

Blog Posts from March 2014

Monday, March 3, 2014

Washington DC

I spent several hours this past Friday trying to write about the personal implications of the two studies I'd posted about in the previous ten days. [One](#) follows people with mild cognitive impairment (MCI) who revert to normal and are then likely at some point to revert back again to MCI or dementia. [The other](#) follows people with subjective cognitive decline (SCD) who are also quite likely to progress to deeper cognitive impairment. Since I am a little further on than the people in the either study, my idea in writing last Friday was to show that my chances of progressing to greater impairment were even greater than the folks in the studies and to ruminate about how that has left me feeling.

As I was writing, however, I wanted to check a link I'd used in the post on people with MCI. While looking for it, I was dismayed to discover that what I had written over several hours last Friday was almost exactly what I'd written at the end of the post on the MCI study. That had been only ten days before and I'd spent a lot of time on it. But now I'd forgotten that completely. Oh dear!

This is the kind of event that indicates to me how much I've declined. Yet I find myself hesitant to write about it here. First, I've written so much about my memory impairment that I wonder about the value of the repetition. Second, whenever I talk to others about memory issues like this, I almost always get the same response, "Yeah, I know just what you mean. It happens to me all the time. Why, just the other day, I was" Although I don't actually say it out loud, what I feel like saying is, "Well it may normal for you, but it wasn't normal for me." Third, it feels as if I'm being defensive in insisting on my impairment in the face of the [normal neuropsych exam](#) in August. Several people have written in essence: "Why don't you just get on with your life instead of concentrating on the negative? You seem pretty attached to your diagnosis. Get over it."

When I think more deeply about my hesitancy, I realize the flaws in my thinking. The purpose

of this blog is to chronicle the course of my impairment. So *whatever* happens is part of the story, even when I go on and on about my complaints. I'm not a good judge of what will be meaningful for others. My principle behind writing for the past year and a half has been that if I'm interested in a topic, then I write about it. Whether it's helpful to others or not, they will have to decide. Further, I'm sure that my situation is not unique. Others are certainly going through similar confusion, and my telling my story, however boring I think it may be for others, may be of interest, perhaps even of help, to those people.

But these deeper thoughts justifying my writing don't much change my emotional reaction, which is to question the value of what I do. I'm not really fishing for reassurance; I just want you to know.

Sunday, March 9, 2014

Washington DC

It's Hard Not to Worry about Uncertainty

A woman in her mid-forties emailed me recently. She is suffering symptoms of cognitive decline, yet thorough cognitive testing shows no abnormality. She's seen her primary care doctor who's given her the basic screening tests for the causes of dementia than can be tested for, and they're all normal. Doctors have suggested that emotional issues (for instance, depression) are the most likely cause (a reasonable possibility that she was willing to consider), but a year of anti-depressants hasn't changed her cognitive symptoms.

By definition, then, she has [subjective cognitive decline \(SCD\)](#) and is wondering how to deal with it. The only relevant medical test she hasn't done is a

[PET scan](#)

for amyloid to look for evidence of Alzheimer's. As

[I've written](#)

, the test can tell you reliably only that you *don't*

have Alzheimer's not that you do: 20 – 30% of those with a positive scan don't, in fact, have Alzheimer's disease. Unfortunately, too, the scan costs about \$4000 and health insurance may not cover it. As a doctor concerned about health care costs spiraling out of control, I would myself be hesitant to order such a test since it wouldn't change treatment one bit. (In fact, as a patient I did decline my doctor's offer to get the scan and only had it eventually as part of a

research study.) Regardless of how the scan turns out, however, there's nothing to do about it.

In my own case, what I needed most was reassurance that I wasn't crazy, that, regardless of the normal objective tests, my symptoms were real and not imaginary. I sensed the same need in this woman's email. Her complaints are real. SCD is a recognized medical phenomenon. While medical researchers are only beginning to evaluate it, [studies](#) so far have indicated that SCD is strongly correlated with a later diagnosis of Alzheimer's.

She wanted any help I could suggest about what was going on and what she could do. Here's some of what I wrote back (or wish I had written back).

So why are you having such disturbing symptoms in spite of the normal test results?

There are a couple of possibilities. First, you may have had a very high intelligence, giving you a significant "cognitive reserve." *You* know you've declined but you're still well within "normal" range, which is just what you'd expect the tests tell you. A neuropsychologist mentioned another possibility to me: There are groups of people (she mentioned doctors especially) who—probably as a result of how they were selected for medical school and how they've been trained—just do much better on tests than they do in their everyday life.

They know something's wrong but they're just too good at taking tests for it to show up.

One important thing is to recognize that you've done everything possible to have your symptoms evaluated. For most people in a situation like this, half of the worrying and anxiety is wondering whether they should keep fighting for a definitive diagnosis. In your case, the answer appears to be No.

So what can you do?

You're a physician and you're appropriately worried that other people's lives depend on your cognitive capacities, so you want to reassure yourself that you're not putting patients at risk. I haven't looked into it, but I would suspect that there are places that will assess you

anonymously, for instance, a training hospital or state medical society. (Especially if your capacity as a physician is *not* objectively compromised, you don't want to be forced into retirement by overzealous administrators trying to cover their butts if rumors get out.) In your email, you've shown honesty and integrity in revealing yourself. If it were to turn out that you shouldn't be practicing, I'm confident you would back off quickly without needing an outside push.

Work at not torturing yourself about whether your symptoms are "real" or not. If they're due to some emotional cause, so be it. You've already done what to can to check that out, so let it go. Wait and see. Recognize that your spiritual task right now is to live with the uncertainty you've been given.

