

**CHALLENGING THE DISCOURSES OF LOSS:
A CONTINUING SENSE OF SELF WITHIN THE LIVED
EXPERIENCE OF DEMENTIA**

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a continuing sense of self within the lived experience of dementia

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Certificate of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Charles Sturt University or any other educational institution, except where due acknowledgement is made in the essay.

Any contribution to the research by colleagues with whom I have worked at Charles Sturt University or elsewhere during my candidature is fully acknowledged. I agree that this essay be accessible for the purpose of study and research in accordance with the normal conditions established by the Executive Director, Library Services or nominee, for the care, loan and reproduction of theses.

A handwritten signature in black ink, appearing to read 'Bryden', with a long horizontal flourish extending to the right.

Christine Bryden AM PSM

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Who am I? This or the Other?

Am I one person to-day and to-morrow another? ...

Who am I? They mock me, these lonely questions of mine.

Whoever I am, Thou knowest, O God, I am thine!

(Bonhoeffer, 1963, pp. 19-20.)

Dementia is often described as a 'loss of self,' implying that the person with dementia at some stage loses what it is to be human. But which self are we talking about? Which of my various selves on my life's journey – child, wife, mother, grandmother? And is it my cognitive, emotional or spiritual self? At what stage in dementia can you deny me my selfhood? Exactly when do I cease being me? This talk of losing self, of becoming an empty shell, means that at diagnosis I faced the awful fear of ceasing to be, not just a physical death, but also a gradual emotional and psychological death, the long goodbye. But I reject this idea, and want to focus on who I am now and what I can still do. I can live a new life in the slow lane. The challenge is to live in a world of hope, alternatives, growth and possibility.

(Bryden, 2015a, p. 229.)

Abstract

My published work forms a portfolio of autobiographic narratives, exploring the lived experience of dementia. In my integrating essay, I use autoethnographic enquiry to reflect on a key theme in my work, that of challenging the concept of loss of self in dementia.

Written from a Christian standpoint, the integrating essay, like my body of work as a whole, aims to encourage the faith community to see people with dementia differently. I propose three aspects of a continuing sense of self within the lived experience of dementia, namely:

Embodied self: my sense of being embodied as an “I” with first-person feelings about the world around me, distinguishing self from non-self;

Relational self: my sense of being an embodied self in relationships with God and with others; and

Narrative self: my sense of being able to find meaning in life and develop a sense of narrative identity in the present moment.

I conclude that as an embodied relational self, I can find a meaningful narrative in the present moment.

As a response by the faith community, I propose a concept of “We-Thou” communion, in which we can all come before God as a community, rather than as individuals. In this communion, we are all gathered up as equals, as “We” before the “Thou” of God, and what is important is who we are, not what we do. This is the good news of the Gospel for those of us living with dementia. I conclude that enfolded within this “We-Thou” communion, *I am who I am* before God, held in grace *to* the Father, *through* the Son, and *by* the Holy Spirit. The Body of Christ remembers *for* me, and *re*-members me.

I have developed the pastoral consequences of my argument as a Letter to the Church (Appendix), proposing love drives out fear of dementia, and hospitality with delight provides a welcome for people with dementia where we feel that we belong. We need relationships overcoming our communication problems, and the faith community to be alongside us in our present moment, carrying our story, and

challenging the discourses of loss. We seek pastoral care and ministry assisting us to find meaning and nourish our spirit.

1 Introduction

The journey of becoming, of leaving behind previous perceptions of who we are, is common to us all, as part of our life's narrative. Yet those of us diagnosed with dementia fear a different journey of loss, of losing our relationships with others and even with God. Do we face a future loss of self? I have explored many of these issues in my published work, such as the fear expressed in the title of my first book, *Who Will I Be When I Die?* (Bryden, 2012.) My fears were exacerbated by social commentary, such as: "She's no longer there."

My diagnosis with dementia was in 1995, and I have published several autobiographic narratives regarding my journey, as well as a literature review on counselling and psychotherapy for people with dementia, when this was a new concept (Bryden, 2002). In addition, in my published talks, book chapters and articles, I have reflected on my lived experience with dementia from a faith perspective. In this integrating essay, I use autoethnography, in the form of a subjective narrative, to explore a key issue emerging from this body of work: loss of self in dementia.

The teacher educator, D. Jean Clandinin, writes that all "humans ... lead storied lives" (2006, p. 45); yet my diagnosis had disrupted my story of a future high-level career reliant on continued cognitive function. It confronted me with the dominant biomedical discourse of dementia of increasing brain damage leading to loss of all faculties, and I became subordinate to the power of the prognosis that I would gradually lose my sense of self and become totally dependent upon others. I felt that my story had become "re-interpreted, re-packaged, and re-presented ... to conform to the objective and scientific basis of medicine" (Clark, 2001, p. 195).

The psychosocial discourse, of dementia being a relational as well as a neurological disability, focuses on improving care of people with dementia, due to their increasing loss of capacities. Similar to the biomedical view, I had become nothing

but a condition that would set me apart from society. The psycho-gerontologist, Tom Kitwood, was an innovator in this area of care, and introduced the term *personhood*: a standing or status bestowed upon one human being, by others, in the context of relationship (1997, p. 8). He suggested Buber's I-Thou as a model for relationships with people with dementia. However, this relationship is between two individuals and differs from my proposed "We-Thou" communion (Section 6, p. 45), which is a communal gathering before God. Even if all individual interactions within the faith community were I-Thou, there would still be an important element missing, which is the gathering of the whole community as equals before God. The suggested concept of the We-Thou communion can and should be a response by the faith community to true inclusion of people with dementia, rather than simply a collection of individual interactions.

Kitwood used a humanist interpretation of Buber's "I-Thou" (Kitwood, 1997, pp. 10-12). Theologian John Swinton critiques this, writing that Buber considers God's presence to be central to our relationships (2012a, p. 142). Without God, if friends no longer visit, family members die and caregivers only care for my physical needs, I can become isolated. Philosopher Stephen Ames highlights this risk: "Defining 'personhood' as an attributed status makes personhood vulnerable as a status to be withheld [if] the person is not recognized, indeed not recognizable" (2016, p. 127). Bestowal of personhood implies a one-way relationship, in which the caregiver actively bestows, and the person with dementia passively receives. This is very different to my concept of a "We-Thou" communion, which is inclusive of people with dementia as equals alongside others in the faith community.

Person and personhood are terms used to imply having certain capacities and attributes, *as observed by others*. In this essay, written from an insider's perspective, I use the term "self," as expressed by first-person language and defined in the social constructionist literature as the "self of personal identity" (Sabat, 2001, p. 17). *Self* expresses how I have a mental representation of myself as the centre of my conscious agency, necessary for me to relate to others, and to think about thinking, deciding and doing (Brown, 1998, p. 108). This self has a mental feeling of "I" as a continuous whole throughout my life, which is making

sense of the world, interacting with my changing physical, emotional and spiritual environment.

Who am I, as a physical, emotional and spiritual being, living with dementia and examining aspects of my self in this context? I have related to the world differently over the time since diagnosis; but my subjective sense of self remains, perceiving and interacting with my changing material, social and spiritual environments. I am not simply a bundle of attributes, or a certain personality; there is much more to my life, my relationships, and my sense of unity, shaping my personal identity (Bryan, 2016, p. 13). I am far more than a deteriorating self in an increasingly empty shell of a body, with disappearing neurones and neuronal pathways.

My published work was aimed at providing a counter-story to the dominant discourses of dementia through the lens of the lived experience. By examining my changing perceptions since diagnosis, and finding new sources of meaning,¹ I have been transforming my story from a “victim plot” of decline, to an “agentic plot” of renewal (Clark, 2001, pp. 203-204). Highlighting what remains in dementia, my aim was to encourage the faith community to see people living with dementia differently. I have drawn on my faith to re-narrate dementia (see endorsement by Swinton; Bryden 2015b), and to see myself as “created, dependent, gifted and loved in all circumstances” (Swinton, 2012a, p. 164).

In the faith community, we should look beyond the dominant discourses of dementia, and include all people as being equal before God. Unfortunately, the community often shares the common view of loss of self, and finds it difficult to minister to people with dementia. In this essay, I explore the continuing sense of self within the lived experience of dementia, thereby challenging these discourses of loss. My aim is to transform views within the Christian community, in order to improve pastoral care and ministry.

¹ Meaning: life’s purpose, beliefs, goals and aspirations in life (derived from Bryan, 2016, p. 57); and who am I, why am I here, and what is my reason for existence. I write from a Christian viewpoint, but acknowledge the role of other faith traditions, nature, art, and so on, in this context.

2 Methodology

My published work forms a portfolio of autobiographical narratives, exploring the lived experience of dementia and suggesting some pastoral implications. However, this portfolio lacks an explicit integrating theoretical framework for analysis and interpretation. In this essay, I address the omission by exploring the key theme of loss of self in dementia, emerging from my earlier work. I examine some relevant literature, and engage with a few selected conversation partners (Antonio Damasio, neurobiologist; Nancey Murphy, Christian philosopher; Steven Sabat, psychologist; and John Swinton, theologian).

My essay is written from a Christian standpoint, challenging the outsider's perception of loss of self, to provide an alternative view of people with dementia in relation to others and to God. I consider that autoethnographic narrative is particularly useful for providing this insider's viewpoint. The following overview of autoethnography outlines its relevance to my enquiry.

2.1 Autoethnography

A key issue emerging throughout my published work is a fear of loss of self and of relationship to God within the lived experience of dementia. Autoethnography provides a valuable theoretical framework for engaging further with this theme, as it uses the techniques of autobiography and ethnography to analyse (graphy) my own lived experience (auto), in order to shed light on a continuing sense of self throughout dementia (ethno). It enables me to draw on my own work, as well as engage with selected literature, for deeper cultural analysis and interpretation. Importantly, by analysing a key issue arising from the experience of a cultural group (people living with dementia) of which I am a member, I have complete member researcher status (Ellis & Bochner, 2000; Anderson, 2006) and can provide an insider's perspective.

There are two major forms of autoethnography: analytical (rigorous) and evocative (emotional). Sociologist Leon Anderson outlines the five necessary features of analytical autoethnography: being a complete member researcher; having analytical reflexivity; ensuring narrative visibility; including dialogue with other informants; and undertaking theoretical analysis of empirical data (2006, p.

378). This essay is a reflexive² narrative, examining my subjective experience as a complete member researcher, meeting the first three features. However, I do not draw on texts from other informants, as I am drawing on my own portfolio of published work. I have not analysed empirical data, as this essay is a reflection on my own experience.

The alternative method is evocative autoethnography, which qualitative researchers Carolyn Ellis and Arthur Bochner describe as an autobiographical genre of writing and research, looking at social and cultural aspects of experience, and exposing a vulnerable self (2000, p. 739). These proponents of the evocative narrative write of “trying to preserve or restore the continuity and coherence of life’s unity in the face of unexpected blows of fate” (Ellis & Bochner, 2000, p. 744). This goes to the heart of my efforts to challenge the threat to the continuity and coherence of my life’s unity in the face of a diagnosis of dementia. Given the particular relevance of the evocative technique to my theme, I have chosen to use this form of autoethnography.

I consider that an insider’s voice is more authentic than that of an independent researcher (Wall, 2015, p. 153). As a complete member researcher, I am inside what I am studying, looking at how my experience has meaning (Ellis & Bochner, 2000, p. 744). How could someone who does not have dementia explore the sense of self within the lived experience? However, I am also “both an insider and an outsider” (Baker, 2001, p. 399), as I once lived without a diagnosis. I can bear witness to the experience of re-storying my life after diagnosis (Frank, 2013, p. 17). Importantly, therefore, I am not only a complete member researcher, but also once shared an outsider’s perspective of dementia.

Evocative autoethnographic texts are usually written in first-person voice, and connect the personal to the cultural in a variety of forms, such as short stories, poetry, art and journals (Ellis & Bochner, 2000, p. 739). I use a subjective narrative to interrogate my published portfolio, examining aspects of a sense of self in dementia from the standpoint of my own lived experience. As Ellis and Bochner write, “by exploring a particular life, I hope to understand a way of life” (2000, p.

² Reflexive process: interrogating the observing self (Walton, 2014, p. xii).

737), which suggests that evocative autoethnography is particularly useful for the goal of my enquiry.

My methodology of autoethnographic enquiry is important to establish an understanding of self, particularly of a continuing sense of self in dementia. I examine the faith community's response to this understanding of self, suggesting that we all need to be in relationships. Within the worshipping community, we can support each other as equals before God, in what I term a "We-Thou communion." This model is of particular value for people with dementia. As theologian Heather Walton says (2014, p. xxxii), autoethnography is a means to reflect on personal experience, in order to prompt the faith community to reconsider its responses to people in need.

In Section 6 (p. 45) I highlight the concept of a "We-Thou" communion, developing this idea as an appropriate response by the worshipping community to my autoethnographic enquiry. It is far more than relationships between two individuals, but a communal gathering in which people with dementia are included as equals in worship, recognising their continuing sense of self in embodiment, relationship and narrative (as developed in my enquiry).

