

Six steps
to making a
DEMENTIA
INCLUSIVE CHURCH



Helpful tips

drawn from real-life experience

Six steps to making a **DEMENTIA** **INCLUSIVE CHURCH**



What is **dementia?**

The word 'dementia' is a Latin word which means, literally, apart from or away from the mind, and is a description not of the disease itself but of the symptoms. The most common types of dementia are Alzheimer's, Vascular Dementia, Frontotemporal Dementia, dementia associated with Parkinson's disease and traumatic brain injuries such as strokes. One in 10 people will have more than one dementia which is referred to as 'mixed dementia'.

Symptoms can include, but are not limited to, forgetting events, names and places, repeating questions, difficulty finding words or putting thoughts across in conversation, problems managing money, getting lost in familiar places, trouble doing work or routine tasks, depression, lethargy and apathy, neglecting appearance and personality changes.

The best treatment for people with dementia is the quality of care that they receive, helping to maintain their sense of identity – good care can help to 'hold the person together' and slow the decline.

What is a dementia inclusive church?

Christians are spiritual beings with an ultimate destination in heaven, and in whom the Holy Spirit makes its home.

A dementia inclusive church is a community which has adapted to make sure that those living with dementia are welcomed and supported to continue on in their journey of faith. Most importantly, it is a place where people understand that while cognitive decline can change a person, the child of God remains unchanged even if they are now masked by changed behaviour.

The local church is crucial to supporting those living with dementia as a place of home and belonging where all can remain a member. After diagnosis there is considerable value in meaningful relationships and 'normal church life', including worship and fellowship, so that their spiritual needs can continue to be met. In fact, meeting the spiritual needs of a Christian with dementia is paramount.

They may be struggling with anxiety, poor short-term memory, and unpredictable behaviour, so attending their own local church where the place and people are familiar, and where they will be reminded of their special relationship with God, is vital.

It is a place where they should feel loved, welcomed and at home. The whole experience of attending their own local church should be an experience that reassures them and reminds them of God's love and past and present blessings. It is a place where they can receive spiritual and practical support from church members as part of normal relationships in an atmosphere where every member really matters.

Churches are the hub of Christian communities. The challenge then is how to make our churches truly dementia inclusive to meet the needs of the Christians who develop dementia.

'For as in one body we have many members, and the members do not all have the same function, so we, though many, are one body in Christ, and individually members one of another.'

Romans 12:5, ESV

Step 1



HAVING THE FULL COMMITMENT OF THE PASTORAL TEAM

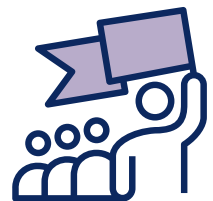
The first step is to ensure the full support and commitment of the pastoral team and the fellowship. When everyone is educated about dementia, no-one will be shocked by someone shouting out or getting up and walking around. We need to be prepared to think outside what church normally looks like to us.

It often helps to ask someone who knows about dementia to come and talk to the church leaders, and indeed the whole church, about it. The surge in the prevalence of

dementia has brought to everyone's attention a condition that is unfamiliar to most, and there is still widespread misunderstanding and misinformed media.

The team needs to be creative in meeting individual needs and it can be helpful to pray, share, and support each other specifically when serving those living with dementia and their caregivers. They will need to reflect on what is working well and what needs to improve.

Step 2



IDENTIFYING PROJECT LEADER(S) WITH VISION

Every project needs a 'project leader' and it helps if church leaders identify members who have a vision for the 'dementia team' – those who will help train and support the rest of the church, and keep a list of dementia caring families so that can be supported appropriately and don't drop off the radar.

Some churches may have members with the appropriate knowledge and expertise, who can start encouraging and training with talks and presentations. This can include not only training for people with dementia already known in the church, but those in the local community that the church seeks to reach and help.

Step 3



MAKING THE MOST OF COMMUNICATING¹

Everyone in the fellowship will benefit from learning how to communicate with those living with dementia. It is important in everything we do and say to convey full respect to him or her as an individual and as a fellow believer in the Lord.

