



‘Is Grandma Still There?’ A Pastoral and Ethical Reflection on the Soul and Continuing Self-identity in Deeply Forgetful People

Stephen G. Post

Stony Brook University School of Medicine, USA

Abstract

This metaphysical and pastoral reflection focuses on a question that over several decades has been posed to me by many family caregivers for deeply forgetful people (persons with dementia). The question may take different forms: Is my loved one still there underneath all of this confusion? Is my loved one’s soul still present? Will she come to rest fully intact in the arms of a Supreme Being? Could she be ‘gone’ but already somewhere experiencing the fullness of divine love? This reflection provides a pastoral response to this big question that has to do with the need to find meaning in caring for deeply forgetful people.

Keywords

Alzheimer’s disease, caregivers, deeply forgetful, dementia, meaning, pastoral care, post-materialism, soul

You do not have a soul. You are a soul. You have a body.
(attributed to C.S. Lewis)

Introduction

‘Is grandma still there?’ This is the big metaphysical question that most caregivers ask when it comes to their loved ones with dementia. I asked it as a young man caring for my grandmother on visits to the nursing home. It is a desperate question driven by the need to find spiritual and moral meaning in many difficult endeavors. Time and again, over 30 years of consulting with families, I have been asked just this question. I have encountered many caregivers who view the syndrome of dementia in its various forms (including Alzheimer’s disease) as a breakdown in the capacity of the brain to connect with a still complete and forever intact biographical selfhood. Their spiritual-metaphysical assumption is not that the hints at continuing self-identity are mere remnants of a mostly ‘gone’ self as located in residual brain tissue. Rather, they view the brain more like a desk top computer that can break down so as to no longer retrieve memories from ‘cloud

storage,’ although those memories remain perfectly intact in an unseen mystery of immortality. One said to me, ‘Stephen, it was St. Paul in *Romans 8:39* who wrote that absolutely nothing can separate us from the love of God, and that includes Alzheimer’s for sure.’ I agreed.

The materialist may deem the idea of any nonmaterial memory substrate, however defined, as nonsensical. But so many caregivers nevertheless assert, ‘We know grandma is still fully there, underneath the chaos and the silence, with an eternal soul that is slowly returning to the arms of the Supreme.’ Indeed, in a eulogy for a family that I knew was deeply religious, I commented as follows: ‘It may have looked like old grandma was ‘gone,’ or ‘a husk,’ or ‘a shell,’ or ‘already dead,’ but let’s just allow that maybe she had already gone down to the station and had one foot on that last train bound for glory. Amen.’

Corresponding author:

Stephen G. Post, Director, Center for Medical Humanities, Compassionate Care, and Bioethics, Stony Brook University School of Medicine, Stony Brook, NY 11794-8335, USA.
Email: Stephen.post@stonybrookmedicine.edu

How Little We Know

Let's start this argument for plausibility by asserting that nobody really knows what biographical memory is, physically or metaphysically, and so it remains a mystery. In the 1920s the great neuroscientist Wilder Penfield offered some bit of overstated evidence that specific memories are located in specific areas of the brain in the form of *engrams* or 'memory traces.' But in the 1940s the great neuropsychologist Karl Lashley gave up on Penfield's idea of localized traces after decades of research. Lashley concluded that memories are not located in specific brain locations, but are instead distributed 'globally' throughout the brain as a whole. Lashley, in his brain ablation studies in rats, failed to identify any unique sites for memory storage in the brain, and at last gave up on seeking a localized 'engram.' The idea that memory is distributed globally over a neural network – an idea taken up later by Donald Hebb – in some synaptic associations is indeed interesting, but also unproven and highly questionable. This drove one of Lashley's students, neuropsychologist Karl Pribram of Yale, to develop the idea that the brain is in some mysterious way holographic, meaning that all memory, including the whole of a life, is contained in each and every brain location like a single spot on a field included the entirety of a holographic image. This idea is quite interesting, but the model lacks any empirical support. It may be proven true one day, and some have tried to defend it articulately (Talbot, 2011). More recently, influenced by Hindu and Buddhist theories of reincarnation, biologist Rupert Sheldrake (2012) has argued that the repeated failures of 'material trace' theories of biographical memory suggest that mind and memory are nonmaterial.