Walton regards reflective³ autoethnography as a particularly useful tool for interrogating personal experience as a way to encourage the faith community "to look with fresh eyes at familiar ... practices" (2014, p. xxxii). This accords with my aim: to give the worshipping community improved insights through an investigation of a familiar, yet devastating discourse of loss impacting upon the lived experience of dementia. The intent of my essay aligns with a description of evocative autoethnography, which is "to change the world by writing from the heart" (Denzin, 2006, p. 422). I write from my heart, hoping to prompt the faith community to see people with dementia through different eyes.

2.2 Methodological challenges

There are challenges in undertaking my chosen methodology of evocative autoethnography, which arise from my lived experience of dementia. These make the process of writing and analysis more difficult, yet at the same time more

³ Reflective process: observation and analysis of roles and context (Walton, 2014, p. xii).

authentic, because my increasing impairment gives insight into my sense of self from within the lived experience.

In my published work, I have criticised the biomedical discourse (Bryden, 2015b, p. 28) that describes an increasing loss of cognitive ability, leading to views of a loss of self. The psychosocial discourse similarly focuses on loss and the need for the bestowal of personhood by caregivers. Neither discourse takes into account the impact of increasing difficulties in my daily life, nor how I experience the world around me, despite and with my dementia. They speak for me and about me, rather than letting me express verbally or non-verbally how I feel my impairment daily.

Impairment has invaded my present moment in what feels like a folded sense of time, so I am continually reminded of loss. This can be seen in my various publications, in which there is a conflict of tenses between being and becoming, and loss and gain. I have attempted to counter the discourses of loss with an alternative story, yet on occasion have returned to a story of impairment. I continue to experience this tension between my sense of a coherent self, and a fear of future loss, and on occasion I am still negatively impacted by the dominant discourses of dementia. There are also variations in my writings, from challenges to the biomedical and psychosocial viewpoints in most of my work from a Christian point of view, to a scientific stance (see Bryden, 2012, pp. 145-167), and a psychosocial perspective (Bryden, 2002). This demonstrates the difficulties that I have experienced in focusing on challenging the dominant discourses from a faith perspective.

I live with dementia, and can reflect both about and from within these difficulties to delve deeper into meaning. Although diagnosis impacted upon my concept of meaning in life, I began to resolve my fears and feelings through my published work. My continuing difficulties provide an authentic basis for my reflections in this autoethnographic essay.

2.2.1 Sense of time, recall and language difficulties

Before diagnosis, I had an anticipation of my future, as well as knowledge of my past, but now my sense of time is impaired. I experience an ever-changing flux of

the present moment, where time passing has become like a flickering light illuminating fragmented and disconnected landmarks in my life. This has been described well by the character Elhanan Rosenbaum in Holocaust survivor Elie Wiesel's novel, *The Forgotten*: "Time no longer flowed, but toppled over the edge of a yawning precipice ... He was losing sight of his landmarks" (1992, p. 262). However, my search for meaning, not an accurate recall for landmarks on a timeline, is the focus for this essay.

My awareness of the present moment, in which to explore meaning, finds resonance with Sabat's discussion of the "personal present" (Sabat, 2001, p. 232). I have an intense sense of the present, yet the discourses of dementia, as well as my impairment, "haunt[s] the present" (Frank, 2013, p. 60). However, I am still able to find meaning within this present moment, in an example of "the intriguing temporal dynamics of memories" (Baars, 2012, p. 151).

My recall dysfunction is more than cognitive recall, and includes feelings, meaning, and my flow of awareness within the lived experience of dementia. I have written of my struggle to grasp for memories, which seem just out of reach (Bryden, 2015b, p. 97). The feelings prompted by these ongoing struggles are again similar to those described by the character Rosenbaum, "But what is man deprived of memory? Not even a shadow ... I'd have preferred death to this agony of memories wrestling and drowning" (Wiesel, 1992, p. 313). However, I can challenge an outsider's view of the importance of memories from my perspective of what it feels like to have recall dysfunction, yet still be able to focus on the meaning in the present moment. This gives a very different viewpoint.

Another major challenge in my reflective writing is my decreasing vocabulary and grammar. There is no thesaurus that will help me find the word or phrase that has become elusive, as all I have left are vague concepts, so cannot search for the synonyms or antonyms. In my head "a string of pictures has formed, but the words for those pictures no longer make their way into [my] consciousness" (Bryden, 2005, p. 118). However, although I rarely find what I am searching for, nonetheless I can still reflect on meaning.

My sense of time, recall and language are gradually becoming more impaired, yet I can still explore my continuing sense of self. I grapple for words just out of reach; I

struggle with many daily tasks (Bryden, 2015a, pp. 215-229), but I am still Christine, loved by God, who can search for meaning within her lived experience of dementia. My cognition is deteriorating, but I can explore my lived experience in the present moment, and reflect on my unfolding narrative to give me a continuing sense of self.

2.2.2 Finding meaning

The fear of a future loss of self that faced me after diagnosis prompted my published work, in which I have examined issues in the context of their meaning, not their factual or cognitive content. I continue to explore meaning in this essay, recognising that: “Often a seeming tragedy can lead us to great spiritual insight and personal transformation” (Grudzen & Oberle, 2001, p. 182). I have found that God’s story has the power to repair a broken story (Swinton, 2012a, p. 24), even within the trauma and chaos of dementia.

With the fading of my factual story, a narrative approach to wisdom⁴ has helped me to explore a sense of meaning in the experience of dementia (MacKinlay & Trevitt, 2012, p. 118). Overcome with feelings of anxiety at a potential future loss of self, I needed to uncover “the strength of the spiritual dimension within” (Kuhl & Westwood, 2001, p. 322). I found meaning by turning to my faith, where at “the heart of ... Christian spirituality is God’s approach to human beings” (Swinton, 2012a, p. 174). I experienced a sense of transcendence,⁵ which can be attained by people with dementia (MacKinlay & Trevitt, 2012, pp. 92-108), as spirituality does not need cognition or language (MacKinlay, 2011, p. 43).

Despite cognitive impairment, I am able to examine my published narratives, refer to relevant literature, and reflect on the meaning of my ongoing experience in the present moment. I can give an authentic experiential account of dementia in an insider’s perspective that provides alternative insights into the discourses of loss of self. In this essay, I explore a continuing sense of self, in relationships with God and others, within a faith community. My aim has been, and continues to be, to

⁴ Wisdom: “the acceptance of our lifestory; as it is, as it has been, and also as it has not been – ‘the road not chosen’.” (Kenyon & Randall, 2001, p. 10.)

⁵ Transcendence: moving beyond self-centredness to other-centredness (MacKinlay & Trevitt, 2012, p. 86).

project a new world of possibility and “redescribe reality,” so that people with dementia can be seen in a very different way (Fiddes, 2000, p. 38).

2.3 Narrative

Considering the concept of narrative is also important, as it underpins the analysis of my autobiographical work. As methodology, narrative is described as a “qualitative or interpretative research method ... [in which] researchers study things in their natural settings, attempting to make sense of and interpret phenomena in terms of the meaning people bring to them” (Moen, 2006, p. 61). This aligns with my purpose in this essay, in which I search for meaning from within the setting of my own lived experience, and reflect on the phenomenon of perceived loss of self. I consider narrative particularly useful for this exploration, in order to transform the understanding of “that experience for [myself] and others” (Clandinin & Roziak, 2006, p. 42).

Narrative is also described as “a crucial conceptual category for ... depicting personal identity” (Hauerwas & Jones, 1989, p. 5), and as revealing the self as a whole, in its indivisible unity of body and mind (Crites, 1971, p. 85). This resonates with an exploration of a continuing sense of self within the lived experience of dementia. I examine my “inner history of self,” which gives a very different perspective to “the outer history of things” (Neibuhr, 1941, pp. 33 & 30). From this inner perspective, my essay exists within a disturbed sense of time, rather than chronological time, therefore it is not a narrative based on precise facts, but on a subjective search for meaning. The essay builds on my existing body of work in a “continuously developing narrative that is constantly forming and changing form” (Moen, 2006, p. 60), aiming to give an insider’s perspective of a sense of self in dementia, and continuing to challenge the dominant discourses of loss.

3 Setting the scene

Some underlying assumptions and a few key events shaped my sense of self and how I perceived God, before my diagnosis with dementia. These influenced the impact of the diagnosis, and were a major driver for my subsequent

autobiographic work in which I sought to examine what might continue through the lived experience of dementia, and what this could mean for the faith community.

3.1 Depending on cognition

Up until the time of my diagnosis with dementia, I was focused on cognition, and regarded my fully functioning brain as a key aspect of my self. “Being highly intelligent was so much a part of who I was. My brain was my identity” (Bryden, 2015a, p. 139). I was task-oriented in my work decision-making, as well as at home, and saw the world through the lens of my intellect.

3.2 Conversion

In 1990, I had a Christian conversion experience: “I felt filled to overflowing with joy and peace” (Bryden, 2012, p. 132). I experienced emotional and spiritual aspects of my sense of self, within the faith community, and my conversion was an ongoing process of transformation and autobiographical reconstruction within this new community (Green, 2008, p. 128). My conversion experience gave me an altered conceptual framework of “those patterns of thinking, feeling, believing, and behavior that animate our lives” (Green, 2008, p. 98). This new framework became the basis for re-evaluating aspects of my sense of self (Bryan, 2016, p. 19), although cognition was still of paramount importance in my work.

3.3 Diagnosis

Diagnosis with dementia in 1995 had a profound impact, because of my focus on intellect. In contrast to the experience of conversion, in which I had discovered positive aspects of a sense of self within a faith community, diagnosis was a negative and isolating event. My cognition was threatened by my diagnosis, and the discourse of loss of self led to an overwhelming fear of future non-being, which was an existential fear, described as “the anxiety of not being able to preserve one’s own being” (Tillich, 1969, p. 47).

In one of my first talks after diagnosis, I described “the toxic power of the ‘pointing bone’ of diagnosis ... [resulting in] extreme fear of further loss, and dread [of] what the future holds” (Bryden, 2015b, p. 20). I turned to the Bible, to such verses as,

“My God, my God, why have you forsaken me?” (Matthew 27:46),⁶ as I struggled with fear and a crisis of meaning. I spoke of how I felt cast out into what felt like the valley of the shadow of death (Bryden, 2015b, p. 19), and later wrote: “Like Job, I trembled with fear: “Truly the thing that I fear comes upon me, and what I dread befalls me” (Bryden, 2016, p. 9; quoting Job 3:25).

Diagnosis was my nadir, yet eventually I was able to find some comfort in the Christian hope of resurrection. This hope underpinned a transformation of my narrative,⁷ as did being supported within a worshipping community. I began to regard cognitive ability as being less important than an ability to love and relate to God and to others. I wrote: “in the face of declining cognition and increasing emotional sensitivity, our spirituality can flourish as an important source of identity ... [we] can be given meaning as a transcendent being ... restored in a relationship with God” (Bryden, 2015b, p. 19). However, I was still on occasion overwhelmed by fear.

During the months of the diagnostic process, I was on team preparing for a Cursillo,⁸ where I met Elizabeth MacKinlay. Realising that she was both a gerontologist and priest, I asked her to journey with me into my unknown future. We became the “storyteller and the story listener,” as we explored a practical theology of my journey with dementia (MacKinlay, 2016, p. 29). My questions were: “Is it possible to find meaning in dementia?” and “Will I lose God as I travel into this disease?” (MacKinlay, 2016, pp. 26 & 27.) Our shared reflections prompted my autobiographic efforts to find meaning, including a re-examination of my perceptions of God and of my self.

3.4 Perception of God

Although I was reassured that God’s move towards humanity lies at the heart of the Christian faith, my understanding of God was caught between my conversion *experience*, and my search for *knowledge*. I felt that I needed more knowledge, and was focused at that time on *knowing about* God, rather than *knowing* God.

⁶ All Scripture quotations are from the NRSV version, Metzger and Murphy, 1991.

⁷ Psychologist and Methodist preacher Jocelyn Bryan has discussed the impact of the Christian narrative of salvation in the transformation of life stories (2016, p. 177).

⁸ Cursillo: global movement for spiritual renewal in the Christian church, in which participants share experiences through teaching, sacraments and devotions, in fellowship and trust.

Reassuringly, Swinton describes the latter as requiring “much more than memory, intellect, and cognition”(2012a, p. 15).

I had a limited understanding of the words: “by grace you have been saved through faith, and this is not your own doing; it is the gift of God – not the result of works, so that no one may boast” (Ephesians 2: 8-9). I could not grasp the concept of a free gift of grace, nor God’s unmerited favour. Although I had learned about grace in Bible study, it was a cognitive concept, not a spiritual understanding: I was trying to explore Scripture through the lens of knowledge.

3.5 Perception of self

My fears after my diagnosis were exacerbated by my dualist view of what I thought it meant to be a self: a person with a mortal brain/body, and an immortal spirit. I thought I was made up of these two parts, and was focused on being an independent thinking self,⁹ without considering my emotions and relationships. I was reminded each Sunday of my mistaken belief in the importance of reason by the words used in the liturgy: “you shall love the Lord your God with all your heart, and with all your soul, and with all your *mind*, and with all your strength” (Anglican Church of Australia, 1995, p. 102; my emphasis).

