**Three-dimensional spiritual care for people living with dementia**

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Although it can be difficult to define Spiritual Care, we generally have a fairly good idea of what good spiritual care looks like. Whether delivered by a ‘professional’ (such as a Pastor, Chaplain, Nurse or Counsellor) or by a volunteer or family member, we expect it to include a number of elements. We expect the carer to listen attentively to the wishes, desires, stories and struggles of the person they are encountering; to participate with them in the search for meaning in their situation, and to leave them feeling happier or more reconciled to their situation. As summarised in a recent large-scale Danish study of healthcare professionals, it recognises the importance of the person’s spirituality and seeks to work with their beliefs and spiritual history to secure the best outcomes for them: “using dialogue to explore their thoughts, feelings and outlook on life; and assisting patients in finding meaning and purpose in the things they value, and, if possible, gaining inner peace and well-being” (Hvidt *et al.*, 2020, 5).

In my experience, the spiritual care offered to people living with dementia does not often look like this. This is particularly true in the later stages of the condition, when if spiritual care is offered at all it is most often in the form of a shortened worship service for a group of people or some prayers with the individual. There is usually very little attempt to explore outlooks on life or to help somebody find meaning in their situation. On reflection, it is easy to see why this tends to be the case.

Although the definition of spiritual care I offered above is good for most situations, it presents problems when we are thinking about people living with dementia, for two reasons. In the first place, it depends very heavily on the use of language and dialogue to establish what matters to a person, what their wishes are, and how their needs may be met. This is in the best traditions of *person-centred care*, the approach to the patient that takes into account their uniqueness and their preferences rather than trying to impose a standard set of solutions on everybody (Kitwood, 1997). However, in the later stages of dementia it is usual for the person to have difficulty in expressing their wishes and preferences. They may also lack self-insight into what they desire and what matters most deeply to them (Kevern, 2015), so a ‘person-centred’ approach may require more information than it is possible to gather by listening carefully to the person themselves.

The second problem with this approach is that we may understand ‘care’ very narrowly and imagine that it is enough to help somebody to ‘feel better’. Part of the confusion is that, as Janice Clarke maintains, Spiritual Care may be treated as an aspect of good, holistic, nursing care (Clarke, 2013). Since nursing is the vocation to help people to get better (or at least to *feel* better), good spiritual care can be judged by its contribution to this overall goal: the question of what makes such care ‘spiritual’ is forgotten. This can lead to some very shallow care in practice: if a person with dementia can participate in a hymn, stay quiet for a prayer and appear calm and content at the end of the session it is counted as a ‘success’ because it represents ‘good care’ although there is very little spiritual about it apart from the use of a few religious words. This is what I have called elsewhere a ‘palliative’ approach to spiritual care (Kevern, 2015): the belief that the role of spiritual care is only to make somebody feel better, without engaging with the task of “finding meaning and purpose in the things they value”. It overlooks the fact that a person living with dementia may have work to do, challenges to meet and tasks to complete, and so remains very superficial.

Underlying both of these issues is the question of identity: who is the person receiving spiritual care, and what do they need? According to the account of the philosopher John Locke, what makes a human being a person is the capacity to tell a narrative about themselves, the ‘story of their life’. What makes the person I call ‘me’ is the story or stories I tell of myself, and they provide a key source of meaning (McAdams, 1993; Hughes, Louw and Sabat, 2006). Hence, in times of illness or existential threat, spiritual care maybe understood as a way of helping somebody to reframe the narrative of their illness in constructive ways (Lasair, 2020). But this presents a problem for thinking about spiritual care when the person concerned has dementia: if there is no clear story, no narrating self, does it make any sense to talk of a ‘spirituality’ that provides the basis for spiritual care?

