



**Support
+ Church family
+ Community
+ Inclusion**

It all adds up to

Livability

**Dementia inclusive
church guide:
travelling together**

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Understanding + Hope + Support



Journeying Together Following Jesus' model

We invited Revd Mhari McLintock, Synod Advocate for Dementia Inclusive Churches in the United Reformed Church (URC) to introduce this resource. Mhari is herself living with dementia and she offers a compelling reason for each church to engage with dementia:



Christians, by our very being, should be encouraged in our engagement with others. We are asked to talk with, to enable, to walk alongside people living with and without dementia. The model from Jesus was to walk alongside people on the margins when others would keep away from those who were different. Jesus saw everyone as members of His community, and so followers of Christ are asked to follow in His actions and His way. For me people should be encouraged to recognise and respond to, be engaged with people living with dementia. Don't exclude by making assumptions or by what you have heard. Taking time to think about what others might need is a sign that we want to welcome everyone into our churches, worship and our community's activities.

What can the church do?

By 2025, an estimated one million people in the UK will be living with dementia, with a similar number undiagnosed. Dementia does not just affect those who have received a diagnosis - there are more than 700,000 people caring for someone living with dementia. In the context of an ageing society – and an ageing church population – these figures can feel overwhelming.

Livability believe that churches have a unique opportunity to offer a gift to those living with dementia. By responding with compassion, we can create communities where those living with dementia can continue to take part. As Christians we are called to hope, and in this, we can show a willingness to journey alongside one another.

We are not told that life will be easy or problem-free, but we are told that God is with us on the journey, both in the good times and equally in the difficult times. Ultimately, we believe that when our communities celebrate each person we all benefit from the gifts each one offers.

Let's be practical

The purpose of this guide is to make a practical difference to your church life. You'll find the principles needed to approach dementia with hope whilst squaring up to the inevitable challenges. This resource draws from experts, most importantly those with lived experience, as well as those who are supporting those living with and affected by dementia. As a result, we hope it offers a rich variety of perspectives.

Using this resource may well raise more questions for churches on the journey towards dementia inclusion, so we've included more help in the Further Resources section at the end of the guide.

Useful for any stage of dementia

This resource mainly covers support for people in the earlier stages of living with dementia, but as person's dementia progresses, the guiding principles remain the same. With the right support - often alongside help from health and social care - it is possible for a church family to continue to offer fellowship and pastoral support right until the end of a person's life, whether at church, in the community, or in residential care.

A person living with dementia may become less able to initiate contact with church family, but it's important that they're not overlooked by their church family, who can continue to hold and to tell their story of hope, faith and love.

...the King will say, 'I'm telling the solemn truth: whenever you did one of these things to someone overlooked or ignored, that was me—you did it to me.'

Matt 25:40

Each person and each community is unique

If you've met one person with dementia, you've met one person with dementia.

Professor Tom Kitwood, pioneer in the field of Dementia Care

No two experiences of dementia are the same, and no two communities are the same; therefore this guide is not a checklist. Instead, the resource is intended to support churches to engage with and consider ways in which they can keep 'journeying together' alongside people living with dementia and their carers.

Some churches will want to initiate a 'dementia specific' ministry, while others will be looking to strengthen existing projects and ministries to be more dementia inclusive.

Reflection + Encouragement + Time



Dementia: where to start

Dementia is the umbrella term for a set of symptoms caused by diseases in the brain. Dementia is also an acquired disability, meaning that a person is not born with dementia. However it is defined, no two people experience dementia in the same way. On page 12 you will find an expanded explanation of some of the main types of dementia.

A 2017 survey¹ conducted by the Church of England and Church Urban Fund found that:

- 22% of churches provided pastoral or prayer support for people living with dementia
- 18% of churches provided activities for people living with dementia

While these findings do not reflect the ministries of all denominations, it provides an insight into the scale and nature of social engagement by churches around the area of dementia.

These statistics reflect Livability's experience in running our Dementia Inclusive Church workshops around the country. More often than not, churches identify a need and willingness to be inclusive of people living with dementia - but aren't always sure where to start. Identifying barriers that may exist, is the first step to removing them and ensuring continued participation of those whose lives are touched by dementia.

As part of our desire to make the good news of the gospel more accessible to all we began to discuss some of the problems that people with dementia and their carers face. We asked ourselves two questions: how can we welcome people with dementia. How can we support their carers?

We contacted Livability and booked a Dementia Inclusive Church workshop, which proved to be both informative and inspirational. We have since been more aware of how dementia can affect individuals and have been able to explore ways we can welcome and support both those who live with disability and their carers.

