

**Social Consequences of Forgetfulness and Alzheimer's Disease:  
A Call for Attitudinal Expansion\***

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\* This presentation is based on the following published sources:

Shabahangi, N. R., Thai, J., Faustman, G. and Fox, P. "Some Observations on the Social Consequences of Forgetfulness and Alzheimer's Disease: A Call For Attitudinal Expansion." *Journal of Aging, Humanities and the Arts*, Vol. 3: 38–52, 2009

Voris, E, Shabahangi, N., and Fox, P. "Conversations with Ed: Waiting for Forgetfulness – Why are We so Afraid of Alzheimer's Disease?" San Francisco: Elders Academy Press, 2009.

Beard, R. and Fox, P. "Resisting Social Disenfranchisement: Negotiating Collective Identities and Everyday Life with Memory Loss," *Social Science & Medicine*, Vol. 66: 1509-20, 2008.

## **A Plea for Change**

Today I will make a plea for changing the way the condition of forgetfulness known as Alzheimer's disease is both publicly and professionally understood in our society. The fear and anxiety that Alzheimer's has engendered in our society has been linguistically encapsulated in its designation as a disease, although age associated cognitive changes such as forgetfulness are an essential aspect of growing older (Foster et al., 2008).

Medical interpretations of life events exert a powerful influence on the meaning of our experiences. Conceptions of the relationship between health and old age permeate social, cultural, and political images of elderly people. In American society, these images tend to reflect a medicalized view of elderly people. Aging is often characterized as a process of biological decline to which an increasing variety and quantity of medical resources are dedicated.

Susan Behuniak notes, in her interesting but also disturbing essay, the parallels between zombie metaphors used in popular culture and both the popular and scholarly characterizations of people living with AD:

In an age of increased sensitivity to the social and political harms caused by stereotypes, stigma, and discrimination based on disease, it is disconcerting to find that frequent and overt references to zombies lace both scholarly and popular accounts of Alzheimer's disease.... (For people living with Alzheimer's disease)...it is not the physical dying that is contagious, but the 'social death' that accompanies the stigma of the diagnosis; a stigma that spreads from the individual patient to family and caregivers. One woman with AD said: 'We've never tried to hide that I have Alzheimer's, but everyone acts like they don't want to get near because they might catch it.' The... AD epidemic constitutes a threat to the social order. One aspect of ageism is to vilify the old for economic strains that come from dependency as if they are undeserving of social concern, made no contribution to society during their lives, and are now sucking the life force out of the community (Behuniak, 2011:70; 83).

Today I would like to initiate a journey that will help lead us to a vision of the possibilities of exploring forgetfulness as we age. I hope that such a journey will challenge you to see an open horizon of meaning that has yet to be generally perceived in our society. Although we are all aware that Alzheimer's disease has a host of diverse expressions, today I will emphasize forgetting as a central theme and refer to it as forgetfulness. "Dementia" literally means away from mind, and since we are still exploring

what mind is, referring to someone as being away-from-mind makes little sense.

Questions that arise when adopting this attitude are, after all, how can we not be afraid of Alzheimer's disease? How can we not dread aging? By posing these questions I am inviting alternate ways of seeing Alzheimer's disease, as well as aging. In doing so I do not want to minimize the suffering that people may experience watching a loved one become forgetful. Nor do I want to minimize that becoming forgetful and growing old can be a painful process.

What I am saying is that we have become socialized to believe that forgetfulness and aging are largely negative phenomena. As the philosopher Henri Bergson so eloquently expressed: "The eye sees only what the mind is prepared to comprehend." Our society has a set of blinders on that negates our individual and collective ability to see the deeper meaning of Alzheimer's disease, and the deeper meanings behind the aging process.

When there is a substantial disruption in our lives such as an unforeseen injury or illness, or the death of someone close to us, we see meanings and possibilities that previously eluded us as we went about the routines of our everyday lives. Alzheimer's disease is just such a disruption. Our aging process presents just such a possibility.

We have only begun to identify the meaningful possibilities of forgetfulness and aging. Today, I hope to contribute to expanding the horizons of meaning associated with our conceptions of time and its fellow traveler, forgetfulness. I believe it is time to create a positive cultural space for people who are forgetful and for those who accompany them on their journey.

