

Dementia, God and Human Identity

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Summary

This paper explores the profound issues of personal identity raised by the phenomenon of dementia. These include the part played by cognition, especially memory function, and social roles and relationships. The paper suggests that an embodied approach to cognition is helpful in elucidating the psychology of dementia and also connects with a Christian theological approach. This approach, organized around an understanding of God's action in creation and redemption, has implications for the ways in which Christian communities learn from and support people affected by dementia.

As mind and memory long since said goodbye,
 'I think therefore I am' does not apply.
 But there are days when I take heart because
 I think I thought therefore perhaps I was. (Anon)

The existential threat posed by dementia

Dementia (literally 'loss of mind') is a catch-all term which refers to a chronic, progressive, irreversible decline in mental abilities due to the deterioration and death of brain cells. This begins with problems in specific areas of cognition and ends with widespread losses in higher cognitive function. Dementia arises in the context of neurological conditions, the most common of which is Alzheimer's disease, or deficiencies in the blood supply to the brain that are secondary to heart and circulation problems – vascular dementia. There are approaching 900,000 people living with dementia in the UK (Alzheimer's Society report, 2014) and 55,000,000 world-wide according to the World Health Organization.¹ The prevalence also appears to be increasing

Dementia has an increasingly high profile in our culture. Even before the Covid pandemic of 2020-2021 it was a regular topic in the media, not least because well-known individuals were affected by it. Then the lockdown threw into relief the plight of the many people living with advanced dementia in residential care homes, and they moved out of the shadows to become the focus of national concern; almost every family seemed to have a story to tell. Perhaps reflecting this heightened interest, Sir Anthony Hopkins received the 2021 Oscar for best actor for his performance in 'The Father' as a man struggling with the personal and existential effects of dementia. As the impact of the Covid-19 pandemic receded, dementia, along with cardiovascular disease, is again the most common cause of death in the UK.

This growing focus on dementia reflects improved diagnostic procedures in recent years; 'senility' is no longer regarded as an inevitable feature of old age. It also reflects the fact that the baby boomer generation has had to confront dementia in its parents and is beginning to confront it directly in itself. Compared to previous generations, this group is well educated, wealthy, and has high expectations regarding self-determination and control. The fact that dementia respects none of these things is profoundly disorienting; faced with its devastating and unmitigated effects on parents and other close relatives the prospect that 'this could happen to me' cannot be escaped.

Dementia also poses an intuitive puzzle. We experience other people as integrated mind-bodies, yet the changes wrought by dementia affect the psychological more than the somatic aspects of the person (at least in the early phases). This means that we can be faced with an individual who looks and

¹ <https://www.who.int/news-room/fact-sheets/detail/dementia>

sounds much the same but who is profoundly changed. The change is not confined to difficulty in carrying out certain functions (such as remembering to turn off the burner on the cooker or where their shoes are kept) but is so pervasive that the individual in question seems to be a different person.

Presented with this puzzle we revert to natural intuitive modes of thinking and embrace body-spirit dualism (Barrett, 2004; McCauley, 2013), talking as if the essential person we once knew has fled and left a shell of their former self. In some sense they are felt to have died or to be in the process of dying. This is why the funerals of people with dementia can feel anticlimactic; the bereavement happened some time previously. We encounter a mode of existence that hovers between life and death, reminiscent of descriptions of *Sheol* in the Hebrew bible - a twilight zone of shadows, referred to by the Psalmist as 'the land of forgetfulness' (Psalm 88:12). More brutally dementia has been constructed in secular public consciousness as the living-death existence of the zombie (Behuniak, 2011), an image that vividly communicates the existential dread and irrational fear of contagion it often evokes.

Dementia shows us that the veil separating life and death is thinner than we had thought or would like, in a way that other distressing conditions such as cancer do not. It reveals the precarious status of personal existence and identity not only for affected individuals but also for those around them. This is particularly the case for people who lose a parent to dementia. The loving and focused parental gaze plays a key part in creating the child's sense of existence and self, something the theologian Hans Urs von Balthasar refers to as 'archetypal identity':

The child Jesus reposed in his Mother's womb in "archetypal identity" and came forth from it to have the experience of every human child as a result of Mary's turning in love towards him – the experience of being two in one... (von Balthasar, 1991, p.30).

When the parental gaze becomes vacant and the child goes unrecognised by his or her primary caregiver, something of the self is lost.

