

**REDEFINING DEMENTIA:
BETWEEN THE WORLD OF FORGETTING
AND REMEMBERING**

Nader Robert Shabahangi, Ph.D.

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More and more we hear of dementia and Alzheimer's in the news. Talk shows abound with jokes about the early signs of dementia. Behind the humor often lies a growing fear that one day we may belong to this group of "demented." No surprise, then, that the race for a pharmacological cure to this "disease" is at full speed.

As a developer of assisted living facilities in California and a psychotherapist with over a decade of experience working with the elderly—specifically with those who have been diagnosed with dementia—I have an understanding of the meaning of "loss" and "forgetting" different from the common point of view. Rather than a debilitating disease that leaves those afflicted in a sad and lamentable state of existence, dementia may be another, altered state of consciousness, as valuable and important as our everyday or "normal" way of being.

This is not to diminish the pain and hardship both caregivers and those afflicted with forgetfulness can suffer. In fact, this proposed alternative view is meant to lessen the suffering and fear often associated with the symptoms described as dementia. It is also meant to broaden and deepen our understanding of human nature.

In beginning to understand the alternative view of dementia, it is important to note that in the mainstream the "twenty-four-seven" work ethic defines our values, connoting vitality, a sense of direction, and a commitment to success. Industrialized societies' desire for measurements, outcomes, and a robust bottom line reinforces our achievement mentality. Indeed, as a society, we expect an almost unconditional dedication to exceeding our own benchmarks.

Our conception of personal and societal growth is embedded within a dominant framework: striving for more — whether more memory, more proven outcomes, or more years to live — represent pleasure and gain.

From this notion of gain, it is fair to assert that loss is anything that prevents us from accomplishing, from being engaged in work, from reaching outcomes, and from remaining youthful achievers. This worldview suggests that evident loss inhibits progress, blocking the progression toward desired outcomes. Finding value in apparent loss contradicts our dominant paradigm, in which our urge for a perennial increase of gigabytes becomes a metaphor for our

anxious quest for prolonged youth, extended life-expectancy, optimal health, and first rate memory.

The world of achievers and “gain” is the world of consensus reality. In it, we embrace everyday reality, including our achievement mentality, attributing value and meaning to it. Anything preventing us from fitting into consensus reality threatens the status quo and is often marginalized.

In fearing and resisting dementia, we do not allow it to fully reveal itself to us. On the contrary, we shut out those we label demented. What is the unintended consequence of this attitude? While we believe that dementia propagates loss, we can benefit from understanding that the loss actually resides in not allowing ourselves as individuals and as a society to reflect on what can be gained from the experience of dementia. For if we pause long enough to understand the phenomenon of dementia—not just its biological causes and concomitant physical manifestations—we will discover something essentially human about those who experience this condition. This discovery may allow for a reconnection to our own essence. In so doing, we give ourselves an opportunity to contact deeper layers of who we are, whether we belong to the group afflicted with dementia, or to the group of caregivers who take care of them.

Clearly, a question begs for attention: *If achievement is the equivalent of gain, what is equated with loss?*

Dementia, a label that refers to a group of symptoms, including forgetfulness, confusion, and disorientation, impacts aging adults and manifests itself as Alzheimer’s disease, among other conditions. In line with our dominant strive for gain, our society’s conception of dementia represents a metaphor for loss. With few exceptions, medicine and society have come to interpret, view, and treat dementia as such. From the medical point of view nothing within dementia, this *debilitating disease for which there is still no cure*, can be rescued as *gain*.

The medical community defines dementia as the significant loss of intellectual abilities, such as memory capacity, severe enough to interfere with social or occupational functioning. This definition reveals a deep truth about the medical interpretation of dementia: We cannot gain anything from it. Dementia is tantamount to the disintegration of the self and the irreversible evanescence of directed action—that is, *action with a purpose*.

In stating that dementia usurps our faculties, our capacity for carrying out social and occupational functions,

this dominant paradigm carries with it an implicit judgment: People with dementia can no longer contribute to society. That is, these individuals cannot contribute anything because, according to the medical interpretation of dementia, society has de facto stripped them of value and meaning. The doors are shut to any exploration of alternative views and understandings of dementia.

