Five sources of hope for the deeply forgetful: Dementia in the twenty-first century

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Abstract

At this point of time, two decades after intense biological research into dementia began, we need to reassess our perspective on hope, and understand the need for some redirection toward the larger questions of care when no cure is in sight. It does seem appropriate to focus more of our hope and possibly resources on care itself, and on the creation of attitudinal shifts toward the affirmation of the deeply forgetful. There is no compound available yet that promised to slow or cure dementia. We can have hope in dietary modifications that may delay onset; compassionate carers who manifest our deepest sense of a shared humanity despite cognitive decline; the increasing evidence for enduring selves beneath the chaos of neurological devastation; and the possibilities of a spiritual–cultural evolution toward acceptance, affirmation, and connection with the deeply forgetful. This paper will discuss and critically assess these sources of hope in the world of the deeply forgetful.

Keywords: Dementia, carers, ethics, respect, dignity, hope, love

Summary

- Redirecting the hope of persons with dementia and families.
- Encouraging a greater appreciation for the enduring self-underlying dementia.
- Developing the ethics and culture of care and respect.
- Recognizing carers as exemplars of compassionate care for society.

Despite all efforts to the contrary, as the second decade of the twenty-first century dawns, biomedical efforts to delay, prevent, or cure dementia have shown no significant success.

The history of science is of course replete with surprising examples of victory plucked from the wings of despair, and indeed ‘serendipity favors the prepared mind.’ Without giving in to scientific defeatism, it does seem fitting to focus our hope on care itself, and on how we can create cultures that value people who are so deeply forgetful. There is no magic bullet for dementia, but we can be hopeful in terms of these three things: the compassionate carers who manifest our deepest sense of a shared humanity despite cognitive decline; the increasing evidence for enduring selves beneath the chaos of neurological devastation; and the possibilities of a spiritual–cultural evolution toward acceptance, affirmation, and connection with the deeply forgetful. In this presentation I will discuss and assess these sources of hope in the world of the deeply forgetful.

Current Science

In the United Kingdom there is wisdom in speaking of ‘dementia’ rather than of ‘Alzheimer’s disease,’ since dementia as a syndrome has so many causes, and any single case may be of mixed casualty. Undoubtedly, there exists a progressive, intractable, and irreversible form of dementia that is characterized through brain imaging as an atrophy of the hippocampus, that part of the brain most involved with memory, and this may be described as dementia of the ‘Alzheimer’s type,’ or even as Alzheimer’s disease. But it is by no means agreed upon anymore that the disease is caused by beta-amyloid protein plaques that develop between neurons. In a much hyped recent study, Eli Lilly’s compound, Semagacestat, successfully reduced beta-amyloid plaques in the brains of people with a diagnosis of probable Alzheimer’s, but this seems to have
worsened cognitive function and activities of daily living in subjects when compared with placebo. Contrarian basic scientists then quickly asserted their view that beta-amyloid build-up is the body’s protective reaction to Alzheimer’s, rather than a causative agent to be eliminated. In a spinal fluid test for Alzheimer’s based on beta-amyloid and tau protein levels was media hyped as ‘100% accurate’ in predicting onset of Alzheimer’s, when in fact, such tests are still lacking in their sensitivity (ability to diagnose Alzheimer’s when it exists) and specificity (ability to only diagnose those with the disorder). It is not the case that persons with normal memories who have these proteins will go on to develop Alzheimer’s. Even if elevated beta-amyloid levels are associated with Alzheimer’s to a significant extent, this by no means is a certain marker for disease, nor is it necessarily causal.

True, then, there is an epidemiology of an irreversible, intractable, and progressive form of senile dementia that is quite heterogeneous in manifestation, marked by hippocampal atrophy, and which we call Alzheimer’s despite the fact that in 1907, Dr Alzheimer himself did not think he was discovering a disease, but simply observed brain plaques that might or might not be associated with the senile dementia that we would probably all succumb to if we just lived long enough. Indeed, the major prevalence study of persons 90 years of age or older indicates a 61.1% prevalence rate of the syndrome of dementia among women 100 years of age or older, some of which is due to hippocampal atrophy, but which may also be due to limited blood flow or small stroke-like events in the white matter of the brain (i.e. multi-infarct dementia). More frequently than not, these ‘mixed’ causes occur together. Maybe dementia just comes with the territory of growing very old as the vasculature system declines and the brain ages. If so, then the primary cause of dementia is age, which we are not likely to eradicate, although a great deal of effort being spent on research into the basic science of aging in the hopes that the process can be delayed.

