

Spiritual Care

and people with dementia: a basic guide



To care for someone involves knowing something about them and this is especially so for those who live with dementia. Before we can offer spiritual care we need to understand a little about this complex disease that can affect every part of the person.

Types of dementia

There are a number of forms of dementia, and while all are characterised by loss of brain functioning they are differentiated by which parts of the brain are affected and how this shapes the nature of the decline.

- **Alzheimer's disease** accounts for the majority of dementias. The chemistry and structure across the main part of the brain are changed, causing brain cells to die. The decline in functioning is usually slow and gradual.
- **Vascular dementia** is caused by problems with the supply of oxygen to the brain following a stroke or small blood vessel disease. Vascular dementia makes up around a third of the total. Conditions that affect the circulation of blood to the brain, such as hypertension, can contribute to vascular dementia, which is often characterised by intermittent decline in cognitive functioning with periods of respite.
- **Dementia with Lewy Bodies** is named after the smooth round protein deposits that develop inside nerve cells in the brain interrupting its normal functioning. It shares symptoms with Parkinson's disease, including slowness of movement. It accounts for a small percentage of dementias.
- **Fronto-temporal dementia** is a rare form of dementia, encompassing Pick's disease, that usually affects the under 65s. It has dramatic effects on behaviour and personality, rather than memory, in the early stages.

The progression of the disease

This varies considerably, but broadly falls into three phases.

Early Stage – symptoms (sometimes misattributed to stress, bereavement or normal ageing) include:

- loss of short-term memory
- confusion, poor judgement, or unwillingness to make decisions
- anxiety, agitation or distress over perceived changes
- inability to manage everyday tasks.

Middle Stage – symptoms include:

- distress, aggression and anger, perhaps due to frustration
- wandering and getting lost, leaving taps running or forgetting to light the gas
- inappropriate behaviour e.g. leaving the house in night clothes
- experiencing hallucinations, becoming increasingly forgetful and failure to recognise people
- may forget to eat, wash, dress and how to use the lavatory.

Late Stage – symptoms include:

- the inability to recognise familiar objects, surroundings or people – although there may be some flashes of recognition
- increasing physical frailty: starting to shuffle or walk unsteadily, eventually becoming confined to bed or a wheelchair
- difficulty with eating and sometimes swallowing; weight loss, incontinence and gradual loss of speech.

If no other illness becomes acute then life expectancy can be between 7 and 12 years.

Special Needs

People who have dementia need help with many of the ordinary tasks of living as the disease progresses, from help with finances and finding their way, to assistance with dressing, feeding and toileting.

As dementia becomes more evident it is important that there is someone who will remind them of their identity. This is more than just remembering who they were; it is about recognising the whole person, someone who is 'more than body, brain and breath.' This search for wholeness includes a recognition of what brings them meaning, purpose and hope: their spirituality.

"Spirituality ... means not just one compartment of life, but the deepest dimension of all life. The spiritual is the ultimate ground of all our questions, hopes, fears, and loves ... It concerns our struggles with loss; questions of self-worth and fear of reaching out to make new friendships ..." (Kathleen Fischer, 'Winter Grace: Spirituality and Aging')

To offer a sense of purpose and meaning in life, a place where questions can be acknowledged, can assist this search for wholeness. For those with dementia, whose world may feel increasingly strange, it could be that this is found within the relationships formed with those who care for them.

It is usual to feel on unsafe ground when visiting those with dementia - after all anything could happen!

It is also usual to feel that we have very little to offer. But what we do bring is ourselves and if that is brought with honesty and openness then that is enough. The most important thing that we can do for someone is to be alongside and stay with them on their difficult journey.

Identity

Dementia is frightening, both for the person in whom it is developing and for those close to them, especially their loved ones. Many people do not want to come into contact with those with dementia. They are often shut away indoors or are behind the locked doors of a home or hospital. The sense of isolation, of not being part of the society in which one lives or the family to which one belongs, is very real. There is a fear that, as the disease progresses, the person becomes 'lost' as they seem to lose the ability to recognise where they are, who they are, or even to recognise close family members.

If all this is frightening for us, then think just how frightening it must be for those with dementia.

Modern Western society is based on the idea of the individual, and that is associated with the ability to reason. As a consequence, those suffering with dementia, where intellectual ability is affected, can be made to feel like outsiders as the disease progresses. But while reasoning is impaired, the ability to respond to beauty, music, art and humour, and to make relationships can remain.

