

*Dementia: Living in the Memories of God*¹ — a review

Kirsty Jones

*'Who are we when we have forgotten ourselves and those whom we once loved? Who are we before God when we have forgotten who God is?'*²

When John Swinton's book *Dementia: Living in the Memories of God* (hereafter, *Memories*) won the prestigious Michael Ramsey book prize in summer 2016,³ disability theology received welcome renewed attention. Swinton's address inspired, and opened people's minds to new ways of being human, and being in relationships. For those enmeshed in the world of hyper-cognition and those inhabiting a world of failing cognition, this book offers hope and help.

Sitting at the intersection between academic and practical theology, *Memories* is not a book which will provide a 'quick fix' for people with dementia and those caring for them. It issues a challenge to move 'beyond current tendencies to perceive the subjective, self-aware, cognitive self as the necessary qualification for humanness and theological construction',⁴ and issues a call for change towards the church and its members. God's memory, not human memory, is key, as Swinton considers 'the possibility that knowing about God may not be as important as knowing God, and that knowing God involves much more than memory, intellect, and cognition' (15).

Rhetoric and readership

'Scripture's task', Swinton holds, 'is to redescribe the world' (17); the style and substance of *Memories* illustrate this. Swinton dialogues extensively with the Bible and with academics from various disciplines, integrating Scripture, scholarship and story. In this way, the cries of the Bible and the cries of contemporary people ring out in unison.⁵

With lucid and engaging prose, informative tables (40) and clearly defined structure, *Memories* is an easy read on one level. Swinton stands apart from most scholars in the subtle way in which he appreciates the diversity of human experiences: 'under normal circumstances, most people are able to effectively negotiate their narrative worlds and gain and retain a more or less realistic state of who they are' (22). The key is in the term 'most', challenging the assumption of 'all' which all too frequently appears in academia.

A tension perhaps inevitably arises between the rigour and skill demonstrated in the book, which is integral to its success, and the need for applicability: many individuals who would benefit from Swinton's work (for example busy carers or individuals in the early stages of dementia) would find the academic nature of the work challenging. Given *Memories'* acclaim, an adapted version, made into a course for groups with links to the book and audio-visuals would be very helpful, extending the call for change beyond the book's initial readership.⁶

Who are dementia sufferers?

*'Personhood precedes capacities'*⁷

Keck's claim that dementia is 'deconstruction incarnate'⁸ is thoroughly refuted by Swinton, who emphasises that 'dementia happens to people who are loved by God, who are made in God's image' (8). Having dementia does not stop people being made in the image of God. Swinton does not break people down into their 'constituent parts' (34, 50), but describes them in terms of what they are, not what they are no longer. 'Words matter' (46) when describing people with dementia, and theories matter; characterising someone by the 'defective model' is what deconstructs their humanity, not dementia itself.

Dementia sufferers are people who live with dementia — whether the condition is located within their body or in the body of someone they care for. Recognising this, and that people with dementia are not always easy to love, Swinton deals with the subjective complexity of what loving someone is, upholding the validity of carer experiences. He offers hope, not of change, but through the changeless God who speaks comfort.

‘Person-centered care’: relationships and relationality

Swinton’s professional background⁹ gives him acute awareness of ‘person-centered care’,¹⁰ and he discusses this byword in fresh ways against a backdrop of secular humanism, biblical truth and Christian thought. Buber’s I-Thou theology is applied to dementia; Swinton states that when relationships are places of ‘experiencing without conceptualizing, of being without knowing’ (159), ‘care and caring relationships are what hold persons in their personhood, not their failing capacity to do certain things’ (140).

Ideally, people with dementia are part of communities which uphold their personhood and remember them as they were, are and will be. In practice, however, people with dementia are often isolated, lonely and afraid. Swinton acknowledges that relational breakdown characterises dementia and that although human relationships model ‘divine relationality’ and are important, they do not make a person (159).

Cognitively centred?

When relationships fail along with cognition, Swinton affirms that personhood stands. Neither lack of ability nor lack of relationships changes personhood. Keck makes cognitive ability a central tenet of personhood for theological reflection (thereby raising questions about other disabilities), an approach which smacks of hyper-cognition. This condition is endemic in ‘liberal western cultures’ (80) where the ability to reason and succeed intellectually is prized so highly while other elements of personhood are devalued. If you do not or cannot think, you are not. Problems thus arise when an individual never has, or loses, memory and intellect.

Spaemann, quoted by Swinton, writes that ‘human beings have certain definitive properties that license us to call them “persons”; but it is not the properties we call persons, but the human beings who possess the properties’.¹¹ *Cogito ergo sum* is reconsidered; human beings are not human ‘thinkings’ or ‘doings’. Having knowledge does not make someone human. When one individual in a relationship does have cognitive ability, however, they have a responsibility to use it carefully and constructively.

