

Deterritorializing Dementia: A Review of John Swinton, *Dementia: Living in the Memories of God*.¹

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One of John Swinton's objectives in his recent book, Dementia: Living in the Memories of God, is to 'deterritorialize' dementia: dementia is not the privileged domain of the neurologist. Following Tom Kitwood, Swinton argues that dementia is as much relational and social as it is neurological. But he does warn against the moral implications of a radical relational approach. The belief that people are kept in the memories of God offers the only adequate description and approach to dementia. This review will present Swinton's argument and raise critical questions about his understanding of the hegemonic role of theology.

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John Swinton's recent book on dementia may become a landmark study because of the original and audacious claims it defends. It is written by a Christian theologian who offers a comprehensive approach to dementia – to the disease, to those suffering from it, and to the care of those living with them. Its far-reaching claims make it vulnerable as well. Because he is not a neurologist, he dares to subject the 'standard biomedical model' to severe criticism. And by putting 'God' right in the title of his book, he runs the risk of being disqualified a priori as a conversation partner in the interdisciplinary dialogue that he so eagerly wants to enter.

Living in the Memories of God is a complex book. It deals with one theme, dementia, but moves freely in and out of several disciplines that normally exist in isolated and

¹ Swinton, J. (2012). *Dementia: Living in the Memories of God*. Eerdmans: Grand Rapids, MI/ Cambridge, U.K.. Page references to this work will be given in parentheses in the text.

separated worlds of discourse. Dementia, Swinton claims, is not the privileged domain of the neurologist. One of his objectives – I will come back to his use of this concept in my final section – is to ‘deterritorialize’ dementia (24). Systematic theology (what does it mean to be created by and held in the memories of God?), biomedicine (the standard model of dementia and its critique), philosophy and ethics (what do we mean by concepts like ‘mind’, ‘memory’? And what is ‘personhood’?), the social sciences (identity), ethics (why it would be better not to talk about personhood in dementia), pastoral care (friendship) and ecclesiology (in the last chapter about churches as places of belonging) – they are all required to make their specific but limited contribution to understanding what dementia is and how to deal with those affected by it. It is one of the merits of Swinton’s book that he brings all these perspectives together into a fruitful dialogue without being too much deterred by frontiers, the power of definition, and vocabularies.

Why such an ambitious project for someone who embodies the virtue of modesty? Because, to put it in one phrase, *the territory of dementia is occupied by biomedical reductionism supported by a liberal culture of hypercognitivist individualism*. Swinton is driven by a mission: dementia needs another, richer narrative; a counter-story, to do justice both to those suffering from it and to the truth. Any instrument he can use to weaken the prevailing paradigm of dementia as a neurological deficit he employs: recent social scientific research on dementia and fundamental philosophical analyses of concepts like mind, person and memory) – both are put to the service of the theological claim that dementia has to be ‘re-narrated in the light of the coming of the kingdom of God’ (24). I cannot do justice in this review to the richness of Swinton’s approach. I can only offer a summarizing reconstruction of Swinton’s critique of the defectological paradigm and raise some critical questions about his understanding of the role of theology in an interdisciplinary dialogue.

Dementia: The Standard Paradigm

The ‘standard paradigm’ (Swinton borrows the term from Tom Kitwood²) defines dementia as a brain disease caused by a variety of different factors. The DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) and ICD-10 (WHO’s International Classification of Diseases) define dementia as a syndrome leading to serious impairment, particularly of the higher cortical functions of the brain. ‘This in turn results in cognitive impairment that either causes or is preceded by emotional,

² Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Open University Press: Berkshire/ New York.

behavioral, and motivational problems. Within this narrative of loss and inevitable neural destruction, the person will lose control of their emotions and social skills, and their ability to interact appropriately will begin to decline, as will their motivation for the tasks of living' (39).

