



## DISCUSSION PAPER

### Inclusive Spiritual Care: Dementia Response and Resources

#### **Purpose**

In ministry to and with older people, a specific Salvation Army response is required regarding dementia and working out how spiritual care can be provided to all who are impacted by dementia, both the older person and those who care for them.

Briefly, Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life. Most people with dementia are older, but it is important to remember that not all older people get dementia.

**It is not a normal part of ageing.** Dementia can happen to anybody, but it is more common after the age of 65 years. People in their 40s and 50s can also have dementia. The most common types of dementia are Alzheimer Disease, Vascular Dementia, Frontotemporal Dementia and Dementia with Lewy bodies (Alzheimer's Australia, 2016).

The number of people affected by dementia is increasing within longer living. How do we nurture well-being in someone who has declining ability to think reason and remember? In order to support well-being it is important to encourage and support the use of remaining skills where possible.

#### **Introduction**

There is much misunderstanding within society and the church regarding dementia and the negative language and unhelpful, even derogatory words or phrases used in regard to dementia include, “sufferer, victim, demented person, dementing illness, dement, afflicted, patient, offenders, absconders, he/she’s fading away or disappearing, empty shell, not all there, losing them or their mind, they are attention seeking, inmates in care facilities, slang such as ‘away with the fairies’, they plural within dementia rather than an individual” (Alzheimer’s Australia).

It is understandable that such terms feed stigma and shockingly rob people of dignity and worth.

The work and writing of Kitwood (1997) has been influential in broadening thinking around attitudes and approaches to caring for those with dementia. His understanding through social psychology was that the human being is a person, not an object. Kitwood has written of two aspects changing for the older person in dementia. Along with increasing decline in mental processes there is also significant change in the social-psychological environment and patterns in relationships.

He sees personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood and the failure to do so, have consequences that are empirically testable” (1997, p. 8).

Of particular influence on Kitwood was Martin Buber’s teaching (a Jewish Theologian) about the “I-Thou” approach to others and that every person is sacred. This approach to relationships is one of grace giving despite individual situations and underpins Kitwood’s understanding of personhood in dementia. However, Swinton (2012) stresses that Kitwood overlooks how the “I Thou” relationship expressed by Buber is deeply connected to relationship with God.

Also, Swinton now sees that the term ‘personhood’ is problematic today and can become malignant. This is because the premise rests on who decides who is a person?

One definition of a person by John Locke is that one is a thinking, intelligent being able to reason and reflect and consider self as self. Such a definition excludes those with dementia as persons. Correspondingly, if personhood is reliant on relationships, what quality of relationship is needed to sustain that person and if the relationship fails or is lacking particular quality, what then?

Both a citizenship and theological response is helpful here. The following definition of social citizenship is an inclusive basis for those with dementia. Bartlett & O'Connor (2010) see that, "social citizenship can be defined as a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level".

This approach would support a fundamental change for those with dementia. Recognition of their social status and supporting their own agency for the range of their lifestyle, social networks and community engagement for the length of their life, could help overcome existing stigma and overlooking individual needs. A relevant point is that the dementia experience is different as people of different ages and stages will have different priorities as they journey through their life. (Bartlett et al.)

Further thinking around relationships, is how valid roles such as husband, wife, mother, father and so on, are suddenly no longer relevant for the one with dementia but also for the one caring for them as they are now a 'carer'. There is a process of reduction for the one with dementia to almost nothingness rather than now being considered a competent thinking person.

## **Discussion**

As the biomedical model continues to look for genetic or chemical cures, there is minimal recognition of what a person is actually thinking or feeling. It is relevant to point out that in order for each person to stay mentally well it cannot be achieved as a

one off event but is a lifelong process and as one with dementia struggles to stay mentally well, how might their well-being be supported? It is important to remember that each person has unique needs, abilities and interests (Cheston & Bender, 2003).

A practical theological response specifically pertinent to Dementia is outlined by Swinton & Mowat (2006). They recognise that “Practical Theology locates itself within the diversity of human experience, making its home in the complex web of relationships and experiences that form the fabric of all that we know”. This underpins both experience of dementia and other life issues as well as the significance and guidance for relationships.