Dementia associated with hippocampal atrophy can occur in early onset families, caused by rare autosomal dominant mutations, especially the presenilin genes PS1 and PS2 (disease onset is typically in the early forties and is especially rapid in progression). It is possible to speak of these genetic diseases as Alzheimer’s disease, but they might be better referred to as PS1 and PS2 diseases, although it is also plausible that they could be very pure or ‘unmixed’ examples of Alzheimer’s disease.

Plural biologies, plural genetics, plural ages of onset, plural progressions, and probably plural diseases are apparent in dementia, and Alzheimer’s is a label being used too widely. As the basic science of Alzheimer’s disease has become confused, scientists have a hard time being able to pick out the right targets for new compounds to attack.

There is, to date, no successful compound, natural or unnatural, that delays, prevents, slows, or cures this atrophy of the hippocampus that we call Alzheimer’s disease. If, on a scale of one to ten, insulin is a ten for the treatment of diabetes, these cholinesterase inhibitors are a 1 at best, and probably a 0.05. The legacy of disappointment is clear. Back in the late 1980s, Whitehouse and others put forward the cholinergic hypothesis, and quickly the hype evolved to a point where cholinesterase inhibitors were going to ‘cure’ Alzheimer’s disease. The results of this entire line of compounds over the past two decades have been so limited that many clinicians still do not prescribe them, or would not were there no pressure from families to do so.

As for delay and prevention, hormonal replacement in post-menopausal women not only failed but actually contributed to dementia levels. Anti-inflammatory drugs have little or no impact. Cholinesterase inhibitors have no demonstrated delaying or preventive impact at all, and their impact on those with PD is slight even in the best-case scenarios. Vitamin E has shown no benefits, though for a while many neurologist friends were gulping down pills.

A 2010 National Institute of Health panel, after reviewing the world’s scientific literature, found that ‘Currently, no evidence of even moderate scientific quality exists to support the association of any modifiable factor (such as nutritional supplements, herbal preparations, dietary factors, prescription or nonprescription drugs, social or economic factors, medical conditions, toxins, or environmental; exposures) with reduced risk of Alzheimer’s disease’. Such honesty is laudable, although the panel errs in downplaying the studies on diet, exercise, and social engagement, which are alluded to in the next section.

**Lifestyle Change**

Hope for delay of onset or prevention may be captured in this prescription: walk (exercise) to a Greek restaurant (Mediterranean diet), ideally with friends (pro-social engagement).

It seems plausible that a Mediterranean-type diet may help prevent dementia. A total of 2148 subjects in upper Manhattan, age 65 years or older with a median age of 78 years at baseline, were
followed for 4 years. Two hundred fifty-three were diagnosed with ‘probable Alzheimer’s.’ Seven different dietary patterns were examined. After adjustment for demographic factors, body mass index, caloric intake, and genetic risk, only one pattern was associated with lower levels of Alzheimer’s – a whopping 38% reduction in a 4-year window! Coupled with moderate exercise, the reduction may be considerably greater – as much as 60% in this study, but the impact of exercise is generally less clear than that of diet.14 That reductive dietary pattern is roughly that of the Mediterranean diet (leafy vegetables, nuts, tomatoes, fish, and fruit, with little or no red meat, butter, or high-fat dairy products). This diet is already linked to heart health, and even to protection against some forms of cancer. What is good for the heart is probably good for the brain. What might be added? Eat blueberries (anti-oxidents), control stress (it elevates cortisol levels, which is bad for vasculature and may be related to hippocampal atrophy), exercise your body as well as your brain, and stay socially engaged.

Vascular health is important in staying healthy and cognitively intact. Indeed, to the extent that the APOE-e4 genotype is a risk factor, it may be due to its association with neurologically widespread longitudinal changes in cerebral blood flow.15 Maybe the Greeks had it right twenty-three centuries ago in that old Hippocratic passage about dietary measures: ‘I will apply dietetic measures for the benefit of the sick according to my ability and judgement; I will keep them from harm and injustice.’

Compassionate Care

Each time we approach a deeply forgetful person with a kind tone of voice, a reassuring facial expression, and call them by name with a smile we are participating in an intervention that is as significant as any biotechnical one of which I am aware. It is the compassionate carers who remain the best hope, and who serve as antidote to violence and Machiavellian values. Carers are the beacons of hope to be acknowledged and celebrated in their depth of commitment. They sway the social balance toward goodness not with single great acts of love but rather with daily small actions done in great love. They model for the human capacity to accept, affirm, and connect with the deeply forgetful.2

The dehumanization of medical care is everywhere. Can we have the unflinching self-awareness, empathic skills, and gratitude for the privilege of caring for the deeply forgetful that exemplifies the art of healing? The goal of every encounter with a person who is deeply forgetful should be primarily these three things, worth repeating: accept, affirm, and connect. And this is basic to all healthcare under all conditions, however much we may tend to forget about the nature of a healing relationship.

