Spirituality and Dementia: A Chaplains Guide to Supporting those with Memory Issues at the Hospital

Introduction:

We are living in an age where a person's rational mind is seen as their greatest means of relating to the rest of the world. However, any approach that recognises the wholistic nature of the personhood of an individual, must also take into account their emotions and spirituality as well as their cognitive function. Spiritual needs will vary between individuals, but may range from a need to be connected to others, to be able to teach or to learn. Needs may include the desire to express themselves creatively, or to have access to those things that bring them comfort, such as music or prayer. A real need is to feel valued. People living with dementia are no less human or valuable than those living without cognitive impairment, they deserve no less respect[1].

Within the hospital setting we will increasingly encounter men and women who are living with one of the many types of dementia as well as needing treatment for the medical condition that has brought them into hospital. These men and women are also in need of support for their spiritual well-being, but offering this support may prove harder when the patient cannot express their need in an overt manner.

Research suggests that a strong faith in God offers a significant coping resource to those with a diagnosis of dementia, and the extent to which individuals can participate in religious events is directly related to their perceptions of overall quality of life. People with dementia wish to maintain spiritual connections as long as possible[2]. This is not to say that those from a non-faith background are not in need of spiritual support. The need to be valued, to express themselves, to access their creativity remain and there may be other emotional support systems available to them which the Chaplain can help them access[3].

Bearing in mind the short interventions that may take place as a Chaplain it is still possible to enhance the experience of a patient living with dementia, and to help assist spiritual well-being during a chaplaincy encounter.

What is Dementia?

The number of people living with dementia is expected to reach 1 million by 2025 and developing dementia is the biggest fear of those over the age of 55[4]. Dementia itself is a term that covers a range of different neurological diseases which give varying symptoms. These include Alzheimer's disease, Small Vascular Disease, Lewy's Disease, Fronto-Temporal dementia, Huntington's disease, Creutzfeld Jacob's disease and Parkinson's. It is also possible to have a combination of different dementias referred to as Mixed dementia. Although Alzheimer's Disease

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[1] Stuckey and Gwyther 292

[2] Stuckey and Gwyther 293

[3] Anna Chaplaincy Handbook

[4] Faith Action

accounts for over 50% of dementias, each type of dementia has its own pathology, and so the experience of dementia will differ. This means that as Chaplains we can make no assumptions about the individual patient.

Dementia is recognised as exhibiting two or more of the following: forgetfulness, memory Loss, confusion, poor reasoning and logic, personality changes, poor judgement, ability to focus and disturbances to visual perception. [5]

How it manifests itself: The bookcase analogy.

One way of helping us to understand how dementia works is through the bookcase analogy which is outlined in an article by Braak[6] which likens the storage of rational/logical memories, and the storage of feelings and emotions as two separate but linked bookcases.

