



Guarding the 'holy fire': dementia and the mystery of love

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Starting from personal experience, this article looks at how the 'holy fire', or spirituality, of a person can be protected as part of the dignity of a person living with dementia. Dementia sufferers can often be portrayed as less than fully human, but this 'normal practice' ought to be challenged. The neurological explanation for dementia does not tell the whole story, and a more person-centred approach seeks to remember the longer narrative of a person's life to understand ongoing communication and to affirm the continuing personhood of the dementia sufferer. Awareness of spirituality is crucial to this approach, and Wesley's line, 'acts of faith and love repeat', gives some framework to how this might be developed.

DEMENTIA • PASTORAL CARE • SPIRITUALITY • IDENTITY • WESLEY'S HYMNS

This article is a transcript of the annual Joseph Winter lecture, delivered in July 2017 to the churches in Wakefield. Most references to this original context remain in the text in order to retain the tone of delivery.



The Shetlandic poet Christine de Luca, who is probably about the same age as myself, has written an extraordinary little poem addressed to her adult children. In it she refers to Suilven, which is a very distinctive and much-loved Scottish mountain range. It's called 'What's in a name?'

If and when I have mislaid my name
and stare at you disconcertingly

let me spend a day parked by Suilven,
perplexed by broken water. Turn

my calendar to the mountain's season,
and set my watch by shadows on the loch.

Forgive me if I lose the reasons that we came
or my gaze clouds in a cod-fish kind of way

or if the name I chose for you eludes me.
I'd still sense mountain, water, love.¹

It's remarkable because it's the only poem I know where someone who does not have dementia has made an effort to imagine what she will need and feel if and when she does. In the past few years I have done a good deal of thinking about mortality, and how we need to prepare for our deaths, but deeply resist doing so – something which is as true inside the Church as it is generally in our culture. But if we find the thought of death difficult, it is as nothing compared with the prospect of contemplating dementia. Yet there can be few of us past midlife who have not been touched by it, needing to accompany older relatives or friends for years, as they live with what is currently an irreversible condition, largely untreatable by medical means, which will increasingly rob them of crucial aspects of their brain function and leave them confused and helpless to manage their own lives. And unless there is a startling breakthrough soon

(and so far nothing potentially viable has emerged), we need to recognise that, with our extended lifespans, dementia is a future that may very well be our own.

Let me say something about myself and why I chose this theme for my lecture, which on reflection I realise could just as well have been titled 'Love and the mystery of dementia'. I have not made an academic or professional study of dementia or dementia care, though I have read around the subject.² My qualification to speak on the subject is because I realise that for the whole of the twenty-first century so far, dementia is something I have been around and coping with at one remove, whatever else my day job has been: first with my mother, who died in 2007 with advanced vascular dementia, who until her final hospital admission lived at home, cared for by my father. I gave as much support as my dad was willing to accept, including helping with a lot of the paperwork around powers of attorney, attendance allowance etc. Then with a very dear aunt, who had no children of her own and for whom I held powers of attorney. She suffered a couple of crises and I, with another cousin, eventually persuaded her to accept a fortnight's respite care in a residential home, from which she decided not to go home again. (In a lovely coincidence, this aunt had a local connection here. She lived in Sandal for some years when she was Director of Nursing for the West Riding.) And finally my father, who will be 97 this year, began a couple of years ago to exhibit odd behaviour and neglect himself at home. He was persuaded by my brother and me to take himself to a residential home. However, when he got there, his geographical disorientation was fully revealed, and he could not settle, or recall the decision he had made, but went wandering and had to be rescued regularly by the police. He was asked to leave, and is now in a dementia wing of an MHA residential home, and I am relieved to say seems now both settled and contented with his care.