A Biblical worldview highlights that dignity and worth of the person is found in our creation in God’s image or likeness. This gives people with dementia great worth and dignity. Isaiah 50:1-4 tells the story of the Israelite people struggling in exile under the power of the ruling nation and at great risk of losing their distinctive identity. The prophet speaks a pastoral word into their hearts, assuring the Israelite people that God over rules other powers and that their distinctive identity is in God’s care.

Allen & Coleman (2006) highlight, “Just as God is not an isolated person but is considered always in relationship, Father to Son to Spirit, so a human person is never to be considered in isolation of the rest of humanity”. This is important to stress as one with dementia struggles in issues of identity and relating to others, how reassuring to know not only the importance of identity to God but the importance of relationship with him and others.

Theologically, The Salvation Army beliefs affirm the basis of God’s love, faithfulness, redemption through Jesus and consequently hope, as all develop in the discipleship journey in community together. However, it is important to note that much of theological teaching and worship is built around cognitive ability.

At an intellectual level there is expectation of ability to think, reason, and have capacity to make decisions. If God can be known through scripture, revelation, personal experience and prayer, there is an assumption of some intellectual capacity

for understanding and development in Christian disciplines. What happens for someone whose cognitive ability, intellect and memory is severely damaged?

Swinton, (2014) asks “What does it mean to be a disciple when you have forgotten who Jesus is?” Two assurances are helpful. Firstly, God does not forget us and is always actively working in the world and people. The second assurance is based on understanding that memories are not simply something to be recalled but a whole person’s life becomes the ‘memory’.

Swinton outlines, “Bodily memory is a product of community, ethos, formal learning and practice. It reveals bodies that are at home in the world in quite particular ways. Bodily memory should not be understood apart from representational memory. Nevertheless, its efficacy and significance are not determined by the presence or absence of recall. There is an endurance of bodily memory that transcends recall and potentially acts as a powerful conduit for knowing Jesus even if one has forgotten who Jesus is”.

Western cultures particularly over the past 60 years or so have developed and place great emphasis on cognitive function and ability. Swinton (2012) questions why functions such as memory, thinking ability, rationality, learning and language have more elite status than attributes such as love, relationships and feelings which form over a lifetime.

Dick-Muehlke highlights that, “It is increasingly being recognised that behavioural and psychological symptoms of dementia, once primarily attributed to neuropathological brain changes, are indeed an attempt on the part of the individual to communicate unmet needs. When understood as a nonverbal language, behavioural expression reveals much about what the person is experiencing, from pain to social seclusion. Undoubtedly such behaviours might also reflect unmet spiritual needs”.

Aged Care Plus has recognised and begun a spiritual assessment program for holistic care to all residents in their care. The term 'spiritual' in the context of ageing and longer living is understood to mean that which brings greatest or deepest life-meaning for the person. It can be seeking answers to what is happening in life and is the indispensable part of our humanity. It is also about relationship to the sacred or transcendent which may or may not lead to or arise from the development of religious rituals and the formation of community.

Each person has the potential and the choice to develop and become more aware of and more in touch with their spiritual dimension. All people in a search for ultimate meaning of life are on a spiritual quest. Religion is one way for people to practice their spirituality. Religion at its best supports the search for ultimate meaning as well as encouraging relationships in community.

However not all people choose to work out their spirituality through religious practice. People differ as to how they express their spirituality, the relevance and impact it may have for their day to day living. Often it is only in crisis or older age that they look for meaning and hope, beginning a spiritual quest.

Elizabeth MacKinlay, an Anglican Priest and Registered Nurse, has contributed widely within an Australian perspective, through written works, seminars and University teaching regarding ageing and spiritual care. She highlights a model of finding ultimate meaning through relationships, with God and others, religious practice, the arts and the environment. This model has formed the basis of the assessment process in Aged Care Plus.

Classifying and grasping the spiritual dimension is not straightforward or easily defined. There are many different definitions of spirituality and in the context of dementia a difficulty around many definitions is that they rely on cognitive ability to help sustain the core beliefs and values (Dick-Muehlke, 2016). Not only are those with

dementia living with the devastating decline in thinking, reasoning and remembering but they also have to contend with societal attitudes that stress the importance of intellect, and quick thinking ability.

