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Dementia
a 21st century challenge

By David G Smithard

Dementia is on the increase, and is often more feared than a cancer diagnosis, not least because it is as yet incurable. But what is it, how can we respond to it, and how does the Bible help us to think about its challenges?

Introduction

There are many different types of dementia, each with its own problems and prognosis. It is predicted that one million people in the UK will have dementia by 2025 and that this will increase to two million by 2050. Globally, 5.2 per cent of people over the age of 60 years are living with dementia. Dementia can affect anyone, usually adults. The first case of Alzheimer's disease was described in a lady of 50 years of age, but most people affected by dementia are older (over 85 years of age). As the population ages, the number of people who have dementia will increase. People frequently live with dementia for many years. Writing about dementia is difficult due to the different types (some people will have a mix of dementias), various manifestations and different trajectories around prognosis. [1,2,3]

People are at increased risk of developing dementia if, for example, they have a history of brain damage secondary to head injury (heading a football, boxing), previous stroke, smoking, excessive alcohol intake, diabetes, high blood pressure and insufficient exercise. Dementia may also occur alongside other conditions; for example, Parkinson's disease, Down syndrome or Multiple Sclerosis.

Dementia may start as a little forgetfulness which can be covered up. This will progress to difficulty in coping with complex tasks and busy environments, resulting in agitation and anxiety. The progression of dementia is not a straight line. The sequence of cognitive loss is intimately connected with people's social and historical circumstances. [4] Even if the dementia is advanced, there may be lucid moments of understanding and recognition. Yuen writes that '*these moments are extremely gratifying, like receiving a postcard from a friend who is constantly travelling*'. [5]

The time eventually arrives when everyday life is interrupted: getting lost when going out and then around the home; problems washing and dressing and preparing food. Places and objects may not be recognised, resulting in misplacing objects, using buckets as toilets. Finally, incontinence and difficulty swallowing occur, which is when families may find it all too much, and the person with dementia is moved to a care home.

The best approach to the management of dementia is prevention: leading a healthy lifestyle, being sociable and active. Once dementia onset has been identified, care and management include holistically looking after the individual and supporting the family through the various stages and eventually planning for death. Presently there are no medications that can cure dementia, but some are thought to slow its progression for some people for a while.

There is no question that dementia presents challenges both to the person affected and to those caring for them. In the initial stages, life continues as usual with a few minor adjustments and those outside the family may not be aware of any problems. Over time there will be changes to memory, personality, behaviour, speech, swallowing and mobility. How will we respond to these changes?

For many, the diagnosis of dementia brings fear and anxiety for the present and the future. Not many people would suggest that dementia could be a gift from God, but this is how Dr Jennifer Bute describes her personal experiences of living well with dementia - fully embracing her dementia and actively seeking to derive something positive from her experiences. She tells and lives her story of faith and how, for her, God is in her dementia. [6]

Identity

My identity is defined by who I am. By my job, my family, my hobbies and my role at church when I am there. If someone with dementia cannot recognise their family, or recall their life story, let alone know who they are and where they are; are they the person they were? [7] Has their identity been lost?

The loss of identity associated with dementia can be very distressing both for the person with dementia and their family. When the ability to continue in these roles diminishes, we can feel that the core of who we are is being lost.

In life, some roles diminish, adapt to circumstances or change. Does a parent or spouse ever stop being one? There is a danger that if we constructively remove people from their societal roles, they will slowly become invisible. Yet as Christians, we believe that our identity is a gift of God, freely given to us by him, not something we need to find externally. He has promised that he will remain with us forever and tells us that he knows us far better than we know ourselves.

Being human

In his song, *Human*, Rag'n'Bone man sings... 'I am Human'. [8] But what do we mean by being human? When does a person become fully human, and protected under the law, as far as society is concerned?

A biblical explanation of being human can be found in Genesis 1:26-27. '*Then God said, "Let us make mankind in our image, in our likeness, so that they may rule over the fish in the sea and the birds in the sky, over the livestock and all the wild animals, and over all the creatures that move along the ground."So, God created mankind in his own image, in the image of God he created them: male and female he created them*'. [9]

At the core of the biblical concept of humanity is to be a bearer of the image of God and to fulfil his work in creation.

In the early stages of dementia, the question of 'being human' is not one that is raised, let alone debated. The more immediate question could be, '*When are we human*'? When do we start being human and do we ever stop? Is being human only a phase of our

life? Are we human only during those years when we are productive? Are we no longer considered to reflect God's image outside of this?