Those of you who have sought to assist older relatives in this situation will be familiar with the many practical and emotional dilemmas that can arise, when you need to insist on intervening to care for the generation that first cared for you. The need arises gradually, but you can be made aware of it only when crisis looms. When my mum went into hospital for a major vascular operation, it suddenly came to me that I should sit in on the interview with the surgeon while she gave consent. It turned out that the wrong leg was about to be operated on, but she did not have the power to notice the error and contradict it. Later, as my father started to grasp that he was becoming my mother's carer, my dilemma was how I could help without taking over. Was it appropriate to

point out that correcting mum's mistakes crossly was never going to work and only made her anxious? From a distance, what could I do in a practical way about helping them cope with housework or gardening, when dad refused to employ anyone? And then, with a fiercely independent aunt, how could I encourage her to accept respite care, which was the only thing that was going to prevent an emergency hospital admission? What about my own feelings as things changed? When my dad was asked to leave his first residential home, how was I to handle the sense of shame that the person who first taught me to behave was now acting aggressively with those trying to look after him?

Practical responsibility and emotional complexity are interwoven in the major renegotiation of relationships that dementia requires.

But I want the main focus for this lecture to be how we should protect a particular dimension of a person's dignity, namely their spirituality – the 'holy fire', in Charles Wesley's language, in the well-known hymn we just sang (reproduced here at the end). Incidentally, I wondered recently where this image of the undying sacred fire came from. It's from Leviticus 6, and concerns God's instructions to Moses and Aaron about sacrifices. The altar fire was to be kept burning always, and not allowed to go out. Wesley has taken this image and applied it not to ritual burnt offerings, but to the sacrifice of his whole life, up to and including his death. Behind this usage will be the words of Jesus quoting Hosea: 'For I desire steadfast love and not sacrifice, the knowledge of God rather than burnt offerings.' The hymn expresses very powerfully the commitment of the Christian life, to 'work and speak and think for thee', thus guarding the 'holy fire'. What then is our role as loved one, or as church, if someone becomes unable to do this for themselves? All three of the people to whom I have been close during their experience of dementia have been lifelong devoted churchgoers; and my dad was a licensed lay reader who only gave up preaching in his eighties. Their relationship with God and with the Christian community has been central to who they are or were. But supporting this spiritual identity is hard, and one of the reasons for this is our culture's demeanour towards those with dementia.

We know that dementia as a disease – or, I should say, group of diseases, as there are several different kinds – has a wholly different status from that of other diseases in our society. It undoubtedly arises in the body. Physical changes happen within the brain. Though these can only be fully confirmed in a post-mortem, they can also be detected by an MRI scan. They eventually render a person completely dependent on the 24-hour care of others; yet

unlike other diseases, this treatment has to be largely funded by the patient. But there is another way in which dementia is distinguished from almost all other conditions. John Swinton has highlighted the way in which dementia, and dementia sufferers, experience what he calls 'malignant social positioning'.³ So instinctive and extreme is our culture's attitude towards the condition, that when Swinton told a colleague, who is both a psychologist and a committed Christian, that he was developing a theology of dementia, this was her response: 'Is there such a thing as a theology of dementia? Is it not just demonic?'⁴ It seemed to me during the 2017 general election campaign that the reason Theresa May appeared to have to row back very fast regarding her proposals for the funding of social care was the phrase 'dementia tax' that critics applied to these proposals. The very word 'dementia' is completely toxic in political terms, rather like the word 'death', which was in an earlier election applied to Labour proposals about inheritance tax.

Let's spell out what constitutes this malignant social positioning, and consider the effects it may be having on dementia sufferers and those near to them. Eileen Shamy, who was one of the pioneer clergy working with the spiritual needs of the very old, tells this anecdote about a lecture given to a class of graduate nurses, who were presented with a case study.