Dementia thus poses profound questions about human existence, mortality, and identity both in a conceptually challenging sense to society as a whole and also in a personally compelling and distressing sense to those directly affected. Before exploring some possible Christian theological responses, more needs to be said about the nature of dementia itself.

The nature of human identity

Much has been written by theologians, philosophers, and, more recently, neuroscientists about the nature of human identity. The concept remains elusive, and the field remains complex and controversial. Yet it is also the stuff

of less formal human reflection. I recently came across a photograph of myself aged twenty-three. I was engaged but not yet married, had just begun my first job as a clinical psychologist, and my beloved children and grandchildren did not exist. 'Who is that little wide-eyed person?' I asked myself. I could see some points of connection; there was a book by Karl Popper to hand, I appeared to be a thinner and less worn out but recognisable version of the person I am now; but the overall experience was of a massive gulf between then and now, there and here, her and me. In contrast, the table lamp on the bookshelf behind me in the photograph now sits to all appearances unchanged in our sitting room.

We casually remark 'I'm not the same person I was then' to refer to the changes wrought by maturational and ageing processes and the impact of life experiences. These happen largely imperceptibly, but when faced with an old photograph of self or others we can be surprised or shocked

by their magnitude. Sometimes these changes involve positive gains (I know a lot more than I did at the age of twenty-three); often they involve losses (I am no longer a competent pure mathematician), and this is increasingly the case as we enter the final decades of life (Baltes, 1997). Yet the pace is sufficiently slow and the extent sufficiently limited to be psychologically

accommodated to, if not fully accepted.

One of the challenges of dementia is that the pace of change is faster and the losses more extensive and profound than in 'normal' ageing (see e.g. Toepper, 2017). So the issue of personal continuity of identity is not readily accommodated by the affected person or those around him or her.

In a previous publication (Collicutt, 2007) I have summarised the characteristics that in everyday life lead us to recognise personal identity in another individual (and ourselves) in the following terms:

- A distinctive physical appearance and bodily integrity, with clear demarcation lines between the limits of their body and the immediate environment.
- The possession of a degree of personal autonomy expressed in terms of liberty and agency.
- Distinctive temperament and aptitudes expressed in habitual behaviours, behavioural style, and skills.
- Distinctive personal goals and values.
- A unique personal history punctuated by self-defining memories.
- A social and geographical place expressed by a name, a tribe, and key roles and relationships.

These correspond relatively well to what the New Testament refers to as *sōma* (bodily structure), *sarx* (bodily material), *pneuma* (the animating spirit that enables personal agency) and *telos* (that for which we live and to which we are drawn)², all of which are aspects of the human

2 For a lengthier discussion see Colicutt, 2020.

psuchē (soul or life). Perhaps this explains the observations of several medical practitioners that damage to the brain is expressed not only as mental disorder but as a wound to the soul (e.g. Prigatano, 1991).

Certainly, many or all of these aspects of personal identity are lost by people living with dementia. If I can no longer care for myself others enter my personal space and cross the boundaries of my body to administer physical care. If I can no longer remember, reason, or plan, so that everyday decisions are beyond me, I have lost agency and live a largely reactive existence. If I am housed in a secure residential setting, and if others have control of my affairs, my liberty is restricted. If the light has gone out of my eyes, if I shuffle about instead of striding confidently, have become irritable or querulous instead of gentle and outgoing, don't knit or love to follow the tennis any more, my 'personality' has changed. If I am no longer in my home, or my home town, and if I can no longer function as the secretary of the bowls club, as grandparent, as the peacemaker in family disputes, I have relinquished my previous social and geographical place and taken on a new one – that of a demented person resident in an institution in a distant town. Above all, if I have forgotten my story I have in a deep sense lost myself.³

The story may not simply be lost; it can be re-written. Some people living with dementia seem to become a worse version of their previous self without the other mitigating aspects to balance this out: *more* critical, *more* self-centred, *more* obsessed with certain themes. This can in its turn distort the memories of loved-ones, who look back and focus exclusively on the person's faults, perhaps in an unconscious attempt to make the story cohere: 'he was always so selfish'; 'he always cared more about his cars than us'; 'she always preferred you to me.' Conversely the pre-dementia person may be idealised and contrasted with the present, infusing a tragic narrative with pathos. Finally, others may seize the story: 'No – it didn't happen that way, Mum.' Remembering is a deeply interpersonal process.

