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My Mother is Fading Away

"WHO CALLS YOU AT THIS TIME EVERY WEEK?" my mother unfailingly asks every Saturday when I answer her FaceTime call (made with the assistance of her caregiver). She still keeps track of the times for her weekly calls but has no clue what has transpired over the past week. She turns to her caregiver to ask, "What did I do today?" Sometimes she dials my landline five minutes later, having forgotten that she already completed the "call son" item on today's to-do list. More recently, she often wonders "Was there something I was supposed to tell you?" One week she worried she had forgotten to call me for my birthday which had been over a month ago.

Philosophers have opined that our fear of mortality is the driving force in our lives. But aren't there fates worse than death? Consider Alzheimer's Disease in which we lose much of our core 'selves' while still alive. Alzheimer's is only one type of dementia but it's the most common form. According to the Alzheimer's Association, 10.7 % of Americans over 65 are afflicted with the disease. After age 65, the number of people living with Alzheimer's doubles every 5 years (per the CDC). Our "self" is eliminated by death, but Alzheimer's starts erasing that self while we still dwell among the living. It assails not only memory, but also judgment, abstract reasoning, attention, ability to communicate, social functioning, impulse control, perception, the ability to take initiative, personality and more.

It is horrifying to realize that this process can begin while one is still able to observe the metamorphosis from sentient, intelligent individual to a caricature of oneself, incapable of a rational, coherent discussion or of contributing to the world in a meaningful way. The grief we experience as our loved ones drown in the murky depths of Alzheimer's is unending and unrelenting. Unlike death, there is no specific date on which the loss occurs. It confronts you day after grinding day.

As we age, we all experience some difficulty finding a word now and then or recalling an acquaintance's name. How do we know when it's gone beyond normal aging? Should we go to a Memory Center for a half-day or more of neuropsychological, neurological, psychiatric, and geriatric exams along with brain imaging and lab testing? What's the benefit? Perhaps we'll get lucky, and a reversible cause of memory problems will be identified. Perhaps a medication is the culprit and could be changed, or an underlying medical condition such as hypothyroidism or a vitamin deficiency could be treated. Assessment could reveal that the failing cognitive functioning is due to a dementia other than Alzheimer's. Vascular or Lewy body or frontotemporal dementia, for example, have different causes, but also ultimately will lead to advancing cognitive losses. But realistically, if one is over 60, has the classic signs of Alzheimer's and these signs are clearly progressing, then expecting a reversal of course unfortunately probably belongs to the realm of wishful thinking and fantasy. Is it beneficial to establish the diagnosis? Well, the Memory Center professionals would surely point out it allows one to prepare for the future and get one's affairs in order by making a will and doing other financial planning, considering future supportive care needs, appointing a medical guardian,

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etc. But the touted benefits pale in comparison with the shock and dread of receiving the diagnosis and the longing to avoid its devastating consequences.

A diagnosis also does allow one to access available treatments. Acetylcholinesterase inhibitors such as donepezil (Aricept) or the NMDA glutamate receptor blocker- memantine (Namenda) may offer some promise of slowing the progress, but the clinical impact is extremely limited at best. Newer options such as Aduhelm which directly target amyloid plaques in the brain tantalize us with the promise of reversing the underlying pathology, but, again, the actual clinical impact is underwhelming to say the least. Unfortunately, it also raises the questions as to whether amyloid plaque accumulation is, in fact, the primary pathology or just a secondary artifact.

On the other hand, studies in mice suggest that promoting gamma brain wave activity in the brain by listening to a 40 Hz sound or being exposed to a 40 Hz blinking light may stimulate glia—the brain’s cleaning cells --to clear the plaque, which may indeed be beneficial—at least for mice. So, there may be hope for a cure, though it is still a rather elusive and distant one as of the moment.