Hippocampus	Amygdala
logic/fact/reason	*Feelings and emotional memories*

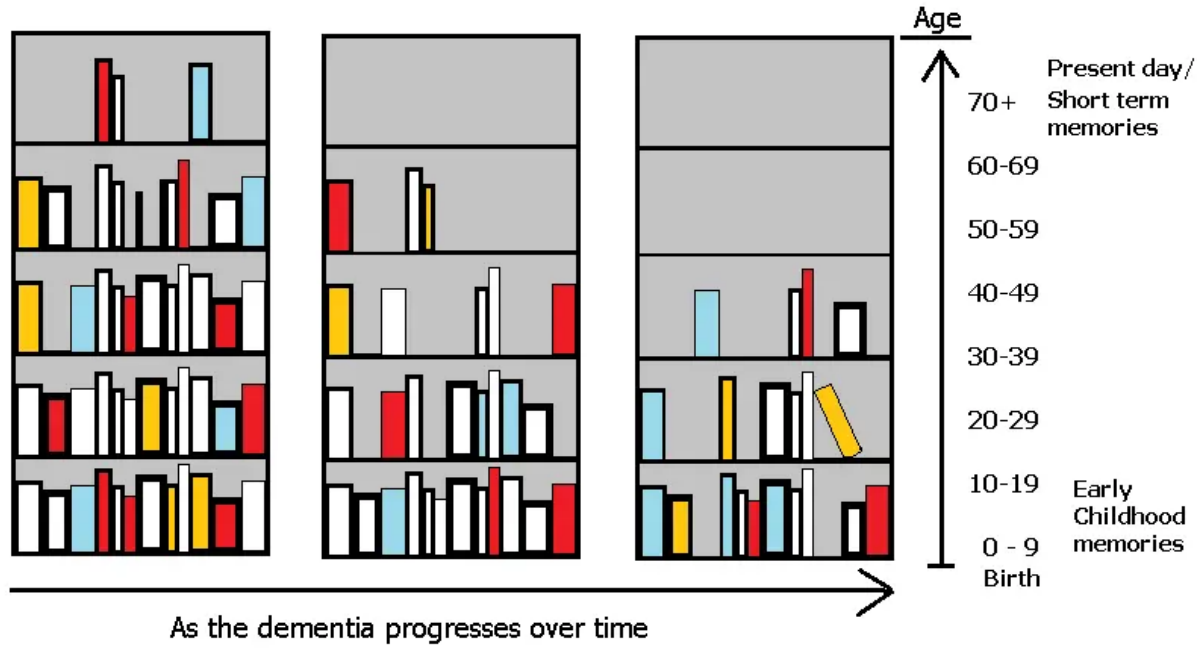
In a healthy brain the factual memory is stored in the hippocampus system, and the emotional memories are stored in the amygdala. Both types of memories can be attached to all experiences.

[5] Janice Hicks, 2018, Spirituality, Religion and Health

[6] Braak, H (1991). Review: Neuropathological stageing of Alzheimer-related changes. Acta Neuropathologica. Vol 82. pp239–259.

For a person with Alzheimer's dementia, the factual memory bookshelf – the hippocampus – is the first to be damaged. In the early days there may only be a small amount of damage to the most recent memories (stored on the top shelves). This may mean that the information is still there – albeit a little muddled or hard to find – for example, dates and times may be confused.

Over time this bookshelf will start to collapse resulting in the loss of factual memory and the order of time. If the top shelves, the recent memories, have been damaged then the person will have the strongest memories from many years ago. This could mean that the person believes themselves to be much younger than they are and if so, they may have difficulty 'placing' those around them in their life. If factual information and the ability to use logic and reason are lost, it is much more difficult to find and make sense of the memories that remain.



[7]

Although in the later stages of dementia both logical and emotional responses are damaged, emotional memories remain intact for much longer, and memories stored via the amygdala are used to make sense of the world. Consequently, although a person with dementia may not remember who someone is, they will know how they 'feel' to them, for example someone who makes them happy and creates a feeling of comfort and security. However, if they can't place the feeling, they may experience fear and mistrust.

Similarly, someone who does not have the ability to use logic and reason may interpret a place not by where it is, but rather where does it 'feel' like. For people with dementia, we need to see all behaviour as a means of communication based on feelings not facts. A person may behave in a manner that is difficult to understand as it does not seem to make any sense. Try to move away from looking at the situation

[7] Blgmind.org.uk

with logic and reason and instead establish and respond to what the person may be feeling on an emotional level. For example someone who is in the hospital may not understand where they are. Their 'memory' of what a hospital looks like may be very different from the environment they find themselves in. Imagine when you picture a hospital you think of 'Call the Midwife' rather than 'Holby City'.[8] Additionally, if their previous experiences of hospital were stressful or frightening, then this may well be the over-riding feeling that they are experiencing.

Spiritual Needs for those with Dementia

According to the Scottish Executive Health Department there is a difference between spiritual and religious care:

- Religious care is given in the context of the shared religious beliefs, values, liturgies and lifestyle of a faith community.
- Spiritual care is usually given in a one-to-one relationship, is completely person-centred and makes no assumptions about personal conviction or life orientation. Spiritual care is not necessarily religious. Religious care, at its best, should always be spiritual[9]

Apart from basic physical needs, those living with dementia also still need to feel loved, valued, and useful. I have encountered a number of patients offering to help others, or pushing trolleys up and down ward corridors believing themselves to be helping staff. The desire to express themselves, or to be able to talk about whatever is on their mind may be paramount. However, it may not be easy for them to express this need, or even articulate what the issue is for them.

