

Hope in caring for the deeply forgetful: Enduring selfhood and being open to surprises

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Hope in the context of individuals with dementia and their carers is defined in this paper in terms of an openness to surprises with regard to indicators of continuing self-identity in the individual with dementia, active agency with regard to carers and affected individuals to the extent possible, and the affirmation of a theory of personhood and related moral status that breaks through the limits and prejudices of hypercognitive values. (Bulletin of the Menninger Clinic, 77[4], 349-368)

In the lives of carers for the deeply forgetful, hope might be best defined as an openness to surprises. This is a definition that is not intended to trivialize the profound anguish felt by carers, or by the deeply forgetful themselves until they reach that point where they forget that they forget. Dementia, in its intractable, progressive, and irreversible form, is often caused by Alzheimer's disease (AD; about 60% of cases). There is much bleakness in the insidious peeling away of memories and capacities. It is known as the autobiographical disease and we read of protracted grief. Where is hope? Is there any at all?

The idea of hope as "being open to surprises" is not something this author simply dreamed up. It emerges from 20 years of work-

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I wish to gratefully acknowledge the Alloway Family.

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ing with carers in support groups and community dialogues. Yes, there is an assault on the story of a life, but despite the losses, there are also sporadic indicators of continuing self-identity that make caring meaningful.

Perhaps we ought not to even speak of individuals as demented because the term is so often used in a derogatory manner, and lends itself to dehumanization and despair. The *deeply forgetful* suggests continuity with a shared humanity, for which forgetfulness is a problem of degree from the absent-minded professor to the shopper who has forgotten where the car is parked, from the patient who has just awakened after shock therapy to the athlete who has suffered one too many concussions, from the young child whose capacities for memory have not yet developed to the adolescent with attention deficit disorder. We all have some problems with memory, but to varying degrees at different times. I recognize that classically, dementia implies a precipitous decline from a former mental state, and has been sharply contrasted with normal age-related forgetfulness. But with such middle ground as mild cognitive impairment and the like, there is clearly a continuum involved. It is all a matter of degree.

In this presentation I consider five sources of hope for the deeply forgetful. The five sources are these:

- (1) Faith and spirituality
- (2) The enduring self
- (3) Moving beyond hypercognitive values
- (4) Love
- (5) Medical progress

1. Faith and spirituality

Hope has a spiritual tonality and is deeper than optimism. Optimism is to hope as happiness is to joy. Optimism is more or less established in the personality as a genetic set point, although it can be affected by social-relational context. Optimism is mostly a dispositional trait. As such, it can be easily diminished in hard times. Hope, in contrast, is a fine-honed virtue that is arrived at through some hardship. Martin Luther King, Jr., could speak of

hope running down the mountains like a river, but the word optimism would not at all fit the bill. I asked an African-American pastor what he thought about hope, and his response was "It is something that we have had to specialize in because we have suffered so much as a people." Hope is shaped and formed over time. It is realistic about the facts, rather than avoidant. It has an interior stability that makes it both more consistently aware of hard realities and also more able to transcend them. People must decide to be hopeful despite all, and they must make this decision again and again. For the spiritually minded, to give up on hope is to give up on God, so faith and hope are also intertwined for them. As theologian Paul Tillich wrote, we "have a right to hope even against hope." By analogy, happiness is dispositional and quite dependent on external circumstances, while joy is considered to be a virtue with a deeper and more stable dimension than happiness, and is associated as such with spiritualities.

For the carer, hope must engage the individual as an active agent whose initiative makes a difference in some immediate tangible manner, and for whom gratification and meaning are enhanced. In this sense, hope is an activity and assertion of agency, rather than something passive, as in "I hope that someday they come up with a better pill."

