

Gentle Discipleship: Theological Reflections on Dementia

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The holiness of the human body does not change because we forget who we are. Dementia does not affect discipleship or humanness; it reveals 'hidden' aspects of both. *Credit: stocksnapper / Getty Images*

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My journey into theology has been an interesting one. For many years of my life I worked alongside people to whom contemporary theology and practice often struggle to understand and respond faithfully - that is, people with enduring mental health issues such as schizophrenia, and those with profound intellectual disabilities or profound cognitive dysfunction such as stroke or advanced dementia.

To have an ailment which affects the intellect and, apparently, strips a person of their autonomy and intellectual prowess, and which brings about apparent radical changes to the self, offers some important theological and practical challenges. The subjective, cognitively aware "I" which is the central focus of much contemporary and historical theology is not available, or at least is radically *revised*, within the lives of people with such life experiences.

A good deal of theology, and indeed much of our worship, pivots on the assumption that the theologian is addressing an individuated, experiencing, cognitively able self, perceived as a reasoning, thinking, independent, decision-making being.

This cognitively able self is assumed to have the potential to know and understand certain things about God - a God who is available at an intellectual level through such things as Scripture, revelation, prayer, or by means of some or other form of communicable spiritual experience. Knowledge of God, sin, salvation, discipleship, sanctification, justification - they all tend to be assumed to relate to a fully cognisant being who can understand certain things, avoid or engage in certain activities and ways of thinking and who is able to make particular choices which have positive or negative implications and consequences for now and into eternity.

At a basic level, the assertion that "If you confess with your mouth, 'Jesus is Lord', and believe in your heart that God raised him from the dead, you will be saved" (Romans 10:10), requires a certain level of subjectivity, awareness and cognitive competence. But what

happens if you cannot confess the Lord with your mouth? How do we understand the spiritual lives of those who have no idea and can have no cognitive idea about who "the Lord" is? How can you call upon the name of the Lord and be saved if you have forgotten who the Lord is? What does it mean to be a disciple when you don't know who Jesus is or you have forgotten who he is?

That is the question I want to explore here: *What does it mean to be a disciple when you have forgotten who Jesus is?* But I want to focus particularly on those people who have advanced dementia, by which I mean people with the type of brain damage brought on by dementia such that they have severely reduced cognitive and intellectual capacities combined with a profound loss of memory. I am thinking about people whose memory has been damaged to such an extent that they no longer recognise themselves or others; people for whom Bonhoeffer's profound question, "Who am I?" has become subjectively unanswerable, at least at a cognitive level.

Worshipping with the forgetful

When I worked as a mental health chaplain, I was always struck by the way in which people with severe dementia who were withdrawn and assumed to be unable to communicate for the majority of their lives would change when drawn into participating in spiritual practices.

People would very often "spring into life" when asked to pray the Lord's Prayer, their words clear and coherent in ways that were deeply dissonant with their normal day to day communicational responses. When I offered people the Eucharist their bodies reached out and responded even when their minds no longer seemed able to grasp the intellectual complexities of the practice. When we greeted one another with the peace of Christ, people would respond and embrace, even if only for a brief moment, in ways that they simply didn't respond in other contexts. As we sang "When I Survey the Wondrous Cross," the movement of my emotions towards tears was often matched by the tears of the worshippers who had forgotten so much but still seemed to remember Jesus.

My medical colleagues told me that it was nothing other than procedural memory: the product of long term memories of skills that were well learned and ingrained into people's memories in ways that more recent memories were not. Technically, from the perspective of their analytical tools, they may have been correct. But I was never fully convinced.

As I watched people worship, many of whom were disciples of Jesus, now deeply forgetful, but still somehow retaining the practices and gestures of the Kingdom, I was haunted by the tension I felt between my experience of a mode of compassion that was tempted not only to reduce and confine their spiritual movements within the boundaries of their medical condition, but also a sense of hopelessness that found me handing them over to God, as if their humanness had been destroyed to such an extent that only the mysterious workings of the Spirit could hold them as persons, as disciples.