My concern was: could I still love God, if I no longer had an intact brain/mind? However, I was reading the Bible from a post-Enlightenment perspective, and focusing on the word “mind” in this command. Biblical scholar Joel Green discusses the polysemous nature of the various words used in the Hebrew and Greek texts, and concludes we cannot discern answers as to the original understanding of the words translated as mind, heart and so on, but we are to love God with “the entirety of one’s being” (2008, p. 64). Theologian Hermann Spieckermann describes the “heart” as being of crucial importance in the Old Testament, responsible for all those activities that today we associate with other parts of the body, such as the “mind” (2014, p. 255). In addition, there are numerous references to “heart,” showing its importance to Old Testament authors as a “source of thoughts and reflections” (Basson, 2007, p. 310).

⁹ Thinking self: having reason and reflection, able to consider itself as self, the same thinking thing in different times and places (Locke, 1975, p. 335).

I now realise that I had misunderstood what the word “mind” meant, believing it was reliant on an intact brain, and that I had a very limited understanding of Scripture. This was affecting my perception of self and my relationship with God, and had particular impact on my reaction to a diagnosis with dementia.

4 Selecting my theme: challenging loss of self in dementia

In my published work, I have described the trauma of diagnosis with dementia, resulting from my view at the time that brain equals mind equals self: therefore a gradual loss of brain would mean loss of self. For example, I wrote, “Having a disease which takes away your mind” (Bryden, 2012, p. 97); and “As I travel towards the dissolution of my self” (Bryden & MacKinlay, 2002, p. 74). These words demonstrate how important it is to challenge these discourses of loss, which dominated my perceptions after my diagnosis with dementia.

Dementia is described as a condition where “the mind is absent and the body an empty shell” (Alzheimer’s Disease International, 2000, p. 1). This bleak picture of loss of self is reflected in the psychosocial discourse, which focuses on the need for improved care of people with dementia, as their families face the “departure of a loved one” (Kevern, 2010a, p. 238). Such views have the power to position us negatively, so that we become “imprisoned in a web of negative stereotypes” (Sabat et al, 2011, p. 286), subject to malignant positioning.¹⁰ There is a resultant stigma, which I consider is an attribution assigned to us due to our supposed deviation from the norm. The label of dementia isolates us, so that “we live within a complex web of social encounters that are tainted with stigma” (Bryden, 2015b, p. 111), because society values competence, intelligence and autonomy, and devalues those of us who appear to be unable to demonstrate these attributes.

The biomedical discourse of dementia is of cognitive and neurological loss, measured by neuropsychological tests and brain scans. These tests are carried out in a clinical environment devoid of any relationships. However, we all function best as communal beings, despite our differing cognitive capacities, and as MacKinlay writes, “Human beings do not exist in a vacuum, in isolation, yet

¹⁰ Malignant positioning: “incorrect, or at least questionable assumptions” that lead to a person with dementia feeling despair at have no value and becoming a burden (Sabat, 2001, p. 124).

sometimes, the way that dementia is defined in the biomedical paradigm, this would seem to be the case” (2016, p. 33). How can my sense of self be measured, if my relationships with God and with others are ignored? “Just as God is not an isolated person but is considered always in relationships ... so a human person is never to be considered in isolation from the rest of humanity” (Allen & Coleman, 2006, p. 213).

People with dementia become described by a set of standard cognitive defects, where the “clinical approach assumes that our brains, our life histories and our individual life experiences are all the same” (Bryden, 2015b, p. 204). “We have lost not only our identity, but also our diversity. Everything that once made us a unique ... individual with value to society, has been lost” (Bryden, 2015b, p. 274). Everything about us is due to neurological loss. In this regard, John Swinton refers to the novel *Scar Tissue*, in which a philosopher professor loves his mother for *who she is*, despite her dementia, in contrast with his neurologist brother who only sees *what is being lost*: it shows “a disjunction and a tension between medical accounts of dementia and the lived experiences of dementia” (2012a, p. 33). Indeed, my cognitive defects are not the place to begin to think theologically (Swinton, 2012a, pp. 43-44), yet many writers, including pastoral caregivers and theologians, do so. Shortly after diagnosis, I was shocked to read theologian David Keck’s words that a loss of memory might lead to the “apparent disintegration of a human being” (1996, p. 15); and his description of dementia as “Destruction Incarnate” (p. 21), where “when there is no self, there can be little self-realization” (p. 38). I sought a counter-story to challenge Keck’s view of dementia, and wrote of how as my cognition fades, my spirituality is flourishing as an important source of identity: “I can seek an identity by simply being me ... My spiritual self is reflected in the divine and given meaning as a transcendent being” (Bryden & MacKinlay, 2002, pp. 71-72). In my first book, I wrote:

We are each a kaleidoscope of personality, which makes up every facet of who we are. But often we are limited in our range of expression of this multi-faceted person, because of our busy-ness, the demands and constraints, the expectations of our lives. I believe that God knows us in our entirety, each and every part of this kaleidoscope of who we are. As I unfold before God, as this disease unwraps me, opens up the treasures of what lies within my multi-fold personality, I can feel safe as each layer is gently

opened out. ... In each of these aspects of my life, the centre of my being will always be there, expressing itself in these many forms of me. This unique essence of 'me' is at my core, and this is what will remain with me to the end. I will be perhaps even more truly 'me' than I have ever been." (Bryden, 2012, pp. 62 & 64.)

I knew that I had changed in my functionality, becoming slower, less vibrant and interconnected in my thought process, and yet I felt there was still more to me. I began to see my dementia as a gift within which to "to travel this path of making meaning in life, and of discovering the glory of God within me" (Bryden, 2005, p. 158), where I was making "an important journey from cognition, through emotion, into spirit" (p. 159). I wrote of a stripping away of masks: of my cognitive work-self, then an increasingly jumbled emotional self, towards my true self (Bryden, 2005, p. 159). I described this as a "journey into the true centre of our being – our spirit deep within" (Bryden, 2015b, p. 292).

In my published work, I expressed these differing senses of self in inner and outer terms, emphasising the inner as the spirit, and the outer as the body or brain. This inner/outer distinction reflected my perceptions around the time of my diagnosis of being a dualistic self; yet now I know that I am a body, just as much as I am a mind. Theologian Owen Thomas notes that a sense of "interiority" is a relatively recent point of view, first emerging in its most developed form with Augustine, and that "inner" and "outer" are spatial metaphors for non-spatial domains (2000, p. 56). Green refers to these domains as dialectical, rather than ontological, pointing to St Paul's "inner" and "outer" in his letters, and the Apostle John's "above" and "below" (2008, p. 11). Despite dementia, I am being made new in a transformation through the work of the Holy Spirit acting on my whole body, strengthened in my "inner being with power through God's Spirit" (Ephesians 3:16).

5 Continuing sense of self within dementia

The quote from the philosopher Rene Descartes expresses the basis for my enquiry into a continuing sense of self within the lived experience of dementia: “I am conscious that I exist, and I who know that I exist inquire into what I am” (1637, p. 88).¹¹ However, the common view would question my ability to do this, due to my decreasing cognitive abilities, with many arguing that a loss of sense of self occurs at some time during the lived experience of dementia. The purpose of this essay is to challenge this discourse of loss with an alternative perspective.

In the following sections, I propose and define three aspects of a sense of self that can continue within dementia, namely:

Embodied self: my sense of being embodied as an “I” with first-person feelings about the world around me, distinguishing self from non-self;

Relational self: my sense of being an embodied self in relationships with God and with others; and

Narrative self: my sense of being able to find meaning in life and develop a sense of narrative identity in the present moment.

I conclude that as an embodied relational self, I can find a meaningful narrative in the present moment. I explore the basis for my assertion, with my aim being to demonstrate how people living with dementia can have a continuing sense of self, so that the church can respond in improved pastoral care and ministry.

Drawing from understandings of Christian anthropology, I know that I experience my life as a body/spirit unity, inspired and empowered by the Holy Spirit (Anderson, 1998, p. 189). I am a heart and body, as much as I am a brain, able to relate to God, to others and to the world. My sense of self cannot be measured by examining neurological defects, as I also have thoughts, images and feelings, although I am losing the ability to express these clearly. Importantly, I know who I

¹¹ Descartes’ view of the body being separate from the mind led to his conclusion that “I think therefore I am.” His Cartesian dualism contrasts with modern Christian views of a holistic view of being, in which we are “psychophysical unities” (Murphy, 2006, p. 22). Modern scientific dualism is seen in claims of what the brain can do or perceive, which is criticised by Sabat (2010), who points out that we are not a body and a mind, but a whole living human being with bodily, spiritual and psychological capacity. Combatting dualism is important in this essay, to address the assumption that as my brain deteriorates, so does my sense of self. It is in and through my body (including my brain) that I express my inward/outward life.

am, and have the ability to distinguish self from non-self. My inability to recall or express information has no impact on my sense of self; yet being able to do this is important in our “hypercognitive culture” (Post, 1995, p. 5). In this description of modern society, our worth is measured by what we know, do and say, and by what we achieve in regard to expectations of rationalism and productivity: these expectations challenge those of us whose cognition is failing.

My cognitive abilities might be decreasing, yet I continue to have a sense of embodiment, in relationships with God and with others, within the faith community. I am the self, knower, subject and agent for my “I” thoughts, which occur in relationships with others around me, and there has been no disruption at any time since diagnosis to my subjective sense of being Christine. The medical ethicist Stephen Post refers to this stability of self: it “is nonsense to bifurcate in any strong sense the self into ‘then’ and ‘now’” (2006, p. 231). I am still the same self and will remain so throughout my lived experience of dementia “despite behaviour and communication having changed” (Allen & Coleman, 2006, p. 206). Why should problems with my recall, sense of time or language diminish my sense of self? I continue to be “me” and to see the world through “my” eyes, in the present moment. From this insider’s viewpoint, I know that I am the same self who existed a while ago: even if I cannot remember the facts or feelings of what I did or felt at that time, this does not mean that I have lost a sense of self.

In today’s Western society, having a thinking self is commonly associated with the brain, giving rise to the view that dementia due to increasing brain damage means a loss of self. Indeed, I am losing the ability to keep track of myself at different times and places, which is a loss of a “thinking self” in the Lockean sense (Holton, 2016, p. 256). However, a focus on this thinking self can lead to the view that there is a loss of self with loss of recall, but when we sleep, we are similarly unable to keep track, although still have a sense of self (Holton, 2016, p. 258; Swinton, 2012a, p. 123). This simple analogy highlights the absurdity of assuming there is a loss of self in dementia. I continue as “me” in the present moment, despite not being able to trace this sense of self accurately over time.

Perspectives on loss of self in dementia have come from outside observers, who can only imagine whether this actually occurs; they cannot *know*. The voices of

people with dementia are more recently becoming heard, and from such an insider's viewpoint, I know that I am an "I," and this "I" is inquiring into who "I" am. What is the "self" and is it solely due to the brain? How can the brain give a subjective awareness of the world? To what extent has science, philosophy, psychology or theology advanced our understanding? Can I counter the modern view of the neurological primacy of the brain as the seat of the self?

5.1 Embodied self

My sense of being an embodied self¹² includes living with dementia, as this is who I am and who I will be until I die. The view of outsiders as to whether I am still "me" presumes that I have forgotten who "I" am, and that with a loss of language and of recall, a sense of self is lost. For example, Swinton writes, "Am 'I' still 'me' when 'I' have forgotten who 'I' am?" (2012a, p. 91). However, my sense of self continues, despite me being unable to keep track of memories because of "the erosion of the temporal glue" (Post, 2006, p. 225). Even if my recollection of taking my tablets a few moments ago has gone, or I cannot find the word for tablets, I still exist as "me" in the present moment. My sense of being an embodied self continues within dementia: I see the world through my own eyes, and it is "that part of me when I am with myself" (Reinders, 2008, p. 21). I suggest that this remains intact in dementia, despite linguistic, thought-ordering and recall dysfunction. Although I am losing capacities to express this sense of self, I still have unique personal characteristics, which are not lost because of failing cognition. Even if I have lost a reliable connection with my past, and to the future, I am the Christine who, even without language, has the *feelings* of "What is happening to me?"

I will always continue as an embodied self who can be addressed as "you" and who asks the question: "Who am I?" This experience of embodiment is very similar to the Self 1 described by neuropsychologist Steven Sabat: my self of personal identity, who thinks of her experiences and beliefs in the first person (2001, pp. 17-18).¹³ I sense that I continue to exist, moment-to-moment, relative to my

¹² Embodied self: I define this as my sense of being embodied as an "I" with first-person feelings about the world around me, distinguishing self from non-self.

¹³ Social constructionist definition: Self 1 of personal identity, experienced as my point of view and expressed through use of person pronouns; Self 2 of my unique mental and physical attributes, e.g.

surroundings, and can express this by saying “I,” “me” and “my” to locate myself in my psychosocial world. This embodied self also includes aspects of Sabat’s Self 2 (2001, p. 18): my mental and physical attributes and beliefs, such as being a Christian, a former scientist and policy advisor, and now having a diagnosis of dementia. I am aware of changes to my Self 2, due to dementia, so I feel despair at “who I am not, but might otherwise be” (Sabat, 2001, p. 117). My constant struggle is not only to battle with my neurological deficits, but also with the external discourses of loss.

