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To cite this article: Gaynor Macdonald (2018) Death in life or life in death? Dementia's ontological challenge, *Death Studies*, 42:5, 290-297, DOI: [10.1080/07481187.2017.1396398](https://doi.org/10.1080/07481187.2017.1396398)

To link to this article: <https://doi.org/10.1080/07481187.2017.1396398>



Accepted author version posted online: 27 Nov 2017.
Published online: 06 Feb 2018.



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Death in life or life in death? Dementia's ontological challenge

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ABSTRACT

Is it possible to end one's life well with dementia? The perception of dementia as death brought into life flows from ideas about humanness embedded in medicine's Cartesian paradigm. Dementia as incurable brain disease exacerbates negativity. But the real impact of dementia is that it changes social relations: to live well with dementia requires a relational not Cartesian understanding of life. A relational ontology prioritizes social health: to live is to be held in connection. Negativity produces the disconnection that is death, with or without disease. When people with dementia are held in connection, they live a better life.

Dementia: The interstices between life and death

Is there a good life at life's end when one has dementia? Dementias are incurable, painless, but emotionally distressing illnesses which progressively impact on a person's capacity. Is it a contradiction to think of dementia as a good end, or is it death already brought into life? In Australia, people with dementia are often thought of as tragic, robbed of life, and having lost their personhood. I entered this "dementia habitus" through the diagnosis of my husband with Alzheimer's. I was taken aback as I experienced how a social world changes when a person is diagnosed—for that person and those who take on caring roles. We had both been plunged into negative space.

It became clear that the ways in which dementia is understood and communicated by medical and health professionals contributed to the fact that supportive information fell far short of what was needed. I began to appreciate why many carers suffer "carer burden" and high rates of depression. To avoid becoming a casualty, I sought to understand how this space was being constructed. This paper is informed by the research I embarked on, shaped by this personal journey.

The dementia space is governed by medical dispositions that constrain the options people have for thinking, not only about dementia but about the meaning of life. Dementias are forms of cognitive decline about which medical knowledge has increased significantly in recent years. That knowledge is not translating into cure. Knowledge produces practice and it is arguably the case that medical knowledge,

particularly in the absence of a cure, is exacerbating rather than diminishing the fear associated with dementia. Why informed understandings are not translating into positive social attitudes seems paradoxical. But the fear and stigma associated with dementia stem not only from the disease but also from attitudes to aging and, ultimately, what it means to live and to die.

Dementia confronts because it seems to bring death into life, implicitly questioning what life, relationship, and death are about. It is an understanding of *life*, rather than dementia as disease, that promotes the fear of dementia. Many terminal illnesses produce shock and grief in their diagnosis, require that someone receive care, and deny a person the prospect of living "to a ripe old age." Dementia is different, not because it is incurable, or might lead to an earlier death (in the case of younger-onset dementias), but because it poses ontological and moral challenges for a secular society.

We die, all of us. However, much time we spend avoiding it, we live in the shadow of our mortality (Becker, 1973). The least we can look forward to is a good death. For most people that means dying—and ageing—with dignity, among loved ones, at home or at least in comfortable, comforting surroundings. But the good death is becoming increasingly elusive. Virilio (2002, p. 14) described the 20th century as a "mass production of corpses." World wars, the Holocaust, genocidal wars, influenza plagues, the "road toll": death on a scale never known before. These deaths are often represented as senseless slaughter: the meaningless death of "innocents." The unvoiced question disturbs: is all death then meaningless? Does aging also become

meaningless, the aged increasingly worthless, regardless of their earlier years?

The contradictions are stark: we are living longer and a celebratory value is placed on the medical sciences that have made this possible. Implicitly, this is value placed on a *death-defying* life. *The Guardian* (2016) ran a podcast that asked: “With advances in medicine, science, and technology allowing humans to live longer than ever, can we finally crack the code of aging and stop it altogether?” The *Australian Geographic* article, “Forever Young,” stated: “The scientific quest for a longer, healthier life—and ultimately defeating death—is one of the grand challenges of our time” (Nogrady, 2016). There is clearly an issue in a society that assumes that not only can all illness be cured but death itself can be resisted, postponed, or avoided (cf. Bauman, 1992).