Comparative research on the cultural influence of values and perceptions in understanding dementia among European Americans and ethnic minorities in the U.S. shows differences among them.¹ European American caregivers perceive dementia as an illness to a greater extent than the ethnic minorities included in this research project. In this study, European Americans typically described in pathological, biomedical terms what was afflicting those for whom they cared. Conversely, Chinese American caregivers were more likely to interpret dementia as a consequence of aging, while Latino and African American interviewees referred to dementia as the result of a person having lived a difficult life. This study indicates that European Americans see those with dementia as sick people, whereas Chinese Americans, Latinos, and African Americans understand dementia as being tied to the passage of time and/or the accumulation of emotions or suffering. Chinese Americans, Latinos, and African Americans find meaning in dementia and do not rely on medical interpretations to the extent that European Americans do.

Regarding the pathological explanation of dementia, it is important to note that the concept of pathology has undergone major transformations. Pathology originally referred to the study (*logos*) of suffering, feelings, and emotions (*pathos*). Over the last hundred years, pathology has come to refer to the study of disease. In other words, suffering, feelings, and emotions have turned into disease. Seen as a disease, dementia and other mental illnesses are explained as “the consequences of a breakdown of the homeostatic control mechanisms.”² This impersonal and mechanistic explanation replaced the intrinsically human experience of the continuum of life, a continuum that included emotions, feelings, and suffering.³ Consequently, we have begun to increasingly fear suffering.

Furthermore, this limited interpretation of dementia blocks any other interpretation, preventing a search for any possible meaning. In its conclusive explanation, the medical community turns dementia into an object rather than a subject of study.

In the meantime, demographic trends in the United States suggest that the nation's elderly population will soon reach unprecedented proportions. Seventy-seven million baby boomers are driving this trend, and by 2006 the oldest of this group will turn 60.⁴

With such large numbers of people aging at the same time, is it fair to assert and expect that many of them will be lost to the current notion of dementia. To counter the medical and public consensus point of view of dementia, we can help create a shift in thinking that returns the person with dementia to a place in which s/he regains value as an individual and thus for whom dignity is preserved. This shift also invites us to learn from an alternate wisdom that surfaces in dementia, a wisdom that can have positive implications for each of us and for society as a whole.

Given our cultural understanding of loss associated with dementia, how do we respond to it?

Typically, as individuals and as a society, we fear and resist it. Imagine a child walking slowly through a dining room toward a cup of milk, but pausing to explore and discover objects lying on the dining room table and pictures on the walls, perhaps forgetting or delaying her goal of reaching her milk. We might notice that this child's experience was enriched by the mere fact of observing, by not marginalizing what surrounds her just because her ultimate goal was to reach her milk.

People with dementia act in similar ways; they inhabit dreamland, and are not focused on consensus reality alone. Thus, their actions, often unexpected, are not socially accepted. These actions are not necessarily directed toward a clear outcome—and even if they are, they may shift halfway through the action. Dreamland allows for actions to shift, feelings to unfold, and fantasies to emerge and develop. Conversely, in our consensus reality world we often marginalize fantasies, objects, subjects, thoughts, and emotions as we diligently move toward the achievement of our planned goals. This is how we measure success; this is how we perceive gain.

Can we find meaning in dementia by turning the gain-loss paradigm on its head and by recognizing that there lie hidden riches if we look at dementia through a different prism, beyond loss and gain? That is, if we open ourselves to understanding dementia in a new light we may find that we 'gain' insight into its "otherness." This otherness is grounded in the realm of imagination and in a human thirst to be creative. It is an attitude that allows life to be lived in amazingly diverse and rich ways that defy the normal or consensual path of life. This otherness allows for the road

less traveled, allows us to live our life in the way important to us, not necessarily in the way prescribed for us. Looking at dementia as an expression of this otherness may allow us to reassess the meaning of our consensus-reality-driven lives.

In *Believing in Mind*, Seng Ts'an, who lived in China in the sixth century, said:

*The great Way has no impediments;
It does not pick or choose.
When you abandon attachment and aversion
You see it plainly.
Make a thousandth of an inch distinction,
Heaven and earth swing apart.*

Is remembering where we put the keys what matters most in life? Is ensuring that the tasks outlined in our endless lists are checked off what defines our human essence? Does checking off chores on a list or achieving material gains while neglecting our emotions, the people we love, our spontaneous observations and fantasies, really increase our quality of life? We inhabit a complex and structured world, one that does not readily welcome unstructured or disorderly action. We value planning and effective follow through. In our dualistic world, dreamlike action is the opposite of consensus reality.