Recognising my continuing sense of being an embodied self within dementia is important for regarding me as having a valid subjective perspective. As Post writes, “What is morally relevant is the experience of subjectivity, of myself as a subject in the sense of being conscious of self as self” (2006, p. 230). My sense of being an embodied self sitting here writing and editing this essay is the same embodied self that sat here a moment ago, even if I cannot recall that moment. This is my sense of being a continuing embodied self, whom I am, then and now, and my damaged brain has not diminished this sense of being present.

5.1.1 Scientific views of embodiment

What we know from science is about the brain, not the self, and as the Christian physicist John Polkinghorne observes: “there is an ugly big ditch yawning between scientific accounts of the firings of neural networks ... and the simplest mental experience of perceiving a patch of pink” (1996, p. 53). How can a brain study itself and identify facts and evidence for what it means, for example, to perceive a patch of pink? How do I know that you perceive this patch in the same way?

I am not a brain in a laboratory, but a self that is situated in my body, of which the brain is but one part. Sabat critiques the attribution of aspects of psychological experience to parts of the brain, emphasising how the brain is a part of the body and cannot operate alone, and noting how this is “creating a new form of Cartesian dualism” (Sabat, 2010, p. 168). The brain is not the self, nor can it interpret or do anything. My brain and my body act in concert: it was my body that first arrived in this world, and then I began to perceive what was around me. I have developed

being Christian and having a diagnosis; Self 3 of personality and character, how I am seen by others in social interactions. (Sabat, 2001, pp. 17-18.)

awareness about what is exterior to my body, and what is part of it, and in that sense my thoughts and bodily perceptions are included in my sense of embodied self. The brain cannot give me this sense of self, as it is part of who I am as a whole unique person of intrinsic value: “a unity that is compiled of different facets,” such as my embodied existence and my experience of the world around me (Sabat, 2010, p. 174).

In order to explore my sense of embodiment, I draw on the ideas of the neurobiologist Antonio Damasio, whose work is well informed by brain research. He proposes that created *within deep brain structures* is a “proto-self” (Damasio, 2010, pp. 20-21), which gave me my feelings of existence prior to my consciousness arising. Damasio suggests this proto-self provided an integrated collection of neural patterns within and about my body (2010, p. 190), interpreting the world, interacting with my brain and having primordial feelings. Next to arise was the “core self” that modified this proto-self to provide a series of images and was able to distinguish self from non-self, and “constitutes a material ‘me’” (Damasio, 2010, pp. 20-23). If Damasio is correct, then I can rely on deep brain structures to be resistant to ongoing brain damage throughout dementia, so that I can have a continuing sense of being an embodied self, with feelings of existence, separate from my surroundings.

Nevertheless, Damasio refers to people in the late stages of dementia as being “shells of the human beings they once were” (2010, p. 233). This appears to contradict his idea of a self that emerges from structures that I assume can resist the type of brain damage resulting in dementia. How can I become a shell, if my core self remains deep within my brain stem? In contrast, I suggest that both my proto-self and core self continue throughout dementia, dependent on the persistence of the brain stem, giving rise to a continuing sense of being an embodied self. I might have reduced recall of past events and difficulties with language, but will have consciousness, awareness of self and non-self, as well as feelings, imagery and a sense of embodiment.

Other neuroscientists also hypothesize a neurophysiological basis of self, such as D. P. Matyushkin (2008), who notes that his views agree with the available data and the ideas of Damasio. The existence of what Matyushkin calls a lower self,

based on a subcortical neuronal network, is confirmed by some experimental electrical stimulation studies and appears to correlate with Damasio's core self. Matyushkin writes of a higher self having acquired knowledge, through memory, for evaluation and environmental interactions. I consider that, at a minimum, the lower or core self persists throughout dementia to give me a continuing sense of embodiment and an ability to distinguish self from non-self.

5.1.1.1 Recall dysfunction¹⁴

An important feature of dementia is problems with recall of past events, yet the neurological architecture for this difficulty is not well understood. We appear to perceive, learn, and manipulate information in an interaction of neuronal pathways to interpret, record and perceive events, with complex patterns for storage and mechanisms of access in a dispositional network of maps and images (Damasio, 2010, p. 135). Given this complexity, at least some of these neuronal pathways might persist in dementia, so as to account for the retention of *procedural* (knowhow), as well as aspects of *semantic* (conceptual) memory. This might explain the so-called "lucid episodes" observed by caregivers (Aquilina & Hughes, 2006, p. 145). What is feared most in dementia is the loss of *episodic* memory, or an ability to recall past events, as the outsider's perception is that this means loss of self. However, this assumes that my sense of being an embodied self is dependent on recalling what I did, rather than on *knowing who I am*. In addition, not all of episodic memory is lost, and it seems that within my neurological architecture, prompts can provide access to neuronal pathways.

An experimental verification for recall for past events persisting, potentially due to the retention of deep brain structures and neural pathways, is the finding of Sabat that people with dementia could be prompted to retrieve some recall of past events (2001, p. 45). I use a variety of prompts to assist in recall, which "is as if the printer ink is running low and it sometimes works and sometimes doesn't ... It is such a hit and miss approach to a life gone by" (Bryden, 2005, p. 106). For example, I use the personal calendar application iCal so as to remain oriented to the current day, past events, as well as future plans. If I have a mental blank when

¹⁴ The term 'memory loss' is often used in dementia, but is more correctly referred to as 'recall dysfunction.' My memories remain, but I need additional prompts to recall them.

looking back in time, I can retrieve some memories from iCal, but: “if something is not written in the diary it has not happened or will not happen. Ask me how my day was and I’ll have to look at the diary and find out” (Bryden, 2015b, p. 130). By seeing what is written, I am given a chance to recognise an event and to be able to retrieve it, otherwise my past and future are devoid of events. This appears to be *recognition* memory, reliant on an external prompt, rather than episodic memory that accurately recalls the flow of events over time.

5.1.2 Philosophical views

Among modern philosophical accounts of the embodied self are arguments for causal reductionism, in which I am ‘nothing but’ my neurones. This gives rise to the conclusion that dementia due to brain damage indeed leads to loss of self, which has been a dominant position, particularly among atheistic scientists. The Christian philosopher Nancey Murphy offers an alternative, which takes into account contemporary scientific views of the retention of a sense of self within deep brain structures. She has developed the concept of nonreductive physicalism, which suggests that I am far more than ‘nothing but’ my neurones, and have a sense of self. This concept allows for divine action supervening on natural events, so that science and theology together can describe the unique nature of humanity and its ability to relate to God through bodily capacities (Murphy, 1998, pp. 147-148; 2006, p. 111).

Nonreductive physicalism gives an explanation for my capacity for emotion, morality and spirituality, without recourse to body-soul dualism. It goes beyond the idea of ‘bottom-up’ causation of my actions (or reductionism), to include downward causation, so I cannot be reduced to brain damage alone: my higher level capacities are dependent on lower level processes, yet also causative in their own right, emerging from complex interactions of the entire brain. Presumably these lower level processes occur within deep brain structures, resistant to the brain damage resulting in dementia. Complex patterns of interaction with the environment have effects on the developing brain in “a dynamic interplay between neurobiology and environment” (Murphy, 2006, p. 101), which includes evaluating cognitive processes in a process that Murphy calls “self-transcendence” (p. 89). The neural complexity involved gives me moral capacity (Murphy, 2006, p. 91),

including the ability to hear and obey God (p. 103). Similar to Damasio's ideas of a dynamic relationship between my deeply embedded proto-self and the environment, resulting in a core self (2010, p. 23), nonreductive physicalism can account for a continuing sense of embodied self in dementia.

Murphy (2006, p. 95) discusses the ability to distinguish self from non-self, and quotes from analytical philosopher Patricia Churchland (2002, p. 309) that such capacities for self-representation emerge in children and *decline in people with dementia*. Concurring with Churchland's view appears to counter Murphy's own arguments of the complexity of the entire brain, and that I am more than my neurones (Murphy, 2006, p. 151). If I am more than my neurones, as she proposes, how can I lose my concept of self on the basis of a loss of some of these brain cells? Churchland herself refers to Damasio's proto-self as the nonconscious platform for higher levels of self-representation (2002, p. 310), which accords with Murphy's reasoning that higher level capacity is dependent on lower level processes.

The three thinkers, Damasio, Murphy and Churchland, have not explored the potential for the persistence of deep brain structures throughout dementia, nor the implication that this would give a continuing sense of self. In addition, there needs to be further consideration of the neuroplasticity of the brain in the face of assaults to its structure. Certainly, I have experienced a degree of such neuroplasticity occurring since my diagnosis, as a result of continuing to challenge my brain, such as by writing this essay. My conclusion is that dementia should not take away my capacity to hear and obey God, as I am far more than my decreasing neurones, and can rely on my life experiences, as well as on God's intervention, for my continuing sense of embodied self, even through the ongoing loss of neurones and neural pathways.

5.1.3 Retention of virtues

Virtues are an important feature of the continuing embodied self, as described by Sabat for Self 2 (2001, pp. 17-18). The retention of virtues has been observed amongst residents of a care facility, who demonstrated mutual care, compassion and concern (McFadden et al, 2000, p. 80). Similarly, Sabat finds continuing virtues in his conversations with people with dementia (2001, pp. 307-308), for

example identifying empathy in Dr. B., who had concerns over Sabat's wellbeing (p. 56). These observations are also supported by a philosophical thought experiment described by Murphy, which shows the importance of a sense of self over time being a mix of continuity of embodiment, as well as of virtues (2006, p. 137).

The philosopher Alasdair MacIntyre discusses the importance of virtues, highlighting giving and receiving in a network of relationships as a virtue of acknowledged dependence (1999, p. 108). He proposes that providing care demonstrates the virtue of independent rational agency, and receiving care the virtue of acknowledged dependence (MacIntyre, 1999, p. 85). His statement: "I can be said truly to know who and what I am, only because there are others who can be said to truly know who and what I am" succinctly suggests the importance of relationship (MacIntyre, 1999, p. 95). Relationships are critical to us all, particularly for people with dementia, which I consider in the following sections.

5.2 Relational self

Dementia is a complex interaction between neurological impairment and social interaction, and is as "much a relational disability as it is a physical or neurological one" (Swinton, 2011, p. 177). The importance of relationships to us all is expressed very well by Post, who writes, "I feel and relate, and therefore, I am" (2006, p. 233), which is in contrast to Descartes' dictum: "I think, therefore I am" (1637, p. 168). A focus on thinking, rather than relating, can exclude people with dementia, but by exploring my embodied relational self,¹⁵ I propose the difficulties due to cognitive impairment can be overcome. This sense of relational self includes aspects of the Self 3 described by Sabat (2001, p. 18), such as my personality and character, and how I am regarded in social situations.

We are all embodied selves who relate to one another as an "I" and recognise an "I." This does not need cognitive ability such as language: when I meet a Japanese friend, we become "we" in a sacred space of two selves communicating without language. We relate to each other in terms of Buber's 'I-Thou' when I see her as an "I" and she sees me as an "I," and between us is a connection in the spirit: "Spirit is

¹⁵ Relational self: I define this as my sense of being an embodied self in relationships to God and to others.

not in the I but between I and You. It is not like the blood that circulates in you but like the air in which you breathe" (Buber, 1937, pp. 88-89).

I do not have the same cognitive capacity as I once had, yet still have a sense of embodiment as an "I" *in relation* to the world. My "I" connects "me" over time, including a material, social and spiritual "me," to create a sense of continuity. My social "me" is formed in relationships with others; my spiritual "me" is developed in connection with God, so that I have developed a sense of being a storied spiritual being (Poll & Smith, 2003, p. 130). I do not feel any less "me" and there have been and continue to be important learnings into this journey with dementia, which is part of my temporal life, towards the Christian hope of bodily resurrection into eternal life. However, my ability to do spiritual practices, and to remember and describe them, is being impacted, yet my "inherent holiness is not affected by neurological decline" (Swinton, 2012a, p. 174). I do not need fully functioning neuronal pathways to have a sense of being an embodied spiritual "me" and therefore I support the view of theologian Ray Anderson that the "existence of brain cells is a necessary but insufficient condition for the expression of [my] spiritual being" (1998, p. 188). There is much more to me than simply my deteriorating brain, and my "spiritual self-identity ... is contingent upon the Spirit of God both as to its formation and growth" (Anderson, 1998, p. 188).

5.2.1 Relating to God

The most important relationship for my continuing sense of self is with God, which is not dependent on my cognitive abilities, my spiritual experiences, or my ability to talk about these. I know that I *experience* God's love, even if I can no longer *express* this experience clearly to others. My inability to describe my experiences of God does not mean that I do not have them, which underscores the importance of an insider's view to examining a continuing sense of self in dementia. My relationship with God "is in no way compromised if grounded in neurological substrate ... a graceful God remains present ... to the very end" (Post, 1998, p. 211), and I continue to have the unique human capacity to relate to God and to others (Brown, 2004, pp. 67-68).

From the Christian viewpoint: “We know each other not as brains ensheathed in bodies but as embodied persons. We are people who relate to each other as beings created in the image of God” (Jones, 2004, p. 31). Indeed, a theology of self, based only on embodiment, fails to understand the importance of relationships to us all, including people with dementia: “It is not good that the man¹⁶ should be alone; I will make him a helper as his partner” (Genesis 2:18). Although this verse relates to the creation of woman, it demonstrates the importance of relationships to God and to each other, where relationality is constitutive of God’s being, just as relationality is constitutive of my being (Shuman, 1999, p. 91). Furthermore, Brown discusses how we relate to God “in a manner that reaches deeply into the essence of our creaturely, historical, and communal selves” (1998, p. 101).

