

Blog Posts from November 2013

Sunday, November 3, 2013

Martha's Vineyard - (visiting my sister)

Thank You!

The responses to my last post about my normal cognitive exam have touched me deeply. Almost all of them have been notes of understanding, appreciation, and love. They've helped me realize what a wonderful little community has formed around this blog. And I suspect that the community is considerably larger than only those who post comments or email me.

Some of the responses have been of empathy and compassion. From these I receive a great deal of emotional support. It is important when one person will listen to another's pain.

There are a few others of you out there who, like me, also have some degree of subjective cognitive impairment, but their objective neuropsych tests and brain scans are normal; you are or have been in a state of uncertainty similar to mine. It's reassuring to know that I'm not alone, that this little community includes those in very similar situations.

Some of you have found a particular solution to your uncertainty and hung on to it; others have taken the route that I find most comfortable, learning just to live with the uncertainty. It is good that we take whatever will work for us.

A number of you have reminded me of the ultimate uncertainty of all medical science and especially with the brain where there are large areas still unexplored and not understood. As a medical person myself, I do at some level know this, so it's good to be reminded. There is still much mystery in disease and healing.

A few readers have suggested that the spiritual task is to let go of the images of my "self,"

whatever those images are. Buddhist teachings are insistent that hanging on to *any* images of self—“Alzheimer’s patient,” intellectual, blogger or teacher—leads to suffering. The self is an ever-shifting shadow that eludes any kind of definition. In the Christian tradition, too, we remind ourselves that whoever would save his life will lose it. Let go! Let go!

And then there are those suggesting other possible diagnoses. In most cases my doctors have ruled these diagnoses out (as much as medical science is capable of it) by the pretty thorough testing I’ve been through. But anything is possible.

A few have urged me try or at least look at new treatments. For a number of reasons that I’ve discussed in previous posts ([here](#) and [here](#)), I’m reluctant to begin treatments substantiated only by anecdotal evidence. (If I had followed one or another of these bits of advice and started coconut oil or done crossword puzzles or tried whatever, I’d now be the new poster boy for that treatment.) I understand well why others try these treatments and would not try to discourage them from that route. But it’s not mine, and I don’t even look very seriously at the details of new treatment. Nevertheless, I appreciate the concern with my wellbeing that the emails evidence. I’m grateful.

All of this indicates to me that there are a lot of us in need of information, community and concern. It’s all the more reason to keep trying to bring this dread disease out of the closet and into the light where we can all look at it and offer one another the help we need.

Thank you all for sharing in this community!

Thursday, November 7, 2013

Washington DC

Normal Aging

“My memory is going, David; I just can’t remember names like I used to, and sometimes I can’t find the word I’m looking for. Am I getting Alzheimer’s?” Before dying, clearheaded, at age 88, my father asked the same question of me, his doctor son, almost every time we visited

for the last twenty or so years of his life. He tried to cover his concern with humor, but he didn't think his memory loss was funny.

His dilemma is common. It's easy to confuse normal aging with the symptoms of early Alzheimer's.

Some of us have minds just as clear as anyone else our age, but we worry that we're impaired. Others of us can have significant cognitive impairment but we dismiss it as just normal aging. It can be difficult to know. It's complicated by the fact that most of us who do develop cognitive impairment are also aging, so the normal changes of aging can slide imperceptibly into cognitive impairment.

While it might be tricky in those transition cases, it's ordinarily not difficult to differentiate one from the other. A rule of thumb: When changes begin to disrupt our daily activities, it's past time to be evaluated.

(Much of the following is derived from the [Alzheimer's Association](#) website.)

Changes in memory are the first symptoms usually noted in both aging and cognitive impairment. It's quite normal for older people to forget names or appointments (although we'll usually remember the appointments later on), but if we find ourselves forgetting *important* dates or events, increasingly needing reminder notes to keep things straight, or needing to ask for the same information several times, then we might want to get checked out.

