

Developing a dementia-friendly church

A practical guide



Creating this guide

This resource has been created by Livability and supported by Alzheimer's Society. Consultations and focus groups with church leaders and congregations have also informed this guide. We hope that this guide will help all our readers to create more dementia-friendly churches and faith communities.

We would like to thank all those who offered their insights and expertise. We are especially grateful to the following people, without whom this guide would not have been created.

Dr Trevor Adams

With 30 years of experience in the field of dementia care, Trevor began his career as a specialist nurse and has written extensively on the subject, presenting his findings in academic settings across the world. Over the past three years, Trevor has led the Dementia-Friendly Church Programme for Livability, enabling over 1000 people and 100 churches nationwide to create dementia-friendly communities.

Alli Anthony

As the Manager of the Connecting Communities Project (CCP) at the Alzheimer's Society, Alli worked within a small team to raise awareness of dementia amongst black, Asian and other ethnic minority groups across eight London boroughs. The Connecting Communities Project reached a total of 16,802 people, with awareness-raising activities both in London and at a national level.

“We want churches to be at the heart of dementia-friendly communities, where the voices of those living with dementia, and those who care for them, are clearly heard. This publication provides practical guidance on developing dementia-friendly churches, drawn from national expertise and local experience.”

Revd Dr David Primrose, Director of Transforming Communities, Diocese of Lichfield

Introduction

There are currently around 850,000 people living with dementia in the UK, and this number is set to rise significantly over the next 30 years. While dementia symptoms can affect thinking, communicating, and memory, each person's experience of dementia will be slightly different. Most people will have specific needs due to their condition.

Who is this guide for?

This guide is for all members of the Christian community. It may be of use to church leaders, clergy, lay preachers, Bible study or small group facilitators, children and youth leaders, alongside the church community as a whole.

We hope people from other faiths may be able to adapt the information offered in this guide to their own faith community.

This guide explains a bit about dementia and how it can affect

people. It also explains how you can help your church become more dementia-friendly. It aims to answer many of the questions churches may have and provide helpful, practical guidance for churches who would like to become dementia-friendly. It also explains how churches can contribute to the development of dementia-friendly communities.

Having faith is very important to many people, including people with dementia. However, due to the difficulties caused by the condition, it can be hard for them to practice their faith as they previously did. By showing understanding, offering support and making small changes to the place and practice of worship, you might help someone with dementia to continue attending



services or participate in faith-related activities in a way that is meaningful to them.

Engaging with all people, including people with dementia and those who care for them, is important for churches. If you already support people with dementia, their families, friends and carers as part of your pastoral care, we want to continue to empower you in this.



“I welcome the publication of this dementia-friendly church guide. It provides a wealth of information about dementia, and gives clear, specific and practical guidance as to how a local church can truly become dementia-friendly. It stresses the need to engage with people with dementia and their carers and encourages partnership with others in the community. The guide is an antidote to despair and a spur to action. I commend it to you.”

David Richardson, Dementia Co-ordinator, Churches Together in Cumbria

What is dementia?

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they become severe enough to affect daily life.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease, or a series of strokes. Alzheimer's disease is the most common cause of dementia but it is not the only cause. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

Your church community may find that a person with dementia has difficulties with:

- ◆ day-to-day memory – finding it difficult to recall events that happened recently, such as visiting relatives, going to church;
- ◆ concentrating, planning or organising – struggling to make decisions, solve problems or carry out a sequence of tasks (i.e. cooking a meal, finding the right passage of the Bible);
- ◆ language – difficulties following a conversation or sermon, or finding the right word for something;



- ◆ visuospatial skills – problems judging distances (i.e. steps or stairs) and seeing objects in three dimensions;
- ◆ orientation – losing track of the day or date, or becoming confused about where they are.

As well as having difficulties with memory and thinking, people living with dementia may also:

- ◆ be more emotional, anxious, irritable, withdrawn or sad;
- ◆ see things that are not really there (visual hallucinations) or may persistently believe things that are not true (delusions).

