



A guide to supporting people with dementia in the local church



“Do not cast me off in time of old age: forsake me not when my strength is spent” (Ps: 71:9)

The numbers of people with dementia in our communities are increasing. As a result, many families are struggling to cope.

The Psalms say, “Do not cast me off in the time of old age; forsake me not when my strength is spent.” (71:9) The Commandments tell us to honour our fathers and our mothers. People of all faiths follow teaching that tells us to respect older people. The Quran says, “be kind to your parents. If one or both reach old age, do not say to them a word of disrespect, or scold them, but

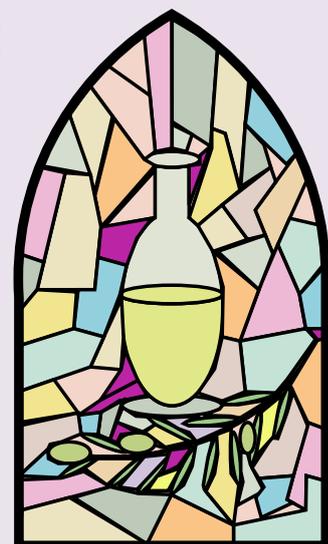
say a generous word to them. And act humbly to them in mercy and say, ‘My Lord, have mercy on them, since they cared for me when I was small’”.

Respecting our elders is easy when they are active, engaged members of our parish. But what can we do when things start to get difficult? Most people with dementia are old, or very old, and their numbers are increasing as our population ages. Working age people with dementia have a particularly difficult time.

Further copies of this resource can be downloaded from the website of the Dementia Services Development Trust at www.dementiatrust.org.uk



Dementia Services
Development Trust



What is dementia?

“Dementia” is the word given for a set of symptoms that affect people who have an underlying disease such as Alzheimer’s disease or vascular disease. It is called dementia when the person has difficulty in thinking, and working things out. It might be hard to get their words out and their behaviour becomes difficult to understand.

Why should churches pay attention?

People of all faiths want to live a good life in a just society and as we are all going to live much longer the incidence of dementia in all our communities will grow. It will be too big an issue and too important to be left solely to health and social care or to Government.

We believe in the dignity of every person.

But people with dementia and their carers can have their dignity undone by others, particularly if care is delivered in an undignified way.

We believe that families are the foundation of community, and the family of the church includes people who may have no other earthly family.

But people affected by dementia may present problems that families alone are unable to manage.

We are our brother’s and our sister’s keepers, and we are required to honour our fathers and our mothers.

But people with dementia are very hard to care for, and at times beyond the skill and knowledge of lay people.

These seem very difficult problems, but with a positive attitude and some practical interventions, we can work wonders for people with dementia and their families, and for the professional care workers among us.

The church has an active role

- when someone might have dementia
- when someone has been diagnosed
- when the person is trying to live the best life possible
- when care becomes hard
- when the person must go into care
- at the end of life

Who is this guide for?

This short guide is to support clergy, parishioners and anyone in the congregation of a local church who wants to help people affected by dementia.





Overview of the guide

This guide is divided into 6 sections

1. When someone might have dementia

It is hard to know what to do when someone's behaviour is giving rise to worry. People are afraid and hide their symptoms. You may be shy about offering help because of fear of causing offence. This section gives some ideas for action.

2. When someone has been diagnosed

Being diagnosed is not something that just happens to the "patient". It is a significant blow for the whole family, adjusting to a new way of living. How to support the person affected and those around them who have a new role of "caregiving" is important knowledge for friends in the church.

3. When the person is trying to live the best life possible

Because diagnosis is coming earlier all the time, people discover that they have dementia when there is still a lot of good living to do. This time can be extended and made more dignified and happy by the actions of those around them. What can people in the church do to help with this?

4. When life becomes too hard

With the best care, and the best environment, things can still go wrong. The person may behave at home in ways that are hard for the family to manage. The care system may not seem to be responding as it should. The response of the church is to protect the dignity of others...but how can we do this?

5. When the person must go into care

When they relinquish care into another's hands, you might think the family can relax and breathe a sigh of relief. But it is not always like that. A night's sleep might now be possible, but every waking moment may be spent wondering, "Are they looking after my dad as they should?" How can church communities help now?

