PART II

CHAPTER 3

ON BRAIN DECLINE

Normal cognitive ageing results from age alone.[1] The ageing brain and mind nowadays entails neuroscientific and psychological approaches.[2] Besides ageing, in other situations head injuries e.g. in boxing, can have neurological and psychiatric effects.[3] The occurrences of dementia rises markedly with age and due to the increases in life expectancy over time, consequently the number of dementia cases is expected to emphatically increase.[4] This is already shaping the contemporary understanding of the person with progressive cognitive impairments, and thus is pertinent for how the soul is understood in a religious-spiritual setting.

Given the brain/mind and mind/body connections seen already, the Catholic belief in the unity of body/soul implies that neurological degeneration affects the person's life and soul. The sciences can influence and perhaps be influenced by a Catholic Christian interpretation of brain, mind and soul. This chapter explores issues of brain and mind identity highlighted by decline in the condition of the brain. It then focusses on dementia and how Christians experience the soul with brain decline; then looking at the ultimate end of the brain and person in brain death. We also offer a critique of neuroscience's reductive limitations in such degenerative circumstances.

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[1] Athanasia M.Mowinckel, Thomas Espeseth and Lars T.Westlye, "Network-specific effects of age and in-scanner subject motion: A resting-state fMRI study of 238 healthy adults," *NeuroImage* Vol.63 No.3 (15 November 2012), pp.1364–1373; Ian J.Deary et.al., "Age-associated cognitive decline," *British Medical Bulletin* Vol.92 No.1 (December 2009), pp.135-152.

[2] Patricia A.Reuter-Lorenz and Denise C.Park, "Human Neuroscience and the Aging Mind: A New Look at Old Problems," *The Journals of Gerontology Series B: Psychological Sciences* Vol.65B No.4 (July 2010), pp.405-415

[3] Robert L.Heilbronner et.al., "Neuropsychological Consequences of Boxing and Recommendations to Improve Safety: A National Academy of Neuropsychology Education Paper," *Archives of Clinical Neuropsychology* Vol.24 No.1 (February 2009), pp.11-19

[4] Hélène Jacqmin-Gadda et.al., "20-Year prevalence projections for dementia and impact of preventive policy about risk factors," *European Journal of Epidemiology* Vol.28 No.6 (June 2013), pp.493-502

The chapter is concerned with the more serious, non-preventable conditions late in life, and not with difficulties that originate earlier in life.[5] We also recognise but bypass matters like the effects of illicit drugs, e.g. chronic use of methamphetamine is widespread and linked with cognitive dysfunction, psychiatric complications and emotional distress.[6]

'Brain decline' is our term to describe any slight or significant neurological deterioration, or impairment. Neurodegeneration and cognitive impairments highlight how brain, mind and soul converge in the context of a supportive faith community. This is the background to what follows. In liberal societies, the prospects do not look good for those with brain decline, handicaps, and disabilities.[7] Christian pastoral care for the whole person, however, enables patients to be treated as people with transcendent dignity.

Brain, Mind and Identity

Changes in the brain are caused by neurological disorders and conditions,[8] e.g. motor neurone disease, vascular dementia, and disorders of consciousness.[9] Neuropsychology and clinical neurology pertain to brain and mind. Neuropsychiatric dimensions such as delusions, mood disorders, euphoria and depression, can accompany neuropsychological deficits.[10] Another area is pain, e.g. in mild traumatic brain injuries (TBI).[11]

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[5] For example, Alvin A.Miller, "CT Scans on Children: Is This a Problem?," *Clinical Pediatrics* Vol.47 No.3 (April 2008), pp.220-223; Kristin Sverdvik Heiervang et.al., "The Chernobyl Accident and Cognitive Functioning: A Study of Norwegian Adolescents Exposed *In Utero*," *Developmental Neuropsychology* Vol.35 No.6 (2010), pp.643-655

[6] Jennifer E.Iudicello et.al., "Longer term improvement in neurocognitive functioning and affective distress among methamphetamine users who achieve stable abstinence," *Journal of Clinical and Experimental Neuropsychology* Vol.32 No.7 (2010), pp.704-718

[7] Hans S.Reinders, *The Future of the Disabled in Liberal Society: An Ethical Analysis* (Notre Dame, Indiana: University of Notre Dame Press, 2000).

[8] A.J.Larner, *Neuropsychological Neurology: The Neurocognitive Impairments of Neurological Disorders* (Cambridge and New York: Cambridge University Press, 2008); James L.Bernat, *Ethical Issues in Neurology,* Third edition (Philadelphia: Lippincott Williams & Wilkins, 2008), chapters 11-18

[9] Katja Kuehlmeyer et.al., "Diagnostic and ethical challenges in disorders of consciousness and locked-in syndrome: a survey of German neurologists." *Journal of Neurology* Vol.259 No.10 (October 2012), pp.2076-2089

[10] Evert C.A.Kaal and Charles J.Vecht. "The Prevalence and Impact of Neurologic Disease in Cancer," in David Schiff, Santosh Kesari and Patrick Y.Wen, (eds.), *Cancer Neurology in Clinical Practice: Neurologic Complications of Cancer and Its Treatment,* Second Edition (Totowa, New Jersey: Humana Press, 2008), pp.3-11

[11] Larner, *Neuropsychological Neurology,* p.2. The fields here are neuropsychiatry and behavioural neurology, where there is overlap between psychiatric characteristics and neurological disorders.

In fact, pain raises issues of mind-body dualism, [12] which are problematic when organic and psychological factors are considered in chronic pain. The belief is that "'psychosocial' is equivalent to 'psychogenic' and that psychogenic means that there is no organic basis for the pain problem and/or that the pain is 'all in the mind'."[13] Although, pain may not be just 'in the mind' and there is no mind without a biological substrate.

Brain degeneration and injury are physical, with changes in mind and personality.[14] The physical can affect the spiritual: the sense of self, mental well-being and the soul overall. Patients with the most common primary brain tumour, gliomas, may experience cognitive deficits in attention, memory, and executive functioning.[15]

It is recognised that brain/mind/body, and body/soul are all interrelated. Yet some worry about mind and soul,[16] where mind/soul/psyche means that the capacity to reason leaves the individual with 'only' the physical aspect apparent.[17] In severely impaired cognition, there is a trend to convert the person-as-individual capable of being in relationships, into patient-as-other, 'object-of-care' and incapable of relationships.[18] This is a different understanding from the traditional Christian view of the soul united to the body.

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[12] Keith Nicholson and Michael F.Martelli, "The Problem of Pain," *The Journal of Head Trauma Rehabilitation* Vol.19 No.1(January/February 2004), pp.2-9; Michael F.Martelli et.al., "Psychological, Neuropsychological, and Medical Considerations in Assessment and Management of Pain," *The Journal of Head Trauma Rehabilitation* Vol.19 No.1(January/February 2004), pp10-28.

[13] Nicholson & .Martelli, *The Problem of Pain,* p.5

[14] Derrick K.S.Au, "Brain Injury, Brain Degeneration, and Loss of Personhood," in Gerhold K.Becker (ed.), *The Moral Status of Persons,* Value Inquiry Book Series 96 (Amsterdam and Atlanta: Rodopi, 2000), pp.209-217; David Greaves, *The Healing Tradition: Reviving the soul of Western medicine* (Abingdon, U.K: Radcliffe Publishishing, 2004), pp.55-65

[15] Karin Gehring et.al., "Predictors of Neuropsychological Improvement Following Cognitive Rehabilitation in Patients with Gliomas," *Journal of the International Neuropsychological Society* Vol.17 No.2 (March 2011), pp.256-266; see too Silvia Scoccianti et.al., "Changes in neurocognitive functioning and quality of life in adult patients with brain tumors treated with radiotherapy," *Journal of Neuro-Oncology* Vol.108 No.2 (June 2012), pp. 291-308

[16] David C.Malloy and Thomas Hadjistavropoulos, "The problem of pain management among persons with dementia, personhood, and the ontology of relationships," *Nursing Philosophy* Vol.5 No.2 (July 2004), pp.147–159

[17] A case is Alzheimer's disease, where issues arise about the possibility and value of relationships. Malloy & Hadjistavropoulos, *The problem of pain management,* p.149

[18] In other words, "we perceive our relation with the patient as being between 'Us' and 'Them' and not between 'Me and You' or 'I and Thou'." Malloy & Hadjistavropoulos, *The problem of pain management,* p.149

W.Glannon considers a useful case of electrical stimulation of the brain, e.g. deep-brain stimulation (DBS). Such neurostimulation seeks to modulate overactive or underactive brain areas involved with motor function, cognition and emotion. [19] It has therapeutic applications in treating psychiatric and neurological disorders. But it may alter several mental states critical to thought, personality and behaviour. It can disrupt the continuity and integrity of psychological properties that comprise the self and personal experience of persisting as the same person through time.[20]

DBS to treat Parkinson's disease (PD) improves motor symptoms but it produces cognitive side effects, e.g. impulsivity, and selectively disrupts the normal capability to pause in a decision conflict situation.[21] A 62 year-old male, three years after having electrodes implanted in his subthalamic nucleus and beginning stimulation treatment, was admitted to a psychiatric hospital in a manic state caused by DBS. A mood stabiliser did not control his symptoms such as megalomania and chaotic behaviour that led to financial debts. The mania was resolved by adjusting the stimulator which also brought back his cognitive capabilities of insight and rational judgment.