Pastoral Coordination Team, St Patrick's Church, Wallington

How is your church doing?

The insights we have gained, from every community where we have delivered training, has shaped this guide. We hope that this resource will encourage churches both to recognise where they are already supporting church family members who are affected by dementia, as well as to take steps towards further dementia inclusion, in the church family and in their local community.

¹ https://www.cuf.org.uk/assets/documents/Church_in_Action_Report_2017.pdf

Many churches will already be supporting church family members who are living with dementia. They may not recognise this as a dementia-specific ministry but rather as offering support in an informal way. This might include offering lifts to church or appointments, or tuning in to particular support that a person with dementia might value.

Examples include support during communion, or larger print service sheets. Small changes can make a huge difference to ensure the continued participation and contribution of people living with dementia.

So speak encouraging words to one another. Build up hope so you'll all be together in this, no one left out, no one left behind. I know you're already doing this; just keep on doing it.

1 Thessalonians 5:11, The Message translation

Pause for thought: time to reflect

We've punctuated this resource with 'pause for thought' questions. They can be used by individuals, in small groups or as a church family.

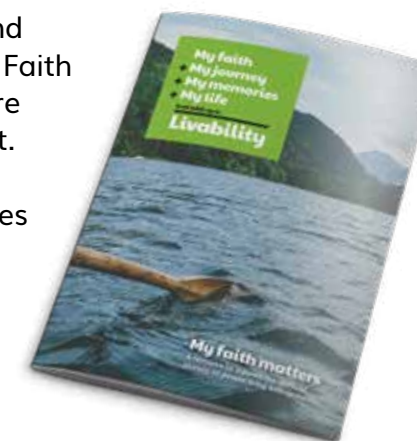
These questions will:

- provide an opportunity to reflect on individual and shared aspects of faith which add up to church family life
- stimulate discussion about action points and next steps
- help you to think about what barriers may limit or prevent participation

As you identify and remove barriers to participation – perhaps changing language or the physical environment - you might find it helpful to return to this guide, to take stock and set new goals. It's worth remembering that inclusion is not so much a destination but a way of travelling together as a church family.

My Faith Matters resource - spiritual support for those living with dementia

As a person's dementia develops, they may be less able to communicate what matters to them, which can be upsetting and isolating, both for that person and their friends and family. My Faith Matters is a practical resource developed by Livability to capture those aspects of a person's spiritual wellbeing that matter most. Whether a person enjoys reading the Psalms or sitting in the sunshine watching the world go by, My Faith Matters encourages spending quality time with a person living with dementia. Its emphasis on pastoral support beyond Sunday worship will support the person to maintain, re-connect with and explore what brings meaning to their life.



Caring + Support + Family



My Faith Matters has proved an invaluable resource for Anna Chaplaincy in Rochester Diocese. In getting to know a person with dementia and their family, My Faith Matters highlights important aspects of spiritual wellbeing to explore and record. It gives ideas for conversations and activities to help lift the person's spirits. It has been especially useful for the Anna Chaplaincy team working alongside the specialist dementia service at our local hospice. It can assist in planning spiritual care for people with dementia in care homes and those living in their own homes, and is relevant for people of strong, little or no faith, because it asks what brings meaning, purpose and a sense of security.

Julia Burton-Jones, Anna Chaplaincy Lead and Dementia Specialist,
Rochester Diocese

My Faith Matters can be downloaded from Livability's website:
<https://livability.org.uk/resources/my-faith-matters/>

Caring for the Carers

Come to me, all you who are weary and burdened, and I will give you rest. Take my yoke upon you and learn from me, for I am gentle and humble in heart, and you will find rest for your souls. For my yoke is easy and my burden is light.

Matthew 11:28-30

When it comes to support, we need to consider carers as much as people living with dementia. One in eight adults in the UK has a caring role, and during the course of our lives, one in three people will have a caring role for someone living with dementia.

While not everyone who supports someone living with dementia would identify as a 'carer' they may nevertheless provide ongoing emotional, spiritual and practical support. While a carer may be a family member, a person's main carer may be a church friend or neighbour, so it's important not to assume who is or isn't a carer.

Challenges of caring

It can be difficult supporting someone living with dementia, in ways that aren't always obvious. As a person's dementia progresses, an increase in the caring role is often not recognised - sometimes even by the carer themselves – especially if the change is gradual.

Many carers experience 'carer stress', loneliness or social isolation, often putting the needs of the person they are supporting before their own. While caring for someone may deepen relationships, in a recent UK carers' survey, 87% of participants stated that caring had a negative impact on their mental health.

How best to help?

