeared to be absolutely cognisant of the situation and Olga's prognosis. I could talk the talk and walk the walk, no one including myself had any idea that I wasn't speaking in my language and I was actually running in the opposite direction. I sat in the car and questioned myself. Was

I deliberately deceiving myself? Was this denial necessary for me to continue with the everyday facade of life? When I could find no hope, did I create a fantasy to dwell and flourish in? All I knew in the moment was I felt no hope. To the outside world and all who dwell there nothing seemed to have changed. Within myself a process began where I would live just for the day. I began to exist in another world for this world held little in it for me. The little was Olga, not little in terms of the space and love which I held for her, but tiny in respect to all that engulfed me. I could not contemplate life without Olga. I felt abandoned, rejected, left adrift in a vast ocean, so I hung on to all I knew, I hung on to Olga and her love to stay afloat until she sank.

4.9 PART THIRTY ONE: SLOWING DOWN TO A STOP

Olga was sinking. Over the next few months more and more I found it difficult to reach Olga. There were some days better than others, but overall Olga was slipping away out of my grasp. I would still try to take her out in the wheelchair for walks to cafes and local parks. Transferring Olga from her recliner to her wheel chair became increasingly difficult. Despite analgesia being administered half an hour or so prior to helping her transfer it was becoming a painful experience, physically and emotionally. Often when I arrived Olga was sound asleep and when she looked so comfortable, I was loath to wake her.

So eventually the shared strolls we enjoyed so much ended and came to join other fond memories. I missed these times so much. I always felt away from the facility and out in the fresh air we had our privacy, our special times together. We were free to do as we pleased and it was just the two of us, together, like always and the way we wanted it to be.

A special effort was made on Friday 3 July 2015. It was Olga's sixty-second birthday and I wanted it to be special for her. I was vigilant in organising her care the night before to ensure she was as well rested and her pain controlled. We were going to lunch together to one of Olga's favourite restaurants. A special taxi was ordered and bookings made and every eventuality accommodated. Organised and looking forward to sharing her birthday as we had done for the last twenty-eight years. Sadly, things didn't quite work out that way.

The special cab didn't arrive on time. I contacted the taxi company who apologised profusely as they had overlooked the booking. Arriving an hour late, I had managed to reschedule the restaurant and keep some hope and motivation that it would be a good day. It was not to be. Olga wasn't hungry when the food arrived. Absolutely uninterested despite all her favourite foods and drinks being on hand, she just wanted to sleep. I checked her blood glucose levels which were fine so there was no need to eat. I couldn't eat alone and Olga was uncomfortable and needed to get back to her recliner where she was comfortable.

I phoned the taxi company and they sent the first special cab available. We had to wait an hour. We travelled back to the nursing home and Olga slept. Olga's needs had changed, she had moved to a different place. I was left at the old accommodation and no one was there anymore. I had to move and find an alternative place to live. I didn't ever envisage this situation arising. I felt empty, not just of food but of feeling. At Christmas I had realised Olga was not going to get better. On her birthday I realised Olga was getting worse.

On Friday 14 August I visited Olga in the afternoon and she was awake and able to be transferred to her wheel chair. I thought I would take advantage of the situation and go to McDonalds cafe with her for some afternoon tea. Olga enjoyed a real coffee and was fond

of the Danish pastries they served. It was a fine day so the brief outing would be pleasant. I chatted to Olga and although it had been a while since there was a verbal response, she seemed engaged and I felt she was with me.

We sat ourselves in-front of the large window which looked out to the rose bushes and garden. You could see the footpath and passersby. The sun was shining and we were alone. It seemed just like the many days before we had enjoyed together sitting in this spot. Olga would not drink her coffee, and she was disinterested in her Danish pastry. There was no response from my attempt to converse with her. I wanted to scream and shake her and say, I love you, come back to me, I miss you so much.

Instead I took a deep breath, kissed her gently on the brow and looked into those beautiful sea green-blue eyes. Her eyes were misty and distant, reminding me of how we would look out to sea on winter mornings as the boats set sail through the fog on the horizon. I could not reach her no matter how I tried. I passed the information onto staff on our return. I visited the next day. Olga had a cold and was a little congested. This accounted for her loss of appetite yesterday I thought.

I contacted Kay the GP who visited and examined Olga. It appeared she did have a cold but her chest was clear and there was no cause for concern. Again, I visited the next day, Sunday. A number of the residents had colds and Olga was one of them. It dampened any further interactions, so my stay was very brief as I believed she needed to rest and sleep. There was little point in me sitting with her as she appeared unaware of my presence. I decided not to visit the next day. I felt so tired and so sad. I felt so full of being alone I could not sit with Olga so left an empty chair with my heart sitting on it for her.

Olga has a cold and just needs to rest. I needed to rest as I felt drained and suspected I had more than likely picked up the bug that was throughout the nursing home. At five thirty on Monday 17 August 2015 I had just left a coffee shop and was heading towards my car when I received a call from the nursing home. The RN in-charge notified me that the carer who was giving Olga her pumpkin soup had accidentally poured it down into her lungs.

4.9.1 PART THIRTY-TWO: EATING ALONE

I would have usually visited on Monday. I would have been the person assisting Olga with her evening meal. I knew Olga had a cold which would have further compromised her breathing and ability to swallow. If I would have visited as usual it would have been me with the pumpkin soup on the spoon. I would have been mindful, focused on Olga's needs and taken my time. I know the personal care attendant may have been doing this however, I had been in nursing long enough to see what often happens. Care staff are often task focused and Olga would have been just another resident to feed.

I quickly shelved all of these emotions dwelling in my heart. This was not about my guilt, regret and anger, it was about Olga. I needed to be clear and found myself rapidly going into professional nurse mode. Operating from the cognitive domain, avoiding and side stepping any emotion or thought of self, without any conscious effort, I found myself in the here and now. I was dealing with the situation at hand and prioritising my attention and energy.

The RN told me the paramedics were there with Olga and wanted to talk to me. The telephone was transferred over to me and the paramedic asked what I wanted to do. He

explained Olga was having a great deal of difficulty breathing. He needed to know whether or not I wanted him to intubate. I felt extremely calm and was very clear. I had discussed this eventuality with our GP Kay and the facility manager. I had filled in the required documents at the nursing home and it was stated in Olga's notes 'Not For Resuscitation' (NFR).

I had gone into professional registered nurse mode. I responded to the paramedic and said to him it should be documented in her notes, do not resuscitate. Please keep her comfortable. I added "Is she distressed?" I asked what her oxygen saturation rate was and whether she was receiving oxygen. He said her saturation rates were improving and that Olga was receiving oxygen. The paramedic went on to say Olga was not unduly distressed at this stage and they were now heading straight for the major public hospital. I replied I will be there as soon as I can. The phone call ended.

I went into automatic pilot. I got into my car and made a one and half hour journey in forty-five minutes. I parked the car and made my way in a hurried manner to the Accident and Emergency (AE) department. On arrival I found Olga immediately. She was breathing well with oxygen. It was very difficult to assess her conscious state because of her advanced dementia. I sat next to her and held her hand. She immediately squeezed my hand and continued to do so for all of our stay in the accident and emergency department.

It wasn't too long before she was transferred to a general medical/surgical ward. She had been diagnosed with aspiration pneumonia and was placed on an intravenous infusion and was receiving intravenous antibiotics. I felt strangely calm and at ease with the situation. I was totally focused on Olga, her care and needs. I slipped effortlessly into a nursing role,

continually assessing her status, identifying her needs and carrying out the required interventions. As soon as I felt Olga was safe I would allow myself to assume a joint role and become her loving life partner with emotional needs of my own as well as nurse.

I found this dual role easy and whatever role I was in I always focused on Olga. I knew the nurse role was always the dominant position and I intentionally held it in place to keep myself emotionally safe feeling far more comfortable sitting in that position. It wasn't a conscious move and it is only on reflection that I saw what was happening. The vulnerability and fragility which lingered just below the surface when I engaged in being Olga's partner was extremely uncomfortable. So, I never fully went there.

This was the first day of what was to become what I refer to as 'the last eleven days.' I stayed with Olga continuously for the next eleven days. She remained in the general ward for the first five days and was transferred to a single room for her last six days. I had placed a chair next to her bed and was able to recline it so that I was level with the bed. We would lie together, and I would talk to her often throughout the day. I ensured I assisted her in changing her position every two hours, I would moisten her mouth with iced water.

Olga was not swallowing and was assessed daily by a clinician to establish whether the gag reflex had returned. For the first three days the consultant would stop on his ward round and converse with me. The hope was that Olga would respond to the antibiotics and recover. He asked if I wanted interventions to prolong Olga's life to be carried out. He offered the possibility of a Percutaneous Endoscopic Gastrostomy (PEG) tube being inserted to allow food to be given to Olga directly into her stomach.

I declined this immediately as I recalled Olga's expressed wishes with regards such procedures and knew she would refuse. Despite this knowledge, I felt conflicted and tormented by having to make the decision. The power to make such a life and death decision, acting on behalf of another person, taking away their autonomy even though her wishes at this point could not be expressed seemed somehow wrong. However, I had a responsibility as Olga's chosen life partner and who was better placed to advocate for Olga than me?

On day four the consultant did not stop to talk to me during the ward round. On day five the consultant walked past avoided eye contact and continued onto the next patient. I was aware of the situation and I knew he wasn't stopping because the antibiotics were not working. The usual routine is to have the patient on antibiotics for three days and if there was no improvement they were usually stopped. They continued Olga's antibiotics but discontinued interacting with me. I approached the Unit Manager's office and asked to have a meeting with the medical team.

4.9.2 PART THIRTY-THREE: FACING THE GRIM REAPER

Later in the afternoon on day five the registrar asked to talk to me privately. I noted how nervous this young man was. Fidgeting in his seat, shuffling papers, he was stumbling over words. I found myself supporting him in what was obviously a difficult situation. I explained that I was well aware that the reason the consultant hadn't stopped to talk to me was because Olga was dying, and the antibiotics were not working. He stammered and informed me we usually stop them after three days, but we kept them going for five in the hope that she might respond. She hasn't, there is nothing more we can do. I started to cry

and then stopped as abruptly as I started apologising to the young registrar and thanking him for his time.

I began to realise three things were happening, firstly there was Olga's journey and that was her journey alone. Then there was our journey, we were approaching the end of our lives together, we were coming to a fork in the road and parting ways. Thirdly, there was my journey and that was my journey alone. The talk with the registrar helped me realise that essentially these events and discussions were quite superficial. It was about following medical protocol, following the correct policies and procedures of the hospital and doing the right thing according to the system. It is easy sometimes when you receive a gift that is beautifully wrapped to mistake it for actually what is in the parcel. I wasn't really interested at this stage of my journey in the gift wrap.

Within a short space of time I was visited by the Palliative Care Nurse. A lesbian woman of similar age to myself who I felt was able to empathise with the situation. She was present and genuine who I felt 'got' the situation. We discussed moving Olga back to the nursing home, but realised she was so frail she may not make the journey. I requested a single room where Olga could remain until she passed away. This was agreed upon and Olga was moved to a single room. I made this our space, filling the room with white flowers, Olga's favourites. I played intermittently Olga's favourite music and had a couple of her favourite photographs on display. It became what I believed was our safe haven where we treasured spending every minute together knowing that time was slipping away from us.

I continually engaged with Olga, I would talk about how we met, our trip around Australia, our pets, our lives together for the last 28 years. The sad times, the happy times, I talked

about them all. Although mine was the only voice audible, when I paused during our conversations, I could hear her responses, her wise cracks, her deep voice sounding her thoughts and perceptions of events. In my mind's eye I could see her wry smile, her gestures with her hands and most of all her calm wisdom in her eyes. She was ever present, and I could sense her there. The last eleven days were a celebration of our relationship of our love together in the face of gradually disconnecting in this life and we left nothing out. As we slept together, we shared our dreams and said our goodbyes in the silent touches and spaces that have no boundaries.

During this time important members of her family and friends called in to say their farewells. Olga's sister Antionette came each day at around five thirty to allow me to walk to the canteen, get myself some food, stretch my legs and clear my head. Antionette brought me a blanket as I was cold at night. She found that I had wrapped this around Olga's legs as Olga's body was closing down and her legs were cold. She was moved by this and the following evening she returned with another blanket for me.

She had begun to take over the role of her brother John and in that short time the difficulties and misunderstandings of the past evaporated in the tears of grief. She was able, in my absence, to reconnect with her sister and reflect on their lives together and their sisterly love. I found great comfort in this as I experienced guilt and regret at seemingly contributing to a rift between the two of them. It was totally unintentional, and although I was aware that many other complex factors were at play, I was not proud of my un-insightful contribution.

Most things were resolved, and healing occurred during this time. Everybody had the opportunity to be alone with Olga and say their good byes. The few remaining conflicts and difficulties between Olga and family were their journeys and for them to travel alone without Olga's companionship. One of the most profound experiences was when Olga's niece, Carly, her first godchild, visited with Olga's new great-niece, Zoe. Five months old, prematurely born, this little girl was sitting quietly on her mother's lap at the edge of the bed whilst her mum and myself engaged in conversation.

Spontaneously at the same time we looked down at Zoe, she was playing with Olga's hand tapping and stroking her fingers. Olga was doing the same with Zoe's hand. Zoe was smiling and joyfully giggling. Carly and I looked at each other, no words exchanged, our watery eyes flooded with shared emotion, the serendipity of the occasion escaping neither of us. Passing from one generation to another, a new life at the start of her journey was briefly meeting a foremother at the end of hers.

4.9.3 PART THIRTY-FOUR: DYING IN MY ARMS

I was acutely aware that Olga's time was nearing her life's end. Kay our GP and dear friend was due to visit at nine o'clock that morning. This was an informal contact to provide support for me. Kay didn't arrive as scheduled. At twelve midday Kay arrived. Olga started to become restless. I noticed her legs had become mottled, her feet and hands feeling extremely cold. I said to Kay "Olga is dying, isn't she? This is peripheral shut-down" I was in professional nurse mode. Kay acknowledged and affirmed my observation and commented how helpful it can be to have the insight and knowledge at these times.

I talked to Kay about restlessness being a sign that Olga was experiencing some discomfort. Agreeing, Kay left the room and went to the nurses' station. She returned only a few minutes later with the RN who had the medication chart. The RN administered more pain-relief and some medication to assist Olga to relax. At twelve thirty Olga's breathing changed. Cheyne-stoking respirations had begun, deep sighing and rapid breaths punctuated by absence of breathing. I held Olga in my arms. She pushed her head against my breasts as if listening to my heartbeat. Our hands were clasped together.

I knew that this was the time of departure, our earthly relationship was coming to an end. I felt Olga had stayed around to be with me because she believed I was not ready to be alone again, so I said to Olga "it's okay Darling, you can go now. I will be alright". I thanked Olga for sharing her life with me, I quietly whispered how much I loved her and how the years we had spent together had been beautiful and joyful. I continually affirmed it was alright for her to leave. Everything would be okay, she was safe and needed time to rest and heal from this life's journey.

On Friday 28 August 2015, whilst lying in my arms, following eleven days together Olga died. I felt her leave. At one o'clock in the afternoon exactly I felt a sudden gush of energy; Olga left her body and the building. As Olga died a surge of white misty light engulfed me as it passed it moved defusing out of the window and away. All that was left was an empty shell. Olga's body like a marble sculpture lay on the white sheets of a hospital bed. Magnificent still and majestic it lay as a testament to her being. Olga was gone and I was alone.

In the past when Olga and I had talked about when we died and what would happen, we discussed it in terms of us being in our home. Traditionally within my culture when a person died ideally, they died at home and they would stay there for three days prior to them going to be buried or cremated. If they died in hospital they were returned home. We no longer had a home. Whilst beneath the surface I raged with anger and self-deprecation I needed to ensure that arrangements were as close to our wishes as possible. There was no way Olga's body was going to the mortuary and being placed in a refrigerator. This was totally against her dying wishes. I entered into discussions with the medical staff, the nursing team who were all telling me that this is what had to happen. I managed to negotiate with them that Olga would be taken to the chapel of rest at the funeral parlor. The required procedure at the hospital was that she had to pass through the hospital mortuary, so that is exactly what happened. I accompanied Olga's body down to the entrance of the mortuary from inside of the hospital.

The hearse from the funeral company was waiting at the external exit doors of the mortuary. I went out of the hospital to where Olga's body came out of the exit doors and was placed directly into the hearse and taken to the chapel of rest. I then booked an apartment which was situated between the funeral director's chapel of rest and the migrant camp where Olga had lived when she arrived in Australia. I could see both venues from the apartment. I would stay there for two weeks where I could arrange a service to celebrate Olga's life.

I contacted the funeral directors and arranged an appointment to organise the ceremony. The usual director was away and there was a replacement for the next two weeks. He was a gay gentleman and he couldn't have been more understanding and helpful. He was able to accommodate all my wishes. The usual flowers were to be removed from the reception

area and the room where the service was to take place. I filled the area with bouquets using only white flowers. One of the things that Olga and I were unable to achieve was to visit Sissinghurst, the former home of Vita Sackville-West, she had created beautiful gardens out of only white flowers. I was creating Olga's version.

The time and place of the ceremony was organised and I had chosen a celebrant. Lorraine the celebrant came to see me at the apartment. What was supposed to be an hour meeting turned into four. I told her Olga's story and we organised who would speak, in what order and the form the celebration would take. I was to make a brief video with appropriate pictures to show during the proceedings. It was a helpful experience to talk to Lorraine. The distance provided in telling the story to a stranger helped me gain a different perspective on events. Giving an overview in a chronological order allowed me to appreciate Olga's journey and how our relationship helped Olga find her desired destination in life.

Over the next few days contending with the practicalities of arrangements, notifying people, placing funeral notices, arranging the wake, receiving international guests and, of course, ensuring Olga was cared for and looked her best for the viewing. During this time, I blocked all feelings and focused on making sure I did the best I could possibly do in providing a suitable send off for Olga. I was kept extremely busy every day planning and preparing. I had one opportunity and one opportunity only to get this right. I was filled with a strong determination to ensure everything was reflective and appropriate to celebrate Olga's life.