Definitions like these only highlight pathology, describing dementia in terms of deficits and dysfunctions according to a generic norm. The message is: 'There is something significantly wrong with your brain'. There may be some benefit in defining dementia in terms of a neurological deficit, Swinton admits (42), but for a theologian it is the wrong place to start (44). Why are the negative aspects of dementia considered to be key aspects? (45) Is this the primary narrative that should be told first about dementia? (45) No, Swinton says. 'The emphasis on defectology does ... require a degree of deterritorialization....', Swinton claims, borrowing a term from the French philosophers Gilles Deleuze and Félix Guattari (47).³ 'Medical definitions are helpful for medical purposes, but they may be considerably less helpful for working through the contribution of theology and pastoral care to the process of defining and responding to dementia'(47). Why should a *theologian* want to identify someone with dementia according to their need for *medical* care? (46) What happens when we describe people with dementia as "patients"? Words shape our worlds. Words matter, Swinton writes. (46)

From Defectology to Relationships

Swinton does not appear to have any problem with biomedicine and neurology as such but only insofar they are presented as telling the master narrative of dementia, the best and only lens to look through – thus defectology, used as a comprehensive, biomedical worldview. In that case, we can understand the individual with dementia as nothing more than a "typical patient" in terms of the medical definition. By means of generic and universalizable categories the patient is divided into components (memory impairment, various specific cognitive disturbances like aphasia, apraxia, agnosia, disturbance in executive functioning as planning, organizing (50)), and his experiences and capabilities are judged in relation to an average behavioral norm. 'By reducing the core meaning of dementia to the universal and biological, other potential core meanings and possible vital dimensions of the syndrome of dementia are excluded or at best downgraded' (53).

³ Swinton refers to Deleuze G. and Guattari, F. (2004). *A Thousand Plateaus: Capitalism and Schizophrenia*, London: Continuum.

Does dementia then have nothing to do with a defective brain? Swinton does not question the classification of dementia as a brain disease as such, but only disagrees when it is presented it as the only or best one. Definitions are powerful storytellers, and stories can become 'misleading or just plain wrong' (54).

The standard story told thus far is: To have dementia is in some sense to lose one's mind (54). The literal meaning of the term "dementia," "deprived of mind," reflects its hegemony. To this diagnosis modern, neo-liberal culture powerfully adds an ethical disqualification: to lose one's mind equals being deprived of humanness. The very term dementia, is, in Swinton's opinion, already 'a misnomer' (63): it represents a culturally biased, lazy kind of thinking. One should be more critical in one's thinking about thinking.

Questioning the common understanding of 'thinking', Swinton then turns to philosophy. How do we actually know that a person's thinking is impaired? How do we know what the concept 'mind' represents? Following the pragmatic turn in philosophy, Swinton considers the ascription of the ability to 'think' to someone a social construction that depends on what one presumes is going on in within that individual's actions and behavior (58). What we call 'mind' and 'mind reading' is in fact a complex hermeneutical practice. Wittgenstein showed that the content of our minds emerges from the language we use and the cultures within which we exist. There is no such thing as an individual mind as an absolute.

Among the key assumptions of dementia, however, is that we *can* know what is going on in another person's mind, that the mind is within the boundaries of the individual's head, and that the mind is the essence of the person (63). The defectological paradigm appears to be powerfully supported and strengthened by our culturally biased hypercognitivism that makes us refer to the "higher" cerebral cortical functions. People with dementia, Swinton argues, are not losing their minds but 'are losing that which society prizes'(65).

By taking the phenomenon out of the exclusive, closed domain of neurobiology, Swinton succeeds in his first deterritorialization of dementia. Dementia is neurological, but it is more than that. Taken out of the territory of the neurological laboratory into society, the concept of dementia acquires new connotations. But both territories, the laboratory and modern culture, seem to confirm and reinforce each other in their negative approach to dementia as 'losing one's mind'. Questioning the allegedly self-evident character of notions like thinking and mind is a first step to loosening the grip of the standard paradigm. But more is needed to weaken its position.