As Julian Hughes put it, “. . . spirituality is part and parcel of what it is to be a person, qua human being in the world. Therefore, our models of dementia – person-centred, palliative, supportive – must be broad enough to encompass spirituality, not as an add-on, but as a fundamental feature.” (Hughes, 2011, 205). Conversely, our understanding of spirituality and spiritual care must be broad enough to encompass people living with dementia, and the definitions above seem to have a problem doing this. It follows that we need to expand our view of what contributes to the spirituality of a person living in the later stages of dementia, and to find ways of understanding their spiritual needs that do not depend upon their ability to reflect and communicate them clearly to us.

In this chapter, I will explore how we may expand our view of spirituality, and so of spiritual care, to make it expansive enough to include people living with dementia. I will argue that to do this we need to come to a deeper understanding of the person by drawing on additional sources of information and insight. We need to use this material to help to construct a self-narrative for the person living with dementia and so to gain enough wisdom to offer spiritual care in an appropriate way. I propose we gain this insight by reflecting on three aspects of the person’s identity that are often set aside when we offer spiritual care:

Past – where has the person’s spirituality come from?

Present – who and what feeds a person’s spirituality now?

Future – what challenges and opportunities for growth are they facing?

**Expanding spiritual care for people living with dementia: past, present and future**

Past – the role of acquired spirituality.

The majority of people living with dementia now in northern and western Europe grew up in a world where religion was a significant and normative part of life. It is easy and natural, then, to assume that a person’s spirituality can be traced by reference to the religious tradition and practices they grew up with, and to shape ‘care’ along the lines of religious worship. However, this approach should only be used with caution (see, for example, Christian Council on Ageing and Methodist Homes for the Aged, 2014). The person may never have been very attached to the tradition of their childhood, and may even have been traumatised by it; there is no simple relationship between the religion of our childhood and the spirituality of our later years. A different approach is required.

One way to understand spirituality is as a set of symbols, beliefs and practices that build up our sense of the meaningfulness of life before we become fully aware of them, and persist long after we have forgotten the reason for them. These may be the main symbols and practices of a religious tradition, but we develop a unique relationship with them over the years. This means that our spirituality is largely hidden from us, comprised of what may be termed EFEMeRA: Early-acquired, Frequently-repeated, Emotionally Memorable Ritualised Activity. The practices and emotions linked to these EFEMeRA do not depend upon conscious awareness, but on procedural memory (e.g. how to make the sign of the cross) and emotional memory (e.g. a response to an image or icon) which persist after the loss of explicit conscious recall. Thus Vance (Vance, 2005) has developed a form of Procedural and Emotional Religious Activity Therapy (PERAT) that identifies and strengthens the support that people with dementia find in their deeply-ingrained spirituality. Similarly, by paying attention to the responses (positive or negative) of the person living with dementia to particular rituals and symbols from their background, it may be possible to reawaken an ingrained spirituality in them that goes beyond words or conscious thought. A rather beautiful example of how this works is given by Oliver Sacks, who had a patient with a memory span of a few seconds and no memory of the last forty years:

One tended to speak of him, instinctively, as a spiritual casualty – a ‘lost soul’: was it possible that he had really been ‘de-souled’ by the disease? ‘Do you think he has a soul?’ I once asked the Sisters. They were outraged by my question, but could see why I asked it. ‘Watch Jimmie in chapel,’ they said, ‘and judge for yourself.’ I did, and . . . I saw there an intensity and steadiness of attention and concentration that I had never seen before in him or conceived him capable of. I watched him kneel and take the Sacrament on his tongue, and could not doubt the fullness and totality of Communion, the perfect alignment of his spirit with the spirit of the Mass. . . . There was no forgetting, no Korsakov’s then . . . for he was no longer at the mercy of a faulty and fallible mechanism . . . but was absorbed in an act, an act of his whole being, which carried feeling and meaning in an organic continuity and unity . . . Clearly Jimmie found himself, found continuity and reality, in the absoluteness of spiritual attention and act. The Sisters were right – he did find his soul here. (Sacks, 1998, 40)