I cannot lose my membership of humanity, nor my ability to relate to God, simply by losing my neurones, and can still express my spirituality within the faith community, where we all are dependent upon God (Swinton, 2012a, p. 162). Being in relationships is an integral part of being human: “Human existence ... is always lived out within human community ... To be a person is to be a member of the human race” (Swinton, 2012a, p. 156). Indeed, as my cognitive ability fades, I have felt a greater sense of emotional connection within the faith community, and an increasing relationship with God, and wrote, “The scrambling of my cognitive and emotional abilities has not diminished my spirit, or my relationship with the divine” (Bryden, 2016, p. 14).

Through God’s eyes I can be seen as perfect and reaching the fullness of my spiritual being, in and beyond this temporal life, “for what can be seen is temporary, but what cannot be seen is eternal” (2 Corinthians 4: 18). I have gained great reassurance from placing my cognitive struggles in this context: “It is rather my eternal life that is important, and that remains ... through and beyond this journey with dementia” (Bryden, 2005, p. 168). I relate to God in the stillness of muddled thoughts, with a sense of timelessness, where “there is only one safe place: ‘here’ with God” (Bryden, 2016, p. 11). My prayers have become dependent on the Spirit, who “helps us in our weakness for we do not know how to pray as we

¹⁶ The word used, adam, is ambiguous, and gender is not important; rather, the meaning is that to be fully human, we need to be in relationships of mutuality and interdependence (see Metzger & Murphy, 1991).

ought, but that very Spirit intercedes with sighs too deep for words” (Romans 8:26). Despite cognitive difficulties, within the liturgy I have a sense of spiritual connection with God, through the familiar words of the Lord’s Prayer and in sharing the Eucharist within the fellowship of my faith community.

5.2.2 Relating from birth

My embodied relational self is a way of *being*, not *doing*; I am part of the human family, relating to God and to others from birth till death. Philosopher John Macmurray argues that the newborn relates to her mother and is able to communicate her needs from birth (1999, pp. 48-50). My mother regarded me from the moment of my birth as an embodied relational self, never as an empty shell of a body until I had full capacities. I could then, and will continue to express my needs in relationship until death. As Swinton points out, a mother *teaches* her baby such things as “relationality, communication, identity and a ... firm sense of self” (2014, p. 242). She does not do this in order that her child becomes a human, but assumes that she is nurturing certain capacities in her infant, who is already a member of humanity. Dementia cannot take this birthright away.

Just as Jesus was not born as an autonomous individual, and relied on parental relationships to nurture and sustain him, we all begin life as helpless infants, then we age and become dependent on others again: dependence and vulnerability are common to us all at the beginning and end of our lives. Wyatt writes of the vulnerability of late life, when he describes how his mother had been transformed into dependency by dementia (2009, p. 65). We cannot regard human life as either emerging or disappearing; we are all embodied relational selves, and this is not dependent at any stage in our lives on our ability to relate, remember or communicate. Babies are not humans in the making, anymore than I am a human in the unmaking. This idea of potentiality, and of its loss, raises the question of why should I lose my membership of the human family? This is a major concern for people with dementia, who are wrongly regarded as empty shells from whom the self has departed. Indeed, when does an ageing and frail woman cease to have a sense of self?

We are all continuing embodied relational selves: “from birth, we are in the process of becoming, and this ‘becoming’ is encoded in our brains by means of synaptic activity as both nature and nurture ... form and reform the developing self” (Green, 2008, p. 85). My relational self began in the form of meaningful images, such as the familiar face of my mother, as I perceived the world around me and distinguished myself from others and from my environment. Gradually I learnt words to label and store these images, and my family told stories about me, and through these stories I began to understand who I was, gaining a sense of being an embodied relational self, and now the experience of dementia is being included as part of my sense of increasing vulnerability.

5.2.3 Capacities for relationship

The psychologist Warren Brown’s view is that we have six enhanced capacities “critical for personal relatedness” (1998, p. 103-104; my emphasis): language, theory of mind, episodic memory, conscious top-down agency, future orientation and emotional modulation. In this section, I discuss the assumption that these capacities diminish with increasing cognitive disability, and therefore that the continuing relational self of people with dementia is at risk. I question whether an outsider such as Brown can describe my experience of relating to God and to others, although I support his conclusion that “it is ultimately God’s sovereign choice to be in relationship with us, and not our ability to reciprocate” (Brown, 1998, p. 125).

Language

Brown’s view that *language* is essential in relationships, to convey complex ideas and concepts of the past and future (1998, p. 103), could exclude all people with communication difficulties, including those with dementia. I dispute this, as I can still relate to others, despite occasionally having to communicate nonverbally due to words failing me. In this regard, I consider that unlike many other observers, Sabat makes a significant contribution towards seeing the world through our eyes, despite communication problems. He is an expert in listening directly to the voice of people with dementia, conceiving of “mind,” or what I regard as self, as a process arising in discourse, akin to an internal conversation (Sabat, 2001, p. 222); this is

what I call the embodied relational self. Sabat understands how communication difficulties form a barrier to meaningful relationships, and how I can feel imprisoned behind the barrier of language difficulties and recall dysfunction, yet I am still here as an embodied relational self. Indeed, Swinton writes of the possibility that dementia “locks people in” behind cognitive incapacity, and reflects on whether spirituality might be the key to unlock the person “in the stillness of that spiritual moment” (2011, p. 181).

I share some of the linguistic difficulties observed by Sabat; for example, Dr. B. had interrupted attention and a subsequent shifted conversation flow, due to being unable to inhibit the processing of other sources of information when trying to communicate (2001, p. 53). I have written of “crossed wires misfiring” (Bryden, 2005, p. 64), when my words become interrupted by visual or aural cues. Negative emotions can also further impede word finding, such as Dr. M.’s anguish at her impaired language (Sabat, 2001, p. 73). I have similar feelings of despair at my inability to come up with the “right” word, when I know one exists. In my writing and speaking, this is becoming increasingly frustrating, as my verbal skills are significantly diminished.

Sabat’s work is in contrast to the much earlier study of sociologist Jaber Gubrium: he interviewed caregivers, who expressed the common view around the time of my diagnosis: “Hidden as it is, mind must be spoken for” (1986, p. 43). I do not agree that the mind, or what I refer to the self, must be spoken for. Instead, we are all dependent on the abilities of others to interact with our social and independent selves (Swinton, 2012a, pp. 60-62). We assume that others have a self with which to perceive the world, and we try to imagine what others mean when they express themselves. I have personal thoughts, ideas, images and concepts, which I might have difficulties expressing, due to word-finding problems, yet this is only one part of communication. We *all* communicate non-verbally, relying on others to *see*, as well as hear, what we are saying. In my talks, I say, “listen with your eyes” to suggest that caregivers should watch for this expressive form of communication (Bryden, 2015b, p. 215).

I have great communicative difficulties in testing situations, in which I need to find words accurately and my actions are “interpreted as being ‘dispositional,’ or due to

[my] way of being, rather than ‘situational,’ or due to the circumstances” of the clinical environment (Sabat & Lee, 2011, p. 316). My cognition is being measured in a situation of stress and anxiety, instead of in a rich social context. I agree “people with dementia cannot and should not be positioned as incapable of acting as social beings on the basis of their cognitive test scores” (Sabat & Lee, 2011, p. 324). Instead, we should be observed in a situation similar to everyday life, which is “lived in rich social, interpersonal context that go far beyond the quality of the interpersonal relationship between a test-giver and test taker” (Sabat & Gladstone, 2010, p. 73).

Theory of mind

Theory of mind is the ability to attribute mental states to others, and to have an awareness of one’s own mental state. I have argued in Section 5.1.1 that people with dementia may retain such a view of self in the form of imagery. This theory states that to communicate effectively, humans also need to be able to read the body language and intentions of others. People with dementia retain this ability, and are sensitive not to the words you use, but how you say them.

Brown writes of metacognition, or “thinking about thinking” and makes assumptions that this ability is gradually lost in people with dementia, despite their lifetime of experiences. Although there has been considerable research on the development of metacognition in children, assumptions concerning its loss may be incorrect: for example, intact social cognition is found amongst people with dementia, and with staff (Sabat & Gladstone 2010, p. 74). There appears to be a social cognition reserve in these adults, developed over the course of their lives.

Episodic memory

I question Brown’s proposal that *episodic memory* is vital to relating to others. Why should a recall of an historical record of my life and that of others be essential in relationships? Although I cannot recall my recent history, nor a friend’s name or her history, I can still relate to her: it feels as if I cannot recall her label, or what is attached to this label. However, I can still connect deeply moment to moment, and my relationships are an important aspect of my sense of self.

Conscious top-down agency

Top-down agency is the ability to regulate behaviour in regard to conscious thought, as well as intentions. An example of the retention of these capacities in people with dementia is the study by McFadden et al (2000), which demonstrates that elderly residents were active agents, engaging with their environments, with staff, and with one another. They showed a wide range of emotions, importantly a caring sensitivity for one another. Sabat & Lee (2011) also observed social interactions in which there were interpersonal understandings amongst people with dementia, based on regulating behaviour appropriately.

Future scenarios and emotional modulation

I cannot envisage *future scenarios*, nor do I have reliable *emotional modulation*, both of which Brown regards as vital to relatedness (1998, pp. 103-104). However, I can listen to such scenarios, and reflect the feelings I am hearing. I am able to be present in the moment, and attend to feelings and emotions. Such *reflective listening* is a vital aspect for all of our relationships, and indeed forms the basis of successful counselling. My capacity to do this has not been diminished.

Summary

All of Brown's six criteria (1998, pp. 103-104) are an outsider's view of human capacities for relationships. They imply that it is impossible to have a sense of being an embodied relational self unless all six capacities are present. In my exploration of a continuing sense of self in the lived experience of dementia, I disagree with Brown's conclusion that personal relatedness is diminished by cognitive disability (1998, p. 124), and suggest that his focus is on examining how humans might be superior to nonhuman species, rather than on how all humans might share in a capacity to relate to each other and to God, despite a range of disabilities.

Nevertheless, Brown does point to the importance of "being related to" by others, so that babies are included (1998, p. 124): therefore people with dementia should also be included. However, our relatedness might require extra effort by others (Brown, 1998, p. 125). Indeed I wrote of my increasing dependence on others, and how caregivers can "smother us with care ... [and we] fade as we withdraw from

trying” (Bryden, 2015b, p. 80). This can impact negatively upon us and result in “excess disability” (Sabat, 2001, p. 94). It is important that our personality, character and how others see us is not placed at risk (Self 3: Sabat, 2001, p. 18), as this can result in negative positioning of people with dementia in social encounters (Swinton, 2012a, p. 89), in which we are stripped of all other descriptors of our lives. I have written, “Maintain our dignity and avoid depersonalizing us” (Bryden, 2015b, p. 224).

5.3 Narrative self

Narrativity is described as a human-forming, meaning-making enterprise” (Green, 2008, p. 121), and as being “part of our survival toolkit” (Bryan 2016, p. 53). However, I dispute the idea “that for human beings stories are an essential part of our *cognitive* architecture” (Bryan, 2016, p. 29; my emphasis), as I can still explore meaning, beyond a limited cognitive timeline of events, towards a fuller and richer expression of all that I am. I continue to be a narrative self¹⁷ who is able to find meaning in the present moment. Despite the lack of a remembered precise chronological record, I have “a concept of self whose unity resides in the unity of a narrative which links birth to life to death as narrative beginning to middle to end” (MacIntyre, 1981, p. 91).

I dispute the concept that recall dysfunction, an unreliable sense of time, and language difficulties means that I no longer have a coherent narrative. Despite disease and frailty, we all have and are a meaningful story, where “Ultimate meaning is about finding who we are in God’s eyes; our journey through life is a continuing one of assigning meaning, reviewing meaning, and reframing our own narrative” (MacKinlay, 2016, p. 33). My life still has meaning, even with dementia, which is mine to “learn how to read and interpret” (Swinton, 2012a, p. 164).

5.3.1 Recall and narrative

The common view that a recall dysfunction means loss of self, and thereby no longer having a meaningful narrative, can be traced back to Plato and Aristotle, who had a simple view of recall as being similar to modern data storage and

¹⁷ Narrative self: I define this as my sense of being able to find meaning in life and develop a sense of narrative identity in the present moment.

retrieval (Keck, 1996, p. 64). In the Christian era, Augustine was influential in regard to ideas of recall, and writes, “It is I myself who remembers, I the mind” (Augustine, 1996, p. 265). This appears to imply that people with dementia, whose recall is impaired, might have no sense of being an “I” or indeed having a sense of self. These early views of recall being an accurate record of all past events still persist, yet none of us has this type of photographic recall from which to create a sense of narrative self.