It is our dignity that is at stake. We should question the increasing powers of biotechnology with regard to the modification and supposed ‘enhancement’ of human nature itself, for such does not by any means ensure the kind of self-improvement of heart that rests at the very center of human dignity. Botox, anabolic steroids, genetic modification to make us faster and stronger, human growth hormone to make our children a little taller (after daily injections over several years), and the promise of a fountain of youth do not strike me as contributing to our human dignity.10 Rather, our dignity as human beings is already ours to claim when we treat another person with love as expressed in celebration and attentive listening, creativity and helping, and loyalty and respect. Etymologically, the English word derives from the Latin dignitas, meaning honor, elevation, and worthiness. We need to preserve our own dignity and can only do so as we conserve the dignity of the deeply forgetful.

The first principle of love for persons with cognitive disability is to reveal to them their value by providing attention, concern, and tenderness. Any experienced carer knows that the person with dementia, however advanced, will usually respond better to someone whose affect is affirming in tone.

Emotional, relational, aesthetic, and spiritual forms of well-being are possible to varying degrees in people with cognitive deficits. There is a ‘culture of dementia’ that is useful in appreciating the emotional and relational aspects of quality of life. There are indicators of well-being in people with severe dementia: the assertion of will or desire, usually in the form of dissent despite various ways of coaxing; the ability to express a range of emotions; initiation of social contact (for instance, a person with dementia has a small toy dog that he treasures and places it before another person with dementia to attract attention); and affectionate warmth (for instance, a woman wanders back and forth in the facility without much socializing, but when people say hello to her she gives them a kiss on the cheek and continues her wandering).3

Jean Vanier, founder of L’Arche, provided me with two stories about the power of love in the lives of the cognitively disabled, and the transformations that those around them sometimes undergo:

The wife of a friend who was a wealthy, prosperous business man, developed Alzheimer’s
disease. He decided not to put her in an institution but to care for her at home. He feels her, gives her a bath and looks after all her everyday needs. Not long ago he confided to me: ‘I am becoming more human.’ His heart has been awoken. His grandson told a friend of mine: ‘Yes, my grandfather has changed totally. He used to be so rigid and difficult. We always had to watch how we behaved at meals. Now, during the meals, his wife says all kinds of funny things that don’t make much sense. And Grandpa is so gentle and kind with her and with us all.

And another story from Carol Sifton Bowlby of Canada:

We can choose to lament, to be lost and lonely, or we can choose to seek out the joy in what we do and let it renew our resolve. Sometimes joy finds us. It may take the form of a fleeting look of recognition and warm embrace from the loved one with dementia. It may take the form of shared laughter from a silly mistake, shared words from a familiar prayer, or shared lyrics from an old song sung just off key. Sometimes joy is present but we are too busy to recognize it.4

These are stories about people drawing closer to those with cognitive disabilities and, in the process, being reawakened to a life of greater love.

The Enduring Self

A person with dementia is rarely as ‘gone’ as we superficially suppose. Carers widely report an openness to surprises.1,4 There are those moments, often early in the morning after having slept well, when a person with severe dementia surprises us with a meaningful word, a moment of recognition. Such sporadic events unveil a self-identity that is more enduring than theories of staged progression envision. A person incapable of conversation may join in with others on a verse of a deeply loved song. 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. ‘Respect’ derives from the Latin re-spectare, to ‘re-look.’ When we re-look at the deeply forgetful with undistracted attentiveness, we can see a presence beneath the surface of decline. Our task is one of affirmation and connection.

