Abstract

Purpose – The purpose of this paper, “Dementia – good living in our churches” co-authored with Dr Bute who is a retired GP living with dementia, is to encourage the Church of England to do more for people with dementia living within their parishes.

Design/methodology/approach – This document was put together using a case study and a literature review.

Findings – As the age range of the country increases there are an increased number of people attending churches who have diagnosed (or undiagnosed) dementia. This document has found that there are a number of areas that the Church of England needs to work on to help people become enveloped within the churches that many of them knew and have grown up with.

Originality/value – New case study and up to date research.

Keywords Wellbeing, Dementia, Social change, Older people, Changing attitudes, Social inclusion

Paper type Viewpoint

What do you know?

An article in the Daily Mail in (March 2014) showed that the figure for “usual Sunday attendance”, in Church of England churches had 795,800 worshippers on Sundays in 2012. Currently, in the UK there are approximately 850,000 people who have received a diagnosis of dementia, mainly affecting people over the age of 65 but there are 42,325 people under 65 have dementia (20,806 women and 21,519 men) which is set to rise to two million by 2051. Not including the many more people living in our communities who do not have a formal diagnosis of dementia but may well be living with it, though fear, loneliness, and cultural differences.

Dementia is not a natural part of ageing, you do not get dementia like you get the flu, it is a terminal illness caused by diseases of the brain which get progressively worse as symptoms develop. There are around 50+ diseases that can result in dementia including Alzheimer’s disease, vascular dementia, and frontotemporal lobe dementia (including Pick’s disease), dementia with lewy bodies. Common symptoms of dementia include memory loss, confusion, word-finding difficulties, problem solving, and for some sight perception issues and hallucinations. In the same way that humans are unique – so is dementia. Different people are affected by dementia in different ways, depending on the type of dementia, an individual’s personality, lifestyle, state of health, etc. Four people can have a diagnosis of Alzheimer’s disease and all experience it very differently. Research is ongoing and developing but presently there is no cure for dementia. Some treatments are available to delay the progression of some forms of dementia but as with many medications, they are not suitable for all types of dementia, they are not suitable for everyone who has dementia and, not always available for people living with dementia.

At current diagnosis rates, 225,000 people develop dementia every year, that’s roughly one person every three minutes. One in three people over 65 will die with dementia, (this also means that two in three of the population will not get with dementia) and this poses a big challenge for
the established church. With attendance rates falling and average ages of attendance at services rising it is highly likely that attendees at services will be people living with dementia, and/or their carers.

In 1995, General Synod’s Board for Social Responsibility published a report called “Something to celebrate”. It was a major report providing a glimpse of family life at the time of writing and highlighting the role of the Christian faith in helping to guide families through the challenges of daily life. There are 232 pages in the document and the only reference to an older population is in passing in the final chapter where it points out that many older relatives help young working families with childcare, money, etc. It is a sad reflection for the twenty first century that this booklet is having to be written with a specific emphasis on a particular group of people who, apparently, can be eliminated from our worship for no real reason other than ignorance, fear, anxiety, and perhaps (as has been suggested while this booklet was being compiled) a belief that by ignoring an ageing church membership we can ignore the concept of an ageing church.

What do any of us know?

Dr Jennifer Bute has the unique gift of being able to experience dementia from a medical practitioner’s aspect as well as someone who is living with it and experienced losing someone close who has also had it. However, has already experienced the churches lack of knowledge and interest in the concept of dementia. Her story leads us into a world that many of us may not see or be able to express.

“It is an unexpected gift and privilege to understand dementia from the perspective of a medical doctor, who had a father with dementia and now, has it herself. It is also an amazing opportunity to encourage enrich and enlarge other people’s lives. The spiritual never dies.

I had a wonderful godly father who brought me up to think outside the box. My mother died when I was a small child, but I learnt to live daily with God. My father had vascular dementia but he still knew who God was and could still pray fervently even when he no longer recognised me.

I qualified from Medical School in 1968. I worked in a mission hospital in Zululand where sometimes I was the only Doctor. God used this busy time to show me so much and I learnt the tremendous power of prayer. I came back and married my husband, Stanley and when our three children were all at school, I became a GP. I loved my work and the plan for retirement was that Stanley and I would return to Zululand and the mission work we loved so much.

I had a mini stroke in my late 50’s but, perhaps more worrying for me was that I began to get lost when visiting patients and could no longer find my way to our branch surgery, no one believed me so I just bought a satnav. Then, when chairing a work conference, I kept asking who everyone was, even though they were colleagues who I had known for 20 years. A specialist consultant told me my intelligence levels had enabled me to cover up my deteriorating skills by find unusual ways of solving problems. She could not say whether I was still safe working and I resigned because of my own high standards and love for my patients. Everyone was surprised at my retirement, as no-one had any idea of the extent of my cover up. It took five years to get a diagnosis of Early Onset Dementia, but I knew then, that my dream of returning to Zululand would now not happen.