‘Dementia is *not* not neurological,’ Swinton admits. But he advances another, more audacious claim: ‘dementia is not only, or, perhaps not even primarily neurological’ (70). Here Swinton finds support in the work of Kitwood and Steven Sabat. Dementia, these psychologists argue, is as much *relational* and *social* as it is neurological: ‘Relationships may be both causative and formative within the development of the syndrome of experiences and neurological damage that forms dementia.... Relationships are part of what dementia *actually* is, not just an aspect of how we should offer care to people once the nature of the condition has been defined’ (71).

Swinton endorses Kitwood’s claim that an explanation of dementia needs – at least partially – to be connected to the prevalence of relational disorder (72). Dementia emerges out of a complicated dialectical interaction between neurological impairment and interpersonal processes and is therefore at least partly socially constructed. ‘The experiences and the relationships we have impact deeply the way in which our brains come to be structured’ (75). Kitwood challenges the standard paradigm in which dementia is located firmly within individual selves. He accepts the medical model but questions the linear causal relationship between brain damage and dementia. ‘The causal direction of neurological damage may not be straightforward (77). In line with Kitwood, Swinton dares to support the claim that relationships ‘*cause*, or at least exacerbate, the process of neurological decline’ (75) (idem, 80).

If we follow Kitwood, ‘we should be concentrating as much on care as on neurology. Relationships and care need to become aspects of how we describe, define, and seek to understand dementia’ (83). Dementia is not just an affair of the individual brain. ‘[S]ociety may well have a profound responsibility for *causing* the symptoms of dementia rather than responding to them’ (80).

The work of Steven Sabat shows how.⁴ Sabat questions the – what he calls – Malignant Social Psychology in our hypercognitive culture, (82) and the individualistic understanding of the self that it implies. The self, Sabat argues, is not in fact as “inner” as we might assume. (92) Alternatively, Sabat develops a social model of the self: the self is something that is constructed within the relational dialectic that goes on between the individual and his/her communities (94). The mind and the self emerge from relationships and are formed and sustained by and in relationships (93). People with dementia may lose their awareness of their personal characteristics vis à vis others (what Sabat calls Self 3) but still keep a sense of their selves in the present

⁴ Sabat, S.R. (2001). *The Experience of Alzheimer’s Disease: Life through a Tangled Veil*. Blackwell: Oxford.

moment (Self 1) and – if they are supported and sustained in that by their environment – their social roles (Self 2).

Both Kitwood, who points to the role of relationality in the explanation of dementia, and Sabat, who develops a richer concept of the self, lend support to Swinton in his conviction that ‘dementia doesn’t entail a loss of self. Understood properly, the self remains intact even in the most severe forms of dementia. Any loss of self relates to a failure of community’ (108). Like Kitwood himself, Swinton stays alert: ‘This is not to suggest that dementia can be cured through relationships.’ What can be said, however, is that ‘neuropathology [is put] *in its proper place*’ (italics mine), by drawing attention to ‘the deep and formative significance of the environment, the relationships, and the attitudes and values that surround a person who has been given the name of dementia.’ (109) The standard model is, to use Deleuze’s term, reterritorialized.

The Problem with Personhood

After a critical analysis of the medical model’s epistemology (what is dementia?), it is now time to question its implications for ethics: how are the lives of people with dementia to be valued? It appears that even Kitwood and Sabat’s relational approach has ambivalent ethical implications. Swinton dedicates two dense chapters to the moral flaws of capacities-based models of personhood. In his view, it is a bad idea to base moral worth on being a person if one assumes that personhood requires one to have certain capacities such as self-awareness, a sense of identity, a sense of self over time, memory. In that case, the consequences for people with dementia are devastating. The moral philosopher Mary Warnock would then be right when she states in a famous article on dementia: ‘the real person has gone already and all that’s left is just the body of a person, and nobody wants to be remembered in this condition’ (quoted on 121). Though there might no ‘Duty to Die’ (the title of her 2008 article) in such a case, killing one’s self, Warnock concluded, is morally permissible, perhaps even appropriate (122). The ethicist Peter Singer would also be right in his contention that care for people with dementia (as he himself did for his own mother) is understandable or excusable but not a moral obligation.