One of the most important things to remember when communicating with someone living with dementia is to accept their reality and communicate within the world they are experiencing here and now. There are kind ways of having a conversation when

someone seems to be living in a different world without lying to them but by deflecting and diverting with positive sentiments.

Body language is also important to be aware of – positive facial expressions and a relaxed posture will say more than words can convey. Often, a person with dementia will understand the emotions you are expressing more than the words you are using.

Sometimes ‘being’ is far more important than ‘doing’, so use touch and gestures appropriately to express emotions.

¹ For more tips on communicating, see the end of this booklet

Step 4



HAVING A BUDDY SYSTEM

A major key to success is appointing ‘buddies’ – people who will develop a relationship with individuals with dementia, and who can sit alongside them during and after a meeting to befriend them.

Buddies may be family members or friends, or an empathetic member of the fellowship. If the person with dementia has a question, the buddy can answer it quietly or can meet a need while limiting disturbance to those

around them. For example, people living with dementia can be distressed if they experience a sensory overload, but a buddy can help offer calming support.

Buddies can also alleviate some of the pressure felt by the primary caregiver, either by taking full responsibility for the person living with dementia during the service, or by simply being an extra pair of hands or an emotional support to the caregiver.²

² For more on supporting the caregiver, see step six

Step 5

MAKING THE BUILDING DEMENTIA INCLUSIVE³



Buildings are often not designed with those who are living with dementia in mind so there can be adjustments that may need to be made to really make the space safe and welcoming. Alongside cognitive decline and the general impact of ageing, there can be some specific visual problems associated with dementia which can make it difficult to discriminate between colours and textures, there can be the loss of peripheral vision, and the ability to interpret an image may be impaired.

It is helpful to consider whether lighting, carpet or other surroundings might be confusing for someone living with dementia. For example, shiny floors can appear wet and patterned flooring which may cause illusions. Good lighting means fewer shadows and less glare, and strong colours on signs make it easier to identify key places like the toilets.

³ For more tips on making buildings dementia inclusive, see the end of this booklet

Step 6

TAKING CARE OF THE CAREGIVER



Being the primary carer of someone living with dementia can be an incredibly hard path to walk. Many caregivers are left to struggle with a raft of negative emotions, including grief, stress, depression, and anger, all of which adversely impact their own health and well-being. Having good support from friends, family, and church can make all the difference.

Finding ways to alleviate some of the pressure and responsibility is a key way that churches

can support dementia caregivers. This could be as simple as a weekly phone call to see how things are going and allow the caregiver to be cared for spiritually and emotionally themselves. If there are others in the church who can sit with the person living with dementia while their caregiver goes to the shops or just out for a walk or a cup of coffee, that can really help to give them some vital space.

Some golden rules for **communicating** *with those living with dementia*

Try to make eye contact and make sure that the person can hear you.

We are used to asking questions as part of our natural way of communicating with each other, but sometimes people with dementia find it difficult to 'compute' the answers and it can be helpful to avoid asking direct questions. For example, instead of asking, "Would you like to put your coat on?" you can show the person the coat, holding it open with an enquiring expression.

Speak for a short time only, in a steady, calm, meaningful way.

Smile! Facial expressions convey a great deal. Be aware of the non-verbal message you may be sending by the way you react and express emotions.

Don't interrupt or contradict, even if the person says something which you know is not correct.

Do not directly confront them but gently steer the conversation around to something more profitable. For example, if a person says her mother will be coming in a short while, you can deflect by saying something empathic, such as, 'What a blessing mothers are! Where would we be without them! Now my mother...'

Do not take words they say literally but instead look for the emotions and message behind the words.

"I want to go home" can mean, 'I'm not comfortable and I don't feel at ease.'
Finding out what you can do to make them feel comfortable may answer the need.

Do not tap someone with dementia on the shoulder from behind to try and gain their attention.