Hope in such hard times will for many carers come from a Higher Power. In Christian tradition, hope is one of the three theological virtues, along with faith and love, all of which are gifts of the Holy Spirit. In the tradition of St. Paul, then, hope is not something that can be equated with any natural dispositional substrate of human optimism, although it may build on the substructure of optimism. We may achieve hope-of-a-sort in purely human terms, but there is for believers an eternal source of hope that emerges in relationship with a Higher Power, and that enhances mere human hope. Carers often rely deeply on their faith, and on spiritual practice like prayer and worship. They must find hope in quiet intimacy with God when they can, and in a belief that regardless of cognitive decline, every human being is in the image of God as an eternal soul that never disappears despite the breakdown in communication and the atrophy of brain cells. These carers rest on the Ground of Being, that ultimate stable at-

tachment that is there even in the shadows of anguish and grief. For many, hope comes from the active love that they never give up on, yet that love is not to their minds merely human love, but a divine *agape* love in which they feel they participate directly, as well as through communities of faith, although generally speaking faith communities could do much more to actively support the deeply forgetful and their carers.

For each of us as finite beings with frail minds, the negotiation with hope ultimately raises questions of ultimate meaning and what can be broadly considered matters of spirituality. There are many carers for whom hope cannot be seriously discussed outside of a spiritual-religious tradition. Whether it is the Roman goddess Spes or the Pauline affirmation of “faith, hope, and love,” hope elicits the theological in many cultures, for in the final analysis, hope is so important to our lives that it demands a sacred canopy. It is fair to say that a human being who has no hope cannot long survive. Cut into stone above the Gate to Hell in Dante’s *The Divine Comedy* are the words, “Abandon all hope ye who enter here” (canto III, l. 9).

2. The enduring self in 12 aspects

In my years of interactions with the deeply forgetful at all stages of decline I have never met an individual who did not surprise me with some sporadic expression of continuing personal identity. The abstract philosophical idea of a total disconnect between the then self and the now self is false (Post, 1995b). Moreover, if taken seriously it is a falsehood that contributes to loss of both meaning and hope in carers as well as to mistreatment, for it denies the enduring self and its dignity over time (Sabat, 2001).

I believe that there are at least 12 aspects to the enduring self under conditions of deep forgetfulness:

- Creative
- Symbolic
- Emotional
- Relational
- Somatic
- Musical

- Rhythmic
- Aesthetic
- Olfactory (smell)
- Spiritual
- Tactile
- Cognitive

Let me highlight some of these aspects of the enduring self with a set of brief cases:

Case One

I met Mr. G. in 1988 in a nursing home in Chardon, Ohio. 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. Then he surprised me by uttering “God is love.” 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 as a Christian 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 the love Mr. G. felt as a boy from his dad. I learned from Mr. G. that even when the present is a buzzing chaos, a person with deep forgetfulness can find an emotional safe haven and tranquility in the past, and from that safe haven can remind us of his or her enduring selfhood (Post, 2011).

Case Two

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 to a considerable degree

living in the pure present, but we need to be very careful not to assume that the connective glue between present and past is ever 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 I gave the reporter about 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 in country and western style. He knew his identity was somehow connected with that cowboy hat, or so stated his daughter, Sharon Eckert, President of the Cleveland Alzheimer's Association at the time. 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 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. He was not conversant and had not been for months. Although generally unresponsive when asked what he was drawing, one morning after a good night's rest he suddenly blurted out, "Directions to my daughter's house."

Despite his decline, this gentleman was still expressing love for his daughter through creativity.

Case Three

Dr. Joe Foley died in July 2013 in Cleveland at the age of 96. A distinguished neurologist, Joe had always had a fabulous sense of humor and innumerable hilarious stories. Over 20 years Joe taught me as many as a hundred Irish jokes, as he was the son of Irish Bostonian immigrants. I stopped by for a visit the day before Joe passed on. Joe was quite forgetful in the last months of his life. He seemed utterly unable to converse. So I started telling Joe old Irish jokes that he had taught me:

"So Joe, what's the Irish definition of hospitality?" No response.

“It’s makin’ someone feel perfectly at home while you be a wishin’ they were.” And Joe broke out in laughter. His sense of humor was still there.

