



Dementia & faith

The prevalence of dementia is such that few families are unaffected by the condition. With an aging population, numbers are set to increase. **Suzanne Hamilton** looks at the difficulties that a fading mind causes to those living with the condition, as well as their carers and the challenge this presents to the Church.

It is estimated that currently 19,000 people in Northern Ireland and 47,000 people in the Republic are living with dementia. By 2051 this number is expected to treble in Northern Ireland, while estimates for the Republic predict 130,000 cases of dementia by 2041.

This poses a challenge for society as a whole, but also for churches as they consider how to support those living with dementia and their families.

“Nearly everyone knows someone affected by dementia,” says Professor June Andrews, the author of *Dementia: The One-Stop Guide*.

While dementia affects children and those of working age, she explains it is mainly associated with older people. Common signs of dementia are saying the same thing every few minutes, being

forgetful and confusion.

“The main problem in dementia is stress; the stress of not having a clue of what’s going on around you. What you do when you are stressed depends on your personality – some people withdraw, some people fight, some people get angry, some people try to run away,” says Professor Andrews.

Our churches need to start thinking about this as our population ages. We can no longer be one-man bands, we will have to have a joined-up approach...

She explains that older people with dementia have the normal changes of aging but a reduced capacity to deal with them. Dementia describes the symptoms, but it can be caused by hundreds of diseases, the most common of which is Alzheimer’s.

“When you get someone in your church or someone in the family, it is useful to know what kind because that helps people deal with surprises,” says Professor Andrews, explaining that someone with vascular dementia can be OK for a while and then take a sudden dip, while the decline is more gradual for someone with Alzheimer’s.

“If you know the lady in your parish has got Alzheimer’s dementia and she suddenly gets ill, make sure she sees a doctor as it may be down to an infection instead of the dementia getting worse.”

Journeys

Professor Andrews says there are two possible dementia journeys – staying well for as long as possible or going downhill faster than necessary – but there are ways that church communities and families can help the journey.

“The amount of damage inside your head isn’t proportional to the amount of dementia you have. The dementia you have can be related to the fact that your environment is wrong, you haven’t enough exercise, are not getting enough stimulation, you’re getting dehydrated, or not eating the right things,” she explains, adding, “There’s things you as a faith community can do to support families and people with dementia.”

As regards medication, Professor Andrews says it is important to encourage people within your congregation who you suspect of having dementia to see their doctor. While recognising this is a delicate conversation and that the form of dementia they have may not be amenable to medication, she says, “If they at least get sorted out with what type of dementia it is, there’s a chance.”

Diet also has a role to play, with Professor Andrews advising that even something as simple as constipation can tip someone over into confusion. Stressing the importance of hydration, she adds, “My father’s church has jugs of water on the front pew... There must be some way to make sure people are well hydrated during long services.”

She would like to see ‘guerilla visiting’ where church members go in at meal times to make sure people are being fed. Professor Andrews tells a story of one man who was passed by at mealtime in hospital. When his wife, who happened to be there, asked why, the staff pointed to a ‘nil by mouth’ sign above his bed. This had mistakenly been left up – it applied to the person who previously occupied the bed. Professor Andrews pointed out that if this man had complained of hunger, the staff would probably just think he had forgotten that he was supposed to be fasting.

Faith

As well as providing practical help, the church family can also support the person with dementia and their family in their faith journey. Professor Andrews says there is evidence that having a faith makes a difference to those who have dementia.

The main problem in dementia is stress; the stress of not having a clue of what’s going on around you.

“People who have always had a faith and who are able to continue with their religious observance find comfort with that. There’s all kinds of secular theories about this – it’s doing something that is familiar, it’s doing something they’ve always done, it’s like mindfulness. People of faith know why they believe...being able to continue your religious observance is really important.

“For those of us who work with patients, clients and families who have dementia, we really understand them better when we see them observing their religious faith; when we see them as a person who has had a belief, who is part of a church community.”

Of course, how the church can still include the person with dementia will depend on where they are. If they are still able to attend services, Professor Andrews says there are ways churches can become more dementia friendly.

Her ideas include shorter services, having clear signage, easy access and perhaps the minister wearing robes to aid identification. “We need awareness of dementia, we need to alleviate fear and be inclusive,” she adds.