At this point, Swinton warns against the moral implications of a radical relational approach. If one defines personhood exclusively – as Kitwood does – in terms of relationships, then the worth of people with dementia will depend on the quality of their relationships (136). What about the lives of those who are no longer able to respond to others in any meaningful way or are abandoned by their visitors? Those

who no longer are involved in relationships are no longer persons. And because one is not a person, one no longer belongs to the moral community.

The better alternative seems to be to leave the language of personhood behind or to redefine the concept of 'person' by radically broadening its scope. Swinton finds support for this in the philosopher Robert Spaemann who defends the concept of person but at the same time argues that human personhood precedes capacities, including even the capacity of relationality. Humans differ ontologically from things, which is why we cannot do without the concept of person. But personhood is a description of the particular way members of the human race live, rather than a reference to a set of capacities of certain human beings. Spaemann equates personhood with the typical way human beings *act out* their humanness. To be a person consists in being a *living* member of the human race. It is being 'born into and participating in the human family' (156).

A Theocentric Concept of Creation

Though Swinton's book already started with an account of the necessity of a theological redescription of dementia, it is only here in fact, half way through the book, that his argument becomes theological and the perspective distinctively Christian. Kitwood, Sabat, and Spaemann only paved the way for a genuine pastoral theology, broadly developed in the remainder of the book. For a Christian, it does not really count whether one has lost one's mind or not; what matters is that one is loved by God. The only thing decisive for the recognition of a human being's eternal worth and the necessity of one's being cared for is the fact that one is 'created by God'. And not a single human being is excluded from that.

Swinton's concept of creation is radically theocentric. There is no creation apart from the Creator, no life without God's divine Breath. We are *creatures* – this means that our lives are radically dependent and contingent. 'Without God, we literally cannot be' (162). Everything we are and have is given. 'Nothing exists apart from God's desire for it to exist.' Dementia, however tragic it may sound, is not excluded from this (184). Anthropologically, this means that there are no human characteristics apart from humans' relationship to God. Though Swinton does not want to develop a full-blown theological anthropology he offers one in concise form. To be human is to be dependent and contingent, embodied, relational, broken, and deeply lost, and loved and profoundly purposeful (161). These are all *theological* qualifications that apply whether one suffers from dementia or not. They lead us towards an attitude of humility, gratefulness, and compassion. On these premises, in the remainder of the

book, Swinton presents three beautiful chapters on good care for people suffering from dementia.

We are what we remember, the standard paradigm of dementia says, supported by our hypercognitivist culture and reductionist biomedicine. The moment we lose our memory, we become nothing. We are no longer ourselves; we no longer have a self. A theocentric understanding of the human condition then puts it differently: 'To be remembered is to exist and to be sustained by God.' (214) *We are not what we remember; we are remembered* (198). To be remembered is to be sustained; to be forgotten is to cease to exist. To be remembered is to be the recipient of divine action. "[i]t is not a person's memory that assures his/her identity; it is the memory of God and, by proxy, the memory of others' (212): those who care for them and the community of the church. Two persuasive chapters about the practices of care as friendship and the church as a community of strangers follow and close the book.

A Theological Coup d'État

I do not need to go into these chapters. Rather, my advice is: just read them and take them to heart! What strikes me, however, is that the tone is no longer polemic in these fully theological chapters. There is no longer a contesting of territories with the standard paradigm. It is obvious from the outset that if one speaks about 'God's memory' in the context of dementia it is a 'memory without neurology' (213). Here theology speaks its own faith language. There is no danger of making category mistakes such as claiming that God has a brain. Dementia is reterritorialized to where it theologically belongs: in the context of creation, in the perspective of faith. 'It is only when we begin to recognize and acknowledge the position of human beings before God that the situation of people with dementia can be *fully* understood, their personhood authenticated, and their care effectively implemented' (160, italics mine).