6. At the end of life

At a funeral, a mourner cried out "We are not burying my wee mum. She died a year ago when she stopped knowing who we all are." What a sad end to a lifelong story of love and grace. How can the church comfort and support people at such a time? And what comfort is there for ourselves?

John 21:18 "Very truly I tell you, when you were younger you dressed yourself and went where you wanted; but when you are old you will stretch out your hands, and someone else will dress you and lead you where you do not want to go."





1. When someone might have dementia

It is hard to know what to do when you are worried about someone. People are afraid and hide their symptoms. You may be shy about trying to help in case you cause offence. This section gives some ideas for action. The first and most important thing is to find out as much as you can about dementia so that you know what you are looking for.

What is the average age of your community and the people around you?

Up to half of people over the age of ninety have dementia. In their eighties, it is more than one in ten. Many more people are affected through being a carer for someone with dementia; a father, an aunt, a brother, a cousin, a husband or a wife. Dementia in working age people and children is rare, but as a result presents huge difficulties for those families affected.

Is it unkind or rude to ask if someone has dementia, or suggest that they need to see someone?

How confident you are to do this depends on your relationship and how much you know about dementia yourself. There are some things that you can do without asking which will benefit people whether they have dementia or not.

- put up a “worried about your memory?” poster on the noticeboard, with details of organisations that people can contact
- pray that people who are worried will find the courage to talk to someone and

discover ways of keeping well for as long as possible

- undertake “dementia friends” training which may offer some guidance on how to raise issues and access your local services
- make sure you understand your church’s safeguarding policies for vulnerable adults
- offer opportunities for shorter worship and make sure to mix old tunes and prayers with the new ones in your services
- keep the lights bright in the church

Activities

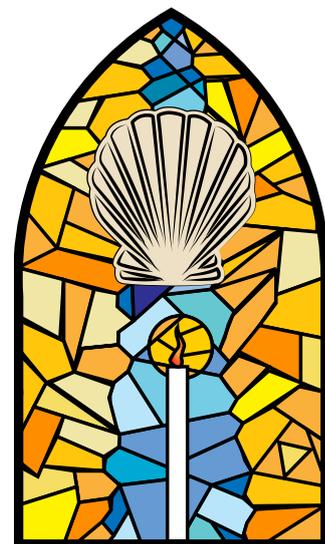
In a group, see how much knowledge you already have about dementia and what is already there to help in your community. Pull together an information file about local resources for people with dementia and their carers. This might include the Alzheimer’s Society, a dementia café, dementia specialist nurses, a day hospital, care homes and day centres. In your group or congregation, you may already have social workers, nurses, and other health workers, even those who have retired, with valuable knowledge. And don’t forget the wisdom of experienced carers.

Reading

Romans 8: 35–39

We fear dementia, but nothing will be able to separate us from the love of God that is in Christ Jesus our Lord.





2. When someone has been diagnosed

Being diagnosed is not something that just happens to the “patient”. It is a significant blow for the whole family, adjusting to a new way of living. How to support the person affected and those around them who have a new role of “caregiving” is important knowledge for friends in the church. Not least, there is a problem when people “come out” to friends. Sometimes the friends have no idea what to do and say, and as a result they just run away.

“A friend is someone who knows the song in your heart and sings it to you when you have forgotten the words”

Why should this happen to me?

Just because you have been good does not make you immune to the laws of nature. Dementia happens because of structural changes in the brain. When people ask why, it’s not a real question, but a cry of pain. The key question is what are you going to do with what has happened to you? How can you help yourself? What do you need to do now? And how can your church help you?

What families go through

The response is very like any other shock. To begin with there may be denial, as they try to pretend nothing happened, and anger follows

behind. That is understandable, as is the grief that people feel when they realise what they are losing – time, memories, social contacts. The financial loss is very worrying. Even if they are resilient people and try to think positively, there is a great risk of isolation and depression.

Activities

What can you do to get alongside people who are going through this? In a group, list the ways you can help with

- keeping in touch and supporting the person to get out and about
- making sure that they can still get along to church services and meetings
- listening to what they are going through and not judging their anger and grief, or falling into that sorrow along with them, but staying strong
- giving practical support with getting to appointments, including reminders and transport

Reading

Andrews J, *Dementia the One Stop Guide*; Chapters 3 and 4 “Adjusting to the News”

Psalm 34:18 “The Lord is close to the brokenhearted and saves those who are crushed in spirit.”