But the patient's motor symptoms returned, rendering him bedridden. The patient and his healthcare providers had a choice: the patient could be admitted to a nursing home due to a serious physical disability, despite preserved cognitive and affective capacities; or the patient could be admitted into a chronic psychiatric ward due to his manic state, despite restoring of motor function.[22]

In the unstimulated brain state, he was deemed competent to make decisions about his treatment: the second option was chosen on quality-of-life grounds. The patient was legally committed to a chronic ward in a psychiatric hospital. Mania was preferable to loss of motor control. He continued neurostimulation because the

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[19] Walter Glannon, "Stimulating Brains, Altering Minds" *Journal of Medical Ethics* Vol.35 No.5 (May 2009), pp.289-293

[20] Glannon, *Stimulating Brains,* p.289

[21] Michael J.Frank et.al., "Hold Your Horses: Impulsivity, Deep Brain Stimulation, and Medication in Parkinsonism," *Science* Vol.318 No.5854 (23 November 2007), pp.1309-1312.;Benedicte Ballanger et.al, "Stimulation of the Subthalamic Nucleus and Impulsivity: Release Your Horses," *Annals of Neurology* Vol.66 No.6 (December 2009), pp.817-824

[22] Glannon, *Stimulating Brains,* p.290. That is, DBS achieved motor control but adversely affected the patient's mental state.

overall benefit of DBS was greater than being without it. It was a choice between the lesser of two evils.[23]

Here Glannon equates psychological continuity for personal identity: persisting as the same person over time, with some changes in mental states.[24] Treatment can change personal identity. If the alteration of mental states is substantial, "then it is unclear who the beneficiary of the treatment would be. The individual experiencing the positive effects of the treatment would appear to be a different person from the one who requested the treatment."[25]

The manic state of PD, Glannon says, is not full disruption to psychological continuity. Thematic unity of mental states is disturbed over time, therefore disrupting narrative identity. But mania would not singly disqualify the patient's capacity to recall what it was like to lose motor control and know the positive effect of restoration. Despite changing from a non-manic to a manic state, there may be adequate narrative integrity and psychological continuity for the man to retain a weaker yet sufficient sense of identity to be the same person.[26] Identity issues accompany normative questions of benefit versus harm.

Personhood and identity discussions are also family-related. One standard is continuity of memory where a person unable to remember a lot of his or her past may no longer be thought the same person he or she had been.[27] Family members may perceive that they have "lost" their loved one on the grounds of memory.[28] Changes in identity after brain injury presume there have been major changes in the patient's identity, something that most patients themselves deny. The implicit or explicit standard of recovery is the pre-injury personality. Clinicians may be inclined to identify with the family's perspective, partly because so few of them have experienced brain injury. It could impede the clinicians' abilities to accept patients as

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[23] Glannon, *Stimulating Brains,* p.290

[24] Glannon, *Stimulating Brains,* pp.291-292

[25] Glannon, *Stimulating Brains,* p.292

[26] Granted there is major change to his identity after DBS, when the patient experiences relief from his suffering when motor control is restored. Glannon, *Stimulating Brains,* p.292.

[27] Sunil Kothari, "Distinguishing 'Personhood' and 'Personal Identity'," *PM&R* Vol.4 No.1 (January 2012), pp.53-54. (p.53)

[28] Kothari, *Distinguishing 'Personhood',* p.53

they are now, rather than seeing them as who they were before. In reality the patient often experiences a devaluing of the person he or she is now.[29]

Spirituality, Soul and Dementia

Brain deterioration or injury affects the mind due to the mind/body link, and it also affects soul since the person is a unity of body/soul. Many with traumatic brain injury (TBI) use religion and/or spirituality to cope with chronic stress.[30] Religious practice and spirituality can have distinctive benefits and predictive value in TBI rehabilitation outcomes. In one study, individuals' religious well-being or subjective feelings of connectedness to a higher power predicted subjective experience of distress and well-being. Remarkably, this sense of connection to a higher power was more strongly predictive than a nonreligious understanding of meaning and purpose in life.[31] Thus, healing of the brain and mind, and hence the soul, seems to be assisted by the spiritual domain.

Such recovery involves adjustments for living life, looking ahead; instead, brain decline involves processes looking towards life’s end. Here it would be helpful to examine the case of dementia as numerous issues coalesce in this contemporary feature of a society whose inhabitants are living longer. Dementias are associated with damage to different cortical and sub-cortical brain structures and interconnected fibres, together with functional brain changes.[32] Memory decline is correlated with an atrophy of the hippocampal formation and surrounding structures of the medial temporal lobe.[33] Alzheimer’s disease (AD) results in dementia of the Alzheimer’s type (DAT).[34] Other types of neurodegenerative disorders also lead to dementia, such

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[29] Kothari, *Distinguishing ‘Personhood’,* p.54.

[30] Brigid Waldron-Perrine et.al., “Religion and Spirituality in Rehabilitation Outcomes Among Individuals With Traumatic Brain Injury,” *Rehabilitation Psychology* Vol.56 No.2 (May 2011), pp.107–116. This study examined the association of religion and spirituality with functional and emotional outcomes of individual living with brain injuries.

[31] Waldron-Perrine et.al., *Religion and Spirituality in Rehabilitation Outcomes,* p.113

[32] Matthias Brand and Hans J.Markowitsch, “Brain Structures Involved in Dementia,” in Gabriela Stoppe (ed.), *Competence Assessment in Dementia* (Wien and New York: SpringerWienNewYork, 2008), pp.25-34

[33] Brand & Markowitsch, *Brain Structures,* p.31

[34] Alexander Drzezga, “Amyloid-plaque imaging in early and differential diagnosis of dementia,” *Annals of Nuclear Medicine* Vol.24 No.2 (February 2010), pp.55-66

as the fronto-temporal lobar degenerations (FTLDs),[35] or Lewy-body disease leading to dementia with Lewy bodies (DLB).[36]

Dementia especially in AD is generally understood as impairments in cognition and memory, with functional disability. Some non-AD dementias like frontotemporal dementia (FTD) and DLB are marked essentially by psychological and behavioural signs.[37] FTD involves mental inflexibility, distractibility and dis-inhibition in behaviour, though memory is spared in FTD until mid to late stages. There are clinical overlaps between FTD and AD,[38] and similarities in pathological characteristics.[39] Yet other indications are of different pathological bases for each dementia, and some difference in behavioural symptoms,[40] even in verbal and non-verbal communications.

Semantic dementia (SD) is also a clinical subtype of FTLD.[41] The greater anterior temporal loss in SD is expressed as 'empty' speech like difficulty in finding words and language comprehension; whereas FTD is expressed in more executive dysfunction stemming from greater frontal loss. Apart from effects on cognitive

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[35] Chiara Cerami et.al., "Frontotemporal lobar degeneration: current knowledge and future challenges," *Journal of Neurology* Vol.259 No.11 (November 2012), pp.2278-2286

[36] Shirlony Morgan et.al., "Differentiation of frontotemporal dementia from dementia with Lewy bodies using FP-CIT SPECT," *Journal of Neurology, Neurosurgery, and Psychiatry* Vol.83 No.11 (November 2012), pp.1063-1070

[37] Frontotemporal dementia (FTD) involves atrophy of the frontal lobes and is marked by behavioral and personality changes; cf. L.Whitwell et.al., "Frontal asymmetry in behavioral variant frontotemporal dementia: clinicoimaging and pathogenetic correlates," *Neurobiology of Aging* Vol.34 No.2 (February 2013), pp.636-639; Marcel J.H.Aries et.al., "Relation between frontal lobe symptoms and dementia severity within and across diagnostic dementia categories," *International Journal of Geriatric Psychiatry* Vol.25 No.11 (November 2010), pp.1186–1195; Blake A.Richards et.al., "Patterns of cortical thinning in Alzheimer's disease and frontotemporal dementia," *Neurobiology of Aging* Vol.30 No.10 (October 2009), pp.1626-1636

[38] Mickaël Laisney et.al., "When the zebra loses its stripes: Semantic priming in early Alzheimer's disease and semantic dementia," *Cortex* Vol.47 No.1 (January 2011), pp.35-46. Laisney et.al., found that in Alzheimer's disease (AD) and semantic dementia (SD), semantic memory impairment follows the same pathway, firstly affecting distinctive attributes, then shared ones

[39] Yuesong Gong and Carol F.Lippa, "Review: Disruption of the Postsynaptic Density in Alzheimer's Disease and Other Neurodegenerative Dementias," *American Journal of Alzheimer's Disease and Other Dementias* Vol.25 No.7 (November 2010), pp.547-555.

