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Personal perspective of the mosaic of living with dementia¹

Christine Bryden PhD²

Abstract: This article is based on a keynote presentation given to the national Spiritual Care Australia Conference in 2017, which had the theme “Engaging a Mosaic of Care.” As a person diagnosed with dementia, it gives a viewpoint from within the confusing mosaic of living with dementia, in which a sense of spirituality at the core of our being can prompt a search for ultimate meaning in life, through relationships with God and with others. This paper is a Christian theological reflection, from the unique perspective of the lived experience.

Spirituality does not need cognition or language, and the person can be ministered to with sensitivity. Each person with dementia is a unique individual with hopes, dreams and emotions, even if these cannot be expressed, and has been on a journey from diagnosis towards an increasingly confusing mosaic of sights, sounds and feelings. Chaplains can be our faithful companions on this journey of decline and despair.

Keywords: Dementia, personal perspective, spirituality, ministry, chaplains.

Introduction

I was diagnosed with dementia in 1995, and have written a number of works reflecting on my experience (Bryden, 2005; 2012; 2015; 2016). Diagnosis with dementia has a profound impact; for example, I was given no hope for the future, only about five years of decline, then about three years in care until I died. This prognosis gave me an overwhelming existential fear of non-being (Tillich, 1969: 47).

Each one of us hopes that we can face death with dignity, but those of us who have been diagnosed with dementia fear “death in a state of unknowing” (Bryden, 2015: 273). “If I were to die of cancer, I would still be the real me ... When I die of Alzheimer’s, who will I be when I die?” (Bryden, 2012: 61.) People with dementia, like myself, face not just a physical death, but also a gradual

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emotional and psychological death, which can be perceived as a journey into ceasing to be.

These fears are exacerbated by the common discourses of dementia, including the use of terms such as: “the long goodbye” and “loss of self.” Believing these negative discourses, and the biomedical prognosis, people with dementia may begin to grieve for future losses that have not yet occurred. Each difficulty in functioning feels like a permanent loss, so the person may give up trying and becomes depressed, and life can become like a “hospice in slow motion” (Bryden, 2015: 27).

Everything about the person who has been diagnosed often becomes ascribed to the storyline of dementia, so that he or she can become excluded from the “dominant hypercognitive culture” (Post, 1995:8): a society that values competence, intelligence and autonomy. The fear of dementia, and of people with the condition, can “lead to a social stigma” (Bryden, 2015: 82), so that they become “imprisoned in a web of negative stereotypes” (Sabat et al, 2011: 286). The negative stereotype of people with dementia is of their lacking insight and being unable to speak (Bryden, 2015: 91), meaning that if the person does speak about his or her spirituality and fears, there can be disbelief.

After years of cognitive decline, people with dementia may ask: who we are now after all the losses that have occurred? Like a classical pianist whose hands and long years of practice have created mastery of wonderful music, the person had abilities that once defined him or her. Now this former multi-functionality and multiplicity of roles is fading, and the person struggles to cope with daily life. Losing a cognitive outer self, even a reliable and coherent emotional self, the person can feel less in control and more disjointed, and as if his or her sense of self has become like a mosaic, no longer making a coherent picture.

However, it is “what lies at our spiritual core that is truly important and this can be ministered to with sensitivity to what is giving us meaning in our lives with dementia” (Bryden, 2005: 157). Spirituality does not need cognition or language (MacKinlay, 2011: 43), and a search for ultimate meaning in life, through relationships with God and with others, “remains intact despite the ravages of dementia” (Bryden, 2005: 159). Chaplains can assist people with dementia to

find ultimate meaning in life, through facilitating relationships with the divine and/or with others. People with dementia are often not beyond such help, and chaplains can refer to texts such as those by MacKinlay and Trevitt (2012 and 2015) for practical ways to connect.