In other cultures those who are different are often seen as special and revered and not as a problem or a threat to their society just because their way of relating to the world is different.

Identity and reality are complex ideas and while, with dementia, the words a person uses to express themselves may be jumbled or almost non-existent, the feelings and emotions a person has are not diminished. Indeed, they may even be heightened as other means of communication deteriorate.

Who is there behind the face of the person with dementia?

The way we look at people affects the way we interact with them, so it is important to understand what assumptions we might be making when meeting someone with dementia.

If people with dementia are seen as just alive, and barely human, then they will tend to be treated accordingly. The response to this attitude will be to ensure that they are kept clean and tidy and quiet, and to use drugs to control their behaviour. One writer has called this way of caring 'minimal warehousing'.

If we recognise that they once had a life, but now just live in the past, then what is important is to get alongside to help them remember who they were, the roles they enjoyed and what brought them fulfilment.

But we could see those with dementia as people who are like us, albeit people who are suffering with a condition that means that they need more assistance from others to live fully. Then, by coming alongside and helping them to be themselves we can help them experience the world in which they live with us, moment by moment.

Models of care

Our motivation for caring for people with dementia, and how we see the person behind the disease, will affect our relationship with them. We need models of care that encourage us to see the person. If we see only the disease then the person, in all their uniqueness, is hidden and they are labelled 'demented'.

Person-centred or person-focussed care asks us to see 'the person who lives with dementia', not 'a demented person'. And in meeting the person we can start to recognise someone who is like us and who needs help to live fully.

What can we do?

Dementia cannot be cured but we can enable life to be enriched by trying to get alongside in appropriate ways. The following approaches offer ways in which our interactions with people with dementia can be focussed:

- **Reality orientation** – providing clues in what we say, or the environment in which the person is cared for to help them make sense of the present. This involves reminding people of what is happening around them and, when they get things muddled, correcting them to help get the facts straight. In this way we can help 'fill in the gaps' of their memory.
- **Reminiscence** – remembering with someone what their life was like and how they lived it is important. It enables the sharing of a personal history that reminds people who they are and gives value to them. This helps people to regain a sense of meaning and purpose, and can make them feel more complete.

- **Validation** – listening to the feelings behind the words that are said. Although people with dementia experience the same emotions as anyone else, living with dementia means that they lack the ability to find the right words to express these emotions. For example if someone was calling for their mum it might be because they need to be reassured that they are safe and loved.
- **Validation in the later stages of dementia** – by speaking aloud the emotions seen in the person, or the body language they are showing, we enable them to be present in the world and have their silent voices heard. It can be a way of giving confidence that their uniqueness is recognised and affirmed.

Dementia in a care setting

Those with dementia who are entering care homes are generally doing so later in the progress of the disease than used to be the case.

This makes getting to know them more challenging but it is never too late. While they live they are people with a past, a present and a future. They are people who have relationships and who are still able to feel and express emotions.

Those who develop dementia while in care need to be reassured that they are still known and loved. It is part of our responsibility to get to know the person behind the dementia and to value them as part of the human family.

Many relatives and friends are reluctant to visit because they believe that the person with dementia will not remember that they have been. Visitors can also worry that they will not know what to say, or that the person they are visiting might do something strange and cause them embarrassment.

So what is the point of visiting?

There are at least two very important reasons for continuing to visit.

One is that the present moment is important. We need to experience what is happening at the time; not judge its value by the memory of, or the pleasure of looking forward to, the visit. If we can share this moment together and make an emotional connection, it will have been a good visit, however brief.

The second reason is that when the visit is over the emotions and feelings from the visit remain. A positive visit or experience can give the person a feeling of well-being for some time after. Your name might not be remembered, but the warmth and attention you bring will be. A visit is not a test to see how much memory is lost, but a meeting of two people, both of whom have needs.

With time, patience and perseverance it is possible to get alongside the person with dementia, to learn their story, and get to know them as a unique individual with hopes and dreams, however severe the dementia.

Communication

Part of our problem is that conversation with people with dementia is not easy. But the question to ask may be not 'is that real?' but rather, 'what must the truth be if the person says or does that?'

One of the ways that dementia shows itself is that people have problems finding the right words. We need to listen to the emotion behind what people are saying. After all, the words we use make up less than 10% of any communication. The rest is conveyed by body language and intonation. Those with dementia are usually able to make themselves understood if the time can be given to listening to what is behind the words. For example, if a person is saying they want to go home it could be that they are looking for reassurance that they are somewhere safe, where they belong, and that people care about them.