[40] Chris M.Bird et.al., "Topographical short-term memory differentiates Alzheimer's disease from frontotemporal lobar degeneration," *Hippocampus* Vol.20 No.10 (October 2010), pp.1154–1169 ; Marc Rousseaux et.al., "An analysis of communication in conversation in patients with dementia," *Neuropsychologia* Vol.48 No.13 (November 2010), pp.3884-3890

[41] Virginia E.Sturm et.al., "Mutual gaze in Alzheimer's disease, frontotemporal and semantic dementia couples," *Social Cognitive and Affective Neuroscience* Vol.6 No.3 (June 2011), pp.359-367

functioning these disorders also affect socioemotional functioning, and thinking of the future.[42]

Other non-AD dementias include: vascular dementia (VaD) and vascular-associated cognitive decline,[43] and Parkinson's disease dementia (PDD),[44] even in motor neurone disease or ALS.[45] A similar situation exists with chronic memory impairment such as those caused by seizures of temporal lobe epilepsy.[46] Dementia is not necessarily associated with impairment; it has been associated with creativity.[47]

All the same, dementia can also be threatening to the self and ultimately soul-destroying as it were. Some report a link between dementia and suicide. One study of Denmark found that a hospital diagnosis of dementia increases the risk of suicide compared to the general population.[48]

Yet an English and Welsh study found dementia suicide deaths to be low.[49] A review questioned the link between the dementia more common in the elderly and some higher suicide rates in many countries among older people.[50] The rate of suicide in dementia is lower than the rate in the general population, exception for Huntington's disease where there is three-times increased risk of suicide. The data is worth pondering.

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[42] Muireann Irish et.al., "Exploring the content and quality of episodic future simulations in semantic dementia," *Neuropsychologia* Vol.50 No.14 (December 2012), pp.3488–3495

[43] Amos D.Korczyn, Veronika Vakhapova and Lea T.Grinberg, "Vascular dementia," *Journal of the Neurological Sciences* Vol.322 Nos.1-2 (15 November 2012), pp.2-10

[44] Jamie Reilly et.al., "Cognition, language, and clinical pathological features of non-Alzheimer's dementias: An overview," *Journal of Communication Disorders* Vol.43 No.5 (September-October 2010), pp.438-452

[45] Julie Phukan, Niall P.Pender and Orla Hardiman, "Cognitive impairment in amyotrophic lateral sclerosis," *The Lancet Neurology* Vol.6 No.11 (November 2007), pp.994-1003

[46] Erika L.Sanborne, "Praying With Those Who Might Forget: Pastoral Considerations with Memory Impairment," *The Journal of Pastoral Care & Counseling* Vol.62 No.3 (Fall 2008), pp.207-217

[47] For example, Bruce L.Miller and Craig E. Hou, "Portraits of Artists, Emergence of Visual Creativity in Dementia," *Archives of Neurology* Vol.61 No.6 (June 2004), pp.842–844; Konrad Maurer and David Prvulovic, "Carolus Horn – When the Images in the Brain Decay: Evidence of Backward-Development of Visual and Cognitive Functions in Alzheimer's Disease," in J.Bogousslavsky and F.Boller (eds), *Neurological Disorders in Famous Artists*, Frontiers of Neurology and Neuroscience Vol.19 (Basel: Karger, 2005), pp.101-111

[48] Annette Erlangsen, Steven H.Zarit and Yeates Conwell, "Hospital-Diagnosed Dementia and Suicide: A Longitudinal Study Using Prospective, Nationwide Register Data," *The American Journal of Geriatric Psychiatry* Vol.16 No.3 (March 2008), pp.220-228

[49] Nitin Purandare et.al., "Suicide in dementia: 9-year national clinical survey in England and Wales," *The British Journal of Psychiatry* Vol.194 No.2 (February 2009), pp.175-180

[50] Camilla Haw, Daniel Harwood and Keith Hawton, "Dementia and suicidal behavior: a review of the literature," *International Psychogeriatrics* Vol.21 No.3 (June 2009), pp.440-453

Identity and Self in Dementia

"Ich habe mich sozusagen selbst verloren"/
"I have, so to speak, lost myself" (Auguste Deter, first diagnosed person with Alzheimer's disease).[51]

This short yet profound observation is substantial for understanding the importance of a person's relationships; this is further reflected below in comments from person's relationships which is illustrated below in comments from a spouse and partner support group for caregivers of persons with dementia.[52]

There "is still a person in there," and, though changed significantly, this is still the person they love. There was gratitude for occasional glimpses the person they once knew. One woman agreed with the view that dementia is "a kind of death," but disagreed that "the dementia made her husband less of a person. "I disagree. It is like pretending he is not there. This is the person I married, the person who is the father of my children, and he is trapped inside; it is cruel, but I still find my husband in that body. When he smiles, that is an alive person… . There is life until there is death'." [53]

One woman remarked how sad she was that her husband no longer recognises her. Friends and family criticised her for visiting him daily in the nursing home because "he does not know you any more." She responds, "but I know him." For another it was important to "give back" to her husband for all of the years that he had given to her and their children." Another stated that "I miss that person … I lost my companion and our life together."[54]

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[51] Quoted at the beginning of the paper by Ursula Naue, "'Self-care without a self': Alzheimer's disease and the concept of personal responsibility for health," *Medicine, Health Care and Philosophy* Vol.11 No.3 (September 2008), pp.315-324. Memory loss is not new and was known in ancient times, e.g. Daniel Schäfer, "No Old Man Ever Forgot Where He Buried His Treasure: Concepts of Cognitive Impairment in Old Age Circa 1700," *Journal of the American Geriatrics Society* Vol.53 No.11 (November 2005), pp.2023–2027

[52] For example, Darby Morhardt, "Ambiguous Relationships: When a Partner Has Dementia," *PM&R* Vol.4 No.1 (January 2012), pp.56-58. Cf. also Judie C.Davies, "Preserving the 'us identity' through marriage commitment while living with early-stage dementia," *Dementia* Vol.10 No.2 (May 2011), pp.217–234. Helen K.Black et.al, "How personal control mediates suffering: elderly husbands' narratives of caregiving," *The Journal of Men's Studies* Vol.16 No.2 (Spring 2008), pp.177-192

[53] Morhardt, *Ambiguous Relationships,* p.57

[54] Morhardt, *Ambiguous Relationships,* p.57

From a 55-year-old husband whose wife was diagnosed with frontotemporal dementia at the age of 48 years, “it is easy for some people to quickly resign themselves to the inevitable, that the identity of the person they once knew is never coming back…the result is that they tend to stop looking for the traits that are still there.” He emphasized the importance of “search[ing] for and savor[ing] what remains … the core of identity and being is the last to fade”.”[55]

The soul is even referred to when describing a once confident woman:[56] “…As she moves farther and farther away from worldliness, she teaches me anew. She, who led me into a physical world filled with possibility and wonder, is turning into soul before my very (amazed) eyes. I find myself following her yet, trying to grasp her experience, to see beyond the tangible horizon. Lee, my aunt and godmother. Did either of us suspect her sunset would dawn me into faith?”[57]

The relationship between identity and autobiographical memory is changed when semantic memory is impaired. “We remember what is important to our self, but how we see our self depends on what we remember.”[58] Others see memory as social and contextual where people with Alzheimer’s disease and their carer(s) remember and describe through social interactions.[59] There can be a turn away from ‘loss of self’ towards ‘locating a self’ in the person with dementia. The turn to the presence of selfhood reflects a tendency to seek aspects of selfhood elsewhere. Nonetheless, cognition and memory remain constituents of selfhood in modern western society.[60]

Returning to AD but focussing on individuals, one study assessed their self-figure drawings to determine the extent to which AD is reflected, based on the idea that

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[55] He had been caring for his wife for 6 years. Morhardt, *Ambiguous Relationships,* p.57

[56] Mary Donnarumma Sharnick, “Vignettes: Scenes of Lee,” *American Journal of Alzheimer’s Disease and Other Dementias* Vol.18 No.1 (January/February 2003), pp.49-50

[57] Sharnick, *Vignettes: Scenes of Lee,* p.50. Sunset refers to the beginning of Sharnick’s vignette, “Seeing Aunt Lee suffer from Alzheimer’s disease is like watching a sunset over the sea. Looking westward, I recall at first brilliance. Orange-pink gashes of sky turn gracefully violet, then quietly pearl, next whisper luminescent gray, and, finally, as if gulped by the waters, gone. Darkness comes.” (p.49)

[58] William L.Randall, “From Computer to Compost: Rethinking Our Metaphors for Memory,” *Theory & Psychology* Vol.17 No.5 (October 2007), pp.611-633 (p.620)

[59] Raewyn Bassett and Janice E.Graham, “Memorabilities: enduring relationships, memories and abilities in dementia,” *Ageing and Society* Vol.27 No.4 (July 2007), pp.533-554

[60] Bassett & Graham, *Memorabilities,* pp.537-538

artistic development is related to the development of cognitive abilities.[61] In most of the drawings, the body was omitted and in nearly half of the drawings, the eyes were omitted. This may signify self-awareness of the mental and physical deterioration; it may also indicate participants' difficulty of accepting it. Using the common belief that the eyes are 'the mirror of the soul,' omission of the eyes may symbolise the intent of the individual not to be seen by others, and an effort to avoid seeing others. Omitting the eyes may also reflect the decrease in their usefulness for the individual as a way to keep control.