When a church family is considering the support it can offer to a person in a caring role, it's important to be 'open - handed' in the offer of help. For example, rather than assuming that the person would like their shopping to be done for them, they may value the offer of support for the person they are caring for, so they can continue getting their own shopping.

Ask a carer if there's any way you can offer support - and be ready to offer again. It's not always easy for people with caring roles to immediately think what might be helpful.

As with the person living with dementia, the goal is to walk alongside the carer, rather than assuming what might be a help to them, or trying to 'fix' the situation.

It's very important to get time away from the situation and time off so you can nourish yourself and recover. As a family carer, it's easy to think you should be doing more than is actually good for you. That's not sustainable because caring can be really draining.

I don't want to put people off – caring means you get very precious moments with the person you love. I'm very challenged by people saying that they have 'lost' the person with dementia. I strongly disagree with that. Dementia is a disorder of the brain but it's not a loss of personhood. The person is disabled, or broken or limited, but they're still themselves until death. Of course, that doesn't mean it's not sad to see anyone you love who is suffering or hurt in any way.

Yo Tozer-Loft, singer, storyteller, a mother, a wife – and a carer

Pause for thought

Are there any members of your church family who have a caring role for someone living with dementia? While this may be a spouse or adult child, it may also be a distance carer (not living with the person they are caring for) or young carer. Has support been offered? Is support regularly offered?

If you have a dementia-specific ministry, like a Memory or Moments Cafe, consider support for the carers. This could be a space where carers can spend time together, or to have a break from their caring role.

Think about creating a directory of help that people are willing to offer, maybe help with lifts, gardening, DIY or baking. Help may not initially be needed or requested, but it's important for people living with dementia and carers to know that the church family is ready to help, and the offer will continue to be open.

Stories + Experience + Identity



Language matters

The language we use, and the stories we tell, directly relate to the way we think about something. So often the media reports dementia with language which reinforces the stigma around living with dementia.

In response to this, there is a shift to using more hope-filled language including 'living well' or 'living as well as possible with dementia' rather than saying someone is a 'dementia sufferer', which may feel like suffering is inevitable.

Whether the person is living with dementia or has a caring role, the language used around dementia should not exclude all hope. The language we use should seek to enable, rather than disable a person. By the same token, for many people who live with dementia or are supporting someone living with dementia, this may well be the most difficult chapter of their lives. For this reason, it is important not to exclude or outlaw the language of suffering that would help a person to put into words what their experience may be. God is with us during these times.

In it together

Whatever a person's experience of dementia, no single way of considering that experience - whether positive or negative - can possibly cover the emotional complexity of a lived experience. It is essential to listen to a person's experience, as a companion on the journey rather than as a 'fixer'. It is equally the role of church family to 'rejoice with those who rejoice' and 'mourn with those who mourn' (Romans 12:15).

Rather than seeing ourselves either as the 'helper' or the 'helped', as Christians we are called to consider ourselves as equal but different parts of Christ's body. Everyone has value, and everyone has something to contribute. Our very presence may be our chief contribution.

The way God designed our bodies is a model for understanding our lives together as a church: every part dependent on every other part, the parts we mention and the parts we don't, the parts we see and the parts we don't. If one part hurts, every other part is involved in the hurt, and in the healing. If one part flourishes, every other part enters into the exuberance. You are Christ's body—that's who you are!

1 Corinthians 12:25-27, The Message translation

Pause for thought

Reflecting on this Bible passage, identify ways it might be possible to recognise and honour those members of our church family who don't usually 'get a mention'?. Consider those contributions which are less visible, like tidying the service sheets, offering a friendly welcome to visitors, or being a listening ear when a member of the church family has had a difficult week.

Think about a time in your life that was difficult in some way. It may relate to a health problem, a relationship or bereavement. What was it like? What helped? Did you value time alone, or did you want to be around others? What scripture, prayers or hymns do you find helpful during difficult times?

Consider the language you use as a church around dementia, and review your communications. Have you used 'dementia sufferer' for example? This could instead be 'person living with dementia'. Small changes can mean the difference between disabling and enabling a person living with dementia.

A Biblical response to dementia

Who am I? I am one loved by Christ.

Thomas Merton

The story most commonly told about dementia by society is one of loss. Loss of memory, loss of ability, and perhaps even loss of identity. In a world that places great worth and value in productivity and independence - in doing over being - when a person receives a diagnosis of dementia they may be prompted ask, 'Who am I?' or 'Who will I become?' The losses encountered can be painful, but are only part of the whole story.