Lack of accurate recall

Recall dysfunction³ results in living an uncertain life in the present moment, which contrasts to previous abilities in accessing memories and being able to plan for the future. The distant past has inexplicable gaps and the recent past disappears into nothingness. For people with dementia, life has become peppered with question marks: Why can't we recall what today is or what we are doing, when you have just explained this?

People with dementia often experience an unsettling feeling of things possibly forgotten or planned for today or tomorrow. Chaplains may find it hard to understand what it is like to lose the thread of the past, and to have no reliable awareness of what is planned for the future; importantly, they may not realise that people with dementia usually still feel cognitively present, despite this flow of cognition being unpredictably interrupted with blank moments.

Prompts can help people with dementia to recall past events, even those recent ones that have become particularly elusive, as well as to make plans for the future. Chaplains can play a vital role in assisting people with dementia through using clues, so that the person can retain and regain a flow of time in his or her life, recapturing a place on a timeline, and being able to look at the past, as well as to the future.

Communication problems

The capacity to communicate has become increasingly impaired, so that people with dementia may experience a disappearing lexicon, in which the correct word has become elusive, as well as more difficult to pronounce. Words and grammar have often disappeared, yet a thesaurus is of no help, as there are no synonyms to document fleeting thoughts and images. Often non-verbal language is used to

³ Memories remain in dementia, but access to them is disrupted; therefore I consider that the term "recall dysfunction" is preferable to memory loss. See also "memory dysfunction" (Sabat, 2018: 30-31).

communicate, as well as slower speech, while a person's mouth seems to be waiting for the words that might capture the thoughts he or she is trying to communicate.

While the person with dementia is with the chaplain, it may be difficult for him or her to find the right words, whilst also grappling for coherence in grammar, so as to be clearly understood. Often what is said is incorrect, yet the person keeps trying, knowing that it is too hard to recapture, retrace, and correct that thought. The person may also interrupt the chaplain, when a thought emerges, so as to avoid forgetting what he or she wanted to say.

Dementia can be regarded as a "disease of communication" (Bryden, 2015: 286), creating an unseen barrier between chaplains and people with dementia.

Chaplains can try to take time to listen, using long pauses to allow for time for the person to capture his or her thoughts into gestures, facial expressions or words. These long pauses may feel very odd at first, but would facilitate the person's ability to connect.

In their relationship with people with dementia, chaplains can slow down, sit quietly, listen and connect: "listen with your eyes" (Bryden, 2015:132) and look for non-verbal communication. Everything a person with dementia is often a way of communicating, but often this non-verbal expression is dismissed as so-called challenging behaviour. Chaplains have a vital role to play, in recognising these behaviours as ways in which a person can communicate unmet needs, and take the time to discern these needs. Goldsmith writes, "Since when has a failure to articulate need meant that there was no need" (2002:130).

"Faking normality"

For people with dementia, trying to function normally – or "faking normality" - is usually becoming harder each day, but normality as a concept is questionable, given that we all experience limits at some time in life, which affect society's assumptions about us (Creamer, 2012: 341). Sometimes people say, "You don't look like you have dementia," but how is the person meant to look? It is hurtful when people say this, as it minimises any struggles to cope, and even implies that the diagnosis has been wrong.

People with dementia might look from the outside as they once were, but then forget that they met the chaplain yesterday, and all that was said, so do not ask about either trauma or joy in the life of others. However, it is not that people with dementia no longer value friendship, but they live from moment to moment, so lose the thread of their connection with others from day to day. No wonder people find it hard to keep in contact, and say: "What's the point? She won't remember that I visited her. He's unfeeling and doesn't care." By these comments, the implication is that people with dementia must recall a visit, as well as what was said during that visit.

By having unreliable recall, it seems as if people with dementia have become unworthy of relationships. However, to require such accurate knowledge about the chaplain, or any other visitor, implies that these visitors are more important than the person being visited. In contrast, chaplains can overcome a need to be remembered, and bring the gift of friendship, where "being alongside is an important ministry" (Goldsmith, 2004:16): this act of true chaplaincy brings Christ's love to people with dementia, and can create a moment of wellbeing.

