

Growing Dementia-Friendly Churches

A Practical Guide



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THIS BOOKLET IS A PRACTICAL GUIDE for all churches who are seeking to be welcoming, inclusive and nurturing communities to all who enter their doors, including people who have dementia and those who share their journey.

To be a 'Dementia-Friendly Church' is to find ways to minister to people with dementia so that they know with everything in their being that they are 'held by God' as they are helped to experience once again life in all its fullness that Jesus promised to all.

This is the fourth booklet in the series on working with people who live with dementia and should be read alongside them as they contain more detailed explanations and resources. The other titles are: 'Visiting people with dementia', 'Worship with people with dementia' and 'Spiritual care and people with dementia'.

This booklet will encourage a deeper understanding of why some of the things we 'do' at church may not be 'dementia-friendly.' As a basis for developing positive action there will be ideas and suggestions for running activities that are helpful and inclusive of people with dementia and their families.

People and situations mentioned in this booklet have been created out of accounts and experiences of those who have dementia and of churches who have sought to care for them, although names have been changed.

What might a Dementia-Friendly Church look like?

The following stories of Mavis and Arthur might give us a clue. They show how the churches responded to specific situations, and what the effect was of their actions.

MAVIS'S STORY

For years Mavis had enjoyed being on tea and coffee-making duty after church. She used to bake delicious cakes to eat with the refreshments, so everyone was pleased when it was her turn on the rota. However, things changed: she developed dementia and no longer baked her lovely cakes. In fact most of the time she even forgot to bring milk and biscuits. The catering team had a meeting and because they cared so much for Mavis and knew it distressed her when she forgot things, they decided that it would be best if they 'retired' her from the duties.

They presented her with a bouquet of flowers as a thank you and explained to her that she had been doing it faithfully for a long many years and now it was time for her come off the rota and to be 'waited on'. This decision was taken out of a genuine care for Mavis, the assumption being that she had done her bit; it was time now for others to serve her. But for Mavis, it just exacerbated her feelings of no longer being useful and she became very depressed now her role was ended.

What might a Dementia-Friendly Church look like?

ARTHUR'S STORY

Arthur had been a librarian during his working life and spoke of his experience often, to all who would listen. His story consisted of how being a librarian had shaped who he was as a person. He said that it was not so much the books that enthralled him, but the people who used the library. He loved being in a position to chat to them, help them find a book or point them in the right direction. He had this one story, which he told many times throughout the day but his message was clear. What he loved most was the relational part of being a librarian.

In his church life, he loved being the doorkeeper, the welcomer to Sunday worship at his church. He enjoyed talking to people, giving out the hymn books and pointing them in the right direction. The problem came when everyone was being held up at the door while Arthur told his lengthy story over and over again to each person who entered. What was this busy church to do? Stop him being a doorkeeper? Take away from him the thing that he loved most? Take away his value and sense of self-worth? After much soul searching the church came to the decision to bring in more welcomers but to keep Arthur as part of the team. Those who knew him would allow him to tell his story and be pointed in the right direction. So Arthur still had his role, still belonged. It is those little things that make so much difference.

Both churches acted with the very best of intentions; both were doing their best to show they cared. What made the difference? One church looked at the strengths and abilities of Arthur, the person with dementia, concentrated on the things he could still do, then supported and encouraged him to use these gifts so that that he was still able to participate and feel useful.

The other church had not realised Mavis's spiritual need to serve and contribute as she always had. If they were being dementia-friendly they could have looked at the whole person and perhaps created a team of people who could be 'her memory'. She could then have continued to enjoyed serving

others but without the burden of responsibility. The result was that Mavis became more isolated and depressed and stopped going to church.

These stories highlight a little of what it means to be a Dementia-Friendly Church and the importance of nurturing a person's spiritual needs as well as their faith life. Spiritual care needs to be woven into the whole of our church life, be it through pastoral care, fellowship or worship.

One of the most distressing conditions affecting people in the West is loneliness. For older people, and especially those with dementia and their carers, this problem is often greatly exacerbated. This is a very real missionary challenge for the Church in our age. For we go in the name of Jesus who brings 'Good News' to the poor, is the defender of the powerless, who identifies with the vulnerable and who brings hope.

The Church should be a living testimony that God cares – if the people of God cannot show that God cares then how will those who are lonely or isolated, for whatever reason, know?