The patient: white female. She neither speaks nor comprehends the spoken word. Sometimes she babbles incoherently for hours on end. She is disoriented about person, place and time. She shows a complete disregard for personal appearance and makes no effort to assist in her own care. She must be fed, bathed and clothed by others. She is toothless so her food must be pureed. Her sleep pattern is erratic. Often she wakes in the middle of the night ... Most of the time she is friendly and quite happy. Several times a day, however, she becomes quite agitated without apparent cause and screams loudly, until someone comes to comfort her.⁵

The nurses were then asked how they would feel about taking care of this patient, and they used words like 'frustrated', 'depressed' and 'annoyed'. The lecturer remarked that he enjoyed taking care of her and their response was disbelief, until he passed round a photo of the patient – his 6-month-old daughter. Now, caring for a helpless infant and a helpless older person are not identical – for one thing we know that the stage of infancy will pass so fast that you can almost see the brain developing, whereas a brain with dementia is

going in the other direction. But this story demonstrates that there is nothing inherently evil or demeaning to human dignity about a state of dependence on others, and nothing instinctive or normal about our culture's reaction to it as disgusting or burdensome. This is crucial, because what people most fear about this stage of life as a prospect for themselves is largely, I think, to do with this cultural disgust, and what dementia is construed as meaning. (I don't want to underestimate the actual deficits and suffering inevitably experienced within the condition, but whatever these are, they are magnified and worsened by what we think dementia means.)

One of the most common assumptions that goes along with this malignant social positioning is that dementia somehow robs us of our personhood. You will hear this assumption frequently within ordinary conversation about people who have the condition or died with it. 'He's just a shell of the person he used to be.' 'You have to remember the person that she was.' Unfamiliar behaviour – typically frustration, anger or disinhibition – is described in terms of 'having become a completely different person'. Sometimes it is even implied that reaching a certain stage of dementia is equivalent to having died, and that therefore a relative suffers actual bereavement of the person they loved, while their body still survives. 'You've already done your grieving by the time they die.' Now let me be clear – many people who say this sort of thing are nevertheless demonstrating through their actions that they continue to love and care for the person whose current state baffles them, and leaves them mourning the loss of the companionship they used to enjoy. But this is the kind of conversational discourse about dementia available to us in our society, and I agree with Swinton that the discourse is potentially toxic and can affect attitudes in devastating ways.

Christians are not necessarily immune from believing in the kind of 'de-personing' this can result in. One particularly startling example of this kind of thinking was produced by the televangelist Pat Robertson, in response to a painful phone-in question. He was asked to advise someone whose friend had a wife with severe dementia who no longer recognised him. The friend felt bitter against God, and had started to see another woman. After indicating how difficult this situation was, Pat Robertson said: 'I know this sounds cruel, but if he's going to do something, he should divorce her and start all over again, but to make sure she has custodial care, someone looking after her.' When challenged about the marriage vows, 'till death do us part', Robertson said, 'This is a kind of death.'⁶ This was a conservative evangelical speaking. To be fair, his remarks sparked huge controversy in the evangelical community, but you see

the assumptions here. The wife with dementia was no longer the person her husband married. Theologically she was dead. Anyone might sympathise with the situation of the lonely and burdened carer, but what seems shocking and heartless in the evangelist is the recommendation to divorce, presumably to preserve the decencies regarding adultery.

Why do we see dementia sufferers as less than persons? Swinton suggests that there are two crucial reasons. One is the priority we give to individual autonomy in our society, de-emphasising the interdependence that we in fact rely on in order to survive, let alone thrive, as human persons. The other is the entirely exaggerated importance we apply to cognitive competence, particularly our capacity for memory.

These assumptions feel as if they are truly hard-wired into us in the West. Anyone who has needed to take over the management of someone else's financial affairs will have experienced how intensely difficult it is for a hitherto financially independent person to allow this, and what an immense line it is to cross for the person who needs to insist on it, in the best interests of their loved one. Even when we have sensibly decided to give someone power of attorney, it feels as if this will never be needed in fact. I notice that when I set up an old enduring power of attorney for myself, I then hedged it about with various legal caveats which I now know would make it very irritating and difficult to apply should the need arise. I thought I trusted my attorneys but clearly I could not contemplate actually doing so. I attend a monthly women's group – we call ourselves crones – who discuss different aspects of life as a woman growing older, and recently we tackled the tough question of how to manage our future care. Independence for as long as possible was a number-one priority, and it was fascinating to see where the imagination of the group failed. Frailty and the need for practical help was foreseeable: the surrendering of the management of our financial affairs was anathema. 'Never that!' cried one of the group. But we all know from experience of being a carer that with dementia that moment will certainly come. We just cannot believe it could apply to us, even though we have watched the older generation deny and deny the reality.