The predicament of people with dementia is thus only in part a direct effect of the cognitive losses they undergo. Their personal and human identity is deconstructed, their story unravelled, their position marginalised, as part of a complex social, even political process. For example, throughout the Covid-19 pandemic of 2020-2021, advocates for residents in UK care homes (only some of whom have dementia) have insisted that their incarceration with lack of visits is a human rights issue.⁴ In the rush to preserve their biological existence their personal wellbeing was overlooked.

The undoing of the self that occurs in dementia is a

whole-person process that is grounded in the brain but lived out in the body and the world of social relationships; these in their turn are located in a wider political context. The same might be said about human identity more generally. The issues raised by dementia thus extend beyond the affected individuals and may offer new perspectives on fundamental questions of human existence and identity. Two of these – embodied cognition and the social construction of identity – are briefly considered below.

Embodied cognition

The concept of embodied cognition has become fashionable in philosophy and neuroscience in recent years, but its roots stretch back to William James and it was fairly well developed in the work of the mid-twentieth century developmental psychologist, Jean Piaget (see, for example, Piaget, 1952). It is in part a reaction against late twentieth-century models of the human mind as an information processor analogous to a computer. Cognitive scientists of the time were interested in the software – the programmes, rather than their material infrastructure – the hardware. With the advent of functional neuroimaging towards the end of the century, the discipline of cognitive neuroscience emerged; it became clear that the behaviour of the software was constrained by aspects of the hardware (for example the shape of the skull determines adjacencies of areas

in the brain and hence the degree and speed of connectivity between them).

The software-hardware analogy invited a dualistic mind-brain approach to the human person, which, as noted above, is intuitively appealing to many, but is philosophically problematic (Bennett & Hacker, 2003). While much philosophical work continues on the various 'intermediate positions' on the spectrum between the poles of strict dualism and monism, it is clear that a strictly dualist position cannot do justice to the increasing evidence that the body's role is not simply to express mental entities or execute mental commands, but actively to influence the way they are configured (Collicutt, 2008, pp. 92-96). Hence the (re) emergence of the idea of embodied cognition.

Quite early in the movement the psychologist Margaret Wilson set out five features of embodied cognition on which there was a good deal of consensus (Wilson, 2002): cognition is situated in a real environment – it doesn't happen in a vacuum; cognition is time-pressured – it occurs in real time; cognition is off-loaded to the environment – for example in libraries or smartphones; cognition is for action – it is not primarily concerned with abstract concepts; cognition is body-based – there is a continuous flow between the body

3 This paragraph is a version of material that has appeared in Collicutt (2012) and Collicutt (2017).

4 <https://www.rightsforresidents.co.uk/A>

and the brain via sensory, motor, and autonomic pathways.

In the case of Alzheimer's disease there is a large body of evidence indicating that while certain modes of cognition progressively decline, other more embodied forms, subserved by distinct neural pathways, are retained and come to dominate. This is seen in the capacity to respond to music, scent, or touch; and the retention of well-learned motor skills such as knitting or playing a musical instrument, as in the case of the composer Paul Harvey.⁵ A different cognitive landscape is revealed, and it is highly embodied (Fuchs, 2020).

Scientists have rediscovered the fact that human beings are not disembodied minds. Acting as if we are does not promote wellbeing. This became very clear during the Covid-19 pandemic. Holding work meetings using Zoom software solved many problems, but on-line team interactions also necessitate long periods of physical inactivity which can lead to weight gain and postural problems, with knock-on effects on cognition. Use of Zoom for religious gatherings has been useful in many ways, but it also throws into relief the need to gather as an embodied group.

Seeing family members on Facetime or Skype is better than no contact at all, but it only makes the yearning for hugs, kisses and cuddles more acute. One begins to wonder if those disembodied faces on the screen, often in front of a synthetic background image, are people who have a real existence.

In the New Testament, Christ is referred to as 'The Word' in the prologue to John's Gospel. The Word did not become a disembodied mind, but 'flesh' and lived in a particular environment 'among us' (John 1:14), at a particular time (Galatians 4:4). The 'wisdom of God' sacrificially gave up his body (1 Corinthians 1:24; 11:24) and his spirit (Luke 23:46). Embodied human beings require an embodied saviour, not a theological information processor.