Present – the spiritual self in the social network

Contemporary understandings of spirituality are a product of a modern world which starts with an isolated, self-conscious individual. This model of the human person distorts the concept of ‘person-centred care’ because it implies that the individual maintains their own ‘self’ and their spirituality without any help from others. In contrast, Stephen Sabat and Rom Harrej (Sabat and Harrej, 1992) discuss the ways in which the ‘person’ is a social construction, made up of the different ways that different members of the community recognise, value, remember and respond to the individual. We only have limited control over how this aspect of our individuality is constructed, and it can be a source of distress or a means of controlling us as well as a way of supporting our sense of self. However, without a network of people who recognise and value us, we are likely to suffer from mental illness and spiritual desolation.

So we need to be alert to the fact that carers and people close to the person with dementia will be bringing their own perspective and interests. As another conversational thread in the same study demonstrated, some carers may wish to find evidence of positive spiritual growth in the person living with dementia while others may see only decline and loss. As Kitwood pointed out in developing his ‘dialectical model of dementia’, sometimes the expectations and hopes of the people closest can make the experience of dementia worse (Kitwood, 1997). It is also striking that clergy who offer religious services in elderly care homes may see one of their roles as monitoring the carers for signs that they are abusing residents: not all carers want the best of the person living with dementia (Kevern and Walker, 2013).

Having said that, for most people their individuality and spirituality is built up and maintained by their social networks. Most of us are very aware of how much we owe to the people and networks around us, but this is particularly clearly the case regarding people living with dementia. One way to understand our life-course is as one in which individual, personal identity is ‘lent’ to us for a time. The community makes each of us an individual in our early years, and if we later develop dementia, may once again take on the role of supporting our individuality. At this time, those around us may take on extra responsibility for maintaining our sense of self, for, “active, collective authorship of the self-narrative” (Radden and Fordyce, 2006, 73). Although we are used to thinking of our spirituality as something very individual and even private, for most of us it takes place in a social context, shared with those closest to us.

It is therefore vitally important that there are people around who can hold and keep alive those stories so that the person with dementia can maintain an identity, even though he or she may forget that identity. . . These are the components which, together, enable the person with dementia to remain a person, with an identity, a purpose and a community. (Goldsmith in Green *et al.*, 2011, 172)

Future – what are the spiritual challenges of dementia?

One of the things that makes us human is that we have things that need to be done. Existentially, we are presented with challenges to face and life tasks to perform as we grow and change. The way we approach these tasks is closely related to our spirituality.

This is true for all human beings, and we must assume that it continues to be true for a person living with dementia. They may perhaps attain a state resembling what Tornstam terms ‘gerotranscendence’ in the very old (Tornstam, 2011). Turning specifically to older people living with dementia, Christine Bryden speaks of a similar sense of fulfilment that arises from the need to live always in the ‘now’ (Bryden and MacKinlay, 2002). Thus, for example, one of the carers who contributed to our study of spirituality and caring said that her mother reached a state of deep enlightenment and peace in the later stages of her dementia (Kevern and Stifoss-Hanssen, 2020), but it is noteworthy that other participants in the conversation reacted strongly to this account by the carer concerned. In the exchange of views that followed, it became clear that, to some extent, carers see what they want to see. Some will see only suffering, others enlightenment, and we need to take care when we guess at what is happening in each person’s spiritual life.

However, whether there is a calm growth into transcendence or a daily struggle with distress, there may be challenges that require spiritual care and support. Referring to older people generally, Pope Francis speaks of them as ‘spiritual pioneers’ who are exploring, for the first time in human history, what it means to develop spiritually in their 80s and 90s (Pope Francis, 2017). Specifically in the case of people living with dementia. Naomi Feil draws on a lifetime of experience to conclude that they, as other people, may have work to do before they die - reconciliation, resolution, forgiveness – which they may manifest as restlessness or anxiety (Feil, 1985). It is, she says, evidence of a struggle between Resolution and Vegetation, requiring spiritual care and support. This is the dimension of spirituality for a person living with dementia that may be overlooked, misunderstood or minimised by those offering spiritual care: they may see signs of distress and respond by offering soothing, distraction or medication in an effort to restore calm, not recognising the possibility of real spiritual growth at that moment. In the terms offered by Naomi Feil, they may encourage the person in distress towards ‘Vegetation’, rather than supporting their attempt to seek resolution.