If aging were not enough of a problem, its scourge is dementia. The perception that death enters life through dementia should alarm us. Dementia is like the canary in the coal mine, there to tell miners if the quality of the air remains good. Attitudes toward it are a gauge of the *social* health of the world in which people with dementia and their carers live. I argue below that a quality social life can only stem from a *socially grounded* ontology, based on an understanding of human life as inherently relational and precarious: the good life is lived in relationship. However, this runs counter to the ontological foundations of medical science. Medicine limits our capacity to live well with dementia because it insists on a *nonrelational* understanding of life. It also, again paradoxically, perpetuates the idea of the unhealthy society, even as it focuses on curing the individual. This fuels the fear of dementia.

Somatic approach

Living and dying with dementia has become the domain of neuroscience. Dementia is an umbrella term for illnesses that produces cognitive decline because of changes taking place in the brain. These lead to difficulties in solving problems, making plans, remembering, concentrating and navigating. They produce gradual decline in cognitive capacity and eventually, in final stages, physical capacity. A person with dementia may live many years, but these symptoms will become so severe that she will be unable to live independently. There is no physical pain, but it can be emotionally disturbing as a person adjusts to her difficulty in understanding and communicating.

Dementia is not new as social experience, but its incidence has increased with longevity and earlier diagnosis. Approximately 1.5% of the Australian population has a form of dementia, including 10% of those over 65 and

30% over 80 years of age. The most prevalent, at 70%, is Alzheimer’s disease. About 7% are younger onset, affecting people under 65 years. It is described as the second most common cause of death in Australia (ABS, 2016). This includes deaths not directly attributable to cognitive decline: compromised communication exacerbates other health conditions and leaves people prone to accidents.

The first information a patient or family member will be given is a rundown of the disease, its various types, its causes, and the sad news that it is—at present—incurable. People diagnosed with dementia, especially younger onset, report contemplating suicide before the symptoms get too bad (Genova, 2010). A diagnosis produces grief: unlike death, the person with dementia is alive and yet spoken of as lost to life.

Dr Alois Alzheimer first identified dementia in 1906 as pertaining to the body (soma). Changes in the brain produce the symptoms of memory loss, confusion, unpredictable, or uncharacteristic behaviors, and language problems. Prior to Alzheimer’s discovery, dementias were understood as problems of the mind. As people became older, it was not unusual that their memory would fade, their “mind would go,” and Granny would be described as “ga-ga.” If they needed to be cared for away from home, they would be taken to a lunatic asylum (Andrews, 2017). Alzheimer’s significant achievement was to reframe dementia as a problem of the body. This brought people with dementia into the orbit of biomedicine, and efforts were made to wrest public images away from madness to understanding dementia as disease. This in turn led to the somaticizing mode of ordering the lives of those with dementia (Moser, 2011).

Somatic, or biomedical, explanations of dementia start with the changes in the brain, and what types of dementia exist. These types have differing symptoms depending on the part of the brain affected. Dementias have in common a process of cognitive decline caused by changes in the protein structures of the brain, the reasons for which remain elusive: some people with the problem proteins do not develop dementia, while others who seemingly do not have them do develop symptoms.

The significance of Alzheimer’s discovery, that dementia was susceptible to biomedical intervention, has to be contextualized within the history of medical science, the foundation of which is the Cartesian mind–body split. When Descartes demythologized the body, handing it over to medical science, and its study to physiology and anatomy, these scientists adopted Descartes’ reasoning: the subject of their study was a machine (Quesnell, 2004). Western medicine continues to see the body as its primary site of concern. The tenacity of this approach, notwithstanding a century

of critique, lies in the fact that the money, energy, and dedication invested in biomedicine “has paid back hugely in terms of technological success” (Mehta, 2011). Medicine’s power stems from its ability to continually reinforce the ideas upon which this biomedical paradigm rests (Kriel, 2003). Its success in relation to infectious disease and surgery has been unquestionable.

Yet lifestyle diseases (diabetes, obesity), as well as physical and cognitive disabilities, cannot be dealt with in mechanist terms. They can be defined as disease, diagnosed in the body, but they resist biomedical intervention because they have to be conceptualized, and addressed, within a *social* context that includes the patient, many other social relations, and cultural and economic influences. Medicine’s adherence to a Cartesian ontology limits its capacity to respond. As Mehta (2011) puts it, “by adhering rigidly to scientific method, [medicine] mislaid its subject matter and gave up its moral responsibility toward the real health concerns of human beings.”