Medication made a tremendous difference to me. Enabling me to regain coherent speech and initially abolishing my awful hallucinations (which included sight, smells and sounds). Things now are not quite so good. I used to be able to speed-read but now find reading, meaningless without remembering the context, and too exhausting, so I find It exciting listening to the Bible from a dementia perspective. When my hallucinations make me question the borders of reality, I am encouraged that the unchanging God, can use our weaknesses to further his purposes as he did with Samson and Moses”.

What has gone wrong?

The legacy left to us by the culture of the 1980-1990s is one of a very isolated, introverted community. Our neighbourhoods are not what they were of the post-war years, 1950s onwards. In
many cases people do not know their neighbours. The only time we share personal information or issues that may cause an upsurge in emotions, generally, these are at funeral visits. But for the clergy and laity in our churches this is where the challenge arises. In the past the vicar/priest in charge of a parish, knew everyone, was seen locally and for many was the first contact if they had any problems.

In response to falling attendance figures, individual parish churches have now become benefices, parish priests, who in the past had been solely in charge of one church, perhaps from ordination to retirement are now in charge of up to six churches and in many instances do not live in the Parishes they are responsible for. But with this in mind, who are we missing either from a pastoral side or from a unique side where people with dementia have something to offer in our parishes and yet, are being overlooked?

But as clergy and laity this is where the challenge comes, Dr Bute’s experience is not a singular one, we know there are people who are losing out from a religious perspective where they are omitted from church life from apparently no other reason than their dementia.

Has anyone in the church checked why Mr Jones no longer stays for coffee after the service – could it be that Mr Jones no longer recognises the people he has known for years or could it be that his wife, who has Alzheimer’s disease is at home and if she is left for too long she may begin to wander? Mrs Ahmed has told you the same story this week after BCP (Book of Common Prayer) service as she told you last week […] are these the safe words she knows to say or is there the start of something that might need investigating (she may have picked up an infection which needs treating with antibiotics). James is a single full time carer for his Dad who has Parkinson’s disease with dementia. He always comes to church late, generally after the first hymn, has he forgotten the time, or have the carers not turned up to look after his mum while he is out – has anyone actually spoken to him?

It is important for our churches to recognise that every ageing person within its fellowship is an active member of the Body of Christ each with unique gifts to contribute. They are there to be ministered to and cared for. They are not past members. They are present members – still on active service.

Older church members, in some cases, have little or no contact with their ministers, friends, and members of their congregations or in some cases even their families. Contrary to popular belief, the NHS Information Centre figures for 2009-2010 in England show that only 77 per cent of the 225,600 council-funded people in residential or nursing homes were aged over 65 and there are increasing moves towards improved social care so that more people can remain in their own homes.

How do we make it better?

Many people with dementia are denied the opportunity to worship. Many more are denied the right to receive the sacrament of Holy Communion. Worship is a resource that adds so much to the quality of life that people with dementia (and many other illnesses) feeding their wellbeing as well as their quality of life. A person may not be able to tell you what they have just heard and received, but they know it made them happy. Our logic and reasoning is lost first when our brains are attacked by dementia but our emotions remain a lot longer. Feeling happy is much more poignant than the reason why we are happy.

The challenge to clergy then is how to incorporate people living with dementia and their carers into a church service. Many churches now hold a variety of services within their parishes to encourage people to come as regular attendees. Does your church hold a BCP communion on a Sunday? What time is it held […] or has it stopped because no one comes? Not many people (young or old with dementia or healthy) can make services at 9 a.m. on a Sunday morning. If you have care agencies coming in to help with activities of daily living (washing, dressing, eating, etc.), there is no guaranteed time of arrival. There is no rule that says church services have to be held on a Sunday morning. Is it worth “experimenting” with a service and holding it at 3 p.m. on a Saturday afternoon, which means that people are “up and about” but can still get home before it is time for tea and evening carers? For some carers of people with dementia this can be the planned activity for the day.
Under the 2010 Equality Act, we have to make reasonable adjustments to our buildings to accommodate people with disabilities. We have ramps, hearing loops, large print hymn books now. But do we have large print service books with “stage directions” telling us when to sit down and stand up? What language do we say the Lords Prayer in? The way our memory works is that you forget “front to back”, so you forget the recent memories first and the older memories last. Even someone with very late stage dementia will be able to say the Lords Prayer – but they know the original language where we “sin and trespass”. It has been widely recognised that music affects a part of the brain that is not used very often and, for some people with dementia, can influence behaviour. For someone who has lost their ability to speak, a song may encourage them to tap their feet. With this in mind, what hymns do you sing and, perhaps more importantly, what tunes do you use? We all learnt “All things bright and beautiful” at school and Sunday school to the tune “Royal Oak”. Not many people know the John Rutter version to sing, but maybe know it to listen to and tap their foot to.

People with dementia will lose much of their memory, some of their communication skills and it is easy for relatives, friends and possibly even clergy taking sick communion to question the purpose of their visit if the relative, parishioner, friend will have forgotten their visit minutes after they have left or simply do not know who they are in the first place.

Not everyone with dementia will forget their loved ones and friends, they may not be able to tell you instantly your name, they may not be able to tell you why they know you but there is something there that they know they do and it will probably return to them during the visit. “What is the point” is a natural question to ask and if the person with dementia does not know me, then how can they possibly remember God and how will they know how to worship them.