And then, second, the importance of cognitive competence as a measure of personhood. The very term 'dementia' means 'with loss of mind', and it is the case that a diagnosis of dementia will usually be made as a result of observing a range of defects in mental capacity, which can't be explained by other causes such as delirium, certain kinds of vitamin or thyroid deficiency, or other central

nervous system conditions like brain tumours, Parkinson's etc. There is no doubt that multiple cognitive deficits may occur, characterised by gradual onset and continuing decline: memory impairment (especially short term); disturbance in language; difficulty carrying out motor activities; failure to recognise familiar objects, people or landscapes; disturbed executive function, such as planning, organising, sequencing, abstracting. All these things gradually make it difficult and then impossible for a person to cope independently. There clearly are neurological changes, which are profound and not ultimately recoverable. However, does this reality in fact take away someone's personhood? If someone has lost key aspects of memory, let's say about relationships, does that mean those relationships are lost? I would say not. Each week I take my youngest grandson to visit my father. Dad can't remember Jesse's name, and enquires each time. He then can't recall that Jesse is a boy and not a girl. Somehow although I remind him of Jesse, the father of King David, he cannot grasp that this is not Jessie with an 'i' – quite a common girl's name when he was young. Dad can't remember who Jesse's father is, ie his own grandson Adam. But he is completely clear that Jesse is related to him and gives him great joy. Jesse brings his toys to share and chats away to his great-grandpa in the confident conviction that he is relating to a full person who loves him, and who is as likely as the next grown-up to take a keen interest in his Fireman Sam rescue helicopter. Personhood – even personality – can be recognised by the attentive, even under the most unpromising circumstances. I remember my mother's last hospital visit, after she broke her hip. She was really barely able to speak at all, even to make her needs known. Yet after she died, the nurses (who had never known her before) spoke to me about her gentle personality in terms that enabled me to understand that they had indeed met the same person that I knew.

It is quite hard to know how much of what a dementia sufferer displays through their behaviour is a result of the undoubted neurological changes that are taking place in the brain, and how much results from the social context and the construction we put on the sufferers' reactions to what they are experiencing. One of the common mantras we are offered in our busy lives is to cultivate the art of 'living in the present' rather than obsessing about the past or worrying about the future. This may be excellent advice for those with typical neurological function, but if you contemplate what it must be like to be living solely in the present – lacking all memory clues about where you are or who is controlling your movements, or what is likely to happen next – I think most of us could accept that this must be a very frightening place to be, a sort

of abyss of meaning, in which your brain will be desperately trying to make some sense of what you are experiencing. You will ransack your long-term memory for some explanation of what is going on, and this is why so often you will come up with scenarios from the past – often associated with responsibilities you feel you must have forgotten. Women often believe they need to meet children from school; my dad sometimes believes he has neglected work tasks; someone who was once a dairy farmer always needed specific reassurance at about 4pm in the afternoon that the cows had been milked.⁷ These people have not just 'lost their minds'; often they are deliberately employing all their efforts to do what the brain does naturally – tells itself narratives around the data that is available to it. They are seeking to exercise their adult responsibilities. How we describe dementia and its symptoms is crucial. It is often noted that a typical feature of the behaviour of sufferers is 'pacing' or 'wandering' – both words suggest a sort of vagueness or meaninglessness in the restless movement they engage in. But a better term might be 'searching', as someone who does this will frequently have a purposive approach, and somewhere, however currently inaccurate, to which they are trying to get. It is not uncommon for someone to become very frustrated when they are stopped from going out, because of this urge to seek some landscape they will recognise and that will therefore provide the meaning of which they feel the lack. In the first care home my dad was in, this need to go searching was a total headache, because he was living somewhere quite different from his home village, so he would never find the place he sought, and then he couldn't get back by himself. It was, in terms of an open residential home, a burdensome problem. Now he is in a secure dementia wing, should he want to go out someone walks with him, and soon he is ready to return. Now that he's settled he recognises the place he set out from, and interprets it as home. One of the most comforting things that was said to me by the manager of the MHA home when he arrived (with a history of irritable and occasionally aggressive behaviour when thwarted) was that what they do in a dementia wing is to interpret that behaviour as an attempt to communicate, and to work out first of all what was being said. These days he is regarded by staff as a 'perfect gentleman' who is generally the soul of politeness.

