

Blog Posts from February 2014

Saturday, February 1, 2014

Washington DC

So Now Nothing

In my [last post](#) I wrote about the good news that's been coming during the last five months: no evidence of Alzheimer's disease; stability of my symptoms during the past year and even perhaps some improvement; cognitive decline but, for practical purposes, no impairment; the reasonable possibility of a stable future; and general happiness with my current situation. The "[elevator version](#)" goes something like this: "I'm doing pretty well. We discovered that I don't in fact have Alzheimer's. I'm still a bit slower than I was, but it's not worsening and I'm fine with it." A couple of days ago, such a summary still seemed a little scary—a more complete letting go than perhaps I was ready for—but it seemed to be the next right step. In that post I ended with: "The only bad news is my attachment to a self that no longer exists; with a little time I think I can let that one go, too."

Miraculously, it seems, the letting go has already happened. I'm no longer attached to the person-with-Alzheimer's identity. At first, I didn't notice the attachment fading, but, in our conversation Wednesday, my spiritual director recognized the difference immediately. I've changed at a deep level, and I'm ready to move on.

So, now what?

So now nothing! I feel no hurry to rush off somewhere and find something else. One of the great gifts of this 16-month experience has been a significant freedom from the trap set for me by my intellectual gifts and my sense of duty and responsibility. In these past months, I've continued to respond to the pain of this world (mostly, but not entirely, through this blog), but, with that freedom, my work has for the first time felt mostly joyful. It's been really wonderful for me, and I don't want to give it away.

I can trust myself, my deeper self (and not just the intellectual self that has been so long trapped by “should”). I don’t feel my usual need to search desperately for the “right” vocation, for a work that *should* be fulfilling.

I can wait.

So I’ll continue the blog as long as I have something to say, and I’ll keep an eye out for what may come my way. But a new vocation can’t be just the thing-that-needs-to-be-done or the thing-that-I’m-good-it. That new vocation also needs to be something that brings me joy.

Will this freedom be permanent? Of course not! It never is. We always bind ourselves again, and I’m sure I’ll find something. Nevertheless, I’ve been changed and won’t ever be the same.

Where will that lead me? I don’t know. Right now I’m not very concerned. As long as the path seems firm and right under my feet, I’ll just follow it out and allow most of the worry to remain at rest.

February 8, 2014

Washington DC

How Could Your Alzheimer’s Be Cured?

In my last two posts ([here](#) and [here](#)), I shared the good news that my cognitive diminishment has not been progressive, is not Alzheimer’s, and (despite the occasional frustrations) is something I can live with. It’s wonderful news although I’ve been able only gradually to embrace it.

The good news may raise the question in the minds of some: If Alzheimer’s is incurable, how could have you been cured? The short answer to that is that I haven’t been *cured*; I never had Alzheimer’s in the first place; the diagnosis I’ve been living with for over a year is wrong. And

that may raise the question: If you had good doctors, how did they miss it? Why did they tell you that you had Alzheimer's when you didn't? And the short answer to that question is similar: They never did tell me that I definitely had Alzheimer's; they said it was

almost

certain, which I've always mentioned in my writing, but usually not emphasized, in articles, speeches, and this

[blog](#)

. The longer answer to both those questions lies in the current diagnostic criteria for Alzheimer's, which are imprecise. I emphasize

current

because, as I'll explain later, those criteria are in flux.

Alzheimer's can only be definitively diagnosed by an autopsy that finds the telltale [amyloid plaques and neuro-fibrillary tangles](#).

Since it's not possible on a live patient to make a certain diagnosis, doctors assemble as much evidence as possible and make the presumptive diagnosis from there. The problem is that the diagnostic criteria for Alzheimer's are necessarily subjective and uncertain. Here they are.

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The cognitive impairment has to be progressive. The trouble with that criterion is that early in the disease it can difficult to be sure that symptoms have gotten worse. In my case, the [second set](#)

of cognitive tests, a year after my first, did seem to show increasing impairment, but the progression was mild and maybe just random. Maybe I had a bad day with the second set of tests.

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Symptoms have to be bad enough to disable you in your daily life or work. My neurologist did tell me the time that I hadn't yet quite progressed that far, but it looked to him that I was heading there. The definition is a little vague. On the one hand, I was working both as a writer of complicated material requiring specialized thinking and as a bookkeeper. I was disabled enough to force me out of those jobs. On the other hand, I could still do *other* kinds of professional work: teaching college-educated people, participating in organizational leadership positions, and so on. Was I disabled because I couldn't do my

usual

work? It's not clear cut.

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There must a pattern of impairment in which memory is more affected than other elements of cognition. I certainly met that criterion, but other kinds of dementia can have the same pattern.