Dementia is progressive, with symptoms gradually getting worse over time. How quickly dementia progresses varies greatly from person to person. Even after symptoms have become clear enough for a doctor to give a dementia diagnosis, many people can maintain independence for several years, providing they receive help and understanding. However, as the condition progresses, it is likely that individuals will need increasing support, as will those who care for them. For some people this will involve moving to residential or nursing care.

Types of dementia

There are many types of dementia. The symptoms of dementia are often different in the early stages but become more similar over time. This is because more of the brain becomes affected as the different diseases progress.

Each person is unique and will experience their symptoms differently. Many people will also have other unrelated health conditions which have an effect on how they experience their symptoms. The support someone gets and their personality can also greatly affect how they experience dementia.

The most common types of dementia with some of the key symptoms are:

- ◆ Alzheimer's disease is the most common type of dementia. Problems with day-to-day memory are often noticed first, but other symptoms may include difficulties finding the right words, solving problems or making decisions.



- ◆ Vascular dementia is caused by interruptions to the blood supply to the brain, sometimes as the result of strokes. Many people have difficulties with problem-solving or planning, thinking quickly and concentrating.

- ◆ Dementia with Lewy bodies is a less common type. Early symptoms can include fluctuating alertness, difficulties with judging distances and hallucinations. Day-to-day memory is usually affected less than in early Alzheimer's disease.

- ◆ Frontotemporal dementia is another less common type, caused by damage to the front or sides of the brain. At first, changes in personality and behaviour may be the most obvious signs. Depending on where the damage is, the person may have difficulties with fluent speech or forget the meaning of words or objects.

Diagnosing dementia requires specialist medical knowledge. If you or someone you know is worried about their memory, suggest that they contact their GP.

“So much of our personhood is held in our faith – from the routine and tradition of church attendance and the relationships we form with other worshippers, to the identity we find in Christ. As dementia strips people of these anchors, we as a church have the opportunity to help those living with dementia preserve this essential portion of ‘self’ that is encompassed by faith.”

Dr Ruth Law, Consultant in Integrated Geriatric Medicine, Whittington Hospital

Why should churches engage with people affected by dementia?

Churches are able to offer people with dementia a sense of value and dignity and help to facilitate changes in their community that will bring about their inclusion and participation.

People with dementia are loved by God



Christians believe that God loves each person, and we are called to do the same (John 13:34). God's love for us can be hard to fully comprehend (Psalm 139:13-16).

Dementia is a considerable challenge for those living with it, who, as well as experiencing one or a range of symptoms, can also find themselves ignored and isolated from their community or family life. They need to be treated with respect and dignity, as well as receiving support to maintain the outward expression of their Christian faith. This is especially true if someone needs care in a residential, nursing or other long stay care setting.

Jesus was concerned with promoting the health and wellbeing of all people. Through his words and actions, he showed compassion and love to all, gave them a new life and enabled them to return to their community.

People with dementia reflect God's image

A key Christian belief is that God made people in his divine image. In Genesis 1:26-31, the distinctive feature of being human is seen as reflecting the image of God. This means that every person, whatever their mental abilities, displays in part what God is like.

People with dementia have much to contribute to the Church

The apostle Paul sees the Church as being like a body in which every part helps and supports the others. This means that everyone has something to offer. Churches should seek ways to receive the gifts and insights of all people. Without people living with dementia, the Church is incomplete and cannot gain from everyone's experiences.



Even so the body is not made up of one part but of many. Now if the foot should say, "Because I am not a hand, I do not belong to the body", it would not for that reason stop being part of the body. And if the ear should say, "Because I am not an eye, I do not belong to the body", it would not for that reason stop being part of the body. ... If they were all one part, where would the body be? As it is, there are many parts, but one body.

.....
1 Corinthians 12:14-20

The person travelling down the dementia road is no less valued or loved by God, ... it is our extrinsic relationships with other persons that confer on us our identity as a 'self', and it is the loving relationship that God maintains with us that constitutes the ... image of God.

Ageing Together: Dementia, Friendship, and Flourishing Communities by Susan and John McFadden (John Hopkins University Press, 2011)

What is a dementia-friendly church?