4.10 PART THIRTY-FIVE: LIFE, DEATH AND LOVING

Prior to the start of the ceremony I had an open coffin viewing for those people who would like to come and see Olga and pay their last respects. I sat talking with Olga half an hour before the viewing commenced. It was quite a surreal experience. I didn't feel Olga's presence and I felt a little uncomfortable looking at her body which somehow resembled Olga rather than be her. From photographs I gave to the undertakers they had gone to great efforts to colour and style her hair the way Olga always had it. I provided the clothes and to all intents and purposes it should have worked.

No matter it just wasn't Olga. Somehow, she just didn't seem right, she was beautiful, but not really Olga. An awareness that Olga's life had ended, and my life had now changed forever gently crept into my being and an understanding of the significance of marking the event, the goodbye and celebration of Olga arose from the stillness. I needed to finalise and close this chapter of my life. Organising and creating Olga's ceremony provided this closure for me. It was a part of letting go and moving forward. It helped me realise I was moving from being a part of a couple to being a single person.

I sat at the head of the coffin as still as Olga but present. As I collected my thoughts and awoke from reflection, I saw the door to the chapel open and quietly and respectfully people started filing in to say their personal farewells. Friends who had travelled from New Zealand were the first to arrive. Walking towards me we embraced and kissed each other's cheeks. Leaning over the coffin they kissed Olga's forehead and spoke their words to her, acknowledging their love, their sadness and their loss. They located chairs, picked them up and placed them around the coffin and sat.

With calm wisdom and gentle energy together, we sat. I felt connected, embraced by the love and warmth of our friends and in the quiet we grieved together. Other friends and family trickled in and some cried loudly, were demonstrative in their outpouring of sadness and loss. Some left some joined the circle sitting mournfully, until there was a group united sitting around the coffin. Quite spontaneously each person in turn started telling stories of Olga's antics. Saying where they met Olga first and recounting memorable stories of knowing her. Olga would have loved the informality, of this random get together.

The sharing of stories and memories, the genuineness of the laughter and tears that occurred warmed the air and I breathed more easily. It reminded me of how in my youth, in the Potteries in England, people joined in wake of my father's sister, my special Aunty, Aunty Win. I was there with my father, called by all present 'Our Billy's Youngest' acknowledging me as my father's youngest child, a member of this family, this group. I was rightfully there, a part of things, connected, belonging safe in the arms of loved ones and able to grieve. This was Olga's wake, shallower in time, as deep in intensity.

I was sharing with friends and family the love and regard that was held for Olga. I was bathed by them in their love and regard. I felt acknowledged, respected by this gift and wonderful gesture they had bestowed upon me. I felt safe to grieve, feel and show my vulnerability. I felt safe to reveal my fragile heart which ached in the pain of losing the woman who I had loved and shared my life with for twenty-eight years. The silence and stillness which had enshrouded the group was broken by a distant voice cutting through the peace.

The funeral director had arrived to request people to leave as the proceedings needed to progress. The room emptied all but for Olga, the funeral director and I. The lid was to be placed over the coffin to seal and securely enclose Olga's body. I kissed Olga's lips and knew this tear would be the last of mine to wash over her face. My eyes would never see her again and I would never see her beauty or touch her majestic body.

4.11 PART THIRTY-SIX: CELEBRATING OLGA'S LIFE

The funeral director had arranged purple ribbons to be provided to everybody who came to the funeral, I was very touched by this gesture. I had asked everyone who attended not to wear black, but to wear women's colours, white, purple and yellow. Most people did this, so the purple ribbons looked terrific for most people's ensemble. I had selected music, Olga's favourite songs and those that were significant to be played in the reception area prior to the funeral. I had a book for people to sign and comment in to acknowledge their attendance, make their mark and pay their last respects to Olga.

I asked to speak first at the service as I wanted to be able to focus on what other people would say and because I wanted to 'keep it together'. The truth is my recollections are limited to my experience when I spoke at the end of the ceremony. I have viewed the video of the ceremony several times so recall the video scenes as if recalling a movie, not as if I was there, but as though it were a personal experience. I sat at the end of the front pew keeping a good space between a dear friend of Olga's who sat next to me.

I recall just waiting to have to get up and speak. As a lecturer and a born performer, I thought this is just another performance; entertain the crowd, give them what they need and want. I had presented at a number of conferences for nurses and carers of people living

with dementia. My presentations had been as a partner of Olga and as a health care professional and nurse. I 'self-talked' myself into the thought that this is just another one of those occasions. People who have known me for a long time are always surprised and often dispute my feedback of these experiences.

When I tell them by nature, I am shy and quite an introvert, and that following these lectures and conference presentations I am totally drained and need to be alone, quiet and sleep, they usually laugh at me and I then continue to perform for them. The duality of my character and the deeply personal side of my life, feelings and self I keep well hidden. As often adults who were hurt children do, I locked myself away in a cage of guilt and self-loathing fearing if anyone should find me, I would implode and vanish. I certainly didn't want to be seen here today as the cage door was already ajar.

I found myself talking to the audience of grieving family and friends. Trying to find the appropriate respectful balance between humour and tragedy, between light and dark, between hope and despair, between life and death. I couldn't breathe. I was standing in front of family and friends and I was naked, exposed, new born and I couldn't breathe. As if being choked by a cord tightening around my throat my voice couldn't escape and no air could enter. I was dying, I was being murdered by grief in front of silent witnesses, some accomplices, others observers of the crumbling facade of my life.

Disconnected and soaring through time and space in a void, feeling nothing, being nothing, there was no meaning or purpose; nothingness. It seemed an eternity. In the distance amidst the white noise a faint voice 'Patricia, Patricia', a little louder, a little more intense, far, far, away I heard a voice 'breathe, breathe, Patricia breathe'. I don't want to go back, I wanted

to stay here where it is safe in nothingness land, I don't want to feel anymore, I don't want to be in the world. Then as involuntarily as when I exited the scene, I landed with a sharp intake of air.

Lorraine was standing in front of me holding my hand. There was silence in the auditorium. Lorraine was looking at me with a concerned expression. Why the concern I thought? I realised where I was. The audience is waiting. Perform, perform, perform. I looked down at my notes and began reading from them, dispensing with them by the second line of text I finished my part. I heard laughter, I saw tears and I did a good job. Satisfied I'd recovered the presentation and left a satisfied crowd, I returned to my seat and sat in limbo.

The forty-five minute scheduled service finished in two hours. I was beckoned to stand and accompany Olga's body as it slowly left the room encased in a wooden box. I was encased in an invisible box. Friends tried to stand with me. I felt their bodies ricochet like projectiles rebounding off an impenetrable wall of solid air dense with pain and sorrow. I walked alone behind the coffin, I left alone and followed in the hearse alone to the crematorium. The driver was talking I wasn't listening. It was a long drive approximately forty-five minutes. Then we arrived. The hearse stopped, this was the end of the road.

The arrangement of white flowers was removed from the top of Olga's coffin and placed in the car which was to return with me to the gathering of mourners back at the apartments I had rented. I removed a single white tulip and placed it onto the top of the coffin. I said my final farewell to Olga as the hearse pulled away from the doors which opened into the incinerators where Olga's body was to be reduced to ashes. I returned and sat next to the

flowers, her farewell Vita Sackville-West style floral tribute. Pure, simple, beautiful flowers cut down in full bloom.

4.12 PART THIRTY-SEVEN: THERE ARE NO WORDS

I had booked an adjoining apartment to accommodate people following Olga's ceremony. I had organised Olga's favourite foods, mainly Dutch cuisine for people to enjoy in farewelling Olga. There was champagne and wine, food and drink by the plenty to share to celebrate the way Olga would have wanted. I had collected all the flowers left at the funeral directors and made up five large bouquets which I gave to the important women in Olga's life. The flower arrangement which had covered and adorned Olga's coffin I took to a bench overlooking the sea and Melbourne.

This is where over the twenty years we had lived and loved. We had sat on this bench taking time to be with each other and enjoy the ambience when walking our pet dogs. I had lost our family home. The financial chaos and debts I had accumulated in the time Olga was unwell meant the sale of all our assets and I had no home to lay the flowers and remember her. So, this seemed the perfect place. This will be my place of remembrance. The sea, to the left, the port with boats from the Netherlands coming and going. We would sit hand in hand and watch. With our pet dogs with us, this was our place, our home.

I laid the flowers on the grass across from the bench. I attached a simple card to the flowers.

‘To My Darling Olga; There are no words, Your Patricia’

There were no words. The Semantic Dementia took the language, the words from Olga. No words could express my grief at losing the woman I had loved and shared my life with. No words can describe the knowing, the tacit thoughts and feelings which joined us and sealed our relationship. No words can fully express my journey.

At the close of the day I returned to my apartment alone. I lay on my bed and waited for sleep to take me to be with Olga in my dreams. Sleep came quickly and the dreams felt more real than the emptiness of life. On asking, I did not feel Olga's presence. I did not feel her presence for several months. My life became an existence. I longed to sleep and cared not if I awoke the next day. If I did then I went on with the day making the most of trying to make some positive difference in someone's life, no matter how small.

A dear friend said at the ceremony to celebrate Olga's life 'Olga was Patricia's feet on the ground whilst Patricia was Olga's dreaming'. Without Olga there was no one to dream for and I was drowning, lost at sea. The grief and loss was tumultuous. Tsunamis of emotions overwhelmed me, and I had no direction. It took all my strength to stay afloat, hanging on to memories of Olga to stop me from sinking, staying connected in this storm of life, all the time knowing it was only a temporary reprieve.

For following the brief calm which followed the storm came more uncharted stormy waters. When together we could hold onto each other and when came another tidal wave, disconnecting us and hurling us against different rocks we were in the same waters. I believed I needed to live to save Olga but I began to realise it was me who was the soul lost at sea, unattached, disconnected once again. Now alone there was nothing to hang on to and no reason to hang on; just nothingness. The spiritual venture was not easy, however

I could conceptualise and cortex[ualise]' this experience. The physical disconnect proved to be the biggest obstacle to climb over to reach an end on this journey and be able to begin a new journey, begin life again.

4.13 CONCLUSION: LIVING AND LOVING

Telling the story as part of the heuristic journey has taken me along new pathways, reviewing old roads trodden in finding a destination. A destination from which to see a direction for the future and look back to see how I arrived there. It informed me and guided me in my travels to find the significance and point in my life without Olga living in my world. Sharing my life with Olga whilst she was living with Semantic Younger Onset Dementia was a new challenge in staying connected and loving a partner. The grief and fears of abandonment awoke the sleeping losses of childhood, facilitating a revision of past connection and disconnections as well as coping with the new.

The formation of my personhood built on the primary relationship with mother, greatly impacted upon by the profound experience of living and loving Olga whilst she lived and died with dementia. The voice and silences caused echoes from the past to reverberate and shake the new ground upon which I was walking and rocked the foundations of selfhood. In the telling of the story the seeds were planted and understanding and awareness grew from nurturing the ground of this lived experience.

The disquieting disconnections, the search for meaning and purpose in life when Olga, my life partner, lived and died with Semantic Younger Onset Dementia was the story told of living and loving through dying and grieving.

CHAPTER FIVE

FINDINGS

5.1 INTRODUCTION

This chapter explicates the findings evolving from the Heuristic journey. Moustakas's dynamic process assisted in identifying three major themes, 'feeling of abandonment', 'there are no words' and 'running in the opposite direction' along with their associated sub-themes and/or paradoxes. Each theme presented commences with an independent literature review. Chapter four, the story provided the rich text and material utilised in enabling the discovery of each theme. Supported and clarified by art works such as lyrics, poetry, drawings, sculptures and music, the living (as per heuristic inquiry) human experience is considered and portrayed.

5.2 THREE MAJOR THEMES

Feeling abandoned was identified as the first of three major themes. The feeling of abandonment surfaced in a variety of ways which commenced in early childhood and continued to surface throughout life at times of stress and uncertainty as an adult. Such experiences of abandonment surfaced as paradoxes in this research journey: Connecting-separating, certainty-uncertainty, and revealing-concealing, presenting as conceptual explanations of the abandonment experience. Discovering ways to live and face death with the fear of abandonment and rejection helped illuminate the second major theme of 'There are no words'. 'There are no words' conveyed feelings and fears of living and dying. The sub-themes of 'Silent witness', 'Muted by internal voice' and 'Empathy - the path to connection' presented themselves.

The third and final major theme of ‘Running in an opposite direction’ consisted of two sub-themes: ‘Que Sera Sera or is it denial?’ and ‘Finding a place to hide and be safe - living the paradox of feeling safe-unsafe’. This journey identified clear thematic patterns to guide understanding and awareness. This chapter provides an illustrated discussion on the themes presented and elucidated upon their meaning.

5.3 THEME ONE: FEELING ABANDONED

Feeling abandoned was identified as the first of three major themes. Feelings of abandonment lay hidden in the shadows of time, commencing from my earliest memory and before. Darkest memories awoke in the light of day, bringing along with them forgotten dreams, feelings of anxiety and abandonment. As an adult in mid-life, a spouse of a partner living and dying with YOD, these feelings of abandonment surfaced with increased regularity and intensity. Throughout the disquieting disconnection journey, the concept of feeling abandoned arose with repeated significance in a variety of different contexts.

5.3.1 Literature Review: Feeling Abandoned

A review was undertaken to establish the current literature available in relation to the feelings of abandonment experienced by the partner, the spouse, who is the primary carer of a person who is living and dying with YOD. In an effort to elucidate current understandings in all relevant disciplines, data bases were chosen across Nursing, Allied Health, Life Sciences and Psychology. It was intended that this would provide a basis from which to further develop the concept of abandonment, however, what followed was the discovery of the paucity of material on this topic. The following, outlines the search

strategies undertaken and then proceeds to discuss the one article located that addresses the concept of ‘abandonment’ in a relevant context.

5.3.2 Search Strategies

This review of literature for this theme did not have any time parameters imposed onto the searches. Data-bases searched were Cumulative Index for Nursing and Allied Health, Medline and PubMed. The initial data bases produced a limited number of articles to explore, so an additional data-base ‘PsychINFO’ was added to the search to ensure adequate rigour and vigilance was applied to the literature review.

The desire to capture all significant literature led to truncating the word ‘abandonment’ to ‘abandon*’ ensuring that any article which had any reference to the concept of ‘abandon’ was listed. Additionally, the Boolean operators of ‘AND’ and ‘OR’ were employed. Originally the term ‘partner’ was utilised, but inputting the Boolean ‘OR’ enabled the search to include other potential terms of relevance, in this instance ‘spouse’. This approach ensured that articles were not unwittingly omitted due to narrow word-search choice.

The initial number of articles generated is outlined in Table 5-1: The literature review search strategy and results for theme ‘Abandonment’ as seen below. As indicated only one article was initially deemed as relevant to the study. Upon a full review however, this article was not selected as relevant, but a scan of the reference list led to the identification of another article which was to be the only article determined as relevant to this topic. The process of review and elimination can be followed in Figure 5-1: The PRISMA flow diagram of literature selection and exclusion for theme one ‘Feeling Abandoned’ is provided below.

Table 5-1 Literature review search strategy and results: Theme ‘Feeling Abandoned’

Keywords	CINAHL	PubMed	Medline	PsychINFO	Relevant to Study
Abandon* AND Younger Onset Dementia AND Partner OR Spouse	NIL	1	NIL	1	0
Abandon* AND Younger Onset Dementia	NIL	1	1	1	1
Total once duplicates removed					1

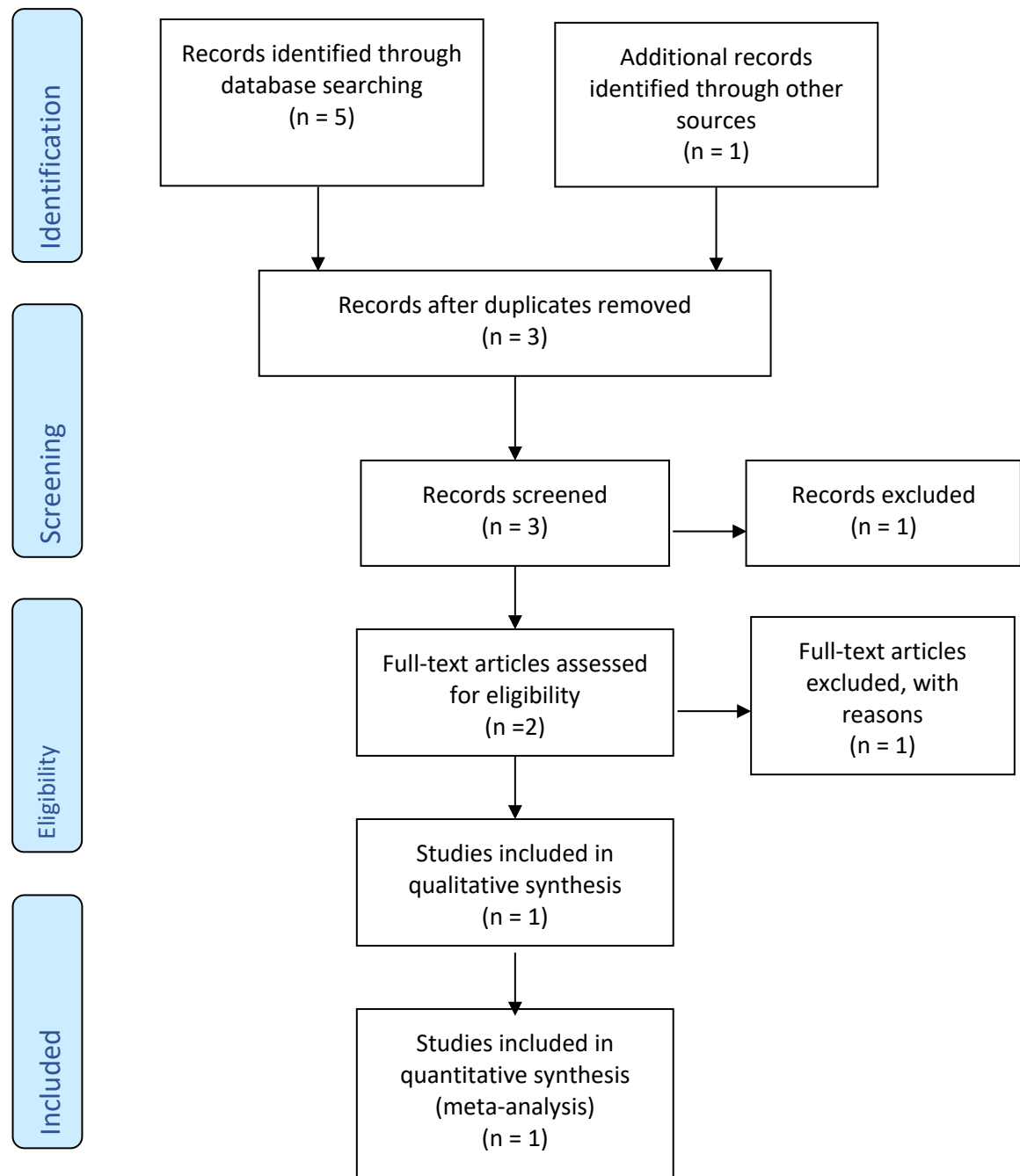


Figure 5-1 PRISMA flow diagram of literature selection and exclusion: Theme ‘Feeling Abandoned’.