Communication is the way we interact with others and while some is verbal most communication is non-verbal. However, conversations are part of what it means to be human – so how can we converse with those with dementia?

We use words because we want to pass on a piece of information or give an instruction. But those with dementia may not be thinking along the same lines as we are, so they don't seem to understand, and communication is seen as difficult and people become frustrated. Another way is to use words as pointers to the feelings the person wants to share and mirror them back, so that they can hear them. This way of communicating allows for a meeting of two people rather than imparting information.

Non-verbal communication

Think too about body language. Can the person tell by the way you stand or sit that you would rather be somewhere else? Real communication is:

- the smile on your face
- a friendly approach
- listening thoughtfully
- the warmth in your voice
- a gentle touch.



Other ways to communicate

When people laugh together the barriers disappear. We no longer have an 'us and them' situation but real human interaction. It has been said that to play and to laugh is human interaction at its most genuine. When those caring for people with dementia are willing to free themselves from their roles and not worry about status or what they look like, then all are able to share in the gift of life without barriers.

Staff in one home presented a pantomime for the residents. A male carer was dressed as an ugly sister, complete with red wig, rugby top, layers of multi coloured skirts and thick football socks that didn't match. One resident, who hardly ever spoke, said to him, 'Well I don't know who got you up this morning, but they didn't do a very good job!' Everyone laughed together.

Laughter can ease difficult situations and perhaps make those difficult times in life more bearable. From patting balloons in the air to joining in when staff are being teased, all bring a lightness of touch to the day and make life more enjoyable.

What we can offer is 'loving attention' and being willing to stay with the person, not being someone who is going to be called away to deal with another problem. Living with dementia means that it often takes time for a response to show, so if we quickly hurry on to the next person we do not give chance for a connection to be made.

So

Go slowly ...

Give time ...

To greet someone with a warm smile and the offer of handshake is a way of saying that we care. This can allow the other person to keep hold of your hand and bring you closer, or keep you at arms length! Dementia makes it difficult for people to communicate and it is so easy to jump in and finish off sentences. But over time people get to know each other and then visits can be rewarding for both the person with dementia and the one visiting.

It is important that we recognise when something 'touches' someone who has dementia. We need to know this so that we can encourage more 'magic moments' and by doing so help to meet their spiritual needs. We need to watch for the small signs that tell us that a special place in their lives has been reached. It could be a foot moving to music while the rest of the body is completely still. It could be a tear that comes to their eyes, or a giggle, or a clapping of hands.

We need to recognise when a moment has been magic, and then tell someone! It is helpful to reflect to the person with dementia what you have seen and then tell the others so they can be aware and encourage the person. When people can't remind us, we need to be their memory and help them access these magic moments.

The Memory Box

Relatives and friends are often at a loss as to what to do when dementia is diagnosed in a loved one. One thing they can do in the early stages is to collect together a Memory Box – a collection of objects that will act as a trigger to help access memories and feelings. The earlier this is done the better as the person needs to be able to choose the special things to go into it that will remind them of people, places and things in their lives. Photos of family and friends can be a wonderful talking point, especially if names and dates are written on the back!

As the dementia progresses the stories of the things in the box can be told, and retold, by those who visit, to cue in the memory. The stories will become familiar and the repetition will embed the memories and feelings. Exploring the Memory Box gives those who come to visit something to talk about and enables a celebration of the person's life. It also gives conversation starters at a time when it can be difficult to know what to talk about. Things can be added or removed from the memory box as time goes on. It is a living thing.

The Senses

Our senses are ways by which we experience the world, and this is especially so for those with dementia. Some senses can be heightened as the dementia progresses.

- The sense of smell is very evocative. The smell of food cooking can bring back memories of family or evenings out. Holding an orange, with the smell it has, can be special.
- Tasting food is one of the joys of life. Special foods that are associated with festivals have their own memories which we can tap into.
- The sight of patterns and colours, either in pictures or nature or even clothes, can open up an individual's world.
- Touch is so important. To feel the hand of another confirms our humanity. Offering hand massage, perhaps using scented lotions, can calm and reassure those who are very frail.
- The sense of hearing is one that is often diminished as people get older. Before assuming that a person is not interested in talking do check that they have a hearing aid if they need one!
- Music is a special way into our emotions and feelings. Songs and hymns from days gone by may bring back memories, and singing itself makes us feel good and if it happens in a group is a good way to remind people they are not alone. Community singing has often been a favourite of older people.