This is why we need Dementia-Friendly Churches. This is why we need to find ways to minister to people with dementia and make sure that they do know with everything in their being that they are indeed 'held by God'.

There are many stories of people who have served their churches faithfully for years in various capacities, only to find themselves feeling forsaken when they were forced to withdraw from church due to the progression of the disease. Yet family members have said that a visit from a familiar friend would have meant so much to their loved one.

If we can get being dementia-friendly right; if we can be welcoming, inclusive and nurturing to people who have dementia, then this could permeate all that is done for everyone who enters the doors of our churches. For in order to be dementia-friendly the focus has to be on the person and on what is important for them, not on what they can or cannot do or how they are seen as being different.

Dementia-unfriendliness

THERE IS A GROWING AWARENESS in some churches of the challenges posed by dementia and people are beginning to ask questions. 'How can we make our churches more friendly, more inclusive? How can they be places where people who have dementia can feel their faith is being kept alive and nurtured?'

It is very easy for any church to assume that they would automatically be dementia-friendly. How could someone following Jesus think it acceptable to exclude anyone, particularly those who are so vulnerable, from their midst? Yet so often people with dementia and their families do indeed become excluded and marginalized.

Dementia unfriendliness does not occur because people do not want to be dementia-friendly, but because most people either do not recognize that something needs to be done, or just do not know how to begin. Sometimes this is simply because of the word 'dementia', which can seem frightening. So when someone develops dementia a myriad of feelings are experienced by those whose lives they touch that can make people feel uncomfortable, and so have good reasons (excuses?) for avoiding them.

- Feelings of discomfort, of fear of the unknown, "What might he do?"
- Feelings of helplessness, "How am I supposed to act, to react?"
- Feelings of hurt and loss, "We used to be so close, now s/he doesn't even remember my name."

So many people are in this uncomfortable place, feeling bad but not quite sure what to do about it. Many carry guilt, deep wounds and feelings of inadequacy because they do not understand how to care for and communicate with friends and loved ones who have dementia. If you are in this place, be assured that you are not alone.

Growing a Dementia-Friendly Church is always work in progress. It will take on a life of its own, it will develop, and it will grow and continue to grow. The most difficult hurdle to overcome is the first one: getting started. Once people do that they are amazed not only at how much easier it is than they thought, but by how rewarding the experience of journeying with people with dementia can be. It is often hard work, and there are many scary times to go through, but by standing firm they are rewarded with relationships, spiritual insights and glimpses of God and the life to come that go far 'beyond all we ask or imagine.' Ephesians 3:20 NIV

Being a Dementia-Friendly Church

It is much more than:

- Installing a ramp and a loop system
- Having a nice warm church with comfy seats
- Having clean toilets and hand washing facilities
- A friendly welcome at the door

While all these are important, all the loop systems, the ramps, and the other outward things we do to make our churches welcoming and inclusive are not what being dementia-friendly is about.

A 'DEMENTIA-FRIENDLY CHURCH' WOULD:

- (1) accept and value people regardless of cognitive abilities,
- (2) ensure that the person who has dementia, and those who support them, are cared for through all the stages of the illness.
- (3) make sure that the person who has dementia, and their friends or family members, are both spiritually and pastorally supported and nurtured in order for them to enjoy being a part of a worshipping community in every sense.
- (4) be open to what people with dementia have to offer, look for strengths and abilities, then support and encourage the use of these gifts so that that they may participate in the community that is the body of Christ.

Most other ways in which disabilities are catered for in church are concerned with adapting buildings, but being dementia-friendly means that people have to change in both their expectation and their approach so that those who are on the sometimes long journey into dementia can still feel part of the church community for as long as is possible. They cannot do it for themselves, but need others to be attentive and anticipate where there might be problems. And this is often the stumbling point, because this requires that people change their attitude and look out for each other.

CARING FOR THE PERSON WITH DEMENTIA AND THOSE WHO CARE FOR THEM.

The person-centred approach to dementia care was developed by Tom Kitwood, and he writes that while the mind might seem to deteriorate the person is still there (Kitwood and Bredin 1992) The spirit is not diminished and that is what needs to be nourished. The things that matter so much to us are the things that matter to them. Work and play, family and friendships; the simple things of life are what make life worth living.

As the Church responds to the needs of people with dementia in their midst they remind us that, *“When memory fails, love takes its place.”* (Goodall 2013)

This is a ministry that will have its challenges but it is worth it. This is what really matters.