The Bible tells us that each individual is made in the likeness of God (Genesis 1:26), whether or not they are a Christian. In this way, we do not 'earn' our value, and there's nothing we can do to lose that value, even if we feel lost, unloved or abandoned. Each person is precious and loved by God, and no cognitive impairment or disability can diminish this truth.

As a person's dementia progresses, they may ask, 'What happens if I forget my faith, if I forget God?' We can be reassured that God remembers us, even when we do not remember him.

What matters supremely, is not the fact that I know God, but the fact that he knows me. I am graven on the palms of his hands [Isaiah 49:16]. I am never out of his mind. All my knowledge of him depends on his sustained initiative in knowing me. I know him because he first knew me, and continues to know me. He knows me as a friend, one who loves me; and there is no moment when his eye is off me, or his attention is distorted from me, and no moment, therefore, when his care falters.

J.I. Packer



Part of God's story

A person living with dementia may be less able to articulate their experience of faith, particularly if they lose their ability to communicate verbally, but this in no way means that they are not able to have experiences of faith. People living with dementia continue to be embodied selves, living stories, with emotional and spiritual gifts and needs.

Being part of a church family provides opportunities for each person, with and without dementia, to be part of God's story of redemption and grace. Dementia reminds us we are saved by grace alone, not our own merits and achievements.

While a person living with dementia may be less able to access memory, or consider the future, what they surely retain is the gift of presence, of truly being in the moment. This is a lesson that each of us can learn from and honour within our church families and communities, to value presence over performance. As church family, we have the responsibility and privilege of reminding one another of God's love for us, through our shared faith practices, and in the love we have for one another.

'By this everyone will know that you are my disciples, if you love one another'

John 13:35

Pause for thought

- Whether or not you are living with dementia, consider how you might answer the question, 'Who am I?' and 'What don't I want to forget?'
- Consider which verses of scripture hold particular significance and encouragement for you. It might be a verse relating to memory or identity, or perhaps a verse or passage that has been particularly important or encouraging during a difficult time in your life. Do you have a place where you have made a note of these passages? Does anyone know these verses are important to you?

Types of dementia

With over a hundred different types of dementia, the goal is not to know about all the complexities and variations of dementia, rather to be an informed church family. No two people will experience dementia in the same way, even if they receive a similar or the same diagnosis. There are four main types of dementia.

Alzheimer's disease

This is the most common disease which causes dementia. About half of those living with dementia in the UK have Alzheimer's disease. For most people with Alzheimer's, the earliest symptoms are memory lapses. In particular, people may have difficulty recalling recent events and learning new information. The person may:

- lose items (for example keys or glasses) around the house
- struggle to find the right word in a conversation or forget someone's name
- forget about recent conversations or events
- get lost in a familiar place or on a familiar journey
- forget appointments or anniversaries
- lose concentration during everyday tasks

Someone with the disease may also have problems with other aspects of thinking, reasoning, perception or communication. A person in the earlier stages of Alzheimer's will often have changes in their mood. They may become anxious, irritable or depressed. Many people become withdrawn and lose interest in activities and hobbies they have enjoyed in the past.

Vascular Dementia

This second most common type of dementia, causes problems with memory, thinking or reasoning. Symptoms may develop suddenly, for example after a stroke, or more gradually. The most common symptoms in the early stages of vascular dementia are:

- problems with planning or organising, making decisions or solving problems
- difficulties following a series of steps (for example cooking a meal)
- slower speed of thought
- problems concentrating, including short periods of sudden confusion
- memory problems, including recalling recent events
- language; for example, speech may become less fluent
- problems perceiving objects in three dimensions

It is common for someone with early vascular dementia to experience mood changes, such as apathy, depression or anxiety. A person with vascular dementia may also become generally more emotional. They may be prone to rapid mood swings and being unusually tearful or happy.

Dementia with Lewy Bodies (DLB)

This type may account for 10-15% of all cases of dementia. An accurate diagnosis is important, mainly because people with DLB can benefit from some medications, but also react very badly to others. Typical features of someone who is diagnosed with DLB are:

- varying levels of attention or alertness
- persistent detailed visual hallucinations and delusions
- movement and balance problems similar to those of Parkinson's disease, including slow and stiff movement (which might mean being prone to falls)
- sleeping difficulties

The symptoms of DLB can fluctuate from hour to hour, and even from minute to minute.

Frontotemporal Dementia (FTD)

This accounts for about 4% of people living with dementia, and covers a wide range of different conditions. It is sometimes called Pick's Disease or Frontal Lobe Dementia. This type of dementia affects behaviour, problem-solving, planning and the control of emotions. It can also affect the ability to interpret the meaning of words and the names of objects, and recognising faces and familiar objects.