It's not just memory, though: changes in *any* area of mental functioning can indicate trouble. As we age, it's quite normal to make numerical or calculation errors when, say, balancing a checkbook or calculating a tip in our heads. However, having difficulty concentrating and taking longer to do things; having increasing trouble following recipes or keeping track of bills, or experiencing challenges in planning or in solving problems are different matters and should be taken more seriously. In my own case, the first sign my daughters noticed, even before I received a diagnosis, was that I was taking longer to complete the little home improvement projects I like to do when I visit them.

As older people, we might normally lose our sense of direction for a while, but when we forget where we are or how we got there, then it's time for an evaluation.

We all lose things and it does seem to get worse as we get older. But when we not only lose them but also have difficulty in re-tracing our steps to find them or when we put things in unusual places (like the lukewarm coffee into the refrigerator rather than the microwave), then we've probably slipped over from normal aging into the area of impairment.

As we age, our judgment can become slightly less reliable, and we can make bad decisions once in a while. But when we make repeated mistakes handling money or pay less attention to personal hygiene, then there may be problems that should be evaluated.

It's quite normal to feel weary of work, family or social obligations and want to quit. But when we actually withdraw from social obligations or don't go to work, then things have changed.

As we age, we can get more set in our ways and less flexible dealing with newness; we can then become irritated when pushed out of our routines. That's normal. But other changes in mood or personality—becoming confused, suspicious, depressed or fearful—are more serious.

Knowing the differences is important. There are treatable and reversible causes of cognitive impairment (vitamin B-12 deficiency, hydrocephalus, insufficient thyroid hormone, depression, medication side effects and other). So if we have any questions about our cognitive abilities, we should have ourselves evaluated earlier rather than later. The first step, however, lies in knowing roughly where the borderline between normal aging and abnormal cognitive impairment lies.

Monday, November 11, 2013

On Amtrak somewhere in West Virginia

Uncertainty and Trust

I'm learning about uncertainty.

I no longer have a reasonable medical explanation for my own experience. An extensive battery of medical tests gives no physical evidence of brain dysfunction. Laboratory results for many of the usual and unusual causes of cognitive impairment have been normal several times over. Two different MRIs of my brain have been negative for brain tumor, stroke or [hydrocephalus](#). Two [PET scans](#) give no evidence of Alzheimer's disease or even dementia. And, most disturbing to me, recent [neuropsychological testing](#) shows no evidence of any cognitive impairment at all. So intensive medical examination that would be expected to explain my symptoms [cannot](#). There are no more tests to take. I must learn to live with the uncertainty. In the past I've not liked uncertainty, but this time it hasn't been so bad. Whatever my impairment is, I've learned a lot over the past year about accepting uncertainty. Despite the uncertainty, I'm actually a lot happier than I was two years ago.

I can only wait and see what develops. Either my symptoms will get better, or they'll stay about the same, or they'll get worse. If they get better, I don't think I'll really care much about what caused them. If they stay about the same, I'll probably never find out what's causing them, but I'm in good enough shape right now that life would be fine. If my symptoms get worse, the physicians will eventually find evidence of my impairment if not a cause. So, I just have to wait.

I can partially explain my acceptance because—regardless *why* my brain function is slowed—there's no treatment anyway. So the waiting becomes more of a spiritual discipline, a training period for living in the here-and-now and accepting the world as it is.

I'm learning to trust myself.

I'm a child of the Enlightenment, which accepts as definitive truth only things ultimately provable by physical evidence; according to that philosophy, just because I experience something doesn't mean it's real. It could be a mirage, a misunderstanding, a hoax, or all sorts

of things that would make my own experience unreliable. As a physician, I had too many patients whose story simply didn't match the evidence I had. True, for many of them their symptoms *were* psychosomatic: very real but due to emotional not physical causes. Some of those contradictions were later resolved by re-examining the lab or x-ray tests. But some were just mysterious. Unlike most physicians, I suppose, I felt responsible to believe those mysterious stories, trusting my patients' experiences even if I couldn't explain them, yet.

