

Blog Posts from January 2014

Sunday, January 5, 2014

On board Amtrak

Letting Go ... Again

It's been three weeks since I've written a post. I've enjoyed not only a wonderful Christmas with my daughter and her family in California, but also the three-week respite from this blog. Today Marja and I are on Amtrak traveling to Washington DC: three days of relative solitude across the country.

For the first time, I've been experiencing the need to write for this blog as something of a burden; the California respite was a real relief. In the beginning fifteen months ago, the blog didn't feel demanding or even like work. There was always something new to write about; my experiences just pushed themselves out, yearning to be expressed. I even worried that I was posting too often. The blog was to be a journal of a mind disappearing; not knowing how much time I had before I could no longer keep it up, I felt some urgency.

As I've written [before](#), finding new material has begun to feel difficult. It's not surprising, I suppose:

- To date, I've written 161 posts; that's a lot of subject matter under the bridge.
- The course of my disease has been much slower than I anticipated, which means that the experience of my impairment has not changed radically these past fifteen months. I don't confront new levels in daily life very often; there's little new to tell.
- Give my more favorable prognosis for a longer period of competency, my sense of urgency is greatly diminished.
- All the confusion around the level of my impairment, the validity of my symptoms and my diagnosis has shaken the base on which I stand, making it much more difficult to understand the significance of my experiences.

There is, however, a set of more confusing reasons. This blog is taken from my daily journal. As I get used to my symptoms, however, I don't journal about them as much as I do about other things: playing with my grandchildren, a low-grade depression, or a disagreement with Marja. Those are important events to me but probably not as fascinating to others; nor are they always relevant to my experience of cognitive impairment. A year ago, almost everything I thought

about was related to my impairment and therefore fit into the blog. Now I have to be much more discriminating. Often there's nothing for days.

Perhaps more important, ever since my [neuropsych exam was reported as normal](#), I've felt defensive writing about my symptoms. As I've written [before](#)

(November 15, The Truth of This Blog), when the symptoms I experience *could*

be construed as normal aging or something that could happen to anyone, blogging about them can feel almost like a pathetic, last-ditch attempt to convince myself and my readers of the reality of these symptoms.

The fact of the matter is that I still ruminate on my impairment several times a day. I'm still surprised by every new symptom even if it seems no different from others. In the past two weeks, for instance, it took me forever to understand the fairly simple rules of a new game my grandchildren taught me; I've been unable to find lost my gloves *many* times; I never found a bungee cord I needed for our suitcase and can't remember even handling it; and so on. Is it, however, helpful to write about such in a public blog when I've written about similar symptoms previously?

What I keep forgetting is that the intention of this blog has always been to chronicle my journey within this disease. Whether it's interesting or helpful to others, whether it belongs here in the blogosphere isn't my judgment to make. If I don't have anything at all to write about, then I should wait until I do, rather than feeling pressure to get something posted. If I notice symptoms, "old" symptoms, write whatever is meaningful *to me* about them and don't worry about whether I'm whipping a dead horse. If I'm feeling conflicted about the loss of my Alzheimer's diagnosis, write about that. If I'm frustrated by an email to me from a reader who wonders why, in the face of all the normal tests, I work so hard to prove something is wrong with me, then I can write about that. This post today is perhaps an example: an interior monologue about finding it difficult to keep the blog up. I'm thinking about it a lot, so I'm writing about it.

I will do my best to let go of the concerns that fewer people will read the blog, that I'm repeating myself, that I'm posting too infrequently, or that the blog is not valuable to others. The disease persists, whatever it is. And that's what this blog is about. This is a journal of my experience as a person with cognitive impairment. I can't be the judge of whether it's helpful to anyone else; and trying to be that judge only makes me anxious.

Friday, January 10, 2014

Washington DC

A Community Responds

I've received almost twice as many comments to the [last post](#) as to any previous one. I'm deeply moved by those responses. Not only did the comments and direct emails offer me much support for continuing the blog, but they also supported my need to write only when I had something to say and not to feel pressure to fill up the space. Those responses confirm my sense of community with you who have gathered around this blog. I am profoundly grateful.

Several of the comments offered specific perspectives that I'd not explicitly considered previously and helped me understand better what I and this blog are about. I've responded to each of them personally, but I'd like to highlight here some of their teachings.