Those living with dementia may be able to give clues of how best to support their religious or spiritual well-being. If they are unable, then family members may be important in giving advice on the spiritual heritage of the person. At this point it is important to recognise that the person's view of God and feelings toward God may also be a blockage to emotional well-being. Unresolved anger toward God may hinder emotional well-being, or having a strict doctrinal conception of God can be a risk to being able to reconcile adverse events in their lives[10]. Research suggests though, when faced with an uncertain and fearful future, faith may facilitate maintenance of hope, meaning and purpose – even for those with dementia[11].

A chaplain is able to help those with dementia access those elements of spirituality which give strength and comfort. It will vary from person to person, but could be something obviously religious such as a Bible verse of icon. Other people will respond more to sensory input such as music, touch, contact with natural elements or seeing flowers, birds, or stroking an animal. Bearing in mind the person's need to be in relationship for others it may be more relational and involve keeping in touch with an important figure in their lives. This could be directly, but it may involve being

[8] When my mum was in hospital she thought she had been kidnapped and was being held hostage in a warehouse.

[9] Scottish Executive Health Department, in Anna Chaplaincy Handbook p17

[10] Stuckey and Gwyther 295

[11] Stuckey and Gwyther 296

able to talk about their memories of an important person, looking at photos, reading letters, or interacting with objects that are significant.

Skills development

All of our skills as chaplains are necessary for walking alongside those with dementia. Especially important is the need to be patient-centred. What is the person's needs at this moment. If we remember that the most important thing is that the person feels valued, that may help us in our approach, our responses and our understanding of what is necessary.

The type of spiritual support a person may need will vary depending upon the stage of dementia and cognitive impairment that they are experiencing. It may be possible to ask the patient what are the practices and symbols that are important to them. What is the music, and what are the words that they enjoy. In any event having an assuring presence is essential.

In mid-stage it is possible to help the person reminisce, either with photos or through gentle conversation. Now it may also be possible to recite words or sing music. Again, the assurance of being valued and loved is important. By now the person may not remember a visit, but they will still feel positive after you have left.

In late stage dementia spiritual support is focused entirely on valuing the person. Mirror their mood and tone, you can even synch your breath with theirs. You can spend time being thankful for this person. Once again familiar words and songs will help. This is much more a ministry of being present and alert to the patient. Touch may be appropriate here to help someone know that you are present with them.[12]

People living with dementia cannot move quickly between topics, and so it is important to be present with them wherever they are in their thoughts. There is no need to move them on – but to listen and enable them to express what they are thinking. It is possible that they may not be able to express much at all. However, being present to them, saying their name, smiling, all are important elements of helping the person to feel valued.

In Joanna Collicut's book[13], she talks of using the acronym VERA to help those offering spiritual care for those living with dementia. In which we Validate what the person is saying, Empathise with the emotion, Reassure, and Act. Practically this may look like the following[14]:

- Use short simple phrases, avoiding abstract ideas.
- Recall positive memories/ use familiar items. It may be possible to get the patient to recount times when they have felt loved or special, heard or understood as they reminisce.
- Reintroduce yourself at each visit.
- Be attentive to body language

[12] Janice Hicks, 2018, slide 21

[13] Joanna Collicut, A Gospel-based approach to spiritual care

[14] Blackpool teaching hospitals chaplaincy team

- Be with the person where they are. Do not try to jolly them along, but allow them to express difficult emotions, this may be the only opportunity they are given.
- Recognise that a past memory may feel as if it's happening right now.
- Use symbols and images that may help the patient, use familiar prayers or items. Even when speech is lost patients may still be able to respond to familiar words, liturgy, or readings.
- Consider things to touch that may enhance worship. Consider visual prompts such as ipads/tablets.
- Provide prayer resources for patient and families
- Actively promote the dignity and value of the person as they are.