Both the person who has dementia and the carer need to feel loved, valued and that they still ‘belong.’ Yet it is often the case that friends, acquaintances and even other family members visit less and less. Consequently, loneliness and abandonment can be felt at a time when contact with others is needed the most.

The person with dementia experiences increasing loss of abilities as the disease progresses and, as a result, can lose both independence and control. For those who watch a loved one change it has been described as a ‘living bereavement’ or a series of bereavements each one worse than the last. It brings with it grief for the loss of life as it used to be and the person they used to know. Added to this is the sheer exhausting challenge of maintaining daily life and the difficulties of staying socially connected.

Some carers have expressed their feelings of abandonment by society and by the church. They have said that they longed for someone to drop in for a chat, someone with whom they could have a ‘normal’ conversation. For, as the disease progresses, the person with dementia may repeat the same story, or behaviour pattern over and over again.

Caring

Carers have also expressed the need for an opportunity to share their feelings with someone who would understand. Caring full time for someone who has dementia can bring out all sorts of feelings: feelings of intolerance and possibly disgust at how their loved one is behaving, feelings of guilt and anger, feelings of envy towards others who still have their freedom, feelings of despair because their task seems thankless and never-ending and feelings of deep sadness because their lives together can never again be what they once were. It is important for them to be able to share these feelings with someone they can trust. It is also important for the carer to have regular breaks, to go to the shops, have their hair done or indulge in something they enjoy, if only for a couple of hours a week.

This is an opportunity for the Church to show concern as it looks for practical ways of helping those who give support as well as the person who has dementia. Dementia is a disease that affects not just the person but the whole family.

What's your name again?

Memory loss, which is one of the early signs of dementia, is distressing. Forgetting people's names, especially the names of those who they are very close to such as a friend or family member can be quite frightening for the person with dementia and upsetting for the family or friend whose name has been forgotten.

JOYCE'S STORY

Joyce and Carol had been friends for a number of years, sitting next to each other in church and occasionally meeting up for coffee together during the week. When Joyce started to lose her memory Carol became impatient with her. She would advise her to make lists, keep a diary, go to bed earlier, stop doing so much, pull herself together. Carol could not cope with the change. Then one day Joyce forgot Carol's name. She knew her face, she recognized who she was, but she could not remember her name.

After this happened a few times Carol was very upset and offended. She had considered Joyce to be a friend and now she could not even remember her name. Eventually Carol stopped meeting Joyce and even found somewhere else to sit in church.

The thing is, Joyce would have loved to remember the names of her friends. Forgetting was even more distressing for her. All Carol had to say to alleviate the situation was, "It's all right Joyce, I'm Carol." Joyce would have remembered immediately, they could have laughed it off over a cup of coffee and the very important friendship would have remained.

A dementia-friendly service

We have noted the importance of **HOW PEOPLE INTERACT WITH EACH OTHER** in church, but there is also the question of the service itself. The time may come when people with dementia are no longer able to cope with a normal church service, so how do we make our services dementia-friendly?

Creating a Dementia-Friendly Church is about delivering a style of worship service which those who have dementia can engage with, and even take part in. This means taking account of low concentration spans, short-term memory loss and any difficulty in processing verbal communication that is too wordy or too long.

This is not an easy task – and it will certainly involve changes, which will be sacrificial to many congregations – but which could actually prove to be very worthwhile. Think about times past, when many saw the need to make our churches more ‘chil-friendly.’ We had to re-think how we did church. The result was, that some people actually enjoyed the more relaxed style that evolved – many have said that they remember the ‘children’s talk’ long after the sermon has been forgotten!

Services in every denomination follow their own pattern. Some of these patterns are helpful as they enable the person to cue in to where they are and what they are doing. But some practices require more dexterity and/or concentration than the person can offer. So if a service is to be truly dementia-friendly consideration needs to be given to how the service is conducted and how it might fit into the rest of the church’s life. Unless there are two or three people with dementia in the congregation it might not be practical, but it may be that you could see your church involved in this ministry.

SUGGESTIONS:

- **A shorter service**

Since this service would take no more than thirty minutes, it would be possible to hold this at the beginning of the usual service of worship. This would be followed by a time of fellowship, after which the people with dementia could leave if they wished, and the service could continue with extended readings and sermon in the way the congregation are used to.