Young Onset Dementia

In addition to these four main types of dementia, about one in every 20 people living with dementia is under 65. While the greatest risk factor is age, it is also possible for younger people to develop dementia. Additional challenges of living with this may include working and having both financial and caring commitments. On top of these challenges, since it is less expected for a younger person to be living with dementia, it can be difficult to get a diagnosis.

Guiding principles

Reading about these symptoms may feel overwhelming, so it's important to remember to keep seeing the person beyond their symptoms or diagnosis, just as we would with any other long-term condition. Nine in every ten people living with dementia will also have at least one other long-term health condition, another reason not to reduce a person to their diagnosis.

Rather than drawing conclusions, a good guiding principle is to ask, 'How is this person different from their usual self?' It is only then we can consider how we can best help that person as we continue to walk alongside them.

Pause for thought

- With each of these different types of dementia in mind, what sort of barriers might there be to participation in church life? How might these barriers be navigated as a church family?
- As well as thinking in broad terms, all challenges are experienced on an individual level. Rather than making assumptions about what a person might find difficult, spend time with someone. Find out from their lived experience what they find difficult, and which aspect of church life they may value some support with.
- It is equally important to find out what a person enjoys and would like support with to continue being involved in church life, whether this is being part of the worship team or helping with the flowers.
- If you received a diagnosis of dementia or started to have memory or other cognitive problems, would you want to tell people? Why? Why not? What would enable you to feel safe enough to share this sort of news?

Safeguarding

As a person's dementia develops - whether or not that person has received a diagnosis - a church family can feel out of their depth as they try to journey alongside. It is important to remember that while the church is well placed to support a person in a pastoral capacity - as 'alongsiders' - support from health and social care is essential, as the person's support needs become more specialist. This is not to say a church family should 'step back'. Rather, it is important to continue walking alongside that church family member, even if a person moves into residential care - people and their families can feel forgotten. My Faith Matters can help your church family to capture what matters most.

Pause for thought

- Share any concerns with the Safeguarding Officer at your church and consider the best next steps to take.
- If you don't have a Safeguarding Officer, speak to someone in the pastoral team, or the church leader.

Connecting with local support

If you are worried about a person who you think may be experiencing memory loss, or they aren't their usual self, ask if there's anything you can do to help. It is important for someone to feel encouraged and supported rather than coerced. Because there is still so much stigma around living with dementia, many people put off making a visit to the doctor. Whether or not a person has received a diagnosis of dementia, tuning in to what local support is available beyond the church family can ensure that life continues to be livable for people.

Anyone who identifies as a carer is entitled to a 'carer's assessment'. This may be completed by the local authority or an organisation in the community and voluntary sector on behalf of the local authority. Since the Care Act was introduced in 2014, a carer is now seen as having the same rights as the person they are caring for. The aim of a carer's assessment is to consider the impact a caring role is having on a person's life and to offer to connect that person to support that will help them sustain their caring role.

Pause for thought

- Do you know what local support is available for people living with dementia and carers in your area? What can you identify?
- Spend time exploring the Further Resources section at the end of this guide to see what else might be helpful.

Environment audit

Church environments range from centuries-old cathedrals to meeting in school halls. An environment audit encourages churches to consider and tackle any barriers that may be preventing the full inclusion of people living with dementia.

Getting inside the building

- Does the building look like it's open? Many churches keep the doors closed to keep in the heat – but this may unintentionally keep people out. A welcomer standing by the door can offer a warm welcome and practical assistance.
- Does the building have level access for wheelchair users and those with limited mobility?
- Is it possible to park close enough to the entrance, particularly in bad weather?
- Is the ground even?
- Are the edges of any steps marked clearly?
- If the building is large, are there occasional 'resting places' if a person's mobility is limited, or they become tired?
- Think temperature. Is your church building warm? This can be difficult to achieve in large buildings. Why not have a selection of blankets on hand for people who might particularly feel the cold?

Quiet space

Do you have a quiet, comfortable space for someone who might be feeling confused or overwhelmed by sensory overload? A few minutes with a supportive person might be all that's needed to feel safe and settled.

Signage

- Are signs clear, in bold typeface with good contrast between text and background?
- Is there a contrast between the sign and the surface it is mounted on? This will allow the person to recognise it as a sign.
- Are the signs fixed to the doors or locations they refer to? They should not be on adjacent surfaces if at all possible.
- Are signs at eye level (or just below eye level) and well-lit?
- Are signs highly stylised or do they use abstract images or icons as representations? These should be avoided.
- Are signs placed at key decision points for someone who is trying to navigate your premises for the first time? People with dementia may need such signs every time they come to your building.
- Are signs for toilets and exits clear? Finding the way out is just as important as finding the way in.
- Are glass doors clearly marked?