Existing in the "now"

Chaplains can turn to a theology of life where, as Goldsmith writes, "it may well be that God chooses to reveal the very heart of the mystery of life and of love through the vulnerability of the person from whom pride and presence has been stripped away" (2002:130). This absence of pride and presence can be likened to becoming naked before God, as were Adam and Eve before eating of the Tree of Knowledge of Good and Evil (Bryden, 2016:10).

In this journey towards a spiritual innocence, a person with dementia might have no knowledge of what a visitor has done to us in the past, nor promised to do in the future, as well as have no idea as to what he or she might have done to, or neglected to do for this visitor. What people with dementia can do is experience the 'now' of their time with a chaplain, in the present moment, with no past or future. By sharing this sense of timelessness, chaplains may be able to make a deep connection, spirit to spirit, when they are relating to people with dementia.

Strange new world

People with dementia often feel as if they have left your world, so that communicating, listening, and speaking have all become difficult. For example, if there is background noise or motion when a chaplain is trying to talk to the people with dementia, they may receive a mixed and jumbled message. In turn, if they want to say something, their words have also become interwoven with the threads of such background disturbances.

Chaplains may approach a person with dementia with great familiarity, but he or she asks: who are you, and how do I know you and what do I know about you? People with dementia often feel increasingly bewildered on entering a new place, surrounded by unknown faces. Therefore, chaplains need to make sure that they introduce themselves, before their interactions with a person with dementia.

An unreliable and slow perception of the environment around them, and of their own bodies, can result in stumbles and falls. Peripheral vision has become impaired, as well as an ability to discern objects, if there is too much surrounding light or reflection. Entering a new space in particular can be problematic, so that people with dementia may need some time to perceive and recognise what surrounds them.

The anxiety of trying to cope with many daily increasing difficulties can result in feelings of distress, particularly by the end of the day. Chaplains can assist people with dementia to find a quiet space at this time, in which to recover from the trials of each day.

Dementia is regarded as a one-way street to death, and people with dementia are experiencing a gradual decline and dysfunction. They can feel as if they have become used to this slowly changing person, finding it hard to connect with, even recall, who they were before becoming this very different person. It can feel like sailing to a strange new land of dementia, from which vantage point the person can share with the chaplain what it feels like, with their insider's perspective, instead of the views of outsiders.

With an insider's view of the struggles for people with dementia, chaplains can gain a better understanding of how best to minister to them, particularly recognising that there are changing ways of experiencing and seeing the world.

Faith can often be a means for connecting with people with dementia in ministry, and can be likened to an anchor chain, securely resting on the bedrock of God. However, chaplains do need to find out more about the person's faith tradition, as now is not the time for conversion, but for upholding and nurturing existing beliefs.

Pastoral care

Pastoral care needs to begin at the moment of diagnosis, when people with dementia face the shock and horror of what might lie ahead. They can feel lost, abandoned, without hope, and fearing a gradual change towards a new world of forgetfulness and confusion. People with dementia need to know that chaplains will not forget them on their journey, and will keep on visiting and ministering to them, as they become more and more dependent on chaplaincy.

Spiritual care is vital, not just physical and emotional care, at all stages on this journey of living with dementia each day, when the person is facing multiple losses and fears. Chaplains are called to see people with dementia with different eyes, to see as God sees, looking beyond declining cognition, impeded communication, and limited understanding. Chaplains should not deny people with dementia their humanity, which is not measured by cognition, focussing instead on what connects all human beings, not what separates any one of us.

People with dementia need chaplains to help them to find meaning in life, and to find ways for their spirit to be nourished, as they face exclusion from society and a feeling of exile from their former roles. People with dementia may ask: Who are we, when we have lost all our labels: worker, wife, and mother, volunteer, church lay reader? Now the only label they seem to have is that of being a person with dementia, and have all become all alike, labelled by their condition. Chaplains can reassure people with dementia of their unique identity, and challenge the negative discourses of loss around them.