5.3.3 Literature Review: Feeling Abandoned by a Loved One Living with YOD

A review of the literature highlighted that there is a clear paucity of research in relation to the feelings of abandonment experienced by the partner of a loved one who is living and dying with YOD. The literature search found that abandonment is most frequently discussed in terms of the person living with YOD feeling abandoned, rather than addressing the partner's feelings of abandonment. Of the articles that discuss abandonment related to the spouse's experience, it was typically in relation to their feelings of being abandoned by family and friends rather than their partner.

The literature search identified only one article specific to both Younger Onset Dementia (YOD) and the experience of partners feeling abandoned by their loved ones living with dementia. Bergman, Graff, Eriksdotter, Fugl-Meyer and Schuster (2016) asserted their intention to elucidate the experiences of the spouse of a person living with YOD from a holistic perspective. Adopting a phenomenological framework, ten candidates were interviewed and a theme of 'The experience of being alone' was identified. Within this broader theme of 'being alone' the feelings of being abandoned by their spouse were briefly presented. Poignantly, Bergman et al. (2016) identified a paradox in spouses' experience when alone, simultaneously experiencing abandonment by their partner, they also experienced relief as a welcomed break from the stress of caregiving.

The presentation of abandonment by Bergman et al. (2016) is encouraging as a dialogue in identifying the feelings of abandonment felt by the spouse in relation to their partner living and dying with YOD is established. Whilst the entire article only mentions abandonment twice, and does so briefly, it nonetheless legitimises and validates the need for the current research establishing the need to explore this identified theme. As the richness and depth

of this topic was explored only briefly by Bergman et al. (2016) it reinforces the need for more attention to this experience.

5.3.4 Contribution to New Knowledge

This review of the literature makes apparent the paucity of research on the topic of ‘feeling abandoned’ within the context of this study. The study herein has identified that the feeling of abandonment is a significant experience and the acknowledgement of such generates an understanding of this phenomenon. Going forward if we are to care for people living with YOD effectively it is essential we also care for their spouse, thus insight into their experience is imperative.

5.4 THEME ONE: ‘FEELING ABANDONED’ *THREE EMERGING PARADOXES*

The experiences of abandonment found expression within this thesis presenting as three paradoxes, providing a conceptual explanation of the abandonment experience: Connecting-separating, certainty-uncertainty, and revealing-concealing. The paradoxes of connecting-separating, certainty-uncertainty, and revealing-concealing, were the waves sweeping in and sweeping out in a constant exhausting dance to a changing tune.

The first paradox identified to express the experience of abandonment in this research journey was connecting-separating. Continually connecting-separating, as sensory and cognitive changes distance and draw closer, oscillating the rope tied to abandonment, leading to the second paradox of certainty-uncertainty. Certainty-uncertainty surfaced at

moments of not knowing while being aware of what was to come as the partner continued to decline. The present-future became transfixed in a world of quicksand. The third paradox of revealing-concealing arose with and simultaneously expressed disclosing-not disclosing, being-seeming, within the illusion of time and space mystically secured the new, whilst letting go of the old. As an individual, as a partner, the relationship was living and dying, connecting and disconnecting, being one with your spouse, your love, the world and the heavens, whilst being by yourself, your odium, alone and in hell.

5.4.1 Connecting-Separating

The physical pain and emotional neglect received as a child of abuse, brings to the fore the paradox of connecting-separating. Birth can be experienced as a disconnection; death can be experienced as a disconnection and paradoxically they both can be experienced as a connection. The first experience of connecting-separating is in relationship with your mother. Consciously and/or unconsciously this is the place you return to, revisit when feeling abandoned. It is impossible to objectively evaluate when you first feel and are cognisant of the experience. However, the tacit understandings lie in waiting, waiting to find a way out, find a way to express, connect and be acknowledged to allow healing. Incubating they hatch forth. I was sitting alone and found myself doodling on a piece of paper, Figure 5-2 ...



Figure 5-2 Pencil sketch: 'Baby in the Wire' (Original Size)

It was a case of Duende, an instinctive, mystical force moving through me, transcending and channelling feelings of abandonment, to tacitly create a work of art illuminating my experience. ‘Baby in the wire’ appeared on the paper in front of me, it was me, I knew this baby, I knew what lay behind those eyes and my body felt the barbs of the wire piercing my soft white skin, I felt. I stayed with the feelings and they seeped through the image into my being. Engaged in ‘Heuristic indwelling’ hanging on, ‘like a dog with a bone’ transfixed resolute and focused (Moustakas, 1990) I anchored onto every shade of the experience. As the light came in I redrew the image, Figure 5-3 ...



Figure 5-3 Colour pencil crayon sketch: ‘Baby in the Wire’(Original Size)

The duende mixed with the explicit knowledge, fed the intuition and I knew of the attempted terminations of pregnancy, the efforts of my mother to abort my being before I arrived. Hot mustard baths and a bottle of gin, maybe a wire coat-hanger? My mother's words of scorn telling me how I had ruined her life and how I was the biggest regret of her life. I could hear her daily taunts, "If only the cord had wrapped around your neck at birth and choked the living day light out of you everything would be alright". Her death bed apology to me when I was caring for her confirmed my memories. Her attempt to connect just prior to the separation of her death was simply, a display of her fear, my fear, frightened together and alone we held hands in lifetimes of silence. Longing for both connection and separation at the same time with joy and despair, the paradox of Connecting-Separating brings life and death, in loving and living. The internal frame of reference illuminated and allowed expression of the feeling of abandonment, the paradox I experienced as a spouse in the dynamic connecting-separating with Olga, living and dying at the same time.

It is paradoxical that the earth-shattering disconnections, pushing away the partner when relating with a person living with YOD, can pull a couple closer together at the same time as forcing them apart (paradoxical disconnection). The apathy associated with the advancement of YOD and the diminished amount of engagement and reciprocity of interactions added to the sense of abandonment. With the desire to remain attached and motivated by fear, the focus is on staying connected to the partner. The drive to create and develop new ways to relate displaces and protects from the fear of abandonment.

As Bergman et al. (2016) identified, simultaneously experiencing abandonment by a partner who is living with dementia and experiencing a strong desire for a break and some

respite from the stresses, delivers the connecting-separating paradox. Conflicted and weary, the anxiety of abandonment is contained by adaptations to disconnections. Touch compensates for lost words; facial expressions replace language to convey love and emotion. These adaptations displace feelings of abandonment with togetherness. This continuous process of adjusting to accommodate losses also nurtures a sense of hope. This unwittingly becomes a double-edged sword, as the belief grows that whatever happens, a new way to stay connected can be found.

5.4.1.1 Connecting-Separating: Leave me not alone

With Olga confined to a wheel chair, unable to talk and with only a precious yet distant recognition momentarily igniting a transient warm embrace with her eyes, I longed to connect to avoid the agony of my separation. I missed our conversation, her deep womanly voice, her use of words and Dutch phrasing, her neologisms created to overcome her lost vocabulary from many languages. I wanted to paint a language she could see to bring light to the gloom of her silence so I could bath in her sun. I felt so cold, so alone.

I always managed to make new connections as old ways of connecting fell away like the falling leaves from the autumn branches of trees preparing for the winter frost. Our stroking hands guiding broken words, carried by the winds of music, to her heart to rest there, to be held there, for my fear of abandonment needed a hiding place. I was unable to declare these all-encompassing emotions which cried out to be expressed. Then I found the brilliance of Jacques Brel's (1959) words and music and sang them to Olga so I could hear.

English	Dutch
Words made of red and blue	Woorden rood en blauw
A language for you alone	Taal voor jou alleen
With a soft touch	En met warme mond
We speak to each other	Zeggen wij elkaar:
Of another	Eens was er een paar
Couple that loved so much	Dat zichzelf weee vond
I will tell you	Ook vertel ik jou
The tale of a Queen	Van de koningin die
Who died from nostalgia	Stierf van nostalgie
Yearning to find you	Hunkerend naar jou
Leave me not alone	Laat me niet alleen
Leave me not alone	Laat me niet alleen
Leave me not alone	Laat me niet alleen
(Brel & McKuen, 1959)	(Brel, 1959)

Laat me niet alleen translated to English literally means ‘leave me not alone’. This meaning reflected my fear of abandonment more indicatively than the English version of the song entitled, ‘if you go away’. It directly implies connection, pleading ‘leave me not alone’, please don’t abandon me. The lyrics spoke of the desire to stay connected with Olga, find new ways to remain a couple with the loss of her ability to communicate with words. The use of the melody from Franz Liszt’s Hungarian Rhapsody mid-way through the song adds further depth and complexity to the original melodic harmonies of the music of Brel’s

powerful ballad. Music speaks a thousand words and evokes emotions not accessible to formal language.

The lyrical language used by Brel, 'Words made of red and blue'; 'Woorden rood en blauw': Give a colour to words so Olga may see them. 'A language for you alone'; 'Taal voor jou alleen': A language belonging just to Olga and I. No one else understood our special way of knowing and understanding each other, our secret code to keep us together and safe. Another sensory connection between Olga and I was touch. 'With a soft touch, we spoke to each other'; 'En met warme mond, zeggen wij elkaar': Often the visits with Olga lasting five or six hours were encapsulated into brief caresses of each-others hands, lasting five or six-seconds, the immense intensity of this connectedness gave a feeling was timeless and eternal.

The final lines of this verse conclude with a fitting summation of where I was at this time in relating with Olga. Though I sang and immersed myself in the music and words of Brel each day, it is only now fostered and nurtured in the warmth of reflections seen through a looking glass that the meanings dawn like a rising sun on the horizon.

Dat zichzelf weer vond.	Couple that loved so much.
Ook vertel ik jou, van	I will tell you, the tale of a
de konin [koningin] die,	king [Queen],
stierf van nostalgie, hunkerend naar jou.	Who died from nostalgia,
	yearning to find you.
Laat me niet alleen.	Leave me not alone.
Laat me niet alleen.	Leave me not alone.

Laat me niet alleen.

Leave me not alone.

(Brel, 1959)

When Olga was at her most distressed, the frustration of her lost language, mixed with the inability to contain her anger and fear, was projected by her onto my mind and body. As she yelled personal insults finding vulnerable chinks in my armour, it became impossible not to hear. As she struck and lashed out at my body it became impossible for me not to feel. I yearned for some relief from the tirade of abuse and chaos. The duality of the abandonment I experienced with Olga added complexity and weight to a fragile bridge keeping me connected and able to safely cross over the often-troublesome waters parting us. Firstly, relating to Olga as her health declined, I was continuously living with feelings of abandonment as she lost the ability to stay connected. As Olga lost ways to connect, I found new ways to be connected with her.

These adaptations displaced my feelings of separation with togetherness. When Olga died, I had no answers to this final type of separation, abandonment. I had no strategy, there was no body to touch, no eyes to see me. I found myself waiting for a magical moment, a mysterious interruption to change our direction and reconnect us. In the past I had always found a way forward, now I hit a dead end. Mortified I hung in the air waiting for divine intervention. The future we had planned was now gone and a future I had never envisaged awaited, alone, abandoned, like new born. I survived before, I can again, as I revisited the paradox of connection – separation.

5.4.2 Certainty-Uncertainty

Certainty can be described as the quality of being reliably true whilst uncertainty is being unsure. The complexity of the human condition allows these two opposites to co-exist, at the same time and be true. The multifaceted face of love can simultaneously cry tears of joy and sorrow. The certainty-uncertainty of attachment, was knowing we are relating together yet feeling the uncertainty of being heard and understood. Certainty-uncertainty is no more felt as when approaching the death of a loved one. Not knowing what happens to your love, your relationship after physical death. Gripped at living in the moment whilst floating into the unknown. Remaining together yet at the same time living alone.

5.4.2.1 Certainty-Uncertainty: Life-Death

The certainty of death, the final abandonment, typifies the paradox, certainty-uncertainty. No earthly strategies are available, there is no body to touch, no eyes to see, no ears to hear, death is definitive, the ultimate physical abandonment. The planned life together, the future has gone and a future never envisaged awaits, alone and abandoned. The certainty you will die and the uncertainty of how and when, the tacit knowing death is not the end and the uncertainty of what happens after death, these fundamental life paradoxes are brought to the fore-front of your mind when feeling abandoned. You are abandoned and alone on earth, yet still together in a parallel world. Death can be seen as the ultimate experience of abandonment. The physical end of life, the inability to touch and connect in the physical world with a loved one can be experienced as rejection. A life partner who has lived and dies with YOD leaves their spouse not only physically alone but emotional empty. When your meaning and purpose in life has been to stay connected and remain attached to the person you love, where is the meaning and purpose living in the nothingness of death? In

analysing feelings of abandonment, new directions in journeying with Olga emerged from the depths of my being.

From 'The Story' page 201

For following the brief calm which followed the storm came more uncharted stormy waters. When together we could hold onto each other and when came another tidal wave, disconnecting us and hurling us against different rocks we were in the same waters. I believed I needed to live to save Olga but I began to realise it was me who was the soul lost at sea, unattached, disconnected once again. Now alone there was nothing to hang on to and no reason to hang on; just nothingness. The spiritual venture was not easy, however I could conceptualise and cortex[ualise]' this experience. The physical disconnect proved to be the biggest obstacle to climb over to reach an end on this journey and be able to begin a new journey, begin life again.

5.4.3 Revealing-Concealing

Experiencing homophobia from family, school, local community, church, the nursing profession and society, revealing-concealing, simultaneously disclosing-not disclosing as a whole had again prepared me well for the solitude of the soul which accompanies the feelings of being abandoned. As a lesbian teenager and throughout my adulthood I had felt alone, a reject, wanting acceptance at the same time rebelling against it. As a working-class lesbian woman in a classist culture I felt lost at sea. Arriving on new shores in New Zealand I was left like an abandoned wreck, sinking in unfamiliar waters. A shining light on the horizon welcomed me into a safe harbor, embracing me for who and what I was, unconditionally loving me. Homosexuality was legal within the nuclear free Aotearoa. No prejudice was experienced for being a Lesbian woman and the English class system

revealing itself in my broad working-class accent was left behind and heard with welcoming ears on this bi-cultural land. I thought having had such rejections in life and being so blessed to be healed in this new country and in Olga's loving arms I could now cope with the lack of attachment to the world and others. I was wrong as it magnified the pains of old and new abandonments.

The impact of family and culture upon feelings of acceptance, belonging and attachment become increasingly visible during adolescence and can be clearly seen in the adult. The weight of sociocultural non-conformity and difference is heavy, often leading a person to feel unattached to the world and feeling abandoned. Lesbianism and homosexuality within the Western world are at the beginning of a socio-cultural venture into acceptance and belonging. Living with revealing-concealing, simultaneously disclosing-not disclosing, remaining in the margins. Although overt homophobia has lessened to some degree, covert insidious behaviours reinforce individuals' feelings of not being safe.

From 'The Story' page 196

I was sharing with friends and family the love and regard that was held for Olga. I was bathed by them in their love and regard. I felt acknowledged, respected by this gift and wonderful gesture they had bestowed upon me. I felt safe to grieve, feel and show my vulnerability. I felt safe to reveal my fragile heart which ached in the pain of losing the woman who I had loved and shared my life with for twenty-eight years. The silence and stillness which had enshrouded the group was broken by a distant voice cutting through the peace.

5.5 THEME TWO: ‘THERE ARE NO WORDS’

‘There are no words’ emerged as the second theme within this study. The sub-themes of ‘Silent witness’ and ‘Empathy became the path to connection’ underpinned the theme. Paradoxically, ‘There are no words’ is discussed within the limits of language. Art work and music provide the soul, longing for a voice, a means of expression, found between the lines and crevices of writing, heard in the melody and rhythm of life and seen in the rainbow of colours is the experience of living, dying and loving.

Not knowing whether words would be received or understood, I remained silent. The helpless observer, ‘The Silent Witness’ made mute by the external and internal voice. As fearful words could be misrepresented or diminish the intensity and sincerity of my love if they were heard, I remained silent. No sound filled the air which surrounded our breath, dense and heavy with unshed tears and unexpressed anger. Remaining mute, staying in control, engaging in self talk replaced conversations. Memories of the sound of Olga’s voice filled my mind to deafen my ears.

Watching, looking for any way to connect my eyes replaced sound with movement. I would catch a fleeting grimace, an isolated flinch, pain reflecting her watery eyes. Olga the wordsmith, who used language to connect with the world, was now trapped in a cage, rendered silent. I empathised with Olga, understanding her frustration and pain as if it were my own. Of course, it was my own, as well as being ours and being hers. There were no words to connect us anymore. Empathy became the last thread of connection, the unspoken glue connecting two souls and protecting two hearts.

