

An Email to Friends

Telling Them of My Diagnosis **

I have been diagnosed with a progressive “[mild cognitive impairment](#),” almost certainly Alzheimer’s disease.** The neurologist told me the diagnosis last September, but I’ve waited to write this letter and make my illness public until now, when my symptoms are becoming noticeable to others.

Actually, I’d been noticing symptoms for a while but was still surprised by my doctor’s diagnosis. Over the past several years, my memory has significantly declined. This is a common complaint for people as they age. For 20 years before he died, for instance, almost every time we visited, my father asked again for reassurance that he didn’t have Alzheimer’s. His memory loss, like many other older people’s, was mostly for names and faces. I’ve always had that kind of poor memory, but I began losing memory in other areas as well. Two years ago, an entire trip to a rural area southern Virginia disappeared from my memory. I drove down to visit my friend Jens Soering in the prison to which he had previously been moved. I could have sworn I was going down for the first time. In fact, I’d been there before several months earlier.

I chalked it up to a single bizarre experience that would probably not mean much to a doctor, so I didn’t do anything except tell the story to friends.

Some months later, I couldn’t recreate a computer spreadsheet formula that I’d written several years earlier. In fact, when I went back and examined the formula from an old spreadsheet, I couldn’t even understand what I’d done. Such calculation difficulties persisted. I went to a neurologist in the fall of 2011 for testing and he said that I did have a cognitive impairment but that it wasn’t severe and the relevant point was whether it was progressive. I returned last fall (2012) and, yes, the impairment had progressed. There aren’t too many likely candidates for causes for progressive cognitive impairment. The neurologist performed tests for them: they were all negative. There is no certain test for Alzheimer’s except to rule out these other candidates, so the overwhelming likelihood is that I have early Alzheimer’s disease.

Since last fall, the disease has progressed. My memory is much less reliable. I’ve had trouble finding words, especially in Finnish as my wife Marja and I try to converse but also quite noticeably in English. Both my daughters, Laurel and Karin, recognized in retrospect that it took me longer to do certain tasks. That slowness in figuring things has gotten worse, too. While I

can still eventually do most computer tasks, they can take a long time, and I can get confused easily. I've even had two experiences of being in locations that should have been quite familiar but, in fact, I didn't really know where I was or how to get where I was going.

I've been apathetic about writing and about my website these last several years. I'm somewhat less interested in politics; for example, I couldn't sit through the presidential debates last fall. (Some of you may feel that the only mentally healthy response to the debates is to turn them off, but it's never been true for this political junkie.) Perhaps I'm just looking for an excuse, but I'd like to believe that this disease is at least predominantly responsible.

So, while there is always a chance that it's something else, my neurologist and I are pretty certain that it's Alzheimer's. So far, the symptoms have been limited. I can still write well, although you may have noticed that my essays have been less frequent lately. When I type, I frequently leave out words and phrases (which I hope I'll edit out before I actually put my posts up). I'm still teaching in small groups, still doing the books for my church, still mentoring some others. Up till now, I've noticed my mistakes well before others do. My judgment seems unimpaired. My life goes on.

It seems paradoxical, but Marja and I are actually doing quite well. In fact, I've noticed some positive changes in my ways of thinking and acting. I'm more emotionally open. I'm less insistent on maintaining my image as prophetic voice or incisive writer. I don't need to prove myself with new accomplishments. For the first time, Marja and I have allowed ourselves to look back on our lives with satisfaction and gratitude. I'm more vulnerable to other people and have been experiencing an extraordinary closeness to some people that I would never have thought possible. While it seems crazy to say it, *so far* my life has been better ... happier ... than before this disease. I have no illusion about what's coming, but, up until now, it's been good.

Garrison Keillor said recently, "Nothing bad ever happens to writers; it's all material." So, at least for a time, this Alzheimer's disease will become material for my website and for a [blog](#). I want to write about what Alzheimer's is like from the inside. What is the experience of losing one's mind? Do I still experience myself as the same "self"? Obviously, I don't know how long I can do this, although my good friend Carol Marsh has volunteered to keep it going with interviews when I can no longer write. We'll have to see.

** As of Oct 30, 2013, the diagnosis is much less clear. (Click [here](#).)