The researchers interpret the omitted body as symbolising a deterioration in self-identity. The body is how human beings exist in their environment and the patient's self-identity is slowly deleted. In moderately severe dementia, patients forget who close family members are, and also have no recollection of who they. Therefore, "perhaps, omitting the body in the self-figure drawing may indicate the perception of losing oneself, the ultimate defeat in the battle over being an independent, thinking human being."[62]

Another study examined people with early-stage dementia and how they perceive the impact of dementia on their sense of identity, specifically what kind of person they thought they were, and how they thought their identity may be influenced by dementia.[63] There was the tension between change and continuity. The emphasis appeared to be on continuity, yet participants could describe changes which had occurred. There are various models of self used: discussion about 'self' as a single entity and at other times participants described different features of 'self', thereby indicating the likely multi-faceted nature of the construct of self .[64]

Critical Comment

A review on the extent to which the self diminishes or persists in people with dementia ranged from studies showing a disintegration of the self to those holding an

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[61] Rachel Lev-Wiesel and Einav Hirshenzon-Segev, "Alzheimer's disease as reflected in self-figure drawings of diagnosed patients," *The Arts in Psychotherapy* Vol.30 No.2 (2003), pp.83-89

[62] Lev-Wiesel & Hirshenzon-Segev, *Alzheimer's disease as reflected,* p.88

[63] Lisa S.Caddell and Linda Clare, "I'm still the same person: The impact of early-stage dementia on identity," *Dementia* Vol.10 No.3 (August 2011), pp.379-398. (p.380)

[64] Caddell & Clare, *I'm still the same person,* p.395

intact self.[65] The review authors note that qualitative methods mostly concentrated on evidence for the self arising from interactions involving the person with dementia. Their limitation includes how these studies sometimes overlook the effects that changes in the brain and cognition may have on the self. The studies tend to seek indications that support the persistence of self, rather than a deterioration in self, which could reflect researchers' beliefs about the effects of dementia on the self.[66]

Quantitative studies of the self include experimental studies which were particular about the aspect of self being measured, and would probably not capture 'the self' as a unitary construct. The advantage is that they can gather evidence for extent to which self remains.[67] Nearly all of the qualitative studies of people with dementia found evidence for the self either via non-verbal behaviours or presented discursively. Some with dementia can use personal pronouns, discuss their physical and mental characteristics and demonstrate multiple personae through speech. However, "it seems that the ability to present a coherent self-narrative is compromised, although not completely diminished, possibly due to the fading of memories as the illness progresses."[68]

There are also numerous ethical issues. Neuroscientist M.Gazzaniga compares a person with dementia, 'Gramps' to one's first car, 'Nelly,' which one learned to drive in and is part of one's mind and life. Nelly has deteriorated, and the company has stopped making parts for her. In comparison, Gramps is

> demented, a shadow of his original self. He is rusted out; his neurons are not working correctly even though he is still conscious in a sort of automatic and superficial way. His soma is there, and when you see him, you are reminded of his personhood, even though he can longer be reminded of his own or

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[65] Lisa S.Caddell and Linda Clare, "The impact of dementia on self and identity: A systematic review," *Clinical Psychology Review* Vol.30 No.1 (February 2010), pp.113-126. Qualitative and quantitative methods were used in studies reviewed, thus results were rather disparate yet meaningful. (p.124)

[66] Caddell & Clare, *The impact of dementia,* p.124

[67] Caddell & Clare, *The impact of dementia,* p.124

[68] However, overall results from studies exploring the self in dementia are difficult to integrate due to the various methods, the stage of the dementia, its particular attention to people with AD – though some examined other dementias. Caddell & Clare, *The impact of dementia,* p.124

> yours...Gramps is a stimulus to your state of mind, not to his. Gramps lives on in you, not in himself.[69]

Gazzainga says few would look to euthanasia for him since it seems impossible to locate a point where the deteriorating or deranged brain becomes undeserving of normal moral status. Some researchers are even more extreme in talking about some patients with dementia in terms of the 'living dead'.[70] The 1985 cult horror movie 'The Return of the Living Dead' features the 'living dead' as fictional zombies which in the film are animated corpses. Researchers have asked, if the 'living dead' are "not just creatures of the imagination but might also be people with advanced dementia. People with dementia can be treated as already dead and as walking corpses to be both pitied and feared, despite their obvious signs of life."[71] But the conclusion is that these are not the 'living dead'. "They are the dying who live and who deserve our care and concern because of their continuing place as persons in the human world"[72] Many philosophical questions abound.

A longstanding feature of Anglophone philosophy (J.Locke, D.Parfit, and others) is interest in identity:[73] Here this relaites to decision-making of incompetent patients, and their validity in dementia cases.[74] Parfit's ideas are cited: psychological connectedness and continuity between stages in life may lessen in dementia. It is claimed that over time, "one body may house successive selves. Following this line of reasoning, the incompetent person with dementia is viewed as another person, in which case the moral force of an advance directive would be undermined."[75]

Some look to Descartes, a very different sort of philosopher, for whom material things like brains are not strongly unified entities as selves or persons. Matter

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[69] Michael S.Gazzaniga, *The Ethical Brain* (New York and Washington, D.C.: Dana Press, 2005), pp.51-52

[70] Carmelo Aquilina and Julian C.Hughes, "The return of the living dead: agency lost and found?," Julian C.Hughes, Stephen J.Louw and Steven R.Sabat (eds.), *Dementia: Mind, Meaning, and the Person* (Oxford and New York: Oxford University Press, 2006), pp.143-161.

[71] Aquilina & Hughes, *The return of the living dead*, p.143

[72] Aquilina & Hughes, *The return of the living dead*, p.158

[73] E.Jonathan Lowe, "Can the self disintegrate? Personal identity, psychopathology and disunities of consciousness," in.Hughes, Louw & Sabat (eds.), *Dementia: Mind, Meaning, and the Person*, pp.89-103.

[74] For example, the Netherlands. Marike E.de Boer et.al., "Advance directives in dementia: issues of validity and effectiveness," *International Psychogeriatrics* Vol.22 No.2 (2010), pp.201-208

[75] Boer et.al., *Advance directives in dementia*, p.204

includes many replaceable parts which can be reorganised, resulting in an unavoidable vagueness.[76] While it is impossible to know exactly which neurons currently compose the brain, no such vagueness plausibly inheres in persons and their continuing existence or defining the state of their brains ceasing to exist.[77]

According to the Cartesian view, since the gulf between existing and not existing seems so unambiguous, it is argued, I cannot coherently identify myself with my brain or any other material part of my body, even as a whole, as these things lack strong unity.[78] Agnosticism could follow, where one is sure of existence and a strongly unified entity, however, "I have no real grasp of what it is that I am…Perhaps, in the end, this is what we really have to learn from the so-called pathological cases."[79]

Modern European philosophy provides other interpretations. P.Ricoeur contrasts *ipse* and *idem* identity.[80] Identity as *idem* asks 'What am I' and is equivalent to 'sameness' close to the Lockean tradition. *Ipse* identity, or *ipseity* is 'selfhood' and asks, 'Who am I?' As dementia progresses, the person we knew fades away, leaving only a body. The Ricoeurean self is 'as another', and can "salvage for a little longer a little more, not only of the sameness of the dementia sufferer but also, perhaps, aspects of their *ipseity* or selfhood."[81] There are practical conclusions. If there is a coherent sense of identity which depends on Ricoeur's *ipseity* and can separate concepts of narrativity, then that conception of a person's identity may permit practical outcomes and moral duties towards those with dementia being cared for.[82]

M.Merleau-Ponty and E.Husserl's phenomenology can advance the person-centred viewpoint in dementia: in particular, the notion of the 'lifeworld,' the space of these

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[76] When it comes to issues about the existence and persistence of such objects. Lowe, *Can the self disintegrate?,* p.98

[77] Lowe, *Can the self disintegrate?,* p.98

[78] That is, "the kind of unity that is possessed by something whose continuing existence is not infected in any way by vagueness." Lowe, *Can the self disintegrate?,* p.102. Descartes' essential 'I' or soul or simple immaterial substance, is not followed.

[79] Lowe, *Can the self disintegrate?,* p.102

[80] Jennifer Radden and Joan M.Fordyce, "Into the darkness: losing identity with dementia," in Hughes, Louw & Sabat (eds.), *Dementia: Mind, Meaning, and the Person,* pp.71-88. Radden and.Fordyce refers to Paul Ricoeur's volume *Soi-meme comme un Autre* (Oneself as Another) and his distinction: that between identity understood in terms of the Latin *ipse* and *idem.* Radden & Fordyce, *Into the darkness,* pp.71-72

[81] Radden & Fordyce, *Into the darkness,* p.85

[82] Radden & Fordyce, *Into the darkness,* p.85

people, their words and gestures about their lives. This model looks at the 'self' that remains. Though a 'self' is lost, this is only the public self, or selves, that is denied life in 'malignant social positioning' which assumes that while negative social responses erode the public selves of adults with AD, the private selves remain intact during the downward progression of the disease.[83]

These philosophical approaches contrast with other models,[84] e.g. the biomedical-legal model of dementia that dominated from the 1980s and into the 1990s. The individual falling victim to AD is redefined as an AD *patient*.[85] The language includes references to victims, loss of self, post-adults, 'retrogenesis' as a return to the infant state. Dementia is a condition so medicalized that it excludes how illness is experienced and lived. This biomedical model of AD documents the losses as the self fades until there is no self left.[86]

Whereas, a more social constructionist approach seeks to place the person back into the dementia situation. In dementia care, memory of past experiences can be nurtured and used therapeutically. Behavioural control and short-term memory loss can be alleviated somewhat. But some think it is also 're-minding', that is reconstructing the person.[87]