The somatic approach to dementia emphasizes brain pathology, about which nothing can (as yet) be done: there are no remedies, no drugs, no brain transplants. “Life” is reduced to keeping a body functioning. Nonbiomedical “treatment” of dementia is handed over to allied health professionals, trained in the same paradigm. Many of the behavioral issues associated with dementia are produced by ineffective care, not what is going on in the brain. My husband, through insights I have gained, now exhibits few of these because most can be addressed quickly and effectively through personal interaction. Yet this “treatment” is not what medical professionals study, which is why the majority of carers, family, or professionals, are left to manage problem behaviors that are often the outcome of their own approach rather than symptoms of the disease itself. Dementia starkly reveals the Cartesian biomedical model’s incomplete understanding of “health,” through its inability, even unwillingness, to develop effective (nonbiomedical) interventions to address a range of experiences of disease *in their social, relational context*. To address the social and relational impacts of cognitive decline, medicine itself would have to come up with a new paradigm, a new understanding of the social embeddedness of being human (Kriel, 2003). Instead, it searches for the cure, leaving the nonsomatic, social impacts to family, and “allied” health professionals.

In the absence of collective meaning systems by which to confront death, the secular society turns to the illusion of immortality offered by the medical sciences. Its illusions, in which we pin our hopes, are encapsulated in this powerful word, “cure.” The promise of the cure is that it moves us back from

abnormality, deficit and death, to re-engage with life. Cure is death defying; it makes disease and illness transitory; it opens up a future.

The intensity of the search for the elusive dementia cure gained momentum in the 1990s and has reached frenzied proportions in response to reports of increasing incidence. While this is said to be due to an aging population, there is also a greater incidence of early-onset dementias, more of which are likely to be hereditary. To complicate matters, there is evidence that the incidence might be on the decline. Dementia is a subject-increased social visibility, with media and advocacy groups striving to make the public more aware of the extent of “the problem,” demanding research funding, and reassuring people that that the cure must be very close. The enormous energy spent looking for the cure demonstrates that attitudes are not neutral: it exacerbates the stigma and fear. Those with dementia and their carers find themselves expected to live away from those who cannot cope with its “demands.” It is hardly surprising that nursing home care is recommended; that geriatricians have low status within the medical profession; and that care staff are poorly paid. They live in the shadow of death.

Each week it seems there is another medical breakthrough immanent, another activity or food that will delay onset or improve memory. These announcements boost sales of coconut, rosemary and crosswords, and no doubt increase funding. But all this activity reinforces the negative message: dementia is tragic, it kills, it robs a person of his quality of life. It leads to a death that is either untimely or, at least, not a good ending. In the face of this barrage, it would be hard to argue that it is possible to end one’s life well with dementia.

The medical model of a broken body that needs medical intervention to fix it does not work: there is no repair and little relief. We are mortal: we age, we die, but dementia is not allowed to be understood as a process of aging: it is a disease, it is abnormal. Because there is no cure, the biological view is that dementia remains “an inaccessible process in neural and biochemical interactions in individualized brains” and “so far there is nothing to be done but let nature take its course” (Moser, 2011, p. 710). Herein lies the contradiction: aged care—and dementia care in particular—challenge the medical ethic to improve life, and yet they have become the domain of medicine.

The focus on diagnosis and research into cure is not commensurate with concern for and investment in the quality of life of those in the dementia space. Moser (2011) argues that the somatic understanding “shapes life with dementia as a more or less given disease trajectory in which the subjective and agential ‘I’ of

the patient is progressively broken down and eradicated.” It is a bleak outlook. For many it leads to “a process of progressive separation, isolation, individualization, and disconnection from practices and interactions, whether at home or within residential care.” Over time, this trajectory has fuelled the disdain many Australians hold of nursing home aged care, as places of antiseptic neglect, depersonalization, and loss of dignity, to be avoided at all costs. Yet the medical profession takes it for granted that dementia care at home will become too much of a burden, so residential care is inevitable. The diagnosis of dementia is replete with messages of loss: loss of control is but one.