5.5.1 Literature Review: There Are No Words

The following provides a review of the available literature pertaining to the theme ‘There are no words’. This theme encapsulates the quest to find connection when access to language and words are denied as a result of one partner living and dying with Semantic Younger Onset Dementia (S-YOD). The literature search returned very few results and the review evolved to include only one article pertaining to each of the sub-themes, ‘Silent Witness’ and ‘Empathy became the pathway to connection’. Therefore, as ‘There are no words’ produced no viable search results, articles identified under the two sub-themes were explored separately within the literature review.

The sub-theme ‘Silent Witness’ is explored via one article, where being a silent witness is a concept expressed as the lived experience of partners of loved ones living with YOD. The second article reviewed explored the experience of loved ones eliciting empathy in relation to their caregiving role. The second article is utilised to explore the sub-theme, ‘Empathy became the pathway to connection’. An analysis of each of these articles will provides a basis to assess current understandings on the topic ‘There are no words’. The review will then consider what new insights have been generated from the study.

5.5.1.1 Search strategies

The initial database search entailed a search for ‘Younger Onset Dementia’ (YOD) along with ‘There are no words’, ‘Silent witness’ and ‘Empathy, became the pathway to connection’. This returned no relevant results. It was suspected the specificity of the phrasing may have prejudiced the results thus the searches were simplified to encompass the main words of the sub-themes with results screened carefully to ensure relevance. Therefore, added to the database searches were the combinations, ‘Younger Onset

Dementia’ AND ‘Witness’ and ‘Younger Onset Dementia’ AND ‘Empathy’. This generated a small number of results which ultimately led to the identification of one relevant article.

Previous literature reviews for this dissertation located an article within which a participant describes the pain of being a ‘Silent Witness’. Given that no other literature was identified which addressed this concept, this example within an article focusing on the lived experience of caregivers of people living with YOD was drawn upon within to explore the theme of ‘There are no words’. See Table 5-2 for a schematic representation of the selection process which informed the review. The process of selection and exclusion can be followed in the PRISMA below, Figure 5-4. The databases employed for the search were Cumulative Index for Nursing and Allied Health, Medline, PubMed and PsychINFO. These were chosen for relevance to the Health Care domain, specifically, Nursing, Allied Health, Life Sciences and Psychology.

Table 5-2 Literature review search strategy and results: Theme ‘There Are No Words’

Keywords	CINAHL	PubMed	Medline	PsychINFO	Relevant to Study
There Are No Words AND Younger Onset Dementia	1	5	NIL	2	NIL
Silent Witness AND Younger Onset Dementia	NIL	NIL	NIL	NIL	NIL
Empathy the pathway to connection AND Younger Onset Dementia	NIL	NIL	NIL	NIL	NIL
Witness AND Younger Onset Dementia	NIL	NIL	NIL	NIL	NIL
Empathy AND Younger Onset Dementia	1	3	1	1	1
Total once duplicates removed					1

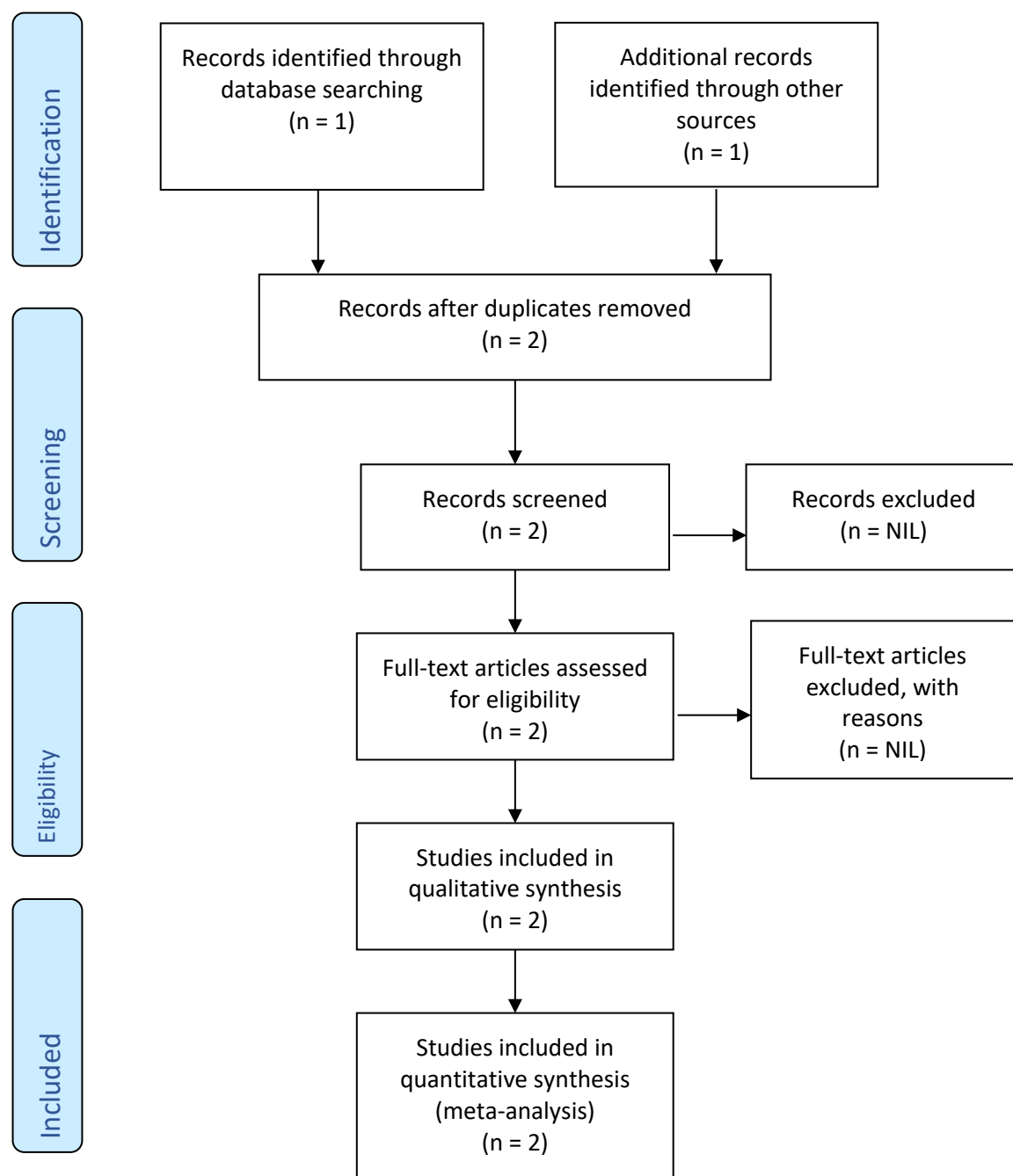


Figure 5-4 PRISMA flow diagram of literature selection and exclusion: Theme ‘There Are No Words’

5.5.2 Silent Witness: Dearth of Research

There is a dearth of research exploring the experience of spouses of people living with YOD. In a Swedish study utilising an interpretative phenomenological framework Bergman et al., (2016) explore the ‘lifeworld’ and lived experience of partners of people living with YOD. ‘Imprisoned’ experiences were described however, it was stated the silence experienced was a “...a comfortable silence, a new way to feel closeness and a deeper bond” (Bergman et al., 2016, p.346). Bergman et al. (2016) concluded maintaining togetherness with their spouses living with YOD was vital for the partner as new ways to connect to replace the old were discovered.

Silence provided space and stillness in the chaos of grief left in the wake of disconnection. “... a kind of intimacy is still found in a wordless relationship...silence create[d] harmony” (Bergman et al., 2016, p.346). This comfort enabled partners to be present. Partners were freed from their prison cells to connect with their loved one. Along with the new intimacies created within the silence came the dark side. With the knowing and learning of different ways of connecting came the knowing and learning of an absolute, an ultimate disconnection, death.

Although Bergman et al. (2016) did not use the term ‘Silent Witness’ the concept was clearly present in their research. A participant made clear reference to the distress of isolation and helplessness of bearing witness, of being a ‘Silent witness’. “It is like being in a glass bubble; I can’t reach out. It is like not being able to participate...” (Bergman et al., p. 346). The feeling of detachment and pending disconnection in a silence where new connections have fed hope exacerbate the feeling of loss. The peace and calm of a shared silence becomes a place of aloneness.

The battlefield of fighting the fear with becoming physically a single person, separated from the person with whom you are attached is a foundational emotional conflict. Revisiting the grief of your own birth, being evicted from familiarity into the unknown, from safety, from connection to disconnection is the first-time rejection is experienced. The sense of aloneness and learning to be in your own skin and contain your own anxiety is a primary need. In the experience of being the ‘Silent Witness’ the grief, anxiety and feelings of aloneness are re-lived, the disquieting disconnection returns.

5.5.3 Empathy

Empathy as experienced by a spouse in relation to finding a pathway to connection with their partner living and dying with YOD is the subject of this literature review. The search produced limited results with only one article included for review. The article, by Hoppe (2018), explored primarily the experience of the intimate carer obtaining empathy for their caregiving role. This implies linking empathy with relating and relationship and the inclusion provides a foundation for the exploration of the concept of empathy in the context of finding a pathway to connection. Hoppe interviewed people living with YOD together with their carers and was unique in exploring empathy in the private ‘personal’ domain, as opposed to discussing professional empathy, the type health care staff develop for their patients. The available literature addressing empathy discussed the concept of professional empathy and this perspective dominated the findings (Hoppe, 2018).

Hoppe (2018) in exploring the concept of private empathy, the empathy experienced in personal relationships, takes the premise ‘if suffering can be shared then it is lessened’. The first complexity of sharing suffering identified and explored by Hoppe (2018) was that the essence of suffering is so great it can never be truly communicated. If it is unable to be

fully expressed it can never be truly be understood by another. The author critiques the concept of shared empathy and whilst proposing the perspective that suffering can-not be totally shared, argues that suffering can be shared in-part. It is important, as to completely embrace the perspective that suffering can-not be shared leads to isolation and consequently additional suffering (Hoppe, 2018). The article continues along the premise that suffering can be shared in-part thus investigating the means and processes by which this can occur.

The participants of Hoppe's (2018) study were able to describe their experience of both wanting to be empathised with and being able to empathise. One participant in the study describes vividly the empathy a daughter felt for her father and the suffering he was experiencing led her to place a pillow over his face. With the intent of ending his suffering, becoming cognisant of the ethical consequences of her actions, the participant describes that she quickly removed the pillow. Nonetheless, her desperate actions demonstrates the suffering she felt via her ability to empathise and share her loved one's pain.

Hoppe (2018) identified that a common perception of empathy, that it is an 'identical' experience. The collective wisdom being that for someone to be truly empathic they need to have had the same experience themselves to understand. Hoppe (2018) interrogates the concept of the 'shared experience' and argues that even when two people have seemingly had an identical experience, the underlying differences between the people and their background means that they will have undergone the experience differently. Hoppe (2018) then cautions against projection and suggests that sometimes, similar experiences can be a hindrance rather than helpful in the venture to reach empathy.

This perspective does not completely align with the experience of all the participants of the study, one of whom, describes seeing a psychologist, but receiving no benefit compared to the help of attending a support group. The participant states that discussions with the psychologist required lengthy explanations to be understood whereas at the support group only a few words needed to be spoken and the others who were undergoing a similar experience immediately understood. Hoppe (2018) encourages the notion of reflecting upon those aspects of the experience that are not shared in order to reach a more authentic understanding of each other. Whilst not dismissing that similar experiences can be helpful in achieving empathy Hoppe, concludes that the complexity of empathy has many more layers and is not as straight forward as people may assume.

Hoppe (2018) also problematises language, the practice of utilising words to obtain empathy. The article explores the limitations of language, it is even suggested that not only can suffering not be communicated by words, but it is also hidden within words (Hoppe 2018). A sophisticated view which grows upon that of ‘shared experiences’ is of ‘sharing worlds’. Hoppe (2018) explains that ‘sharing worlds’ with someone could facilitate empathy. This process was seen as a means of gaining empathy that replaced words. Rather than explaining a situation to someone, it could be preferable to invite them into your world so they live and thus learn the experience by participating in your life.

Another thread of the study was that of the use of pictures. Hoppe (2018) argues that pictures propel emotions much more effectively than explanations. Utilising pictures also negates the need for words on the part of the empathiser. Rather than needing to respond with words within a conversation, in response to a picture a respondent is more likely to display emotions which in turn enables the person seeking empathy to see that they are

being understood. Finally, the importance of emotional connection is explored by Hoppe (2018) who puts forth the notion that having a complete understanding of what someone else is experiencing is perhaps less important than sharing via an emotional connection. Hoppe (2018) concludes that suffering can be shared via an emotional connection.

5.5.4 Contribution to New Knowledge

The literature review elucidates the concepts relating to ‘There are no words’. These conceptual understandings have not previously been explored in relation to YOD. The two subthemes, ‘Silent Witness’ and ‘Empathy became the pathway to connection’ have each only just begun to be acknowledged in the literature and as such this study contributes and adds to this conversation. The theme identified within, placed at its core the significance of having no words to communicate and to connect. It scrutinised how this can both hinder and contribute to new connections.

5.6 SUB-THEME: SILENT WITNESS

The first sub-theme of the ‘Silent Witness’ surfaced while engaged and immersed in the process of staying connected to Olga when there were no words. Olga had lost the ability to express or comprehend their meaning and I was muted by an internal voice and found no way to express myself. In the experience of being the ‘Silent Witness’ the grief, anxiety and feelings of aloneness were re-lived and the disquieting disconnections resounded. The feeling of detachment and pending disconnections in a silence where new connections had fed hope exacerbate the feeling of loss.

Within the caged self, muted by the internal voice came the deafness of the world to cries for freedom and a desire to silence us further. Whilst fighting our own demons the world dished up a culture of oppression and control.

An example of being a ‘silent witness’ can be illustrated by the following experience. Olga was a patient on a Neurosurgical Ward in a major city public hospital following surgery to drain a subdural haematoma sustained when she experienced a head trauma during a seizure. Against my explicit directions not to administer Olanzapine medication the nurses administered the drug when I briefly left her bedside. A short time following this, Olga became confused and agitated. Nurses restrained Olga and directed me to withdraw. I was to be a ‘Silent Witness’:

From ‘The Story’ page 159

My pleas fell on deaf ears and Olga’s terror increased further. I felt I was living in a horror movie. I was awake in a terrifying nightmare. Four male security guards arrived and begun to physically restrain Olga. Olga started screaming and crying, yelling at me “Mommy, why aren’t you stopping these men raping me, please stop them Mommy”. I had never felt such rage. My heart was pounding as I stood helpless and mortified. Olga’s screams increased in intensity, as did my rage as it exploded sending my heart into overdrive. I stood transfixed as if in slow motion, tears streamed down my face

Akin to observing your own birth, the ‘Silent Witness’ watches on. Petrified. The desire to save and rescue your Mother from her pain is fused with the desire to save oneself. To live, to die, to be.

5.6.1 ‘You Blew Me Away’

The sculpture ‘You blew me away’ by Penny Hardy, ‘You Blew Me Away’, Figure 5-5 below. I discovered this work of art inadvertently shortly after Olga moved into the nursing home. This visual representation allowed sensory release. I could see words and meanings. A silent voice triggered an emotional expression, freeing my heart to feel and my tears to flow. When I initially engaged with ‘blew me away’ I saw the sculpture as Olga, a woman of steel, facing the elements, standing steadfast taking all that nature could throw at her. Though her body was ‘being blown away’ she remained Olga and she remained and did not abandon me, she hung on transformed, despite the harshness of the world. Her psyche, her spirit was intact, holding firm against these cruel winds of change.

Despite destructive forces ripping, destroying parts of her, she remained Olga. The oxidised iron of the sculpture, changed by the rain, still held the woman’s shape, who she was. This dynamic beautiful form remained for all to admire. The degeneration of Olga’s nervous system, continued each day, cells oxidizing, changing her. Each day I saw her, metamorphising, still a beautiful woman, essentially the same, her personhood remained for me to see, and to be connected with and love. Then with gentle ease emerging into consciousness the sculptured woman did not just represent Olga. I saw a visual representation of us. It was not just Olga being ravaged by dementia, she embodied our couplehood being exposed to the severity of the life and dying.

Together alone, a couple, two unique and linked individuals battling for ourselves as well as our union. Standing tall, silently witnessing the physical destruction of Olga, I absorbed the horrors as well as the marvels of life, battling with the changes. Two myocardial infarctions blasted my heart, destroying part of its muscle power, yet my heart remained

strong, compensating for the change of beat. Witnessing Olga's increased vulnerability and helplessness, I saw my own fragility reflected in her mortality. My difficulties in connecting whilst pulling my heart apart, blocking my heart, gave me new insights, strengthening my resolve, fortifying my soul. From birth I had heart block, now intensified by the damage caused by the heart attack, my heart grew bigger holding more whilst being blown away.

The Cardiovascular Accident (CVA) that followed the heart attack, the loss of oxygen to my brain, knocked me down. I struggled and stood up again, unsupported, alone. Not the same as before, physically more vulnerable but wiser, to be with Olga and loved by her. Staying connected my feet remaining firmly anchored to the earth, channeling my life force, my love, finding new ways to connect with Olga and new ways to stay connected with self.



Figure 5-5 'You Blew Me Away', by Penny Hardy. Adapted from Pinterest, photographer unknown

When I read the words accompanying the image 'You blew me away' I was astounded by their profundity. It was as if they had flowed from my pen, my heart, my soul.

'Have you ever felt utterly consumed by someone, your thoughts are their thoughts, you no longer know where you end and they begin, your soul has been touched, it will never be the same again, I am altered, changed, re-shaped, you blew me away'

Anon

5.6.2 Muted by My Internal Voice

I was greeted one afternoon when I arrived to see Olga by her running towards me and grabbing my hand frantically. She was almost incoherent, but I was able to decipher from her salad of words that she had been out and purchased a compact disc (CD). There was a song on it that she desperately wanted me to hear.