### **The Fear and Stigma of Alzheimer's Disease**

Alzheimer's disease is one of the most feared diseases associated with aging. The reconstitution of senility as Alzheimer's disease transformed the meaning of cognitive impairment associated with age from an inevitable process to a medical condition that might be delayed or avoided altogether (Fox, 1989).

When memory loss was viewed as a natural part of the aging process, any problems associated with it called for a social response, but when this loss was blamed on a disease, the needed response became clinical. Constructed in biomedical terms, AD was now a disorder that called for research, pharmaceuticals and interventions: 'With the popularization of Alzheimer's, the subjective experience of aging and of 'senility' have become increasingly horrific and monstrous; we are all afraid of losing our minds as we grow old. (Behuniak, 2011: 84).

The fear and anxiety associated with Alzheimer's disease is mainly due to the loss of the ability to function in the social world in normatively acceptable ways. This has contributed to the creation of what has been called a "malignant social psychology" (Kitwood, 1997a). This refers to a situation wherein the unintentional deprivation of the social self of the person with Alzheimer's disease can occur in many ways, including disempowerment, infantilizing, labeling, stigmatization, invalidation, and banishment, as well as negative stereotyping, to name but a few (Kitwood, 1997a; Scholl and Sabat, 2008). All of these can result in a form of excess disability resulting from an unnecessary constriction of the lives and social roles of people with Alzheimer's disease.

This life and role constriction was poignantly noted by a woman who was in the early stages of Alzheimer's disease:

That's something that people never take into consider[ation]... I mean, before when I was free to go, I'd go take a walk around the block rather than blow my stack. By the time I got back my feet hurt so that I quit worrying what I was mad about. You can't get away from everybody now. Your husband will go with you, and that doesn't do it. Your neighbors will stop and talk to you, just for a minute. Then they'll say, "Well, I'll walk around with you." And I wish I'd never told them I have it because it took away my freedom. (Female, AD) (Beard and Fox, 2008: 1514)

### **Sources of the Social Disenfranchisement of Forgetful People**

This example illustrates what can happen when one reveals to others that they have Alzheimer's disease and illustrates the "social disenfranchisement" that can happen to people living under the description of Alzheimer's disease (Beard and Fox, 2008). That is, habitual ways of being and living are limited or eliminated when individuals are deemed unable to potentially or actually function in socially appropriate ways due to cognitive impairments.

This social disenfranchisement has arisen from at least three sources: 1) in social contexts from the difficulties people with forgetfulness and their families have accepting and understanding these cognitive changes; 2) in political contexts by the demonization of Alzheimer's disease as a consequence of efforts that are part and parcel of what one observer has called the "health politics of anguish" (Butler, 1986) that characterize disease-related advocacy efforts in the U. S.; and 3) in scientific contexts where the features of people are reduced to their behavioral and biological component parts in an effort to unlock Alzheimer's complex mysteries. These social forces emphasize the interdependence of social relationships that not only bestow the status of "personhood" on others, but even define others' humanity in a web of social relationships.

In social contexts, the difficulties both people who are forgetful and their family members have accepting and understanding the cognitive changes wrought by the progression of the disease are part and parcel of the transition from previously normal experiences to what are deemed abnormal changes that interfere with a person's ability to function in accustomed ways. For example, in interactions between family members and people diagnosed with Alzheimer's disease there is often a strong

negative reaction when someone with forgetfulness can't remember his or her or our names. Names are emotionally linked with identity. They differentiate us from others. Forgetting personal names is often a shock to those in contact with forgetful people.

It has been argued that Alzheimer's disease and its symptoms have come to represent an obliteration of selfhood (Kontos, 2004), resulting in the person so afflicted being stigmatized as a member of a socially undesirable group. Previously held identities of people as autonomous and competent are often questioned by others as a result of the diagnosis, which significantly complicates everyday life and often reverses roles such as parent, nurturer, or partner:

I think the disease itself is enough [of a] problem but [also] the constrictions that [family members and doctors] place around you. You can't do this, you can't do that. You can't drive. You end up being extremely frustrated. (Male, AD)

We are treated differently obviously. We have to be because there are certain things we can't do, and they have to do them for us. [You now need to have help with *life* [original emphasis] for one thing (Male, AD).