- **A monthly event**

The shorter service model could be held monthly, perhaps the first Sunday of the month which would make it easier to remember. An invitation could be offered to those in other churches to join.

- **Change the day**

The dementia-friendly service could be held on a different day of the week, though the disadvantage of this model is that it would limit the contact that people with dementia would have with many of the people from the usual church congregation.

- **A different way of doing church**

It is still possible that, even after all these ideas have been put in place that those who accompany the person with dementia to church can no longer cope with the embarrassment to themselves and their loved one, or the disruption to other people, so they choose to stay away. But perhaps they could be encouraged to choose a time when there is no one else in the church. The person with dementia would then be free to walk around, explore, sing, cry, or whatever they wished, without fear of any embarrassment. It might be possible to sing a hymn or two. In this way a person's relationship with the physical space remains and may serve to remind them of so much, and be part of their spiritual nurturing. Indeed it has been found that many people find in an empty church a sense of God's presence and an inner peace that they can no longer find in a church service.

A dementia-friendly service

- **Worship in their own home**

There are complexities in even the most well thought out dementia-friendly service, so the time may come when church attendance of any kind is no longer a possibility. For some the exertion of going out becomes harder and harder. Even the process of getting in and out of a car becomes stressful. This may be due to painful joints, poor co-ordination or just general weariness. The effort just becomes too much. Now is the time to minister to the person in their own home, or in their care home.

What can we do?

If you feel that having a service specifically for those with dementia is not suitable for your situation, your church could become dementia-friendly in other ways.

1. KEEP IN TOUCH.

Don't lose contact, and try to find out why the person is no longer in church or at church events as regularly as they once were. Someone needs to visit them, preferably someone who has known them for a long time, who is trusted and the person feels at ease with.

2. LISTEN WITH EMPATHY.

Stay present in what is real at that moment for the person. Listen to their story with compassion and respect, not trying to put them right. The important thing to remember is not what is true or not, but that as the person may no longer find connection in our reality we must enter theirs, and by listening, truly listening to their story, we might also learn something from their vast storehouse of experiences.

3. AFFIRM THE PERSON.

Things we have experienced can be brought back to memory through reminiscence and the senses: sight, sound, taste, smell and touch. As we go through life we build up a personal history of trials and tribulations, joys and sorrows; all we have done, all the places we have lived, the people we have encountered through life, family, friends, colleagues; that special person who has had a profound influence on our lives. These experiences help to mould us into the people we have become, so that we each have our own story to tell. All of this is wrapped up in our memory, so to lose our memory is to lose a very precious part of ourselves. So remember that you are with an individual who has lived a life full of experiences and you need to find out about the other person's background, particularly the things that interested them so that you can help them to remember.

What can we do?

4. OFFER A CHURCH FRIEND.

This idea of the 'Church Friend' is based on a model that has been used to help parents of young children, where an individual takes care of the child in order for the parent to have some space. Though we need to reiterate that people with dementia are not children and should not be treated as such, there are similarities in the challenges that dementia can present, especially to their carer but also to the wider church.

Some churches have adopted this idea of 'Church Friend', who should be DBS checked, in order to ease the burden of caring by taking responsibility for the person with dementia. The 'Church Friend' could meet the person at the door and be with them during the service so that the carer can relinquish their responsibilities for a while and find some normality in their worship. They could be ready to take the person with dementia out into another room if they became restless. A room would be prepared with books and photographs, items of memorabilia that might capture their interest, as well as music, Bible stories, a cross a candle, reminders of their faith and belief.

5. SHARE FELLOWSHIP.

After a dementia-friendly service it is good if your Church offers refreshments. Fellowship with other believers is an important part of our faith life and this might be the only opportunity the person with dementia has to share this, especially as their world is becoming smaller as the effects of dementia increase. This is the time we connect and re-connect with friends, find out news, share our concerns. The person may only be able to engage a little but it is important that they are given the opportunity.

6. HELP THE PERSON TO MAINTAIN THEIR SPIRITUAL/PRAYER LIFE.

When a diagnosis of dementia is given, part of the worry for those to whom their faith is important is, how can I remember God? To say that God remembers them may be enough, but it is important to support their personal life of prayer and Bible study for as long as possible.