Ain't no sunshine when she's gone

It's not warm when she's away

Ain't no sunshine when she's gone

And she's always gone too long

Anytime she goes away

Wonder this time where she's gone

Wonder if she's gone to stay

Ain't no sunshine when she's gone

And this house just ain't no home

Anytime she goes away (Withers, 1971)

From 'The Story' page 166

She sat me on her bed in her room and with tears running down her face she put the CD into the player and pushed the start button... "Ain't no sunshine when she's gone..." Olga had found the words to express her feelings and I was lost for words on how to respond. (

Olga had found the words to express her feelings in music and the voice of another and I was in essence unable to respond. I remained expressionless, muted by my internal voice with no way to express myself.

5.6.3 Fear of the Dark

Elisabeth Kübler-Ross in her pioneering work on grief identified drawing as a medium to express the feelings experienced by those grieving. She proclaimed only children, the psychotic and the terminally ill dying person were honest about their experiences and did not sensor the 'true' emotions (Kübler-Ross, 1983). Language can palliate and keep fears and anxieties hidden beneath its cloak. Visual images can let light in allowing exposure of emotion and the person can appear and be seen. In silence the eyes can hear as well as see. Movement, touch and drawing can connect where language corrupts (Kübler-Ross, 1983).

Kübler-Ross (1983) gave family members of children who were dying a task to draw a picture of how they felt (Kübler-Ross, 1983). A short, limited time was given. I gave myself ten minutes to sketch my feelings, Figure 5-6, following writing these words...

From 'The Story' page 167

The sun was now setting and there was little I could do about it. I could see the darkness approaching and I always feared the dark.



Figure 5-6 Ten-minute pencil crayon sketch: 'Setting Sun'

I always saw Olga as the sun in my life and in this sketch the sun was setting, Olga was dying, disconnecting. Softly to the left-hand side of my black silhouetted image is a faint, barely visible outline of myself, fading away into invisibility, the old me dying with the setting of the sun. Remaining a black figure, a woman, narrow shouldered and waisted with broad hips. The childhood self, had grown up and was disappearing, leaving standing alone

in the water of life, a woman, reaching for a setting sun, silently witnessing a birth and a death.

5.7 EMPATHY: PATHWAY TO CONNECTION

The sub-theme of ‘Empathy became the pathway to connection’ tacitly dawned a month following Olga’s death. I was presenting a paper based on this developing thesis, at the International Qualitative Research Conference in Toronto Canada. I had Olga’s ashes with me as I left a few days following her funeral and felt I didn’t want to leave her behind. During the conference I took her framed picture and placed it next to the box of Olga’s ashes which stayed by my side wherever I went during the week. At a workshop I was attending at the conference they were teaching ‘how to make a video for teaching purposes.’ After instructing us how to use an iPad recording sound and image, they gave the group attending the workshop a title, ‘Empathy’. Directed to plan and perhaps draft a video, we all left to create something. It took me less than twenty minutes to create the video, Figure 5-7 (Appendix A). It made itself. I did not think or plan anything. I went to the corner of an empty reception room. I just grabbed the hotel paper pad and pen, I drew pictures, wrote the script and turned on the iPad.

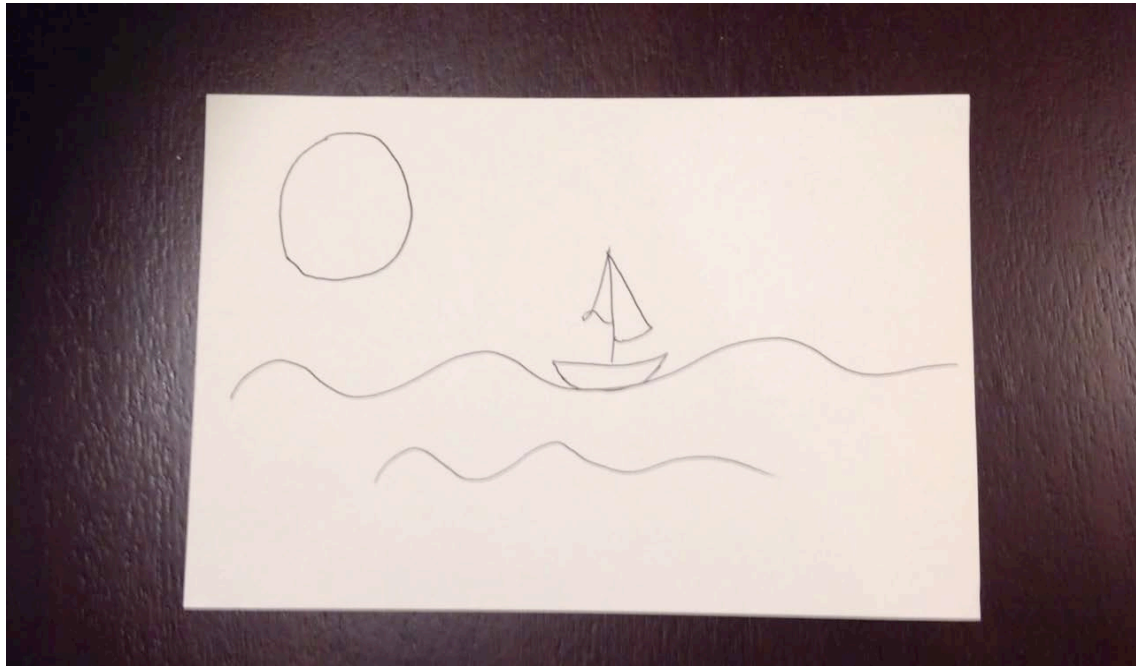


Figure 5-7 Video: ‘Empathy’ (*Double click on centre of image*)

Tacitly the video was created. From the initial engagement with the heuristic process I had been immersed in the journey and from this the concept of ‘Empathy became the pathway to connection’ hatched following the incubation, the workshop cracked open the ripened egg. A gestation process, where the concept cultivated and matured had been occurring and then ‘Duende’, something moved through me, illuminating on an iPad the shared suffering, our symbiotic creativity materialised in this exposition. It explains itself and the explication stage of the heuristic process culminated in the creative synthesis of this one minute twenty second video.

The song “It’s Only a Paper Moon” lyrics by Yip Harburg, (nee Isidore Hochberg, 1896-1981) and Billy Rose, music by Harold Arlen (nee Hyman Arluck, 1905-1986) was originally called “If You Believe in Me”. I sang this song in the video for Olga. It came to

mind when creating the video and was voiced immediately. I sang this song to Olga from when we first met, throughout our relationship and I sang it to her on the day she died.

5.7.1 Shared Suffering

The awareness of shared suffering and knowing Olga as she knew me, enabled my empathy. Olga knew my childhood history and I knew hers. The shared emotional traumas facilitated an empathetic connection. There are no words for empathy, it is born of the soul and no matter how we attempt to cognitise the sharing of an emotion, it falls short and lacks accuracy and exactitude. ‘How do you hold a moon beam in your hand?’

I had an intense understanding of the importance language and words held for Olga. For Olga to have no access to words and language, Olga the wordsmith and the linguist, I could only imagine her pain, frustration and sense of isolation. When I met Olga she had a 1920’s typewriter on her desk in her bedroom. She would sit typing letters, writing prose only stopping to read a Virginia Woolf or Katherine Mansfield novel or James Joyce, Chaucer, Shakespeare or some Dutch prose or Latin text.

Olga’s greatest love was language and the irony of her developing Semantic Younger Onset Dementia (S-YOD) never escaped me. I didn’t have the academic background in language and literature Olga had and I didn’t speak any other languages, unlike Olga who spoke several. However, I shared a love of the English language and words, albeit from an oral history, story-telling and folk music perspective. I missed the interactions we had, the intense conversations and intellectual exchanges. I missed the connection, the secret language, the personal meanings we attributed to words, phrases, stories created over our years of sharing our lives and love together. There were no words to express this sorrow.

There were no words to express the profundity and breadth of our experiences, this experience. I would look into her eyes and she into mine. Nothing could be said, that would be just semantics. Empathy was shared in our touching hands, our watery eyes and our gentle kisses.

The concept of shared suffering and empathy becoming the pathway to connection was there for all to silently witness immediately following Olga's brother John's funeral. John had died unexpectedly following an acute illness and Olga was devastated. In a wheel chair she had sobbed uncontrollably throughout the funeral service, the painful creaking and grinding of Olga's wheel chair caused by her swaying and rocking backwards and forwards filled the church. As we left the church Olga calmed and contained her grief. We held each other and moved outside to join family members and friends.

Olga met her childhood friend who also came to Australia as a child from the Netherlands and had similar traumatic experiences as Olga.

From 'The Story' page 177

They both embraced each other and begun crying uncontrollably. No words were needed for what was happening between them. The crowd surrounding us fell silent as we all watched on with a sense of sorrow and despair. United in grief and trying to embrace the two lost children the crowd held firm. My hurt child wept silently in harmony at the discord of the unheard songs of the abused children muffled in the veil of time

5.7.2 A Dream Within a Dream

Shared suffering and empathy entered my dreaming and I began to journey the pathway to connection when physically away from Olga when I slept. Everything began to feel surreal, there were times when I was not sure whether I was dreaming or awake. I desired to sleep to be with Olga, to see her, hear her voice, feel her warm flesh against mine. I felt more alive and in this world when I was asleep than when I faced the drudgery of the day.

‘A Dream Within A Dream’ (Poe, 1849) is a poem written by Edgar Allan Poe (1809-1849), which was first published in 1849. The poem comprises of only twenty-four lines, which are divided into two stanzas, yet they so eloquently explore the concept of reality, life and the experience of grief. Within the poem, he elucidates human life slipping away, trickling like “sand” and he questions the meaning and purpose of life, and the futility you feel when there is a loss of hope in the loss of a loved one. What is the significance of love, or life? Is it all just an abstraction of the mind? Edgar Allan Poe penned the poem “A Dream within a Dream” following the death of his beloved stepmother in February 1829. Although the original manuscript the poem was completed and signed, dated March 17, 1829 the work was not published until September 1849:

A Dream Within A Dream -
Edgar Allan Poe (1809 – 1849)

Take this kiss upon the brow!
And, in parting from you now,
Thus much let me avow -
You are not wrong, who deem
That my days have been a dream;
Yet if hope has flown away
In a night or in a day,

In a vision, or in none,
Is it therefore the less gone?
All that we see or seem
Is but a dream within a dream.

I stand amid the roar
Of a surf-tormented shore,
And I hold within my hand
Grains of the golden sand -
How few! Yet how they creep
Through my fingers to the deep,
While I weep - while I weep!
O God! Can I not grasp
Them with a tight clasp?
O God! Can I not save
One from the pitiless wave?
Is all that we see or seem
But a dream within a dream?

(Poe, 1849)

5.7.3 Nightmare Empathy

The light of the sun was darker than a starless night, the moon lay hidden behind clouds of tears. ‘Is all that we see or seem, but a nightmare within a nightmare?’ Olga’s torment of living with her dying body and her life’s struggle slipped between the edges of time, infiltrating the pleasure of my dreaming, stirring the deep waters into a swirl of filth from the ocean bed into my bed, into my head. I started having nightmares, repeating nightmares. Olga had died and I reflected on her pain and suffering. I wanted to connect with her, I knew empathy was a path I had travelled to connect with her and in the past dreams ferried me across the water of time and space. Now there were just nightmares, upon nightmares.

I kept a note book by my bed and would journal and write if I awoke or prior to sleeping. One night I awoke and was very distressed. I wrote quickly in my notebook the repeated nightmare I would have most nights but was failing to remember in the morning.

Notes from journal dated 24 April 2016

Olga tortured

I was hidden but could see her face

Nothing I could do

Olga comforting me with her eyes whilst bleeding and being beaten

Hanging from Dutch house gable

(These notes are as they were originally written)

The next morning, I translated and added to my notes. I could see Olga was being tortured. I was hidden from the view of the torturers but Olga could see me and I could see her face. There was nothing I could do but witness the events. Olga was trying to comfort me with her eyes whilst she was bleeding and being beaten. Olga was hanging from the gable of a Dutch house. Empathy is a two way process. In her dying, Olga still empathised with me in my sleeping 'trying to comfort me with her eyes' knowing I was feeling her suffering and I knew she was knowing mine. Paradoxically I was comforted by this empathetic nightmare post death from Olga. I could no longer see or touch Olga but we could still share our empathy and love for one another, the last thread of connection.

5.8 THEME THREE: ‘RUNNING IN THE OPPOSITE DIRECTION’

The third major theme identified within this study was ‘Running in an opposite direction’. The concepts and processes involved in fleeing the consequences of relating with Olga are addressed in this section. The two sub-themes: ‘Que sera sera or is it denial?’ and ‘Finding a place to hide and be safe - living the paradox of feeling safe-unsafe’, are discussed. The concepts of fate and denial, reality and illusion along with safety and the paradox of feeling simultaneously safe and unsafe are explored. The cognitive behavioural approaches of problem solving and emotional coping strategies are analysed and synthesised within the light of a spiritual domain in addressing the most human of experiences, life, death and love.

Scrutinising the motivations underpinning the perceptions and behaviours of the spouse, whether they are motivated by conscious mechanisms and/or unconscious coping strategies, helps in the understanding of the complexity of the human experience of death and dying. The theme of ‘Running in an opposite direction’ explores the processes experienced in finding meaning and purpose in life, living with the consequences of the death of a spouse who lived and died with YOD.

5.8.1 Literature Review: Search Strategies

A review of literature was undertaken in relation to the theme of ‘Running in the Opposite Direction’. The search engines used were CINAHL, PsycINFO, PubMed and MEDLINE. Key terms used were ‘Younger Onset Dementia’ AND ‘Running in the Opposite Direction’. ‘Younger Onset Dementia’ AND ‘Denial’; ‘Younger Onset Dementia’ AND ‘Fate’; ‘Younger Onset Dementia’ AND ‘Safe’; and ‘Younger Onset Dementia’ and

‘Unsafe’. See table 5-3 for a schematic representation of searches. The process of selection and exclusion can be followed in the PRISMA, Figure 5-8 below.

Table 5-3 Literature review search strategy and result: Theme ‘Running in the Opposite Direction’

Keywords	CINAHL	PubMed	Medline	PsychINFO	Relevant to Study
Running in the Opposite Direction AND Younger Onset Dementia	0	0	0	0	0
Denial AND Younger Onset Dementia	1	1	3	1	1
Fate AND Younger Onset Dementia	0	0	0	0	0
Safe* AND Younger Onset Dementia	4	9	10	0	0
Unsafe* AND Younger Onset Dementia	0	0	0	0	0
Total	1				

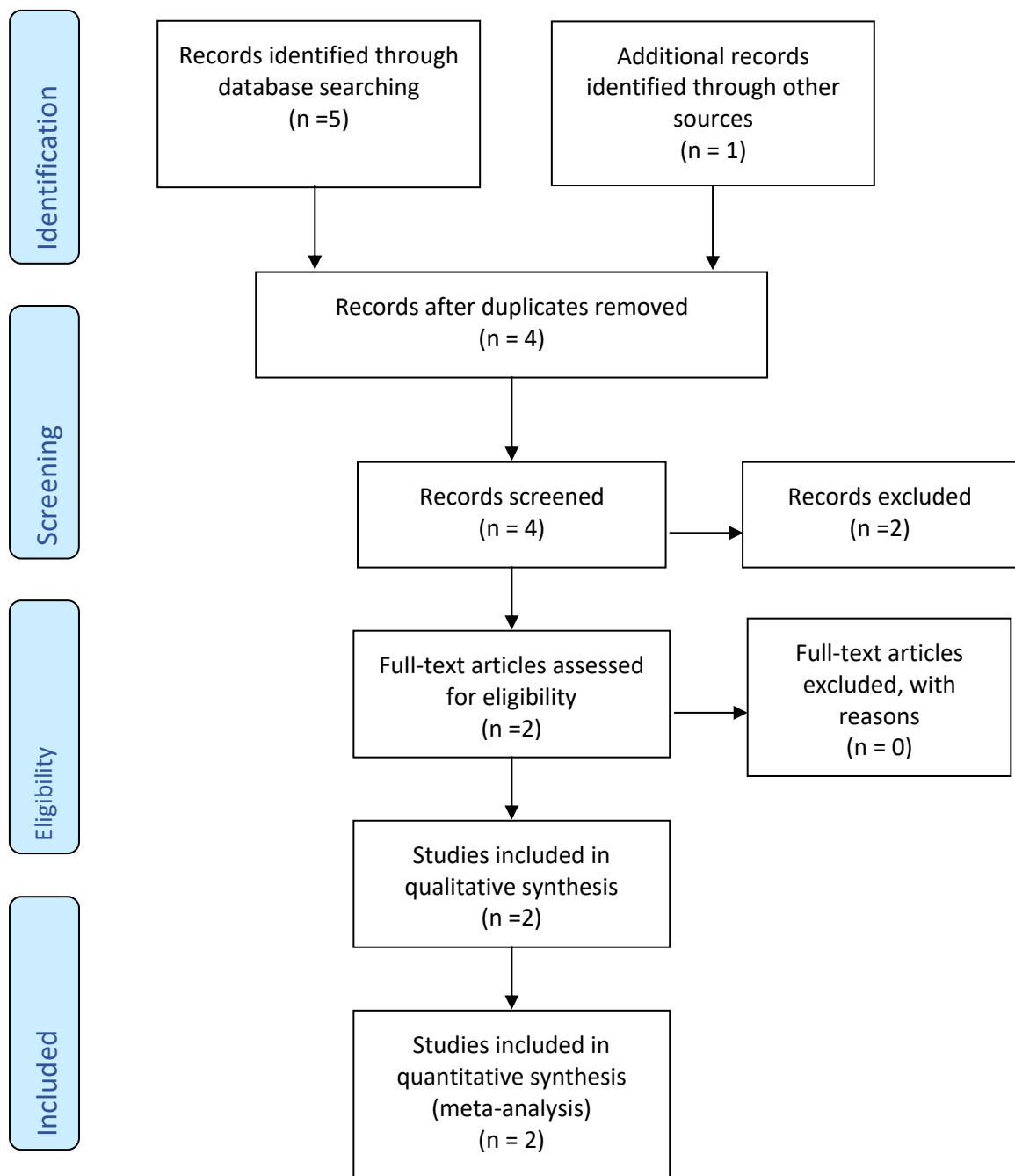


Figure 5-8 PRISMA flow diagram of literature selection and exclusion: Theme ‘Running in the Opposite Direction’.