Like my medical colleagues, part of me had been formed in such a way that I assumed memory merely to be the ability to recollect. "When I can no longer recall who God is," I assumed, "I have forgotten God." At that time in my life, I hadn't come to realise that memory is not just what we recall. *Memory is, in fact, something that lives within our bodies; our memories are our bodies and our bodies are our memories. Memory is all that we are.*

On becoming a Christian

Christian education is a complex and diverse phenomenon. At one level it has to do with passing on facts and information. But at a deeper level it has to do with character building,

discipleship, learning to be faithful to the prodding's of the Spirit and spiritual and physical formation - things which may well include formal learning, but which find their centre in the fullness of life together.

Within the overt educational activities of church and academy, there is a temptation to focus on formal didactic practices as the primary modes of education, be that within the Sunday school, the lecture room or the pulpit. There is, of course, nothing wrong with striving to know things or with forms of education that promote intellectual modes of knowledge and learning. The problem is that, culturally and theologically, knowing things can easily be perceived as more important than *being* something.

In his essay ["The Gesture of a Truthful Story,"](#) Stanley Hauerwas suggests that "the church does not 'do' religious education at all. Rather, the church is a form of education that is religious." Put simply, he says:

"religious education is the training in those gestures through which we learn the story of God and God's will for our lives. Religious education is not, therefore, something that is done to make us Christians, or something done after we have become Christian. Rather, it is ongoing training in the skills we need in order to live faithful to the Kingdom that has been initiated in Jesus. That Kingdom is constituted by a story that one never possesses, but rather constantly challenges us to be what we are but have not yet become. The primary task of being educated religiously, or better Christianly, is not the achievement of better understanding but faithfulness."

At a minimum, the church in all of its diverse forms is the place of formation for the disciples of Jesus; a place where we are trained to be faithful. It is within the fellowship of the church that we come to learn about the stories of redemption and in various ways discover what it means and what it looks like to follow Jesus. Such learning contains formal didactic components, but much of the education we receive within the church goes unnoticed - it is implicit, precognitive and subtly *physical* rather than cognitively formative. As we practice the Kingdom, so our bodies take its shape. The apostle Paul makes this point in an interesting way in 2 Corinthians 3:2-4:

"The only letter of recommendation we need is you yourselves. Your lives are a letter written in our hearts; everyone can read it and recognize our good work among you. Clearly, you are a letter from Christ showing the result of our ministry among you. This 'letter' is written not with pen and ink, but with the Spirit of the living God. It is carved not on tablets of stone, but on human hearts. We are confident of all this because of our great trust in God through Christ."

Discipleship is authored by Jesus and written on human hearts. It is worthwhile clarifying the term "heart." By *heart*, I refer to the Hebraic way in which the term was used to designate the centre of things. Within a Hebraic anthropology a person was perceived as a unitary whole - an embodied soul or an ensouled body, with the heart conceived as the governing centre for all of the aspects of the whole. There seems to be no suggestion in Scripture that the brain is the centre of consciousness, thought or will. The heart is regarded as the seat of the entire person.

So when Paul talks about writing the gospel on people's hearts, this is not merely a literary device but a profound statement of the full-bodiedness of the gospel and of discipleship. The language of the "renewal of the heart" is a way to talk intelligibly about having been turned in a new direction, even if we do not yet act like it, or even though we often act otherwise. It's an orientation towards the world that is gifted to us in and by the spirit. It is in this sense that we can begin to understand [Hauerwas's conviction](#) that:

"Christianity is unintelligible without witnesses, that is, without people whose practices exhibit their committed assent to a particular way of structuring the whole. Christianity is much more than an idea ... rather it is a bodily faith that must be seen to be believed."

The point is not that being a Christian boils down to doing the right things and being seen to do the right things (although it clearly includes such things). In one sense, the opposite is true: being a Christian has to do with recognising that, on one's own, one *cannot* do the right things.