Being a dementia-friendly church is about more than welcoming people with dementia. It also involves making adjustments and adaptations to the places and practices of worship in order to allow people with dementia to continue to participate in the life of the church, however they choose to.

Dementia-friendly churches include people with dementia and their carers and recognise how they can make a positive and welcome contribution to the church. For some people, a connection with a local church can make all the difference. By showing understanding, offering support and making small changes, you could enable someone with dementia to continue attending services or taking part in church life in a way that is meaningful to them. This could include visiting people with dementia in their homes or places of residence when they are no longer able to attend church, considering the way services are delivered, providing extra support, minimising distractions or raising awareness of dementia amongst the congregation.

Dementia-friendly churches also work with local organisations that are seeking to make their local neighbourhood a dementia-friendly community. A dementia-friendly community is one in which people with dementia feel confident and are empowered to express wishes



and feel confident, knowing they can contribute and participate in activities that are meaningful to them. These communities support people with dementia to participate as far as they are able to community life.

The development of dementia-friendly communities improves

the knowledge and awareness of dementia across the country. This initiative draws on the Prime Minister's challenge on Dementia 2020, and the National Dementia Declaration, both of which encourage local organisations such as shops, banks, libraries and churches to become more dementia-friendly.

The principles of dementia-friendly churches

Adopt a positive attitude

Negative thinking inhibits and discourages people with dementia from doing everyday activities they could probably manage. Keep a positive, optimistic and realistic view of what people with dementia can do. Just because someone has dementia does not mean they cannot hear what is being said around them, or cannot participate in conversation or activities. Things might just need doing a bit differently.

Encourage supportive relationships

Personal relationships and someone's social environment are central to life, regardless of age or mental ability. We all know what it is like when someone shows that they care for us. People with dementia would benefit from being shown love, understanding and support, and feeling included in the church family. People within churches can recognise this need by being as supportive as possible. Support should be sensitive to the person as an individual, and focus on promoting their wellbeing and meeting their needs. People with dementia may not always remember what was said to them, but may remember how you made them feel. It is important to focus on making the person feel comfortable and supported. Decision making can be a

struggle for people with dementia. With support and understanding, they can make worthwhile choices and retain a sense of control over their lives for longer than otherwise would be the case.

Facilitate communication

People with dementia sometimes find it difficult to tell others how they are feeling and what they are thinking. This can be frustrating and difficult for them. It is important that they are given a chance to express themselves. When they are talking, it is important to focus on the person and listen attentively to what they are saying. We all express ourselves through our bodies, gestures, facial expression and tone as well as through the words we speak, so pay close attention to these too. People with dementia may struggle with spoken language, yet they can often still read and use body language to express themselves.

People with dementia may say things that, although not factually accurate, are important to them. Contradicting or correcting them might cause distress and confusion. Although at times it can be difficult for family members to hear things that might not be true, it is still helpful to try and understand how



the things they say make them feel, and respond appropriately.

Create an accessible environment

Small, inexpensive changes to the physical environment can help a person with dementia find their way around and feel more comfortable and at ease. In church buildings, this could include clear signage at an appropriate height or the use of an induction loop for people with hearing difficulties. More information is available on the Dementia Action Alliance website (see 'Other useful organisations' below).

Some aspects of church buildings – such as patterned floor tiles and large spaces that can cause echoes – might be difficult to change. However, just being aware of the difficulties of a physical environment, and making changes to those aspects that can be altered, is a positive first step to help people living with dementia to feel included.

Encourage creativity

We all thrive and flourish when we are able to display our creativity as God is Creator, and there is evidence that creativity contributes to both our physical and mental health. All people, including those with dementia, thrive and flourish when they are given the opportunity to be creative. This could be flower arranging, writing or delivering a prayer, or sharing their story with the church community.

Part of a local network

Dementia-friendly churches exist within a wider network of people, agencies and organisations that contribute towards the well-being of people with dementia. These networks include health and social care professionals, the private and voluntary sectors, and the family, friends and neighbours of people with dementia. Dementia-friendly churches have an important place in this network and should work with others to offer support.