The database search produced one article relevant to the theme ‘Running in the Opposite Direction’ which specifically explored ‘denial’. The article by Lockeridge and Simpson (2012) presented ‘denial’ as one of four major themes in their study which explored the coping strategies of younger carers of people living with YOD. The authors discussed denial both prior to receiving a diagnosis of YOD and following. The discussion and exploration of the concept of denial prior to receiving a diagnosis was unclear and in part confusing. The research indicated participants were unaware of Younger Onset Dementia (YOD) believing Dementia only occurred in older adults (Lockeridge & Simpson, 2012). This strongly suggested that lack of knowledge and awareness of YOD rather than a process of denial was responsible for their inability to consider Dementia as a potential diagnosis.

The authors’ discussions and explorations of caregiver experiences post-diagnosis of YOD demonstrated greater thoroughness and rigor. Participants narratives and disclosures clearly indicated the process of denial was employed as an emotional coping mechanism. It was evident that the degree of stress experienced as a result of living with the diagnosis of YOD impacted directly on the degree of utilisation of the coping strategy denial (Lockeridge & Simpson, 2012). The authors classify ‘denial’ as an emotion-based strategy which is engaged in an attempt to mitigate emotional distress. Caution was given however that the use of denial may have contributed to participants experiencing increased anxiety and depression. Despite providing this caveat the authors portrayed denial as a helpful coping strategy for caregivers as it allowed time to emotionally process and cope with the diagnosis of YOD and its implications.

Another interpretation of the concept of denial is provided when paradoxically it was said to be used consciously by caregivers in efforts to protect their partners (Lockeridge &

Simpson, 2012). A diagnosis of YOD was experienced as an assault on self and that the person living with YOD tended to deny their diagnosis. In an attempt to support their partner's personhood, carers proceeded to partake in supporting the denial with behaviours such as avoiding using the term 'Dementia' and hiding information relating to Dementia from their partner. Lockeridge and Simpson's (2012) use of the term 'denial' thus shifts from denial being an unconscious defense mechanism to being a conscious shielding tactic. Rather than using the term to imply a passive unconscious process whereby the spouse has no awareness that they are in denial and unknowingly partaking in an emotion-based coping strategy, denial becomes an active considered strategy to protect their partner. This is exemplified by one participant who requested that the doctors not inform her partner of his diagnosis as she believed it would destroy him (Lockeridge & Simpson, 2012).

Lockeridge and Simpson (2012), discuss briefly how being open and conversing in regards to a dementia diagnosis can be advantageous. They discuss the ability of people living with LOD to be able to reminisce upon their life and draw a sense of self from this reflection, consolidate personhood and this in turn contributes to maintaining the couplehood of the dyad (Lockeridge & Simpson, 2012). The authors note however that people living with YOD, who are at a different stage of psychosocial development, are not necessarily able to reflect upon life's achievements which are often disrupted. This presents as a paradox as denial which manifests in the deliberate concealment of the diagnosis in order to protect personhood and couplehood, impedes rather than promotes healthy adaptation.

From the initial literature review undertaken in Chapter 2, a doctoral thesis by Peyser (2017) was examined. This dissertation briefly mentions, in one paragraph, denial within a section pertaining to coping. Peyser (2017) outlines a participant in her study who stated

that in relation to her future she experienced denial. Interestingly, the subject in Peyser's study was a healthcare professional and as such had a lot of knowledge of Dementia. This knowledge is credited as the reason for the denial as the participant knew what was ahead of her and thus had a basis to fear her future. It is strongly implied that denial is unconscious and thus the usage of the term 'denial' is consistent with the findings of this research.

There is an absence of literature pertaining to the theme of 'Running in an Opposite Direction'. One article, which only addressed in-part the sub-theme 'denial' was identified in this literature review. The initial literature review undertaken in chapter two of this study identified a brief acknowledgement of the sub-theme denial in an article in relation to YOD. Brevity and inconsistent usage and interpretation of the concept of denial within the limited sources found, is far less than the concept appears to warrant. In terms of exploring the experiences of the spouse with their partner living with YOD, studies are in initial stages and as such, further research in this area is essential. The research herein examines the theme 'Running in the Opposite Direction'. This theme is presented as new knowledge and adds to the ever-growing discourse surrounding experiences in relation to the partner of a person living with YOD.

5.8.2 Que Sera Sera or is it Denial?

Que sera sera, is a socio-cultural construct, a philosophical approach, that could be said to be applied naively by the spouse caregiver of a partner living and dying with YOD to protect themselves within a hostile and unsupportive world. Denial is an unconscious mental defense mechanism employed to protect self from what feels unbearable. The passive fatalistic concept of Que sera sera whilst differing with the active mental coping mechanism of denial can be occurring simultaneously and often makes for an inseparable

complex survival technique. Exploring and discussing these concepts helps in the appreciation and understanding of the experience of the spouse of a person living and dying with YOD and informs us of appropriate care and strategies that can be applied to help support the YOD dyad at their time of need.

5.8.3 Que Sera Sera

Que sera, sera, is an English phrase dating back to the sixteenth century and is defined as a ‘Cheerful Fatalism’ (Hartman, 2013). The meaning of the phrase, que sera sera, is ‘whatever will be, will be’, and clearly expresses a fatalistic notion of resignation and passivity. The origins are thought to lie within the Italian language though resembling a Spanish phrase, however its contemporary use in everyday English language, can in part be attributed to the popular song released in 1956 composed by Jay Livingston and Ray Evans. Doris Day, an American star of film and song, popularised the song, which is viewed as a classic of the 1950’s / 1960’s and is still taught to children today. The lyrics of the song go on to say “...whatever will be will be, the future is not ours to see, que sera sera” (Evans & Livingston, 1956) and its influence on social and cultural belief systems should not be overlooked.

Lyrics written by two American heterosexual men stating “When I was just a little girl , I asked my mother what lies ahead, will there be rainbows day after day, this is what my mother said, que sera sera, whatever will be will be, the futures not ours to see, que sera sera.” (Evans & Livingston, 1956). Sung by a beautiful, blond haired, blue eyed woman, with a sweet angelic voice, creates a strong message. White, Western, American, male values, applied and taught overtly and/or covertly impact upon attitudes and perceptions of personhood, womanhood and couplehood. The growing ‘little girl’ under the pretense they

are 'Mothers' words is exposed to numerous negative stereo-types and is feeding upon ideas of helplessness and powerlessness.

What is meant by 'que sera, sera'? One common interpretation is that it is not a fatalistic notion. It is more reflective of an attitude of, it is impossible to know what is going to happen in the future, we have no control over what will happen. Placed within a cultural context, the message is there is little you can do, you are unable do anything about what you do not know. So don't worry, take things one day at a time. If translated into 'que sera, sera' in coping with caring for a partner living and dying with YOD, the message is who knows what will happen, do your best, don't worry. Continually throughout my journeying I was given this message. This is an acceptable sociocultural response and reflects a resignation, helplessness and sense of powerlessness, reinforced by the health care professionals, institutions and systems.

Friends and family members adopted an attitude of que sera, sera as a helpful strategy in coping with Olga living with YOD. They continually told me, I needed to 'let go', what will be will be, accept, move on. However, although I listened and respected their thoughts and feelings, it never fit into my schema. I sang the song on numerous occasions and admit to singing to my nieces at frequent times. I could not 'que sera, sera'. There is a subtle, however important difference between the fatalism of que sera, sera and the ability to let go when appropriate, reframe and/or adjust changing what you can in order to improve the situation.

Upon Olga's death I found a part of prayer written on a piece of aged paper, secreted away in an old photograph album. The words were taken from 'The Serenity Prayer' attributed

to Karl Paul Reinhold Niebuhr (1892-1971), a Lutheran pastor and theologian. Written in 1926, the words Olga preserved in her memorabilia were “.....grant me the serenity to accept the things I cannot change, the courage to change the things I can and the wisdom to know the difference...” (Niebuhr, 1926). It resounded with my internal voice and the philosophical stance I tacitly attempted to uphold.

When disquieting disconnections occurred, I never said *que sera sera*, I attempted to make new connections, move on, adapt and create new ways to connect and be with Olga. However, this ability/skill I developed from my childhood was only available when I was conscious of a disconnect. Denial was the strategy I unconsciously employed extensively and my awareness of this increases each day as my understanding of self and search for meaning and purpose in life continues.

5.8.4 Denial

The pioneer in listening to the experiences of death and dying from those terminally ill and their families was Elisabeth Kübler-Ross. Her identification of stages of grief served as a heuristic (Day, 2012) and acknowledged to the world for the first time a process of grieving. The concept of denial, is described by Kübler-Ross as the first stage of grief and a phenomenon experienced by all. The linear and prescriptive nature of Kübler-Ross's stages of grief, has led to a great deal of criticism of her work, however her analysis and understanding of denial in the lived experience of spouses of the terminally ill is invaluable. The concept of denial originates within Freudian psychology, where it is seen as an unconscious mental defense mechanism. A person's inability to cope with a painful reality results in a 'blocking out'. The person unknowingly puts their head in a bucket of sand.

Elisabeth Kübler-Ross' perspective implies a tacit knowledge and an active hidden awareness. "There is a grace in denial. It is nature's way of letting in only as much as we can handle" (Kübler-Ross & Kessler, 2005b). A natural intrinsic process is suggested if not directly expressed by Kübler-Ross. Sher (2019) supports Kübler-Ross in her article. As a medical student Sher describes her own experience of denial when her father was diagnosed with a terminal illness.

With her newly acquired medical knowledge she argued with neurologists providing alternative non-fatal diagnoses to her father's condition. Her father was subjected to a series of tests and unnecessary treatments before eventually she accepted the original diagnosis and prognosis. Sher explains that denial provided her and her family with "6 months of relative peace before things became unbearable." (Sher, 2019)

It is unclear what was at play in Sher's seemingly unconscious denial of the fatal diagnosis. Did a different knowing intervene in a culturally acceptable way to give an adjustment period and space for grace? As a Registered Nurse specialising in Mental Health, having worked extensively with people and their spouses diagnosed with YOD, I had acquired significant knowledge and awareness. Did this provide a different knowing, intervening in a culturally acceptable way to give an adjustment period and space for grace, for me? The reality of my own denial is evident from the following excerpt from the story, detailing my realisation of the situation as I was driving home on Christmas day 2014:

From 'The Story' page 181

I was only about 20 minutes from home when I pulled over and stopped the car. It was like an epiphany; Olga was not going to get better. The profound realisation that Olga was not

going to come running towards me on my arrival at the nursing home and say 'Everything is alright now, I am well, please take me home' dawned on me. It was like a bolt from the blue. How could I have not realised this?

When I talked about Olga to family, friends, colleagues and clinicians I appeared to be absolutely cognisant of the situation and Olga's prognosis. I could talk the talk and walk the walk, no one including myself had any idea that I wasn't speaking in my language and I was actually running in the opposite direction. I sat in the car and questioned myself. Was I deliberately deceiving myself? Was this denial necessary for me to continue with the everyday facade of life?

5.8.4.1 Crossing the line to invisibility

If taking flight eludes escape then maybe creating a new reality, a cloak of invisibility to hide from a world of pain is an option. Crossing the line into invisibility and existing in a pseudo-psychotic domain of illusions of the heart and soul, evading contact in a maze of smoke and mirrors we run through the labyrinth in the opposite direction. Arriving at the same point we discover we have only managed to lose our self in the guise of being present for others, lost in denial and helplessness. Ah well, *que sera, sera*.

5.8.5 Finding a Place to Hide and Be Safe

Finding a place to hide and be safe from being cut down from witnessing the inevitable swing of the grim reaper's scythe we escape nothing. Living the paradox of feeling safe-unsafe in a different corner of the same field we bear witness only changing the angle of our gaze. Finding safety we become unsafe and there is safety in being unsafe. As the brain dies, a person can no longer communicate. They are unable to connect in the same way as

they did prior to the physiological degeneration. We feel unsafe and yet safe in the knowing. We are in the physical quadrant of being, described by Kübler-Ross (2011).

There is a safety in the knowing of these scientific facts. With degenerative brain disorder, the hard drive is broken, the body is dying. The uncertainty however of the principle of life leads to the paradox. There is more to a person than their body. It is the spiritual quadrant according to Kübler-Ross (2011). As her work progressed she became more interested in the spiritual domain leading to criticism by the medical profession to the point of their attempts to discredit her work and theory. The body of a person is dying, however they live on. The uncertainty of the nature of this existence creates the paradox. The person can't communicate, you cannot physically reach them. However they are still present.

Finding a place to hide and be safe, living the paradox of feeling safe and unsafe is witnessing the death process, living in the dying. The experience feels unsafe and safe, knowing and not knowing at the same time. In finding a place to hide your soul becomes visible, your vulnerability becomes your strength. The uncertainty of what happens when you die leads to the certainty of life, a contradictory statement well founded and true.

From 'The Story' page 192

On Friday 28 August 2015, whilst lying in my arms, following eleven days together Olga died. I felt her leave. At one o'clock in the afternoon exactly I felt a sudden gush of energy; Olga left her body and the building. As Olga died a surge of white misty light engulfed me as it passed it moved defusing out of the window and away. All that was left was an empty shell. Olga's body like a marble sculpture lay on the white sheets of a hospital bed. Magnificent still and majestic it lay as a testament to her being. Olga was gone I was alone.

5.9 CONCLUSION

The heuristic processes of immersion, acquisition and realisation continually drove the research through the six dynamic phases: Initial Engagement, Immersion, Incubation, Illumination, Explication, Creative Synthesis. These wheels within wheels, driving forward, continually reflecting the circles of life, visiting new places, revisiting old and gaining new insights in both. Intuitively immersing in self-dialogue led to tacitly illuminating the story, informing and supporting the researcher's journey. The internal barometer deciphered and focused on the internal frame of reference, to uncover the three major themes that lay living in hiding. These 'self-processes' and 'self-discoveries' emerged in heuristic indwelling, maintaining connection with self, with partner, with life.

5.10 CLOSING REMARKS

The three major themes identified within the findings (summarised in Table 5-4) are discussed and explored within this chapter. Abandonment, there are no words, running in the opposite direction are written in a linear order, as if prioritising and suggesting a hierarchy or/and a chronology. However, these themes have arisen in no specific order, they emerged at different times sometimes singularly, sometimes simultaneously and in no particular sequence. As suggested in the last theme discussed 'running in the opposite direction', they didn't always go forward. The dynamic process and intertwining of feelings of abandonment, having no words, empathy and running in an opposite direction held a commonality. The process of grief, the intense sorrow, the disquieting disconnections looking for the reassurance of connection is the dynamic journey undertaken in looking to find meaning and purpose in life.

Table 5-4 Summary of findings

Theme	Sub Theme	Meanings and Interpretation	Literature Review
<i>Feeling Abandoned</i> Feelings of disconnection surfacing in a variety of ways commencing in early life	<i>Three Paradoxes</i> Connecting-Separating Certainty-Uncertainty Revealing-Concealing	<i>Disquieting Disconnections</i> Continually connecting-separating as sensory & cognitive changes distance & draw closer Certainty-uncertainty, not knowing while aware of what was to come Revealing-concealing, simultaneously disclosing-not disclosing, securing the new, whilst letting go of the old	<i>Search Strategy</i> Four data-bases Abandonment One Article - Bergman, Graff, Eriksdotter, Fugl-Meyer & Schuster (2016)
<i>There Are No Words</i> The quest to find connection when access to language and words are denied	<i>Two Sub-Themes</i> Silent Witness Empathy – the pathway to connection	<i>Disquieting Disconnections</i> Bearing witness and coping with the feeling of detachment, helplessness and pending disconnections in a painful hopeless silence Empathy was experienced in relation to finding a pathway to connection	<i>Search Strategy</i> Four data-bases Silent Witness One Article, Bergman, Graff, Eriksdotter, Fugl-Meyer & Schuster (2016) Empathy One Article, Hoppe (2018)
<i>Running in the Opposite Direction</i> The concepts & processes involved in disconnecting, fleeing the consequences of relating	<i>Two Sub-Themes</i> Que Sera Sera’ or is it Denial? ‘Finding a place to hide a be safe’	<i>Disquieting Disconnections</i> Conscious philosophical stance, que sera sera &/or denial, an unconscious protective mechanism employed to protect self Finding safety, we become unsafe and there is safety in being unsafe. Living the paradox of feeling safe-unsafe	<i>Search Strategy</i> Four data-bases Running in the Opposite Direction One Article Lockeridge & Simpson (2012)

CHAPTER SIX
CREATIVE SYNTHESIS
‘THE END AND NEW BEGINNING’

6.1 INTRODUCTION

The heuristic journey of finding meaning and purpose in life as the spouse of a partner who lived and died with Semantic Younger Onset Dementia (S-YOD) was a longer and far more arduous journey than I ever envisaged. Whilst it concludes in the context of this dissertation, it continues under a different guise. There is no beginning and there is no end. Life evolves and death and grieving are destinations in journeying. The three major themes arising during the roads travelled, which were revisited again and again during the process, led me to these new insights and understandings. I will always be grieving. It is a dynamic process that does not begin or end.

The ongoing creative synthesis grew from the findings. The initial engagement with the phenomenon and the immersion in the multitude of questions allowed time for incubation. The incubation provided light and illuminations, disclosing, clarifying and deciphering. Explication opened the door and generated and provided an opportunity to creatively synthesise the findings of this study. During the research process, it became apparent, in each theme there was a common thread of returning to the first experiences of grief .

When I was grieving for Olga, I relived and revisited the grief of my birth, babyhood and childhood. The revelation that grief was a living breathing part of life came to light. The experience of Olga’s death was a conduit for my past grief, an opportunity to face childhood

pain as an adult, to revisit death, birth, life and love. The grief I have always been living, in different seasons of the years, are the seasons of grief.

