

More and more we hear of Dementia and Alzheimer's in the news. Talk shows abound with jokes about the early signs of forgetfulness. 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.

We 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 forgetfulness symptoms. 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

Deeper into the Soul – continued

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 Forgetfulness. For if we pause long enough to understand this phenomenon—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 Forgetfulness, 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 Forgetfulness as such. From the medical point of view, nothing within this condition,

Deeper into the Soul – continued

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: We cannot gain anything from it. It is tantamount to the disintegration of the self and the irreversible evanescence of directed action—that is, *action with a purpose*.

In stating that Forgetfulness usurps our faculties, our capacity for carrying out social and occupational functions, this dominant paradigm carries with it an implicit judgment: People with Forgetfulness can no longer contribute to society. 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 this condition.

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. European American caregivers perceive Forgetfulness 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 Forgetfulness 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 suggests that European Americans see those with Forgetfulness as sick people, whereas Chinese Americans, Latinos, and African Americans understand this condition 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 Forgetfulness and

Deeper into the Soul – continued

do not rely on medical interpretations to the extent that European-Americans do.

Regarding the pathological explanation of Forgetfulness, 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.” This impersonal and mechanistic explanation replaced the intrinsically human experience of the continuum of life, a continuum that included emotions, feelings, and suffering. Consequently, we have begun increasingly to 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 Forgetfulness into an object rather than a subject of study.

In the meantime, demographic trends suggest that the elderly population will soon reach unprecedented proportions. With a multitude of people aging at the same time, is it fair to expect that many of them will be lost to the current notion of Dementia. To counter the medical and public consensus point of view, we can help create a shift in thinking that returns the person with Forgetfulness 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 Forgetfulness, a wisdom that can have positive implications for each of us and for society as a whole.

In addition to the anxiety stirred by the medical understanding of Forgetfulness, it evokes another fear, deeply rooted in our Western

Deeper into the Soul – continued

values and lifestyle. It is the fear of being dependent. So much effort we put into proving our individual abilities, setting boundaries, taking care of ourselves, learning to be self-sufficient physically, financially, emotionally – how can we make space for the experience of being dependent on the other? How can we learn to rely on somebody else's care, good will, awareness without betraying our empowerment path that we proudly walked within our individualistic society? Is there another way of defining this situation, different than feeling like a burden?

Thus, Forgetfulness creates a new cultural challenge: how to integrate individualistic achievements of the past generations with the deep recognition of our basic interconnectedness.

Another moments of panic come when we think that - while demented – our Psyche will not be treated with respect. If the inner reality of a person with Forgetfulness is judged as less important, or not important at all, how can we expect that it will get the respectful treatment? If we are no longer productive and effective, who will pay attention to our Soul meandering between the world of remembering and the world of forgetting?

Given our cultural understanding of 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 Forgetfulness 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

Deeper into the Soul – continued

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 Forgetfulness 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 Forgetfulness 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 forgetfulness symptoms 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 Forgetfulness. 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 forgetfulness symptoms 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 Forgetfulness 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 forgetfulness symptoms are not present in the way that our consensus reality expects them to be, but they are there in their own way. Because they 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.

Deeper into the Soul – continued

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.

He told his parents about 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 attentively 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 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, which allowed them to connect to their son? Or was it just a chance encounter where, as the medicos would have it, the veil of the ‘disease’ had lifted for a moment?

The medical definition of Forgetfulness does not allow for any other possibility than the one it itself proposes: The person with Forgetfulness 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 it from a different point of view, we

Deeper into the Soul – continued

will observe that as people 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 call Dementia can be understood as an invitation to remember something we may have forgotten in our hurried lives. Those “suffering” from Forgetfulness—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.

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This book is meant as a practical guide for people who work and live with relatives or residents with symptoms of forgetfulness. We offer tips for dealing with aggression and wandering, but we also explore a new way of understanding the people for whom we care. In search of meaning, we ask the basic existential questions: What happens to those afflicted with Dementia? And to those of us who care for them?

A nurse employed at the Intensive Care Unit of a large European hospital told us this story:

During the usual morning rounds, a group of doctor, 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.

Deeper into the Soul – continued

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.”

With the elderly, we are confronted with this mystery again and again. We experience deep moments of closeness with people who are supposedly not ‘here’ anymore, who have problems with the simplest tasks of daily living.

In this book we invite you to see contact with the forgetful elderly as an enriching journey for both sides. We draw from both modern science and spiritual traditions, all the better to understand this journey of forgetfulness, and to make it more meaningful.

Four characters will guide us on this journey. They offer different perspectives and have different types of knowledge to share. We see all these perspectives as important and valid. For many of us, contact with forgetfulness symptoms in the elderly evoke different emotions, as represented by the characters.

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In this book we strive to counter the fear that Alzheimer’s and other forms of Dementia engender in many people. So many of us are afraid that we could lose the minds of our parents, relatives, and partners while their bodies are still with us. And we are jolted by similar 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. From this point of view, life makes little sense for the four million Americans and countless others around the world afflicted with Alzheimer’s disease.

We would like to invite you to shift this attitude got them to where they are.

Deeper into the Soul – continued