Worship - Cues and Clues

Most care homes and housing schemes do not have a separate chapel, but while it is sometimes good to have a place set apart, it does not seem to matter where a service takes place. The important thing is that people are enabled to worship. It is the action of saying prayers, singing hymns and sharing bread and wine together that makes the place special.

The rituals we use give a framework for the action and enable those with dementia to be confident that they can find their way in it. This is especially true of the rituals of worship.

When we use signs, symbols and rituals we are giving clues to people about where they are and what is happening. And so by placing a cross, a Bible and a candle on a table we show that a place has become special and that an act of worship is about to start.

We don't always know what memories the symbols or the ritual are going to trigger. It could be that they enable the person to access deep memories that bring sadness and regret as well as good feelings. But this is not a bad thing in itself. To be human is to experience a range of emotions. What is needed is someone who is able to 'hold' the situation and so enable these emotions to be expressed safely without judgement. Use familiar hymns and don't worry about repeating them often! And make use of hymns that have choruses as they enable people to join in more easily.

When saying prayers, think about keeping your eyes open. People with dementia often like to keep eye contact so that they remain connected and not feel shut out.

Holy Communion seems to reach the person at the deepest level. The easiest way for them to participate is to ask them by name if they would like to receive the elements and then, using real bread, offer the elements by intinction, in which the bread is dipped into the wine and so both are offered together. Visitors and staff are important resources and are vital to a service. They help to give a sense of a worshipping community which those with dementia are able to join in with as far as they are able.

After the service having a cup of tea together acknowledges the importance of the community aspect of church and allows for the sharing to continue.

And finally

The guidelines offered in this leaflet suggest ways in which it is possible to offer spiritual care to those with dementia. But how each person develops this ministry of loving attention will depend on the gifts and graces they offer.

The joys and challenges of this work can be a well kept secret, but if you can find a way, it's well worth sharing with others the gift that there is in working alongside those with dementia.

There are no absolutes to help you, but many resources that can spark your own ideas.



Some Helpful Resources

Caring:

- 'Caring for someone with dementia' Jane Brotchie (Age Concern)
- 'Person to Person' Tom Kitwood & Kathleen Bredin (Gale Publications)
- 'And still the music plays' Graham Stokes (Hawker Publications)
- 'Visiting people with dementia'. (MHA and CCOA)
- 'Pictures to Share' books. Details at www.picturestoshare.co.uk

Autobiography:

- 'Living in the Labyrinth' Diana Friel McGowin (Mainsail Press)
- 'Dancing with Dementia' Christine Bryden (Jessica Kingsley)

Worship:

- 'A Guide to the Spiritual Dimension of Care for People with Alzheimer's Disease and Related Dementia', Eileen Shamy (Jessica Kingsley)
- 'Spirituality and Ageing', ed. Albert Jewell (Jessica Kingsley)
- 'Being with God', a set of three booklets of worship outlines with related CD (Scripture Union)
- 'Worship and People with Dementia', (MHA and CCOA)

Children's books:

- 'What's happening to Grandpa?' Maria Shriver (Little Brown & Co and Warner Books)
- 'Wilfred Gordon McDonald Partridge' Mem Fox (Puffin)
- 'Memory Bottles' Beth Shoshan (Little Bee)

Films:

- The Notebook
- Eternal Sunshine of the Spotless Mind
- In Memory of Her
- Iris

Notes

This leaflet is published by MHA in co-operation with the Christian Council on Ageing.

MHA is a charity providing a range of high quality care homes, accommodation and support services for older people throughout Britain.

Established almost 70 years ago, MHA now serves approximately:

- 3,000 older people in residential, nursing and specialist dementia care homes;
- 1,500 older people in sheltered housing and housing with care;
- 8,000 older people in community projects

MHA's services are open to all in need and are delivered by 5,000 dedicated staff and enhanced by the commitment of 5,000 volunteers. Its mission is "to improve the quality of life for older people, inspired by Christian concern".

The Christian Council on Ageing is the main national fully ecumenical organisation that focuses on the spiritual needs and development of older people. It has been in existence since 1982 and provides a Christian voice and action on issues that matter to older people in church and society. For more information see www.ccoa.org.uk

Further copies and the companion leaflets 'Worship and People with Dementia' and 'Visiting People with Dementia' are available from Epworth House, Stuart Street, Derby, DE1 2EQ.
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