And so here we have some of the mystery of this progressive disease of the brain: what is neurology, and what is context or social construction? Is my dad an inevitable problem to be contained, or is he a person with particular difficulties to negotiate, who can be helped to find contentment? As Swinton points out, we should always offer 'the benefit of the doubt'.

One of the key people who challenged normal practice in dementia care, and proposed a 'person-centred' approach that is now applied in most good care homes (and that was pioneered in MHA), is Tom Kitwood. He pointed out that the solely neurological explanation of what is happening will not do when we consider the evidence.⁸

- There is a lack of continuity between the level of neurological damage and the manifestations of dementia. Sometimes people have displayed these and later have been found to have no more brain damage than others who have not displayed the symptoms.
- There is an issue of rapid decline. It is well documented that people can deteriorate very much faster than the neurology can account for, when they are taken into an unfamiliar context, whether that be a care home or hospital. I noticed that my mother, when taken into hospital, suddenly became incontinent within the space of an afternoon having waited for hours on a trolley. Many sufferers rapidly lose some cognitive functions or mobility when they move from their homes into care. If everything is based on inherent neurological decline, why does social change and uncertainty have this sort of impact?
- And then there is the issue of stabilisation or so-called 're-menting'. People can improve when treated in certain ways. My aunt was in a parlous state when she went for respite care, and she wasn't really thriving for a couple of months – we all thought she was on her way out. She wouldn't eat. But then it was her ninety-fifth birthday and 30 of her extended family including children came to her care home for tea. Suddenly she was into singing herself Happy Birthday, blowing out her candles and grabbing a sandwich in one hand and slice of cake in the other. And then she began to thrive again and lived another couple of years. She knew that her family knew where she was and she was dramatically 're-remembered'.

So, the person-centred approach offers a real challenge to the perception that dementia destroys our essential personhood. He focuses on trying to understand sufferers by adopting as far as possible the perspective that currently makes sense to them. This involves knowing something about the past achievements and preferences of that person, so that any guesswork about what might be worrying or preoccupying them may have a greater chance of accuracy. It involves assuming that old interests may be reawakened by particular kinds of activity session or conversation. We attempt to understand

what gestures or frustrations may be trying to communicate. People who are important to that person are encouraged to visit whenever it suits them, so that these crucial guy ropes of a sufferer's identity may be kept strong.

Sometimes you hear people say that there is no point in visiting people with dementia because 'They don't remember who I am any more' or 'She forgets my visit instantly, so what's the point?' But this view is surely mistaken. After all, we, the visitors, *do* remember both the person and the visit, and their personhood is held securely within the relationship with them that we continue to maintain – a relationship that is special and has deep roots, and is not the same as the connection that even the kindest carer can develop. Personhood is not confined solely to a person's individual autonomy; it exists between us, in relationships of love and respect. Staff observe that the pleasure of a visit in terms of mood can last much longer than the memory of the event; and over time, someone who is regularly visited often displays improved mental well-being. One of the very moving experiences I have with my dad is that now he is settled and well cared for, and has come to understand that he needs to be cared for, he has been able to let go of some of his anxieties, which he couldn't do while he had the responsibility to look after himself. I always knew he loved me, but now he says this much more than in the past, and he likes to sit with me and hold my hand; he has become quite touchy-feely. Some of his habitual carapace of worry has been shed. Nobody suggested to me that dementia, well cared for, could bring actual benefits. And yet I would say that this relaxation on his part has an important spiritual dimension, which is about the last part of his journey on this earth.