Learn from others

We can all probably remember an occasion when we lacked support during a time of difficulty and how lonely that felt. We have perhaps all felt at times more like an object than a person. By supporting people with dementia to express their faith, we can in turn all learn to better express our own.



Case Study: Castleford Parish

When Castleford Parish in West Yorkshire signed up for Livability's dementia-friendly church training, interest was expected from a handful of people. "When 34 people turned up, which is huge for us, we realised that there really is a need for this in our community," says Father Kevin, who took on the parish's pastoral development for dementia.

"Since November 2014, we have hosted a number of 'Dementia Friends' awareness sessions, which are open to all, and have been attended by the lead dementia nurse for our area. We have developed dementia-friendly church services and invited those living with the condition and their carers. We have also been contacted by other parishes and have given them support on how to become more dementia-friendly.

As a parish, we are still growing and learning ourselves how we can best support those with dementia and those who care for them. As a Christian community we are called to serve as part of our mission. As people are living longer, we believe this need will continue to grow. Through prayer, listening to God and to those around us, we look forward to the challenges ahead and the support we can offer to those living with dementia, so that they can still live well and feel that they are part of their community."

Fr Kevin Greaves, Assistant Curate, Castleford Team Parish

Practical steps to make your church dementia-friendly

Becoming a dementia-friendly church requires planning, as well as the concerted effort and support of the clergy and lay people from the church fellowship. People with dementia, their families, friends and carers should be involved in the planning as much as possible.

It is important to seek the views of people affected by dementia and understand their specific needs. Avoid making generalisations or assuming you know what others want in order to participate in the life of the church.

Dementia-friendly worship

A number of churches hold dementia-friendly services and events, specially designed to cater for the needs of people with dementia. This list is not exhaustive, and not every suggestion will be right for every church, but the following are some ideas and suggestions to consider:

- ♦ **Hold a short service, perhaps half an hour long.** Include a short sermon or address. Identify a suitable day and time for this service in consultation with carers. Consider appropriate places to advertise it, such as in a GP's surgery or local newspaper.
- ♦ **Consider who the service is for.** Is it for people with dementia and their carers or more to raise awareness for whole congregation?
- ♦ **Choose familiar hymns with well-known tunes.** Select prayers and familiar readings using a version of the Bible familiar to the congregation.
- ♦ **Offer support to people with dementia and their carers to attend regular services.** This will help to maintain relationships with the wider church community. This might include a pastoral visitor offering extra encouragement to the family to attend and having a nominated person to help individuals feel welcome on arrival.
- ♦ **Have a designated quiet space in the church.** This provides somewhere for people to go during the service.
- ♦ **Consider having additional volunteers and congregation members on hand.** This provides support to people who need some extra help following the services. It is important that dementia awareness is built into their preparation. This ensures that vulnerable adults are safeguarded and supported.
- ♦ **Plan the worship in advance.** However, be prepared to be flexible if things need to change as you go along. Try to involve people in the worship as much as possible – people may like to choose a hymn, for example.
- ♦ **Consider the practicalities of the venue.** Access to the building, the use of appropriate chairs for those who struggle with continence, toilets being nearby and accessible, the room being warm in winter and ventilated in summer – all these factors need to be considered.

“I sometimes find it hard to follow the sermon but I enjoy singing the familiar hymns and listening to the Bible readings, they stimulate my memory and make me feel I belong.”

Congregation member living with dementia



- ◆ **Try to minimize distractions.** Noisy activities taking place during the service in adjacent rooms can be distracting for people with dementia. Make sure the church is well lit so as to avoid shadows, which can cause confusion.
- ◆ **Make sure whoever is leading the service can be clearly heard.** They should also be able to make good eye contact and engage with the congregation.
- ◆ **Be prepared to be supportive.** If someone chooses to walk round the church or becomes disorientated, try to comfort the person and gently encourage them to return to their seat, if possible.
- ◆ **Keep the service relaxed and try to maintain eye contact with people, even during prayers.** Some people may find praying with their eyes shut makes them feel disconnected or disorientated.
- ◆ **Think about having volunteers on hand to assist with communion.** This provides assistance for people taking communion – for example, helping them back to their seat. You will need to consider that not everyone is able to swallow easily or hold a cup, and you may need to use a spoon for wine or juice or a smaller piece of Host or bread. Alternatively, consider blessing the person instead.