Kevern appears to share the common view of recall dysfunction: that it leads to a loss of “meaning and emotional connection. We are narrated creatures, and as the narrative is interrupted, so we sense our very being becoming incoherent and intermittent” (2012, p. 48). Similarly, Baldwin and Estey suggest that I *must* be able to sequence events in time in order to create meaning, which implies that a remembered chronology is vital to having and being a story (2015, p. 216). I disagree with both of these outsiders’ views of my narrative becoming incoherent or disrupted as a consequence of recall dysfunction. They assume that my narrative is reliant on having an accurate recall of events on my time line, but without help, I am unable to recall such events today, or in the past few days, weeks, months, or recent years.

Despite a lack of precise recall, I can still write this essay and reflect on meaning. I do not consider that my remembered history is critical, as I am who I am now, and my meaning is what I can find in this present moment. Indeed, I suggest a robot could be programmed to recall accurately the entire record of its “life,” yet it cannot be regarded to know what it is, or to have a sense of meaning. I question why a lack of a remembered timeline is so important to outsiders, who then regard me as having “lost my self.” My narrative results from finding meaning in life and developing a sense of identity *in the present moment*, not based on events in the past.

5.3.2 Language and narrative

Language is not critical for me to *be* a story, although to *share* my narrative I will need to be helped to convey this to others. Therefore I dispute the suggestion that narrative “brings experience into language” (Baars, 2012, p. 155), as I can still have

and be a story despite linguistic problems. My own experiences and observations of people in the later stages of dementia support Damasio's idea of a nonverbal narrative, dependent on the coordination of deep brain structures where the autobiographical "self comes to mind in the form of images, relentlessly telling a story of such engagements" (2010, p. 203). I still have the ability to have this stream of images depicting my narrative, despite difficulties in finding the right descriptors or sorting these pictures into accurate order over time. Therefore, I can find meaning in life, and develop a sense of identity, in the form of imagery, despite language loss.

5.3.3 Present moment and narrative

Recall dysfunction has given me a new relationship with time, so that I feel situated in the present, no longer able to recall the past. However, I am still an historical being, who lives in time, and my narrative conveys "what it is to live in the world or in worlds, but also what it *means* to live in time" (Baars, 2012, p. 150). I continue to be a story in my world: of the relationships and environment around me (Baars, 2012, p. 161) and I agree with Orthodox theologian John Zizoulas that a "capacity for memory is not necessarily a unique characteristic" of self, nor needed for me to have and be a narrative (1975, pp. 416-417).

Reflecting on my narrative in a process of making meaning involves feelings and emotions, as well as my sense of the present moment, and episodes in my life exist "in a tensed temporal modality; both past and future are inseparable from lived present experience" (Bryan, 2016, p. 27). This modality is like Sabat's "personal present" (2001, p. 232), within which a fear of future possibilities, as well as an awareness of my past, re-shaped my narrative shortly after diagnosis, and continues to influence my search for meaning. The discourses of loss and my struggles with decline both impact negatively on my personal present. However, my present moment is still filled with many aspects of my life, despite needing help to recall these, and within this abundance, my sense of self can continue to flourish.

Recall of cognitive facts, and an awareness of time, is not important to finding meaning in my life. MacKinlay and Trevitt verify this in their spiritual reminiscence work with people with dementia, and find that meaning can be found

in the moment, where narrative is still possible for people with dementia (2012, pp. 16-17). Sabat also writes that his interlocutors were able to make and derive meaning in the present moment (2001, p. 160), similar to my goals in this autoethnographic enquiry. I can find purpose and unity in life, “creating a coherent, meaningful spiritual self-story” in which I transcend self, not by separating from, but by connecting to others, and to God (Poll & Smith, 2003, p. 139).

5.3.4 God’s “memory” and narrativity

Through looking to God I find meaning, where God “is not far from each one of us” (Acts 17:27). From my Christian worldview, I know that I can still relate to God and others, even without accurate recall or awareness of time. I am so much more than my recall dysfunction, disrupted sense of time and communication problems: even if I can no longer speak, and my thoughts become more muddled, I know I will remain secure in God who created me. I have a continuing sense of being upheld by God in the fullness of my identity. Ultimately, it is God whom I trust to hold to all who I am, have ever been, and will ever be.

In writing of narrative loss when recall of events fades, Swinton poses the question: “Who will tell our stories well when we have forgotten who we are?” (2012a, p. 23.) I suggest we do not forget who we are, but we need help to uncover a narrative of meaning in the present moment, in which can be found many aspects of our story. Swinton’s work focuses on our story being held in the memory of God, and similarly I wrote of a reliance on God, “I will trust in God, who will hold me safe in his memory, until that glorious day of Resurrection, when each facet of my personality can be expressed to the full” (Bryden & MacKinlay, 2002, p 72). For a Christian, this concept of being held in God’s “memory” can be of great comfort. In this divine non-cognitive and mysterious “memory,” I am seen as God sees me and sustains me in the past, present and future: acting and re-memorizing me forever (Swinton, 2012a, pp. 214).

Keck writes of God’s remembering in the Old Testament as a bringing into mind, implying divine sustenance and action (1996, p. 47). To be remembered by God was to be sustained; to be forgotten meant that life would cease (Swinton, 2012a,

p. 214). Keck concludes that “we are also what others remember of us, especially what God remembers” (1996, p. 43), joining other commentators in referring to Deuteronomy as offering “a theology of God’s remembering,” whereby a forgetful Israel is sustained by God’s mercy and remembrance (p. 45). Swinton further develops this concept, writing that “we are not what we remember; we are remembered” (2012a, p. 198). God’s unfailing “memory” can offer comfort: dementia might be tragic, but ultimately the outcome of all human life is decay and death (Swinton, 2012a, pp. 184-185). I believe that God is, has been, and will be there always, which contrasts to some views held of God abandoning me to the “slipping away” of dementia (Kevern, 2010b, p. 174). I set my life in the context of eternity, and wrote that I am held in God’s remembrance, referring to Isaiah 49:16: “See I have inscribed you on the palms of my hands” (Bryden, 2016, p. 10).

For ancient Hebrews, *memory* and faith are closely interrelated, based on a remembrance of God’s saving works (Keck, 1996, p. 49). Biblical texts point to the present reality of Christ, where we join in a community of remembrance to profess the truth of our *belief* (Keck, 1996, p. 50). An emphasis on belief, rather than on remembrance, is reflected in Christian creeds, which start with the words “I believe” rather than “I remember.” I wrote of the Eucharist as being increasingly important to me, questioning why recall dysfunction should deny me this sacrament (Bryden, 2015b, p. 291). I find meaning in the present moment, where “I am part of the Body of Christ and can partake in all acts of remembrance – despite my failing memory – and of worship - despite my failing understanding” (Bryden & MacKinlay, 2002, p. 73). The Eucharist can give me a glimpse of “a sense of redemption to the tale of life within time ... [where] Salvation is tasted, eternity touched, when through this life and death the fragmentation of time is overcome” (Worthen, 1999, p. 516). I can participate in liturgical acts of anamnesis¹⁸ in worship, where I am touched far more deeply than at the cognitive level. Worthen writes, “we are graced with a form of remembrance that does not come simply from us, ... but which comes as gift” (1999, p. 518), which I can share, and thereby gain a sense of being held in communal remembrance. The transcendence of the present moment resonates with my own experience of

¹⁸ Anamnesis: Recall in worship of God’s saving acts, through metaphors such as the sacrament in which the past speaks into the present moment.

sharing deeply from my sense of “now” in the sacrament: at that moment, I am far more than my ability to recall, and I am able to find and share a sense of meaning.

God’s love impinges on my life at all times: with recall dysfunction and a disturbed sense of time, I rely on God’s continual active sustaining of my living being, past, present and future (Swinton, 2012a, p. 214). My lived experience with dementia has no relevance, as my identity in God never changes. With or without dementia, God knows more about my narrative than I do. Who am I, a mere human, to assume such knowledge about my embodied relational self, which is one of the works of God’s creation? Why do others question whether I can relate to God? I can be sustained in relationship with the divine, and need not rely on others.

I am inspired by the story of Jimmie, whose recall dysfunction was severe. Neurologist Oliver Sacks thought of him as having no soul, until in chapel, he observed Jimmie’s experience of “continuity and reality, in the absoluteness of spiritual attention and act” (1985, p. 36). Sacks wrote, “there remains the undiminished possibility of reintegration by art, by communion, by touching the human spirit: and this can be preserved in what seems at first a hopeless state of neurological devastation” (1985, pp. 37-38). Like Jimmie, my sense of the numinous gives me great hope and meaning in the present moment, despite my cognitive difficulties.

My narrative continues to be formed and reformed in embodied relationships within the worshipping community, where we are all “living narratives” (Bryan, 2016, p. 44). I still am and have a meaningful story, even though my language and recall are impaired. However, I have a diminishing ability to *express* this unfolding narrative of meaning. I describe my lack of recall of past events and a disrupted awareness of the future as “my life is like a carpet unrolling before and behind me” (Bryden 2015b, p. 130). In this metaphor, life before and behind me is unseen, yet the pattern of meaning on the carpet beneath my feet is nonetheless vivid, although I might need more help and time to describe it.

My functioning on neuropsychological tests is becoming increasingly defective, yet these do not measure my sense of embodied relational self, nor my ability to find meaning in the present moment. I can still explore my fears of loss and develop the concept of having a sense of being an embodied self in relationships with God

and with others. My published work has been a process of finding meaning, which is furthered in this essay, as I challenge the discourses of loss with an insider's perspective from within the lived experience of dementia.

6 “We-Thou” communion before God

Reflecting on the need for people with dementia to be supported in the faith community, I consider a *communal* form of relatedness is vital as this can enfold us all as equals before God. Therefore I propose a “We-Thou” communion before God as a model for the church, to include all people, despite their varying physical and cognitive capacities. “As persons in relation, we are called ... into community where the weak and the strong, the insightful and the forgetful flourish together” (Hudson, 2016, p. 65).

In suggesting this proposal, I have examined theologian Martin Buber's concept of “I-Thou,” which is an extensive exploration of the nature of individual relationships, both interpersonal and objective, focusing on the “I” of the I-You and I-It (1937, p. 54). I support the need for the presence of God in our interpersonal relationships, where the I-You should “intersect in the eternal You” (Buber, 1937, p. 123), but do not feel that this model of *individual* relationship can offer an adequate template for our Christian communities. Therefore I agree with theologian Peter Kevern who writes, “we do not hold our identities as individuals, but as members of communities” (2012, p. 48). He goes on to highlight that in such diverse communities, the face of Christ can be seen in all of us, including people with dementia (Kevern, 2012, p. 52). This liberates us all from the concept of cognitive function being necessary for reflecting the likeness of God, and moves us towards participating in a community of people, of varying physical and cognitive capacities.

I suggest that in order to do this, we need a collective model for our faith community, if we are to be truly inclusive. The idea of a collective identity might be difficult for modern Christians to understand, but I believe it has great merit for pastoral care and ministry to people with dementia. Indeed, Eastern Orthodox tradition is also helpful here, as it views “individuality as a perversion” (Zizoulas,

1975, p. 441). The concept of individual autonomy is a characteristic of modern times, and theologian Stanley Grenz discusses how this concept arose in Christian thought, commencing with Augustine looking for an inner self (2006, pp. 71-77). Individuality is rarely seen in the Old Testament, in which well-defined personal boundaries were less important than living in community. “Hebrew men and women experienced personal identity as they lived in community with other persons ... worship acceptable on God’s sight was worship which emanated from the collective life of the people” (Weaver, 1986, p. 447). As Green points out, in these texts “human beings cannot be understood in their individuality” (1998, p. 158), even those who play a prominent role remain embedded within the people of God.

Theologian D. Brent Laytham emphasises how Christianity is public and shared, and “God’s economy is neither personal nor private” (2004, p. 19). The reality of the church is that we *share* in worship (Hauerwas, 2014, p. 190), and we gather around the Eucharist, as a baptism community, in which “we know and are known” (Clapp, 2004, p. 36). The Christian body is meant to glorify God, caring for each other as part of the baptised body in the people of God (Hauerwas, 2014, p. 186). Coming together in community contrasts with the individualistic approach of some churches today, as well as with Buber’s focus on person to person relationships of “I-Thou” or “I-It.”

In exploring how we can embrace community within the church, Grenz (2006, pp. 77-79) outlines the importance of belonging as *ecclesial selves*, where we participate in the Body of Christ through the work of the Holy Spirit. We are all held in love within the church, as *ecclesial beings*, drawn into the communion of the Father, Son and Holy Spirit (Reinders, 2008, p. 262). People with dementia belong equally in Christ’s ecclesial community, or in my proposed “We-Thou” communion. The origins of our communal Christianity can be found in the Lord’s Prayer, which teaches us to pray communally:

This, then, is how you should pray: *Our* Father in heaven ... give *us* this day *our* daily bread ... forgive *us our* debts ... as *we* also have forgiven *our* debtors... and do not bring *us* ... but rescue *us* (Matthew 6:9-13; my emphasis).

They can also be found in the Nicene Creed:

We believe in one God, ...
We believe in one Lord, Jesus Christ, ...
For us and for our salvation, ...
For our sake ...
We believe in the Holy Spirit, the Lord, the giver of life, ...
We believe in one holy catholic and apostolic Church.
We acknowledge one baptism for the forgiveness of sins.
We look for the resurrection of the dead, and the life of the world to come
(Anglican Church of Australia, 1995, pp. 103-104; my emphasis).

