

Dementia: Living in the memories of God

John Swinton

SCM press, 2012, p/b pp.298 ISBN

9780334046721 **Book Review by Dr Alison Gray**



This book looks at the Christian theology of dementia. John Swinton is the Professor of Practical Theology and Pastoral Care in the University of Aberdeen, and a former psychiatric nurse and hospital chaplain.

Swinton articulates a theological reading which, whilst acknowledging the pain and loss of advanced dementia, provides hope and fresh possibilities even when memory has failed that enables us to respond to those living with dementia in a positive and affirming way. The theme of enabling people with dementia to tell their own story, and telling the right stories about them comes through strongly.

The book takes us in ten chapters, from the limitations of the medical view of dementia through the meaning of personhood to a point where even if we cannot remember, what is fundamental is that we are remembered by the community and by God'.

Dementia has been described as the 'Theological disease'ⁱ because it seems to damage the self, raising difficult questions about personhood, sin and salvation. Much of Christianity is heavily intellectual, concerned with believing the right things. What happens when someone loses the intellectual capacity to seek and know God in that way? Knowing God is so much more than knowing intellectually *about* God.

The medical story of the continuous decline of dementia, is accurate but limited. It is not the only narrative that can be told. It can be challenged by the Christian story, and by individual stories. A personal example would be a woman I recently met whose mother has moderately advanced dementia. She described how her mother's character had changed in a way that enabled them to heal a relationship which had been strained for many years. 'There is more love there now than ever before'. Such individual stories counter the automatic assumptions of nothing but failure, pain and suffering.

There is more to life than biomedical reductionism, and there is more to the experience of dementia than neurological deficits. The neuropsychiatric definition of dementia is couched entirely in terms of what the person can no longer do. Whilst this is necessary for appropriate medical care, it is not the appropriate place for the pastoral care literature and theology to start.

We interpret the behaviour of the person with advanced dementia as more or less meaningful depending on the particular lens we are looking through. Giving people the 'benefit of the doubt' by assuming their actions are meaningful, can reveal true meaning.

The author revisits Tom Kitwood's argument that the negative ways we think about and treat people with dementia actually exacerbates their neurological decline. We can all think of cases where people have gone into nursing homes and rapidly gone downhill. Conversely where care is good, examples of improvement and 're-mentia' can occur.

Although dementia leads to many losses, some of these are a consequence of withdrawal of friends and neighbours rather than a direct consequence of the disease itself. Swinton describes the stigma of dementia, which parallels the stigma experienced by those with severe and enduring mental illnesses, leading to social rejection and isolation, inappropriate loss of employment, and underfunded services.

'Dementia is the product of both damaged neurons and the experience of particular forms of relationship and community.' p107.

The author goes on to tackle the question 'are people with advanced dementia still people?' quoting several examples of such individuals being labelled as 'gone travelling, sending an occasional postcard home', 'empty shells', even as 'Zombies'. This is a fundamental question since if the individual's mind is really completely absent then he/she is no longer a person, and if we follow the arguments of Peter Singer, can be legitimately killed. Swinton then highlights the failure of Singer's argument from Singer's own case; instead of arranging euthanasia for his mother with severe dementia, Singer paid for round the clock care saying 'because it's different when it's your mother.' (p133). Several internet videos show the effect of music on those with advanced dementia, demonstrating that they are not empty shells, and briefly enabling communication which had seemed to be lostⁱⁱ.

Basing the value and meaning of a person's life on their cognitive capacities is problematic since those with advanced dementia then lose their personhood. Kitwood argues that they should still be seen as persons because of their relationships. For Swinton this is problematic, since relationships shift and change, and as people with dementia tend to lose their relationships over time, again they would be deprived of personhood. The author then argues (after Spaemann) that it is not capacities or human relationships we should be focussing on, but that being a person is a status that flows from being a human individual in the world. Swinton affirms Christian teaching that it is our relationship with God which gives us value.

The book then turns to consider the view of being 'held in the memory of God'. Swinton allows Christine Bryden, a Christian woman with pre-senile dementia, to speak. *'I believe that I am much more than just my brain structure and function, which is declining daily. My creation in the divine image is as a soul*

capable of love, sacrifice and hope, not as a perfect human being, in mind or body. I want you to relate to me in that way, seeing me as God sees me.' (p.193)

In this view, cogito ergo sum - I think therefore I am - is replaced with 'We are because we are sustained in God's memory.'

The author considers how human memory is widely viewed as a tape recorder dispassionately recording events, and then demonstrates how memory is more like a jigsaw puzzle, restructured depending on emotion and on subsequent events. In the same way that personhood is partly internal and partly external so memory is also held externally, both in objects like mobile phones, and in other people. When other people remind us of stories about ourselves we are given back those memories. Being remembered well sustains people's personhood.

God does not have a brain, and God sits outside of time, so cannot have a memory in the same way as humans have, yet throughout the Hebrew Scriptures there are many references to God remembering. God says 'I will not forget you. See, I have engraved you on the palms of my hands.' (Isaiah 49: 15-16). God's memory is viewed as sustenance and action. 'To be remembered is to be sustained, to be forgotten is to cease to exist.' (p214). The memories of God are re-enacted in religious rituals, and in interactions of the community of believers.

People with dementia are living in a continuous present; they feel joy or sadness in the moment. Many value religious ritual and are fully present, for example, at the moment of taking communion, even though they don't remember it afterwards. People often do not call on those with dementia since they are not going to remember their visit, but since they can enjoy the moment, and since the emotion generated will linger on, so visiting is very worthwhile.

Swinton's final chapter covers the need for hospitality to strangers, suggesting that in deep dementia even well-known people become strangers. The Christian community is one place that should be welcoming and open to people with dementia, although Swinton acknowledges it isn't always soⁱⁱⁱ.

This book is very helpful for Christians working with people with dementia. The theology is clearly presented and built up step-by-step to a nuanced statement of what it means to be held in the memory of God. It is an important challenge to the prevailing negative rhetoric regarding those with advanced dementia.

ⁱ David Keck, *Forgetting Whose We Are: Alzheimer's Disease and the Love of God*. (Nashville: Abingdon press, 1996)

ⁱⁱ Gladys Wilson and Naomi Feil <http://www.youtube.com/watch?v=CrZXz10FcVM> and *Alive Inside*, Available at: <http://www.youtube.com/watch?v=NKDXuCE7LeQ>

ⁱⁱⁱ Livability Dementia Friendly Churches. Available at: <http://www.livability.org.uk/church/dementia-friendly-churches/>