Case Four

There is a major care movement called *Music and Memory* (see www.musicandmemory.org). I visited the Long Island Veterans Nursing Home in March of 2013 and spent some morning hours in the facility for vets with severe dementia. There were about 30 vets 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 Sinatra and then Dean Martin sang out. Then came “It’s a Grand Old Flag,” and it seemed like 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. Deeply learned music, including hymns, with which individuals identify autobiographically, touches their enduring selves at a profound and hidden level, eliciting a renewed sense of who they are. After the music session, at least ten 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 arisen from a slumber, at least for a few minutes.

Recent research indicates that it is the medial prefrontal cortex (just behind the forehead) that links memory, music, and emotion. This appears to be one of the last parts of the brain to atrophy in progression of AD (Janata, 2009).

Case Five

de Kooning painted for 13 of his 14 years after a diagnosis of possibly mixed Alzheimer’s disease, and his art, while greatly less complex, was still beautiful. He had shed his old anxiety and roughness.

Case Six

Here is an e-mail written by a daughter soon after her father passed away with advanced dementia:

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.

Case Seven

Olivia Hoblitzelle (2008), author of *Ten Thousand Joys & Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's* e-mailed 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 had 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 looks at me intently and said forcefully, 'God, physics and the cosmos.'

In these cases and countless others like them we see or hear hints of continuing self-identity. Yes, these tend to be sporadic hints, but they are all revelations that underneath the communicative chaos or the glassy stare there is something that has been referred to as *the mind behind the mind*. Yes, it is possible to diminish the significance of these hints as the last residues of a deteriorating brain.

But my Hindu friends in Gambier, Ohio, have another interpretation. They are all professional carers at a nearby facility. Dr. Foley and I took them to lunch one day and asked them why they care so well for so many patients with dementia. Their response was that each human being carries within a small particle of divine mind, or as the Hindus state it, *atman (soul) equals Brahman (god)*. No matter how much the brain is harmed, there is still a mind or consciousness that is more than the brain, and that does not arise from the workings of the brain. The individual mind has primacy over the brain and is not merely epiphenomenal; it seems that materialism cannot explain or give rise to it. One thinks here of the well-documented concept of terminal lucidity, where people suddenly say something very meaningful before death despite their general incoherence. If such lucidity does sometimes occur even in the deeply forgetful, where does it come from? The brain? Or is mind and personal identity more than the brain? I cannot pursue a philosophy of mind herein, but I will raise the metaphysical question of whether there might be more to mind than matter.

Metaphysics aside, the bottom line is that if we take the time to be present, we can notice an enduring self. Therefore, let us learn to respect and find meaning in caring for such selves. Let us respect, as in *respectare* (Latin, to re-look, or look deeper). In this enduring self carers can find stimulation and hope amid decline. This may be found in a rosary recited, a hymn sung, or a prayer recited.

A person with dementia is rarely as gone as we superficially suppose, and carers widely report an openness to surprises. 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. Our task is

always one of exceptionless affirmation and connection. 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. The deeply forgetful focus their self-identity on the past rather than on the present or the future. A person with dementia can find an emotional safe haven and tranquility in the love of those around them.

But what blinds us to the signs of the enduring self? What makes some prefer to see the glass as half empty rather than as half full? 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.

3. Moving beyond hyper-cognitive values

Almost all contemporary philosophers espouse hyper-cognitive values (Post, 1995a), a term I originated in 1995, and as a result they have been blind to the emotional, relational, aesthetic, creative, and spiritual values that give worth to the lives of the deeply forgetful. They are not interested in the enduring selves of the deeply forgetful. The lens isn't right. Instead, they tell us, following their forbears, that to be a person requires the ability to project rational plans as moral agents into the future. People with Alzheimer's disease do not have this capacity, and therefore they are deemed something less than persons. Over the years, the philosophical response to hyper-cognitive values from various philosophers is that even nonpersons have sentient awareness of pain and the like, so they should not have to experience pain—which is to say that their deaths should be painless. Well fair enough, but labeling a deeply forgetful individual a nonperson diminishes most, if not quite all, of their moral considerability in the human community of equal regard.

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. From the Stoics and without interruption into Kant, Locke, and modern bioethics we find the rude assertion that the major criterion for moral membership is reason, and this tends to include only the intelligent in the protected community. 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 overnight air (Post, 2000).

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, p. 48). 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).