One reader emailed me directly with a story remarkably similar to mine. In 2008, after noticing significant confusion, doing poorly on screening cognitive testing, and having brain scans suggestive of AD, she began quite intentionally to live with Alzheimer's, joining a support group, writing a memoir, involving herself in advocacy, and so on. She discovered this past summer that she is, in fact, cognitively normal, and very likely does not have Alzheimer's. Her entire story is fascinating in itself, but what she specifically wrote to me about was her difficulty giving up her previous identity as a cognitively impaired person. It's been harder than she'd realized to think about her future as a normally competent person. Even after thorough neuropsych testing showed no impairment, she continued to limit herself as if she were still a person with Alzheimer's. So she's changed her attitude to consciously reminding herself she's normal and wants to act that way. It's made a great deal of difference in her life. She and I both recognize that our situations are somewhat different from each other's in that she no longer feels impaired, but her experience raises similar concerns within me: Am I making too much of my impairment? Should I just act as if I'm not cognitively impaired despite my feeling impaired? Am I too invested in my diagnosis? The line between accepting the reality of my impairment, on the one hand and becoming so invested in that reality that I am not open to changes as they occur, on the other, is a fine line, indeed. It takes wisdom and care to recognize the ambiguity of my situation and not invest myself too deeply in any particular identity.

One person commented that I sometimes seem to be saying, "I'm sorry if I don't, in fact,

have Alheimers!" It's a good observation and succinctly put. I started the blog with a pretty fixed idea of what it would be like: "Watching the Lights Go Out." The blog turns out to have become something different. Flexibility has never been my strong suit. I have the tendency to feel guilty, as if I've promised one thing and delivered another. It's an irrational sense that I have something to apologize for. Many of the comments to the last post have reinforced the idea that I can hold the purpose of the blog lightly, not worry so much about consistency, and let the blog become what it will become. That's been a comfort

In her comment, another person suggested that I might "have come to a new stage where less and less are you defining yourself by your 'illness,' whatever that may be." For me I think I have been defining myself not so much as a person who has an illness but as a person who writes about that illness. And through the ups and downs of the last months, I've been pushed (fortunately) into seeing a broader point of view. I've always been a person who defines himself by what he does; perhaps I can move toward letting go of definitions altogether.

This has been quite a journey. I'm grateful to have this community of readers accompanying me.

Monday, January 13, 2014

Washington DC

When the Experts Disagree (Part I)

Not long after I wrote ([here](#)) about the results of my August 2013 neuropsychological examination, I shared those results with my faith community that has been accompanying me on this journey with cognitive impairment. Carol, a friend from the community who is also a neuropsychologist, offered to review the official report I'd received from the National Institutes of Health (NIH).

In her professional capacity, Carol administers and interprets the same tests so I was grateful for her offer. After reviewing the results, she told me she disagreed with the NIH interpretation and that the examination showed clear evidence of cognitive impairment.

On the one hand, her comments shocked me. I'd studied the results of the examination, which comprises multiple separate test items. All but one individual item had been within normal limits. How could the overall examination, then, show impairment? On the other hand, because her conclusion confirmed my own *experience* of impairment, it left me feeling less crazy and paradoxically relieved.

Just before my recent trip out West, Carol and I sat down and went over her interpretation of the test results item by item. The following is my summary of our conversation.

My IQ was 133, which the narrative described as "superior." The importance of my IQ, she said, is that it affects the interpretation of some of the individual test in the rest of the evaluation. Considering my overall IQ, the scores of a number of the individual items should also have been considerably higher than the normal range. Many of my scores, however, were only slightly better than average, some of them were below average, and one was so low as to be outside the normal range.

For example, the tester read me a "story" comprising fifteen to twenty discrete "pieces" (for instance, in the sentence "He got up from his chair and left the room" there are two pieces, "getting up" and "leaving.") I was to re-tell the story, including as many pieces as possible. The normal range for this test is to remember anywhere between 7 and 13 elements. I remembered only 8, still within normal range. Carol said, however, that a person with my IQ should be able to remember at least 13 elements. In other words, taking my IQ into account, my low-normal score indicates impairment in that particular area that measures a certain kind of memory.

Part of the official report is a narrative account in which the interpreter summarizes the implications of the evaluation as a whole. The report, Carol felt, was too brief and did not explore the inconsistencies that Carol had noticed.

