

Dementia and pastoral care



A guide to visiting and worship

Introduction

This resource is intended as a guide for those who support the spirituality of people living with dementia. It offers advice and information for those visiting people with dementia and gives recommendations for worship, including suggested hymns and songs.

Professor Tom Kitwood famously said: "When you have met one person with dementia; you've met one person with dementia".

It is important to recognise that each person living with dementia is a unique individual. This individuality equally applies to a person's spirituality. For some people spirituality refers to a belief system, a set of values or something that gives meaning and purpose. For others spirituality relates to religion, faith and worship. Even people from the same religious tradition may have different beliefs and be at different points in their faith, so it should be acknowledged that approaches will need to be adapted depending on the individual.



For many people, receiving a diagnosis of dementia can lead to people questioning their own sense of purpose and spirituality.

"At first I kept asking why God had let this happen to him. All the evil people in the world and yet this happened to him, it seemed so unfair."

Wife of MHA care home resident living with dementia.

Despite this, many people find that their spirituality becomes stronger and helps them come to terms with living with dementia.

"My faith reminds me that there is a purpose to this. I don't know what it is yet but that's what faith is isn't it?"

MHA community group member living with dementia.

For others, spirituality becomes an anchor of stability during the happiest and darkest moments of living with or supporting someone with dementia.



"I walk to the local church every day. It has been my source of support and without it I really don't know how I would have managed."

MHA retirement living resident living with dementia.



How can we help?

This guide showcases the many ways in which we can support people living with dementia with their spirituality when visiting them.

"Sometimes I just need time to be me again, to find myself. It is not only those with dementia who lose themselves."

Wife of MHA care home resident who was living with dementia.

The key to supporting people living with dementia is that you are present and open to engage with them regardless of their beliefs and their ability to communicate. Our chaplains in our homes and retirement living communities are there to support residents, families and colleagues of all faiths, backgrounds and religions.

"I try to see the resident in the fullness of who they are, spiritual beings made in God's image, I acknowledge their individual stories and how precious each of them is to God. Knowing who someone is and giving them value – it's a powerful way to bring God's love."

MHA chaplain, Glen Rosa care home.

Visiting a person in their home, hospital or care setting

Visiting a person living with dementia or their family provides an opportunity for spirituality and relationships to be maintained. Visiting someone living with dementia can be difficult; it is common to feel like you're not connecting with the person or unsure of what to say. Overcoming this feeling is important as it shows the person and their family that someone cares. This is significant as many people living with dementia and their families recount losing friendships and relationships with others.

> "A lot of his old friends don't come anymore, even the ones we have known for many years." Family member, MHA community group.

"A resident's husband told me that he was worried because his visits to see his wife were gradually becoming shorter. I told him that it is not about how long the visit is but the quality of the time spent together."

MHA care home manager, Claybourne care home.



Some tips to consider when visiting

Be aware, when visiting, you may need to change the ways in which you communicate to suit the person's needs and abilities.

- Try to approach the person from where they can see you and make sure they are aware of your presence
- Introduce yourself clearly, explaining who you are and your connection with them. For example, "Hello I am Alison.
 I've come from St John's Church". Try not to presume that the person will remember who you are
- Wear or take something with you that may remind the person who you are, for example a clerical collar, a name badge or a symbol of faith such as a Bible
- Read a familiar passage from a religious text which reflects the individual's faith, sing together or share a prayer
- Try to be comfortable with periods of silence
- Avoid asking questions that test a person's recent memory, for example rather than asking "have you been to church this week?" ask "is going to church important to you?"
- Take time to recognise the feelings shown by the person living with dementia, whether they are positive or negative respond to expressions of happiness, sadness or anger. It is important to recognise that a person's behaviour is a form of communication.

Leading worship

For some people living with dementia their world can feel very unfamiliar and confusing. Beginning and ending worship with the same words every time can provide familiarity and security. Using objects, symbols and rituals can help people living with dementia connect with their spirituality and act as reminder.

"I have a box of objects that residents can choose to have during the service if they wish. This includes rosary beads, Bibles, crosses and figurines."

MHA chaplain

We don't always know what memories the symbols or the ritual are going to trigger. It could be that they enable a person living with dementia to access deep memories that bring positive feelings as well as sadness. People living with dementia will benefit from having someone in their lives to communicate with, in whatever way, so they are able to safely express a range of emotions without judgement.

Many of our care homes and retirement living communities do not have a separate room for worship, worship does not have to occur in a specific place. It is the action of saying prayers, singing and sharing time together that makes the place special, not the room itself.

"Hymns are incredibly powerful, they seem to access a part of the brain that dementia hasn't touched."

MHA chaplain, Belvedere Manor care home

Things to consider

When planning worship with people living with dementia, start with the belief that everyone is unique and this will be reflected in their abilities, strengths, wishes and experience.