Memories in the Making is a nationwide program that explores whether people with dementia can reveal themselves through art. Many artists from around the United States now volunteer to lead these programs in most major cities and towns. What we have discovered is that even in the most advanced stages of dementia, individuals will express remnants of self-identity. They may not be able to communicate by speech or proceed from point A to point B over time. True, they are mostly living in the pure present, but we need to be very careful not to assume that the intense link between present and past is completely gone. Sometimes, such assumptions evaporate when we allow these people opportunities to express their self-identity through the recreation of a symbol. In October 2006, the Columbia Daily Tribune (Missouri) ran an article that included a story of a man with dementia who clung to his cowboy hat until the very end of his life, even bathing and sleeping with it. It turned out that he worked in the steel factories of Cleveland and dressed ‘Country & Western.’ He knew that his identity was somehow connected with that cowboy hat. The article ends with a comment from Debra Brook, local director of the Alzheimer’s Association in Columbia, who told of one elderly person with dementia who, barely able to communicate, did not recognize his daughter any longer. ‘When the man joined the Memories in the Making program, he worked for weeks drawing a series of horizontal and diagonal lines on paper. When asked what he was drawing, he suddenly blurted out, ‘Directions to my daughter’s house.’ Despite his decline, this man was still expressing love for his daughter through creativity, and even if he could communicate with her in the present, or even identify her on most mornings, he nevertheless lived for her and in relationship with her.

We are often astonished by the unexpected moment in the morning after a good nights rest when a person who is severely demented will be surprisingly insightful.1 Again, the anecdotal literature is replete with examples of sporadic insight as evidenced by a few uttered words or chiming in with the words of an old song that was once upon a time meaningful and remains so. We know how persons who have not communicated verbally for months will chime in to the words of a tune they loved years ago.

People with dementia can focus their self-identity on the past rather than on the present or the future. Let me provide an example of a transformative experience that I had some years ago:

I met Mr. G. in 1988 in a nursing home in Chardon, Ohio. He taught me that love is the
ultimate reality that ties our lives together. I read a brief biosketch about his life, and sat down to talk with him. I asked him how his sons were doing. Although he could not understand or respond, he placed a twig in my hands and gave me a huge warm smile. I thanked him and then gave it back. I asked the nurse to tell me about the twig. She said that when Mr. G. was a little boy growing up on an Ohio farm, he loved his father very much. Every morning, his father gave the boy the chore of bringing in kindling for the fireplace. Mr. G. had retreated back in time to his boyhood, to a period of fatherly love that provided an emotional safe haven. The twig was a profound symbol of who he was and who he is.

I learned from Mr. G. that even when the present is a buzzing chaos of uninterpretable experiences, a person with dementia can find an emotional safe haven and tranquility in the past.

A Spiritual–cultural Evolution

I do believe that we will see a spiritual–cultural shift away from the ideology of ‘hyper-cognitive values’ that has regrettably blinded us to the enduring selves underlying the deeply forgetful.

How can we encounter the deeply forgetful outside of hyper-cognitive ideologies? How can we bear witness to the reality that persons with this cognitive disability possess inherent qualities, and create a culture where all are welcomed and celebrated regardless of cognitive limits and vulnerability?

It is ethically important that the person with dementia not be judged by ‘hyper-cognitive’ values. The self is not cognition alone, but is rather a complex entity with emotional and relational aspects that should be deemed morally significant and worthy of affirmation. Rationality is too severe a ground for moral standing, allowing, if not requiring, the relational and emotional deaths of many individuals who may, in fact, continue to enjoy simple pleasures despite their lack of rationality. The appropriate moral response to people with dementia, according to classical western ethical thought and related conceptions of common human decency, is to enlarge our sense of human worth to counter an exclusionary emphasis on rationality, efficient use of time and energy, ability to control distracting impulses, thrift, economic success, self-reliance, self-control, ‘language advantage,’ and the like. The perils of forgetfulness are especially evident in our culture of independence and economic productivity, that so values intellect, memory, and self-control. Yet emotional, relational, aesthetic, and symbolic well-being are possible to varying degrees in people with progressive dementia. In general, quality of life is a self-fulfilling prophecy. If those around the person with dementia see the glass as half-empty and make no efforts to relate to the person in ways that enhance his or her experience, then quality of life is minimal.

An adequate ethical theory or moral life requires us to include everyone within the moral domain of care and respect. This universalism asserts that all human lives have equal moral standing with the exception of those who are dead by brain death criteria. There is a troubling tendency, however, to exclude human beings from moral concern while they are still among the living. This occurs most frequently when we differentiate ‘them’ from ‘us,’ depersonalizing and dehumanizing others for reasons of race, class, gender, age, culture, or cognitive disabilities, including forgetfulness.

Some years ago, I coined the term ‘hypercognitive values’ in arguing against so-called ethicists who diminish the moral status of the cognitively impaired. The cognitively limited fall outside the protective range of ‘do no harm,’ they argue, although their deaths should be painless.