Relationships

All human beings are created to be in relationships, including people with dementia; Post writes, "I feel and relate, and therefore, I am" (2006: 233). Chaplains can model the essence of their loving interactions with people with

dementia on God, who is love; enable them by unconditional love, be present to them, listen to their pain and be in relationship with them.

People with dementia still seek to be held in a web of loving interactions, despite their changing needs. They increasingly need caring relationships, despite being unable to bring a great deal to these interactions. Therefore, it is all the more important for chaplains to relate to people with dementia, and to challenge the way in which society isolates them, as they appear to fall outside its norms for relationships. The chaplain can focus on how the person is still present, still fully human.

The capacity of people with dementia to relate to others might be changing, but, from a Christian theological standpoint, we are all held in God's remembrance and within the Body of Christ. Chaplains can mirror Christ's concern for the marginalised, when they relate to people living with dementia, helping them to find meaning, purpose and hope in their lives.

Job's suffering

People with dementia are not solely their condition, but fully human, created in the image of God. Their journey should not mirror that of Job, who found he had no one to turn to, apart from God, in his time of need. This story is one of the oldest stories of suffering, isolation, and a turning to God, and can be regarded as a parable for people living with dementia. Job says: "truly the thing that I fear comes upon me, and what I dread befalls me" (Job 3:25)⁴ and "I loathe my life; I will give free utterance to my complaint" (Job 10:1).

One of Job's unhelpful friends, Bildad (Job 18:17-20), had spoken of the extinction of Job's name and memory. This makes for particularly poignant reading for those diagnosed with dementia, as it speaks to the fear that overwhelms them as each day they struggle with blank spaces in the thread of life, and their life story seems to be becoming increasingly fragmented.

However, there is a wonderful conclusion to Job's wrestling with his friends, with his own fears, and with God, for finally he is able to say: "For I know that my

⁴ All scripture quotations are from the New Oxford Annotated Bible: New Revised Standard version. New York, NY: Oxford University Press.

Redeemer lives and that at last he will stand upon the earth” (Job 19:25).

Chaplains can help people with dementia to nurture their faith tradition (if any), to sustain them throughout the journey with dementia, particularly travelling further into this valley of the shadow of death.

Carry the person’s life story

Biomedical texts all speak of inevitable loss and cognitive decline. Psychosocial views are that personhood is being lost in dementia, but can be bestowed by caregivers. However, as an attribute, this concept of personhood appears to be at risk if no one visits us or remembers us: “Defining ‘personhood’ as an attributed status makes personhood vulnerable as a status to be withheld [if] the person is not recognized, indeed not recognizable” (Ames, 2016: 127).

Although people with dementia are usually unable to tell you the storyline of events in their life, they nonetheless still have a sense of self, which does not rely on an attributed status such as personhood. An outsider’s view might be that the person with dementia no longer has a story, but this places far too much importance on events on a chronological time line, rather than being able to find meaning in the present moment. Chaplains can assist people with dementia to find such meaning, drawing on the disjointed stream of images depicting their life story.

People with dementia often rely on chaplains to help them to hold their story faithfully, just as their birth family once did. Therefore, chaplains can play a key role in countering the powerful negative narratives in society that the person is disappearing, facing nothing but loss and decline. These negative narratives can be challenged with an alternative story that focuses on living well, despite and with dementia.

Chaplains are part of the surrounding mosaic

Chaplains are an important part of the mosaic around people with dementia in this confusing world, by seeing the person within. They have the opportunity to show the hospitality demonstrated by Jesus, and to love this person because God first loved us all. Instead of society’s overwhelming focus on pushing people with dementia to the margins because of their diminishing capacity, chaplains

can welcome the person as belonging, which is so much more than being included. Inclusion would mean a chaplain simply tolerated the person's presence, despite any limitations, rather than welcoming him or her with delight. Most people with dementia want to be welcomed in loving friendship, and missed when they have been absent.