Dementia awareness sessions

An information session is a good way to increase your church's awareness and understanding of dementia. In addition, it will allow you to develop the skills and knowledge necessary to become a dementia-friendly church. One awareness workshop that is available is a Dementia Friends session. This is a free workshop that offers a basic understanding of dementia so that they can make important differences to the lives of people with dementia through their actions. See Further information for more details.

Further training workshops are available and offered by Livability. These workshops provide information about people's experience of dementia, and offer specialist training on becoming a dementia-friendly church. The training workshop is usually designed in collaboration with individual churches or group of churches so that it addresses their specific requirements and needs.

Peer support for carers

You may want to consider supporting carers by setting up a carers peer support group, and recommend you contact Alzheimer's Society for information on how to do this. A peer support group allows carers to get together with others in a similar situation and provides opportunities for them to share experiences, exchange tips and discuss issues they may be facing. You might want to consider having a pastoral presence in meetings to ensure that it is a safe space where people are supported appropriately. Contact your local carers' group or services for peer support, access to information and specialist help.

Memory cafés

Alzheimer's Society's Memory Café service provides a safe and supportive environment for people with dementia, their carers, friends and family. Memory Cafés provide the opportunity to take part in activities or simply have a cup of tea and chat with others in a similar situation. Church halls are often good venues for cafés as they are usually well known, visible and designed to accommodate

community groups. Please contact Alzheimer's Society for guidance before setting up a Memory Café.

Tips for running events

Working with people affected by dementia brings its own challenges, and setting up events such as outreach in homes needs careful planning. Some issues you might need to consider include:

- ◆ being clear who in the church is responsible for each group and who is going to be involved
- ◆ having good communication and clear expectations – for example, can a relative drop off an individual with dementia to attend by themselves?
- ◆ being clear with volunteers and those running a group on what they need to know/what to do if there is a difficulty
- ◆ having a named contact for the person with dementia in case they become distressed
- ◆ setting clear boundaries.

Care home outreach

Some people with dementia need long-term residential care, and maintaining their faith in a new environment will remain important to them. Churches may need to proactively engage with care homes within their neighbourhood. Care staff may welcome the help that a visitor from the church can provide, in listening to and supporting a person with dementia. In turn they may feel encouraged to support residents with dementia

to express their faith. People may turn to the church at times of bereavement or as they near the end of their lives. Being available to people affected by dementia is a part of Christian outreach. Many care homes welcome church visitors, whether it is to hold a dementia-friendly service or to visit individuals.

Join the Dementia Action Alliance

A good way to begin to make your church dementia-friendly is to join your local Dementia Action Alliance or Dementia-Friendly Community. The Alliance was formed in October 2010 and since then hundreds of organisations in both the public and private sectors have signed up to be members in order to transform the lives of people with dementia. The Alliance aims to bring about the seven outcomes identified in the National Dementia Declaration, created in partnership with people with dementia and their carers. Member organisations range from schools and faith groups, to the emergency services, hospitals and sports clubs.

Each member organisation draws up an action plan outlining how it will deliver better outcomes for people affected by dementia. By encouraging collaborative working across local areas, these alliances are an integral part of dementia-friendly communities. Churches can play an important



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part in the Alliance, which works towards building dementia-friendly communities. See Further information for more details.

Contact local support services

Alzheimer's Society offer a range of services including dementia advice, dementia cafés, peer support and activity groups. Details of all these services are on the website or you can contact the helpline (see Further information for more details). You can search by postcode for local services or people can connect with each other using Talking Point, an online community for anyone affected by dementia. It's a safe place to ask questions, share your experiences and receive advice and support.

There may be other charities and groups focused on dementia who are providing a range of services in your area.