The narrative memories that constitute self-identity do have infinite 'megabytes' of information as deep as a boundless ocean or a limitless sky, and even the smallest microchips cannot store this infinity. People often state that small computers can hold great amounts of memory, so by analogy they look within the brain to unlock this boundlessness. But at a certain point this sort of model breaks down logically because it is easier to view the brain not as a finite cupboard for infinite vastness, but rather as a transmission device otherwise unspecified. Like a TV set, the shows are not in the TV but outside of it. The infinite cannot be contained in the finite, or so the argument would go.

Given how little we know, let us be respectfully open-minded with those caregivers who affirm the eternal essence of self-identity. Just maybe *the brain is an uploading and downloading device that has space for habituations such as those a rat develops in learning a maze, but not for the infinity of our life histories and related endless imaginings*. This opens the door for higher inspiration, synchronicity, premonitions, and the like. But my focus is merely memory here.

Of course it may be true that all the hints at continuing self-identity in deeply forgetful people are the last

disintegrating remnants of a person's autobiographical self as located in an entirely 'local' and deteriorating brain. Yes, perhaps the large number of synaptic connections will someday explain all things, and true, no one has proven the reality of a nonmaterial soul that exists in an unseen dimension of reality. Still, logic suggests that a fathomless sea of infinite richness and textual detail is too much to engrave in a small mass of chemicals, cells, synapses, and tissue. Contrary to even the most 'nonreductive' of the physicalists, we need not give up on our eternal souls just yet, although some theologians have given up on *their* eternal souls (Brown, Murphy, & Malony, 1998).

Some very thoughtful philosophers and scientists assert the eternal soul. The list is endless (e.g. Plato, the author of *Genesis*, the author of *The Gospel of John*, St. Paul, Buddha, Mohammed, Christ, Meister Eckhart, T.S. Eliot, C.S. Lewis, J.R.R. Tolkien, Emerson, David Bohm, William James, C.G. Jung, Ken Wilber, Huston Smith, Aldous Huxley, Larry Dossey, Seyyed Hossein Nasr, Sir John Templeton, and Joseph Campbell).

One of the most respected philosophers of our time, Thomas Nagel, in his 2013 book entitled *Mind and Cosmos: Why the Materialist Neo-Darwinian Conception of Nature is Almost Certainly False*, comments that his doubts about materialism will strike most people as 'outrageous' because they have been 'browbeaten' to believe in a mindless universe (p. 7). But Nagel takes a view very different from materialism – 'one that makes mind central, rather than a side effect' of the material (p. 15).

Autobiographical Memory as a Soul Field

The Muslim philosopher Avicenna, along with Augustine in his famous *Confessions*, waxed eloquent about how in memory we can envision and hear the entire universe and everything we have encountered in life. The great Hindu sages have asserted the same, and therefore held that memory is an aspect of consciousness or mind that is primary in itself, underived from matter. What we can call up and envision from memory with eyes closed is unlimited in detail and scope, although the brain retrieval of information is complex, as well as potentially inaccurate at times (Brady et al., 2008).

The French theo-philosopher Henri Bergson, in his classic *Matter and Memory: An Essay on the Relation of Body and Spirit* (1896), described aspects of image remembrance and personal narrative as profoundly spiritual in nature. Bergson's brain has a retrieval function, but brain injuries then do not erase that which they retrieve. Bergson acknowledged that the brain is the locus of engrained habituated memories, as we find in many nonhuman animals as well as humans, but not of 'image remembrance' of the past, or 'pure' memory, which is of a contemplative and nonmaterial nature. Bergson concluded, 'The idea that the body preserves memories in the mechanical form of

cerebral deposits, that the loss or decrease of memory consists in their more or less complete destruction, whereas the heightening of memory and hallucination consists in an excess of their activity, is not, then, borne out by either reasoning or by the facts' (p. 176). He asserts that memory is 'absolutely independent of matter' (p. 177). For Bergson, it seems that *the brain is more an organ of percept and habituation than of storage*. The cupboard of autobiographical memory lies elsewhere.