Personhood

Defining personhood is a controversial topic in philosophy and law. It is closely tied with legal and political concepts of citizenship, equality, and liberty. [10] Personalities are complex, a balance between behaviour governed by rational thought and that governed by emotions. If personhood is a balance between the rational and the emotional, might one dominate the other at times? Does personhood diminish if the capacity for autonomy or independence is lost? Personhood can be maintained where interaction is maintained. But if our response to people with dementia is to withdraw, either because we don't know what to say or do for the best, or because we (wrongly) assume that 'there's no-one at home', then we fail to acknowledge and celebrate their personhood and miss the opportunity to affirm their value.

Do people stop being human persons when they develop dementia?

We can easily attribute too much value to our intelligence and functional capacities. God, however, does not measure our value on such scales. He sees our value rooted in nothing less than our being made in his image and redeemed by Christ. [11] Seen through the eyes of God, a person with dementia is no less human, has not lost their selfhood.

Whilst from a human and clinical perspective in advanced dementia key elements of perceived personhood may appear severely impaired, the ultimate issue is '*not the cognitive and relational capacities of human beings but the infinitely greater cognitive and relational capacities of God Himself*'. [12] That which makes us human and constitutes the image of God in us is the fact that God holds us in mind. '*O Lord, you have searched me and known me*'. (Psalm 139:1)

Spiritual separation

Does dementia separate someone from God? Learnt tasks and words such as songs/hymns and liturgy may persist far longer than the ability to converse. The ability to understand the significance of Liturgy and Holy Communion may remain even when others may assume otherwise. Conversely, the loss of ability to comprehend God's presence or be able to speak to him can be frightening and engender in some people with dementia the fear that God has forgotten or abandoned them.

Will God abandon, or forget someone with dementia, even if their capacity or competence is reduced? Can God forget? *Neither dementia nor any other illness can separate us from God*. As Paul writes, '*For I am convinced that neither death nor life, neither angels nor demons, neither the present nor the future, nor any powers, neither height nor depth, [nor dementia], nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord*.' (Romans 8:38-39)

Theologian Karl Barth says that God seeks us more than we seek God. [13] Our personhood depends less on our own particular state than on God's love and grace. He cannot and will not forget us. [14] As John Swinton says, even if our memory is compromised, we are living in the memories of God. Confident that God is with us no matter what, it is contrary to our teaching to reject the body in any way. [15]

Physical separation

Many older people have no family or friends still living. With increasing age, their social circle diminishes. As cognitive and physical function declines, the ability to leave home to go shopping or attend a place of worship is reduced. Any opportunity to meet others is restricted, and isolation may set in. It may not take long before they are forgotten by the congregation that they used to attend, reducing opportunities for fellowship.

The time may come when their physical or cognitive needs are too great to be supported any longer in the community. Social services often cannot provide night cover or continuous day cover, leaving a cognitively or physically frail person at risk. Moving into a care home may mean moving out of the area they have lived in for many years, fracturing any remaining support or reference points that they may have had.

Residential care means moving into a setting full of strangers, with a loss of familiar surroundings, restricted freedom of movement, shared facilities and maybe even a shared bedroom. This can ultimately mean a loss of dignity and privacy.

Liberty and safety

There will come a time as a person's dementia progresses when a balance must be struck between liberty and safety. A time when decision-making needs to be challenged because awareness of danger is deficient. When is behaviour unacceptable or dangerous, rather than just eccentric?

At this stage, we have to ask: are decisions always made in the best interests of the person with dementia, or to placate the sensibilities and anxieties of family and clinicians? When going for a walk can be fraught with danger as familiar landmarks are no longer recognised and the ability to find the way home is lost, inevitably a conflict will arise between freedom of movement and keeping a person safe.

Technology can provide some help. Sensors linked to a computer can trigger an alarm when the door is opened unexpectedly; GPS in a mobile telephone, smartwatch or bracelet can help track someone's position. An alarm can be programmed to alert someone if a predefined boundary is breached. Within the home, families often use webcams and other devices to monitor movement around a flat or house.

However, technology can never replace human care, and we must carefully consider the implications of monitoring a person's actions and whereabouts without their knowledge and consent.

Capacity is important in this context – the ability to make a decision and understand its consequences. Does the person with dementia have the capacity, and therefore the freedom to decide, even if to everyone else that decision would be bad? [16, 17] If there is concern amongst carers or healthcare professionals that a person with dementia lacks the capacity to make an informed decision about their care they can apply for 'Deprivation of Liberty' (DOLs) authorisation, via the local authority or the Court of Protection to put appropriate, proportionate restrictions in place. However, where health and social care are not involved, this statute does not apply.