Neurological research cannot address the core issue: dementia is a *social* experience not a somatic one. It is behavior and relationship that are of concern. The person with dementia cannot experience what is happening in their brain/body, only its impact on their lived life. Dementia challenges the hegemony of biomedicine, not only in so far as it eludes cure but because it has social and moral expressions that a biomedical approach cannot address. This leads to what Mehta (2011) describes as the “paradigmatic error,” the discordance between what medical professionals have to offer and what lay people expect from them (cf. Kleinman, 2015). The medical model treats an embodied patient as an individual, yet the experience of dementia will be shared. The impacts on others are arguably more intense than they are for the person diagnosed. It is carers—family members, friends, allied health workers, neighbors, and others—who come in contact day by day with a person undergoing cognitive decline. It is they who should be, but rarely are, the focus of concern. Whether the person with dementia can live a livable life depends on these people, not on the medical profession.

Personhood: Care in the context of cognitive decline

Through the 20th century, medicine’s somatic paradigm exacerbated the lack of personalized care. Concern mounted:

Back in the early 1970s, at a time of rapid growth of high technology, reductionism, and bureaucracy in medicine, there had been rising anxiety that clinicians weren’t treating patients as individuals whose lives and disorders had a richly human background and social context. ... physicians’ narrow focus on diagnosis and treatment led them to miss or intentionally exclude the centrality of the patient’s experience (Kleinman, 2015, p. 1376).

In the 1990s, Kitwood extended this critique to dementia care. He sought to change the perception that

a person experiencing cognitive decline had “lost” whatever it was that made life worthwhile. Dementia was a progressive loss of personhood, but care must be person-centered, focused on what “remains” of this person. Kitwood (1997, p. 8) defined personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.” It is based on the idea that all behavior has meaning, even if difficult for others to access. Each person has their own abilities and interests, their life stories, which should be incorporated into care, leading to better outcomes for person and carers. It is now well established that higher levels of challenging behavior, distress, or apathy occur more commonly in care settings that are not person-centered. Person-centered care places the onus on carers to treat a person with dementia as a person of value: it steps in where biomedicine cannot go.

Person-centered care has since become the buzzword of the rapidly growing industries charged with caring for the aged. But how are these “persons” imagined? What characteristic or normative ideas of personhood implicitly inform research, policy, and practice and, in doing so, become implicated in the making and unmaking of persons? How do these ideas play out in the social world of dementia? In the literature on person-centered care, a pattern has emerged: the dominant model is a rational, self-aware, independently functioning, communicative individual. It is the emphasis on memory and cognition that leads to a person quickly “losing” personhood: the pathos of loss is conveyed in comments, “he’s not the same person,” “she looks like my mother but she’s not,” “she’s no longer the woman I married.” Personhood discourse reinforces dementia as a form of death within life, the progressive, and tragic unbecoming of life as “a person” diminishing before one’s eyes.

Four assumptions emerge in the dementia care literature: (1) *Personhood is a static attribute, it does not change over an adult’s lifetime but can be lost with cognitive decline.* This runs counter to lived experience, for all people, limiting our capacity to change and adapt; (2) *Personhood depends on a capacity for rational social engagement.* People with cognitive disabilities or inadequate education are thus diminished; (3) *Persons have status.* But what is status, and who confers it? This ignores ageism, sexism, racism—which diminish status; (4) *Persons are conflated with humans.* This contradicts the anthropological and philosophical distinction between humans as members of the human species (biological humanity) and personhood, as a status given to some humans as well as nonhuman/nonorganic persons (gods, sacred animals, sacred foods, and minerals).

Persons are culturally constituted, socially recognized and valued, their moral and legal status known through specific social norms (Mills, 2011). They are not equal, as contestation over rights for refugees or those with disabilities attests. Romanticized conflation of person = human conceals the value judgments that shape the dementia space: ageism, racism, sexism, poverty, class, place of residence, lack of education.

There is effort to enhance the model of personhood. Post (2016) points out that cognition does not embrace the totality of human experience. It cannot account for emotions: passion, rage, grief, sadness, empathy; nor the senses: touch, hearing, sight. But more enlightened understandings of person-centeredness do not challenge or compete with somatic ones because they are relegated to care, based on a hierarchical division of labor between medical and care professionals.