Further information

About Alzheimer's Society and Livability

Alzheimer's Society

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. Alzheimer's Society provide information and support to people with any form of dementia and their carers, campaign for better quality of life for people with dementia and greater understanding of dementia. They also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

Alzheimer's Society, 58 St Katherine's Dock, London E1W 1LB

E: dementiafriendlycomm@alzheimers.org.uk

T: 0330 333 0804 (helpline)

W: www.alzheimers.org.uk

Livability

Livability is a national Christian disability and community engagement charity. They deliver disability services, community projects, education and training resources that promote inclusion and wellbeing. Livability also share their expertise internationally. They are an enabling network of people, tackling barriers in society to make community livable.

Livability is a proven and trusted provider of commissioned care and community projects throughout the UK. Created by a merger of the Shaftesbury Society and John Grooms, Livability has a 160-year track record in community and inclusion work.

Livability, 6 Mitre Place, London SE10 0ER

E: joinin@livability.org.uk

T: 020 7452 2018

W: www.livability.org.uk

Other organisations

Alzheimer Scotland

The leading dementia organisation in Scotland, who campaign for the rights of people with dementia and their families and provide an extensive range of innovative and personalised support services.

T: 080 8808 3000 (24-hour helpline)

W: www.alzscot.org

Carers UK

Offering expert advice, information and support, this organization aims to improve life for carers. They also put carers in touch with each other, so no one has to provide care alone. Carers UK campaign for lasting change and are committed to finding new ways to reach and support carers nationwide.

T: 080 9909 7777

W: www.carersuk.org

Catholic Church in England and Wales

The Catholic Church has published videos on their website on relevant subjects, including the effects of dementia, understanding spiritual needs and being a welcoming parish, aimed at helping carers and parishes support people with dementia. These videos were commissioned by CSAN (It's Still Me Lord). The Catholic Church also support the National Day of Prayer for Dementia on 19th March.

E: admin@csan.org.uk

T: 020 7633 4973

W: www.catholic-ew.org.uk/Home/Videos/Dementia-and-Spirituality

Christians on Ageing (CCOA)

A national ecumenical organisation that focuses on the spiritual needs and development of older people. In collaboration with FIEP and Methodist Homes for the Aged, they have produced a report, 'Growing dementia-friendly churches' full of practical solutions and ideas.

T: 016 0988 1408

W: www.ccoa.co.uk

Dementia Action Alliance

Brings together organisations across England committed to transforming the lives of people with dementia and their carers, including churches. They offer action plans created by churches including Diocese of Lichfield, Diocese of Bradford, Rotherham & Dearne Valley Circuit of the Methodist Church, Trinity Community Church, Manchester and Sprotborough Churches Together. They provide a simple checklist on creating dementia-friendly environments.

W: www.dementiaaction.org.uk/resources/

Dementia Friends

This organisation offers free workshops providing a basic understanding of dementia for carers, family and friends.

T: 012 4545 4319

W: www.dementiafriends.org.uk

Faith in Older People

Faith in Older People (FiOP) is a Scottish National Charity based in Edinburgh with a focus on 'spirituality and ageing'.

E: info@fiop.org.uk

T: 013 1346 7981

W: www.faithinolderpeople.org.uk

Methodist Homes for the Aged

Methodist Homes provides many useful resources, including a free dementia-friendly church service guide, a guide on creating dementia-friendly churches and resources on spirituality and dementia. Also available online, and to order by post, are the leaflets: 'Visiting people with dementia', 'Spiritual care and people with dementia' and 'Growing dementia-friendly churches'.

T: 080 0085 6962

W: www.mha.org.uk

MHA Freepost 499, Derby, DE1 9BR (to order leaflets: suggested donation 50p each or £2 for the set).

Pilgrim's Friend Society

This society offers 16 schemes throughout England, providing a range of services for older people, from dementia care, retirement living as well as home-leave accommodation for missionary families. They also provide other resources to Christians, including a range of books, a dementia pack and other publications and material for conference seminars. They also run their own conferences each year.

T: 030 0303 1400

W: www.pilgrimsfriend.org.uk

Relatives and Residents Association

The Relatives and Residents Association support and inform residents, families and friends to find out all they need to know about residential care and provide help and guidance should things go wrong. They speak out on behalf of a sector who cannot always speak out for themselves.

T: 020 7359 8136

W: www.relres.org



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