Trusting my *own* experience in the face of contrary objective evidence, however, is new for me, and it's taking a little bit of practice to get used to it.

I *know* I'm experiencing cognitive impairment. I trust that it is real despite the evidence. I'm choosing to trust myself more than the evidence. This isn't easy for me. Even writing this I feel defensive, vaguely guilty. (Just for you who worry about me, I don't *believe I'm* guilty of anything; it just feels that way.) But this past year of living with uncertainty about my future has given me some small confidence to trust that I'm okay in the here-and-now. When I live in the here-and-now, uncertainty about the future ceases to matter.

Friday, November 15, 2013

Seattle WA

The Truth of This Blog

I notice that I'm allowing the uncertainty of my diagnosis to inhibit my blogging. As I said in the [last post](#), the uncertainty is not that difficult for me personally; my symptoms are no less real to me than before. I do realize, however, that, for many other people, the lack of objective evidence of cognitive impairment renders the value of this entire endeavor questionable. Whatever my subjective experience, if there's no medical evidence of Alzheimer's (or, worse, no evidence of cognitive impairment at all), then, for many others, this blog might be an interesting study in psychosomatic illness but of little interest to those who are concerned about the inner experience of Alzheimer's. For those particular people, my writing about my symptoms may seem an almost pathetic, last-ditch attempt to convince myself and my readers of the reality of these symptoms.

All of which makes me a bit defensive writing this blog. Nevertheless, this blog is about my

experience of whatever-I-have, so that's what you'll get. In fact, of course, the doubt of others and my defensive reaction to it are all part of the process, anyway. I just wanted you to know what's going on internally as I try to sort out this new phase.

Anyone with early Alzheimer's, I suspect, has such doubts. As I've worked with my uncertainty of the past few months, it's been helpful to categorize my symptoms into two rough and overlapping groups.

First, there are the "Well-that-could-happen-to-anyone" complaints, such as loss of memory, difficulty in word finding, deterioration of my ability to type, and so on. Everyone has experiences like these and they increase as [one ages](#). They're poor evidence of disease.

Then there are the "Now-that's-real-impairment" symptoms: [getting lost](#) in a place I knew fairly well, the severe loss of ability to work with [spreadsheets](#), the [episode with the keys](#) and others. These are not easily dismissible.

Over the course of the last three years, I've had a number of the latter "Now-that's-real-impairment" symptoms. They occur only infrequently—the last was at the beginning of August—but they've been important in helping me and others to accept my diagnosis.

There are also two things about the "Well, that-could-happen-to-anyone" symptoms that remove my doubt. First, their frequency has been staggering:

- I now search around the house multiple times a day every day to find things I've just put down. Not only have I lost my backpack three times over the past couple of years but I would also have lost it several more times if someone else hadn't noticed and pointed it out to me.
- Anyone can have trouble word-finding, but I am daily having to use less-than-satisfactory substitutes for the word I want

Second, these symptoms may be normal for some people but they are decidedly not normal for me.

- It wasn't until yesterday when I reread [last week's post](#) on the difference between Alzheimer's and normal aging that I recognized I'd written about the same thing at least twice before ([here](#) and [here](#)).

- I've been forgetting some of the "shortcut keys" that I've used in my word processing program almost every day for over ten years. Only later do they come back to me. My wife Marja is unimpressed: "I can't remember any of those shortcuts at all."

Maybe some other people have trouble with such things, but I never did before.

Because I've been aware, however, of how my normal tests this might seem to some others, I've become almost embarrassed to be writing these posts. But then I remember the purpose of this blog: to describe my own experience of cognitive impairment, whether or not it's convincing to others. I'm to write down the truth of my experience, and it's up to others to decide whether it's helpful for them or not. My truth at this point *includes* my defensiveness and my reluctance to write about my symptoms. If this turns out to be a chronicle of a "worried well," so be it.