As concerning, the person-centered model has become trite—undermining what it was meant to foster. Designed to counter the erasure of the person, “recognizing the person” is being turned into a “technique” of care, part of the carer toolkit, something to record on a patient’s file—their personal history, the name of their husband or dog, ways to deal with agitation. It can be divorced from the lived experience and reduced to techniques of distraction or occupying time. It has become, to paraphrase Kleinman (2015, p. 1376), a “cultural competence movement”: physiology is still separated from the self and interpersonal relations, while efforts to humanize care reduce “complex lives to limiting, biased stereotypes.”

Nor does the personhood approach challenge the *social* impact of the way medicine defines some humans as (physiologically) abnormal or deficient. Swinton (2012, p. 49ff.) argues that the reason descriptions and categorizations of dementia “tend to result in a deep fragmentation and reduction of human persons,” is in large part because the idea of personhood feeds into notions such as typical and normal. The language of personhood can narrow understandings of a worthy life, diminishing the humanness of people with dementia, to the extent that “some would argue that having dementia is equal to death.”

Personhood is always bound up in cultural ideas. Kittay (2002) reveals how discrimination regarding disability and care stem from liberal notions grounded in masculinist (white, independent, adult males) ideas about the *normal* human capacity for rationality and self-sufficiency. A person with dementia is not only abnormal from a biomedical perspective but always also an abnormal “person.” A normal life results in “successful aging,” assuming healthy, active and financially independent lifestyles for those over 65 years of age

(cf. Timonen, 2016). This rejects the vast majority of aging persons: by default they become the negative. In the concept of “normal,” medical ideas mesh with economic and social values in debilitating ways. Abnormality legitimizes intervention, control, stigma, and fear, reinforcing the normal as that which is valued, recognized, and included. Care activities are devalued because they are associated with socially *devalued* dependencies.

Normative conceptions are forms of cultural violence and social control: life is not made livable for those who sit outside powerful social norms (Butler, 1999, 2004). They have to be challenged to make way for *the vast majority of us*, including those aging with dementia, who live with physical, cognitive, emotional, social, and economic vulnerabilities, the ups and downs that are the vicissitudes of all human experience. Models of personhood that downplay vulnerability, irrationality, stress, and inequity lie behind fear and stigma. People who “deviate” from the norm, in education, prosperity, gender, disability, ethnicity, or age, are rendered social outcasts, prone to abuse, and seen as a drain on the public purse.

Reconceptualizing “the person” to add emotions, senses, and life histories does not shift the primacy of the Cartesian individual as the underlying ontology of being. It simply encourages a more humane way in which one individual (carer) can act on another individual (patient)—if they have the time and inclination. A more holistically conceived Cartesian “person” still denies that human beings are inextricably social, interdependent, bound up in moral, responsive relationships.

Relationality: Rethinking dementia as relationship

A relational approach in dementia studies is gaining traction (cf. Barnes, Henwood, & Smith, 2016; Dupois, MaAiney, Fortune, Ploeg, & de Witt, 2016; Greenwood, Loewenthal, & Rose, 2001; Moser, 2011). Discussion is largely confined to the context of dementia care, but it is an understanding of humanness that has profound implications for thinking about life and death. A relational approach—to life not just dementia care—has as its central premise that to be human is to be a social, *relational being*. This is in opposition to Cartesian individualism. “Life” is not about whether an “individual” is breathing, their heart is pumping or they can think and reason: the focus is on participation, shared experience, social connection. *To live is to be held in relationship*, regardless of the health of one’s body. Connectedness and care are fundamental to human life, not just for infants, the sick, disabled, or the dying. It requires an acknowledgment that all life is inherently vulnerable

and precarious: “always in some sense in the hands of the other” (Butler, 2009, p. 14). The livable life of a person with dementia is the responsibility of everyone else in that person’s environment.

A relational approach does not deny the reality and objectivity of dementia as a biomedical condition but proposes a different way of acting upon it, of shaping ways of living and dying. It thus counteracts or at least postpones the processes of disconnection that characterize dementia. It is not simply “doing care” better. It requires a *moral* response to seeking forms of engagement that hold people in connection. Some carers intuitively “get this,” others do not. Relationships are not techniques of interaction; a relational approach is not a strategy to include in a curriculum for health professionals.