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Other causes of dementia have to be tested for and ruled out. But no tests exist for some causes of cognitive impairment (for instance, [Lewy body dementia](#)), other tests (such as an MRI for vascular dementia) are not always conclusive. So it's not really possible to rule out all other causes of dementia.

The point is that, especially early in the disease, a doctor *cannot* make a definitive diagnosis; as a doctor, you do the best you can, but you're often wrong. I fit three of these criteria and was close to the fourth. Using these old criteria, a diagnosis of "mild cognitive impairment, almost certainly Alzheimer's" was justified.

So the answer to the question about how I can now be cured of Alzheimer's is that I never had it in the first place. The early clinical diagnosis was wrong, as it sometimes is. And the answer to the question about my doctor's competence is that he did exactly what he was, at that time, supposed to do. But medicine marches on; the symptoms previously diagnostic of Alzheimer's are no longer enough. By the old criteria I had it; by the [new, not-yet-quite-in-place criteria](#) , I don't. I'll review that in my next post.

Thursday, February 13, 2014

Washington DC

Loose Ends and a Miracle

In my [last post](#) I wrote about the possibilities for error that lie in the fuzzy borders around each of the current diagnostic criteria for Alzheimer's. I'd like to tie together some loose ends from that post.

New Diagnostic Criteria Involving PET Scans and Other “Biomarkers”

The diagnostic criteria for Alzheimer's are becoming more precise and reliable as new laboratory and x-ray tests for physical evidence (called “biomarkers”) become available. The current definitions (that I examined in the [last post](#)) use only the outward symptoms of the disease. Once biomarkers are added to the diagnostic criteria, the diagnosis becomes more reliable. The [PET brain scans](#) now being evaluated, for instance, can see the [amyloid protein deposits](#) in the brain that are directly associated with Alzheimer's. Analysis of cerebrospinal fluid can detect the [tau protein](#) that is similarly associated with Alzheimer's. Much research is still being conducted to determine exactly how to [incorporate these biomarkers into the diagnosis](#)

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Some things are already very useful. If the PET scan for amyloid is negative, for instance, you almost certainly don't have Alzheimer's. (If there is amyloid, it's not so clear since about 20% of those people apparently do not have Alzheimer's.) But the several biomarkers that will soon be available in clinical practice will make the diagnosis of Alzheimer's much more reliable.

The Trouble with Anecdotes

My experience of the past sixteen months is a good example of the problems with anecdotal evidence, that is, individual stories that cannot be statistically evaluated. Over the past year, friends and readers have recommended dozens of different treatments (sometimes even suggesting that doctors or drug companies are hiding them from us). These sincere recommendations have usually been based on stories of individual patients who took the treatments and got better. I responded to the comments ([here](#) and [here](#)) that I probably wouldn't even look into the suggested treatment because, basically, I trusted medical science to look into any reasonable possibility for cure. If medical science wasn't looking into it, I wasn't going to bother, either. I keep myself healthy with diet and exercise, but I haven't taken any special treatments.

What might have happened if I had taken, say, coconut oil, as a treatment? How many would

interpret my “cure” as “proof” that coconut oil worked. In reality, it would have been just a coincidence. The purpose of rigorous scientific testing is to make sure that coincidences, improvements based on the placebo effect, original misdiagnoses (as in my case) or other issues are not involved.

Isn't it possible, some of my friends ask, that a new untested treatment works and will later be scientifically justified. Of course. I criticize no one who wants to try one of the many suggested treatments. But I wasn't personally willing to spend my emotional energy going back and forth trying one or another on the basis of the latest anecdotes. I know some readers will jump on me for this, but, before you comment, please at least go back and read the two posts ([here](#) and [here](#)) that I wrote on the subject.

It's a Miracle Anyway

In spite of all I've written above, I still experience this “cure” as a miracle. It's not that the natural laws of the universe have been overruled or suspended or that something scientifically impossible has actually happened. Finding myself free of Alzheimer's is a miracle because it's something completely unexpected, something that I would have considered impossible a year ago, something that gives me hope, something that returns my life when it seemed to be disappearing. Sure, I can go back and explain each step scientifically, as I have over the last several posts. What has happened broke no laws of science ... but it's nevertheless a miracle.

A New Title for My Blog

Given that I don't have Alzheimer's and that my cognitive impairment is not progressing, the title of this blog, “Watching the Lights Go Out,” seems to me a bit inappropriate, so I'm inviting suggestions for a new title (or, perhaps, reasons to keep this title). My son-in-law suggests “Stop Playing with the Dimmer.” What are your suggestions?