Lighting

- Are entrances well lit? Try to make as much use of natural light as possible. Good lighting can make an enormous difference for people living with dementia to find their way and make sense of their surroundings.

Sound

More people than we are aware of have problems with their hearing, but people with dementia often have further difficulties as they may be easily distracted by different sights and sounds, or find it tricky to fit or adjust their hearing aids.

- Is there a hearing loop in your church?
- Is it switched on for every service?
- Is there a clear sign to indicate it is available?
- Does the service leader draw attention to it at each service?
- Does everyone involved in leading the service use a microphone, and check in with the congregation at the beginning of the service that they can be heard?
- Is the singing led clearly, so that it is easy to follow and join in?
- Is the band too loud or too quiet?

Flooring

- Are there any highly reflective or slippery floor surfaces? Reflections can cause confusion.
- Do you have bold patterned carpets? Plain or mottled surfaces are easier; patterns can cause problems to people with perceptual problems.
- Are changes in floor finish flush rather than stepped? These changes can cause some confusion due to perceptual problems.

Toilets and changing rooms

- Do you have a unisex toilet cubicle or other facility which would allow someone to have assistance without causing embarrassment?
- Toilet seats that are of a contrasting colour to the walls and rest of the toilet are easier to see if someone has visual problems.
- Do you have a changing room where a carer or partner can help out if the person needs help with their clothes? If not, are members of the pastoral team briefed in how to support this need with sensitivity?

Seating

- In larger churches and buildings, do you have occasional seating, especially in areas where people are waiting?
- Is the seating comfortable? Additional cushions may be welcome.

Navigation

Research shows that people with dementia use 'landmarks' to find their way around, both inside and outside. The more attractive and interesting the landmark (which could be a painting, or a plant), the easier it is to use it as a landmark. Have you had a good look round and thought about these landmarks? They may also be used as talking points if the person living with dementia has a 'buddy' or 'accompanier'.

Pause for thought

When considering potential challenges, if a specific focus on people living with dementia might cause any embarrassment, why not invite all of the church family to reflect on what barriers might be preventing full participation?

Check in with everyone who uses the space before making changes. What might be helpful for one person may introduce an unintended challenge for another person.

Walk the route. What are the challenges? For example if a path is uneven or overgrown, or a light is faulty, addressing these would be a help to everyone, not only those living with dementia.

Are there any small changes that can be made, while you consider any larger projects? A few small changes can really add up to a person with dementia feeling much more a part of the church family.

Inclusion + Welcome + Responsive



Worship and services

Let us hold unswervingly to the hope we profess, for he who promised is faithful. And let us consider how we may spur one another on toward love and good deeds, not giving up meeting together, as some are in the habit of doing, but encouraging one another...

Hebrews 10: 23-25

Dementia inclusive worship and services recognise the continued gifts of people living with dementia, offering the support that will enable continued participation. Inclusion ensures that church can be a place where we model the belief that everyone has a role to play.

Welcome

- A warm welcome really helps to put someone at their ease, whether they are a part of the church family or visiting for the first time.
- Whatever the size of your church, extending a warm welcome is not just the role of the welcome team.
- Greet a person by their name, if you know it. A handshake or hug can also help someone feel welcome, although when in doubt, better not launch in.
- If welcomers wear name labels, check that the text is legible.
- If someone is welcomed warmly, they are far more likely to feel settled and fully participate in church life.
- A person living with dementia may of course be a member of the Welcome Team.

Where to sit

- While some people like to be tucked away at the edge in a quiet spot, others like to be in the centre of it all. We are all different. Don't assume where a person living with dementia might like to sit.
- If a person living with dementia becomes restless during the service and they begin to walk around, rather than seeing the goal as remaining seated, why not offer to accompany them on their walk?
- If your church has an outdoor space, why not walk outside, weather permitting, or even spend some time in a quieter room together. In their own time, a person may like to return to their seat, and may need support to find where they were sitting.

Music + Participation + Prayer



Hymns and songs

- Research is increasingly confirming the value of music for people living with dementia. Music has the power to connect with a person beyond spoken language. If a person has known a hymn or song for many years, the ability to sing or play that piece may remain intact, even if a person has lost a lot of verbal communication.

...sitting in a church in Essex on a Sunday in June, I look across at my friend Julia's mother. She is in her nineties and has dementia. There are days when she is wretched, chaotic and scared, but each Sunday she is soothed and even enraptured by the experience of singing the hymns that she sang when she was a girl. The music has worn grooves in her memory and, while she may not be able to speak in full sentences any more, she can sing 'Abide with Me' in true voice and her face, lifted up, looks young, eager, washed clean of anxiety.

