

Finding Out I Had Alzheimer's Disease

After a year believing I did have Alzheimer's, tests in Aug 2013 revealed that I didn't. I have left unchanged most things written before major change.

The Years Before My Diagnosis

All of the following description of finding out I had Alzheimer's is at the end of my [autobiography](#), but I've placed it here in case you don't want to read about the earlier part of my life.

Alzheimer's Disease was not part of the future I was planning. I suppose it rarely is.

In retrospect, I can see signs going back quite a few years. I began to find writing more and more difficult, and I found myself taking more and more excuses not to write daily. Although I didn't identify it clearly then, I felt increasingly apathetic about writing, wondering what I had to say.

I was increasingly forgetful and began losing things more often than usual. I made many more mistakes typing. But I never suspected anything significant was going on.

In June 2010 I experienced a disturbing event. For a decade or so I'd been driving two or three times a year down to southern Virginia to visit a friend, Jens Soering, who was serving a life sentence for two grisly murders he almost certainly didn't commit. This time, because Jens had been transferred to another prison, I would have to figure out how to get to a new place in an isolated rural area. Jens sent me the rather complex directions for which I had to carefully study the Google map to avoid getting lost.

During my visit with Jens, the prison chaplain stopped by to say hello. I introduced myself, but he said something like, "Yes, I remember you from last time." I'd had a terrible memory for names and faces since forever, so I'd developed a coping mechanism in these circumstances. I faked it. After the chaplain moved on, I asked Jens whether the chaplain had moved from his previous prison where I might have met him. Jens seemed a bit confused by my question and

told me that I'd met the chaplain during my last visit to this new prison several months earlier.

I was absolutely certain I'd never been there before. The route planning had been meticulous. It was a complex 3½-hour trip to the prison. I would have visited with Jens for four-hours and drive the 3½-hour trip back? I couldn't possibly have forgotten it!

But I had. To this day I remember nothing about that forgotten trip. Nothing remotely similar had ever happened before (or since, actually). When it didn't recur, I pushed it to the back of my mind, rationalizing that if it was a completely isolated event, a doctor would not be able to make much of it.

Months later, however, I was working on a spreadsheet for my church's next year's budget. I needed a relatively complicated formula that I'd developed in previous years. Since I'd enjoyed working on spreadsheets, I decided to recreate the formula from scratch. Not only was I unable to recreate it, however, but, when I went back to old spreadsheets and looked at the formula, it was too complex for me even to understand! Even looking at it in some detail I couldn't figure out what I'd done. What was going on?

Perhaps I didn't want to know, but I did ask my wife Marja and several close friends if they had noticed any strange symptoms that might indicate decreasing mental function. They hadn't, but I asked them to tell me if they did. No one ever said anything.

In late summer of 2011, however, just to put my mind at rest, I made an appointment with a neurologist to get a professional opinion. After interviewing me and administering the appropriate tests, he told me that given, my previous IQ and professional history, I should have scored higher on the screening test for mental function. Even though my scores were not yet low enough to warrant an official diagnosis of dementia, I had a "mild cognitive impairment." But he didn't seem very concerned either about my worsening memory, forgetting the entire visit with Jens, or the difficulty with the spreadsheet. He asked me to come back in a year "just to check." Although he probably guessed what was coming, he didn't seem too concerned.

Somehow I was reassured. Given what I know about dementia, however, even a "mild cognitive impairment" should have sent off warning signals and I should have pressed him harder for his impression. In retrospect, I'm amazed I wasn't more concerned.

Over the next year I became more apathetic about my writing and chastised myself repeatedly for not just “making myself do it.” But writing is a fickle gift, so I certainly didn’t put it in the context of the cognitive impairment. Once again, though, I asked around to see if anyone else had noticed anything. They hadn’t.

Over that next year there were small events that I didn’t tie in with the earlier symptoms. Three times within a few months, I left my hat on the Metro and my backpack once. On my way out to visit my daughter Laurel in California, I left my belt pack in an Amtrak bathroom. These are *tiny* bathrooms. How could I not notice a belt pack when I left? I got my belt pack back (although not about \$200 in cash).

Ten days later, while still at Laurel’s, I lost it again. Ordinarily when I lose something, I have some recollection of how and where it happened. But not this time. I retraced my steps but had no memory of doing anything with it. I went back to every location I’d visited in those few hours. Nothing. We never found it.

I continued to lose things. My typing slowed down and I made many more mistakes. I thought perhaps it was age, but since I was then only in my mid-sixties, it seemed awfully early to be losing so much. After all, Fred Taylor, my eighty-year-old friend, seemed not to have lost a step. This level of impairment was certainly not normal.

I got lost in downtown Philadelphia. I attributed it to a city I didn’t know much about, and I did eventually find my way back on my own. I had had a good sense of direction all my life and nothing like this had ever happened before.

What bothered me the most was my failing memory. I was frequently embarrassed by what I forgot, yet I had been able to explain it away to myself and others as my chronically bad memory, so no one, as far as I know, recognized my symptoms for what they were.

In retrospect, I knew even then that something important was going on. But I’d asked my friends, I’d visited a specialist, and I’d had no symptoms that couldn’t be at least reasonably confused with normality. In retrospect the diagnosis seems obvious, but I didn’t tumble to it until

the one-year follow-up visit with the neurologist. As part of the cognitive exam, he showed me a three-dimensional cube and asked me to reproduce it in a space next to it.



I couldn't do it.

This is not a difficult task; the model was right there in front of me, but I couldn't get all the lines to connect. I had administered similar tests to patients before. I knew immediately what was this meant. A knot quickly formed in my gut, and I felt almost sick. I realized that my mind was going.

So when the doctor told me I had a "progressive cognitive impairment," I wasn't really surprised. Stunned yes, but surprised, no!

I have journaled almost every day after that and then have taken from my journal entries some things I can make public. It might seem strange to want to make something so intimate public. But I'm a writer. This is how I process my own reality. My first two books had their origins in my attempt to understand, first, the contradictions of practicing medicine in a rural area and, second, the pain and joy of doctoring in the inner city. Carol Marsh, a good friend and writer, has agreed to edit my writing. As the dementia worsens and I can no longer write, I hope we will be able to talk and I can communicate through her. In my imagining, I will not be the one to finish this chronicle. In the end she will be writing *about* me, describing who I become.

It may seem surprising that I feel almost no apprehension about exposing my mental decline and my reactions to it. The value of my books on rural practice and on inner-city doctoring, after all, lies in my willingness to report candidly, so I have some experience in sharing the messy details. In my lecturing, speaking and teaching, I have tried to be open about my depression, believing that the millions of people who are shamed into hiding their diagnosis should have some models for self-revelation. Likewise, I hope that others with an early diagnosis of dementia and those who are in relationship to a person with dementia (including medical people) will find my experience helpful.