In spite of autobiographies illustrating the experiences of people living with the disease (Davis 1989; McGowin, 1994; Rose, 1996; DeBaggio, 2003), such experiences have historically been marginalized (Mills, 1997; Usita, Hyman & Herman, 1998; Vittoria, 1998; Braudy Harris, 2002). Dominant assumptions that it was impossible to meaningfully determine the experiences of people living with Alzheimer's disease arise from the stigma of being diagnosed with the disease. As Behuniak notes:

Whether used inadvertently, as metaphor, or as a consciously chosen descriptor, the social construction of people with AD as zombies is a destructive representation...because it invites and supports the oppression of human beings by encouraging fear and disgust. An attribute of the zombie trope is that AD is viewed not primarily as a disease but a lethal threat at both the individual and social levels.... Will those with AD be sympathetically viewed as fully human, worthy of respect, and deserving of compassionate social support, or feared as already dead, lacking in dignity and a costly burden? Such fears are fanned rather than damped down by a metaphor that evokes disgust – a reaction of deep aversion that constitutes a fundamental refusal of another person's full humanity. As an object of disgust, the person with AD is viewed as a 'loathsome contaminant to the body politic' and as such becomes vulnerable to targeting and subordination (Behuniak, 2001: 85-6).

Such stigmatizing (Goffman, 1963) emerges as a result of the focus being on the disease and its manifestations, rather than the experiential aspects of living with Alzheimer's disease. The geriatrician Dr. Al Power has outlined some ways in which views of people living with Alzheimer's disease are framed, depending on our presuppositions regarding the disease. He contrasts the "Biomedical Model" of Alzheimer's disease with the "Experiential Model" and comes up with some interesting contrasts. For example, in the biomedical model the behavior of people living with AD is viewed as confused and purposeless, largely driven by disease and neurochemistry. In the experiential model behavior is viewed as attempting to cope, problem-solve, and communicate needs (Power, A., Grand Rounds, Laguna Honda Hospital, 5 August 2010).

In political contexts, the demonization of the disease as a consequence of the "health politics of anguish" has increased the public's awareness of Alzheimer's disease largely by characterizations of the negative consequences of the disease on caregivers. Such characterizations as "the never ending funeral," a "slow death of the mind,"

and “the mind robber,” have demonized Alzheimer’s as a part of efforts to focus public attention and political support to address the impact of this social and health concern (Thomas, 1983; Froelich, 1986; Cutler, 1986). These important advocacy efforts have largely been successful in increasing funding for biomedical research with the hope of finding effective treatments, and even a cure, for this dread disease (Beard, 2004b; Fox, 1989, 2000; Fox et al., 1999).

In scientific contexts, social disenfranchisement emerges when the person is reduced to their behavioral and biological component parts in an effort to unlock the disease’s extremely complex mysteries (Beard and Fox, 2008). The novelist and essayist Jonathan Franzen poignantly describes the problem with scientific reductionism in relation to his father’s diagnosis:

I can see my reluctance to apply the term Alzheimer’s to my father as a way of protecting the specificity of Earl Franzen from the generality of a nameable condition. Conditions have symptoms; symptoms point to the organic basis of everything we are. They point to the brain as meat. And, where I ought to recognize that, yes, the brain is meat, I seem instead to maintain a blind spot across which I then interpolate stories that emphasize the more soul-like aspects of the self (Franzen, 2002).

The reduction of the “soul-like” aspects of a forgetful person to quantifiable biological and behavioral features that are symptomatic of an underlying disease pathology has led to medically diagnosed people finding themselves in an interpretive dilemma. Caught between a sort of biological determinism and a desire to retain a sense of personal and social efficacy, people struggle to avoid a dramatic rupture in biography (Beard and Fox, 2008). Being perceived as somehow “compromised” leads people living with AD to express feelings of aggravation and, despite acknowledging their shortcomings, often plead not to be conflated with those shortcomings:

I'm still the same person I've always been. It's just that now I'm *me* with Alzheimer's. (Female, AD; original emphasis)