An awareness of the spiritual dimension, which of course is well recognised by MHA, makes a significant contribution to the person-centred approach. As Swinton points out, it is not enough to say that other people preserve the personhood of the dementia sufferer; for what are we to say about those sufferers who do not have loved ones who maintain their identity for them? We have to go further than this and affirm that for all of us, whether we remember ourselves or not, our very existence depends on being remembered by God, being held in God's memory.⁹ This reality is painfully clear in the case of the dementia sufferer. Margaret Hutchison recounts the case study of a woman who paced the corridors of her nursing home repeating endlessly just one word: 'God, God, God.' The staff didn't know what was causing her distress or how to help. Then one nurse had an inspiration, and enquired, 'Are you afraid that you will forget God?' 'Yes, Yes!' she replied emphatically. So then the nurse said, 'You know that even if you forget God, he will not forget you. He has

promised that.' Immediately the woman became calmer, and she ceased this distressed behaviour.¹⁰

We should not underestimate the spiritual pain that dementia sufferers can feel, especially when they have been devout, and they feel that their spiritual practices are slipping away from them. There is a remarkable little book written by Robert Davis and his wife, dating back to the late 1980s, *My Journey into Alzheimer's Disease*. Davis, an evangelical pastor of a huge and successful church in the USA, was struck very suddenly with early onset Alzheimer's, which had a big impact on his whole experience of faith. He made the effort, before his symptoms became too severe, of writing down what this felt like from the inside, and this book remains one of the most significant testimonies from a dementia sufferer about spirituality. Not everyone will experience the same things, of course. But Davis found an immediate impact on how he experienced his faith. Having been able in the past, when he prayed, to recall many inspiring visual memories for which he was thankful, he entirely lost this capacity all at once. Instead, he frequently felt the descent of a fog or a darkness which filled him with horror; he felt gripped by paranoia instead of the easy willingness to trust in the Lord, which he had rested in before. And here he gives us some additional insight about the impulse towards 'pacing' that I spoke of earlier. He affirms that vigorous exercise really helped dispel this fog, so he used an exercise bike, as well as asking others to gently point out to him when his paranoia was taking over. It is also interesting to see which parts of Christian practice remained helpful to him, and which things fell away. Having been a passionate user of modern translations of Scripture, and modern church music, these things became no longer helpful. The old translations were better, especially the Psalms and the sayings of Jesus. And the only kinds of music that remained important were the old gospel or traditional hymns he grew up with. But these did still carry important emotional resonance and comfort.¹¹

There was a lovely article by Nicci Gerrard in the *Observer on Sunday* about a new parliamentary report on dementia and the arts, and she tells this story:

Sitting in a church in Essex on a Sunday in June, I look across at my friend's mother. She is in her 90s and has dementia. There are days when she is wretched, chaotic and scared, but each Sunday she is soothed and even enraptured by singing the hymns that she sang when she was a girl. The music has worn grooves in her memory and while she may not be able to speak in full sentences any more, she can sing 'Abide with Me' in a true voice and her face, lifted up, looks

young, eager, washed clean of anxiety. My friend thinks that at these moments her mother's brain comes together, 'like a flower reviving when it's being soaked in water.' People with dementia, she says, need to be drenched in art.¹²

Now, I'm sure this woman's daughter is not wrong about the power of art and music. But this story is clearly also about her mother's spiritual life, her walk with God, which she is free to celebrate in this familiar hymn.