Nevertheless, there is a sense in which (to misuse Leslie Newbigin's phrase) human beings are the hermeneutic of the gospel - that place where the gospel is seen, lived out and made persuasive. The dynamic of such hermeneutical, divine reflection is important. As our hearts are renewed by the Spirit, so we learn to practice faithfully; as we practice faithfully, our bodies are transformed into the shape of the object of our worship. Our practices do not bring about our sanctification. They are nothing more, and nothing less, than embodied faithful responses to a divine gift.

Living before cognition

However, while formal practices - prayer, sacraments, baptism, forgiveness - may be important for Christian education and formation and for the proper interpretation and living out of the Christian story, they actually emerge later in the process of Christian education than we might initially assume. Much of our Christian education occurs *before* cognition.

It is estimated that around 5% of what we do is cognitive and reflective. Important as the concrete, formal activity of engaging in Christian practices may be, most of what we know and learn occurs prior to practice, at the precognitive level wherein we are schooled intuitively and implicitly to see and understand ourselves and the world in particular ways. We might describe this as the *ethos* of our communities; the characteristic spirit of a community which is often not formally noticed and acknowledged, but which is profoundly formative for its beliefs and practices. Charles Taylor describes something similar in his concept of the "[social imaginary](#)":

"an affective, noncognitive understanding of the world. [The social imaginery] is described as an imaginary (rather than a theory) because it is fuelled by the stuff of the imagination rather than the intellect: it is made up of, and embedded in, stories, narratives, myths, and icons."

There is a useful resonance here with Hans Ulrich's description of *ethos*:

"Ethos in fact does have two different notions: one is the Greek word *ethos* ... what indicates the rules and laws obligatory to everybody ... and *aethos* ... which we can describe as the context, where we can live, where we can dwell, and where we are together with other people at home. This second notion is at stake here. Where are we at home, what is the context to which we belong?"

As Christians the particular social imaginary that we call home emerges from the narratives of Scripture - what Neil MacDonald, after Karl Barth, has called the "strange new world within the Bible." The place where we are most at home is within the Body of Christ. It is here that we discover and encounter the *ethos* of homefulness and over time soak up and inhale the meaning of discipleship. Ritual and worship are concentrated places where we see this quite plainly. As [James Smith](#) notes:

"there is an understanding of the world that is carried in and implicit in the practices of religious worship and devotion. These rituals form the imagination of a people who thus

construe their world as a particular kind of environment based on the formation implicit in such practices. In just this sense Christianity is a unique social imaginary that 'inhabits' and emerges from the matrix of preaching and prayer. The rhythms and rituals of Christian worship are not the 'expression of' a Christian worldview, but are themselves an 'understanding' implicit in practice - an understanding that cannot be had apart from the practices. It's not that we start with beliefs and doctrine and then come up with worship practices that properly 'express' these (cognitive) beliefs; rather, we begin with worship, and articulated beliefs bubble up from there. 'Doctrines' are the cognitive, theoretical articulation of what we 'understand' when we pray."

If this is so, then the task of Christian education is not simply to try to *understand* the world in cognitive terms, but to learn to *be in the world* in particular ways. Learning to be in the world in such ways requires imagination, *ethos* and practices which remind us in deep ways of who and whose we are.

Christian education emerges gradually and dialectically from the way in which the gospel locates us in the world and helps us, over time, to reorient ourselves in the light of what it means for our bodies to belong to and to learn to love Christ. This is more than knowing things with our minds. As Smith puts it:

"It's not that we don't think, but rather that our thinking and cognition arise from a more fundamental, precognitive orientation to the world. And that precognitive or prerational orientation to the world is shaped and primed by very material, embodied practices."