Little children, as well as people with dementia, are included in this prayer and communal statement of belief. It seems obvious that you should not exclude children, for at what stage do they become fully human? But I am also included, for at what stage do I become no longer human? We are all to celebrate wholeness in the Body of Christ, sharing the joy of Jesus' incarnation and resurrection, where we all become a new creation (Hudson, 2016, p. 62).

The church is Christ to me, and can offer love, belonging, welcome and hospitality, throughout my lived experience of dementia. Instead of society's perception of my diminishing capacity, the church can enfold me within a "We-Thou" communion, in which the Body of Christ holds me in grace to the loving Father, through the Son, by the power of the Holy Spirit. In this We-Thou communion, I am equal before the loving God, within a fellowship emphasising equality. We have identity in the faith community, not as individuals (Kevern, 2012, p. 48), where "grace is essentially shared and corporate" (p. 49). I need others to be with me in my present embodied moment, where "it is the experience of Christ's love that you bring us, not a memory of an event" (Bryden, 2015b, p. 288). By bringing love in the moment, the Gospel counter-story of being held within the Body of Christ provides me with a narrative of meaning in life.

7 Conclusion

Conclusion

My published work forms a portfolio of autobiographic narratives, exploring the lived experience of dementia. In this integrating autoethnographic essay, I have reflected on a key theme emerging in my work: challenging the concept of a loss of self in dementia. I offer an unique insider's perspective, and my aim is to

encourage the faith community to see people with dementia differently, as having a continuing sense of being an embodied self in relationships to God and to others, with a narrative of meaning in the present moment. Instead of the terms person and personhood that are used by outside observers, I use the term “self,” which has a mental feeling of “I” as a continuous whole throughout my life, interacting with a changing physical, emotional and spiritual environment. I know that I am an “I” and this “I” is inquiring into who “I” am.

The purpose of my essay is to challenge the discourses of loss of self with an alternative perspective, by proposing and exploring three aspects of a sense of self that continue within dementia, namely:

Embodied self: an aspect of my self that gives me my sense of being embodied as an “I” with first-person feelings about the world around me, distinguishing self from non-self;

Relational self: an aspect of my self that gives me my sense of being an embodied self in relationships with God and with others; and

Narrative self: an aspect of my self that is able to find meaning in life and develop a sense of narrative identity in the present moment.

My aim is to project a new world of possibility, so as to encourage the faith community to respond in improved pastoral care and ministry.

There are challenges in writing my essay, which arise from my lived experience of dementia. These make the process of writing and analysis more difficult, yet at the same time more authentic, because my increasing impairment gives insight into my sense of self from within the lived experience. I live with dementia, and can reflect both about and from within these difficulties to delve deeper into meaning. Although the common view of dementia would question my ability to do this, with many arguing that a loss of sense of self occurs at some time during the lived experience, I am still able to examine my published narratives, refer to relevant literature, and reflect on the meaning of my ongoing experience in the present moment. My cognitive abilities might be decreasing, yet I continue to have a sense of embodiment, in relationships with God and with others, within the faith community. I am the self, knower, subject and agent for my “I” thoughts, which

occur in relationships with others around me, and there has been no disruption to this subjective sense of self at any time since diagnosis.

In order to explore my sense of being an embodied self, I draw on the ideas of the neurobiologist Antonio Damasio, whose work is well informed by brain research. I reflect on the work of Christian philosopher Nancey Murphy, who takes into account these scientific views to develop the concept of nonreductive physicalism, which suggests that I am far more than ‘nothing but’ my neurones, and have a sense of self, with an ability to relate to God. I am far more than a deteriorating self in an increasingly empty shell of a body, with disappearing neurones and neuronal pathways. By examining my changing perceptions since diagnosis, and finding new sources of meaning, I look beyond the dominant discourses of dementia, and include all people as being equal before God.

Let me liken my sense of being an embodied relational self to a can of baked beans, which is gradually losing its label (my ability to relate effectively to God and to others). At what stage will my metaphorical can of baked beans be so defective in having lost its label that it will have lost its “baked bean-ness”? Surely it will always be a can of baked beans, even if the label is totally stripped away. No matter how little communication or recall ability that I have left, I remain an embodied relational self within the faith community. My “baked-bean” analogy may seem ridiculous, but no more so than the logical consequence of any idea that loss of communication and increasing recall dysfunction might mean loss of self. I may be less able to be defined by my *doing*, but I will always remain an intact *being*, who needs to belong, to be related to, and to be included.

The most important relationship for my continuing sense of self is with God, which is not dependent on my cognitive abilities, my spiritual experiences, or importantly my ability to talk about these. I know that I *experience* God’s love, even if I can no longer *express* this experience clearly to others, which underscores the importance of an insider’s view to examining a continuing sense of self in dementia. We are all embodied selves who relate to one another as an “I” and recognise an “I.” I cannot lose my membership of humanity, nor my ability to relate to God, simply by losing my neurones, and I can still express my spirituality within the faith community. My embodied relational self is a way of *being*, not *doing*.

I can still explore meaning, beyond a limited cognitive timeline of events, towards a fuller and richer expression of all that I am. I continue to be a narrative self who is able to find meaning in the present moment, despite the lack of a remembered precise chronological record. I dispute the concept that recall dysfunction, an unreliable sense of time and language difficulties might mean that I no longer have a coherent narrative. Nor is language critical for me to *be* a story, although to *share* my narrative, I will need to be helped to convey this to others. Outsiders' views assume that finding meaning is reliant on having an accurate recall of events on a time line, yet we all have and are a meaningful story. Despite a lack of precise recall, I can still write this essay and reflect on meaning: I am who I am now, and my meaning is what I can find in this present moment. Indeed, I suggest a robot could be programmed to recall accurately the entire record of its "life," yet it cannot be regarded to know what it is, or to have a sense of meaning. Recall dysfunction has given me a new relationship with time, so that I feel situated in the present, no longer able to recall the past. However, I am still an historical being, who lives in time. Reflecting on my narrative in a process of making meaning involves feelings and emotions, as well as my sense of the present moment. My present moment is still filled with many aspects of my life, despite needing help to recall these, and within this abundance, my sense of self can continue to flourish.

I conclude that as an embodied relational self, I can find a meaningful narrative in the present moment. I have an increasing awareness of my spirituality as my cognition diminishes, which is expressed very well by theologian Christopher Cook:

Our theology must allow for an encounter of the immanent and transcendent, in inseparable and dynamic engagement with each other, within each present moment, as a matter of divine grace that is not contingent upon our cognitive capacity (Cook, 2016, p. 96).

Through looking to God I find meaning, and I know that I can still relate to God and others, even without accurate recall of events or awareness of time. I am much more than my increasing recall dysfunction, disrupted sense of time and communication problems. Even if I can no longer speak, and my thoughts become more muddled, I know I will remain secure in God who created me. I have a

continuing sense of being upheld by God in the fullness of my identity. Ultimately, it is God whom I trust to hold to all who I am, have ever been, and will ever be.

God loves us all, not based on what we achieve, or do, or have the potential to do, but on our existence as part of the fullness and diversity of creation. Even if I am less able to participate as part of the life of the worshipping community, God still sees me as a child of the divine. My worth is determined in God's eyes, who looks to my heart, not to what I can do or say. I am a witness to what it means to be human: simply to be, rather than to do. God bestows value upon us all, not us who contribute to God in any way. We are all alike in being humble receivers of God's love, and my worth is no less than that of those around me; we all receive divine love and grace. I have a calling, despite and with my dementia: God sees "our heart and spirit, regardless of our mind or body. We are fearfully and wonderfully formed in the image of God. The breath of life given to Adam and Eve is that which draws our spirit into relationship with the divine" (Bryden, 2016, p. 8).

Reflecting on the need for people with dementia to be supported in the faith community, I propose the concept of a "We-Thou" communion, in which we all come before God as a community, rather than as individuals. This collective identity, including all people of varying physical and cognitive capacities, has great merit for pastoral care and ministry to people with dementia. The foundation of our communal Christian life can be found in the Lord's Prayer, as well as in the Nicene Creed. In the Body of Christ we are all gathered up as one, as "We" before the "Thou" of God. Within this "We-Thou" communion, what is important is who we are, not what we do: each one of us is included, despite our limitations and differences, which is the good news of the Gospel for those of us living with dementia. The church is Christ to me, and can offer love, belonging, welcome and hospitality, throughout my lived experience of dementia. Instead of society's perception of my diminishing capacity, the church can enfold me within a fellowship emphasising equality. By bringing love in the moment, the Gospel counter-story of being held within the Body of Christ provides me with a narrative of meaning in life.

In the Appendix to this essay, a Letter to the Church,¹⁹ I have written of how we are all created in the likeness of God, despite our cognitive and physical differences. We can look to Jesus in order to understand how best to reach out to and support people with dementia. By “casting off the straitjacket” of society’s views of loss, the church can see Christ within people with dementia. My aim is for the community of faith to hear the story of a continuing sense of self in dementia, and to respond in ministry. Can it be a remembering community and help me to keep my story safe? Can the faith community relate to me and respect me, despite my impairments?

I may be less able to be defined by my sense of cognitive self, but I still continue to be an embodied relational self with a narrative of meaning in the present moment, who seeks to be loved, to belong, be welcomed, and be shown hospitality. I am still “me” to whom my friends in church can relate, and to whom God relates; we are all alike. What I need is for the faith community to look towards a Gospel model in which my life has meaning, just as I am, not healed in some miraculous way; all of us need spiritual healing (see Bryden, 2012, p. 115). I need the faith community to “hear others into speech and assist in the re-patterning of broken and fragmented lives” (Walton, 2002, p. 3).

Enfolded within a “We-Thou” communion, I am not my dementia: *I am who I am* before God in communion with others, held in grace *to* the Father, *through* the Son, and *by* the Holy Spirit. The Body of Christ remembers for *me*, and *re-members* me.

¹⁹ The suggestion for this approach came from Dr. J. Foulcher.

8 APPENDIX - LETTER TO THE CHURCH

Dear sisters and brothers in Christ Jesus

Christine, a daughter of God. To the church of God that seeks to minister and include people with dementia. Grace and peace be with us all.

My aim in this letter is to encourage our faith community to think differently about the lived experience of dementia. I want to encourage my friends in church to look to our continuing sense of being an embodied self in relationship with God and within the community, and help us to search for meaning in the present moment. Remember we *all* reflect the divine likeness or image (Genesis 1:26-27), and in this creation story, God saw *everything* “was very good” (Genesis 1:31). This surely means my lived experience of dementia is part of the diversity of God’s good creation, and varying capacities are not part of reflecting the likeness of God. As I wrote, people with dementia “can seek an identity by simply being who we are, ... created in the image of God” (Bryden, 2015b, p. 289). What is important is who we are, not what we do: *I am who I am* in the Body of Christ.

I believe there is no difference between us, and God sees us all in our weakness as being a “treasure in clay jars” (2 Corinthians 4:7). As my cognitive capacities decline further, God will still love me, as we all receive divine love and grace, not because of what we achieve, or do, or have the potential to do, but by our common existence as part of the fullness and diversity of creation. Jesus came to us all, *not only to those with cognitive capacity*. Indeed, if I need cognitive capacity to respond to this act of grace “then Christ died for nothing” (Galatians 2:21). Divine love remains constant, despite my failing remembrance of God and is not dependent on my recall, but is an unconditional gift.

We are all dependent upon God, despite varying capacities to articulate our experience, and I am an equal *recipient* of God’s love, even if I am less able to participate in worship. Compared to God, none of us can claim superiority, and “When I look at your heavens, the work of your fingers, the moon and the stars that you have established, what are human beings that you are mindful of them, mortals that you care for them?” (Psalm 8:3). I am no different before God than those in the community who regard themselves as “normal” and John Swinton puts

it very well, writing there is “no real *norm* for being human” (2012b, p. 178). We have many differences: physical and cognitive ability, looks and many other aspects of our lives, yet we all reflect God’s likeness in a mystery beyond our understanding.

We are one in Christ Jesus, and in St Paul’s words “all the members of the body, though many, are one body, so it is with Christ. For in the one Spirit we were all baptized into one body ... If one member suffers, all suffer together” (1 Corinthians 12:12-13 & 26). I embody Christ just as much as others in the faith community, and we can all be enfolded within a We-Thou communion. As I wrote, “Through the power of the Holy Spirit, we are in communion with each other and with God. There is no need for cognition, for this is a spiritual communion” (Bryden, 2015b, p. 290). The faith community is Christ to me, and needs to continue to relate to me throughout my experiences of dementia.

8.1 Love drives out fear

Remember, “There is no fear in love, but perfect love casts out fear” (1 John 4: 18). This Gospel truth shows how the faith community can respond to me. Society fears dementia and we can become isolated, as people do not know how to relate to us, nor what to say. In the Body of Christ we are called to be radically different, by seeing beyond our differences towards seeing Christ in all of us and being Christ to all of us. The community is called to show Christ’s love for me, which I have described as shining “the Christ-light for us” (Bryden 2015b, p. 291). Certainly, my circle of friends diminished after diagnosis, due to their fears of whether I could behave in socially accepted ways. Now, with increasing recall dysfunction, I forget my friends exist, and what is happening in their lives, so I am increasingly dependent on my friends in the faith community. However, people cannot be forced or embarrassed into being friends with me, so a change in the hearts of the faith community is needed. I write that the best way to do this is to “put yourself in my shoes” (Bryden, 2015b, p. 201).