Social constructionist models acknowledge AD has a neurological basis but uses knowledge of how brain function mixes with other factors like relationships and the social responses: discrimination and stigma.[88] It can have social and political consequences. Indeed political models of dementia are highlighted.[89] Individuals are citizens but also vulnerable people, entitled to compassion, legal rights and protections. It requires responding to issues of the dependence, gradual cognitive

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[83] Behuniak, *Toward a political model,* p.235

[84] Susan M.Behuniak, "Toward a political model of dementia: Power as compassionate care," *Journal of Aging Studies* Vol.24 No.4 (December 2010), pp.231-240

[85] Behuniak explains, "given this medical construction, the appropriate response to this neurological assault were medical interventions that attempted to control this out-of-control disease by controlling the body of the patient—in essence meeting force with force." Behuniak, *Toward a political model,* p.233

[86] Behuniak, *Toward a political model,* p.233

[87] Bruce Jennings, "Agency and Moral Relationship in Dementia," *Metaphilosophy* Vol.40 Nos.3-4 (July 2009), pp.425–437 (p.426)

[88] Behuniak, *Toward a political model,* p.234. Cf. also Annette Leibing, "Entangled Matters—Alzheimer's, Interiority, and the 'Unflattening' of the World," *Culture, Medicine and Psychiatry* Vol.32 No.2 (June 2008), pp.177-193 (p.190)

[89] Behuniak, *Toward a political model,* p.235

decline, continuing humanness and rights as adult members of society. A biomedical–legal model can remove from the vulnerable their personhood.[90] Continuing critical debates will always accompany the profound issues that dementia contains.

Identity, Dementia, Soul and God

Turning to Christian responses, one can use E.H.Erikson's notion of the pure self, the loss of self in AD could be that the self prior to the infant's encounter with the objective world, formed in a dark yet nurturing environment, survives the disease. This challenges the disease itself: "its power to destroy the other selves bring this pure self to light and remind us that nothing, even a disease that is capable of destroying the brain, can separate us from the One to whom we ultimately belong."[91]

Improving quality of life and preserving personhood in the face of dementia is the aim of 'Personhood-Centered Care'.[92] It includes sociocultural ideas on how the body is the ground for individual and collective human identities; and how many recognise personhood to be spiritual.[93] With decreasing communication skills, dementia can threaten personhood and the sense of self.[94] Cognitive losses can mean that "relationships with God, self, and the environment may primarily be experienced only through meaningful relationships with others."[95]

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[90] Behuniak, *Toward a political model,* p.232. (p.238)

[91] Donald Capps, "Alzheimer's Disease and the Loss of Self," *The Journal of Pastoral Care & Counsel*ing Vol.62 Nos.1-2 (Spring-Summer 2008), pp.19-28 (pp.24-25). Capps explains that this pure self is contained in the epilogue of Erikson's book *Young Man Luther.* This is one of three things Erikson sees when looking through a glass darkly (1 Corinthians 13:12). But for Erikson this is a 'nostalgia' in which the glass shows the pure self. (p.24)

[92] Elizabeth Herskovits Castillo, "Doing Dementia Better: Anthropological Insights," *Clinics in Geriatric Medicine* Vol.27 No.2 (May 2011), pp.273-289. This can counter negative cultural assumptions about dementia like excessive disability.

[93] Castillo, *Doing Dementia Better,* pp.280-282

[94] Ellen B.Ryan, Lori Schindel-Martin and Amanda Beaman, "Communication Strategies to Promote Spiritual Well-being mong People with Dementia," *The Journal of Pastoral Care & Counseling* Vol.59 Nos.1-2 (Spring-Summer 2005), pp.43-55. The spiritual needs of persons with dementia can be met by connecting through life stories and through participation in religious life. Cf. Elizabeth Vreugdenhil, "Non-Speech Based Pastoral Care: A Pastoral Care Program for Aged Care Residents with Little or No Ability to Speak," *Journal of Religious Gerontology* Vol.16 Nos.3-4 (2004), pp.147-160

[95] Ryan, Schindel-Martin &Beaman, *Communication Strategies,* p.44

Christian ministry extends to those who have dementia,[96] and others who realise for instance, “at least I’ve still got my brain.”[97] S.G.Post notes how countless family members respect the ‘deeply forgetful’ due to belief in a non-material soul that still exists beneath the neurological losses of dementia.[98] But Post does not hold this view; he recognises it as a way of asserting the moral intuition relating to the inviolability of the deeply forgetful and some notion of continuity of self.

Theological responses to dementia offer a differing concepts of soul. K.Kevern considers the possibility that Christ “demented” on the cross, losing self-awareness and knowledge of his own motivation. Thus in the midst of dementia, “God is present; and that this means that grace and the redemption of the cosmos is at work in and through those who are dementing. In turn, this constitutes a challenge to the prevailing secular view of those who are dementing.”[99] This ‘soul’ is seen as being inherited from pre-Christian Greek ideas, identifying self-awareness as the manifestation of the immortal soul.

There is a fear that when awareness of selves is lost, people’s actions and well-being are missing, so too is that part of them which is receptive to God. Without this ‘soul’, it can be asked, “what is there to receive grace, to exercise faith, or to respond to God? We may conclude that this person has been ‘lost’ in more ways than one, and it may even appear that their salvation is in question.”[100] Later, Kevern calls this idea the ‘sub-christian’ association of the consciousness with the immortal soul, with the implication that to be human is necessarily to be self-conscious and competent. Dementia could be construed in way that bolsters the notion that humanity cannot be

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[96] Karen MacKinlay, “Listening to People with Dementia: A Pastoral Care Perspective,” *Journal of Religious Gerontology* Vol.13 Nos.3-4 (2002), pp.91-106. See also Hilde Lindemann, “Holding One Another (Well, Wrongly, Clumsily) in a Time of Dementia,” *Metaphilosophy* Vol.40 Nos.3-4 (July 2009), pp.416–424; Arthur Kleinman, “Caregiving: the odyssey of becoming more human,” *The Lancet* Vol.373 No.9660 (24 January 2009), pp.292-293, and dramatically in Maura McIntyre and Ardra Cole, “Love Stories about Caregiving and Alzheimer’s Disease: A Performative Methodology,” *Journal of Health Psychology* Vol.13 No.2 (March 2008), pp.213–222

[97] This was a defensive comment when observing other residents in the dementia specific aged-care facilities. MacKinlay, *Listening to People with Dementia,* p.97. MacKinlay’s question to interviewees here was ‘what helps you get through difficult times?’ (p.96)

[98] Stephen G.Post, “‘Respectare’: moral respect for the lives of the deeply forgetful,” in Hughes, Louw & Sabat (eds.), *Dementia: Mind, Meaning, and the Person,* pp.223-234 (p.231)

[99] For instance, Peter Kevern, “Sharing the mind of Christ: preliminary thoughts on dementia and the Cross,” *New Blackfriars* Vol.91 No.1034 (July 2010), pp.408–422 (p.414)

[100] Kevern, *Sharing the mind of Christ,* p.410

experienced in them; thus absolving the responsibility to look for a relationship with them.[101]

Yet C.Bryden who has fronto-temporal dementia,[102] favours a reference to soul and she challenges Alzheimer's Disease International's view that the 'mind is absent and body an empty shell'.[103] She asks if cognition is the only measure of her presence and is her soul connected with failing cognition. She answers, "as I lose an identity in the world around me, which is so anxious to define me by what I do and say, rather than who I am, I can seek an identity by simply being me, a person created in the image of God. My spiritual self is reflected in the divine and given meaning as a transcendent being."[104]

Fronto-temporal dementia damages the temporal lobe. Stimulation of the temporal lobe can cause intense spiritual experiences. Bryden wonders if God-experiences are electrical storms in the brain or are they the means God provides for appreciating his presence.[105] Her 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 am confident that even if the continuing damage to my temporal lobe might diminish the intensity of my God-experience."[106]

Bryden quotes the words spoken to Jesus, 'remember me when you come into your kingdom' and asks her visitors, "If I enjoy your visit, why must I remember it?...If I forget a pleasant memory, it does not mean it was not important for me."[107] She also quotes Jesus' words, 'Do this in remembrance of me' and suggests that is an action, "my mind, my cognitive function, my actual memory of the Scripture, is not what is asked of me but an act of faith. An act of sharing in a sacrament."[108] The Holy Spirit

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[101] Kevern, *Sharing the mind of Christ,* p.412

[102] Christine Bryden and Elizabeth MacKinlay, "Dementia - A Spiritual Journey Towards The Divine: A Personal View Of Dementia," *Journal of Religious Gerontology* Vol.13 Nos.3-4 (2002), pp.69-75

[103] Bryden & MacKinlay, *Dementia - A Spiritual Journey,* p.71.

[104] Bryden & MacKinlay, *Dementia - A Spiritual Journey,* pp.71-72. See Elizabeth MacKinlay, "Mental Health and Spirituality in Later Life: Pastoral approaches," *Journal of Religious Gerontology* Vol.13 Nos.3-4 (2002), pp.129-147, particularly MacKinlay's discussion of *imago Dei,* pp.142-144

[105] Bryden & MacKinlay, *Dementia - A Spiritual Journey,* p.72. Her belief is that she is more than just her daily-declining brain structure and function.