The best way to prevent Alzheimer’s Disease? Don’t get old, as age is the main risk factor. Good luck with that. Genes may play a role, but, likewise, there’s not much we can do about that. On the other hand, the same healthy lifestyle approaches that can protect the heart from the slings and arrows of aging appear to partially shield the brain. There’s no doubt that we’re generally better off treating high blood pressure, getting regular exercise, eating a healthy (Mediterranean) diet, engaging the brain, getting adequate sleep, and not smoking. Such general advice, while valid, simultaneously delivers the subtle, discouraging message that we have no specific, highly effective cure or preventative method.

Eventually, only the remote past—or at least fragments of it-- and that which was memorized long ago stay alive in the brains of those suffering from Alzheimer’s Disease. My mother can still enjoy dancing while singing every word of “Down by The Old Mill Stream” and recite by heart Leigh Hunt’s poem “Abou Ben Adhem,” which she memorized in her adolescence. She remembers playing ping pong with her cousin Ronnie. But she didn’t recall my visit from abroad the prior week. Old habits remain ingrained in the mind so an individual might get dressed in the middle of the night and wander off in the misguided belief they are heading for work just as they did on countless days in the past.

My mother trained to be a teacher at Montclair State Teacher’s College in New Jersey. Now she can barely carry on a conversation. She had also studied bookkeeping and, for a time, worked as a bookkeeper for the kibbutz on which she lives in Israel. These days the only sum she manages to recall (by constantly repeating it) is the total number of her grandchildren and great-grandchildren whom she loves so profoundly. She always loved reading novels. Now she still regularly takes out books from the kibbutz library, but when asked what she is reading and what it’s about, she is at a complete loss.

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So how could one respond to this terrible diagnosis which threatens the demise of one's very self? Of course, one may be struck by waves of fear, numbness and despair. Questioning whether life is worth living any longer is bound to occur for many. In her book "In Love: A Memoir of Love and Loss," Amy Bloom describes her husband's decision to travel to Switzerland where euthanasia is an available option. In the movie "Still Alice" based on the novel written by neuroscientist Lisa Genova, the protagonist unsuccessfully attempts to end her life when her diminishing capacities become devastatingly obvious. When my mother witnessed her own mother's dementia deteriorate to the point she required nursing home placement, she often remarked "If I ever get like that, just shoot me." Yet, now when she is, in fact "like that," she only issues mild and sporadic complaints that "my memory isn't so good anymore." Sometimes she follows that up with the comment that once upon a time she had been a member of Newark's Weequahic High School's Honor Society where she had met my father. My father, who also held strong views about the need to recognize when life is no longer worth clinging to, seemed to undergo a similar change of heart. He certainly never intimated that he thought my mother would be better off dead. In old age, he focused on finding reasons to live rather than pining for death. In any case, for those who truly prefer the euthanasia route, there is a narrow "window of opportunity" between the point one's condition has deteriorated enough that living no longer seems worthwhile and the point when one can no longer make that decision due to gross mental incompetence.

For the vast majority of people who opt to carry on (or do so by default) after learning their brain has begun to betray them, it may facilitate a focus on what really matters in their lives such as relationships with loved ones and friends. Life—altered though it may be—can still offer times of joy and happiness. As Ronald Reagan wrote following his diagnosis with Alzheimer's Disease (Ronald Reagan Presidential Library and Museum): "*At the moment I feel just fine. I intend to live the remainder of the years God gives me on this earth doing the things I have always done. I will continue to share life's journey with my beloved Nancy and my family. I plan to enjoy the great outdoors and stay in touch with my friends and supporters.*"

One's world constricts with dementia. Possibilities are gradually shed and lost forever. The potential for new adventures vanishes. Memories form our sense of a continuous self, constituting the glue holding that self assembled, but it gradually dissolves, causing some to fear they will turn from a vibrant individual into meaningless flotsam drifting away in a vast, indecipherable sea. As my mother's memory fades away, so does much of my mother herself. Her caregiver and anyone else in her immediate vicinity will be subjected to incessant, repetitive questioning about the plans for lunch or dinner. But my mother is mostly undaunted by the pitfalls of failing memory and cognition. Perhaps her good-natured acceptance of her fate is a role model for how to grapple with such a fate, and thus demonstrates one can still have a positive impact on the world even in later stages of dementia. This woman who once posed like a movie star in photos still has a winning smile. She can enjoy a walk outdoors, savor a hot cup of tasty coffee, and most of all relish spending time with family. Despite being unable to retrieve any relevant facts, she accurately identifies the ambient emotions. My sister has noted that sitting in her presence