Dr Bute would tell you, and rightly, “People with dementia have as much value and worth as anyone else, God sees us complete in Christ. When I told a friend I was unraveling and it was a challenge she said her grandmother only unraveled things to make them more relevantly usefull! This was a great encouragement to me!”

It is hugely important to remember that God promised never to leave us and when Jesus ascended to the Father he gave us the gift of the Holy Spirit:

26 But the Advocate, the Holy Spirit, whom the Father will send in my name, will teach you everything, and remind you of all that I have said to you. 27 Peace I leave with you; my peace I give to you. I do not give to you as the world gives. Do not let your hearts be troubled, and do not let them be afraid (John 14:26-27).

The Holy Spirit is not selective about who it chooses and it works in ways that we cannot possibly understand. If a person has accepted God into their lives, no illness will separate them from the love of God, even something as detrimental to life as dementia. “13 In him you also, when you had heard the word of truth, the gospel of your salvation, and had believed in him, were marked with the seal of the promised Holy Spirit; 14 this is the pledge of our inheritance toward redemption as God’s own people, to the praise of his glory” (Ephesians 1:13-14). And we as friends, relatives, pastoral visitors, and clergy need to remember this during our relationship with dementia.

Everyone has a value, both to God and to society. Tom Kitwood who is a psychologist and a pastor identified that there were five psychological needs that everyone needed to be a “person”. We needed to have:

1. comfort;
2. attachment;
3. inclusion;
4. occupation; and
5. identity.

Kitwood turned dementia care on its head by pointing out that we should treat people with dementia the same way as we would want to be treated ourselves. Although this on the outside seems quite logical, up to then, it was not happening on a general scale.
Even in church, someone with dementia can be actively involved, even if they need some prompting. There is nothing to stop someone who has dementia from collecting the offertory and taking it to the altar during the communion hymn. There is no reason why they cannot give out hymn books before the service and welcome people into the building.

Dr Bute uses her gift of knowledge and experience to educate people in the knowledge of dementia. “I was asked to produce some 2 minute video modules for a wider audience and my son was able to do this with me. The DVD is sold around the world and I am so grateful I can help families and professionals become positive and passionate about dementia”.

“I started a twice weekly ‘Japanese Memory Group’ more than two years ago which has made a tremendous difference to people; similar groups are being run all around the country – nothing to do with learning a new language but because of the Japanese ethos of increased respect for older people and a Japanese Professor’s evidence on retraining the dementia brain. One of my joys is that God is the God of the whole earth. We need all cultures to reflect the greatness of his character and discover new things”.

“I have had opportunities to do staff training locally, with groups further afield and at conferences around the UK. I am amazed how things have progressed as I also respond to questions and concerns through my website from folk around the world, which is such a privilege whether others with dementia their families or carers as they share their concerns. Each day is an opportunity to share what I learn within the certainty of knowing God’s love and acceptance as I am. For many, becoming more aware of the spiritual as other things become challenging or uncertain”.

There will always be frustrations with dementia, as Dr Bute would tell you, “I can still get lost when I go out, hurry to complete things before I forget”. Some people will tell you that aggressive behaviour is part of dementia. It is not, aggression is symptomatic of something that is happening, that the person does not want to happen. If you are washing my hair and I do not want you to wash my hair, I am going to react. If my dentures do not fit properly, then I am not going to eat and then I will react because I am hungry.

It is not necessarily up to clergy of parishes to take on dementia in their parishes. But could a “visiting team” be created out of people in the congregation and as part of their remit they keep their ears open for stories of people in the village who are perhaps alone and need a quick coffee occasionally? Volunteers would need to have a Disclosure and Barring Service (DBS) – old CRB’s check but for volunteers these are free.

Dementia is a journey that takes in a number of different aspects. As long as everyone is supported there is no reason for it not to be a “nice” trip. Dr Bute points out that “Isaiah 26 says there will be a highway where we can never get lost, where we can linger, clearly signposted with God’s decisions. When I revert to behaviour previously left behind as an adult, I hear Jesus saying we need to become like little children to enter his Kingdom. Meanwhile I remember all the way God has led me and I am content he knows the way I shall take”.

Now what?

- Are you and the people on your PCC aware of dementia? Could you invite someone from your local Alzheimer’s Society to talk at one of your meetings so you have a basic awareness? Or even better, could someone with dementia come and talk to you?
- Are you seen in and around the benefice, do people in your parishes know who to contact if they have any kind of problems?
- Everyone has a role within their church, (even as small as vacuuming and dusting) is there a group of people in your churches who would like to work together as a “visiting team” – could they pick people up and bring them to church on a morning, could they perhaps “pop in” to see people during the week or make those odd telephone calls – and where appropriate fill you in? They would need to be DBS cleared, but most people would not mind this.
When was the last time your service plans and service sheets updated? Could someone with memory problems help to “redesign them” with you?

Could you change service times for evening/afternoon services when the clocks change so people are home in the daylight? Do services need to be on a Sunday?

You do not suffer with dementia – you live with it and the challenge of dementia does not have to be an unpleasant one.

Further reading


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