[106] In other words, "there will be other ways in which I can maintain my relationship with God." Bryden & MacKinlay, *Dementia - A Spiritual Journey,* p.72

[107] Bryden & MacKinlay, *Dementia - A Spiritual Journey,* p.73

[108] Bryden & MacKinlay, *Dementia - A Spiritual Journey,* p.73

is within her and does not leave because her brain is diseased. She says, "don't abandon me at any stage, for the Holy Spirit connects us. It links our souls, our spirits – not our brains or minds. I need you to minister to me, to sing with me, pray with me, to be my memory for me."[109]

When she dies with dementia, Bryden realises a continuity from life to death, "My soul is me, and will always be me. Even through the ravages of dementia, my soul will remain intact and continue to be the primary way in which God works within me. I can survive this disease with dignity, confident that God sees my soul – true me."[110]

While persons with dementia may be recognised as "just a shell now," or the person who "left us a while ago,"[111] believers in God know that the person is truly present and loved by God.[112] Christians believe that created in the image of God, "each person is unique and has something to offer no matter how much the world might tell us otherwise. Even when the body and mind falter and fail, the spirit and soul remain."[113]

Spirituality endures even in dementia. A study measuring the spiritual aspects of dementia among patients with dementia and their carers found the overall pattern of spiritual beliefs and strength of beliefs of patients and carers similar. The patients found comfort in routines of spiritual practices. The results stress the reality that people with dementia are whole persons and must be treated as such.[114] The Catholic

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[109] Bryden & MacKinlay, *Dementia - A Spiritual Journey,* p.73 & p.74; see the poem by Seung Hee Kang, "A Song for the Elderly with Dementia," *The Journal of Pastoral Care & Counseling* Vol.62 No.4 (Winter 2008), p.410

[110] Bryden & MacKinlay, *Dementia - A Spiritual Journey,* p.74. Bryden remakrs, "He speaks within my soul which is given life and meaning in my Christian community."

[111] Catholic Health Australia (CHA), *Ministering to People with Dementia: A Pastoral Guide* (Deakin, Australian Capital Territory: Catholic Health Australia, 2008), p.8.

[112] Julian Hughes, "Don't tuck me in," *The Tablet* Vol.257 No.8493 (5 July 2003), pp.8-9. A wife hit by a husband of 40 years may lament, 'He's not the man I married'; "similarly, the woman who stares blankly while being hoisted on to the toilet might seem to bear little resemblance to the loving wife or competent mother of former days." (p.8); and Ruth Hodder, "Alzheimer's and the complexity of being," *American Journal of Alzheimer's Disease and Other Dementias* Vol.19 No.3 (May/June 2004), pp.198-200

[113] CHA, *Ministering to People,* p.13. See also Noel C.Schultz, *Forgetting But Not Forgotten: Understanding, support and spiritual care for people with dementia and those who care for them* (Adelaide: Openbook Publishers, 2004).

[114] David Jolley et.al., "Spirituality and faith in dementia," *Dementia* Vol.9 No.3 (August 2010), pp.311-325 (p.321); Len Sperry, "Working With Spiritual Issues of the Elderly and Their Caregivers," *Psychiatric Annals* Vol.36 No.3 (March 2006), pp.185-186,188-190,192,194.

Church understands that people with dementia have spiritual needs and "it may only be through the Sacraments that the person can be truly touched. Even when there is no outward response, God can be reaching the person in the depths of their soul, bringing peace and healing."[115] As indicated above, there are a range of ways of how one might understand this faith belief.

End of Self, Brain Death and Identity

Since neurodegeneration and neurological disorders are essentially progressive in nature, the inevitable endpoint is brain death. Person, self and personal identity questions are relevant particularly at the end of life in a technological age. The brain is at the centre of death described neurophysiologically.[116] 'Brain death' is a relatively recent concept.[117] first described by French neurologists as irreversible coma or *coma depassé* and later enshrined by the Harvard Ad Hoc Committee (1968).[118] In the industrialised world death presumably occurs at a precise moment, either cessation of the whole brain function, Whole brain death criteria is used in the United States,[119] and in most states of Australia,[120]or the death of the brain stem, as in the United Kingdom.[121]

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[115] CHA, *Ministering to People,* p.22, and as narrated in the first-person account of bringing Holy Communion to an aphasic patient by Hellena Moon, "Pastoral Care to Patients with Aphasia," *The Journal of Pastoral Care & Counseling* Vol.61 No.4 (Winter 2007), pp.379-381; Debbie Everett, "Forget Me Not: The Spiritual Care of People with Alzheimer's Disease," in Larry VandeCreek (ed.), *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice* (New York: The Haworth Pastoral Press, 1999), pp.77-88

[116] D.Gardiner et.al., "International perspective on the diagnosis of death," *British Journal of Anaesthesia* Vol.108 Suppl.1 (January 2012), pp.i14–i28. See too, P.L.Lutz, G.E.Nilsson and H.M.Prentice, *The Brain Without Oxygen: Causes of Failure - Physiological and Molecular Mechanisms for Survival* (Dordrecht: Kluwer Academic Publishers, 2003), pp.1-2; 61-101

[117] Raymond Hoffenberg, "Christiaan Barnard: his first transplants and their impact on concepts of death," *BMJ* Vol.323 No.7327 (22 December 2001), pp.1478–1480

[118] Megan Stern, "'Yes:—no:—I have been sleeping—and now—now—I am dead': undeath, the body and medicine," *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences* Vol.39 No.3 (September 2008), pp.347-354

[119] Guidelines for the Determination of Death: Report of the Medical Consultants on the Diagnosis of Death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research *JAMA* Vol.246 No.19 (November 13, 1981), pp.2111-2269

[120] Australian and New Zealand Intensive Care Society, *Recommendations on Brain Death and Organ Donation,* Second Edition (Melbourne: ANZICS, Australian and New Zealand Intensive Care Society, 1998), p.9

[121] See Academy of Medical Royal Colleges, *A Code of Practice for the Diagnosis and Confirmation of Death* (London: Academy of Medical Royal Colleges, 2008)

Death also has been understood using other criteria: higher-brain death and death using circulatory-respiratory criterion.[122] There are regional variations. In Britain, a brain scan is not needed as brain stem death alone is sufficient for diagnosis of brain death; whereas in the United States a brain scan is required to show whole brain failure.[123] Those close to a patient diagnosed as brain dead find it difficult to understand how a warm body, breathing, can be actually dead.[124] The matter continues to be discussed.[125]

The use of the term ‘brain death’ rather than ‘death’ implies a distinction between brain death and subsequent cardiopulmonary death. Brain death is essentially, “a way of representing something. It does not exist outside of its own diagnostic criteria.”[126] Philosophical discussion of brain death is sophisticated, e.g. it pertains to bioethics, organ procurement,[127] and there are debates even about the brain death concept itself.[128] With technology there are doubts about the criteria of death. For instance, better technology for mechanical ventilation has been thought by some to have held back the recognition of brain death.[129]

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[122] Some defend an *organismic* notion of death, the loss of function of the overall body system integrating all or most of the critical subsystems, e.g. in plants and animals which have no brains. David DeGrazia, “Persons, Organisms, and Death: A Philosophical Critique of the Higher-Brain Approach,” *The Southern Journal of Philosophy* Vol.XXXVI No.3 (Fall 1999), pp.419–440

[123] Eelco F.M.Wijdicks, “The transatlantic divide over brain death determination and the debate,” *Brain* Vol.135 No.4 (April 2012), pp.1321-1331. In one American state New Jersey, unlike New York, families have a right not to recognise brain death such that “this creates the strange situation in which somebody is simultaneously dead and alive in two neighbouring states.” Stern, *Yes: - no,* p.350. See also J.M.Elliot, “Brain death,” *Trauma* Vol.5 No.1 (January 2003), pp.23-42

[124] Stern, *Yes: - no,* p.350

[125] Kevin McGovern, “Brain Death and the US President’s Council on Bioethics,” *Chisholm Health Ethics Bulletin* Vol.14 No.4 (Winter 2009), pp.9-12. McGovern summarises and comments on the US President’s Council on Bioethics White Paper, ‘Controversies in the Determination of Death’, December 2008.

[126] Stern, *Yes: - no,*, p.350. Crucially says Stern, “the unacknowledged ambivalence of brain death leaves the ‘brain dead’ individual in a very vulnerable state, judging at least, on the protocol for using anaesthesia during organ procurement from brain dead donors.” (p.351) That is, donors are often anaesthetised, with different practices and protocols. Use of anaesthetics during organ procurement would clearly raise questions about the status of donors says Stern.