Always approach the person clearly from in front, so you can be seen clearly.
Sit at their eye level but not directly face to face.

Get comfortable with repetition and be ready to repeat things out loud to remind the individual of what they have just said.

Things to *think about* when it comes to church buildings



THINGS TO AVOID:

- dark flooring and shadows which may appear as holes,
 - blue/grey tones – warm tones are easier to see,
 - dark wooden thresholds may appear as a hole or barrier,
 - furniture which is the same colour or tone as the flooring.
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YOU WILL ALSO NEED TO ENSURE THAT:

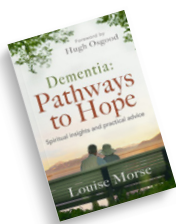
- different floorings laid adjacent to each other blends to avoid making the appearance of a step,
 - where there are steps fluorescent tape is laid along the edge so they can be seen clearly,
 - strong colours are used so objects are clearly visible and distinguishable. For example, lavatory walls are best painted with a bold colour so that the white lavatory 'stands out',
 - there should be clear picture signage, cues or familiar objects to signpost for toilets and entrances.
 - There should be seating which is easy to access. Often, people with dementia and their buddies will prefer to sit at the back of the church so they can leave when they want to and rejoin again with the minimum disruption.
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Recommended reading

BOOKS BY LOUISE MORSE...



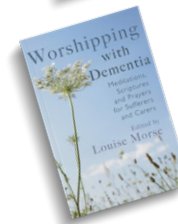
DEMENTIA: Frank and Linda's Story – a true story of childhood sweethearts where the husband now has dementia, and the things that helped them in their journey.



Dementia: Pathways to Hope – written to cut through the narrative of despair and despondency that surrounds much public discourse of dementia with facts and stories of hope.

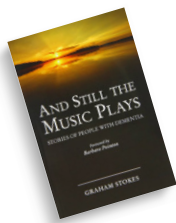


Could it be Dementia?
– a ground-breaking book that looks at dementia through a holistic, Christian lens.

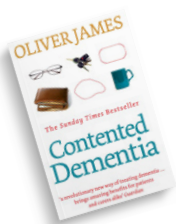


Worshipping with Dementia
– a series of short devotions, beginning with a Scripture verse, some thoughts, a prayer, and an old favourite hymn reflecting the theme.

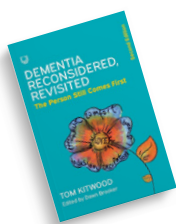
OTHER BOOKS...



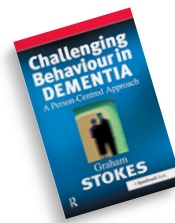
And Still the Music Plays, Graham Stokes – a compassion book written with expertise, showing how people with dementia behave according to their intrinsic values and beliefs.



Contented Dementia, Oliver James – outlines the SPICAL method of relational care themed over 30 years by Penny Garner; recommended by the Royal College of Nurses.



Dementia Reconsidered, Tom Kitwood – a seminal work by the late Professor Tom Kitwood of Bradford University who revolutionised the care of people with dementia.



Challenging Behaviour in Dementia, Graham Stokes – written mainly for health care professionals, Dr. Stokes' book explains the possible reasons behind challenging behaviour and the best ways of understanding and coping with it.



www.gloriousopportunity.org
– valuable practical and spiritual insights by Dr Jennifer Bute, a GP diagnosed with young onset dementia.



About Pilgrims' Friend Society

Rooted in our Christian faith, at Pilgrims' Friend Society we believe that as well as providing secure, comfortable homes and professional care, older people can be supported and encouraged to spend the later part of their lives contributing to the world around them, growing and enjoying fulfilling lives.

We have been supporting older people to flourish for more than 200 years, since a group of Christians concerned about "the aged and infirm Christian poor" established the Aged Pilgrims' Friend Society in 1807. We started off by providing pensions and support through volunteer visits before developing housing and care schemes for older Christians.