Rereading the book, I wonder why Swinton employs such apologetic language in the rest of his book. The tone is militant from the start. The book is, as Swinton writes in his Introduction, 'a self-consciously theological book. It is written for Christians and it is firmly located within that faith' (5). Its aim is to develop 'a specifically theological perspective on dementia' (6). Swinton is not satisfied with occupying a niche in the biomedical domain where theology is allowed to enter (e.g., as pastoral care in the domain of generic spirituality) but commits a theological *coup d'état*: the only adequate perspective on dementia is a faith perspective 'that presumes that the world is created by God, broken by sin, and in the process of being redeemed through the saving works of Jesus' (6).

In this regard, the way the metaphor of territory is used is perhaps revealing. 'The point is not necessarily to take territory away from established understandings, but to *retake territory* that rightly belongs to the story of God and the practices of the church' (24-25, italics mine). The military metaphor reminds one of Karl Barth's claim that Christian ethics should take the same belligerent stance towards secular, philosophical ethics that the Hebrew people once took towards Canaan. It should act out 'an annexation of the kind that took place on the entry of the children of Israel into Palestine'.⁵ Swinton, too, seems to be engaged in a kind of ground battle with neurobiology. Interdisciplinarity is 'fully appropriate as long as each of the participants is read critically and none is allowed to define the *whole of the terrain* that dementia inhabits' (154, italics mine). But theology's perspective is not one among others. For Swinton, it seems that theology is not a discipline with its own methodological restrictions but the narrative articulation of a comprehensive worldview, to which all the other sciences are subordinated willy-nilly – theology as the old fashioned *regina scientiarum*. 'We do not do theological reflection on dementia within a medical, psychological, or neurobiological context', Swinton writes. It is, rather, the other way around: 'these disciplines are practiced within the context of creation and under the providential sovereignty of God. This is even so if that theological context is not formally acknowledged' (8, italics his; cf. also 154).

On the one hand, theology is presented as a humble servant of the truth. Himself a psychiatric nurse, Swinton has no polemical intentions regarding medicine as such. He writes 'for theologians and pastoral carers and not *against* any other perspectives' (28). His counter-story does not *replace* others: 'Neurology, psychology, biomedicine, and psychiatry all remain important aspects of dementia care, but they will be seen in a different light. Aspects of this large standard story of dementia remain significant, although challenged and countered' (24). On the other hand, however, we read that: 'the point of this book is not necessarily to take territory away from established understandings, but to *retake territory* that rightly belongs to the story of God and the

⁵ Barth, K. (1957). *Church Dogmatics*, II/2, (G.W. Bromiley, Trans.). Edinburgh: T&T Clark, p. 518. Cf. p. 519: 'Whatever form the relationship between the two may take, there can be no question either of a positive recognition of Christian ethics by that conception or of an attachment of Christian ethics to it. Christian ethics cannot possibly be its continuation, development and enrichment. It is not one disputant in debate with others. It is the final word of the original chairman-only discussed, of course, in Christian ethics-which puts an end to the discussion and involves necessarily a choice and separation.'

practices of the church.’ (25, italics mine) And having redescribed dementia within the framework of his theological anthropology, Swinton concludes: ‘In this way we have *retaken some of the territory* that rightly belongs to theology and pastoral care’ (186, italics mine).

The Blind Men and the Elephant

One can ask if this is what Deleuze was pointing to with his concepts of de- and re-territorialization: a movement of declassification in which things, signs, concepts, etc. are liberated from their conventional habitat (‘territory’) and acquire new meanings by being reused in other contexts. In our globalizing network society, that is what constantly happens in popular culture. Swinton’s understanding of theology, however, stays close to the political metaphor of colonizing nation states, contesting their power, and hegemony. In the political arena all disciplines are equal, but some are more equal than others.