While Hauerwas believes that Christian practices and formation entail "the most determinative cognitive claims we can make," Smith reminds us that such practices have an underlying precognitive dynamic that is shaped and formed within a particular *ethos* and which is, in fact, the primary educational context for discipleship. Put slightly differently, *Christian learning begins before we think about it and, by implication, it continues after we have ceased to think about it*. Or, as Smith puts it, Christian education is:

"not something that traffics primarily in abstract, disembodied ideas; rather, education is a holistic endeavor that involves the whole person, including our bodies, in a process of formation that aims our desires, primes our imagination, and orients us to the world - all before we ever start thinking about it."

The point is not that intellect and cognition are somehow bad things or that we shouldn't think about the things pertaining to the Kingdom. The point is that much of what we know about what it means to be a disciple occurs before we have the opportunity to think about it and continues without our having to think about it.

That being so, any suggestion that somehow the forgetfulness of dementia negates or undermines a person's ability to be a disciple becomes at least highly questionable. It is quite possible to know Jesus and to remain schooled in the practices of the Kingdom, even if, strictly in terms of recall, a person has forgotten who Jesus is.

Knowing Jesus in our bodies: Re-memembering memory

In order to deepen this point and bring us back to the experience of dementia, let me briefly explore the nature of memory. In his book *Matter and Memory*, Henri Bergson contradicted the predominant notion that memory is defined primarily by recall, and introduced instead the idea that there are two modes of memory: *habit memory* and *image memory*.

Image memory relates to representational memory. This form of memory represents particular things that have happened in the past; it replicates the past and gives a person a sense of history. In this understanding, memory is synonymous with recollection. Habit memory is of a different order. It is, according to Bergson:

"the mode of inscribing the past in the present, as present ... it differs from other types of memory because it brings the past into the present by acting, while other kinds of memory retrieve the past to the present by summoning the past as past - that is, by remembering it."

Bergson thus offers a holistic and full-bodied model of memory which both draws upon the past, but which simultaneously relives and re-enacts the past in the present. Habit memory has a different movement in and through time. Whereas image memory can transgress time moving backwards and forwards between what has been and what is, habit memory does not look backwards. It contains the past and relives it in the present; the past is wholly immanent. Perhaps most importantly, habit memory is an action, not a representation. As Bergson writes, "it no longer represents our past to us; it acts it."

Habit memory - or, as others have framed it, "body memory" - is not a mere shadow of a previously cognitive and representational memory. It has a conceptual framework and a potency of its own. It lives out the past in the present. [Thomas Fuchs](#) suggests that:

"Bodily learning means to forget what we have learned or done explicitly, and to let it sink into implicit, unconscious knowing. By this we acquire the skills and dispositions of perceiving and acting that make up our very personal way of being-in-the-world. We might also say: What we have forgotten, has become what we are."

What a fascinating and enlightening thought! We are deeply embedded in our memories not just because we can recall them, but because we *are* them. Even when, in terms of cognition and recall, we seem to have forgotten everything, we still remain held in our memories. In this sense, *everything that we are, is memory*. While most of our thinking about memory tends to focus on its intellectual, cognitive and representational dimensions, in fact, memory is full-bodied; carved into our bodies through the processes of formation and development that goes on implicitly and explicitly throughout our lives.

Bodily memory is a product of community, *ethos*, formal learning and practice. It reveals bodies that are at home in the world in quite particular ways. Bodily memory should not be understood apart from representational memory. Nevertheless, its efficacy and significance are not determined by the presence or absence of recall. There is an endurance of bodily memory that transcends recall and potentially acts as a powerful conduit for knowing Jesus even if one has forgotten who Jesus is.

Worshipping with our bodies

If at this point I return to my opening reflections on the experience of worshipping with people who have advanced dementia, things begin to look slightly different. My initial reaction was that "these people" may be disciples, but they are disciples who had no memory of Jesus. My escape route was defensively to frame them as people whom only the mysteries of God's Spirit could make sense of. That certainly got me off the theological hook!