Her conclusion was unequivocal: the testing that had previously been interpreted as showing no impairment did in fact show considerable impairment.

Carol's report has been quite important for me emotionally, which I'll look into in my next post. I realize that I'm just choosing one expert's opinion over another's without having the professional expertise to evaluate one over the other. The NIH version, however, makes me

feel crazy, and I'm not crazy. For now, I'll stick with not feeling crazy.

Friday, January 17, 2014

Washington DC

When Experts Disagree (2)

In my last [post](#) I reviewed a reinterpretation of my neuropsych tests, that, in contrast to the official NIH interpretation, indicates definite impairment. The essential logic was that the NIH report analyzed the results of each of the many separate test items in isolation rather than in relationship to one another. While almost all of the individual tests were within normal limits, the new interpretation by my neuropsychologist friend, Carol, was that the relationships among the tests indicated impairment.

Carol also said that there were subgroups of people who seemed to do significantly better on tests (even when compared to academic peers) than in daily life. Doctors, she said, are often in that group. Apparently, it's a combination of an ability to concentrate better than others with a similar IQ and having developed test-taking abilities, ie strategies that enabled better test scores than people who didn't strategize.

I don't know whether or not I belong to this subgroup, of course. But it would help explain why almost all my individual tests were normal. Aware of the importance of the test, I remember concentrating intentionally and intensely on each item. I wanted to make sure there were no careless mistakes. Even as I took the test, I was surprised by how well it seemed to me I was doing.

I'm also aware of specific strategies I've developed, mostly based on having taken the previous tests, which have had some of the same items as in the NIH test. One item, for instance, required me to come up with as many words beginning with a certain letter, say "f," within the space of a minute. I'd done poorly on this item in previous testing, so, as I ruminated about my poor showing afterwards, I found myself repeating the test mentally using different initial letters. I discovered that once the initial rush of words beginning with, say, "f," slowed, I could add a second letter, say "r" and began thinking of words that began with "fr," which brought a second rush of words to mind. Once that slowed, I changed the second letter again

and so on. It made a huge difference. Another test item asked me to remember a series of unrelated words or numbers. This time, I concentrated deeply and repeated under my breath the words or numbers several times as each new word or number was given to me, thus creating an inner “aural memory” that significantly augmented my ability to remember.

So there are good reasons to consider the possibility that the cognitive exam interpreted previously as normal does, in fact, show evidence of impairment.

This new interpretation helps me understand why my own perception of my cognitive abilities is so much more dramatic than it is to most others. I *do* generally function normally, but at a lower level than before. This is called “subjective cognitive decline” (ie the perception of impairment in the face of normal objective testing). And perhaps the word “decline” is better than “impairment.” Mostly I’m not impaired in a way that others would notice, but I know I’ve declined.

Perhaps the most important result that came out of the retesting was that Carol noticed something I’d overlooked in the background of the NIH narrative summary. Commenting on the reports from last summer’s MRI, the report stated that “the recent brain MRI was read as showing generalized cerebral volume loss and small vessel occlusive disease.”

I was shocked, actually! These findings are consistent with *vascular* cognitive decline, ie impairment due to the obstruction of tiny arteries in the brain, sometimes called “mini-strokes” or “multi-infarct” disease. I had been under the distinct impression that both MRIs during the past year had been normal.

Even after my brain scans indicating [no evidence](#) for Alzheimer’s, I never seriously considered vascular impairment; I thought it had been ruled it out. (Several correspondents on this blog and in personal emails, however, suggested the possibility.)

I’ll write on vascular impairment next time.

January 21, 2014

Washington DC

Vascular Cognitive Decline

As I wrote in my [last post](#), the background summary to my neuropsychological test results reported that my “recent brain MRI was read as showing generalized cerebral volume loss and small vessel occlusive disease.” These findings are most consistent with vascular impairment. Since I had been under the assumption that my previous MRIs were normal, this is a powerful indicator that my cognitive decline is due to vascular disease, which had previously been ruled out. (I’ll be checking my conclusions with my neurologist in a few weeks, but I think my conclusions are correct.)