The resolution of this struggle is complicated by biological and psychological models of pathology that generally disregard the social interactions and socio-cultural contexts within which forgetfulness is manifest (Ehernberger Hamilton, 1994). The psychologists Richard Cheston and Michael Bender note in this regard:

The assumption that people with dementia are almost non-people means that it is hard to arouse practitioner interest in exploring their subjective world.... We have very little understanding of what it is like to have dementia largely because this has not seemed to be an important question to answer. In the standard paradigm, the internal world of dementia sufferers is almost irrelevant.” (Cheston and Bender , 1999: 82)

Understanding the experience of AD is complex, in that each individual is equipped with a repertoire of resources that are acquired through differentiated experiences, and these resources define one's personality and coping styles. Unfortunately, what has, until very recently, been largely left out of the discourse on AD is the experience of the individual who has forgotten.

But thinking about this in a broader context of potential meanings may help us expand our horizons of the role of medicine and science in influencing our conceptions of health, and even our notions of the variety of experiences that define our humanity as social beings living in the community of others. What we may accept as taken-for-granted may need to be challenged so that as a society we are individually and collectively

opened to understanding difference and the diversity of experience as something to be embraced rather than stigmatized.

## **Challenges to Stereotypical Notions of People Living With Alzheimer's Disease**

Counters to the stigmatizing terms representing Alzheimer's disease in popular and professional discourse have arisen from the perspectives of religious belief (Ballenger, 2006), bioethicists (Post, 1995); sociologists (Beard 2004a;), psychologists (Kitwood, 1997a; Kitwood & Bredin, 1992; Bender and Cheston, 1997; Sabat & Harre', 1992; Shabahangi & Szymkiewicz, 2008), support group facilitators (Yale & Snyder, 2002); and physicians (Whitehouse and George, 2008). These perspectives have challenged the notion that a person with Alzheimer's disease becomes a hollow shell.

They have begun to create a cultural space that emphasizes the dignity of all humans, even those severely impaired by Alzheimer's disease. The preservation of human dignity in the face of such challenges is critical, because characterizations of Alzheimer's disease that serve

political or scientific ends do not wholly represent the dimensions of the disease. As Franzen noted about his father:

Consider, too, what I believe are the last words he ever spoke to me, three months before he died. For a couple of days, I'd been visiting the nursing home for a dutiful ninety minutes and listening to his mutterings about my mother and to his affable speculations about certain tiny objects that he persisted in seeing on the sleeves of his sweater and the knees of his pants. He was no different when I dropped by on my last morning, no different when I wheeled him back to his room and told him I was heading out of town. But then he raised his face toward mine and – again, out of nowhere, his voice was clear and strong – he said, “Thank you for coming. I appreciate your taking the time to see me.” Set phrases of courtesy? A window on his fundamental self? I seem to have little choice about which version to believe (Franzen, 2002).

Another important trend that has the potential to counter the dehumanizing tendencies of the demonization of Alzheimer's disease is, ironically, fueled by medical researchers in their efforts to identify its “preclinical” indicators and predictors. This has largely occurred under the assumption that for treatments to be effective, they must be introduced earlier in its course than has heretofore occurred. The rise of diagnostic

categories such as *mild cognitive impairment* is the most salient indicator of this effort (Peterson, 2004).

A consequence of this trend is people who are diagnosed with memory problems but who retain a substantial degree of their cognitive and functional abilities. We are moving into a period where people living with the disease are beginning to be incorporated into the advocacy efforts that are part and parcel of the “Alzheimer’s culture” in the United States. This signals the beginning of a new public face for Alzheimer’s disease that has not previously been readily evident—the face of the person so diagnosed, her or himself.

This might heighten the potential for a reorganization of the social typing of people with Alzheimer’s to be more inclusive of the notion of personhood. It might also temper the demonization of the disease so we don’t lose sight of our social responsibility to care for people with Alzheimer’s disease in ways that recognize and preserve their dignity as human beings. Such efforts are already underway as models of person-centered, relationship-centered, or family-centered care begin to emerge. The expansion of the clinical gaze has implications for caregiving, if for no

other reason than we will have more and more people labeled with the diagnosis for longer periods of their life than ever before. This raises the important question of what does the forgetful person bring to our lives? This question is often put aside in the attempt to understand the disease at the expense of the person who has the disease.