True, they were mysteriously (or so I thought) moved by the sharing of the bread and the wine, but I managed to psychologise that without much difficulty. What I didn't realise was that their revived movements and apparently pointless and sometimes disjointed repetitive words were much more than meaningless residual memory. Their movements *were* memory. Many of the people in the chapel had been shaped, formed and educated in precisely the ways

that I have been highlighting. Their minds had been renewed through their encounters with the Spirit and their bodies had been shaped and formed by faithfully practising the memory of Jesus over many years. They could not recall who Jesus was, but their love for Jesus and their memory of him, their faithfulness over time was made manifest in their bodies and was obvious if people had eyes to see.

Viewed in this way, their frail movements, their taking of the bread and the wine, their fragile embrace, the apparently unknowing sharing in the words of the ritual are reflective, not of loss, but of enduring love. They represent the habits of a lifetime inscribed by Jesus on the bodies of those who love and, in an odd way, remember Jesus "in the now" in ways that do not require recall or cognition. They know and remember Jesus in their bodies.

Unless we choose to yield to the apparently inevitable thrust of dualism here, we can do nothing other than recognise that *the memory of the body is a real and profound conduit that leads people into the presence of Jesus*. Their years of training and education in the ways of the Kingdom come to fruition as they remember the one in whose memory all things are made new (2 Corinthians 5:17).

Kneeling before Jesus

One thing that always strikes me when I am ministering to and with people with advanced dementia is that I have to adopt a certain posture. By that I don't mean an attitude of mind. I mean that in order to administer the sacrament, my body has to do certain things that it doesn't regularly do: I have either to bow down or to kneel before the person. In other words, I have to adopt the postures of worship in order that I can enable the rituals of worship.

As soon as my body adopts such postures, I see the world differently. I can't avoid looking into their eyes. I begin to notice their bodies in new ways as my body is placed before them in a different way. I see lines on their faces; I see scars on their hands; I see their histories etched into their bodies. I notice the posture of their bodies; I hear whispered words that I could not have heard were I standing above them. I feel the warmth of their hands as they hold my hand as I help them drink the wine.

When I begin to see and feel the world in this way, I cannot be other than deeply moved. Here, on my knees before the person, the idea that all I am in contact with is vague residual memory makes no sense. That is not what I find "down here." Here I discover a world that not only takes the precognitive seriously as a mode of knowing and learning, but also looks at theories differently. Theories that make sense, and indeed may be useful "up there," mean nothing in this place. This place is a place of deep learning. I begin my encounter by thinking that I am "leading worship," but suddenly I discover that I am encountering God. The power of Jesus's words, "When you do this to the least of them, you do it to me" seems to surge between us - though precisely which one of us "is the least of them" is not at all clear.

In order to share the wine and the bread, I need to kneel down - but I also have to reach out. There is no time for haste; only love, patience and gentle perseverance can fill this space of connection. In order to greet the person with the peace of Christ, I have to stoop low and reach out. I need to realise that this may be one of the few times when this person feels loving human touch that has no instrumental end. I need to remember that, within this context of worship, my embrace contains and reveals Jesus, as does theirs.

In the midst of that encounter, I have to remember at least two things. First, I have to remember the body of the person before me, and in so doing learn what it means to *read bodies*. If I take time, even though the person's words may be slurred and confused, they are nonetheless meaningful. Reading bodies has to do with watching and listening properly,

taking time to give people the benefit of the doubt rather than assuming the worst. In order to do that, I need to be schooled in the practices of gentleness, patience, kindness and perseverance. (By "bodies," of course, I mean the whole mind-body unit that is a human person. Reading bodies does not exclude the mind. There is [plenty of evidence](#) to suggest that in advanced dementia people often use the wrong words or concepts, but are nonetheless communicating important things.)

Second, I have to recognise fact that the person before me is a disciple of Jesus Christ, who continues to love and know Jesus even though they have forgotten him. As a disciple, they retain their calling and their vocation. But what does it mean to have a calling to God and to have forgotten who God is? Think of it this way. The person before me has reached that time in their lives when they are no longer able to care for themselves. However, reaching such a position is nothing more, and nothing less, than another aspect of the human vocation to care. Care lies at the very heart of the human vocation given to them by God in creation. That being so, the prerogative of care is not effective cognition nor an ability to reason effectively. The prerogative of care is to love. To be human is to love like God and to be loved by God.