Nicci Gerrard, 'What Dementia Teaches Us about Love'

- While a person living with dementia may have a stronger memory for more traditional hymns, modern music may also be enjoyed, so long as support is given to learn, and take part in these songs. A simple help like a large print service sheet can make all the difference.

Sermon

- If a person is living with dementia, it may not be possible to simply make efforts for a sermon to be 'memorable'. Rather than asking 'How can a person remember the sermon?', consider how a person living with dementia can be engaged during the sermon. This may be through simple sermon headings, a sensory prompt like a palm cross, or a couple of key verses printed on a card, which can then be taken home.
- If a service is held specifically for people living with dementia, it may be that a sermon format isn't as helpful as a simple reflection, inviting interaction and contributions throughout, and making use of sensory prompts like a cross, candle, or sprig of fresh herbs.

Prayer

As church family, we have the great privilege of praying together. Knowing how to pray or what to pray for isn't always easy, but we can be encouraged that the Spirit will help us.

God's Spirit is right alongside helping us along. If we don't know how or what to pray, it doesn't matter. He does our praying in and for us, making prayer out of our wordless sighs, our aching groans. He knows us far better than we know ourselves

Romans 8:26-27, The Message translation

As a person's dementia develops, it may become more difficult for a them to connect their inner self with outer articulations of their faith.

In prayer, I get muddled and vague, wandering off. I can hear you now, 'that always happens to me' - but it is now much more than when I was 'normal'; it happens all the time, even if I am not tired. So I find using the Prayer Book daily services is one way of really helping me focus my time with God.

Christine Bryden, author, advocate, person living with dementia

- Prayer books or printed prayers may support a person living with dementia to maintain their prayer life, as well as using familiar prayers, like the Lord's Prayer.
- Wherever a person is on their dementia journey, we can continue to hold that person in prayer. Offer to pray for and with a person living with dementia and their carer, even if this means a short time of silence together.
- Consider that a person living with dementia may want to hear your prayer requests. It is possible that if someone has prayed throughout their life, even as their dementia advances, they may continue to enjoy and value being asked to lead in prayer.

I used to take Dad to a little informal service in a Christian nursing home once a month. One of the carers, a guy who was outwardly very ordinary, tattooed, and in my opinion, humble, was leading the service. My dad loved the hymns and sang with gusto but couldn't say much otherwise, having lost touch with so much spoken language. This part of his condition was obvious to all.

I was surprised and wide-eyed when this lovely guy called my dad by name and said: 'Would you like to close in prayer?' We all waited patiently and rather uncertainly until my dad said slowly, 'Thank you Lord...for this beautiful...beautiful time together.'

Yo Tozer-Loft, singer, storyteller, a mother, a wife – and a carer

Communion

...when he had given thanks, he broke it and said, 'This is my body, which is for you; do this in remembrance of me.'

(1 Corinthians 11:24)

Communion provides an opportunity for church family to reflect together on Christ's sacrifice, and is not dependent on an individual's ability to remember. We remember together. The sensory aspects of Communion may stimulate the memories of a person living with dementia, and while a person may not be able to recall the Communion once it has taken place, there is great value for that person in the moment.

It can be helpful to consider a person's 'Communion journey' to see what might be tricky. While a person living with dementia may have no difficulty queuing up to receive communion, it may be difficult to find their seat again. In this example, having a 'Communion accompanier' lightly helping the person find their seat again would be a huge help. Or perhaps a person's mobility isn't so good. Here, the servers could come to the person in their seat.

Content ideas

A model of ministry called 'Songs & Prayers' can be useful in contexts including a residential care setting. Based on a simple shared circle time, it incorporates well-known hymns and prayers, which are selected by the participants from pre-printed sheet in large clear text.

With this regular predictable rhythm, a sensory activity can be offered, which includes interaction and reflection. A series based on some of Jesus' 'I am' statements can be helpful. This could include:

- I am the light of the world: pass around fairy lights, reflecting in a tarnished mirror - Jesus' light still shines in us brightly, however we feel.
- I am the bread of life: share a plate of soft bread together as you give thanks for all of the good things in life.
- I am the true vine: draw a vine and place leaves with everyone's names written on them, to remind us we grow out of Him.
- Jesus offers the water of life; not an 'I am' statements, but a powerful image: share still and sparkling water- still for those who needed peace, sparkling for those who needed joy, both for those requesting both!