This is poignantly brought out in Swinton’s observation that there is a tendency to make everything people do a characteristic of the illness. Consider a lady with dementia who is terrified when she sees a black dog across the street. Her paid carer attributes this reaction to her condition, and to her forgetting that she owned a dog; her daughter knows that her mother and her dog were attacked by a black dog and that her mother has been wary ever since. Swinton reminds us that knowing someone changes something, and that God’s knowing everyone changes everything.

Memory

‘Memory is first and foremost something that is done for us, rather than something we achieve on our own.’¹²

This is a deeply poignant statement when one has ceased to remember. For Swinton, memory can be ‘done for’ people with dementia by the communities which surround them, but is ultimately a divine act. Although Swinton is aware of, and skilfully explains, theories of memory (semantic, episodic and procedural), he also weaves them together with a theology of memory. He observes that when God forgets, things cease to exist. God’s remembering, on the other hand, is purposeful and powerful. Being held in the memory of a God who remembers the covenant provides the insurmountable comfort that God remembers people with dementia, standing with and advocating for them. In Swinton’s words, ‘if God remembers me, then my “vanishing self” will be in some sense preserved’ (205).

God is completely certain about who a person is, and his memories are not the coloured and convoluted constructions of human memory. This means that when God remembers someone, he remembers them as they are. When other humans remember, following the model of divine-human relationality, they are called to love abundantly when they see deep flaws, to love patiently when they are rebuked and to love graciously when they are hated.

Knowing God

Swinton addresses the key questions of how God can be known if one cannot think, and how God can be remembered when one's relatives are forgotten. A simple but resonant truth is contained in the observation that the creeds do not start with 'I remember' but with 'I believe'.¹³ Although there is much merit in understanding one's faith, there is also merit in acknowledging that faith does not always come through understanding. This vital insight exposes how many churches intellectualise faith, with the result that many people are effectively left outside. If churches would consider more carefully how humans, and faith, come in many forms, they could move closer to becoming real communities of belonging.

A call to action

Hope and healing are topics with which disability theology constantly grapples. In *Memories*, Swinton provides a possible insight into these in his discussion of 'excess disability' (86). 'Excess disability' refers to the extra disability that society adds to a disabling condition. The idea combines the medical and social models of disability by recognising that disability is not only part of an individual but also part of their community. With this understanding, it holds that people with a disability, like dementia, are more disabled in some social contexts than others; a lady with dementia has more disability at an intellectually-based Bible study than when attending a craft morning. Churches, I suggest, have a role in healing insofar as they are called to strip away the 'excess disability' and accept the person who remains without always looking to change them — even when that is uncomfortable.

Whilst I agree that we should not use the 'defective' model of human sufferers, I think that we can use it of human societies. Societies fail when they do not adequately care for and acknowledge the divine nature of everyone, regardless of their human state. Swinton writes that a hallmark of a fallen creation is that 'dementia is but another example of the limitedness and mortality of the human condition' (186). I would only add that, although a failure to remember marks limitation, the failure to remember people with dementia is more serious than the failure of people with dementia to remember.

If failure of society is marked by impaired relationships, what marks successful relationality? For Swinton, it is modelled on divine-human relationality. Dementia is a 'hard condition to be around' (104). This is so, I suggest, because it cuts to the core of what being human is — how we find being loved, being lovable and loving so incredibly difficult.

Because experiences of people who are 'different' shape our perspectives on humanity, so 'experiences of people with dementia matter for the ways in which we understand humanness' (161). Dementia, like other disabilities, shows the messiness of being human, and this invites (indeed compels) us to love people as they are, as God does. When one conceives relationality as necessarily reciprocal, or assumes that human remembering underpins human relationships, the divine-human relationship is not mirrored. Swinton proposes that a more open approach, adopting Vanier's oft-quoted phrase, is based on the multiple, sometimes challenging and novel ways of saying to people 'it's good that you exist; it's good that you are in this world'.¹⁴

Keys to radical relationality are becoming 'friends of strangers' and becoming a 'friend of time'. When dementia causes people to appear strange, or as strangers, Swinton calls the church to fight strangeness with love — accepting and embracing it. The strangeness of people with dementia reflects the strangeness of all Christians, people who live as strangers in their own land, people whose 'true home is heaven' (267). If all Christians are strangers, then hospitality is always 'among strangers'.

In becoming 'friends of time',¹⁵ one remembers through presence, 'being with another without doing anything for another' (229). God, Swinton writes, remembers us by being present with us, so Christians are called to remember through real presence with people with dementia. Spending 'being' time is not wasting time, but it gives people little to hide behind, and points towards a novel conception of being in relationship.