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 (Zagzebski, 2001). 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. And in this sense, the deeply forgetful can be surprising.

Our task as moral agents is to remind persons with dementia of their continuing self-identity, of who they are. In other words, our task is to preserve identity, rather than deny it. It is for this reason that many units for the deeply forgetful in nursing homes will post biographical sketches on the doors of residents, or fam-

ily members will remind a loved one of events and people who have been meaningful along life's journey.

Will we see a spiritual-cultural shift away from the ideology of hyper-cognitive values and open our minds to the enduring selves underlying the deeply forgetful? Perhaps intergenerational schools can help, and any other structures that bring together the deeply forgetful and youngsters. How can we encounter the deeply forgetful outside of hyper-cognitive ideologies? How can we bear witness to the meaning of these lives, and create a culture where all are welcomed and celebrated regardless of cognitive limits and vulnerability? Giving affected individuals a public voice early on in the progression and allowing them to speak for themselves will help. Perhaps more caregivers need to tell the story of why they value their loved ones despite cognitive deficits.

Rationality is too severe a ground for moral standing. The fitting 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. Emotional, relational, aesthetic, creative, olfactory, spiritual, and symbolic well-being are possible for 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 will be abysmal.

4. Love

Alas, there is so much loss and anguish that carers experience. And yet with each passing year I am surprised by carers, both family and professional. So many of them are role models for me when it comes to the ways and power of love in hard times. They are my source of inspiration.

In his classic work, *Dementia Reconsidered: The Person Comes First* (Kitwood, 1997), Tom Kitwood's definition of love within the context of dementia care includes comfort in the original sense of tenderness, closeness, the calming of anxiety, and bonding. Kitwood defined the main psychological needs of persons with dementia in terms of care or love. He drew on the narratives of caregivers to assert that persons with dementia want love, "a generous, forgiving and unconditional acceptance, a wholehearted 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.

Each time we approach a deeply forgetful person with a kindly 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 an 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. 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 healing art? The goal of every encounter with a person who is deeply forgetful should be primarily these three things, worthy of repeating: accept, affirm, 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 (Post & Binstock, 2004). 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, 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.

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 businessman, developed Alzheimer disease. He decided not to put her in an institution but to care for her at home. He feeds 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 awakened. 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. (Bowlby, 2004)

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

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” (1 Cor. 13:1). 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.

5. Medical science

I will not harp on new compounds. I will assert that on a scale of 1 to 10, if insulin is a 9.5 for the treatment of diabetes, cholinesterase inhibitors and glucose antagonists in combination or apart are about a 1. Fair enough, they may delay nursing home placement by a year or so for some patients, but family members wonder aloud about the effects because they still see progressive symptomatic decline. Perhaps this decline is slowed down a bit in some patients, but there is no slowing of the overall course of the disease. Yes, there is hope in all of this, but in fact almost all current pharmaceutical development is focused on anti-amyloid drugs, since everyone recognizes that in the final analysis, cholinesterase inhibitors are low impact and are pretty much an exhausted avenue.

Alzheimer's disease is often mixed with other causes of dementia. No doubt 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.

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.

A 2010 National Institutes 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. (National Institutes of Health, 2010)

Maybe 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 (Scarmeus et al., 2009). This study followed 2148 subjects in upper Manhattan, age 65 years or older with a median age of 78 years at baseline, for four years; 253 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 four-year window! Vascular health is important in staying healthy and cognitively intact. Maybe the Greeks had it right 23 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.”

But even I, a skeptic, believe that there will be something new coming around the corner that will greatly surpass what we currently have available for treatment. Hoping for a new drug is for the most part a form of passive hope. Hope rises and falls and rises and falls and on and on because it is dependent on news of a breakthrough in some lab and then with some pharmaceutical company that decides to take a gamble. The volatility of such passive hope results from the fact that it does not involve active agency and a sense of efficacy. It is a matter of waiting and waiting. We should hope for a new compound, but that form of hope should be somewhat peripheral to the active hope where we roll up our sleeves and make a difference.