3. When the person is trying to live the best life possible

Because diagnosis is coming earlier all the time, some people discover that they have dementia when there is still a lot of good living to do. This time can be extended and made more dignified and happy by the actions of those around them. What can the church do to help with this?

The health services are finding and helping people with dementia as early as possible. Although being diagnosed is a terrible shock, for some it is a relief to finally have a name to put to the terrible symptoms that have been frightening them. Early diagnosis is a good thing, because it increases the time you have available to put your affairs in order, and complete a wish list of things you want to do before it is too late.

You can do things to stay well for as long as possible. "What is good for your heart, is good for your head." This includes exercise, stopping smoking, taking the Mediterranean diet, and reducing alcohol. Socializing is vital, and keeping up as much as possible with the things you enjoy. You need to keep any underlying other illness under control, such as diabetes, blood pressure or depression.

Food and conversation is an important part of church life. How can we make sure that the person with dementia and their carer stay fully involved? Even though she has dementia, someone might be still able to make the cakes that she once did, with a bit of encouragement.

Laughter while helping in the kitchen at socials or being around the children at Sunday School is life enhancing. These activities can keep the person feeling alive and well.

Activities

In a group, ask each person to think what their most familiar passages are in the Bible or prayers, and copy them down. Then compare notes and see whether there are verses that are more likely to be remembered, or are special. Think about whether these are the words that will comfort you if you are ever ill or lost. Save these in case you ever are affected yourself and tell your family why these verses matter to you and will help you to continue to live well. Remember that a person with memory problems may still remember Bible verses learned at school, a lifetime ago.

Look up some of the information about "dementia friendly design" and audit your place of worship. Can you make some inexpensive changes now? Make sure everyone knows why you are making the changes.

Reading

Andrews J, *Dementia the One Stop Guide*; pp.193–220 for dementia design ideas that work at home and in public places. Also information about practical issues such as access to drinking water and toilets.





4. When life becomes too hard

With the best care, and the best environment, things still go wrong. The person may show behaviour that is hard for the family to manage. The care system may not be responding well. The church's response is to protect the dignity of others...but how? We can start by preserving the right to worship.

We know that the person may be soothed by a familiar song or prayer. It may give a sense of security to take part in a simple religious ritual.

When people want to support others, the best start is to find out as much as possible about the difficult symptoms of dementia, so that life and worship are not disrupted by things that can be avoided such as agitation, anxiety, aggression, wandering, or other psychological symptoms.

People in a church can give the greatest gift, which is time. Time to listen, time to go for a walk, time to keep company with the person who has dementia, time to free the carer for an hour or two. The difference from an ordinary day centre or private services and the support given by a Church is the focus on God and the affirmation that everyone matters to Him.

Activities

The practical elements – can you do any of these?

- limit the length of a service to 20 minutes
- keep the singing focused on old, familiar hymns
- say short prayers such as the Lord's prayer, or just a few short words

- make sure that carers and people with dementia know that they cannot ever embarrass themselves in the service, because the focus is not on "being proper" but on their need to worship and our overwhelming desire to support that
- work up a good flyer/poster to let people know about it
- have a prayer group or bible study class that allows people with dementia to sit in, and just be there
- add value by contributing a hot lunch

Discussion

Discuss this comment:

People shouldn't be viewed as disruptions. Disrupting moments provide opportunities to demonstrate patience and gentleness. People must be treated with dignity and respect. How leaders respond in the moment can speak louder than any prepared sermon. We must learn to navigate the fine nuances between discouragement, distraction, disruption, and danger in a service.

DeYmaz M in "Should churches try to minimise disruptions?" compiled by Moon R, 2011, Christianity Today

Reading

For guidance on how to manage distressed behaviour, see:

Andrews J, *Dementia the One Stop Guide*; Chapter 8 "Disturbing behaviour"





5. When the person must go into care

With the relinquishing of care into another's hands, you might think the family can relax and breathe a sigh of relief. But it is not always like that. A night's sleep is now possible, but every waking moment may be spent wondering, "Are they being looked after as they should?" How can we help now?