In overcoming the mosaic within the person, and connecting with him or her despite the confusing surrounding mosaic, chaplains can look past linguistic difficulties, such as allowing for perhaps long pauses, while a person searches for what he or she wants to say, often trying to communicate non-verbally. Post describes this as a way to "serve as *prostheses*, filling in the gaps and expecting that now and then the cues we provide will connect with the person" (2006:229). A question such as "Wasn't it lovely yesterday?" can leave the person feeling blank, with no memory of any event, let alone an awareness of yesterday. A better question is to say "Wasn't it lovely yesterday, when we went for a picnic to the park, and you wore that top with sunflowers?" Chaplains should keep going with such prompts, until they see the light in the person's eyes that means he or she recalls something from this event and can relate to the memory,

Present moment

People with dementia usually live intensely in the present moment, so do not have that sense of a time just past. Chaplains can gift us with their presence, relaxing into the present moment, by sitting with the person in silence and being attentive in language of non-verbal listening. As Swinton writes, this is a "sacrament of the present moment" which enables a person to connect deeply (2012:235). This connection is akin to being asked to watch, wait and pray, as Jesus asked of the disciples in the Garden of Gethsemane.

Chaplains can be truly present and connect without words, by using touch, eye contact, music and aroma, as they try to breach the barrier of communication. Look into a person's eyes for that spark that may alight when there is a connection that has created within him or her a moment of wellbeing. By the end of the day, with a string of such moments, the person will feel good, even if he or she does not know why.

People with dementia usually treasure visits as a “now experience” so why must they remember who the chaplain is, or that he or she came before? Is this just to satisfy a need for identity and recognition on the part of a visitor? However, a visit is not a cognitive experience that people with dementia can necessarily store and recall, but they can still enjoy the gift of a visit in the present moment. Chaplains need to realize that it is not important that a person remember a visit, for it is their presence that is experienced in the moment, not a memory of an event.

Chaplaincy

Pastoral care of people with dementia is about being with them and connecting without words. Chaplains can assume all verbal and non-verbal expressions have meaning, and accept the person just as he or she is, listening to what is often a fractured voice within tangled emotions, as well as disrupted memories.

Chaplains can be present to the person with dementia, and bring him or her a sense of peace, as they connect spirit to spirit. In so doing, the chaplain can look beyond what the world sees to the reflection of the divine image in each person with dementia. By discarding their own focus on cognition and emotion, chaplains can be present in the moment, able to connect without words.

Chaplains can find out more about the person, so as to assist in finding meaning in his or her life, where a life story is a springboard for meaningful engagement. The chaplain can help a person to treasure this life story, and find meaning in the present moment, by focussing on what the person can still do, rather than the many things he or she can no longer do.

Spiritual care

“As we lose an identity in the world around us, which is so anxious to define us by what we do or say, rather than who we are, we can seek an identity by simply being who we are, a person created in the image of God. Our spiritual self is reflected in the divine and given meaning as a transcendent being. As our cognition fades, and our emotions flatten, our spirituality can flourish as an important source of identity.” (Bryden, 2016:289.)

Chaplains can support people with dementia to find meaning, such as through guided spiritual reminiscence, familiar rituals, prayer or sacraments. Whatever gives meaning in life needs to be nurtured, whether this is the divine of a particular religious tradition, nature, the arts, animals, music, so that the person with dementia can find meaning, despite the confusing mosaic reigning within and around him or her.

Care of people with dementia is palliative, as there is no cure, just steady decline till death.⁵ Every moment, every caring encounter and connection with the person, can be a moment of spiritual relationship and compassion. Chaplains can connect without words, be present, carry a life story and relate to the person as a whole human being, with dignity and respect. The spirit remains deep within, despite the ravages of dementia, and chaplains can connect spirit to spirit, even at the last stages.