I have certainly witnessed something like this in the MHA care home. They have a special large-print hymn book with 100 favourites in, and I was delighted to see, when Dad started at the Meadow, that they hold substantial 'proper' services and include plenty of old hymns. My dad sings out lustily, and so do many of the residents, even if they can no longer read, because the words, tunes and no doubt the feelings associated with them are reawakened in this context. The chaplain uses the King James Version of the Bible, and she offers proper sermons, brief though they may be. There is clarity but no patronising of this congregation. They are addressed as full grown-up people with needs, regrets and longings such as we all have. They are expected to need confession as well as affirmation. They do not need simple words or childish phrases: they need old words which their long-term memories and their years of religious practice have invested with personal meaning. Music seems to address and involve multiple parts of the brain, and hymns of course carry the familiar words too. My dad, who had come from a much more typical care home where a very short communion service was offered, minus any hymns, only once a month, evidently fell on this twice-weekly worship as balm in Gilead. He had re-entered a world where his sacred fire was being guarded and nurtured.

But this is not true for many sufferers of dementia, and I think it's a huge issue for the Church as a whole, not just those of us who have immediate loved ones for whom we have responsibility. I think the Church's ministry to this community of people is inclined to be patchy and not well thought through. It's so easy for gradually declining members of congregations just to fade out of sight and then perhaps be moved away and beyond their church's radar, even if they have devoted a lifetime of service there. Let's think about the different forgotten populations:

- Churchgoers who become housebound, who need help to get to church or to manage the service when they are there.
- Churchgoers who have to move away to be nearer relatives or into

residential care, which may be a good distance away so that visiting becomes impossible.

- Churchgoers who move into the area for the same reasons, who used to have strong church connections elsewhere, but need real help to be welcomed into a new context and get to a new church. Their relatives may or may not know how to support their particular spiritual needs.
- Churchgoers and sympathisers who are now housebound in residential care locally to us and who would really appreciate Christian visiting and regular worship, especially in care homes that have no chaplain.
- In the wider community, local dementia sufferers and their carers who would come to weekday activity sessions and socials – and maybe gentle worship – if these were dementia friendly.

Why should we make these communities a priority in ministry? I'm sorry to say that I have heard ministers speak disparagingly about how they don't want their own ministry to be about 'palliative care', and take it as read that targeting the young is much more important for the future of the Church. Well, if we only consider these things in a self-interested way, let's remember that all of us are being touched by dementia these days: our friends, partners, parents, grandparents, great-grandparents. Just as no one ever forgets how they have been treated by the Church around the death and funeral of someone they love, so they never forget how the Church embraces or neglects the spiritual needs of their loved ones with dementia. When, for reasons of what she could afford and where a care home place was available, my aunt had to move beyond visiting distance from her usual church, I discovered that the village's parish church, which had a connection to the home, was in an interregnum. A local Methodist minister was covering, so I rang him and explained my aunt's move and her lifelong, inspiring Christian faith, and asked him to make a visit. He refused. No doubt he was stretched to breaking point, but so was I, and so was my aunt. At the same time I have a powerful, very different memory about my mother. My dad cared for her and used to take her with him to all the activities they used to do together, including choral society. One day they were singing a Mass in the local Catholic church, and the Eucharist was taking place. The choir were in the gallery, and I attended in the body of the church to look after my mum. Non-Catholics were not expected to go up for communion, but Mum was past making distinctions, and went forward in a determined way. The priest was fully aware that she was Anglican, and I had no idea what he would do. She beamed at him. 'May I?' she enquired. He beamed at her: 'You

may', and gave her the host. I still weep when I think of how effortlessly and graciously that man broke his Church's rules in the interests of respecting the personhood of my mum, who had become one of God's little ones before whom we must not place a stumbling block.

Of course, the Church should minister to dementia sufferers for their own sakes, because they need us and because we have, in the name of God and of the wider Church, made promises to all of the baptised that we ought to keep. Where they can no longer guard their own holy fire, we should seek them out and help to guard it for them. We should do this because they are held in the memory of God even when their own memories have partly or wholly failed, and because it is for us to act in God's name and to show forth that steadfast love which is what God requires of us. Going back to Charles Wesley's hymn, I think one of the most significant words in it is that word 'repeat' – 'my acts of faith and love *repeat*'. Such an ordinary little word, but potentially covering so many years of devotion. Love in this context is frequently a matter of repeating what needs doing, over and over. Nothing as dramatic as a burnt offering; just faithful, loving repetition.