### **Towards Reconceptualization: Forgetfulness and Alzheimer's Disease as Our Teacher**

If we approach forgetfulness from an open, radically present perspective we can begin to see Alzheimer's as more than a symptom of disease, but rather as a natural process which needs to be understood *in its unfolding*. We must not lose sight of alternative ways of characterizing forgetfulness and Alzheimer's that deemphasize notions of pathology and demonization, and instead see forgetfulness as a phenomenon that has purpose and meaning. Disease is the way in which the body, with its unconscious processes, is attempting to express itself. In fearing and resisting this, we do not allow the body to fully reveal itself to us.

This attitudinal expansion encompasses a number of reconceptualizations. First, rather than simply a disease, the embodied phenomenon of Alzheimer's has purpose and meaning. The label of

Alzheimer's disease is an expression of social control and oppression, while at the same time can be a signifier of empowerment for individuals trying to cope with forgetfulness. The label creates an "identity irony" that can simultaneously rob people of their uniqueness while at the same time solidify group identity among people sharing common circumstances. Second, rather than people simply in need of our care, people with forgetfulness can teach us about life and living. Third, rather than a burden, people with forgetfulness offer us an opportunity to deepen ourselves—to go deeper into our souls.

This expansion of attitude demands more than a slight adjustment in how we perceive the world; it requires a fundamental change in the way we look at ourselves and the world we inhabit. What is required is, foremost, a curiosity, an openness to all that **is**. An attitude of "not-knowing" allows that which manifests itself in front of or within us to present itself in the way it **is**, not in the way we already know it. This attitude demands a willingness to live in the question, to appreciate the mystery that envelops us (Shabahangi & Szymkiewicz, 2008).

Our belief that we can control and direct our lives is only one possible

truth. It is this belief, lying at the heart of the scientific paradigm that is the foundation of the hope of medical science to find effective treatments for Alzheimer's. While belief in this truth is robust in American society, it would be foolish to only focus social attitudes and efforts in this one direction. This is because the fruits of such an approach are elusive and difficult to obtain, and no clear timetable can be set for harvesting the fruits of this belief. In the meantime as the population ages, the phenomenon of forgetfulness will become ever more pervasive.

Another possibility is the belief that places our fate in the hands of some other force, whether it is called God, Nature, or some other concept or idea. From this point of view, events and relationships occur with meaning—that is, we ascribe meaning to them. As such, what happens to us, events we often categorize as good or bad are part of our life-path -- our destiny. The core issue is our attitude towards the difficulties and hardships we encounter in life: do we see them as unnecessary, as unneeded, or do we see them as exactly that pain we need to become more complete and deeper as human beings?

Biomedicine seeks symptom removal or disease cure as primary

goals. While this is a valid and important approach, we can, alongside this, also seek for a deeper meaning of the symptom and/or condition. In the context of Alzheimer's, we try to understand forgetfulness as having a larger meaning or wisdom. This is why in everyday life I suggest moving away from using the label "dementia," for it stigmatizes and demeans the forgetful person. Although we are aware that Alzheimer's disease has a host of diverse expressions, I emphasize forgetting as a central theme and call this phenomenon simply Forgetfulness.

A person who experiences Forgetfulness forgets what you and I may have no difficulty remembering: our name, address, age, profession, and the like. Remembering such facts is certainly convenient. What's more, a keen memory is often rewarded with appreciation, accolades, even money. Forgetting, in contrast, is seen as a weakness. Why? What is so undesirable about forgetting? Perhaps it is we who are forgetting that the values we tacitly accept as "givens" are part of the paradigm we are born into, part of the narrative we tell ourselves about what is of value in life. In line with our striving for gain, our society's conception of Alzheimer's disease primarily represents a metaphor for loss. This definition reveals a disturbing truth about the medical interpretation of Alzheimer's disease: we

cannot gain anything from it. Having Alzheimer's disease is tantamount to the disintegration of the self.

