Our Dementia Crisis: Who is crazy?

It is amazing to me that Alzheimer’s disease has not only confounded our medical and scientific ambitions, but also our humane and compassionate models of care. What an existential mess for you and me, and of course Mom.

Almost unheard of 100 years ago, and spoken of only in secret 10 years ago, today it is a silent epidemic. We all know the grim reaper of time and memory is coming, and we Baby Boomers wait in passive resignation. Now Mom, soon me. This is like AID’s in 1984 except much worse in terms of numbers. Five million this year, seven million in 2020. So despite the fact that we live in a world of crises: global terror, global warming, and over population, we are also as a generation, quite literally that is losing our minds.

At this moment, if your loved one is diagnosed with dementia, which as a practically matter means the decimation of short term memory; the overwhelming desire is to stop the disease process and preserve the short term memory of the person you love. This makes sense. I don’t want to lose my wife. So we feast on drugs that purport to fend off the loss of short term memory: Aricept, Exelon, and even jellyfish supplements. And our models of care tell us that computer games such as Lumosity and Sudoku will also help keep my wife near me if she works hard enough. But the facts are less comforting, and in fact quite stubborn. According to Consumer Reports, dementia medications intended to delay the loss of short term memory have little more effect than a placebo. And in a landmark study completed by St Michael Hospital of Canada in 2013 by the Li Ka Shinga Knowledge Institute, which focused on early stages of the dementia onslaught tells us that “cognitive enhancers for dementia, don’t work”. So for those families stricken by this disease, the question is; what should be the goal of “dementia care” if the pharmacological hopes for short term memory drugs are fool’s gold? How should we be caring for our loved ones stricken by this disease? And in a selfish way, how do we want to be cared for since half of the people reading this essay will be directly affected in a few short years. But for the vast majority of our society and medical community, we are not even asking those questions. Like Godot, we remain paralyzed by the hope of a cure. And in our denial of self-evident facts as we see no improvement from the drug regimen, we continue to trap our loved one’s in the Sisyphean task of playing memory care saving computer games and producing a world of frustration without end. This is absurd. If we know that death is the end game of the disease and that short memory is being ravaged, and that we want our loved ones to be given comfort and gentle stimulation, should we not look to their long term memories?
All of us have passions in our long term memories that continue to give bliss and stir our souls. Religion is a great example of this reality. I like to tease that I was a raging atheist in my 20’s, but an altar boy when I was 12. That reverence will never leave me. Tchaikovsky Violin Concerto also comes to mind. Some of us have wondered at the stars for a life time and that astonishment does not simple cease with a diagnosis. If we read any of the many autobiographies from people with the disease, this is obvious in the way they think and reflect. These touchstones are imbedded in each of us. Rather than discussing current events, we should be discussing marriage, sports, religion, and music. Subjects that gave us comfort in our pasts, which remain our guiding constellations as we march forward in our lives regardless of the disease. As a care model, we Baby Boomers should stress less the desire to save short term memory, and embrace the things that give our loved ones real joy, and that will be in their past. And that is how we will want to be cared for. We need to embrace this curiously counter intuitive approach. And if we have doubts, consult with any experienced caregiver about what is obvious to them. Speaking for my 57 year old self, I am fairly certain that as I age, I will find more joy in a Beatle record, a Mass, or photo of my mother, than in all the hours of CNN and social media available in the world.

Respectfully,

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