Dementia is very unsettling, and presents spiritual challenges for both sufferers and those who accompany and witness it. It upends our expectations about relationships and it invites us creatively to break many social rules. It makes us question the nature of human autonomy and what we mean by dignity. It denies us the normal logical rules by which a conversation proceeds, and invites us to enter a reality that is not the reality that we, the caretakers, recognise as accurate here and now. It asks of us that we strip down our ways of relating to people so that we prioritise the communication of love and touch, surrendering quite a lot of the knowledge, reason and status that is normally negotiated between adults. It takes us to a place where babies and toddlers instinctively show us the way to connect warmly and directly with those we love. It asks us to step outside of the malignant social attitudes that surround our thinking about this condition. It invites us to prioritise people who are more vulnerable than any we will ever come across, and who are never, in this life, going to get better. It asks us not to be afraid. It asks us to keep faith. It asks us to become like God.

O Thou who camest from above
The pure celestial fire to impart,
Kindle a flame of sacred love
On the mean altar of my heart.

There let it for thy glory burn
With inextinguishable blaze,
And trembling to its source return
In humble prayer and fervent praise.

Jesus, confirm my heart's desire
To work and speak and think for thee;
Still let me guard the holy fire,
And still stir up thy gift in me.

Ready for all thy perfect will,
My acts of faith and love repeat,
Till death thy endless mercies seal,
And make the sacrifice complete.¹³

Notes

1. Christine de Luca, *Dat Trickster Sun*, Edinburgh: Mariscat Press, 2014, p. 29. Used with permission.
2. Readers are directed to an earlier article in *Holiness* by Christopher Collins, 'Reimagining dementia: seeings ourselves more fully in the dementia-diagnosed', *Holiness* 3(1) (2017), pp. 57–69.
3. This concept, developed by Tom Kitwood and Steven Sabat, is discussed extensively in John Swinton, *Dementia: Living in the Memories of God*, London: SCM Press, 2012, especially pp. 88–91 and 122–134.
4. Swinton, *Dementia*, p. 281.
5. 'Food for Thought – on Caring', *World Federation of Occupational Therapists Bulletin* (1985), quoted in Eileen Shamy, *More than Body, Brain and Breath: A Guide to the Spiritual Dimension of Care for People with Alzheimer's Disease and Related Dementia*, London: Jessica Kingsley Publishers, 2003, p. 34.
6. Erik Eckholm, 'Robertson Stirs Passions with Suggestion to Divorce an Alzheimer's Patient', *The New York Times*. Access at: www.nytimes.com/2011/09/17/us/pat-robertson-remarks-on-alzheimers-stir-passions.html, quoted in Swinton, *Dementia*, pp. 117–118.
7. Shamy, *More than Body, Brain and Breath*, p. 136.
8. The following points are taken from Swinton's summary of the work of Tom Kitwood, in Swinton, *Dementia*, pp. 72–74.
9. Swinton, *Dementia*, p. 149.
10. Margaret G. Hutchison, 'Unity and Diversity in Spiritual Care', paper presented at the Sydney University Nursing Society Conference in NSW, September 1997. Access at: http://members.tripod.com/marg_hutchison/nurse-4.html. Quoted in Swinton, *Dementia*, p. 196.

11. Robert and Betty Davis, *My Journey into Alzheimer's Disease*, Amersham: Scripture Press, 1993, pp. 133–135.
12. Nicci Gerrard, 'Art Can Be a Powerful Medicine against Dementia', *Observer on Sunday*, 16 July 2017.
13. Charles Wesley.

Update from the author

At the time of editing, in October 2018, Janet's father Frank is still living contentedly in The Meadow, and has recently been delighted to meet his latest baby great-grandchild. He cannot retain her name, but spontaneously sings to her, 'Happy birthday, dear darling', making her smile.