Final thoughts

Those individuals diagnosed with probable Alzheimer disease can cope best by being active agents. I knew a man who, after his diagnosis, blossomed as an altruist. He rode in the van each morning to help bring more severely forgetful people to the Elder Care Center for art classes and support. He thrived for two years doing this until he was no longer able. In the moderate stage of the disease we must also encourage individuals to be active with their creativity, their emotions, and their continuing capacities. Engaging such individuals in decision making to the extent that they are able, using close-ended rather than open-ended questions, and giving them what freedom we can to ambulate and enjoy nature—agency is a source of coping and hope.

I have argued herein that hope for carers is being open to surprises. I hope that this does not sound as trivial to the reader as it might have initially. The experience of the deeply forgetful is uncertain in its nature, and within the glimmers of continuing self-identity we find real hope, because dementia has not read the textbook, and love can have an unexpectedly dramatic impact. In the paradox of loss and continuity nothing is absolutely determined, and as there is reason to fear there is also reason to hope.

The hope of carers is important to them. They need room for a little positive thinking. We find chapters such as “The Biology of Hope” in Jerome Groopman’s (2004) *The Anatomy of Hope*, or “Hormones of Hope and Healing” in Esther Sternberg’s (2010) *Sacred Spaces*. Sternberg points out that the biology of hope is partly determined by spacial and architectural environment. Let us acknowledge that some of the carers have higher depression rates than the general population, and some die before the individuals with Alzheimer’s disease, presumably because they are stressed while the person with dementia is living largely—not entirely—in the pure present. Thus, hope for the carer is a crucial protective dynamic, and their engagement with the continuing self-identity of a loved one is a significant aspect of that dynamic.

Positive thinking is a part of the life of any carer, as it must be of any individual diagnosed with Alzheimer’s disease while still insightful and in the early stages. They know that there will be no big miracles. But they can find small miracles of continuing self-identity if they are willing to look deep enough. And these small miracles are always also large ones because they affect the spirit of the carer with immense meaning and hope.

As I finish this essay I am fresh from a hospital where a 90-year-old woman was crying out as if in agony all day. She is quite heavily demented. They put a plastic face piece over her mouth and nose with a breathing tube of some kind down her throat. She was moaning in agony when I arrived at 8 a.m., and all through the day patients in nearby rooms listened to this loud agony. Family members insisted that she be kept alive. There is a selfhood underneath it all, but there was no way in the world that I could approach its hints because they were overwhelmed by the cries of suffering. Part of hope rests in setting such souls free from the technologies that are sometimes still imposed on them.

Finally, let me offer this point of practical guidance: We are on a unique adventure with each individual with progressive dementia, and we do not know exactly what is going on with him or her. We need to be open to the idea that there is a way to reach everyone. We need tools, like interesting objects to touch, something nice to smell or taste (actually, a bit of chocolate works well), personalized music, poetry, dance, and picture books of some re-

ally famous people like Marilyn Monroe or Joe DiMaggio, or of some landmarks like the Lincoln Monument. It is a good idea to sing little tunes like “You Are My Sunshine” or “Take Me Out to the Ball Game.” For folks with a religious history, try a hymn. Enter into this world, because I have found that there is some way to connect a bit with pretty much everyone, however limited. Small gratifications go a long way. This holds even with those individuals who seem just to be staring out into space with a blank expression. They will have their better moments usually in the morning after a good sleep. Be always open to surprises. St. Paul wrote that “Love never fails.” I don’t believe that it does. Under the umbrella of the Thou of divine love we can make the connections.

And one final question to leave open: Are we human beings who have spiritual experiences, or spiritual beings having a human experience? If there is a small piece of eternal soul in each of us, then maybe that deeply forgetful individual who seems so distant much of the time is already, if you will permit, on a spiritual plane of consciousness, and living in that world of betwixt and between as he or she leans into eternity and the energy of divine love. Something like this is characteristic of Buddhist cultures such as China and Japan, and of Hindu cultures as well, where the deeply forgetful are thought of as on the path of detachment and Enlightenment. Maybe that deeply forgetful person very near the end has already hopped on that last train for glory, but it just hasn’t quite left the station yet.

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