Wednesday, November 20, 2013

Seattle WA

Alzheimer's Anonymous

Since I began this blog in January, I've received hundreds of comments and emails in response. Many have written to express appreciation for my posts and the subsequent comments. Especially over the last two weeks, people have written to encourage me to keep writing despite the [uncertainty of my own diagnosis](#) . It's very gratifying, of course, but I do ask myself why the blog is so helpful.

Part of it, I think, is that I try to speak honestly, and that seems to encourage others to respond in kind. Isolation is a source of great pain for both the caregiver and the person with Alzheimer's (or other cognitive impairment). This is still a disease that provokes [shame](#); most people are afraid to speak of it or relate to it, which leaves both the person with Alzheimer's and their caregivers alone with their disease. But here in this blog, the taboo can be broken, and we can think and speak more openly, sharing with one another, overcoming to some degree our isolation. For some readers, it seems that the embarrassment and humiliation are so acute that simply reading here about others' openness and honesty is cathartic.

I'm reminded of Alcoholics Anonymous (AA), actually. A close friend suffered from alcoholism for many years. Before she got sober, I suggested a few times that she attend AA. No, she said. She wanted to get sober on her own. She didn't want to be with *those* people. She tried to stop several times on her own, but it was only when she finally started going to AA that she began to recover. AA very quickly became the lifeline that enabled her to stay sober. For many years she went at least daily (sometimes several times a day), even when she was traveling. Today, years later, she still goes almost every day, and many of her friends are exactly "those people" she previously didn't want to associate with.

AA is many things, but at its heart it's a place where alcoholics can share openly about the day-to-day struggle to remain sober. There's no "cross-talk," that is, no one criticizes you, gives you advice, or even comments on what you said. Meetings are confidential, so members feel safe to speak candidly. Much of the miracle of AA, it seems to me, is simple: if I can talk without fear of censure about my pain and if others will simply listen and understand, my pain becomes more bearable.

I wonder if this blog doesn't operate in somewhat the same way. Emails sent to me personally and comments on this blog frequently commend my "honesty" in describing my own struggle with my impairment. Part of what they are referring to, I think, is that they have no safe context in which they can speak openly about their experience: their fears, their grief, their mistakes, their anger, or even their joy. It's not difficult to speak honestly when we feel secure and protected, so I'm assuming that those who find my candor helpful don't have many places where they feel safe enough to speak honestly. They have no Alzheimer's Anonymous.

Actually, there are groups all across the country that may be the equivalent of Alzheimer's Anonymous. The [Alzheimer's Association](#) has lists of groups for caregivers and increasingly of groups for those with impairment themselves. The groups are sorted geographically so that you can find one in your area. People write that these groups can be their lifelines. But too many people, I suspect, continue to struggle in isolation.

We all need a place where we can share without fear about the realities our experience, where another person will listen without judgment. This blog is one such place for me. It's my hope that each one of us touched by this disease will find his or her own place to speak and be heard.

Monday, November 25, 2013

Seattle WA

The Challenges of IKEA

I'm visiting my son Kai in Seattle. He's a carpenter and currently building a basement apartment in his house. While I've been here, we've been installing kitchen cabinets together.

IKEA cabinets are, apparently, of good quality and relatively inexpensive ... but you have to assemble and install them yourself. IKEA sells internationally and has chosen to obviate the need for translation by creating assembly instructions comprising only pictures and diagrams, no words at all. The instructions are very clever, walking you through complicated procedures one small step at a time. They are thorough and accurate, but they are not simple.

Since Kai's the carpenter and it's his kitchen, I've been the assistant, deferring to him in interpreting the diagrams. Yesterday, however, Kai asked me to attach a cabinet door. The assembly was a little different from the others we'd done, but not particularly complicated. On my own, however, I was completely flummoxed. The two of us had previously put one small part of the drawer together, but I couldn't even find the place in the instructions where we'd stopped. I looked for ten or fifteen minutes and just couldn't figure out where to begin. I told Kai, he took over, and we got the job done.