### **Expanding Our Conceptions of Identity**

The question of what is undesirable about forgetting can also be answered in part by one of the above-noted social trends I have identified that contribute to the demonization of Alzheimer's disease – difficulties forgetful people and family members have in understanding and accepting the changes in their own and their loved one's identity wrought by forgetfulness. But what is this phenomenon called identity? It's who we are, we say. And we know how rich and complex we are. When asked to identify ourselves, we often say, I am a man/woman, this young or old, live here or there, have this job, like this or that food, am with this or that person. Yet we also know that these describe only a small part of who we are. When we are in an intimate relationship, we speak less of these demographic facts and focus more on what is not as obvious: our dreams, desires, ambitions, vulnerabilities, and hopes.

These less obvious characteristics also form part of who we are -- the most important part, many would say. Thus, we see at least two aspects of

how we define our individuality: a public, objective way and a private, subjective way. As the sociologist Georg Simmel noted: "Although this individuality cannot, on principle, be identified by any name, it surrounds our perceptible reality as if traced in ideal lines. It is supplemented by the other's view of us, which results in something that we are never purely and wholly. It is impossible for us to see anything but juxtaposed fragments, which nevertheless are all that really exist" (Simmel, 1971: 11).

This is not the place to enter into the rich topic of exploring the nature of human identity. Rather, I simply want to point out how malleable this concept of identity is and how it may only partially be related to our ability to remember. I suggest here that certain parts of our identity might even benefit from forgetting. Forgetting may allow for other, deeper parts of our identity to come to the foreground, parts our remembering keeps forgetting. Thus the stories behind identity, behind remembering and forgetting, are not fixed but fluid; they depend much on our vantage point, our priorities, and our lives.

### **Appreciating Multiple Meanings of Forgetfulness**

I think it is the time to strive to counter the fear that forgetfulness

engenders in many people. We become fearful that we could lose the minds of our parents, relatives, and partners while their bodies are still with us. Moreover, we are jolted by the same fears every time we can't find our keys or remember the name of a friend. We seem to take it for granted that a meaningful life is possible only when one is blessed with excellent memory and cognitive abilities, a byproduct of what one observer has called our "hypercognitive" society (Post, 2000). From this point of view, life makes little sense for the ever-increasing numbers of people around the world afflicted with Forgetfulness.

I think it is time to shift this attitude from a narrow, fearful one, to a more expansive, inclusive one. The physicist Richard Feynman observed: "You can know the name of a bird in all the languages of the world, but when you are finished, you'll know absolutely nothing whatsoever about the bird." I invite the exploration of new ways of understanding the people for whom we care and how we might prepare for our own Forgetfulness. The search for the deeper meanings of forgetfulness can begin with the asking of two basic existential questions: How do we understand what happens to those with symptoms of Forgetfulness? And how do we understand what happens to those who care for them? As the neuropsychologist Steven

Sabat notes:

What is required to make... improvements involve a journey far beyond the goal of palliative care, a journey in which caregivers of all types seek out and support the sundry aspects of Alzheimer's sufferers' remaining abilities – indeed, their very humanity.... This rather “simple” recognition changes the social dynamics because in order to support and sustain the humanity of the afflicted, caregivers must delve more deeply into and develop further their own humanity (Sabat, 2001: 340).

A nurse employed at the Intensive Care Unit of a large European hospital told this story: During the usual morning rounds, a group of doctors, nurses, and students stood around the bed of a young boy in a coma. The doctor looked at the boy's chart and announced, “Well, nothing will come out of this one!” A moment later, the nurse saw a tear fall from the boy's eye. Others saw it too and they all stood in shocked silence. Later, the doctor said, “From now on nobody talks about the patients as if they were not present, no matter how unconscious they seem. We may discuss our opinions elsewhere. Perhaps that tear was just an automatic reflex, but the truth is — we don't know. Let's take it as a lesson in humility: what happens between body and soul is a complete mystery”

(Shabahangi & Szymkiewicz, 2008).

Albert Einstein once observed: "The most beautiful thing we can experience is the mysterious. It is the source of all true art and science." With elderly people, we are confronted with a mysterious connection between body and soul again and again. We so often experience deep moments of closeness with people who are supposedly not "here" anymore, who have problems with the simplest tasks of daily living. I believe it is time for an attitudinal expansion in our society in which we start to perceive contact with forgetful elderly people as an enriching journey for both sides. We can draw from both modern science and spiritual traditions, all the better to understand this journey of forgetfulness and to make it more meaningful.