This could be by:

- Helping the person to put together a memory box with things that will remind them of their faith, perhaps through favourite Bible stories or hymns. Telling the story to a friend as the object is placed in the box means that that friend can tell the story to them as the objects are unpacked.
- Supporting the person by encouraging them to have a prayer partner. When they are less able to pray alone they may feel comforted having built up a relationship in prayer with others. Even those in late stage dementia can surprise us with their prayers, but they need to be given the opportunity.
- Maintaining links with worship when they are no longer able to come to church by having a simple service in their home, or perhaps singing a favourite hymn.
- Supporting daily Bible reading for as long as possible by using devotional material written for those with dementia such as the 'Being with God' series (Scripture Union)
- Encouraging a wider spirituality by using books such as 'Pictures to Share'. This can enable memories, experiences and situations to be explored.

START A NEW MINISTRY.

The church can show care through its mission and ministry to people who have dementia and to their families, whether or not they belong to a church and regardless of their beliefs. What about providing the opportunity for those with memory problems and their carers to meet in a safe space? Here are some examples of what churches are already doing.

What can we do?

A MEMORY CLUB

This is run fortnightly for people with dementia and their carers. They have about 10 members on the register, who come with one or two of their carers.

The morning starts with everyone meeting together over tea, coffee and biscuits, after which the carers move into another room where there might be a talk and an opportunity to ask questions and share their problems.

Meanwhile those with dementia enjoy a morning of reminiscing and sharing stories of life in years gone by, often with much laughter. Volunteers plan these sessions and the subjects cover a wide range including childhood, work, winter, keys and Christmases past. These mornings are invaluable for all the people who attend and some have said, 'they are a lifeline.'

THE FRIENDSHIP CLUB

One church became concerned and recognized the loneliness and isolation and the result was a 'Friendship Club.' This is a place where people with dementia and their carers come together where they are not only accepted, but are supported, valued and loved. It is a place where true friendships can flourish.

This is something that any church can do, large or small. All that is needed is a warm room, a kettle to make tea, and a group of volunteers who would genuinely care for and befriend people with dementia and those who support them. This particular church had only a small number who were able to volunteer, so they approached other churches in the area with the idea and it became an ecumenical project enlisting volunteers from all the churches.

Stimulation is such an important part of spiritual care of people with dementia, so the volunteers gathered objects of interest such as old photographs of the area, various magazines of interest, board games, dominoes and music. However, the activity they enjoy most is talking: reminiscing together over photos of holidays, weddings, and grandchildren. These are a source of great stimulus and give much pleasure.

AUDREY'S STORY

On one occasion people were having so much fun laughing and sharing stories when Audrey said, "I love it here, I don't feel like I have dementia when I come here. The response came, "We forget about your dementia when you're here," to which she answered, "Well I forget everything else, I might as well forget about my dementia."

Everyone saw the funny side of her joke and laughed with her. This is the success of the club; they forget about the dementia and concentrate on the person. In the love and friendship God was there, God's Spirit was there.

In the gospel of Matthew, Jesus said that what we do for the least of his brothers and sisters we do for him. Matt 25: 35-45

For I was hungry and you fed me; I was thirsty and you gave me water; I was a stranger and you invited me into your homes; naked and you clothed me; sick and in prison and you visited me.

It's not hard to imagine Jesus saying:

*I was hungry and thirsty for understanding and friendship and you visited me.
I was a stranger in the strange land of dementia and you visited me.
My loss of faculties and social skills left me vulnerable and naked and you visited me.
I was in the prison of my failing mind, I was sick and you visited me.*

Wouldn't it be good if someone with dementia heard it like this?

In conclusion

It is when we are **being** Christ among his people, walking alongside and showing God's love in action, that we see God's love most clearly.

Dementia-Friendly Churches offer an opportunity to reach out to those who are most vulnerable and voiceless in society and to show the love of God in action.

These actions are not without cost, but the riches experienced and glimpsed offer new insight into what it means to be church.

Methodist Homes (MHA) is a charity providing care, accommodation and support for older people throughout Britain. We are one of the most well respected care providers in the sector and amongst the largest charities in Britain, providing services to older people for over 70 years. Our mission is to improve the quality of life for older people, inspired by Christian concern and our services have always been open to all faiths and none.

Christians on Ageing (CCOA) is the main national fully ecumenical organisation that focuses on the spiritual needs and development of older people. For more information visit www.ccoa.co.uk

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By Revd Dr Margaret Goodall and
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