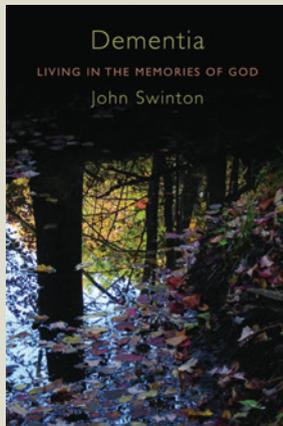


Dementia and what it is to be human



Matthew Sleeman has been reading a book which takes a critical look at how society and the church treat people living with dementia



Dementia: Living in the Memories of God

John Swinton
Eerdmans, 2012

Given our fixation on youth, vitality and the power of personality and individual human choice, dementia is one of the horsemen stalking our contemporary culture. It lurks only just below the surface in discussions of the 'problems' raised by an increasingly aging society. But it is submerged, avoided, even in churches and the experience of many believers.

As John Swinton says in this very thought-provoking book, 'Cancer evokes concern; dementia evokes fear.' It forms the photographic negative of humanity living under the fear of death (Hebrews 2:15). For many, it is the unaddressed fear of losing one's memory, and thus one's self.

John Swinton urges us to see dementia differently and to relate Christianity with its sufferers and

their carers. He opposes the standard neurobiological explanations of dementia as 'deeply inadequate'. These defect-based understandings of dementia are, he claims, reductive and destructive.

Dementia also has psychological and social dimensions but, to be seen properly, Swinton locates it as a theological disease, afflicting how personhood is lived out within God's creation. The second half of his book addresses that pastoral-theological side of dementia, but not before the opening chapters have critiqued dementia's 'standard story' with the seeds of a counter-story for approaching its impact on both its sufferers and their carers.

Since our words shape worlds, Swinton resists reducing dementia

sufferers to patients at the expense of their personhood. Herein lies his first challenge to believers and the churches. What is needed, Swinton contends, is an expanded medical perspective which is alert to what he terms 'malignant social interactions' which threaten the very humanness of the dementia sufferer.

Rather than dementia itself entailing a loss of mind and of self, he says the disease often provokes others to assume this is happening. The sufferer then becomes their diagnosis, and their other social roles and positions become forgotten.

Citing how even Ronald Reagan's circle of friends and visitors diminished with his advancing condition, Swinton powerfully contrasts the progressive isolation and loneliness dementia engenders with the continuing and even strengthened moral and social obligation felt by friends supporting those suffering terminal cancer.

Within this contrast, Swinton takes issue with what he terms 'capacities-based practices of love'. He reaches instead for a view of humanity made in a relational image of God, where personhood precedes relationship and relationships are possessed by persons, rather than relationships legitimating personhood.

Our identity and worth is not bounded by our skulls or our skills. Rather, the basis for this is our dependence on God's existence, his creating and sustaining marked by his

remembering of us. God remembers, therefore I am.

For Swinton, dementia does not erase this priority and prior reality. As such, he is well positioned to critique secular humanist models of 'person-centred care' which provide only 'a synonym for good care rather than a statement about someone's moral standing'.

At the same time, he questions some restrictive assumptions which can neuter Christian responses to dementia. Subjectivist Christian songs can be unwittingly reductive. Swinton highlights Darlene Zschech's 'Shout to the Lord' as assuming 'a self-aware, cognizing self': singing 'my Jesus, my Saviour' assumes a 'me' who 'can remember what such knowledge might mean for one's salvation'.

More brazen implications arise in some triumphalist forms of Christianity which actually jettison the dementia sufferer. Pat Robertson's 2011 broadcasted advice to the husband of a dementia-sufferer to divorce her and 'start all over again' since 'that person is gone' provides a clear, if chilling, example of this deficient

understanding of personhood and the non-relating which flows from it.

For me, though, the challenge came much closer to home in more subtle ways which impact more directly on ministerial education and everyday Christian living. Swinton quotes one writer who asks whether middle-class friendships can bear the weight of deep and diffuse obligations to care in the face of dementia.

He asks whether a need for distance and safety means that we turn people into strangers. He quotes a repentant church leader who wonders where the dementia sufferers and their carers had been during his busy ministry, commenting that if such people were elsewhere, then, in terms of the church, actually they were nowhere.

One big strength within Swinton's analysis is that his constructive strategies centre around the practices of the local church. This comes into focus in the book's second half. If God will remember sufferers and carers even while wider society seems or seeks to forget, then the church stands as 'the only community that exists

Swinton powerfully contrasts the progressive isolation and loneliness dementia engenders with the continuing and even strengthened moral and social obligation felt by friends supporting those suffering terminal cancer

Swinton looks for churches to offer hospitality to those who are becoming strangers, to offer welcome which breaks the alienating processes afflicting both sufferers and carers

solely to bear active witness to the living memory of Jesus... the place where people learn to see what God's memory looks like.' The weak and the vulnerable can here find their place.

Swinton's proposals are varied. He commends song, music, art, dance and ritual as able to function as modes of extended memory, which can unlock emotions, feelings and recollections. This will be a challenge for a culture (and its churches) which celebrates individualism, innovation and change.

More foundationally, his urge to believers to become 'friends of time' confronts my busy, activist self. Can I prioritise attentiveness and 'soulful companionship', a caring which learns (and yearns) to hear and call the individual by name in an extended way that counters and inhabits the sometimes terrifying affliction that accompanies the dementia process? What will this mean, in terms of my time, energies, attention and relational stamina? These questions are searching ones.

Swinton looks for churches to offer hospitality to those who are becoming strangers, to offer welcome which breaks the alienating processes

afflicting both sufferers and carers. Churches, he hopes, will embrace enduringly real people, a relational and spiritual condition, not simply confront a neurological decline. With rethought gestures of love and a biblically robust theology of visitation, Swinton calls for practices which follow God's initiatives in visiting us.

His vision is that through care and support, carers and sufferers can find in churches somewhere to belong, to express their experiences and to think about dementia differently.

'Dementia may be a tragic affliction, but there is much to be hoped for as we can create the types of relationships and communities that will allow us to see properly, hope realistically, and remember with a love that drives us into the presence of people with dementia.'

My biggest concern with this book concerns its relatively vague contours for God's love. As I read, I was reminded of Don Carson's little book *The Difficult Doctrine of the Love of God* (Crossway, 1999). I longed for Swinton's powerful advocacy 'to rethink the practices of love within the context of dementia' to take on board Carson's variegated

dimensions of divine love within its overall biblical revelation.

Many of Swinton's most powerfully hopeful statements struck me as particularly – even narrowly – applicable to those with trusting faith in the saving work of Jesus, even if Swinton appears, on the surface at least, to pitch them more widely, as more general in scope. This is not to deny a dignity to every and each dementia sufferer: there is another dimension of God's love for all that he has made, and for all who are made in his image.

But fallen humans living in the memories of God is a sharply double-edged reality when we are speaking of the holy God, 'from whom no secrets are hidden', who will judge the living and the dead. Ultimately, divine remembrance is good news only within the context of covenant grace.

Thus understood, perhaps Darlene Zschech does serve the believing dementia sufferer well: 'nothing compares to the promise I have in you.'

These concerns are fundamental, but require a nuancing of Swinton's argument rather than its rejection. Here is a book with much to resource individual Christians and churches. It has opened my eyes to *how* to reach out to, and include, those affected by dementia within the life of the church.

This is a book to feed on and return to. It provides nourishing challenges and ongoing and growing questions, as well as directive and generative answers.