A line of contrarian neuroscience today asserts that we need a paradigm shift in our thinking about memory. In 1993, Simon Y. Berkovich of George Washington University presented a speculative model of the brain as the local computer terminal connecting to some larger informational system. Fifteen years later, writing in the highly regarded *Proceedings of the National Academy of Sciences*, T.F. Brady and team showed just how massive visual memory is, and concluded that it seems to 'pose a challenge to neural models of memory storage and retrieval, which must be able to account for such a large and detailed storage capacity' (2008, p. 14325). This is no trivial challenge to the reigning paradigm.

In the late 1970s the renowned British pediatric neurologist John Lorber famously reported that some perfectly intelligent adults with fine memories had no more than 5 percent of normal brain tissue after having been cured as children of hydrocephaly (water on the brain). Roger Lewin's 1980 article entitled 'Is Your Brain Really Necessary?', which appeared in *Science*, dismissed Lorber's research as unscientific and 'overdramatic.' While initially disbelieved, Lorber's observations, based on brain scans, have been independently confirmed by neurologists in Brazil (deOliveira et al., 2012) and in France (Feuillet et al., 2007).

Bringing this quarrel up to date, Donald R. Forsdyke (2015) in his article 'Wittgenstein's Certainty Is Uncertain: Brain Scans of Cured Hydrocephalics Challenge Cherished Assumptions', appearing in *Biological Theory*, urges the open-mindedness that Lorber's work seems to press upon us. Forsdyke, a distinguished researcher at Queen's University in Ontario, has studied microcephalic cases where intelligence as well as long-term memory are normal. The upshot is that information content and memory do not correlate with head size. He cites Fusi and Abbott (2007), with their calls for a radical remodeling of memory. Because brain size does not scale with information quantity, Forsdyke gives us three hypotheses to work with:

1. The 'standard model' by which long-term memory is held in the brain in some chemical or physical form;
2. The hypothesis that long-term memory is held in the brain by 'some extremely minute, subatomic form, as yet unknown to biochemists and physiologists' but akin to computers storing large amounts of information in progressively smaller spaces (p. 339); and

3. The hypothesis that 'Information relating to long-term memory is held outside the brain. Since most non-neural tissues and organs appear unsuited to the task, this extrapolates to long-term memory being *outside* the body – extracorporeal! Amazingly, this startling alternative has been on the table for at least two decades.' (p. 339)

It is hard for scientists raised under the ideology of materialism to imagine this third alternative. But for most religious people in all the great spiritual traditions, Mind (a.k.a. Ultimate Reality, Platonic *nous*, Supreme Being, Eternal Consciousness, Infinite Mind, Pure Unlimited Love, Ground of Being, God, etc.) precedes and sustains mere matter. It is certain that bone marrow creates blood cells, and so forth, but there is no fully convincing evidence that neural tissue produces mind, conscious awareness, biographical memory, and the like. This is all a mystery.

A Post-Materialist Model

Good careful science should never be interfered with. But whether we interpret findings in a materialist or a post-materialist metaphysical model is a matter where we should welcome diversity. From 7 to 9 February 2014, 100 scientists from a variety of fields convened at the Canyon Ranch in Tucson, Arizona, to discuss the emergence of a post-materialist paradigm for science, spirituality and society. This group produced *The Manifesto for a Post-Materialist Science*, which is available at <http://opensciences.org/about/manifesto-for-a-post-materialist-science>. It challenges the 19th-century assumption, now turned into dogmas and known as 'scientific materialism,' and in particular the belief that 'mind is nothing but the physical activity of the brain, and that our thoughts cannot have any effect upon our brains and bodies, our actions, and the physical world.' These experts argue that we need a new and non-dogmatic science that follows the methods of the best science, but does not presume materialist explanations. The manifesto takes seriously the idea that minds 'are apparently unbounded, and may unite in ways suggesting a unitary, One Mind that includes all individual, single minds.'