Pause for thought

- Think about a time you received a warm welcome – what made it memorable? Consider if any of those elements could be incorporated into your church.
- Do you have a favourite place to sit at church? Why do you like sitting there? Whether or not we are living with dementia, comfort is important.
- If you miss church one week, for whatever reason, what's the thing you miss? While one person may especially value the content of the sermon, another may enjoy singing hymns, or having a chat over a cuppa and a biscuit at the end of the service. The goal here is not to think about what the 'right' answer is, so much as considering what aspect of church family you value being a part of. This can provide an insight into what people value about coming to church and their connection with the church family.

Next steps on the journey

The next steps on the road to dementia inclusion will be different for everyone. Whether it is adjustments to the church building or accompanying someone to receive Communion, consider when you might review them as a person's support needs change or develop.

Whatever the next steps to dementia inclusion look like, it is important to keep in mind that the guiding principle is 'to love your neighbour as yourself' (Mark 12:31). This is equally true for existing members of the church family who are living with dementia or have a caring role, as for members of the local community to whom are seeking to show the love of Christ.

**Love is patient, love is kind. ...
It always protects, always trusts, always hopes, always perseveres.**

1 Corinthians 13

Further resources



Alzheimer's Research UK

The UK's leading Alzheimer's research charity. Anyone can sign up to take part in research, whether or not they are living with dementia

Contact: 0300 111 5555

Website: www.alzheimersresearchuk.org/

Alzheimer's Society

Campaigning, information and support for people living with dementia and those affected by it. Factsheets, links to local services, and 'Talking Point' forum of support

Contact: 0300 222 11 22

Website: www.alzheimers.org.uk/

Carers UK

Advice, information and support for carers, including around finances and requesting a Carer's Assessment

Contact: 020 7378 4999

Website: www.carersuk.org/

DEEP (Dementia Engagement and Empowerment Project)

The UK Network of Dementia Voices: 'Nothing about us without us', including guidance on language

Contact: 01392 420076 (DEEP is hosted by Innovations in Dementia)

Website: www.dementiavoices.org.uk/

Dementia Action Alliance

Bringing together health and social care professionals, organisations and businesses to take action on dementia. Join a local DAA, or set one up in your area

Contact: www.dementiaaction.org.uk/contact

Website: www.dementiaaction.org.uk/

Dementia Diaries

UK wide project that brings together people's diverse experiences of living with dementia as a series of audio diaries, with the aim of prompting dialogue and changing attitudes

Contact: niblock@myid.org.uk

Website: dementiadiaries.org/

Dementia Friends

A social action movement increasing awareness around dementia to improve understanding and lead to making communities more dementia friendly. Get in touch to host an information session at your church

Contact: 0300 222 5855 (contact preferred via the website)

Website: www.dementiafriends.org.uk/

Dementia UK

Specialist dementia support with the Admiral Nurse service. Free UK helpline for anyone affected by dementia. Calls are taken by specialist dementia nurses

Contact: 0800 888 6678

Website: www.dementiauk.org/

Faith in Later Life

Inspiring and equipping Christians and churches to reach, serve and empower older people in every community. Look up local events and resources near you, and add your own

Contact: 0300 303 8405

Website: faithinlaterlife.org/

Glorious Opportunity

Resource website of Dr Jennifer Bute, retired GP, living with dementia, who offers a 'Christian, medical perspective from the inside'

Contact: www.facebook.com/gloriousopportunity

Website: gloriousopportunity.org/

Livability

The charity that connects people with their communities. Dementia Inclusive Church workshops, resources and events

Contact: 020 7452 2110

Website: livability.org.uk/

McIntyre

The MacIntyre Dementia Project supports people with a learning disability who are developing or at risk of developing dementia

Contact: 01908 230100

Website: www.macintyrecharity.org/

Playlist for Life

Encourages and equips people living with dementia to have a unique, personal playlist – all the tunes that are most deeply attached to memories and emotions, gathered together in one place

Contact: 0141 404 0683

Website: www.playlistforlife.org.uk/

Rare Dementia Support

UK based charity that works to support people affected by rare dementia conditions

Contact: contact@raredementiasupport.org

Website: www.raredementiasupport.org/

The Gift of Years

Resources supporting the spiritual journey of older people, including Anna Chaplaincy training

Contact: 01865 319700

Website: www.thegiftofyears.org.uk/

Unforgettable

Online shop including technology and community of support

Contact: 020 3322 9070

Website: www.unforgettable.org/

Young Dementia UK

Help and support for people whose lives are affected by young onset dementia

Contact: 01993 776295

Website: www.youngdementiauk.org/

It all adds up to

Livability

Email: Communications@livability.org.uk

www.livability.org.uk   LivabilityUK

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