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can be akin to a meditative, relaxing trance as she repeats her repertoire of phrases like reassuring mantras; issues sporadic grateful observations about the blue sky or sunny day; and provides a non-judgmental space. Indeed, nourishing a sense of gratitude—as my mother does when she observes the beauty of the day—is crucial. Most important of all, her underlying personality somehow does remain intact so, although Alzheimer's continues to mercilessly chip away at aspects of her former self, my mother has by no means completely faded away. She remains a unique, recognizable individual, though she increasingly struggles, on her part, to recognize her family.

Even when she realizes she has made a major error such as informing the woman sitting in front of her, who happens to be her daughter, that this daughter is supposed to visit today, she shrugs it off with a laugh. Another constantly repeated saying is "It's good to laugh and laugh at ourselves." This ability to see humor in her situation allows her to remain in positive spirits despite the disease that progressively ravages her mind.

Yet another recurring comment from my mother—"We all enjoy our family, and we enjoy seeing each other." And indeed, she does enjoy spending time with her family. It is fortunate that my mother remains in such good spirits, as agitation and distress, understandably, frequently accompany dementia. Imagine the frustration and anxiety triggered by not recognizing one's surroundings or loved ones, not knowing how to get to a store and back, what year it is, where one placed one's wallet, and not even being able to retrieve the word for wallet. The inability to answer simple questions may trigger a "catastrophic reaction" in which a person reacts with anger, agitation and even violence. Questions posed as part of cognitive screening can sometimes trigger such reactions. It's also important to adapt such questions to the person's background, education level, and culture. One elderly farmer, who had dropped out of elementary school to help on the family farm, was asked to perform "serial sevens" (count down from 100 by sevens) as part of cognitive function screening, and responded by jumping to his feet, shaking a fist at the doctor and shouting: "You might be book smart, but I bet you don't know how to shoe a horse do ya'?"

Alzheimer's also wreaks havoc on the lives of family members and caregivers as seen with heartbreaking clarity in the movie "The Father." My mother's incessant questions are indeed a test of anyone's patience. My father was not a particularly patient man, but somehow managed to develop a superhuman degree of patience through his love and desire to protect my mother. Nor is the burden typically equally distributed. In my mother's case by far most of the caregiving burden falls on my sister who lives on the same kibbutz. Finding a way to meet caregiving needs while maintaining a reasonable quality of life for the individual and family is no easy feat. My mother is extremely fortunate to have a compassionate live-in caregiver who has been a lifesaver. My mother's good humor has also been a blessing. Many caregivers have to deal with agitation, violence, incontinence, wandering, sundowning, psychosis, anxiety, constant yelling and other serious behavior disturbances. These behaviors frequently precipitate nursing home placement.

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Alzheimer's is frightening—and the hope for a genuine cure lies over a dishearteningly distant horizon, but there is always something to be gained by facing our fears and grief head on. This is undoubtedly a dreaded disease that steals our loved ones away from us while they are still alive, and mercilessly stalks so many of us. Acknowledging the threat and recognizing that our loved one's or our own minds may crumble under its weight in the future, provides no easy solace but allows us to consider how we might respond if we are among its victims, and perhaps leaves us standing more firmly on the ground, where we must appreciate life while we're capable of living fully. Despite Alzheimer's cruel attacks on the mind, life can still be worth living, love from family and friends continues to exist and a beautiful flower can still evoke joy. A plea is expressed by the title of Julie White's article (Neurodegenerative Medicine Management Vol.20, No.6) about her husband's experience with Alzheimer's: "Please remember the real me when I cannot remember you." This too, we can do for our loved ones throughout their baffling and frightening slow-motion fall into this dark abyss.