The care home

Although there are many care home workers who have a faith and understand the need of people to worship and pray, some don't. The design of the care home may not seem to offer a quiet place that could be used for services. You can transform a day room into a chapel. Put up a roller banner of a church window, and use a plain cloth for the table and a cross. A recording of church hymn music supports frail voices to sing along. Simple changes give the message that we are here to worship. Encourage clergy to wear clerical dress, so confused people can be very clear about who is who. Use a visiting card so that families have the comfort of knowing you were there. But don't forget that you can always offer to take the resident out of the home, and back to their church, if they would find that comforting. Always be flexible on any occasion about whether any things you plan to try are going to work.

Other things to do

- When families are choosing a care home, they might have to visit a few to decide what is best. Can you keep them company in that search?
- When someone goes into a care home, they might spend a long time without activities. Can you go to see them?
- Some families still have a significant time commitment to visiting their loved one in the care home. Can you offer to take over some of the visits, or cover a holiday time, to give them a break?
- Visiting someone who does not speak a lot and seems not to understand can be hard work. Can you take some photos to look at, or show them something on your iPad? Could you read out loud from the paper, or just sit together? Would they let you rub some hand cream on their hands? Can you listen to a tape of last Sunday's service with them?

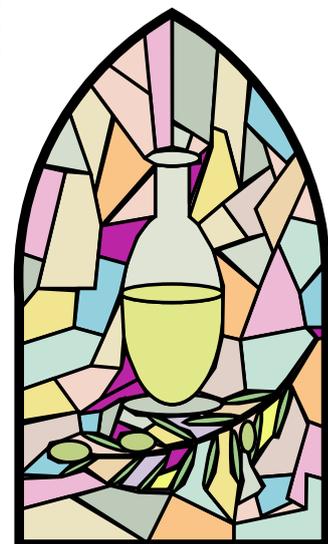
We visit the sick in care homes and support their families, not just as an act of kindness, but because it is what we are required to do by the teaching of the Bible.

Reading

Andrews J, *Dementia the One Stop Guide*; Chapter 14 "How to choose a care home"

Matthew 25:40 "Whatever you did for one of the least of these brothers and sisters of mine, you did for me."





6. At the end of life

At a funeral, a mourner cried out “We are not burying my wee mum. She died a year ago when she stopped knowing who we all are.” What a sad end to a lifelong story of love and grace. How can the church comfort and support people at that time? And what comfort is there for ourselves?

What brings the end

‘Yes, we are of good courage, and we would rather be away from the body and at home with the Lord’ (2 Corinthians 5:8)

Towards the end of their life a person with dementia will be more vulnerable to infections and have difficulty moving about independently. Swallowing and eating may become difficult, and it will be hard to sit up independently. They will be dependent on others for everything. Communicating with words will come to an end, and even facial expressions may fade away making it hard to know how they feel. They might be at home, or in a care home, in a hospice or taken to hospital at the end. They may seem like a completely different person.

‘Many are the afflictions of the righteous, but the Lord delivers him out of them all’ (Psalm 34:16–19)

Preparation

We must remember the importance of discussing the end of life with our families long in advance. Settling issues such as powers of attorney and where we want to be when the time comes, means those left behind can be clear with health and social care workers. We need to say, “I love

you now and if I reach the point where I can’t say it again, you need to remember it.”

Death is not the Enemy

Grief is natural and healthy for families. There is no short cut, and we must let people express it as they need, but let them know they are not alone. When facing a dread diagnosis, the person might fear that they will forget God, and must be assured that God will not forget them. If families feel the person they love has died because they stopped recognizing their family, they must be assured that this is just the disease, and the person is always there.

Activities

Take time to consider how you would design a service of remembrance for someone who died with dementia.

“A service such as this needs to be prepared with great care and should involve discussion with colleagues and, if possible, with staff members ...”

Goldsmith M “In a Strange Land; People with Dementia in the Local Church” 2004, 4M publications

Reading

Romans 8:38–39 For I am sure that neither death nor life, nor angels nor rulers, nor things present nor things to come, nor powers, nor height nor depth, nor anything else in all creation, will be able to separate us from the love of God in Christ Jesus our Lord.