This is well illustrated in an insightful case study by Moser (2011). She tells the story of Mrs Olsen who, as her dementia advanced, went from being a silent person to screaming, day and night. Staff had to act because of the impact on other residents of the sheltered ward. They isolated Mrs Olsen in her room, putting a large table in front of her chair to stop her walking out. The screaming got worse but staff were resigned: “yes, it is sad, but there’s nothing to be done. This is the disease expressing itself and taking its independent and inevitable course ... it will eventually give way to a more severe but less noisy phase as it burns itself out.”

Moser points out that, when spoken language is impeded, other forms of nonverbal communication take over—body language, screaming. Nonverbal ability is not a sign of emotional or sensory collapse, nor that a person with dementia cannot or does not wish to communicate. The carer has to learn to become less dependent on verbal communication and use a broader repertoire of communicative strategies—touch, visual stimulation such as direct eye contact and pictures, sounds that soothe (voice tone, music), and sight—watching for movements or expressions that might indicate distress or pain.

Emotions and bodily sensations are less affected by dementia than cognitive abilities. This is underestimated when an adult cannot communicate in accustomed ways. The idea that, if people cannot communicate, they cannot think or feel, cannot process emotion or react, cannot engage in moral or goal-oriented behavior remains strong. Gone are the days when neonates and infants were thought of as “blobs,” but the same lessons are not applied to dementia. Carers of small infants quickly learn to read signals—facial expressions, different kinds of crying—that enable them to discriminate between hunger or distress: carers of people with dementia require the same attention to detail.

Moser was able to observe how one care worker opted for a relational approach, using music, appetizing food, and gentle touch to engage and calm Mrs. Olsen. To counter the “separating, setting off, singling out, individualizing, bounding, and somatizing,” this carer worked “to build connection and hold the patient with dementia in relations.” Reconnection was brought about by music, food, eye contact, and touch, such that Mrs. Olsen was able to be reincluded in the collective practice and life of the ward. This carer transformed the experience of dementia: “Not through words and memory understood as a form of accountability to chronological time, but through emotion, experience, and memory embedded in wider, more distributed, and complex forms of embodiment than those that are simply neural.”

Moser notes that engagement has limits: dementia is a slow progress toward more total disconnection, but a relational approach allows for people to be held in connection a great deal longer because it recognizes that life is not just lived, it is shared. Moser’s (2011, pp. 713–5) use of *connection* is the core of a relationality ontology. Death “is the opposite of connection”:

In the relational ordering, dementia presents itself as a growing mismatch and problem with relations between the patient, the daily environment and fellow beings. It is not so much an objective and object like condition internal to the individual brain, as a problem with relation, interaction, and communication.

Only when a person’s body no longer allows for social connection, in very advanced dementia, is that person close to death. To understand human life as connection and participation implies that to do nothing, or to focus simply on tasks of caring (feeding, washing) are tantamount to treating a person as the living dead. Relational care is explicitly about establishing and maintaining connection, on the understanding that it is *social connectedness* that is fundamental to life—not drugs or cures.

People with dementia often want to remain at home, among neighbors, family, and friends, but the economic, social, and educational resources to enable this are not forthcoming. Their highly stressed “informal” carers will be expected to confine them to an institution. Their dementia will invariably increase in severity, compounding carer guilt: understaffed, they provide inadequate care and hasten disconnection. This is normative violence: exposing a vulnerable person to erasure and exclusion, including to physical and emotional harm. This does not mean that people with dementia can always be held. When they cannot, they have entered death, and palliative care takes over. But

we have a right to expect institutional care that holds people in connection when we are unable to do so ourselves—and we know this is rarely the case.

Improvements in the quality of dementia care will only come from “moving away from the individualist model proposed by person-centered care and toward an understanding of relationships and interconnectedness” (Smebye & Kirkevold, 2013). The risk is that people will see a relational approach as merely an improvement on person-centeredness. But relationality has a different ontological and moral foundation, requiring radical changes in the personal moral universe of all those who support a person with dementia. Medical and health professionals also have to shed cultural assumptions to live relationally, so as to design policies, practices, and forms of advice that enable connectedness. Some carers manage this intuitively, a great many do not. It is the carer rather than the person cared for who is on the roller coaster ride, who is required to adjust, to challenge their own comfort zone. Currently, those around them rarely have the insight to assist and support them.