'Ineffable,' Emerson wrote, 'is the union of man and God in every act of the soul.' This concept is eastern (Emerson was widely read in Hindu classics). But Christianity also speaks of our being 'in the image of God,' and St. Paul wrote, 'Do you not know that you are God's temple, and that God's spirit dwells within you' (*1 Cor. 3:17*).

The Ground of Human Dignity

It is for many religious people very difficult to affirm the human dignity and moral status of the deeply forgetful unless we place some faith in the idea that every human

being has within a drop of the infinite cloud of a Supreme Being, Ultimate Reality, Infinite Mind, Grounds of Being, 'God,' etc. The famous materialist philosopher Bertrand Russell was at least able to acknowledge that if materialism is true, if all we are is an admixture of chemicals and cells, then the sum total of the meaning of a human life is no greater than bacterial 'pond scum.'

But let us put these metaphysical questions aside and accept for the moment the comfortable materialist's assumption that human beings have no eternal soul/selfhood. Let us assert, however, that even on the materialist paradigm, continuity of self-identity in the deeply forgetful is the residual or remnant norm, and that this does afford them due respect.

Hope in Residual Hints of Self-Identity

I define 'hope' in the experience of caregivers as 'openness to surprises,' at least in the context of dementia (Post, 2013). In other contexts, hope might be defined very differently, for example in terms of the pursuit of clearly envisioned goals. Deeply forgetful people do not generally have such goals, beyond the mild stage, but surprises occur. A medical student recently (November 2015) described his grandfather's 'terminal lucidity' – a frequently described phenomenon in psychiatric and hospice literature – after months of being entirely unable to communicate due to Alzheimer's disease. My student chose to focus his essay on his mother's interaction with her father just before his death:

It was in his last moments that my mother seemed to be rewarded for all her hard work. My grandfather looked at my mother and spoke to her with complete lucidity for the first time in a year. He talked about the old times when he used to walk her to school. Then he talked about me and told her to make sure I kept working hard in school. And the last thing he said was how proud he was of her and that he loved her. The next morning he was gone.

Again, hope is being open to surprises such as my student describes.

In a similar case, Olivia Hoblitzelle (2008), author of *Ten Thousand Joys & Ten Thousand Sorrows: A Couple's Journey through Alzheimer's*, emailed me on 12 April 2013, a few days after we shared a panel together at the Times Center in Manhattan for the New York Alzheimer's Association's *Charles Evans Lecture*. Olivia has read something of mine, and wrote:

It reminded me of a moment with my beloved mother, a poet, author, and something of a philosopher. In that late stage when words are gone except for those very occasional moments, she looked at me intently and said forcefully, 'God, physics and the cosmos.'

Over the years of witnessing many cases of sudden insight, I ask: Where does such lucidity come from? Yes, it could be some remnant of a neurologically grounded memory if personal identity and biographical memory actually exist in matter, which from the perspective of a purely megabyte analysis can and is being questioned. But it could also be a sign that underneath the neurological deterioration a whole self continues on. Given the current state of brain science, we must all be agnostic. We simply do not know. Moments of lucidity are the norm among the deeply forgetful, rather than the exception, especially early in the morning after a good night's rest. Do they point toward remnants of autobiographical narrative in a devastated brain, or to something fully intact housed in 'cloud storage' but now more difficult to access?

Whatever the answer, ethically we as a western culture need to move a little closer to, for example, some Indian attitudes toward the deeply forgetful. From that perspective, one need not question the continuing self-identity of deeply forgetful people, and the mystery that it points to. It is only our western 'hypercognitive' (a term I coined in my 1995 first edition of *The Moral Challenge of Alzheimer Disease*) and utilitarian values that separate us from ancient wisdom on this matter.

Beyond Hypercognitive Values

One need not be a metaphysical idealist who believes in an eternal soul to observe that hypercognitive values discriminate badly against the deeply forgetful, who have other aspects of the self that are equally important as cognition (Post, 2013), and even more so: symbolic, creative, emotional, relational, somatic, musical, rhythmic, aesthetic, olfactory (smell), spiritual, and tactile.