What I am suggesting is that we need to begin to expand the horizons of what forgetfulness can mean beyond loss - which has yet to be commonly sought in our society. Such an open horizon challenges our taken for granted conceptions of forgetfulness, Alzheimer's disease, memory, personhood, aging and time. Our understanding of personal and social growth is embedded within a dominant framework of striving for more

– more outcomes, more memory, more years to live. From this notion of gain, it is fair to assert that loss is anything that prevents us from reaching outcomes – from accomplishing, from being engaged in work, from remaining youthful achievers. Forgetfulness falls on the loss side of this equation.

Alzheimer's disease is predominantly defined by its symptoms interpreted as the decline and final loss of memory and other cognitive abilities and the pathological traces left on the brain. Many of us might place most, if not all, of our hopes on finding a treatment and ultimately a cure for Alzheimer's disease. But the fruits of such an approach are elusive and difficult to obtain, and no clear timetable can be set for harvesting the fruits of this hope.

What if, in spite of all our best efforts, these goals remain elusive into the foreseeable future? How do we care and support people who are different from our expectations of what is normal, and what does that mean in terms of a philosophy of care? Do we treat them as diseased? Would that imply a certain derogatory stance toward the people for whom we care about? Or do we approach forgetful people with an attitude of respect,

kindness, and acceptance of who they are in their new realities?

I invite you to think for a moment: how does your attitude change if you know you are approaching someone who you think is diseased, cognitively impaired? The psychologist and philosopher William James once said that “The greatest discovery of my generation is that a human being can alter his life by altering his attitudes.” We are very sensitive people and can sense the attitude behind those who interact with us – whether we are forgetful or not. A central question thus becomes: How would you like to be approached if you were forgetful? What would you like the eyes to see that look at you?

Some argue that even if substantial therapeutic advances will be available in the near future, they may not be robust enough to slow the progression of forgetfulness among the many people who are experiencing cognitive changes as they age. The unfortunate by-product of the belief in the discovery for a cure is that we have not begun thinking about ways that our society can see forgetfulness as something more than a demon to be exorcised by a hoped-for medical treatment.

Yet, rather than a debilitating disease that leaves those afflicted in a sad and lamentable state of existence, Alzheimer's disease may be another, altered state of consciousness, that can contribute to deepening our sense of who we are as humans linked to one another in fundamental ways. This requires, foremost, an openness to all that is, to look at forgetfulness as it is, not in the way we believe we know it.

By engaging people to think about forgetfulness in the context of a wider horizon of possibilities, social change is possible. We may reduce the social stigma that people labeled with Alzheimer's disease experience. In that way we may not only accept and help others who are forgetful, but we may also be better prepared for our own inevitable forgetfulness. I believe it is time for society to think about and act toward forgetfulness and forgetful people in ways that may be currently unthinkable, but perhaps will become a reality in the future. The artist M. C. Escher once quipped: "Only those who attempt the absurd will achieve the impossible. I think it's in my basement – let me go upstairs and check." Instead of being a crisis, forgetfulness may one day soon present an opportunity for knowing and deepening who we are.

Similarly, the issue of forgetfulness relates closely to the process of aging all of us experience. To live is to age, to age is to live. We cannot have it otherwise. To fear aging is to fear life itself. Yet, so many of us feel burdened by the many negative associations connected to aging and growing older. The decline metaphors we relate to aging, however, are based on some normative view of optimal health and functioning, a view that marginalizes important dimensions of life only made possible through time and experience.

As with our needed attitudinal change toward forgetfulness, it is crucial that we change our perception of aging to one that understands its importance for deepening our maturation and eldership. Such eldership is of vital importance as we face the many challenges that confront us today. It is from the perspective of the elder that we can ground our hope for transformation and change of our behavior toward our planet and fellow human beings. Such behavior and attitude needs to be based on an understanding of how deeply planet and people are interconnected, how we inhabit a living universe on whose health our own is dependent. This knowledge forms part of the wisdom our elders hold, and which the world's societies need to implement more urgently than ever.

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