Communication

Over time, communication can become increasingly difficult, and the person with dementia may seem not to be behaving rationally or logically to us. However, it may be entirely logical to them. Understanding may be hidden in past life experiences.

Expression of pain or physical needs may be difficult, which may result in agitation, frustration and aggression. We must not forget that communication is two-way. We may not understand their needs, but they may not

understand our requests either. Non-verbal communication may be more effective and will need to be learnt for each individual to identify some of their needs.

Collusion or orientation?

As people progress through the stages of dementia, they may well become disorientated in time and place. What is the best course of action for carers in these situations? Should they collude, correct or reorientate? As with many things, the answer is yes and no, or it depends. In the early to mid-stages, reorientation and correction may be the best option. Bringing someone into the here and now will provide the opportunity to interact in a meaningful way. Later in the disease progression, collusion is probably the best strategy. Why? Simply because of the time frame that person may be living in. Their brain may be firmly situated, for instance, in the time of their youth, when they had no children; therefore, they will deny being married or having children.

- **Example A**: On one occasion, a lady could not understand why her mother denied having children or being married, until one day, when her mother signed the visitors' book in a church using her maiden name - then everything clicked. Reorientation attempts for this lady had caused great distress.
- **Example B**: A gentleman living in a care home, would sit in the corridor shouting at people as they went past. Eventually, the staff learned that he had spent time clearing minefields after the war. To him, the hallway was a minefield, and his shouts were to ensure their safety. Colluding and following his advice took a few extra seconds but also pleased him and reduced tensions.

Are either of these lies, or are they good, empathetic care? I would suggest this is an example of the right care at the right time.

Behaviour

Different parts of the brain control various aspects of our physical, sensory and emotional being. A person with dementia may suffer a personality change, from being placid to aggressive; polite to rude; calm and collected to erratic. It is important to interpret these in the context of their dementia. Is the aggression due to frustration and the way people respond to them; or are they aggressive because the frontal lobes are disproportionately affected? A display of aggression or rudeness may be an understandable response to carers who fail to show respect to a person with dementia, by adopting a paternalistic attitude, treating them as children! A sudden movement towards someone with advanced dementia, invading their personal space without warning, may result in them being startled and to a physical push back. Should we be surprised?

Physical functions

When we talk about dementia, most people tend to think about the cognitive and communication losses involved and forget the physical implications. All bodily processes are, however, controlled by the brain. Some, such as walking and continence, had to be learnt, and as parts of the brain deteriorate, those skills are lost. They can be managed with help, though – catheters for incontinence; support from carers, and later wheelchairs for mobility issues.

Eating & drinking

Swallowing, however, is harder to manage. Initially, swallowing can be maintained by altering the consistency of food and liquids, but ultimately a person with dementia may lose the ability to swallow. An immediate reaction is to consider the use of tube feeding. Certainly, tube feeding provides nutrition, but there is no evidence that its use in the end stages of dementia improves someone's condition, improves their quality of life or prolongs their life. This does not mean that food should not be offered for comfort. Decisions regarding eating and drinking are difficult and distressing for all concerned, and the arguments surrounding the withholding or withdrawal of feeding are explored further in *CMF File* 69. [18]

Note that having a compromised swallow does not mean that the elements of communion cannot be received. A wafer dipped in wine and placed on the tongue to dissolve, is no less than many people do each week.

End of life

As life draws to an end, appropriate care needs to be considered. Eating and drinking may become difficult, mobility will reduce and incontinence, if not already a problem, may well become so. This can be a stressful time for all concerned. Best care may not mean transfer to a hospital. People will naturally eat and drink less as their life comes to a close. Repeated attendance at a hospital just causes distress with no added benefit to life and should be avoided wherever possible. If possible, care should be provided within a home environment, with support from healthcare, social care and the church.

What does the Bible say?

The Bible has little to say specifically about dementia, but it does say a lot about older people, illness and infirmity. Solomon writing in Ecclesiastes chapter 12 sums up frailty; when King David was '*old, [and] advanced in years*', he could not keep warm [19] Isaac said, '*I am now an old man and don't know the day of my death.*' (Genesis 27:2) Paul writes '*I have fought the good fight, I have finished the race, I have kept the faith.*' (2 Timothy 4:7)

When something negative happens, and people are physically damaged, the questions 'why me?' and 'why would God allow it?' naturally arise. Job asked similar questions when he was afflicted with skin sores and had also lost his family and wealth. [20] Risner states that '*everything in my life can direct me to Christ*'. [21] We may never know the answer to the question, but God invites us to trust in him. Christ has experienced our physical and emotional pain and will walk with us through all our struggles.