A further important point is made by Dick-Muehlke in recognising it is people who in their spiritual work, continue developing, not simply their core beliefs and values. In Aged Care Plus we are re-working the assessment to be more inclusive of those with dementia as the current assessment engages more readily with those who respond cognitively.

To support understanding, the lived experience of Christine Bryden and dementia is important here: She questions:

Is cognition the only measure of our presence amongst you as spiritual beings? Certainly my capacity for accurate communication of thought is diminishing daily. It is difficult to find the words for the pictures in my head so as to communicate with you. Does this mean my mind is absent? Even if these pictures may one day fade, is my soul connected with this failing cognition?

I do not believe this is so. I might have difficulty feeling the presence of God, or being able to speak the words of a prayer in my mind, but I can commune without words.

As my cognition fades, my spirituality can flourish as an important source of identity.

As I lose an identity in the world around me, which is so anxious to define me by what I do and say rather than who I am, I can seek an identity by simply being me, a person created in the image of God. My spiritual self is reflected in the divine and given meaning as a transcendent being.

At the same time, Kelly (2012) recognizes that in order to provide compassionate pastoral or spiritual care to others, begins with self-reflection and understanding ourselves as we enter an encounter with another. The Christian perspective of understanding one's own identity in Christ can be helpful to model to those who are frail and coping with changing cognition while respecting their choice to not accept

that perspective. How vital to stress that each person is beloved of God as his creation, not for what they can do.

Thinking through the struggle for identity for the one with dementia who may find their own story eludes them, the pastoral response is to remind them of their story within God's narrative or in relationships.

Shamy (2003), after many years of ministering among people with dementia, argues that, when the brain fails, God is known in the human heart. She claims that people with dementia sometimes express spiritual wisdom in the hours before death.

So, valuing the non-rational is vital if we are to nurture spiritually a person with failing cognitive powers. Dick-Muehlke outlines that "compassion, empathy, humility and recognition of the person's ultimate value lie at the core of healing relationships in dementia. In the absence of these, the most touted approaches to dementia care are no more than a collection of techniques designed to manipulate the confused into behaving appropriately."

For those who struggle to intuitively emphasise these qualities in engagement with others, there needs to be a conscious choice and change of attitude and willingness to try other ways of communicating. Sensory stimulation is important and the tactile experience of holding and touching symbols as used in worship can be helpful too as well as fragrances for those with dementia. The use of visuals and photos can be extremely helpful. Photos are provided to assist with the current Spiritual Care Assessment.

An extension to other relevant information around someone's life is Life Story Work. Bill Mearns (2007) sees, "Life Story Work with people with dementia is as critically important as lotions and potions." Life story work can tap into residual long term memory and is a way of communicating which improves self-esteem and well-being. Another valid point is that of safeguarding personal identity and reminders of

relationships. Knowing other's stories can improve understanding when there is confusion or distress and can assist in care-planning.

A final helpful approach in all spiritual care is to program intentionally for meaning and connection. Although written from the perspective of retirement living or residential aged care, the Church too could factor this in their planning. Gordon (2016) sees "social programs that bring residents together around intellectual, cultural, creative, physical, recreational and celebratory pursuits - spiritual programs that encourage and support resident in their spiritual pilgrimage – service programs that enlarge the residents' capacity for service to other in their community, the wider community and world". A separate attachment is a document called 'Dementia Friendly Church Guide'.

I conclude with more words from Christine Bryden,

"My soul is me, and will always be me.

Even through the ravages of dementia, my soul will remain intact and continue to be the primary way in which God works within me. I can survive this disease with dignity, confident that God sees my soul - the true me.

He speaks within my soul which is given life and meaning in my Christian community. You play a vital role in relating to the soul within me, connecting at this eternal level. Sing alongside me, touch me, pray with me, reassure me of your presence, and through you of Christ's presence.

Be creative and trust in God to help you bring his love to me. Identify where I find meaning in life, to discover and enrich my spirituality. Through this I can find spiritual healing and transcend my sense of loss and fear".

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