Sensory memory and the sensorial God

'things such as songs, music, art, dance and ritual actually function as modes of extended memory'.¹⁶

Swinton speaks of cognitive and bodily knowledge and the inextricable link between mind-body-soul. He states that 'in order to be present and to hold someone well, we need to understand the language and memory of the body as well as the language and memory that springs from our neurons'.¹⁷ I would suggest here that an important

unexplored avenue relates to the theology of dementia and sensory processing. Sensory processing, which embraces epistemology and embodiment, relates to the way in which sensory stimuli are processed by the brain. Different sensory stimuli provoke remembering and response, and individuals with dementia often respond well to sensory therapies which encourage them to remember through stimulating a sense.¹⁸

Studying the ways that sensory ritual has been used in Christian practice in the past and present, and how communion between God and man, as well as man and man can be fostered on sensory (rather than emotive or cognitive) grounds may prove fruitful. If it is the role of the church to remove 'excess disability' but promote meaningful ritual activity, then a collective remembering of the sensory rhetoric which underpins revelation and response in Scripture, and the sensory heritage of the church, could profoundly benefit people with dementia.

Conclusion

Offering an original and carefully constructed theology of dementia, *Memories* is essential reading for academic and pastoral work on disability and anthropology. Swinton effectively shows why the church should care about people living with dementia, and how it can care well. God, he emphasises, cares because he remembers persons as they were, are and will be, holding their reality in his hands and cherishing each moment of joy and sorrow. Remembering, for God, is purposeful and powerful; his memory is the foundation of humanity and each human life. Inspired by such a vision, the book moves us cognitively beyond narrow conceptions, emotively beyond apathy, and practically into action.

For further reading

- C. Bryden and E. MacKinlay, 'Dementia: A Spiritual Journey Towards the Divine: A Personal View of Dementia', *Journal of Religious Gerontology* 13.3/4 (2003), 69-75.
- D. Keck, *Forgetting Whose We Are: Alzheimer's Disease and the Love of God* (Abingdon Press, 1996).
- R. Spaemann, *Persons: The Difference between "Someone" and "Something"*, trans. Oliver O'Donovan (Oxford University Press, 2006).
- J. Swinton, *Becoming Friends of Time: Disability, Timefulness, and Gentle Discipleship* (Baylor University Press, 2016).

Kirsty Jones is a KLICE Research Associate and has recently completed her MPhil in Old Testament at the University of Cambridge, with a research interest in Disability in the Old Testament and Biblical Ethics of Disability.

¹ SCM Press, 2012. Also published by Eerdmans (2012).

² *Memories*, 187.

³ <http://www.archbishopofcanterbury.org/articles.php/5761/john-swintons-dementia-living-in-the-memories-of-god-wins-michael-ramsey-prize>

⁴ *Memories*, 15. Subsequent page references in the text are to this work.

⁵ Fittingly, since we 'actually [live] within the strange world that is described in the Bible'. *Memories*, 19.

⁶ See also the excellent resources provided by the Liveability team: <http://www.livability.org.uk/blog-and-resources/training-and-events/dementia-friendly-churches/>.

⁷ *Memories*, 155.

⁸ *Memories*, 190, 194, cf. D. Keck, *Forgetting Whose We Are: Alzheimer's Disease and the Love of God* (Abingdon Press, 1996), 32.

⁹ Swinton worked in mental health and learning disability nursing, remains part of the Scottish Association of Healthcare Chaplains and Nursing and Midwifery Council and sits on the National Board of Social Responsibility of the Church of Scotland. <http://www.abdn.ac.uk/sdhp/people/profiles/j.swinton>.

¹⁰ See chapter 6.

¹¹ *Memories*, 155. See R. Spaemann, *Persons: The Difference between 'Someone' and 'Something'*, trans. Oliver O'Donovan (Oxford University Press, 2006), 257.

¹² *Memories*, 197.

¹³ *Memories*, 193, quoting C. Bryden, E. MacKinlay, 'Dementia: A Spiritual Journey Towards the Divine: A Personal View of Dementia', *Journal of Religious Gerontology* 13: 3/4 (2003), 69-75, at 72.

¹⁴ See *Memories*, 180, 182, 230, 280.

¹⁵ See e.g., *Memories*, 228-9, 251, and J. Swinton, *Becoming Friends of Time: Disability, Timefulness, and Gentle Discipleship* (Baylor University Press, 2016).

¹⁶ *Memories*, 250.

¹⁷ *Memories*, 247. See also 251.

¹⁸ Consider how one smell or song can evoke a powerful memory, and sometimes an emotional response.