Today we continue that legacy by running residential care homes and independent living housing schemes around the UK, providing environments in which older people are comfortable and secure, whether they need care or are living independently.

The Pilgrims' Friend Society bespoke approach to care, The Way We Care, ensures that we create communities where older people can flourish in their later years, especially as their physical needs increase.

We are committed to seeing the whole person – the history, the experiences, the joys and the sorrows of life, and to knowing who the important people are who make up the bundle of each person's living.

The Way We Care is grounded in our Christian faith and draws inspiration from the Bible. Every part of what The Way We Care looks like in the daily lives of our care homes is rooted in how the Bible tells us to treat and support others around us.

Find out more about The Way We Care by visiting www.pilgrimsfriend.org.uk/thewaywecare or by scanning the QR code



Our HOMES and HOUSING



Residential care homes

BETHANY HOUSE, PRESTON

☎ 0300 3031724
✉ bethanypreston@pilgrimsfriend.org.uk

BRIDGEMEAD, BATH

☎ 0300 1319115
✉ bridgemead@pilgrimsfriend.org.uk

EMMAUS HOUSE, HARROGATE

☎ 0300 3038450
✉ emmaushouse@pilgrimsfriend.org.uk

EMMAUS HOUSE, WHITEHAVEN

☎ 0300 3031440
✉ emmauscumbria@pilgrimsfriend.org.uk

EVINGTON HOME, LEICESTER

☎ 0300 3031455
✉ evington@pilgrimsfriend.org.uk

FINBOROUGH COURT, GREAT FINBOROUGH

☎ 0300 3031450
✉ finboroughcourt@pilgrimsfriend.org.uk

FRAMLAND, WANTAGE

☎ 0300 3031470
✉ wantage@pilgrimsfriend.org.uk

KOINONIA CHRISTIAN CARE HOME, WORTHING

☎ 0300 3038480
✉ koinonia@pilgrimsfriend.org.uk

LUFF HOUSE, WALTON-ON-THE-NAZE

☎ 0300 3031495
✉ luffhouse@pilgrimsfriend.org.uk

MIDDLEFIELDS HOUSE, CHIPPENHAM

☎ 0300 3038470
✉ middlefieldshouse@pilgrimsfriend.org.uk

MILWARD HOUSE, TUNBRIDGE WELLS

☎ 0300 3031460
✉ milward@pilgrimsfriend.org.uk

SHOTTERMILL HOUSE, HASLEMERE

☎ 0300 3031475
✉ shottermill@pilgrimsfriend.org.uk

Independent living housing schemes

CAREY GARDENS, KIRBY MUXLOE

☎ 0300 3038455
✉ carey.gardens@pilgrimsfriend.org.uk

DOROTHEA COURT, BEDFORD

☎ 0300 3031490
✉ dorothea@pilgrimsfriend.org.uk

FINBOROUGH COURT HOUSING, GREAT FINBOROUGH

☎ 0300 3031450
✉ housingmanager.finborough@pilgrimsfriend.org.uk

HOMESDALE, WANSTEAD, LONDON

☎ 0300 3038485
✉ homesdale@pilgrimsfriend.org.uk

LUFF MEWS & SELHURST COURT, WALTON-ON-THE-NAZE

☎ 0300 3031495
✉ luffhouse@pilgrimsfriend.org.uk

MILWARD HOUSE HOUSING, TUNBRIDGE WELLS

☎ 0300 3031460
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PILGRIM GARDENS, LEICESTER

☎ 0300 3038455
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ROYD COURT, MIRFIELD

☎ 0300 3031480
✉ roydcourt@pilgrimsfriend.org.uk

STRATHCLYDE HOUSE, SKELMORLIE

☎ 0300 3038465
✉ strathclyde@pilgrimsfriend.org.uk

*“Even to your
old age and grey hairs
I am He, I am He who
will sustain you.”*

Isaiah 46:4

**This booklet is inspired by
the work of Louise Morse**



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