Disability and community engagement charity, Livability, also has useful suggestions, including choosing familiar hymns and well-known tunes, having a designated quiet space in church, trying to minimize distractions and making sure whoever is leading the service can be clearly heard.

For those who are housebound, in hospital or in a care home, visiting and

Workshop



PCI hosted a dementia and faith workshop in Assembly Buildings, Belfast recently to look at how people in faith communities can work together to make life easier for people with dementia and their carers.

The key speaker was Professor June Andrews, who is leading the Reframing Dementia Project along with Mark Butler. The initiative’s aim is to change the way people think about dementia.

Explaining the purpose of the workshop, Lindsay Conway (Secretary to PCI’s Council for Social Witness) says, “Working closely with other churches and faith-based organisations, we want to discuss

how dementia impacts on church life and how best to equip and give practical support to clergy, pastoral care workers, carers and professionals to work more effectively in a faith setting with people living with dementia.

“Today’s workshop is part of a process that will ultimately lead to the publication of a special resource that will better equip those pastoring, supporting and working with older people with dementia, as it is important to remember that if faith and religious observance is an integral part of a person, it must be an integral part of their care, even if they have dementia.”

providing recordings of services are ways of connecting. Stressing the importance of maintaining that link, Rev. Norman Harrison, who is chaplain at the Royal Group of Hospitals, says, "Every person regardless of age or stage in life is valuable in the kingdom of God and an invaluable asset in the church," adding that the pastoral challenge

for Christians and ministers is to take account of all people, regardless of their "capacity, age and stage".

As regards those whose mind has started to diminish, Mr. Harrison says, "There is no barrier that God cannot penetrate, because if the mind or the body is weak the soul is still strong and we are able to connect with the human soul."

He says pastoral ministry involves being stretched and developing "elastic comfort zones", but warns that time is a major factor in ministering to involve people with dementia and properly support their families. "Where are we going to find the time and the people who can give the time? How can we best manage time? I don't think we can do it on our own. We need a joined-up approach. I believe our churches need to start thinking about this as our population ages. We can no longer be one-man bands, we will have to have a joined-up approach with one another to properly minister to the aged generation."

The importance of faith as part of a person's identity has been recognised by Abbeyfield and Wesley. Following a spiritual needs and care survey in 2014 which assessed the care given to residents and staff, the housing association has appointed a chaplain to one of its regions in England.

"Everybody matters. We're putting the individual at the heart of what we do," explains Sally Campton, who is the organisation's Volunteer Coordinator.



Pictured at the dementia and faith workshop held in Assembly Buildings are: Pamela Beattie, Rev. Norman Harrison, Sally Campton, Professor June Andrews, Lindsay Conway (Secretary of the Council for Social Witness) and Professor Martin Bradley.

It's a big challenge to us as people of faith. How do we still hold people in the same regard as God has them?

She says, "In supported sheltered houses we are very keen that residents, as far as possible, are still part of the communities in which they are living and yet they can become invisible...It's a big challenge to us as people of faith. How do we still hold people in the same regard as God has them?"

While pastoral visits by members of the congregation are important, it does not necessarily need to be done by the same person. Sally says, "Dementia is a feelings based illness. When we recognise that and how to address feelings that's how we make a difference."

As Mr. Harrison puts it, "There's a whole body of people who are vulnerable and yet are also ready to be reached, and we can't not take account of them – that's the pastoral challenge."

"A person is there in that body. They are not departed because their mind has gone and we must and still can reach them."



A personal perspective



Pamela Beattie's mother has been a resident of PCI's Sunnyside House in Bangor, Co. Down for the past five years. Two years ago, aged 91, she was given a diagnosis of vascular dementia and prescribed medication to slow the progression of the illness.

"It's almost two years since the diagnosis and, as you would expect, her level of cognitive functioning has been greatly affected, and we do see a change in her." She no longer has a short-term memory, her logical thinking is impaired and lately she has found greater difficulty navigating around the home.

"On a one-to-one basis she still loves to have a chat. You get good eye contact and she's listening to what you are taking about. She won't remember, but she enjoys the interaction," says Mrs. Beattie.

Their church has been supportive with someone allocated to visit. "She knows someone from church has come to visit."

Mrs. Beattie pays tribute to the staff in the home, saying, "they are just so wonderful and understanding, so patient. She is content in Sunnyside."