

Learning to live as “Alzheimer’s Marv”

In a prior era of infinite wisdom, I was a chemistry professor. I can remember talking to my students about the need to be honestly introspective about one’s intellectual and academic abilities. I would stress the need for them to realistically assess their abilities before embarking on difficult and challenging tasks. In their case, I was specifically addressing their early desire of “wanting to be a premed student,” which I often saw expressed before time had been spent self-reflecting and asking “do my academic skills and abilities match a premed program?”

I retired from teaching in 2010, and in 2012 was diagnosed with amnesic Mild Cognitive Impairment due to Alzheimer’s disease. Now, four years into this journey, I frequently find myself challenging myself the same way I challenged my students: with every choice, before selecting what I want, I need to determine if I have the skills and abilities to still be able to do it. It is an ongoing exploration of the interplay of how my cognition can work to compensate for my declining or absent memory. Cognition cannot replace memory, but it can certainly help mitigate the effects of serious short-term memory loss. I try to keep an informal list of what I can and cannot do, both as a form of mental exercise, and also as a gauge to help me keep my physical and social activities in line with my current abilities. Being a retired scientist, I find I have both the time and inclination to study and explore my personal journey with Alzheimer’s.

In 2010, I had no feeling or suspicion



that I was having serious memory problems. I felt I was still doing a very demanding job, and my memory issues were related to information-overload. After I retired, we moved from Illinois to Minnesota, to be closer to our family. In this totally new environment, I soon realized I was clearly not learning my way around as quickly or as well as my wife was. Once we started having questions about my memory, there was a tentative acknowledgement by me that yes, there was a change, but also a sense (a hope?) that I was still OK. It was almost “Yes, I am having trouble remembering, but no, I don’t have memory problems—I am just stressed—it is a new environment—I’ll get over this.”

But I didn’t. It only got worse.

Within a year we were discussing my memory concerns with our new doctor, who thankfully respected our judgment and initiated lab work, an MRI, and testing with a neuropsychologist. The results were below what would be expected for

my age and experience, and that led to more tests. After another year, the confirmation of my memory problems led to the diagnosis of MCI—Mild Cognitive Impairment. Initially, I was in denial, and used my cognition to challenge my doctor’s assertion that my memory was as poor as the tests showed. I think I was ready to acknowledge that I had memory problems, but I was slower to internally process the severity of the problem. It took me awhile to sort out the basic separation between memory and understanding, and what still surprises me today is how cognitive I feel. I often express that I have perceived a serious loss of recall (memory), yet retain a robust sense of understanding (cognition), which I can use to some extent to compensate for the loss of memory ability.

Knowing and accepting that I have significant memory loss has paved the way for my wife Elaine and me to better understand my limitations, make our plans, and ensure our practices fit more closely with these realities. It is unfortunate, but necessary, that many of my responsibilities are now taken up by Elaine, or have been transferred to others we pay. For example, we now have someone else prepare our taxes instead of me. We recently moved into an apartment to remove the need for me to care for lawn and house. As I accepted the fact that my memory could not be relied on, the scientist in me looked at it as a data storage and retrieval issue—which led me to recognize that what I needed could be thought of as an external hard drive. I quickly honed in on an iPad as a portable memory device which could work well for me. I carry the iPad with me to many places, and it allows me to look up

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my schedule and write notes to myself and generally serve as my portable memory.

My personal experience is leading me to be much more cautious in assuming that I can evaluate how self-aware other people may be who are living with a mental illness. It is so easy to slip into a pattern of not including people in a conversation by assuming that they cannot contribute or they will not understand. This is one of the key messages I would like all physicians to understand. I can follow the logic of many discussions, knowing that I may not remember the supporting details and the arguments. It is like saying I can read a novel and understand the story, without implying that I could later write a detailed synopsis of the book.

I can still understand things that I may not be able to easily express. I want physicians to understand that no immediate response does not mean that a person with Alzheimer's does not understand what is being said. No immediate response simply means no immediate response. It may mean that a longer response time is needed. In my own case, I sometimes just have difficulty in responding immediately because I lose my train of thought as I am thinking of my response. I sometimes feel like I need to stop mid-sentence and say "I lost my train of thought" or "can you repeat the question?" No immediate response does not necessarily mean there is no comprehension, or that the conversation should cease. I may have a disease that is taking away my short term memory, but I can still think and express myself.

To offset that challenge, another piece of advice I offer to physicians is that shorter sentences help. Any sentence that

requires a second breath may be too long. For me, big words are not as daunting as long, complex sentences. Separating choices into two short sentences, at least by cadence, is a big help. However, I certainly do not want anyone to simplify or "dumb down" their vocabulary. Being able to gauge an appropriate level of communication to a specific person should certainly be guided by your knowledge of the person's prior life and medical history.

I have found all of my doctors to be helpful (I would not go back if they were not.) I have been impressed with how supportive they have been and how they project a feeling of empathy and caring for my situation. I have not pursued treatments outside of our medical programs. I am a scientist and would find it hard to think that on my own I could find therapies that are unknown to the medical profession. I am interested in taking part in clinical trials that are testing new therapies. (Now, I would of course prefer to only enroll in ones that are guaranteed to cure my Alzheimer's, but for some reason those are hard to find.) Currently I am in a 26-month drug study of subjects with amnesic MCI due to Alzheimer's disease. Of course, I do not know if I am taking a placebo, the low dose or the high dose of the drug, but, for me, it seemed only natural to want to be involved in a clinical trial.

Alzheimer's is a terrible disease. Until we have a cure, the best way to soften the effects of dementia is through the support of family and friends. It is the personal connections that sustain my wife and me. The



medical professionals, the people at the Alzheimer's Association, and the many people we have met in various programs have been a great source of information and are a continuing emotional support.

I know I am not alone on this journey, and that makes all the difference. I have Alzheimer's, but Alzheimer's does not define me. In a way, I had to have a funeral for the old Marv and now learn to live as the new Alzheimer's Marv. The new Marv is very open with people about the memory loss and what that means for my ability. Both Old Marv and Alzheimer's Marv cohabit in me, and both are constantly changing. There is certainly a flow over time that brings more of Alzheimer's Marv, and weakens and reduces the presence of Old Marv. But the lines are not a firm separation, and there is a flow between the two faces of the one Marv.

I am still Marv, and that is what matters. ♦

Marv is always open to meet with physicians and/or groups about this journey with Alzheimer's disease. Please contact Karen Peterson, Executive Director, Honoring Choices Minnesota, kpeterson@metrodoctors.com.

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