Dementia & Christian hope

God became human to enable humanity to be restored to a full relationship with him. When this occurs, the new order will come in, and the old order will be washed away. Then there will be no suffering and pain. At the resurrection, everyone will have a close and restored relationship with God. We do not know what our bodies and brains will be like, but we are promised that there will be an end to death, mourning, crying, and pain after the resurrection. [22]

God is present in all our suffering. He is present in and through our forgetfulness. Dementia has the potential to be a grace-filled moment in our existence to show us something more of who God is and what it means to know him. How we treat people as their minds and bodies move towards death can either confer value and dignity upon them or rob them of it. God calls us to be his ambassadors in the world and beacons of light in the darkness. We are reminded in the Scriptures that whenever we help a person with dementia in need, we have an opportunity to reflect God's glory and love. Society values people according to their intelligence, looks and abilities; God, however,

sees our value rooted in the fact that we are made in his image, redeemed by Christ and adopted into his family. In his eyes, a person with dementia is of no less worth than the professor, the film star or the sporting legend.

Caring for people with dementia

Acceptance of the diagnosis by the person and their family is key to accessing and accepting good care. Deal with concerns as they arise. Encourage independence and the status quo where possible. Ensure identity is maintained; look for role adaptation rather than removal where possible.

Fear and concern following the diagnosis can lead to overprotection – an attempt to remove all risk and danger - resulting in the person with dementia becoming patronised, marginalised, isolated, having needless dependency imposed on them (eg taking a driving licence away, taking over tasks before being requested) and deprived of autonomy. This approach is likely to accelerate the rate of decline from dementia with increased memory loss, functional decline and dependency, resulting in early institutionalisation.

Care provision for people with dementia needs to be integrated: families, social care and healthcare, and voluntary agencies (including the church) must work in collaboration to provide a holistic, effective and prompt service, tailored to need, including discussions around where someone with dementia should best live. Books by Bute, Gwande, and Neuberger provide interesting insights into opportunities around care (see suggested further reading).

Dementia can be accelerated, slowed and partially put in reverse (sometimes called *rementing*) by our response to the person with dementia. Their personality may have changed, but our reaction to the person may also change. The command to love our neighbours as we love ourselves does not expire when they no longer recognise us or welcome our care. In 1 Timothy Paul reminds us not to '*rebuke an older man* (or woman) *harshly but to exhort him as if he were your father* (or mother)' (1 Timothy 5:1-2); in the latter stages of dementia, the temptation to be harsh is all too real.

The whole Christian community must recognise and respond to the challenge of continuous, ongoing spiritual engagement, support and care for those with dementia. The best approach is to retain familiarity, surround people with memories; recognised favourite objects; photograph albums, and family members. Congregations should be encouraged to increase their dementia awareness, for example, by becoming members of Dementia Friends (Alzheimer's Society). You may not be recognised, and your visit may not be remembered, but during the visit, you are bringing friendship and company, being a conduit for God's love and reflecting his glory.

Christian healthcare professionals

Christian healthcare professionals are likely to be called upon to support a person with dementia as a part of their professional role. They will also be part of a local fellowship. They can assist that community by raising awareness of dementia care, by helping it develop a welcoming and supportive environment for those with dementia, and by promoting collaboration with wider support services that can provide invaluable advice.

Given the above challenges, is there not a case to be made for more Christian healthcare professionals to pursue direct vocational involvement in the care of people with dementia? There are many opportunities not only to provide care but to influence research and policy at both local and national levels.

Research is needed into all areas of care and treatment, including community integration, the effectiveness of dementia villages, use of artificial intelligence and robotics. Biomedical research needs to concentrate on aetiology, avenues of prevention, intervention, and possibly cure.

Concluding remarks

Dementia is a complex disease, that has a major impact on all those affected by it, as patients, families and carers. People with dementia deserve to be treated with respect and love, remembering that they are made in God's image and remain part of God's family no matter how cognitively impaired they may become. Whenever we meet someone who is vulnerable, such as someone with dementia, we are meeting someone precious to God; let's be sure not to turn them away!

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