Socially constructed identity

The psychologist Margaret Wilson considered one further feature of embodied cognition on which there was less consensus: the environment is part of the cognitive system – information flow between the individual and her setting is so continuous that the concept of individual minds is brought into question. Wilson was sceptical about this idea - referred to as 'distributive' or 'extended' cognition - arguing that its usefulness to cognitive science was very limited. But it offers a helpful approach to understanding dementia:

In dementia many aspects of the psyche that had, for a long time, been individual and 'internal', are again made over to the interpersonal milieu. Memory may have faded, but something of the past is known; identity remains intact, because others hold it in place (Kitwood, 1997, p.69).

This is well illustrated by the case of Paul Harvey mentioned above. He was able to compose a wonderful piece of music, initially on the piano, because of the support and encouragement of his son; it became a reality because an orchestrated version was performed by players from the BBC Philharmonic, and the publicity enabled him to reconnect with previous students who joyfully reminisced with him and treated him as a respected teacher rather than a 'dementia patient'.

This brings us to another aspect of embodiment – the corporate. The community of the church is traditionally understood to be the *body* of Christ. The Apostle Paul brings the sacrifice of Christ's physical body together with an interpenetrative understanding of corporate identity:

The cup of blessing that we bless, is it not a sharing in the blood of Christ? The bread that we break, is it not a sharing in the body of Christ? Because there is one bread, we who are many are one body, for we all partake of the one bread (1 Corinthians 10:16-17).

Here Paul interprets Jesus' instructions to 'remember' him in the sharing of communion not simply as an act of cognitive recall but also as a physical remembering of fractured individuals into a gathered community through shared story and fellowship. As a priest once remarked, 'Whenever we celebrate the Eucharist, we remember who we are.'

Dementia is in many respects a socially constructed phenomenon. The narrative of dementia is often tragic, with affected individuals described as 'sufferers'. In an 'I think therefore I am' cognitivist culture there remains a good deal of stigma and shame associated with the word 'dementia', rather as there previously was with cancer. Being diagnosed with dementia is less a medical procedure and more a social rite of passage, accompanied by 'Do Not Resuscitate' paperwork and 'Lasting Power of Attorney' advice. This often has a negative impact on the affected person who may become anxious or depressed. Perhaps most important of all, the funding of long-term care for people with dementia in the UK has languished at the bottom of government spending priorities for years, compounding the biological burdens of the condition. It is often said that the tragedy of people with dementia is not that they forget but that they are forgotten.

Personal identity also has socially constructed aspects. We absorb our values from our surrounding culture and frame our goals in terms of the options available to us; we internalise the judgments of others ('She's a naughty girl', 'He doesn't like hugs', 'She's the musical one in the family', 'He'll never amount to anything', 'Who would look at her?', 'He's a golden boy' etc.) or react against them; we co-construct stories of our lives with those around us, attentive to their approval or dissent (McAdams, 2001).

⁵ <https://www.bbc.co.uk/news/uk-54684038>

Speaking into this, the 'good news' of Christian faith is that our true identity is constructed by God in cooperation with us (Romans 8:16); that God's redemptive act in Christ means a better story can be told for each of us (Romans 8:31-33); and that no extremity in this life can separate us from God's loving remembrance (Romans 8:34-39).

A theological response to identity in dementia

Christian theology offers several insights which can helpfully address questions of identity in dementia and inform approaches to the spiritual care of people affected by it (see Collicutt, 2017 for a full discussion). They can be summarised under God's action as Creator, Sustainer, and Redeemer.

God our cherishing Creator

The starting point for all human beings is that God created us. Psalm 139 speaks powerfully of the way that we are known by God precisely because he brought us into being in our mother's womb (Psalm 139:13). We are wrought with tender intimate knowledge and care. The creation account in Genesis 1 asserts that humankind is created in God's image and that we were blessed by and pleasing to God (Genesis 1:26-31).