[127] Matesanz et.al., “Benchmarking in the Process of Donation After Brain Death: A Methodology to Identify Best Performer Hospitals,” *American Journal of Transplantation* Vol.12 No.9 (September 2012), pp.2498-2506; See also Kevin McGovern, “Organ Donation after Cardiac Death,” *Chisholm Health Ethics Bulletin* Vol.14 No.3 (Autumn 2009), pp.6-9

[128] For example, Ari Joffe, “Are Recent Defences of The Brain Death Concept Adequate?,” *Bioethics* Vol.24 No.2 (February 2010), pp.47–53

[129] William T.McGee and Patrick Mailloux, “Ventilator Autocycling and Delayed Recognition of Brain Death,” *Neurocritical Care* Vol.14 No.2 (April 2011), pp.267-271; James M. Dubois, “The Ethics of Creating and Responding to Doubts about Death Criteria,” *Journal of Medicine and Philosophy* Vol.35 No.3 (June 2010), pp.365–380

After death, there are personal identity questions about the body in decomposition,[130] where skeletal remains can be recognised even after cremation.[131] Brain death identity issues can be explored via thought experiments. In one brain-transplantation experiment, the brain has all its memory accidentally erased and is ‘unwired’ so thoroughly that it permanently removes all the owner's mental capacities and traits.[132] According to this account, there is no need to regard an individual that results from implanting of the unwired brain in a ‘new’ body as the person formerly linked to that brain.

But some argue that brain identity alone is insufficient for personal identity because the ordinary causal processes which connect events in a personal history need more than spatio-temporal continuity of brain tissue. They also need continuity of particular brain processes.[133] The notion of ‘biographical continuity’ is used in ‘brain switch’ experiments,[134] where the brains of two people are swapped; each has the life history and self-awareness of the other. These cases demonstrate what is valued: personhood not organismic life. Personal life is understood as “the interconnection of remembered events integral to conscious self-awareness, and it is claimed that when this biographical continuity is lost, then the ‘person’ is gone."[135] The raising of such issues awaits a complete resolution, if that is ever possible.

Critical Analysis

In neurodegeneration and cognitive decline, and their associated personal and social impacts, the leading cause is the brain, as in the case of death when framed as brain death. This well-defined brain focus has been subject to critique from secular and Christian thinkers, which we now consider; it complements the earlier identity discussion of personal identity in relation to dementia.

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[130] M.Lee Goff, “Early post-mortem changes and stages of decomposition in exposed cadavers ,” *Experimental and Applied Acarology* Vol.49 Nos.1-2 (October 2009), pp.21-36

[131] For example, Tosha L.Dupras et.al., *Forensic Recovery of Human Remains: Archaeological Approaches* (Boca Raton, Florida: CRC Press, 2006), pp.110-128

[132] Michael B.Green and Daniel Wikler, “Brain Death and Personal Identity,” *Philosophy and Public Affairs* Vol.9 No.2 (Winter 1980), pp.105-133

[133] Green & Wikler, *Brain Death and Personal Identity,* p.125

[134] George Khushf, “A Matter of Respect: A Defense of the Dead Donor Rule and of a "Whole-Brain" Criterion for Determination of Death,” *Journal of Medicine and Philosophy* Vol.35 No.3 (June 2010), pp.330-364

[135] Khushf, *A Matter of Respect,* pp.351-352. See also Marya Schechtman, “Empathic Access: The Missing Ingredient in Personal Identity,” *Philosophical Explorations* Vol.4 No.2 (May 2001), pp.95-111

The brain thought experiments referred to above are worth a second look as they can address critical matters relating to the identity of persons. Imagine the brain of person X is transplanted into donor body Y, where X is a patient dying of some wasting disease like cancer. Y has suffered massive cerebral damage but the body is unhurt. With the consent of Y's next of kin, X's brain is transplanted into Y's body.[136] The "composite" Z is seen as having the identity of X.[137] Likewise, if the brain of ten year old John (J) is transplanted into the body of a middle-aged female (MF), then after six years into the body of a young girl (YG), and lastly into the body of a young man (YM) around ten years later, whose brain is it?

R.Puccetti explains that if J, MF, YG and YM are all distinct persons because of their separate body biographies, then they ought to have different memories. However this is not so, as after the transplant MF has no memories of being a girl and growing to adulthood. Each one's composite memories "start off from the previous store and build on that…I have no doubt that J, MF, YG, and now YM would all be the same person P. For however jarringly disparate the individual links are, they do form a single, temporally consistent chain."[138] This thought experiment and others are open to much philosophical debate.

E.T.Olson refers to the 'brain view', any position where humans are said to be identical with brains.[139] It arises because humans can survive the loss of organs but not brain loss. Humans think with their brains; the main reason for the view that we are brains. The presumption is that all parts of a genuine thinker must be in some way directly involved with its thinking. Similarly, the person would continue with any transplanted brain, that is "to transplant your brain is literally to transplant *you:*

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[136] Even if brain transplantation was possible, much remains unknown about how neurophysiology causes higher mental functions. Giovanni Boniolo, "The Ontogenesis of Human Identity," *Royal Institute of Philosophy Supplements* Vol.80 Suppl.56 (December 2005), pp.49-82

[137] Roland Puccetti, "Brain Transplantation and Personal Identity," *Analysis* Vol.29 No.3 (January 1969), pp.65-77. See too a later paper, Roland Puccetti, "Borowski on the Relative Identity of Persons," *Mind* Vol.87 No.346 (April 1978), pp. 262-263

[138] Puccetti, *Mr.Brennan on Persons' Brains,* p.30. In each phase of its body, "P stores a definite set of memories, and there are constant features running through the whole chain. For instance, P has but one set of parents." (p.30)

[139] In other words, "not that we 'are' brains in some looser sense…nor is it that our brains constitute us, or that we are temporal parts of brains. The brain view is that we are literally brains." Eric T.Olson, *What Are We? A Study in Personal Ontology* (New York: Oxford University Press, 2007), p.76

to cut out of your head, move across the room, and then re-house you in a new head."[140]

According to this view, humans could not exchange their old brains for a new one since humans *are* their brains. We could not be completely inorganic, as theoretically where silicon and metal prostheses gradually replace that which functioned as brain parts. However, Olson says the persistence of my brain "does not appear to be either necessary or sufficient for *me* to persist...those who say we are brains will have to say some surprising things about our identity over time." [141] The idea that we are brains comes from the view that the parts of a genuine thinker are only those directly participating in mental activity, a 'thinking-subject minimalism'.[142] Even if it can be said which parts are directly involved with mental activities, then he asks why only those parts, why can't a thinker have parts not directly involved, and why accept thinking-subject minimalism?

Others argue that persons do not follow their brains.[143] Here the dominant image of the human being is the 'cerebral subject',[144] understood as the property of 'brainhood': the property of being, rather than having, a brain. This belief in brain-self consubstantiality seems to have impelled brain research generally. The idea that 'we are our brains' is viewed as a criterion for neuroscientific research rather than a repercussion of the research.[145] Locke's notion of 'person' is cited, requiring continuity of consciousness and memory. Each individual's self-ownership is absolute, now applicable to the brain. The highest value of individuals as autonomous agents is emphasised at the expense of social bonds, as sustained by neurocultural[146] discourses and brainhood ideology.[147]

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[140] Olson, *What Are We?,* p.78

[141] Olson, *What Are We?,* p.85 & p.87. Earlier Olson observed how brains developed after arms, legs and even mental properties; brain history differs from our other histories.

[142] Olson, *What Are We?,* p.94

[143] E.Steinhart, "Persons Versus Brains: Biological Intelligence in Human Organisms*," Biology and Philosophy* Vol.16 No.1 (January 2001), pp.3-27

[144] Fernando Vidal, "Brainhood, anthropological figure of modernity," *History of the Human Sciences* Vol.22 No.1 (February 2009), pp.5-36. Vidal argues that the cerebral subject is the anthropological figure inherent to modernity.

[145] Vidal, *Brainhood*, p.6

[146] 'Neuroculture' refers to "the incorporation of neuroscience knowledge into our life, culture and intellectual discourses. Several new terms with a 'neuro-' prefix have been used to designate the set of transformations taking place in society in light of advances in neuroscience (for example, neurosociety)." Giovanni Frazzetto and Suzanne Anker, "Neuroculture," *Nature Reviews Neuroscience* Vol.10 No.11 (November 2009), pp.815-821 (p.819)

A similar concept is ‘neuro-essentialism’ which interprets the brain as the “self-defining essence of a person, a secular equivalent to the soul.”[148] Neuro-essential brains become shorthand for other concepts e.g., self, which expresses features not ordinarily contained in the concept ‘brain’. Neuroscience reveals the ‘essence’ of persons: ‘The brain holds your memories, your emotions, your hopes, dreams and understanding. (...) It holds ‘you’.’[149]

Neuroreductionism has been challenged, are independently of Christian scholarship.[150] Humans are constituted by their brains but are not identical to brains. It is necessary but not sufficient to explain the physiological and psychological properties of persons.[151] Embodied minds means that mental states are produced by the brain as it interrelates with the body.[152] The experiential *content* of my memory, “what I saw, heard and smelled - cannot be divorced from the social and physical *context* in which the remembered events occurred.”[153]

These thinkers raise important identity questions of brain and self within a reductionistic scientific worldview. But persons are deeper and richer than their brains. In an ageing population, brain decline is a known phenomenon with many implications,[154] especially for the meaning of human existence and at the end of life. Both life and its end are related to a person’s soul. Ideally a Catholic understanding of the soul should include dialogue with the full spectrum of scientific studies of what brain decline entails for persons and communities.

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[147] Vidal, *Brainhood*, p 7 Vidal also discusses the self before brainhood, the origins and development of brainhood, the demise of phrenology, as well as twentieth century cortical maps and neuroplasticity.