Some people living with dementia will still be able to access their places of worship in the community with no or very little support. Others may prefer to stay in the safety of their own home or care setting to worship. Depending on what people are used to and when they feel most comfortable, some will prefer formal worship, others will want a more relaxed and informal approach. In whichever circumstance, remember to focus on the needs of the people living with dementia you are supporting and modify the style to be appropriate and welcoming to them.

Some tips for leading services with people living with dementia

- Use recognisable music, songs and hymns there is an order of service in the back of this booklet for your use
- Encourage the families of people living with dementia to be involved in the worship. They may like to choose a hymn, read from the Bible or offer a prayer
- Try to maintain as much eye contact as appropriate, even in the prayers. Prayers with eyes shut can make people feel disconnected
- Choose familiar readings and prayers
- Use an appropriate version of the Bible Good News (or similar) if the focus is the story or the Authorised Version if it is the poetry and rhythm of the words which is important (e.g. Psalm 23 or the opening verses of Genesis or John's Gospel)
- Consider a short address or thoughts for the day that confirm God's unconditional love and presence
- Think of ways to make the worship multi-sensory. For example, to feel the hand of another can reassure or calm.

"I soon learnt that you can't stick rigidly to a plan of worship; you have to be flexible and go with the needs of the residents you are with."

MHA chaplain, Warde Aldam care home

Communion

Communion remains an important aspect of faith for some people living with dementia.

Some people will be able to say or read the responses and follow the liturgy. Others may find hearing the words and prayers more meaningful.

Think about how to offer the elements, it could be in a combined way (known as intiction), by dipping the bread into the wine.

If possible, engage with each person at eye level and ask by name if they would like to receive the bread and wine or a blessing.



"The Eucharist lies at the very heart of many Christian's faith and practice. Receiving Christ in this particular way is always beyond cognitive understanding, and so for many living with dementia to receive the sacrament is vital, it draws and holds them in a place they have known, a mystery beyond words, and a peace can flow."

MHA chaplain, Anjulita Court care home

Ideas for worship

Suggested words for opening regular worship

Leader: My name is... and we have come together today, on (date) at (place) to worship God. O, give thanks to the Lord for He is good.

All: His mercy endures forever.

Leader: In the beginning, when it was very dark, God said, "Let there be light."

All: And then there was light

The sign of the light, a lighted candle is placed on an empty table

Leader: In the beginning when it was very quiet, the Word was with God.

All: And the word was God

The sign of the Word, the Bible, is opened and placed on the table

Leader: When the time was right, God sent His Son.

All: He came among us and was one of us.

The sign of the Son, a cross, is placed on the table.

Leader: Eternal God, creator of all things, giver of life, we praise you and we worship you. We thank you that you have always loved the world you have made: And that however far we stray from you, your love is always there to welcome us home. **Amen**

At the end of the service:

All: The grace of our Lord Jesus Christ, the love of God and the fellowship of the Holy Spirit be with us all, now and for evermore, Amen. Blow out of the candle, close the Bible and offer a sign of peace to each person present.

Suggested hymns

Abide with me All things bright and beautiful Blessed assurance Dear Lord and Father of all mankind Give me joy in my heart Great is thy faithfulness Kum ba yah Lord of all hopefulness I ord of the dance Love divine, all loves excelling Now thank we all our God O God our help in ages past O love that wilt not let me go One more step along the world I go Rock of ages Tell me the old, old story Tell me the stories of Jesus The Lord's my shepherd The old rugged cross There is a green hill Trust and obey We plough the fields and scatter What a friend we have in Jesus When I survey the wondrous cross

Suggested readings

Creation – Genesis 1: 1-4 Noah – Genesis 6-9 Joseph – Genesis 37-50 The birth of Moses – Exodus 2: 1-10 Moses and the burning bush – Exodus 3: 1-12 Samuel - 1 Samuel 3:1-10 Saul – 1 Samuel 9: 15- 10:9

Psalms of trust, praise and confession: 23, 27, 40, 50, 62, 63, 67, 84, 91, 95, 100, 117, 121, 139, 146

Psalms reflecting our confusion or distress: 42, 55, 69, 71, 86, 88, 131, 142

Gospel stories:

The Beatitudes – Matthew 5: 3-12 The Magnificat – Luke 1: 46-48 Simeon and Anna – Luke 2: 29-32 The Good Samaritan – Luke 2: 29-32 The Lost Sheep – Luke15: 3-7 The Lost Coin – Luke 15: 8-10 The Prodigal Son – Luke 15: 11-24 The Light shines in the darkness – John 1: 1-5 I am the Good Shepherd – John 10: 7-11 I am the Way, the Truth and the Life – John 14: 1-6

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