A stricter distinction between the perspective of the sovereign God, Christian faith as a hermeneutical tradition, and theology as one discipline among others, would already be helpful here and make theology more modest in its epistemological claims. ‘We very easily mistake these maps for the terrain itself,’ he writes about the defectological paradigm. ‘The danger is that in concentrating so hard on the maps, we fail to recognize that aspects of the terrain don’t quite match up.’ (53) But why not admit that theology too offers only one map among others? ‘*Theology* provides us with a lens through which we can look at the world’, Swinton writes, whereas I think he should have written: ‘Christian faith’ (17, italics mine). Yes, theology *interprets* the lens through which Christians look at the world, but it does not own the lens nor does it have any privileged access to the light that shines through it upon the world.

Simone Weil once used a similar metaphor when she wrote that the Gospel contains a conception of life, not a theology: ‘If I light an electric torch at night out of doors I don’t judge its power by looking at the bulb, but by seeing how many objects it lights up. The brightness of a source of light is appreciated by the illumination it projects upon non-luminous objects. The value of a religious or, more generally, a spiritual way of life is appreciated by the amount of illumination thrown upon the things of this world. Earthly things are the criterion of spiritual things.’⁶

⁶ New York Notebook 1942, quoted by Rozelle-Stone, A. Rebecca & Stone, Lucian (2013). *Simone Weil and Theology*. Bloomsbury T & T Clark: London, New Dehli, New York, Sydney, p. 5.

Looking – as the Indian tale about the blind men and the elephant illustrates – is about seeing more or less of reality. But no single blind man can claim to have seen the whole elephant, except God himself.⁷

Swinton is fond of the metaphor of looking and its narrative counterpart, description. ‘The task of theology is to redescribe the world in the light of Scripture and tradition and to look carefully at what dementia *really* looks like’ (19). Still he prefers the belligerent language of ‘territory’ when dealing with interdisciplinarity. Why? I surmise that it is because in his view theology is not only about epistemology and hermeneutics but also contains strong ontological claims. Swinton wants to develop the “whole sight” (9): he thinks he can describe the whole elephant because theology has a special access to where it comes from because it is created by God. Swinton presents the notion of creation not as a lens to look through but – again, notice the spatial metaphor – as a ‘quite specific context’ (154). Apparently, ‘creation’ as a theologoumenon is not seen as a light that shines upon things but as a territory to be retaken by theology from the colonizing power of other disciplines. I think a category mistake is being made here. ‘Creation’ is not one context competing with others but a way of looking at (all) contexts. God does not have a brain, and neither does creation have contexts. ‘Creation’ is a way to describe life as a gift of God, but does not contain any explanatory information about causal connections. Theology, yes, indeed, *theology* has a context: the Christian tradition and the church as a faith community in which life is lived as a gift of God. They make you look at and behave in a specific way towards people suffering from dementia and – as Swinton wonderfully exemplifies in his book: ‘to re-narrate dementia in the light of the coming kingdom of God’ (24). But the claim that theology can describe things *as they really are* represents in my view an epistemological and ontological overkill in the interdisciplinary dialogue with neurobiology. Like a soldier raising the flag on the enemy’s government building after a war, Swinton writes: ‘In a real sense, *neurology is theology*’ (8). I think his book would have been strong enough without such combative language. Substantial parts of his argument are supported by psychological research whereas other parts only make sense within the context of a community of believers. Neurology is *not* theology – and that is why neither of them can do without the other.

⁷ ‘Blind Men and the Elephant’, a poem based on the tale by John Godfrey Saxe (1816–1887), concludes with: ‘So oft in theologic wars, / The disputants, I ween, / Rail on in utter ignorance / Of what each other mean, / And prate about an Elephant / Not one of them has seen! [http://www.wordfocus.com/word-act-blindmen.html]

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