6.2 SEASONS OF GRIEF

Grief is as much about life as it is about death. We will always be grieving. It is a dynamic process that does not begin or end. Grief evolves, it doesn't go away, it doesn't start and end, it evolves; it changes expression, it changes form. To live you have to grieve. There is no better illustration of this than the disquieting disconnections of being the spouse of a partner who lived with and died from Semantic Younger Onset Dementia (S-YOD).

Trying to define and explain a nebulous concept using linear boundaries of containment, language and words is like trying to explain to someone who has always been blind the colour gold. Grief is a nebulous concept. It is as much about life as it is about death. As we are continually living we are continually grieving. There are times when we are full of joy and the focus of life is in full sunshine. The warmth of summer, the light, the sounds of nature, the smell of flowers and the taste of a honey sweet life. The all-consuming joys of life. In the background however, out of focus, hiding in the shadows and not centre stage is the cold desolation of grief and death.

The line 'Grief is the price we pay for love' was popularised in a speech by Queen Elizabeth II, and has been attributed to her, a psychiatrist and numerous others, from new age poets to commercial greetings card and poster merchants. The poem that begins similarly 'The risk of love is loss, and the price of loss is grief' was written by an American author and high school teacher, Hilary Stanton Zunin (n.d.) who was deemed to have penned the words of wisdom below to eloquently express the human condition.

The risk of love is loss, and the price of loss is grief –
But the pain of grief
Is only a shadow
When compared with the pain
Of never risking love

Hilary Stanton Zunin (n.d.)

The seasons of life are reflected in the seasons of grief. Without winter there is no spring, no summer and no autumn. The wind of change can transform and change a picture in a milli-second. We can be thrown from summer's full light into darkness. The cold of winter, the dark, silence, the smell of decay and the bitter taste of tears. Olga's heart stopped, she left, my heart stopped and I remained.

We can be thrown from summer's light into darkness. Autumn can be short-lived or linger on. Seasons change and each year there is no way of predicting their length or their expression. So it is with grieving. Each time we grieve it is a unique, deeply personal experience. There is no right way and there is no wrong way. It is the way it is. A sudden storm can transform a landscape in seconds. A dry barren field can become a swamp. A lighting strike can trigger a fire and a forest is burnt to the ground. The death of a loved one, a sudden disconnection can be an emotional tsunami that transforms our inner-landscape, changing the seasons of the soul.

Below Figure 6-1 is the dynamic linking circles of the seasons of grief. The 'I' of grief is in the centre of all the circles; grief is individual and the person is at the centre of their unique experience. Each circle is linked with all the others. Whilst transitioning through one season all other seasons are still present to lesser degrees. Constantly moving, flowing through, journeying through life, death, dying and love. Grief is ever present.

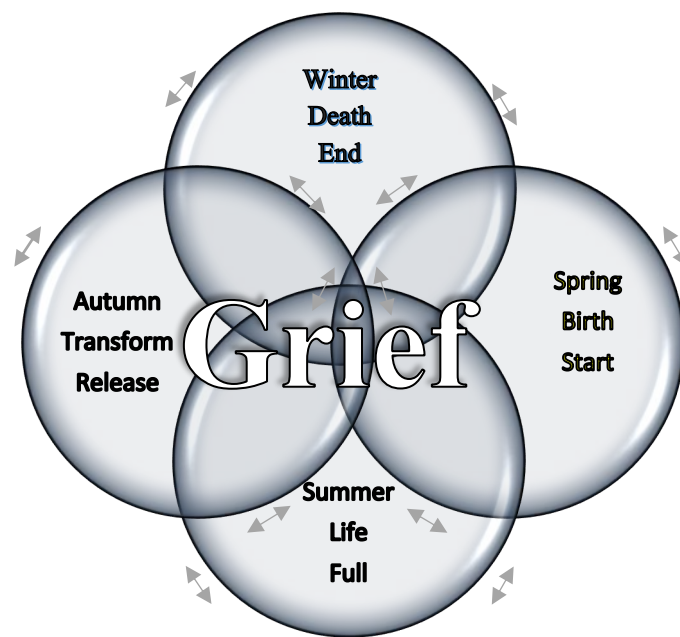


Figure 6-1 The dynamic linking circles of the seasons of grief

6.2.1 Spring

Like the nature of the seasons, the dynamic flow from one season into the next, year by year, has no true beginning and no end. Spring is a logical place to begin. However, it is not the start. Our travels, as with a new physical life, begins with our birth and new growth. Moving from Winter to Spring, connected and attached, in harmonious relationship with each other, growing and flourishing, so it is in the primary human relationship. Safe and warm inside the womb, we are nurtured by mother, earthing and containing, feeding and

growing, living together in perfect harmony, two souls entwined as one; nine months of connection.

Within a season the subtle changes occurring with each day, give little indication of the trauma about to occur, the disconnection about to hurl the two apart. The grief of detachment and disconnection provoking fear and anxiety, transforming into freedom and joy. The first experience of grief in this life is our birth. The breath-taking emergence into the cold air and light of day engulfs our body. Alone, free of containment we spring forth, a new individual, a new soul, now connecting with fear and anxiety, disconnecting with mother (Kübler-Ross, 1983). A new dimension to this, our first relationship occurs. An interdependence, a different connection to meet newly identified needs and new ways of being. We need to re-connect, attach and be in a relationship. The touching of the mother's hand, her skin against the trembling baby's body calms the storm and contains the raging waters, anxiety and fear of the new life and the mother.

The nourishing milk flows to feed the relationship, the sensory pleasures of touch, the new sounds and sights, eyes wide open joining, meeting, attaching the two as one again. The same but different, reconnected and attached. This experience can be interpreted as the first experience of grief, the disquieting disconnection from mother. We return to this first disconnect, the first experience of grief usually unconsciously when we grieve again.

Journal

I was standing ready to read my next paragraph in my eulogy to Olga. From seemingly nowhere I felt this drawing down from my very core, an all-consuming pain, I was suffocating. I could not breathe I could not move I could not speak. Everything was fading away I was imploding. In the distance far, far, away I heard a voice, breathe, Patricia breathe. It was the celebrant. I tried to take in air, to focus, to breathe. It was as if something was choking me, restricting squashing the life out of me. I became aware of the celebrant touching my arm and I riled against it jerking my body into being. I focused and said to myself breathe, breathe. I felt my heart beating, pounding like when you over accelerate push down too heavily on the accelerator pedal of the car when stationary, so you feel the loud empty sound of the speeding engine vibrate through your body but you are going nowhere. I thought my heart would burst out of my chest. This is for Olga, this is for Olga, I repeated to myself, over and over in my head. I felt surrounded by a bright light I could not see beyond my own hands on the lectern all I could see beyond was light. A calm swept through me, a stillness and I continued to read my tribute, the ache in my chest ever present accompanying the awareness of the non-presence of Olga with me.

I was unaware, at the time, what was happening to me. I was revisiting my birth, the feeling of abandonment. There were no words and I became my own silent witness before something engaged with me. It was the empathy of family and friends present who provided the pathway to connection and I breathed in the first breath of spring and took a tentative reluctant step into a new life. The sense of abandonment by Olga transported me back to the first experience of being separated and disconnected.

My birth, an explosion into light and sound. My body remembered and I felt the air on my skin and I began to breathe independently. I felt the pain of physical separation. There was an experience of shock, of severance and abandonment. There was a paradoxical fear of independence and/or a fear of not being able to be independent. This is what makes the womb experience mystically precious. The newborn becomes calm again when against its mother's heart. I was reliving this experience now, on the podium at Olga's funeral reading her eulogy. I could never return to the place I had always yearned for. I became calm when I felt the arms of family and friends at the ceremony hold me symbolically to their breasts. There is a lifelong body sensory memory of being in the womb and we spend a lifetime making do with substitutes. The person spends a lifetime trying to find that Nirvana again, mainly through relationships with others, especially trying to find the one, the soul mate. Looking for a soul mate is just one of many ways to describe the search for connection, the search for home. Buddhists are looking for 'non self', others to transcend self. All of which is simply the yearning to be back in the womb of pre-consciousness; to be safe, to belong and to be connected.

The forgotten childhood traumas of failed maternal attachment quietly slipped from hiding to unite with my feelings of abandonment by Olga. The familiarity of abandonment too easily filled my exhausted soul. When the energy to continue to create new ways to connect with Olga and avoid falling back into the abyss waned, abandonment filled the void echoing in my dreams, resounding through my body.

The first experience of abandonment is at our birth and we revisit this when we grieve. Our body remembers the birth experience even when the birth journey remains in the unconscious mind. During the birth process we are physically compressed and this 'tunnel'

experience where the heart races, darkness replaces filtered light, and we are squashed replaces the floating free containment of the uterus. This terrifying confinement may go on for hours or even days. This is the existential origin of our universal dread of dying. The separation from the womb and the birth experience combine to form an experience of non-existence or of dying, suffocating, drowning, that stays with us at a sensory, visceral level. Birth is our first experience of loss, our first encounter with abandonment. Paradoxically, at our birth we first fear our death.

6.2.2 Summer

Connecting with self and keeping in touch with who you are through the pain of the gradual detachment from others and the loss of childhood, we emerge an adult in full life. In the developmental analogy, it is when we transform from adolescence and become an adult, separate from parents. The relationship from being a dependent child to becoming an independent adult, looking to connect and find a soul mate, feel connected with another, be one, find safety, trust and love. In the summer of life, it is not the order and usual way of things to go into an early autumn.

When the disquieting disconnections begin in the prime of living and the wintery storms of Younger Onset Dementia begin in summer, the cold hits hard. There was no time for preparation, no time to consolidate love and dying, grief and loss together. Your loved one is becoming less able to connect and there is no preparation for the transition. You become the ‘stand-alone’ adult, and summer has gone overnight. Whilst physically still present and with you, your loved one’s ability to initiate a connection and maintain an ‘adult’ relationship has gone. No-longer do you both have an equitable role in the relationship and

the cold assault on your couplehood is left to be warmed by the standing partner not entering the fall.

There is a point when you become ‘a parent’ in the relationship process, supporting and facilitating your partner’s independence. There are no words as you silently witness your loved one’s demise. Loss upon loss, you are both dying, you are both heading for winter when you should be in the throes of summer, when the relationship flourishes and love grows in the living not in the dying. Though empathy provides the pathway to connection, you fight the paradox of feeling safe and unsafe and there is less sunshine.

6.2.3 Autumn

Following the short summer there is an erratic and unpredictable autumn. Trying to prolong the warmer days whilst often unconsciously making ready for the winter. Hanging onto the pleasure of a sun rapidly setting, there is the pull to linger and bask in the beauty of the crimson skies reflected on the waves creeping across the sands of time. Some days your loved one seems to be their old self, the conversation flows and returns to what was. Their smile, their touch and the connection is apparent. The cruel illusion fades as quickly as it flooded in. Changeable weather, with colder and more blustery conditions dominating, with fewer sunny days. Hanging on-letting go is the paradox faced of finding a pathway to ease into the future, knowing there isn’t one. The end of an everlasting voyage is fast approaching

6.2.4 Winter

With Olga’s death, came winter. Her cold frozen body lay like ice, her body did not survive, she was dead. Or so it seemed. As we know, below the ice, things are waiting for the

warmth of spring to melt the frosty crust so life can begin anew. We must endure the winter, be patient, have faith, life continues and seasons change. It is difficult when we awake in the middle of a dark winter's night, following a nightmare, to see anything other than death; there is no hope, no future, the end. It is a reality at that point. As time ticks by slowly, a second at a time, inevitably it will pass and the sun will rise tomorrow. Knowing this, it is essential to remind oneself, nothing is endless and sometimes things need to be endured to find meaning and purpose.

As we are continually living, we are continually dying. Life and death exist together, it does not start and/or end, it evolves. There has to be death to be life, sometimes it is impossible to distinguish one from the other. Does the caterpillar die or evolve into a butterfly? Finding meaning and purpose in life we need to find meaning and purpose in death. Grief, the intense emotion and sorrow accompanying profound loss and associated with death, needs to be lived in order to gain understanding of the heuristic journey of disquieting disconnection; finding meaning and purpose in life when journeying with a partner who is living and dying with S-YOD.

6.2.5 Winter To Spring

Winter freezes and stops to contain the grief, numb the pain. Time to just be. Stop. It takes the time it takes. Some winters are short and intensely cold, some are long and mild and every combination imaginable as to duration and temperature. There is no right, wrong, healthy, unhealthy. It belongs to the individual, it is their own unique journey. The darkness and cold of winter belies what lies beneath. We feel and begin to think things are frozen forever, this will never end, the sun will never shine again. Slowly the ice begins to melt from deep below, the warmth of the inner core softens the earth, waters the seeds which

gently come to life, spring begins. Sometimes slowly, sometimes overnight, we see the burst of yellow and smell the sweet scent of a new day. The sights of buds escaping their winter slumber promising tomorrows new fruit. The sun breaks through the clouds and we begin to believe that the stillness of winter was an illusion and it will pass. Things are moving as they have always been. Have faith in the order of things, see hope and hold it. Spring will follow winter and time was needed to stop, contain, reflect and be still. Winter is needed in order to rest, recover and replenish so spring can be spring.

The transition from winter to spring can be depicted through the story of a dear friend of mine who lost her beloved son without warning. He dropped dead in-front of her when he was thirty years of age. I never understood why for ten years his name could not be mentioned, if it was spoken, she would leave the room. There was no mention of anything to connect her to him. There were no words.

Her parents died when she was a child and she was raised by her grandparents. Her Grandmother died when she was thirteen and so it was just her Grandfather and her until she married. My friend felt abandoned and no words were spoken or expressed by her. Empathy, became our pathway to connection. My friend's childhood grief was never disclosed to friends. Her family knew little and she disclosed nothing of her feelings, talking to no one about her grief. I met and began my friendship with the woman I called "my Aussie Mom", ten years following the death of her son, who was born the same year as I.

It had been eleven years since the death of her son when I asked if she would accompany me to an Australian Rules football game. I'd never been. She went with her son weekly,

prior to his death, and had not been to a game since his death. Our connection melted the ice enough for her to risk going to the game with me. We went to the ‘footy’ each week thereafter. She talked about her son at every game, tears of joy, tears of sadness, spring showers, summer sun, and autumn rain. It is only now, completing this thesis, I better understand her grief and the long winter.

6.3 THE POWER OF COLOUR

Dalal (2008) discusses how so little is mentioned about colour within psychoanalytic theory and literature as it is like stating the obvious. Its absence in text reflects the obvious importance rather than its insignificant. The power of colour in expressing deep complex emotions and the power of colour upon the soul reflects a subtheme of this thesis, there are no words. To tell of blackness, darkness and the black dog, wise women witches in black, black magic, mystical, to tell of before there was light. The paradox of end – beginning, confinement – freedom. As a child I feared the dark, the blackness. I would say to my siblings ‘please turn on the light so I don’t have to see’.

Leah Kaminsky (2016) declares ‘Death is the new black’ as she concludes her book ‘We’re all going to die’. She discusses the increased disquiet about the way we tend to ‘whitewash’ the truth about our own mortality. Kaminsky (2016) describes death as being the last taboo, and how the modern culture is obsessed with blackness reflecting a paradoxical fear of the unknown, death. The coming of light, the white light, the joy of yellow, of the sun, spring time. The success of orange, of summer, of life and living, happiness, creativity. Colour transcends culture and is seen by all. The passion of red, life blood, the fading warmth of autumn fires, the darkness approaching, the courage to contain anger, and fears of the blackness of winter.

Table 6-1 places into context the meaning of colour in regards to the seasons of life, love, death and grief. The perpetual cycle and the disquieting disconnections, as well as joyful connections of living and loving.

Table 6-1 Seasons: Meaning, cycle and colour

SEASON	MEANING	CYCLE	COLOUR
Between Winter & Spring	Evolution Change in the nature of connectedness Between end & beginning	<i>Transition</i>	White Birth Marriage Men Thought Spirit Coldness Light Purity Good
Spring Growth Fresh	New beginnings New Connections	<i>Birth</i>	Yellow Joy Newness Sun Gentle Subtle Hope Happiness Freshness Energy
Summer Full Bloom Hot	In the fullness living Connecting	<i>Life</i>	Orange Warmth Energy Brightness Wealth Enthusiasm Happiness Creativity Success Stimulation
Autumn Fading Warmth	Preparing for body to die Disconnecting	<i>Transform</i>	Red Passion Blood Fire Warmth Bold Danger Courage Anger
Winter Cold	Endings Death of body Disconnect	<i>Death</i>	Black Death Sorrow Dark Women Magic Evil Bad Fear Soul

6.4 SEASONS OF GRIEF – CONCEPTUALISATION

A process of grieving evolved in a ‘Seasons of Grief’ thematic descriptive conceptualisation. The image below, Figure 6-2, is a depiction of the ‘Seasons of Grief’. The circle, like the circle of life, is ongoing. Each season follows the one before, the delineation between each season is not clear. The transition from one season to the next often occurs without realisation of the change. When does the yellow of spring become the orange of summer, when does the orange of summer become the red of autumn? Individual unique perceptions determine the time and nature of the transition.

This is the grief experience and the nebulous nature of this journey is best expressed using the fluidity of colour, a circle where there are no clear beginnings and no clear ends. White can be described as the absence of colour and black the inability to see any colour as it is the combination of all colours. The paradox of opposites being the same in terms of being unable to see colour, yet opposite in terms of all colour and no colour. This can be compared with life and death. Life is tangible because it can be seen and death is the death of the body but where is the spirit? Is there such a thing?