Afterwards, we watched football together, went for a long walk and picked up a pizza. On the way home, I asked him whether he had noticed any impairment in my cognitive capacities, anything other than my reports of what I was experiencing. He pointed to the difficulties with the IKEA diagrams. He told me that that's the kind of thing you used to do better than I could.

He's right. That kind of capacity to translate diagrams and interpret the proper sequence of steps to complete that task had always been a strength. I'd enjoyed similar tasks and would have looked forward to it as a challenge, knowing that if I took my time, I'd get it done. But that's changed.

Kai and I talked about it later, and he asked if such impairment is frustrating for me. I would have thought so, too, but, in fact, it hardly bothers me at all. I'm cognitively impaired, I understand I'll be increasingly limited and, importantly for me, that I am not to blame, so it's been easy to let it go. I remain surprised by such equanimity, which had previously not been my forte, to put it mildly. I'm very grateful.

In diagnosing cognitive impairment, there are several different domains. Most common in Alzheimer's is problems with memory, the so-called "amnesic" type. Non-amnesic symptoms include limited abilities to make sound decisions, judge the time or sequence of steps needed to complete a complex task, interact socially, or translate visual cues. In addition to a dominant impairment in memory, a second, lesser impairment in another of these domains is additional evidence for Alzheimer's.

What surprises me is how symptoms can be so specific. Despite my inability to assemble the door to the cabinet, I was able to analyze several single-step problems that initially confused even Kai. Also surprising is how sporadic symptoms can be. On another day, I could probably have gotten the cabinet door assembled.

Thanksgiving, November 28, 2013

On Amtrak somewhere in eastern Montana

I'm finding it difficult to come up with material for this blog. I think it's a form of writer's block.

I suspect it has to do with my fixation on the scientifically determined medical diagnosis. For those of you who haven't been following this blog, all my objective tests for causes, or even for cognitive impairment itself, have been normal, yet I'm still convinced it's Alzheimer's:

- I know I'm impaired;
- 80% of all people with cognitive impairment have Alzheimer's;
- the pattern of my symptoms is typical of Alzheimer's; [\[1\]](#)
- my medical tests have shown no evidence for any other cause of cognitive impairment;

- therefore, I'm convinced, the [likelihood of Alzheimer's disease is high](#) .

So I'm comfortable referring to my cognitive impairment as Alzheimer's as long as I can take a few minutes to explain the scientific uncertainty of the diagnosis. But what do I do in a two-minute explanation? How do I refer to myself in a posting here for someone who might be visiting for the first time?

My discomfort, I think, comes from the fact that when I was practicing as a physician, my patients expected me to confirm their diagnosis scientifically. I was certainly aware that medical testing could be in error, so—if the science couldn't explain their symptoms—I didn't discount their experience, but my job, nevertheless, was to report the scientific facts. If the science and the patient's symptoms didn't agree, my job was to describe the discrepancy (usually at length) and give an *opinion*, not to make an absolute judgment. So, in those cases, I always felt the longer explanation was always necessary.

Furthermore, honesty is almost an absolute value for me, and saying, "I have Alzheimer's" when the objective testing suggests otherwise feels misleading. Yet, if I describe my illness in the elevator version as a "subjective cognitive impairment," almost no one's going to understand what I'm talking about, so such a description is misleading, too. So, in fact, describing myself as having Alzheimer's is *less* misleading. Nevertheless, I'm emotionally uncomfortable without the qualification.

I believe I need to get over my qualms. I will change the introduction to the blog and to my website to reflect the uncertainty, but, despite my discomfort, I'll include the word "Alzheimer's" in my two-minute, elevator version.

I hope that getting over my irrational scruples will help break this writer's block.

I remain grateful for the support so many of you have expressed.

[1] There are [several different groups](#) (formally referred to as “domains) of symptoms of cognitive impairment: loss memory (amnesic memory loss); impairment in concentration ; general slowing of capacities (for example; taking long to do things); trouble following recipes or keeping track of bills; and challenges in executive function (for example, in planning or in solving problems)

[December Blog Posts](#)

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