As I wrote in my post of Oct 30, “[Letting Go of Alzheimer’s](#),” the false negative rate (the percentage of tests incorrectly indicating Alzheimer’s) for the PET brain scan I had is very low; I’ve since found out that it is under 3%. Since I’ve had two of these scans, we can say with some confidence that the Alzheimer’s diagnosis I’ve been living with for the past sixteen months is almost certainly incorrect. I do not have Alzheimer’s. That has left me quite confused. As I explained in my post of November 28, “[The Elevator Version](#),” in brief conversations with others where I’ve had no opportunity to explain the ambiguity of the test results, I have continued to say that I probably had Alzheimer’s. I can no longer say that.

What is vascular cognitive impairment? It can most easily be described as many mini-strokes affecting tiny areas of the brain that cumulatively lead to a decline in mental function. These strokes occur because tiny blood clots block (“occlude”) very small blood vessels (thus, the name “vascular”) sometimes without leaving a trace on MRI scans. The occlusions then impair or kill multiple small areas of the brain. Exactly what is impaired depends on where the mini-strokes are. How great the impairment is depends on the number and size of the affected areas. Symptoms early in the disease are sometimes indistinguishable from Alzheimer’s, which is why my neurologist said at my [first visit](#) that there was a small chance I did not have Alzheimer’s.

The eventual course of vascular impairment, however, is ultimately different. Typical Alzheimer’s follows a continuous downward curve. Although the steepness of the curve can vary, the gradual worsening is always the same: declining mental function, dementia, and death.

The downward course of vascular cognitive impairment, however, is not usually continuous. Although not invariable, symptoms usually worsen in a step-wise function, that is, there is a period of stable plateau without new or worsening symptoms followed by a sudden decline of mental function (caused by a new shower of clots and occlusions) followed by another plateau. This could explain why my symptoms have not changed much in the past ten months: I've been in a plateau period.

In vascular impairment, the frequency and seriousness of the sharp declines can vary enormously. Sometimes small occlusions happen continuously, causing a steady downward course very similar to Alzheimer's. Other times the clots can be bigger or hit more important brain structures, leading to sudden major changes in cognition, the usual stroke symptoms or death. And still other times the declines can be small and very far apart (or never happen). You just don't know. I could remain this same way for a long time ... or not.

The huge difference is that I can do something that might prevent further decline. There is not treatment for Alzheimer's, but vascular disease is the same process that causes heart attacks and strokes. So the same preventative measures apply: reduce my blood pressure by a diet low in salt and reduce my bad cholesterol levels with aerobic exercise and a cholesterol-lowering diet, or, if necessary, medications to reduce both blood pressure and cholesterol. I already exercise regularly and have normal blood pressure and cholesterol, but for both blood pressure and cholesterol, the lower the better. So a low-salt, cholesterol-lowering diet may be helpful.

This is very good news. I may be cognitively impaired, but the future is not predetermined. As you might guess, this is causing a rather marked shift in my thinking, planning, and emotional state. I'll explore those changes here as I can better understand and name them.

Saturday, January 25, 2014

Washington DC

Dragging My Legs along

We had four inches of snow in Washington on Tuesday evening, not much, actually, but enough to bring the city to a halt. Record-breaking cold weather, down into the teens and even single digits, has accompanied the snow, so it has stuck around for a while. True, we would hardly have noticed this weather when we lived in northeastern Minnesota, but it brings up a longing for the winters there. My memories of cross-country skiing through the forest near our house are among my happiest.

The city was beautiful, however. Marja and I stretched our regular evening walk to about an hour, enjoying the snow hats on the front-lawn bushes, the empty streets, the wind swirling down the main corridor of our local business area, one house with Christmas-tree lights still on the pine tree in its front yard, and the occasional person struggling against the wind and the cold. When the temperature is this low, the snow gets crunchy underfoot, evoking memories of walks in Finnish winters where we also lived for awhile. When it's this cold, the snow is no longer slippery, nice for an old man whose balance ain't what it used to be. It was absolutely glorious to be out in the quiet city.

As we walked, however, I noticed that I kept leaning forward. Marja noticed it to. We always walk quickly to get the exercise as well as our nightly togetherness, but Tuesday evening, I almost couldn't help speeding up. Unintentionally I kept leaning forward, and legs seemed to be hurrying up to catch up to my upper body, which seemed to be dragging my legs along. I stepped off a curb and almost tumbled forward into the street. I didn't fall but only because Marja and I often hold hands, as much for balance as for tenderness.