We 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. Reinhold Niebuhr wrote of the tradition from the Stoics that has proceeded without interruption into Kant, Locke, and modern bioethics 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’. We easily demean those whose memory has dissipated by treating them with indifference or even with cruelty. We act as if they are not 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, persons with dementia, selected for hypothermia experiments, were taken out of German mental asylums and left to freeze in the cold overnight air. Memory is a form of power. We sometimes mock and ignore those who have lost such power, sending the message that their very existence rests on a mistake. What of voluntary pre-emptive assisted suicide? Here I am
unwilling to be too critical, though I am no advocate. The rationality that philosophers select for moral considerability is generally limited to one property. They define rationality procedurally as an ability to do certain things, such as act consistently based on clear thinking, arrive at decisions by deliberation, envisage a future for oneself, and so forth. But, in fact, rather few of us go through life with consistent rationality. We act on emotion, intuition, impulse, and the like. We go through periods of considerable irrationality due to variation in mood. Rationality as a decisional capacity is not morally important. It is rationality as a source of self-identity that matters — i.e. ‘who’ we are rather than ‘how’ we proceed.

Our task as moral agents is to remind persons with dementia of their continuing self-identity, of who they are. We must serve as a prosthesis, with dementia of their continuing self-identity, of their love of the hearted emotional giving, without any expectation of direct reward. The first component of love is comfort, which includes tenderness, calming of anxiety, and feelings of security based on affective closeness. It is especially important for the person with dementia who retains a sense of his or her lost capacities. Attachment, the second component of love, includes the formation of specific bonds that enhance a feeling of security. Inclusion in social experiences, occupation in activities that draw on a person’s abilities and powers, and, finally, identity are important components of love.

Love is a resurrection-of-a-sort for the disabled, and it is equally so for ourselves. We shed grace on the lives of those who receive as well as on those who give.

Conclusions

Let us hope that biomedical advances will surprise us with new gains, and perhaps these are around the corner. But more promise seems to be found in long-term lifestyle commitments to healthy aging, with special emphasis on diet, exercise, and prosocial engagement. The very groundwork of hope still lies in the human capacity for caring, and in the recognition if an enduring self underlying the layers of dementia that, to some degree, is sustained and supportable. With enough evolution, society at large may get to a point where hyper-cognitive values become secondary, and with the common good in view we refuse to disregard the deeply forgetful.

Allow me to conclude with the following e-mail written by a daughter soon after her father passed away:

‘Hello Dear Friends:

As many of you know, my father has been suffering from Alzheimer’s disease for the past 4.5 years. It has been a long and often very hard road for him, for my mom, and for me too. However, as of 7 p.m. last night, my father no longer has to struggle with the disease that robbed him of every part of his being, except one. He never once stopped recognizing my mom and never, ever stopped reaching out to her and wanting to give her a kiss. No matter how many parts of his personality were lost, no matter how many hospital visits full of needles and catheters, no matter how many diapers, he always retained his kind, gentle sweetness and his European manners as a gentleman. In the end, things went very quickly for him. He simply closed his eyes and closed his mouth, indicating no more food or water.’

The gentleman described above was in the advanced and therefore terminal stage of
dementia, marked by some combination of the abilities to communicate by speech, recognize loved ones, maintain bowel and/or bladder control, ambulate without assistance, and swallow without assistance. Yet throughout, he seems to have benefited greatly from the giving and receiving of love, consistent with the relational context found meaningful over his life course. His subtle expressions of continuity in subjective experience and enduring self-identity were respected and cherished.

St Paul, in First Corinthians, tells us to speak in the spirit of love, and that without this spirit our words are unbecoming: ‘Though I speak with the tongues of mortals and of angels, but have not love, I am as a sounding gong, or a clanging symbol.’ It is the affective tone of our words, our facial expressions, and our actions that draw the cognitively disabled into the light of love. And we discover in this exchange that the disabled can still smile and appreciate our affirming presence.

May the scientific world come up with some marvelous compound. But the scientific battle to make a world without dementia is less immediately helpful than our own efforts to find meaning in the care and love of the deeply forgetful. And so it is that we gather here in London to celebrate thousands of carers for their compassionate love, their courage, their innovative brilliance, and their astonishing achievements each and every day. May we as a society provide you all with the necessary support, and resist the barbarians who have knocked at the door in the past and wreaked great havoc, for the line between acceptance, affirmation and connection, on the one hand, and hyper-cognitive exclusion on the other, is too often thin indeed. You are the proverbial salt of the earth, and may you continue to inspire a better world.

References
Author Information

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