Love is commanded of us, and we are to love God and each other because God first loved us (1 John 4:19). This command has no caveat that might exclude people with dementia. As I wrote, the faith community can “tap into the rich resources of

the Holy Spirit” (Bryden, 2015b, p. 290), responding to this call to love. Jesus’ command “Just as I have loved you, you also should love one another” (John 13:34) includes me as both a giver and receiver of love. Love is emphasised throughout the Gospels, such as in: “You shall love your neighbor as yourself” (Mark 12:31). I ask my sisters and brothers to look to love as the Holy Spirit’s greatest gift (1 Corinthians 13:13)..

I seek to be supported within a We-Thou communion, where “God is spirit, and those who worship him must worship in spirit and truth” (John 4: 24), and we all reach out to God in love, not in cognition. The unknown author of *The Cloud of Unknowing* describes the importance of love, rather than cognition. “God ... is always incomprehensible to our knowing, but entirely comprehensible to the loving soul ... taken and held by love, but not thought” (Walsh, 1981, p. 123 & p. 130). I question why we should consider ourselves as being able to communicate with God at the level of human understanding. God’s remarkable speeches to Job are of the mystery of creation, in which human cognition is of so little value, and Job responds, “I am of small account; what shall I answer you?” (Job 40:4), and “I have uttered what I did not understand, things too wonderful for me, which I did not know” (Job 42:3), recognising his insignificance in comparison with God.

I will increasingly rely on others to love me and help me to participate in worship, which will be the calling of the Body of Christ. Instead of society’s perception of my diminishing capacity, I seek to be held in a We-Thou communion, where the Eucharist brings Jesus into the present moment, uniting us all in God’s everlasting love. I seek to be seen through Godly eyes, as part of the fellowship of the Body of Christ, in communal relationship before God.

8.2 Offer hospitality and welcome, so that we belong

Our face might be familiar, but our behaviour and language are changing, so that the faith community may feel increasingly uncomfortable around us. This can result in us becoming isolated, pushed towards the margins of society, as well as of the pews. We are becoming like the strangers of the Old Testament, to whom the Hebrews were to show hospitality (Leviticus 19:33-34). Swinton discusses this

issue, noting that these people *were always* strangers in Hebrew communities, whereas people with dementia *are becoming* strange (2012a, p. 273).

However, I read in the New Testament how Jesus reached out to those who had become strangers in their own communities, such as the woman who had been bleeding for twelve years (Matthew 9:20-22), or the leper who came to Jesus (Matthew 8: 2-4). Jesus offered them the hospitality of healing and wholeness. In his teaching, Jesus says, "I was a stranger and you welcomed me" (Matthew 25:35), and he also welcomed little children (Mark 10:13-16), who are perhaps like people with dementia in disturbing worship.

Offer hospitality, not out of pity or in hoping to be seen to be doing your duty, but knowing our equality in receiving God's grace. St Paul also emphasised the importance of hospitality to the marginalised, in meals such as in the Eucharist, where "*the etiquette of the Spirit was always breaking the teacups of polite convention*" (Koenig, 1985, p. 62; my emphasis). This lovely quote captures the Spirit-empowered hospitality that we need, as we cannot meet the community's expectations of polite and so-called normal behaviour. I ask the church to offer *hospitality with delight*, and thereby overcome the power of dementia to isolate us. Welcome us by saying, "It's good that you exist; it's good that you are in this world!" (Kingham, 2016, p. 112.)

Importantly, Jesus spoke of the importance of being made welcome: *welcome me and you welcome him* (see Matthew 25:31-46). This is what we want to hear from our faith community, a welcome that makes us feel as if we belong. *We all belong* in Christ's ecclesial community, which is so much more than simply being included. Inclusion would mean the church simply tolerating my presence, rather than welcoming me with delight. I seek to belong, which means I am welcomed in loving friendship, and missed when I have not been to church for a while. I find the imagery of the vine and the branches in the Gospel of John (15:5) provides a good metaphor for all of us belonging within the Body of Christ, with Christ as our head. People with dementia are an integral part of this vine, and together we are all rooted in Christ, so that we can bear fruit.

Jesus sought out the outcasts of society, challenging the norms of his day. I wrote people with dementia are "like outcasts in today's hypercognitive society. Like the

lepers of Jesus' day" (Bryden, 2015b, p. 287). Unfortunately, some people stop sitting with us during worship, perhaps because we may have forgotten who they are and they want to be remembered. I have described my struggles to recall names, yet how I can still "know" people in a different way:

Your name, the label that belongs to you, often is not there. Your face is familiar somehow, but meeting you happens too quickly for me to search through my disjointed memory and find a label for you ... Don't just give me your label, as I need more than that to really know who you are ... The way I know people is in a spiritual and emotional way. There's a knowing of who a person is right at their core. But I have no idea who they are, in terms of who they are meant to be in your world, of cognition and action, and labels and achievement. ... (Bryden, 2005, pp. 109-110).

I believe that Jesus would sit with us, despite our struggles, and would be impartial to us all. The faith community needs to recall, "if you show partiality, you commit sin" (James 2:8-9). Sit with us as Jesus would, being alongside us in our present moment and accepting us as we are. Remember that the Body of Christ is broken if it excludes "the members of the body that seem to be weaker" (1 Corinthians 12: 22). I might seem odd in my cognitive decline and increasing strangeness, but there can be no "us" and "them" in the Body of Christ. Paraphrasing Galatians 3:27-28: "There is no longer cognitive competence or incapacity, for we are all one in Christ Jesus."

8.3 Relate to us, overcoming communication problems

I seek relationships that recognise my difficulties. I wrote it is important to enter into my reality: "Be imaginative, be creative, try to step across the divide between our worlds" (Bryden, 2005, p. 148). Post takes a similar view, writing "We are not obliged to reorient them into our reality, but we are obliged to be an attentive presence in theirs" (2004, p. 14).

Unfortunately, the faith community can often reflect society's views, and stop visiting us, as we might not remember previous visits. However, we will respond in the moment to the emotion and warmth of a visit (Bryden, 2015b, p. 133). I have questioned the need for us to recall a visit:

Why must I remember who you are? Is this just to satisfy your own need for identity? Your visit is not a cognitive experience that I will store and recall. Let me live in the present (Bryden, 2005, p. 110).

We have difficulties in communication: in finding words and phrases, in following what is said, and in responding quickly enough. These can seem like insurmountable problems for the faith community, but I suggest we need “*cognitive ramps*” (Bryden, 2015b, p. 214; my emphasis). Psychologist Steven Sabat is very skilled in this regard, and accommodates linguistic difficulties, as well as perhaps uncomfortably long pauses, bridging the gap of these problems by taking what he calls “the intentional stance” (2001, p. 37). He searches for meaning in “extra-linguistic communication such as tone of voice, facial expression, gesture” (Sabat, 2001, p. 217). Similarly, I have written of the need for slower communication, allowing for pauses, and looking for meaning in non-verbal as well as verbal expression (Bryden, 2015b, p 286).

Medical ethicist Stephen Post uses a different term for the way in which to bridge these communicative difficulties: writing of “*prostheses*, filling in the gaps and expecting that now and then the cues we provide will connect with the person” (2006, p. 229; my emphasis). For example, I need such cues or prompts, such as instead of saying, “Wasn’t it lovely yesterday?” say “Wasn’t it lovely yesterday, when we went for a picnic to the park, and you wore that dress with sunflowers?” I want my friends in the faith community to keep going with such prompts, until they see the light in my eyes that means that I recall something from this event.

8.4 Be alongside us and carry our story

I live without a sense of time, so I seek to be accepted without this awareness of the hours or days passing. Theologian Jean Vanier spoke of being a “friend of time” when writing about the tensions of life in the L’Arche community for people with disabilities (1979, p. 89). I ask the faith community to befriend me within my sense of time, and to be with me in my present moment. I seek the simple gift of the community’s presence, to watch, wait and pray, as Jesus asked of the disciples in the Garden of Gethsemane. This ministry of “being alongside” is important for connecting with people with dementia, where people sit with us in silence, using gesture, touch, and eye contact in a language of listening. Swinton’s description of this ministry as “the sacrament of the present moment” speaks to me of its nature as a meeting of spirit to spirit (2012a, p. 235).

I want the faith community to hold my story faithfully, and to challenge stories of loss with the view that I continue to have a sense of being an embodied self, in relationships with God and with others. Theologian Elizabeth MacKinlay highlights the importance of this role: “As Christians, we are one Body in Christ. If this is so in reality, then it doesn’t matter whether people can carry relevant memories themselves, but it does matter that other members of the body can carry those memories within a loving community” (2016, p. 35).

In countering negative stories of loss, it is important to use Alzheimer’s Australia’s language guidelines,²⁰ which are referred to globally as a guide for how to speak to us, about us and about our caregivers, as well as about our condition. I wrote: “Language has great power to tear down or to lift up – to demean us or to encourage us” (Bryden, 2015b, p. 208) and “There is so much you can change in our lives simply by taking care about how you speak to us and about us” (p. 230).

I seek support in my efforts to “choose a new identity as a survivor ... I want to live positively each day ... free of fear of loss of self, and in so doing can also help you to lose your fear that you are losing me” (Bryden, 2005, p. 170).

8.5 Reach out in pastoral care and ministry

The faith community plays a crucial role in offering pastoral care, as “it is a physical as well as a spiritual community” (MacKinlay, 2016, p. 32), and represents the resurrected Christ, with a mission to uphold us within an “attentive community of memory and hope” (Swinton, 2012a, p. 223). We seek the ministry that would be offered “for Jesus himself as we wait for that day” (Shuman, 1999, p. 159).

I face a gradual decline in function until death, yet may spend many years in the community and in the pews. Therefore my pastoral care and ministry needs to affirm my humanity as I “approach the end of life, when it is important to reflect, find a sense of meaning and nourish our spirit” (Bryden, 2015b, p. 190). We need to be reassured that we can be enabled to bring meaning to our experience, such as through spiritual reminiscence (MacKinlay and Trevitt, 2012, p. 273), and be helped to find ultimate meaning in the light of God’s enduring love.

²⁰ Alzheimer’s Australia (2016). *Language Guidelines*. Retrieved from <https://www.fightdementia.org.au/files/NATIONAL/documents/language-guidelines-full.pdf>. Accessed 31 December 2016.

I have described the type of care that we seek:

Our increasing disability urgently needs your pastoral outreach and reassurance that we are in your memories, that you will keep visiting us and will minister to us as we become more and more dependent on the spiritual care of our Christian fellowship. (Bryden, 2015b, p. 287.)

Pastoral care of people with dementia is true chaplaincy – it's about 'being alongside.' It's about being with us and connecting with us without words. Heal us by your presence – bring us peace – as you connect with our spirit deep within.

Try to find out more about us, so you can help us to find meaning in our lives. Our life story is a springboard for meaningful engagement. You can carry our story for us and relate to us as a whole human being, with dignity and respect. Focus on what we can still do, rather than all the many things we can no longer do ...

Try to discard temporarily your own masks of cognition and emotion, so that you too can be truly present in the spirit, able to connect without words. Use touch, eye contact, music and aroma, and try to breach the barrier of communication between us. Look into our eyes and look for that spark that may alight when you connect. You are creating within us a moment of wellbeing...

Try to realize that it is not important that we remember that you visited us, for it is the experience of Christ's love that you bring us, not a memory of an event ... does it matter that a few hours later we will have forgotten that you have given of yourself and brought the Christ-light to us? (Bryden, 2015b, p. 288).

8.6 In conclusion, sisters and brothers

In my essay I have explored my continuing sense of having an embodied relational self in relationships to God and to others, with a narrative of meaning in the present moment. Within my lived experience of dementia, I am still part of God's good creation, and our common vulnerability before God joins us together in the faith community. I may not be able to take an active part in worship, but I can receive the gifts of love and grace. This is the good news of the Gospel for those of us living with dementia: we are equal before God in receiving divine love and grace.

Look to Jesus in order to offer us love, hospitality, welcome and a sense of belonging, and delight in our presence. Overcome communication problems to relate to us, being alongside us in the present moment. Hold our story faithfully, challenging the discourses of loss and taking care to use appropriate language. Reach out to us in pastoral care and ministry, assisting us to find a sense of meaning and to nourish our spirit.

Challenging the discourses of loss:
a continuing sense of self within the lived experience of dementia

I am who I am before God, enfolded alongside others in my faith community, in a “We-Thou” communion. We are held in grace to the loving Father, through the Son, by the power of the Holy Spirit.

Now to God who strengthens us and gives us wisdom, to the only wise God, through Jesus Christ, to whom be glory forever! I urge all of my sisters and brothers in Jesus Christ to see people with dementia through Godly eyes. Look to the example of Jesus, reaching out in hospitality, to welcome us and make us feel that we belong. Relate to us in the present moment, overcoming our communication problems, so that our story is held safely against the discourses of loss.

May the grace of our Lord Jesus Christ, the love of God, and the communion of the Holy Spirit be with all my sisters and brothers in the faith community.

Amen.

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