Focusing on the musical self, for example, there is a major care movement called *Music and Memory* (see www.musicandmemory.org). I visited the Long Island Veterans Nursing Home in March 2013 and spent some morning hours in the facility for vets with severe dementia. There were about 30 veterans in an activities room devoted to individuals with severe dementia. As far as I could observe, almost none of them were conversant or responsive when called by name. Most had that thousand mile empty stare. Then came the big moment. The activities director started the music – 'New York, New York' and 'That's Amore' – and about two-thirds of these old timers started to chime in as the words ran across the big screen on the wall and the voices of Frank Sinatra and then Dean Martin sang out. Then came 'It's a Grand Old Flag,' and it seemed liked the singing got louder – a few more vets chimed in, and five of them were standing up, saluting the flag. I felt like I was witnessing a miracle. After the music session, at least 10 or so of these vets seemed to be able to respond to the activities director when she asked them close-ended questions about the meaningful

people in their lives. It was as though they had awakened from a slumber.

Yes, these tend to be sporadic hints, but they may all be revelations that underneath the communicative chaos or the glassy stare there is something that has been referred to as *the mind behind the mind*. Metaphysics aside, these episodes inspire caregivers with renewed meaning. A deeply forgetful person is rarely as 'gone' as we superficially suppose, and caregivers report an openness to surprises. The glimmers of a fuller presence merit our respect. Therefore, sit down, make eye contact, and call that person by name as if expecting an answer that may not come today. This action is more than symbolic. It is how we affirm the enduring self. Our task is always one of exceptional *affirmation and connection*.

But what blinds us to the signs of the enduring self? Why do we hear metaphors such as *absent, gone, husk, dead, empty*, and the like? Here I believe we must confront various biases and prejudices, many of which have their roots in what I have long termed *hyper-cognitive values*. We all value cognition of course, but let us not make too much of cognitive dexterity. The great Stoic philosophers achieved much for universal human moral standing by emphasizing the spark of reason (*logos*) in us all. This is, however, an arrogant view in the sense that it makes the worth of a human being entirely dependent on rationality, and then gives too much power to the reasonable. We easily demean those whose memory has dissipated by treating them with indifference or even with cruelty. We act as if they aren't there. Once (less than seven decades ago), the step between psychological and physical elimination proved notoriously short. As part of the Nazi extermination program known as T-4, individuals with dementia, selected for hypothermia experiments, were taken out of German mental asylums and left to freeze in the cold night air (Post, 2000).

Theologian Reinhold Niebuhr wrote of the tradition from the Stoics that 'since the divine principle is reason, the logic of Stoicism tends to include only the intelligent in the divine community. An aristocratic condescension, therefore, corrupts Stoic universalism' (Niebuhr, 1956). We sometimes mock and ignore those who have lost the power of reason, sending the message that their very existence rests on a mistake (Post, 2000).

A Pastoral Conclusion

Whether you believe in an eternal soul or you believe that mind and memory are all merely in the brain tissue, we can agree on this: when it comes to the deeply forgetful love is the question, love is the answer, and love is the way – even in the hard times when caring feels overwhelming and perhaps for the moment even a bit meaningless, although it is always meaningful. It is all about the power of love, not about the love of hyper-cognitive power. After all, we can

hopefully acknowledge that in an era of heightened sensitivity to the equal moral status of people with physical and cognitive disabilities, we should not dismiss the consciousness and awareness of an individual with dementia as somehow less significant than that of someone who is more lucid of mind.

'Is grandma still there?' I always affirm caregivers who believe in the eternal soul of a loved one, and they may be correct. Their hopes have not been falsified, and phenomena such as 'terminal lucidity' and even the near-death experience may point to an 'eternal return' to the light and warmth of a pure unlimited love. Open-mindedness follows wherever good science leads.