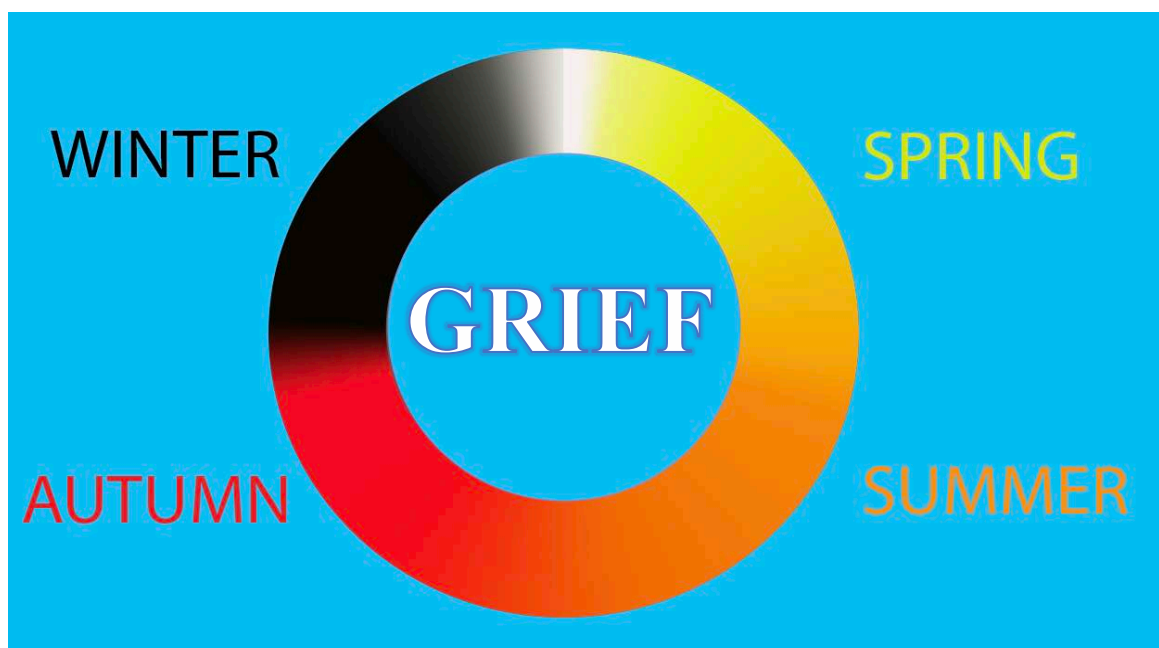


Figure 6-2 The seasons of grief colour circle

6.5 GRIEF AND ELISABETH KÜBLER-ROSS

Elisabeth Kübler-Ross (1969) planted the seed for the growth of understanding of the experience of death, dying and grief. Interviewing people living with terminal illness and their partners, family and friends she nurtured the ground to feed starving souls facing death alone. Her stages of grief served as an experience, an heuristic (Day, 2012) which blossomed and established the garden for people to walk in and tell their stories. Whilst the apple is said never to fall far from the tree, it is no longer attached to the tree from which it originated and the apple has its own unique identity.

The fruit which grew from the tree of grief first acknowledged by Kübler-Ross (1969), the concept of denial, is described as the first stage of grief and a phenomenon experienced by all (Kübler-Ross & Kessler, 2005a). Kastenbaum (1998), along with others, challenged the linear and prescriptive nature of Kübler-Ross' stages of grief, seeing the process as dynamic and unique to the individual. Whilst Kübler-Ross (1969) stated that stages can be missed and not always experienced in a specific order, it is strongly implied in her writing, and certainly it has been interpreted by many, as a set process.

Kübler-Ross' grief process is taught in schools of health worldwide in a dogmatic linear fashion. The acronym DABDA; Denial, Anger, Bargaining, Depression, Acceptance (DABDA) is used as a universal tool, applied in assessment and care planning with people experiencing grief and loss by health professionals and nurses in palliative care environments throughout the western health care system (Kübler-Ross & Kessler, 2005b). With this notoriety comes heavy scrutiny. Kübler-Ross' model has been critiqued, often harshly, as being ethnocentric and dated (Maciejewski, 2013).

The evolution of Kübler-Ross' work within a medicalised western framework diminishes her essential and primary holistic perspective. Accusations of neglecting to include essential humanistic concepts such as natural 'psychological resilience' (Bonanno, 2013), are due to viewing the application of her pioneering work rather than the underlying philosophical foundation, which is problematic and similar to applying the attributes of a tree to the assessment of an apple. The origins of the concept of denial lie within Freudian psychology where it is seen as an unconscious mental defense mechanism (Telford, Kralik, Koch, 2006). A person's inability to cope with a painful reality results in 'blocking out' (Telford et al., 2006).

Elisabeth Kübler-Ross' perspective implies a tacit knowledge and an active hidden awareness. "Denial helps us to pace our feelings of grief. There is a grace in denial. It is nature's way of letting in only as much as we can handle" (Kübler-Ross & Kessler, 2005a). An intrinsic process is suggested, if not directly expressed, by Kübler-Ross (1969). The significance of a spiritual domain identified within Kübler-Ross's four quadrant theory challenged conventional medical theory and is congruent with Kübler-Ross' philosophical perspective (Kübler-Ross, 2011).

Sher (2019) provides a contemporary critique of Kübler-Ross and supports the perspective in her article. As a medical student Sher describes her own experience of denial when her father was diagnosed with a terminal illness. With her newly acquired medical knowledge she argued with neurologists who were providing alternative, non-fatal diagnoses, to her father's diagnosis. Her father was subjected to a series of tests and unnecessary treatments before eventually she accepted the original diagnosis and prognosis. Sher explains denial provided her and her family with six months of relative peace before things became

unbearable (Sher, 2019). It is unclear what was at play in her, seemingly unconscious, denial of the fatal diagnosis. Did a different knowledge intervene in a culturally acceptable way to give an adjustment period and space for grace?

Trying to define and explain a paradoxical, nebulous concept using linear boundaries of objectivity, containment, language and words is like trying to explain to someone who has been blind all of their life, the colour gold, the rising sun changing hue uniquely each morn, yellows and golds. The sun setting casting varying shades of reds, oranges, pinks and peach over blue green seas each night. The art is the provision of sufficient containment to allow scrutiny and examination of a complex delicate concept without changing and crushing its nature by restricting its dynamic and unique nature. Yellow can be the taste of honey, red the warmth of a log fire on a winter's night, pink the smell of an old-fashioned rose and blue sadness, shades of blue missing out on the last chocolate in the box, to the loss of a beloved pet dog and more, much, more.

6.5.1 Body, Mind and Spirit

In children, grief often gets somatised and Kübler-Ross (1983) talks about this phenomenon quite extensively in her work 'On Children and Death'. Asthma in children is seen by Kübler-Ross as 'unresolved grief' and the link between breathing, the birth process, anxiety (Kübler-Ross, 1983) and had been discussed by both Freud and by Klein in her work about containment (De Bianchedi, Scalozub De Boschan, De Cortinas, De Piccola, 1988). I had not resolved my grief as a child and developed ways to contain anxiety because my mother was not present. I was only diagnosed with asthma at the time when Olga became unwell, my grief was somatised. My heart was breaking.

Journal

'...I experienced my first heart attack on 24th December in the early hours of the morning... A crushing pain in the centre of my chest began to radiate down my arm and into my left shoulder blade. I stayed still, as still as I could be. I could not breathe. In a split-second, numerous options were filtered through my mind. I must not create a fuss. This was Christmas, everybody in my family, our family, had gone to a great deal of trouble and effort to ensure we felt accepted and welcomed. I needed to stay by Olga's side. I needed to breathe, so I focused my mind and efforts on breathing. The 'elephant' sitting on my chest must be ignored. I must breathe and relax. On the 9th January 2008, when we returned to Australia, I visited my General Practitioner (GP). Following blood tests and an electrocardiograph (ECG), I discovered I had experienced a Myocardial Infarction (MI). Another minor MI followed in May 2008 and I continued to experience Angina related to emotional distress, following the initial heart attack. It was not until 2017 that I was diagnosed with Broken Heart Syndrome...'

Broken Heart Syndrome also known now as Takotsubo Syndrome is a condition seen more readily in women than men and is triggered by severe emotional stress, such as grief. Whilst it can develop at any age, it is seen most often in post-menopausal women. The word 'takotsubo' originates from the name for a Japanese octopus catching pot, as the coronary arteries constrict around the heart resembling the aforesaid pot (British Heart Foundation, 2020). The idea you can die of a broken heart, fell into folk law and the western world focused on the physical world of science and has only recently (1990) acknowledged 'Broken Heart Syndrome' or 'Takotsubo Syndrome' exists. Samuel Pepys in 1663 (Pepys, 2000) referred to the song, Barbara Allan, as an acknowledgment grief and loss can quite literally break your heart. When I was a child at school, I remember singing a folk song

entitled 'Barbara Allan' it tells a story of how a young woman rebuffs a young man's love and he dies. The last verse of the song tells of how Barbara Allan dies for her heart is broken too.

Barbara Allan

The final verse...

Oh Mother, Mother

Make my bed

Make it soft and narrow

Since my love died for me today

I will die for him tomorrow

(Anonymous, n.d.)

Linking grief with matters of the heart was viewed as a lot of romanticised superstitious nonsense. There needs to be an acknowledgement of loss and grief, it doesn't go away. Containment strategies can be adopted which may help in the short term however, if grief is not lived as a part of life and expressed, it can cause death by implosion. The body remembers grief and disconnection. So even if the mind denies the pain in order for the person to cope and survive, at some point they are physically brought back down to earth.

6.6 PERSONHOOD AND COUPLEHOOD

With Olga, I had learned to connect and now I felt the fear of abandonment as her cognition and ability to express and communicate with me became increasingly compromised and when, ultimately, she died. The sense of being a 'Person' evolves in relationships with

others (Smebye & Kirkevold, 2013). Our primary relationship is the relationship with our birth mother, whether our birthmother is present or absent after our birth. This is the foundation stone of relating and connecting with others and is in place from conception. This primary relationship cannot be overlooked when discussing the concept of abandonment.

John Bowlby and Mary Ainsworth outline in 'The Origins of Attachment Theory' from birth we yearn for and seek a return to the security, of the womb. We are in pursuit, in life, of what we lost at birth, the belongingness, safety, regular heartbeat, and quietude of the womb (Bretherton, 1992). The inability of my mother to attach or connect with me, from the time of my birth, and her inability to nurture and demonstrate love, contributed to my difficulty in attaching and trusting people (Bretherton, 1992), especially women. Melanie Klein was acknowledged extensively by Bowlby (1960), in the development of attachment theory. Klein identified how the mother contains the anxiety of a new born child; if the mother does not, then the child learns to contain their own anxiety (Bowlby, 1960).

Whilst this enables the child to survive, it leaves a developmental shortfall in developing relationships and identity. Klein repeatedly emphasised the importance of consistent, loving care in healthy development (De Bianchedi et al., 1988). Klein identified links and perceived the way children were treated was reflected in their happiness and ability to trust and develop healthy relationships (Sherwin-White, 2017). If 'healthy' attachment is not established with the birth mother, then this can occur at a later stage of development, especially in the formation of an adult romantic relationship (Pittman, Keiley, Kerpelman, Vaughn, 2011). Whilst healthy attachment did not occur with my mother, it did with my relationship with Olga

6.7 CONCLUSION

Clarity briefly arose, only to fade and then re-appear for closer inspection in another form. Constant immersion in the heuristic process led to the acquisition of new realisations. More pathways were taken and more distance travelled delivering greater clarity, allowing more processing and reflection on meaning and consideration. The creative synthesis, the final phase of Moustakas' dynamic six phase heuristic process, occurred at the stage of being most conversant and fully acquainted with findings and the journey.

At the close of this research journey, the main themes were synthesised and integrated into the experience as a whole. The connectedness with self, others and the world were established and came to light (Moustakas, 1995). The disquieting disconnections lessened and the reassuring connections dominated, giving meaning and purpose to life. As an integral part of this heuristic journey the notion of spirituality became an intrinsic factor. Because of the linear nature of the writing process, it now seemed that in the order of things, I talked about creative synthesis, however this process had been occurring throughout the journey. The information had rendered down and the flavours became more intense and more easily identified than at any other phase or time during the process.

6.8 LIMITATIONS OF STUDY AND RECOMMENDATIONS

The limitations of this study can, paradoxically, also be seen as their strengths. It is one person's journey and it can be argued it is only one person's perspective. However, the depth, intensity and close scrutiny provides insights and detail unable to be seen from a distance. Taken in context, the human experience can be applied and it can raise awareness giving new understanding as to the spectrum of the lived experience of finding meaning in death and dying.

The research process required to undertake a doctoral thesis is linear. It has a start and an end, with time constraints. On the other hand, Moustakas' heuristic process is perpetual and there is no rule as to how long immersion needs to occur before incubation and illumination occurs. Whilst understanding in the world in which we live, this is the way things are done, I was unaware how the continual battle to put a round peg into a square hole, applying a heuristic process within an academic system, would play out. Working within an objective system, using subjective processes needed for a heuristic journey is like trying to swim in sand, or run in water.

As the study, herein, is one person's perspective, it is the recommendation there be further studies highlighting the experience of others. The more lenses we are provided to look through, the richer our understanding will become. More studies on spousal experiences of living, loving and grieving a partner who lives and dies with YOD are required, in particular from those who represent minority groups. This has to be viewed in a cultural context, I am an English, working class, lesbian woman. My perspective is contextual and culturally limited. The diversity of experiences, in their many forms need to be explored, validated and spoken. Every painting is limited by the size of the canvas and the colour of paints and tools available.

The findings from this study can be helpful and supportive in assisting other spouses on a similar journey of having a partner living with and dying from YOD. Helpful, not in how to navigate the arduous terrain, but rather provide a map of where someone else has travelled, to share insights of the journey and lessen the loneliness. In regards to health professionals, these deeply personal disclosures will increase insight, for it is their understanding and kindness that will so profoundly impact upon the journeys of others.

Further, open discussion of the experience of lesbians and same-sex partnerships acknowledges difference and contributes to acceptance thus decreasing the battles and prejudice experienced by people at their most vulnerable.

6.9 PERSONAL REFLECTIONS

Disquieting disconnections, finding meaning and purpose in life when your partner lives and dies with S-YOD was an undertaking I entered into well informed, with blind faith and naivety. When I began this Heuristic journey, I believed it was going to be a way to help other people, to turn something negative into a positive. When she was first diagnosed with Dementia, Olga and I discussed how we could learn from our journey. We were beginning a difficult road and we believed in finding ways to inform and help others in a similar situations and believed it would give meaning and purpose to the cruel twist of fate happening to us.

I had no idea I was going to relive and unearth past griefs, especially my relationship with my mother. I was not prepared for the amount of exposure and deeply personal revelations required to be authentic to this process. I believed it would be confined to my grief in regards to Olga; I did not expect to be discussing my past childhood abuse, I had no idea the grief of my birth and my relationship with my mother would collide with the usual stress created by undertaking such a considerable academic undertaking.

I was searching for a concrete solution, boundaries for a nebulous concept to provide containment and safety to hold my grief, to answer the question. However, the heuristic process needs to be open to allow insights to deliver themselves and was the pathway followed on this research journey. Receiving the findings and synthesis with grace and

acceptance is required. As challenging as the process itself, this openness and receptiveness is necessary for the genuineness, credibility, legitimacy and validity of this study.

I fully appreciate the actual process I started to find meaning and purpose in life will never end and it is the research journey which is concluding. The mixing of oil and water is very difficult; although, temporarily, it can be done and it provides new understanding and valuable insights, I am relieved it is concluding and this particular learning journey separates back into oil and water...

The haunting melody along with the graphic images created by Bergman, Legrand & Bergman (Appendix B) provide a concluding sensory expression of the heuristic journey undertaken which concludes without concluding (Figure 6-3):

Windmills of Your Mind

Round like a circle in a spiral, like a wheel within a wheel
Never ending or beginning on an ever spinning reel
Like a snowball down a mountain, or a carnival balloon
Like a carousel that's turning running rings around the moon
Like a clock whose hands are sweeping past the minutes of its face
And the world is like an apple whirling silently in space
Like the circles that you find in the windmills of your mind!
Like a tunnel that you follow to a tunnel of its own
Down a hollow to a cavern where the sun has never shone
Like a door that keeps revolving in a half forgotten dream
Or the ripples from a pebble someone tosses in a stream

Like a clock whose hands are sweeping past the minutes of its face
And the world is like an apple whirling silently in space
Like the circles that you find in the windmills of your mind!

Keys that jingle in your pocket, words that jangle in your head
Why did summer go so quickly, was it something that you said?
Lovers walk along a shore and leave their footprints in the sand
Is the sound of distant drumming just the fingers of your hand?
Pictures hanging in a hallway and the fragment of a song
Half remembered names and faces, but to whom do they belong?
When you knew that it was over you were suddenly aware
That the autumn leaves were turning to the colour of her hair!
Like a circle in a spiral, like a wheel within a wheel
Never ending or beginning on an ever spinning reel
As the images unwind, like the circles that you find
In the windmills of your mind!

(Bergman, Legrand & Bergman, 1968)

Figure 6-3 Windmills of your mind: Sung by Patricia Awty (*Double click image*)



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APPENDIX A

Information pertaining to **Figure 5-7** video ‘Empathy’

This video was created by Patricia Awty. All of the artwork and the script are of her creation. The voice recording is of Patricia Awty singing the song ‘It’s only a paper moon’, lyrics by Yip Harburg and Billy Rose, music by Harold Arlen.

If unable to play video attached within Phd document, please refer to the accompanying file, Figure 5-7 video ‘Empathy’.

Instructions to play accompanying video

- To open the video place cursor over file icon of video
- An arrow appears in the centre of the icon, click twice briskly
- A larger picture will appear on your screen
- Slide cursor onto the image (the image should be of a sun and a sail boat on the sea)
- A panel appears with video controls at the bottom centre of the image
- Click once on the large triangle to play

APPENDIX B

Information pertaining to **Figure 6-3** audio ‘Windmills of your mind’

This audio was created and sung by Patricia Awty. The song, ‘Windmills of your mind’ was written by Michel Legrand (music) and the English lyrics were by Marilyn and Alan Bergman. Audio to be played to conclude the thesis

If unable to play audio attached within Phd document, please refer to the accompanying file, Figure 6-3 audio ‘Windmills of your mind.mp3’.

Instructions to play accompanying audio

- Place the cursor over the audio file icon
- An arrow appears in the centre of the audio file icon
- To start the audio click once on the arrow in the centre of audio file icon
- To stop the audio click a second time on the centre of the audio file icon