If care is fundamental to what it means to be human and to act faithfully towards God's creation, then this raises a crucial point. *To be a recipient of care is a profound and vital aspect of that process.* God calls human beings to care for creation because God loves creation; human beings as part of creation are recipients of God's desire to love and care for them, and for them to care for one another. To care for others and to receive care from others is a crucial aspect of human beings' dominion over the earth.

That being so, to be in a position where one can only be the recipient of care is not degrading or indicative of a loss of dignity or a failure of discipleship - it is in fact a holy place. To receive care is a deep reflection of divine love for dependant human beings. To have severe dementia is not in any sense indicative of a loss of dignity or a diminishment of humanness. It is simply a time in a person's life where the human vocation to care for creation and have dominion over it takes on a particular form. The holiness of the human body and the sanctity of the human person does not change because we forget who we are. Encountering advanced dementia does not affect either discipleship or humanness - it simply reveals "hidden" aspects of both.

It is this fundamental caring dynamic that I am called to seek out, embody and respond to in my ministry with people who have advanced dementia. As I reach out in worship and sacrament, as I share the words of prayer, as I slow down and take the time gently to learn to read people's bodies, not only am I fulfilling my vocation as a minister of Word and Sacrament, I am also enabling this disciple to fulfil that aspect of their humanness that is marked by their need to receive care. Together we worship, touch, feel and remember Jesus as we work out different aspects of our calling and our humanness.

More than that, if I am to see the person in all of their fullness, I have to approach them in faith: sure of what I hope for and certain of what I cannot see. I need to give the person the benefit of the doubt; to encounter and discover a new hermeneutic for reading the movements of their bodies and the rhythm of their practices. I need to be formed in a quite particular way to achieve this task of proper looking.

"In our weakness"

It could certainly be argued that the things that I am suggesting enable people to remember Jesus when they have forgotten him could easily be applied to other non-religious practices - such as pop music or any kind of human presence. People may well be similarly moved by other modes of practice. But in order to make such a move, one needs to step outside of a

theological framework and allow some other mode of knowledge to guide one's encounter. One needs to discount the suggestion that being a disciple schooled in the ways of the Kingdom is radically different from being a citizen schooled in the ways of consumption. The distinction is not medical; it is theological and the manifestation is not proof but hopeful faith based on the knowledge of who God is and what it means to worship and remember that God with our bodies.

My point in helping us to notice the significance of such things as community, *ethos* and body memory is not, of course, to turn either sanctification or worship into a purely human endeavour. Memory on its own in whatever form is not enough to enable us to worship well. Worship, for all people, is something we participate in through the power of the Spirit with a view to encountering God and offering God the best that we can. As Paul says in Romans 8:26, "the Spirit helps us in our weakness; for we do not know how to pray as we ought, but the Spirit himself intercedes for us with sighs too deep for words." If people with advanced dementia have forgotten how to pray, that is nothing more than a reminder of the condition of all of us.

My point is that if the church is, in fact, education in the ways that Hauerwas, Smith and others suggest, and if we are, as Augustine put it, *terra animata* - "animated earth" or inspired dust, body and soul inextricably interconnected - then Christian education will involve the whole body even if part of that body no longer functions as it once did. Physical formation through practice and faithful Christian discipleship should not be separated from its fundamental theological ground in the nature of human createdness.

Theological reflection on worshipping with people who have advanced dementia helps us to see that Christian education is *life together*. Ministering with such people brings to the fore some of the complexities of what the church is and what it is intended to do as an educational institution. When we learn to live lovingly and gently, we can begin to see the world - even the world of the deeply forgetful - quite differently. We can thus be enabled to recognise one another properly and worship God more faithfully - which, of course, is precisely the goal of Christian education.

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