Acknowledgements

I wish to acknowledge the great Roman Catholic neurologist Joseph M. Foley, MD (1916–2012), with whom I had countless conversations at Case Western Reserve University about mind, memory, and brain, and who himself thought that materialism was an unnecessary assumption. I wish also to acknowledge several conversations with Nobel Prize Laureate Sir John Eccles (1903–1997).

References

- Bergson, H. (1994 [1896]). *Matter and memory: An essay on the relation of body and spirit*. New York: Zone Books.
- Berkovich, S. Y. (1993). On the information processing capabilities of the brain: Shifting the paradigm. *Nanobiology*, 2, 99–107.
- Brady, T. F., Konkle, T., Alvarez, G. A., & Oliva, A. (2008). Visual long-term memory has a massive storage capacity for object details. *Proceedings of the National Academy of Sciences*, 105, 14325–14329.
- Brown, W. S., Murphy, N., & Malony, H. M. (1998). *Whatever happened to the soul?: Scientific and theological portraits of human nature*. Minneapolis, MN: Fortress Press.
- deOliveira, M. F., Pinto, F. C. G., Nishikuni, K., Botelho, R. V., Lima, A. M., & Rotta, J. M. (2012). Revisiting hydrocephalus as a model to study brain resilience. *Frontiers in Human Neuroscience*, 5, 181.
- Feuillet, L., Dufour, H., & Pelletier, J. (2007). Brain of a white-collar worker. *Lancet*, 370, 362.
- Forsdyke, D. R. (2015). Wittgenstein's certainty is uncertain: Brain scans of cured hydrocephalics challenge cherished assumptions. *Biological Theory*, 10, 336–342.
- Fusi, S., & Abbott, D. R. (2007). Limits on memory storage capacity of bounded synapsis. *Nature Neuroscience*, 10, 485–492.
- Hoblitzelle, O. (2008). *Ten thousand joys & ten thousand sorrows: A couple's journey through Alzheimer's*. New York: Penguin.
- Lewin, R. (1980). Is your brain really necessary? *Science*, 210, 1232–1234.
- Nagel, T. (2012). *Mind and cosmos: Why the materialist neo-Darwinian conception of nature is almost certainly false*. New York: Oxford University Press.
- Niebuhr, R. (1956). *An interpretation of Christian ethics*. New York: Meridian.
- Post, S. G. (1995). *The moral challenge of Alzheimer disease*. Baltimore, MD: Johns Hopkins University Press.

- Post, S. G. (2000). *The moral challenge of Alzheimer disease: Ethical issues from diagnosis to dying, 2nd edition*. Baltimore, MD: Johns Hopkins University Press.
- Post, S. G. (2013). Hope in caring for the deeply forgetful: Enduring selfhood and being open to surprises. *The Bulletin of the Menninger Clinic: A Journal for the Mental Health Professions*, 77(4), 349–368.
- Sheldrake, R. (2012). *Science set free: 10 paths to new discovery*. New York: Deepak Chopra Books.
- Singer, P. (1993). *Practical ethics, 2nd edition*. Cambridge: Cambridge University Press.
- Talbot, M. (1991). *The holographic universe*. New York: Harper Perennial.

Stephen G. Post, PhD., is a graduate of the Divinity School of the University of Chicago with training in clinical pastoral care. He is one of just several individuals awarded

the Distinguished Service Award by the National Board of the Alzheimer's Association (U.S.). His book *The Moral Challenge of Alzheimer Disease: Ethical Issues from Diagnosis to Dying* (2nd edition, 2000, The Johns Hopkins University Press), was designated a "medical classic of the 20th century" by the editors of the *Journal of the British Medical Association*. He has published more than 120 articles on ethics and the care of deeply forgetful people in venues ranging from the *Journal of the American Medical Association* to *First Things*. He is President of the Institute for Research on Unlimited Love, which he co-founded with Sir John Templeton in 2001. He was Professor of Religion and Ethics at Case Western University School of Medicine (1988–2008), and then Founder of the Center for Medical Humanities, Compassionate Care, and Bioethics at Stony Brook University School of Medicine in New York).