Dementia as life or death? The ontological shift

Dementia’s demands on relationships disturb totalizing notions of ethics, morality and personhood because it disturbs the assumption of an underlying stable, knowable ontology upon which a morality can be based. But the trauma and demands of caring would be very different if life and relationship were understood differently to start with. And so, too, would a diagnosis of dementia be experienced differently, if we felt safe that we would be held in connection.

To ensure that a person with dementia is held in connection requires nothing less than a major ontological shift in what it means to be, to live, to die. Socrates argued that death was not to be feared just because it was unknown. But death in 21st century modern societies is feared because life itself is not valued, its meanings are held in question. The English poet, John Milton, blind in his old age, concluded a poem about feeling useless with the reminder, “He also serves [God] who only stands and waits.” Milton’s God would care for him, even when he could do little. When Bonhoeffer asked in his anguish, “Who am I”? he answered himself: “Whoever I am, Thou knowest, O God, I am Thine”! Bonhoeffer and Milton looked to their God to hold them in connection. Their belief extended life into death.

What the concept of relationality in dementia care implicitly points to is the relational quality of *all* life.

It invites a different understanding of how “being” and “life” should be understood. This is true of any relationship: to the extent that people are not held in connection, the relationship dies. The fear of dementia makes sense: it threatens disconnection before “one’s time.” Disconnection looms as the lack of a social commitment to relational care; losing the capacity to make others accountable, not being treated with dignity, being sent to a nursing home regardless of one’s wishes. We fear becoming dependent in a society that disdains vulnerability. We fear the demeaning of our life more than we fear our mortality.

Powerful ideational and economic forces hold dementia in the grip of death rather than the connectedness of life. The extent to which a person with dementia can live well is limited not by their disease, nor even the care they receive, but by the cultural discourse that sets up limiting norms of personhood and health, that privilege cognition and memory as the mark of social value, and stunt the ways in which we are taught to think of selves in relationship from birth to death.

In a secular society, in which social value is economically defined, and which increasingly emphasizes self-construction, disconnection begins with economic uselessness. Ageism brings death into life: there is no guarantee that we will be held in connection by even close kin and the demands are financially and socially costly for those who want to care. The prospects become bleaker when we can no longer control who we are because of dementia. We are completely, frighteningly, dependent on people whose commitment to hold us in connection is tenuous to say the least.

To live a good life at life’s end with dementia depends on whether we trust those around us to continue to hold us in connection. By ensuring those with dementia are held in connection, we ensure they die a good death.

The moral challenge of dementia through the centuries has been met through various expressions of the intergenerational contract, to care for one another from birth to death. This contract has been broken. It was broken when medicine took up the Cartesian model, thereby denying us the full experience of our humanness, and our inextricable relationality. We can change the treatment of those with dementia and pour more money into their care, but this will not restore livable lives to them unless we rethink the ways in which dementia is framed within medical science.

A growing number are concerned that the dementia-canary is sick, dying in the absence of a world that will ensure it a livable life. People are challenging the “hypercognitive” society (Post, 2002), demanding an ethics of care (Kittay, 2002) and recognizing the power of relationality (Moser, 2011). Dementia might seem an

unlikely space in which to find a radical social movement fermenting but that is indeed the case. This critique is not limited to dementia: it is challenging various practices of disconnection. It is implicitly moves us toward a caring society, in which people understand life, first and foremost, as holding and being held in connection.

Dementia disturbs, not because it is a tragic way to end a life but because it sheds light on our understandings of life and death and finds them wanting. To return to the question with which I started, can we live a good life at life's end with dementia? Yes, when we know there are people who will hold us in connection, and will be supported themselves to do so. A caring society requires ontological, moral, and economic shifts that sometimes seem more illusory than the cure for dementia.

Funding

This work was supported by the Faculty of Arts and Social Sciences, University of Sydney [Grant Number M3FRSSGM].

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