Before I was aware of my cognitive decline, I would hardly have noted an isolated instance like this. With my impairment, however, my medical mind switched on, and I thought immediately about Parkinson's disease. One of its signs is a "festinating gait," which is one image I have from medical school: a guy pulled faster and faster by his upper body. Parkinson's is often a cause of dementia, too. Naturally, I googled it when we got home. It turns out, however, that my gait didn't really meet the criteria to be festinating. I'd forgotten the other elements it comprises: stooped position; short, shuffling stride; absence of an arm swing; difficulty starting and stopping; and so on. It also turns out that a festinating gait doesn't show up until late in Parkinson's when many other symptoms would have become obvious.

The mental jump to thinking about my impairment is understandable, I suppose. My diagnosis is uncertain, different diseases have different prognoses, and I'm a doctor with a natural curiosity.

But I also wonder if it's an unhealthy preoccupation with the future. In the months following my diagnosis, I felt a wonderful freedom from concern about the future. I lived more in the present, more in tune to others and the world in general. It was wonderful. Some of that remains. On the other hand, I find myself now, twelve months later, a little less in tune with the others, more often pre-occupied with past and future. Is this thinking about Parkinson's a "preoccupation" or something less neurotic?

I don't feel *worried* about the future, mostly *interested* in it. It's a mental challenge to put together all of my symptoms and test results, and wonder about the different futures. So I don't really feel worried. In any case, this is my present moment. Wondering about what's happening now, even wondering about my future is what I'm doing in this present moment. And the present moment is where I want to live.

Wednesday, January 29, 2014

Washington DC

Letting Go --Third Time Around

I had my appointment with my neurologist yesterday. He had reviewed the records from NIH, including the [MRI](#) that showed "generalized cerebral volume loss and small vessel occlusive disease." He didn't seem impressed. He acknowledged that the MRI was consistent with cerebral vascular disease (which I thought was the likely diagnosis) but then said it could be from normal aging, too. Neither was he impressed by the [alternative interpretation](#) of my [neuropsych report](#).

He sees no good evidence of brain dysfunction or cognitive impairment. It's good news. "Come back in a year."

Marja heard the note of frustration in my voice as I told her about my visit. "Why are you so attached to having a diagnosis," she asked. Another friend commented: "Sounds like you're going to have to let go of your 'self' again."

It's true. A year ago, as I was getting used to the diagnosis of Alzheimer's, I wrote about having to [let go of self](#) and I've mentioned it a lot since, for instance, [here](#) and [here](#). The Buddhists point out that hanging on to one's sense of self is a sure recipe for unhappiness because our self is always changing. A year ago I was letting go of my self-image as an intellectual, as the independent, competent one who needed no help. That was difficult enough, for that self-identity had been a long time in the making.

But the self always changes. Now I have to give up the self who is the Alzheimer's patient, the one who would create much suffering for his family as he declined, yet also the one who is losing his intellectual capacities but accepting it with grace, the one who is progressing steadily toward severe dementia yet not being overwhelmed by the pain of it, and the one who is willing to speak and write about his disease publicly. That identity was an attractive self that I had become very attached to over the past year. It's hard to let it go.

The Buddhists are right again: In spite of the overwhelming good news of the last several months, I have felt almost cheated, suffering this loss of identity, unable to embrace the good news in all its fullness.

It seems, however, that my visit with my neurologist today severed most of the cords binding me to that old identity. It's curious, for there was no new news, just a reiteration of what's been said before, yet I feel much more freedom from that tension between who I am and who I thought I was.

I am certainly left with questions but mostly wonderful news. The question has to do with the cause of my cognitive decline and what it portends. That's far outweighed, however, by the wonder of it. I suppose it's that I previously had enough cognitive reserve that my decline doesn't really hamper me in any important way, and it's rarely noticeable to others. My cognitive capacity has stayed stable or even slightly improved over the last sixteen months, and there is no reason to believe it will decline further. My brain scans rule out Alzheimer's. Some other people with documented mild cognitive impairment have stayed stable or even improved, so—while there's no good explanation—I am no rarity. There's no bad news here except uncertainty about my future ... and who doesn't live with uncertainty about his future?

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.

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