Tuesday, February 18, 2014

Washington DC

What Happens After Mild Cognitive Impairment?

Since I was originally diagnosed with [Mild Cognitive Impairment](#) (MCI) almost a year-and-a-half ago, I've read that some people with MCI get better, others stay about the same, and the rest go on to develop dementia, but I've never read any definitive statistics. The Mayo Clinic, however, just released a large [study](#) of people with MCI. There were two findings that were significant for me.

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When the people with MCI returned for their follow-up visit, over a third (38%) of them who had been cognitively impaired were now not impaired. Their tests were normal.

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However, the study continued to follow up on that subgroup of now-cognitively-normal people for about five years. During that time, almost two-thirds (65%) of them had become impaired again, either to MCI or to dementia.

Simply stated, it's not unusual for cognitively impaired people to become normal again. Wait a while, however, and the majority of those people will eventually become impaired once more, with either MCI or dementia.

My own situation is not completely comparable to the study subjects.

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First, unlike the study subjects who initially reverted to normal, my impairment has not reverted completely since my diagnosis in the fall of 2012; I do, however, feel somewhat less confused.

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Second, my normal [PET scans](#) demonstrate pretty conclusively that I [don't have Alzheimer's](#).
Does that change the odds of my getting worse again?

The research also raises some questions that need to be studied, for instance:

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There are many causes of cognitive impairment.

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Are there some in which MCI doesn't revert to normal ... or revert back?

So this Mayo Clinic report doesn't resolve any of the uncertainty about my future. The chances are good, says the study, that I'll get worse, but there's also a chance I won't. The reality is that, like anyone else, I don't know my future.

The most important thing for me, however, is not to allow my emotional or spiritual balance to yo-yo up and down with each new research fact that bears upon my future. I certainly am not going to ignore studies like this; I want to be more informed, and I'm convinced that knowledge is almost always better than ignorance. In fact, the study helps me a great deal: I know I'm not alone in feeling confused about what's happening to me.

Statistics are only one kind of information: they only tell you what the odds are that something will or won't happen, not what the reality is. So I'm doing my best to put them in their proper place: helpful but relatively unimportant in how I choose to live. I won't ignore facts that concern my future, but I won't be dominated by them. Life goes on!

Tuesday, February 25, 2014

Washington DC

Subjective Cognitive Decline (SCD)

As a physician, I always told my older patients that a decline in memory as they aged had nothing to do with the risk for Alzheimer's. I have repeated the same thing in this blog several times, for instance, [here](#) . Apparently, I've been wrong.

As the results of a number of [research studies](#) presented at the Alzheimer's Association International Conference (AAIC) in July 2013, get around, they will worry a lot of older people and bring them to their doctors for testing. According to the studies, people with subjective complaints of cognitive decline (for example, memory loss) but no objective findings (ie, their tests for impaired thinking are normal) are considerably more likely to progress to mild cognitive impairment (MCI) or dementia than people who have no such complaints. In plain English, if you think your memory is getting worse as you age, you have good reason to be concerned about Alzheimer's or other dementia even if your doctor tells you you're fine.

These findings are in complete contradiction to what most physician believe, which is that memory complaints are a normal sign of aging and have nothing to do with the Alzheimer's.

One of the doctors interviewed acknowledged that "you clearly don't want to worry everybody who's aging," but, it seems to me, since so many people experience worsening memory as we age, these findings are going to worry almost everybody. I can just see the rush to doctors' offices.

Each of these studies has a different design. Some look at people who have already come to their doctors with symptoms; others are more reliable studies of the unselected general population. Some include data about whether family or friends notice the symptoms; others don't. At least one study includes autopsy results (the only way to definitively diagnose Alzheimer's). One study includes progression to MCI as well as to dementia. Another includes MCI or dementia from any cause, not just Alzheimer's. The advantage of these multiple designs is that the results are less likely to be due to some flaw in the design. The disadvantage is that none of the studies has been explicitly replicated, which is usually necessary to draw valid conclusions.

But all point in the same direction: if you think your memory is getting worse (or you're having trouble with other kinds of thinking), you have a good chance of progressing toward something more serious. One study suggested that your chances are about two out of three.

- As usual, these kinds of studies raise more questions than they answer.
- Is your risk increased (and by how much) if your PET scans (like mine) are normal?
- If the only problem you have is remembering names, how serious is that?
- If your only symptom is not being able to find the right word exactly when you need it, is the risk of progressing to MCI or dementia higher?
- Is the real problem only with Alzheimer's or does it include other causes of cognitive impairment?

It will be interesting to see how these findings affect both patients who worry about their memory and doctors who care for them.

[Blog Posts from March 2014](#)

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