[148] Eric Racine et.al., “Contemporary neuroscience in the media,” *Social Science & Medicine* Vol.71 No.4 (August 2010), pp.725-733 (p.728)

[149] C.T. Hall, “Fib detector; study shows brain scan detects patterns of neural activity when someone lies,” *The San Francisco Chronicle* (2001) November 26, p. A10, quoted in Racine et.al., *Contemporary neuroscience in the media*, p.730

[150] A view that minds are merely a function of brains, mind is reducible to brain, and that mental states are just comprised of brain states. Walter Glannon, “Our Brains Are Not Us,” *Bioethics* Vol.23 No.6 (July 2009), pp.321-329. In other words, “We are essentially our brains,” (p.321), echoing the ‘neuro-essentialism’ of Racine et.al. above.

[151] Glannon, *Our Brains Are Not Us*, p.321

[152] Glannon, *Our Brains Are Not Us*, p.322

[153] Autobiographical episodic memory and life narratives are a first-person experience, unified from events and have meaning and persisting through time. Glannon, *Our Brains Are Not Us*, p.325

[154] Michele J.Karel, Margaret Gatz and Michael A.Smyer, “Aging and Mental Health in the Decade Ahead: What Psychologists Need to Know,” *American Psychologist* Vol.67 No.3 (April 2012), pp.184–198

However the clear success neurology and neuropsychology have had in accounting for the mental effects of brain deterioration has been perceived as a threat to the official and traditional account of the soul. Dementia affects consciousness and memory and is physically a neurological disease. However the experience of carers and families as discussed above shows that paradoxically it is when the brain and mind decline that there are openings for turning to the soul.

The traditional Catholic teaching is that the human body shares in the dignity of "the image of God",[155] even when body and mind are affected by brain injury or a progressively failing brain. There is an obligation “to regard his body as good and to hold it in honour since God has created it and will raise it up on the last day.” [156]

In the Catholic philosophical and theological tradition, Tommaso’s ideas look outdated and naturally unable to explain what neurology comprehensively does today with neurological disorders especially dementia (which in its current understanding is a relatively recent discovery[157]). In Tommaso’s view, reasoning souls do not share that particular activity with any bodily organ; for him such as having an organ for thinking is like having an eye for seeing. Therefore the “life-principle of a thing with understanding has to act autonomously. Mind is a kind of undecomposable substance.”[158] According to neuroscientific studies, however, the many medical cases of neuropsychological deficits and accompanying brain degeneration attests to the centrality of the brain for memory, movement, lucid thought and regulation of body functions.

Another difference between the modern neuroscientific account and that of the medieval Tomasso can be seen in his reference to human ageing. While the intellect or the soul’s faculty of understanding is a power of the soul that needs no organ;[159] Tommaso adds that it is not weakened either in itself or by accident, nor by old age

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[155] *Catechism of the Catholic Church,* no.364, p.93

[156] *Catechism of the Catholic Church,* no.364, p.93

[157] N.C.Berchtold and C.W.Cotman, "Evolution in the Conceptualization of Dementia and Alzheimer’s Disease: Greco-Roman Period to the 1960s," *Neurobiology of Aging* Vol.19 No.3 (May–June 1998), pp.173–189

[158] Aquinas, *Quaestio Disputata de Anima* 1, Aquinas (McDermott), Passage 18 “in reply” (Respondeo), p.188 and “to 11”, “to 12” p.191.

[159] Aquinas, *SCG,* Book 2, Ch.68 [12], p.206-207

or infirmity. If fatigue or some other bodily hindrance affects the operation of intellect, “this is due not to any weakness of the powers which the intellect needs, namely, of the imagination, the memory, and the cogitative power. Clearly, therefore, the intellect is incorruptible. And since it is an intellective substance, the human soul is likewise incorruptible.”[160]

On a first reading, the documented cases of cognitive decline and memory failure can be counted against Tommaso’s ideas. Nonetheless, it seems to be that the bodily hindrance and fatigue which affects the intellect’s operations belongs to the body. It is the intellect or soul which remains vital and in his view incorruptible. Thus a damaged brain does alter the operation of the soul. Whereas in the scientific view, there are no causal powers in the soul and there is no scope for the soul in any explanation of decline. Neurological deterioration is sufficient reason.

As discussed in Chapter 1 of Part I, the Pontifical Academy of Sciences holds that the brain is the centre of the nervous system, but it functions with essential parts throughout the organism; and the organism only functions with its centre. There is physiological unity and consciousness, but ontological unity is conferred not by the brain but by the soul.[161] The brain is the centre of the nervous system and “the first instrument of the soul in its dynamic and operative function in the body.”[162] The destruction of the brain (or the destruction of the brain cells) causes “the body to lose the capacity or disposition to receive life, thus preventing the soul from giving life and being to the body.”[163]

Conclusions

The centrality of the brain is unquestioned. In physicalist, secular (and soulless) thought, the source of reason and intelligence *is* the brain/mind. But if the brain deteriorates and cognition and memory falter, then questions arise, for those who believe in the soul, about the body-without-soul. Neurological injuries and diseases cause damage to the brain and frequently result in troubled minds, even perhaps lost

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[160] Aquinas, *SCG,* Book 2, Ch.79 [11], p.257
[161] Various speakers, Questions For Neurologists and Others, p.xliv
[162] Various speakers, Questions For Neurologists and Others, p.xlvi
[163] Various speakers, Questions For Neurologists and Others, p.xlvii

souls so to speak. Within a Christian community, soul, mind and brain find supportive care rooted in a transcendent vision of the human body/soul.

Despite neurodegeneration, the experience of family members, as heard above, indicates a belief that human dignity and personhood cannot be fully equated with memory, cognitive capacity, and rational self-consciousness. Because of the spiritual nature of the soul in the psychophysical unity of the person, the presence of spirit in humans can test and press on the limits of hard materialism and reductionism.

Moreover, it must not be forgotten that while death is always personal, death is also a social reality. An Australian state coroner once remarked that it is "a hallmark of our civilisation that we regard it as an affront, an indignity, an abrogation of our responsibilities, that a person could live amongst us, die and be buried without a name."[164] The spiritual nature of persons, in particular, their life after death is characteristic of the Catholic belief in the Communion of Saints which is a communion of spiritual goods, of charity, of communion with the dead and one family of God.[165]

Overall, the Catholic thinking about the soul can contribute to an important yet neglected side of the neuroscience revolution by seriously questioning the orthodoxy and assumed dominance of the healthy brain, implied in the idea of "no brain, no mind"[166] and its consequences for sustaining the life of mentally-damaged persons. It can also be a genuine contribution to life ethics: championing dignity in brain decline, in the elderly, frail and infirm, young people with severe brain damage and a whole life ahead, people dying of stage cancer and people with dementia.

As in previous chapters, there are differences between the traditional Catholic understanding of the soul and contemporary neuroscience. One possible area of dialogue is the nature of identity. With philosophical tensions between a biological brain view and a psychological continuity view, recognition of the spiritual part of

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[164] Ian Freckelton and David Ranson, *Death Investigation and the Coroner's Inquest* (South Melbourne: Oxford University Press, 2006), p.386

[165] *Catechism of the Catholic Church,* no.946-962; pp.247-250

[166] Raymond S.Nickerson, "Foreward," in William R.Uttal, *Mind and Brain: A Critical Appraisal of Cognitive Neuroscience* (Cambridge: The MIT Press, 2011), p.xi

human beings, which is united with the body in health and sickness, could be considered an alternative anchor for exploring identity and self-questions.

The psychological accounts arise from thought experiments involving brain transplants or where the human body is replaced by synthetic one but the mental functions are unchanged. D.B.Hershenov reflects on these from a hylomorphic persective. First he suggests that any view which insists that humans are not animals is inconsistent with Catholic philosophical thought.[167] Humans do have an animal nature. But our animal nature is that we are contingently animals, i.e., humans are living creatures who can still *exist* without being *alive;* for instance, being in purgatory.[168] We are unlike all other animals having been made in God's image with certain mental capacities and are persons capable of free, rational and moral action.

Hershenov thinks, "such an account provides some reason to believe that our persistence conditions are unlike those of other animals and thus deserve a different treatment in the standard thought experiments."[169] Thus hylomorphism may be regarded as a third way between psychologism and animalism. A hylomorphic account of personal identity enables humans to be considered animals while also facilitating an intuitive response to thought experiments which point to our identity being important to our survival.

For those Christians not favouring hylomorphism it would be helpful if they could recommend other interfaces where dialogue could occur, which respects the physical and spiritual nature of human beings. The physicality is clearly demonstrated by the sciences, and the spiritual nature is upheld by Christianity which is more open to accepting the scientific accounts. If the very neural foundations of personhood are not stable over time and are subject to ongoing debates, then perhaps the spiritual dimension is worth further consideration. Thus there are prospects for dialogue.

This can be fortified by considering the evolutionary background to the physical nature of human beings, the subject of the next chapter.

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[167] David B.Hershenov, "A Hylomorphic Account of Thought Experiments Concerning Personal Identity," *American Catholic Philosophical Quarterly* Vol.82 No.3 (Summer 2008), pp.481-502

[168] In the 'time' after death and before resurrection, "we will not be metabolizing, homeostasis-maintaining bodies." Hershenov, *A Hylomorphic Account of Thought Experiments*, p.483

[169] Hershenov, *A Hylomorphic Account of Thought Experiments*, p.482