Perhaps it helps to think of Dementia as something new, a different way of being. Our role is journeying with the person a few steps on this journey. The Chaplains role is to affirm the identity of the patient, and to offer meaning and hope. In a condition when many people emphasise loss, the Chaplain can offer an alternative mind-set. One which views this time as transition, and where meaning and hope is found in the acceptance of this new person. One way of assisting in this could be to use Mindfulness, or a Contemplative type of prayer using a simple phrase or expression and timing your breathing with the patient.

As Chaplains we recognise that each person has their own valid identity and that this is not lost with Dementia. If we are able to help someone express themselves, this affirms their identity, gives value and meaning to the patient.

Validation Therapy

Validation Therapy is a technique pioneered by Naomi Feil[15]. It does not restore the person's mental health, but it enables the person seeking to support them to enter the world of the person with dementia, and to seek to find out the underlying issue and to spend time with them in that place. It involves a variety of techniques which include centering yourself on the person. The use of simple expressions and phrases but is worth watching the videos and reading some of the literature about it. In the limited manner in which I have explored it I have found it useful.

On the ward one day I met a woman who was extremely anxious that she had no money. It was clear that no amount of explaining that no money was necessary would console her. I realised that this was a 'presenting issue' and that there was a much deeper issue at foot. Validation therapy uses reflective responses to draw out of the person what the important issue is. The conversation went something like this:

Patient: " I haven't got any money'
Me: 'money is important for you'?
Patient: 'what if I run out, then I won't live'
Me: 'you're worried that you'll run out of money?'

[15] Feil, N. (1993). *The Validation breakthrough: Simple techniques for communicating with people with "Alzheimer's-type dementia."* Health Professions Press.

Patient:’ yes my parents ran out of money and they died’
Me: ‘You miss your parents?’
Patient: ‘oh yes, I miss them very much’

--a short conversation ensued in which we reminisced about her parents.

Patient: ’but I haven’t got any money?’ My parents ran out of money and they died.’
Me: ‘Are you worried you’ll die too?’
Patient: ‘Yes, am I going to die?’

This was the underlying issue. The patient was expressing two major spiritual needs. The first to re-connect with her parents on some level, and the second her own anxieties about dying. Having found out the nub of her concerns her whole manner and conversation changed.

People living with dementia may also be confused and angry at hospital. Any well-meaning approach may be rebuffed. In keeping a person-centred approach to spiritual well-being accepting the rebuff graciously is still a way of giving the person agency and value, in a place where they may not feel they have any control at all.

Implications for Working in the Hospital

The skills needed by the Chaplaincy team are mostly the skills that are used every day in caring for the spiritual wellbeing of patients, it does suggest though that Chaplains need to alter their expectations of what a ‘positive encounter’ may look like. An encounter in which the Chaplain just makes eye contact with a patient, smiles at them, touches their hand or face, and repeats their name to them may have little or no obvious response. Yet this affirmation of identity and acceptance of the other validates the patient’s experience.

It is unlikely the Chaplaincy team will get many referrals from wards for patients with dementia, as they are less able to express their needs for spiritual support. Dementia patients may not respond well to an initial intervention by a chaplain as they are unable to identify them in time or space at that moment. This suggests that chaplains may need to take a more proactive approach to spiritual wellbeing of those living with dementia.

Proactive types of intervention will vary between hospitals, and even between wards. However, where there are groups of patients with dementia it may be possible to have a short service with familiar hymns, readings and prayers in a space where patients can hear and take part. Where there are individuals with dementia it may be appropriate for Chaplains to speak with family members, or care providers, to find out what spiritual history the patient has, and to see if there is any spiritual input the Chaplain can offer for them. Otherwise, the chaplain is able to offer the gift of presence, time, and acceptance to a patient in a busy ward where the spiritual wellbeing needs of a patient can be overlooked by presenting medical issues. Do not underestimate the value of this gift.

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