Using Seng Ts'an's perspective, it behooves us to pause and reflect on the unbound altered state of those with dementia. If we were to move "*a thousandth of an inch*" away from the dualistic core of our prevailing definition of dementia, we might find that those with dementia don't lack in expressing their sensitivities, emotions, and human essence as they look at the world from a different angle. While moving at their own pace, they do what we, in our twenty-four-seven world, have often forgotten to do: They tune in to their feelings, expressing them through verbal and non-verbal means, observing objects and circumstances in their own ways. We, on the other hand, often ignore feelings and marginalize objects and circumstances that do not fit into our goal-focused world. Too often we are fully engaged in our consensus reality, in our world of accomplishments and gains. The demented, much like the little girl moving through the living room towards her glass of milk, have their way of going about their tasks. For them the journey matters as much as, if not more than, their final destination.

Accounts of caregivers and spouses of people with dementia tell us that their loved ones change as a result of this condition. They also tell us that their loved ones are

still “there,” that a real person still lives inside. Perhaps people with dementia symptoms are not present in the way that our consensus reality expects them to be, but they are there in their own way. Because the demented live in altered states of consciousness, their behaviors are typically non-linear, and their actions are non-directed; they often inhabit dreamland and move fluidly through it.

The story of an Australian psychiatrist illustrates this point further. One day he visited his parents—diagnosed as “demented”—at their house, where he spent some time exchanging basic pleasantries with them. As he was driving away he sensed an urge to tell his parents about his relationship with a woman he had just met and the difficulties he was having with the relationship. He turned his car around, drove back, and reentered their house. Both parents were surprised by their son’s quick return. Immediately, he began to tell his parents the story of his new girlfriend, that it had been difficult to communicate with her and that he was confused about what to do next. The parents listened intently to their son’s story. After he’d finished, the father addressed his son in a reflective tone, saying that it would be best to tell his girlfriend his concerns and to have her do the same. This way they would gain clarity and openness and an understanding about each other’s needs. The mother nodded in approval, adding that it would be wise to exchange these concerns as openly as possible early in the relationship so there would be no false expectations.

The psychiatrist, suddenly aware that he was supposedly talking to demented people, listened with astonishment to his parents’ astute and wise suggestions. After he left his parents that night, he remained puzzled by their clarity and wondered to what a degree his attitude towards them influenced their behavior toward him. Was it his momentary openness to their world, his trust in their ability to “know” on a different level, that allowed them to connect to their son? Or was it just a chance encounter where, as the medical point of view would have it, the veil of the ‘disease’ had lifted for a moment?

The medical definition of dementia does not allow for any other possibility than the one it itself proposes: The person with dementia is “less than normal,” and hence nothing can be gained or learned from demented people. This closed-minded definition does not allow for other possibilities and attitudes. In contrast, if we try to understand dementia from a different point of view, we will observe that as the demented forget and enter dreamland, they can allow us to remember and capture that which is

essential: to appreciate them for who they are and for what they show us from their place of forgetfulness. That is, if we do not make their dreamland a disease, make their condition wrong, they can give us a chance to search for a deeper understanding of who we are, for our essential humanity. People with forgetfulness symptoms can allow us to be with what frightens many of us, namely staying open to the unknown, staying open to the flow and the unpredictable process of life.

What is called dementia can be understood as an invitation to remember something we may have forgotten in our hurried lives. Those “suffering” from dementia—through their very forgetting—can remind us of the rich and complex essence of our humanity, an essence at least as much about being as about doing, as much about wonder as about knowing, as much about forgetting as about remembering.

¹ P. Dilworth-Anderson and B. E. Gibson, *The Cultural Influence of Values, Norms, Meaning, and Perceptions in Understanding Dementia in Ethnic Minorities*. *Alzheimer Disease and Associated Disorders*. Vol. 16, Suppl. 2, pp. S56-S63.

² S. L. Robbins, R. S. Cotran, and V. Kumar, *Pathologic Basis of Disease* (W. B. Saunders: 1984) 1.

³ Robert Nader. Dissertation. Beyond Human Suffering: Money, Power and the Image of the Human Being in Late 20th Century Psychotherapeutics. Stanford University, September 1994.

⁴ Seventy-seven million baby boomers were born in the U.S. between 1946 and 1964. The Federal Interagency Forum on Aging-Related Statistics estimates that by the year 2030, 20 percent of the U.S. population will be 65 years of age and older, compared to 13 percent in 2000, and just 4 percent in 1900.