Much has been written on what it means to be made in the image of God. Augustine of Hippo (354-430) gives a particularly interesting account. He proposed a trinitarian structure to the human soul consisting of the capacities of intellect, reason, and love. While this might seem to imply that people who lack such capacities are not made in God's image or have lost God's image, Augustine himself does not draw such a mistaken conclusion. First, he contrasts a mental structure which, though tripartite in form, is only concerned with the things of this world with a threefold capacity to respond to the divine. It is in the latter that the image of God can truly be seen (*On the Trinity* 12:4). This spiritual capacity is not to be confused with cognitive abilities and presumably cannot be affected by their decline. Karl Barth draws a similar distinction between the spiritual and cognitive capacities of mentally impaired persons against the backdrop of the eugenic policies of the Third Reich (Barth, 1946, pp. 88-89). Second, Augustine describes people with mental impairments as being engaged in a distinctive if mysterious form of vocation and thus having divinely ordained meaning and purpose in life (*Treatise on the merits and forgiveness of sins* 1.32). The idea that such people have a place in God's creative plan forms a startling counter-point to the dominant narrative of dementia-as-tragedy.

God our gracious Sustainer

Augustine's thought is part of a strong Christian tradition that understands the image of God to be ineradicable by cognitive impairment or physical decline. Nevertheless, the lived experience of faithful people can feel different.

For example, Psalm 71 questions whether God's love and care for one he has known from infancy (v.6) may fail as the frailty of old age advances (v.9). The psalmist seems to believe that he will be favoured by God only as long as he is capable of actively proclaiming his praise, something that is beyond those in Sheol (Psalm 88:10).

This sort of questioning sets the stage for a (re)discovery of the radical nature of God's grace. It is not that God created us and then left us to our own devices, occasionally checking to see if we are OK. *Everything* we do throughout our lives is sustained by God. We exist from moment to moment, we are recognisable human beings, because God keeps us in mind (Psalm 8:4). It is not about whether we can

remember: if we forget God remembers us (Isiah 49:15). It is not about whether we can know God or actively proclaim him: it's about whether God knows us (Matthew 7:22-23; Galatians 4:9; 1 Corinthians 13:12). It's not even about whether we are capable of loving God: 'This is love: not that we loved God, but that he loved us' (1John 4:10a). As our faculties slip away or as our parents cease to know us, God maintains his loving creative gaze and so we continue to exist, held in his mindful embrace.

The dependence of frail or cognitively impaired adults on God's moment by moment memory, knowledge, and love of them reveals a universal truth, something to which we can be blind in the fit and active seasons of our lives when we delude ourselves that we are in control and that everything depends on us. Ironically people living with dementia can remind the rest of us of a vital truth that we are in the habit of forgetting.

God our loving Redeemer

Finally, we return to the incarnation – God's loving act of becoming a fully embodied, enfleshed, solid human being. The word 'solid' reminds us that the incarnation was an act of solidarity, of 'presence with'. In his life Jesus was present with all sorts and conditions of human beings: powerful people in the centre of Jewish society, the sick and demonised, little children, those on the margins, and even gentiles. In his dying and death he was present with convicted criminals, responding to a dying request to *remember* from a man who would otherwise have been a 'nobody' (Luke 23:42).

Most pertinent of all, there is a tradition, evident in the Apostles' Creed, that in the period between his burial and raising, Jesus was present with another group of individuals - that he descended into the bowels of the earth (Matthew 12:40; Ephesians 4:9) and spoke to 'imprisoned spirits' (1 Peter 3:19).

We do not know the precise origin and referents of these texts, but they all point to the idea that Jesus' presence extended to ambiguous and hidden places, to twilight zones where individuals were incarcerated and in need of liberation. The take-home message is (as in Romans 8),

that there is no such thing as a godforsaken place, nowhere beyond God's reach in Christ.

An embodied theology that makes demands

This threefold theological response is not simply a means of addressing intellectual questions and perplexities; it demands a practical response. If the church is truly the body of Christ it – both corporately and in the lives of individual members – is called to live out the implications of these three aspects of God's activity. In my book on spiritual care for people with dementia (Collicutt, 2017), I set out numerous practical ways of doing this in some detail. These are organised around these three principles.:

First we are to treat individuals living with dementia as made in the image of God. We are actively to look for that image, not least in reflecting on what we may learn from them and their loved-ones about God's dealing with humanity.

Second we are to join in God's sustaining activity by being mindful of them as individual human beings and intentionally re-membering them as part of our worshipping and wider communities, enabling their story to continue to be crafted and told.

Finally, and perhaps most importantly, we are called to follow Christ into 'the land of forgetfulness' (for which we

might read 'residential care home'), simply to be present with those who crave loving human touch and connection.



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