A rare insight into the challenges of a living spirituality in the face of dementia is given by the words of Robert Davis, a Baptist Minister reflecting on his experience. They raise the question: how may this journey be supported and encouraged by sensitive spiritual care?

. . .Perhaps the journey that takes me away from reality into the blackness of that place of the blank, emotionless, unmoving, Alzheimer’s stare is in reality a journey into the richest depths of God’s love that few have experienced on earth. Who knows what goes on deep inside a person who is so withdrawn? At that time, I will be unable to give you a clue, but perhaps we can still talk about it later in the timeless joy of heaven. . . .

Right now, I walk in partial moonlight. How depressing it would be if all I had to look forward to in life was to journey down into this darkening moonlight only to end up in the cold blackness of the grave. However, I can look beyond the moonlight and see glorious ‘Sonlight’ emanating from . . . heaven. This view makes life makes sense, gives me patience, and produces a yearning in my heart.(Davis and Davis, 1989, 137)

**Conclusions – feeding back into SC practice**

When we visit a person with dementia to offer spiritual care, we usually see only a part of what makes them a unique person. They may have forgotten a lot of the experiences of their past that make them unique and continue to shape them. They may be living in a residential home away from their social network and the people who know them really well; they may find it difficult to imagine their own future or to communicate about the challenges they face. Because we see only a small part of the person, it is easy to fall into a trivial sort of spiritual care that is only about trying to give them a fleeting sense of comfort and calmness. This may itself be a valuable outcome, but it is a very small view of what spiritual care is – it does not engage with questions of meaning and purpose, or help somebody to grow or develop into their unique vocation as a person. If we believe in the value of each person living with dementia, we should be trying to offer them more.

In this chapter I have tried to argue that, if we want to offer better spiritual care, we need to start by knowing more about the person, We need to learn more about what has shaped then and continues to live on in their habits, their attitudes and their fears. We need to get to know the people who are close to them and love them, who continue to weave the ‘self-narrative’ that tells the story of this person, of their meaning and value, their place in the world. We need to be alert to the spiritual insights they may be gaining and the challenges they may be facing, as they lose some capacities to interact with the world and, perhaps, turn to embrace death.

There are two stories that can be told about the spirituality of people entering the world of late-stage dementia. The first is a story of decline and dehumanisation: in this story, everything that makes the person unique and valuable is taken away from them until they are a walking corpse, an empty sack of meat, and there is nothing for the spiritual carer to do but to keep them comfortable until the body has died alongside the mind. This is what Franck would call the ‘Chaos’ narrative of sickness (Frank, 1993)..

The other story, what Franck would call the ‘Quest’ narrative, is one of continued growth and change, as the person adapts to a life of dementia and rises to the challenges that it brings. In this story, the role of the spiritual carer is to discern and support a process of transformation in which what is being stripped away is the surface layer of distractions and activism, and what is left is the person themselves:

I believe that people with dementia are making an important journey from cognition, through emotion, into spirit. I’ve begun to realise what really remains throughout this journey is what is really important, and what disappears is what is not important. I think that if society could appreciate this, then people with dementia would be respected and treasured. (Bryden, 2005, 159)

In the end, the story we tell and act upon says as much about ourselves as about the person living with dementia. In what has been called a ‘hypercognitive’ society (Post, 2000) we are conditioned to value people who can remember, decide, communicate and act with speed and efficiency. This cultural background makes it hard for us to see the spiritual journey of a person living with dementia. When we offer spiritual care for a person living with dementia we do not just challenge them – we challenge ourselves to see beyond our own prejudices and enlarge our understanding of what it means to be human

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