The basis for spiritual care should be drawn from the core values of the Australian National Guidelines for Spiritual Care in Aged Care: respect and acceptance, compassion and empathy, inclusion and diversity, and dignity.⁶

Walk with the person into this valley

Never let it be said, “My God, My God, why have you forsaken me?” Chaplains can walk alongside the person as he or she approaches the valley of the shadow of death. As people with dementia travel this journey, their relationship with God may need increasing support from chaplains. Do not exclude people with dementia from their normal spiritual practices, as they need to receive nurture to their spirits as they approach death with and from dementia. Chaplains can minister to the person, singing, praying, and drawing on whatever has meaning for him or her, which may be the liturgy, familiar choruses, or the Lord's Prayer.

People with dementia might become agitated or not seem to understand, so “tap into the rich resources of the Holy Spirit” (Bryden, 2015:290). Chaplains can rely on the fact that they are connecting with the person's spirit, not his or her brain, so can be creative and trust in God to help make this connection at this eternal

⁵ Dementia is now the second leading cause of death in Australia: see www.alzheimers.org.au.

⁶ See www.meaningfulageing.org.au/national-guidelines-for-spiritual-care-in-aged-care.

level. We are all in communion with each other and with God. There is no need for cognition, for this is a spiritual communion between the chaplain and the person with dementia. Worship is in spirit and truth, not in cognition, and we are in communion with God, whose nature is to be in relationship.

Knowing God

People with dementia may ask: Will we know God if we can no longer remember? However as they lose their memory of who they are and who God is, they can become reflected in others, and see Christ in others. In the family of God, the body of Christ, we are all what others remember of us, and we all connect with Christ in fellowship with each other. People with dementia need chaplains to be Christ for them, to affirm their identity, and to walk alongside them in their confusion. The person may not be able to affirm the chaplain, to remember who he or she is, or whether he or she has visited before, but the chaplain represents Christ's remembrance to the person with dementia.

The question is sometimes asked whether the Eucharist should be offered to people with dementia, as they do not appear to understand its meaning. However, this sacrament is a sign of grace by which God works invisibly in us all, and those without the ability to remember should still be a sacred part of this Eucharistic meal. The thief said to Jesus "Remember me when you come into your kingdom." We may forget God, but we remain secure in the mystery of divine memory: "See, I have inscribed you on the palms of my hands" even through dementia (Isaiah 49:16).

"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. God's everlasting arms will be beneath me, upholding me." (Bryden, 2012: 62-63.)

Journey into a deepening I-Thou

The journey - from diagnosis to death from dementia - is a journey into the true centre of being - the spirit deep within, despite the brain becoming diseased, resulting in dementia. Diminishing communication and less reliable emotion does not mean that the spirit is disappearing. Even though the person might

have trouble telling the chaplain about his or her experience of God, or of speaking the words of prayers out loud, he or she has been able to have an experience of God's presence. However, the person has been unable to communicate this to the chaplain clearly.

By reframing the experience of dementia as a journey into a deepening I-Thou relationship, where the barriers of cognition and emotion are being stripped away (Bryden, 2016: 13), chaplains can offer pastoral care for people with dementia. A person with dementia can be given life and meaning in the Christian community, and chaplains play a vital role in relating to him or her, by the reassurance of their presence, and through them, of Christ's presence.

Welcome the outcasts

God sees our heart and our spirit, not our cognition. We are all fearfully and wonderfully formed in the image of God. The breath of life given to us all draws our spirit deeper into relationship with the divine and with each other.

Chaplains can travel alongside people with dementia on their journey, helping them to find meaning and purpose in life. It will be challenging to see beyond cognitive and emotional deficits, but chaplains can do what Jesus did, welcoming the outcasts and ministering to them. Be alongside people with dementia, include them, and surround them in Christ's love: show them the beacon of hope, by being Christ for them, drawing them ever closer to God. By reframing an understanding of dementia, chaplains have a chance to reflect on what it means to be truly human and to be in relationship with God and with others.

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