Your situation can be a learning laboratory for spiritual growth. Most of us need to learn patience. Here's a place to practice. There's nothing to *do*; only live with who you are and what you've been given. Can you accept the uncertainty as your opportunity to learn to live with it without exacerbating worsening your suffering? The Buddhists point out (not in these words) that the only thing worse than being in a miserable situation is attaching yourself to the goal of getting out of it and, therefore, fighting it.

That approach rarely ends happily.

Monday, March 17, 2014

Washington DC

Better

Ever since I announced that I don't have Alzheimer's but some other form of cognitive decline, I've had friends and acquaintances say something like: "I heard the good news! I'm so happy that you're better." In one way, they're right, of course. Having a stable cognitive decline of uncertain cause is better than having inevitably progressive Alzheimer's disease. If "better" means "back to normal," however, then I'm not better. I have by no means regained my cognitive losses.

I notice my impairment in three areas: difficulty in finding the right word, forgetfulness, and occasional confusion. The **word-finding** problem probably annoys me the most. I was an intellectual. I still do some teaching. For me, communicating has always meant finding the precise word to express myself. If I want to tell you I'm feeling "frustrated," synonyms won't do it. I don't mean I'm "irritated," or "upset" or "disturbed." I mean I'm *frustrated*.

Forgetfulness: I can't count on my memory anymore.

- Have we met before? It's my first question on meeting a new person in church. I just can't remember. So I ask.
- What did we decide at the last meeting? I have no idea. If I hadn't written it down or reviewed it before today's meeting, it's disappeared.
- What did I agree to do before Sunday? I don't remember agreeing to do anything. Everything has to be written down and reviewed.
- Without my calendar I have no idea what my week looks like.

It's the intermittent **confusion**, however, that's the most bothersome.

- I was downtown earlier this week and got off the bus to walk the four blocks to my doctors office. I wasn't lost; I knew exactly where I was. I knew where the office was. DC is laid out in a grid, so there's no confusion about how the streets go. I ordinarily have a good sense of direction. This time, however, I got completely turned around and got to the office only by guessing.
- Several days ago I was helping a friend. She was working 21 hours a week and getting paid \$900 a month. What was her hourly wage? This is not college calculus. She's working three hours a day for thirty days in the month, which is \$10 an hour. But I got into multiplying 21 hours by four weeks (84 hours per four weeks) and then trying to estimate the fraction of the fifth week in every month; soon I had to get my pencil out and even then I got confused.

None of these is a big deal. My impairment isn't getting worse. I'm enjoying myself as much as I ever have.

But I don't want people to think that I'm cured. I can't quite explain that, but it has something to do with wanting an honest relationship between us. Whatever. In a longer conversation with

anyone who's actually interested, of course, it's not difficult to describe the situation more fully. What bothers me is how to respond to someone in the elevator (see [here](#) and [here](#)) or when meeting each other at the checkout counter. I think the answer is to suck it up.

It occurs to me that my situation is not that different from many older people with arthritis in their knees, bladder problems, generalized weakness, or widespread aches and pains. Most of the time, when I ask those older folks how they are, I don't really want to know! I'm not interested in hearing their "organ recital." I want to express my happiness with their recent successful surgery or hospital discharge or express my concern for them. What I want from them is a smile and "Oh, I'm doing as well as can be expected." Or "It's going okay." "Or, yes, I'm happy the surgery went as well as it did." If they're smart, those aching older people will make very sure I want to know before they tell me the truth.

It's no different for me. Usually people want to hear I'm okay, that my life is going well, that I'm relieved about not having Alzheimer's. They would prefer, at least for the time being, not to enter into my pain. I can deal with it. Mostly.

Tuesday, March 25, 2014

Napa CA

How Did I Do That?

I'm visiting my daughter Laurel and her family in Napa CA. I've been doing this regularly for the past several years during the grandchildren's spring vacation so that they're able to stay at home without Laurel having to make special arrangements. At 9 and 11 years old, Madeline and Otto are getting to the place where they need less babysitting than they do a simple adult presence. As I write, they're quietly entertaining themselves as they usually do in the morning. In the afternoon, we'll ride our bikes downtown to visit the library. Other days we'll go for a hike, go bowling, visit a museum in San Francisco, or stay home and play board games. I have never enjoyed younger children, but I certainly seem to be enjoying my grandchildren as they grow older.

Laurel said last night that she hadn't noticed that my cognitive impairment causing any problems, and, as she said, "You know I'd tell you if I did."

But I've noticed it.

Otto has a soccer game this Saturday, and I told him I'd be sorry to miss it since I'm starting my three-day return train trip on Friday. Laurel interrupted and said she thought I was leaving on Sunday. Knowing better than to trust my memory, I checked my calendar and, sure enough, she was right. I had reserved my train tickets to leave Sunday morning and arrive in Washington next Wednesday. But, somehow, for the last several weeks, I've had it in my mind (and have been telling Marja and my friends) that I'll get home on Monday.

Because weekends are special family times at Laurel's, however, I always try to stay in Napa through most of the second weekend while I'm here. So I would never have planned to leave on Friday without exceptionally extenuating circumstances; I was bothered by having to leave on Saturday but I never thought it through enough to notice my mistake. It just didn't occur to me. Furthermore, I have no idea why I hadn't noticed my error since the correct schedule is plainly written in my calendar on both my phone and computer and I check them at least daily.

To make matters worse, I had scheduled a lecture to a well-established community group for next Wednesday morning. But the train isn't scheduled to arrive in Washington until Wednesday afternoon. That meeting, too, was on my calendar and must have been there when I made my train reservations. I have no idea why I didn't see the conflict.

And to make matters even worse, last Friday when I became aware of all of this, I wrote an email to the sponsor of the event canceling my presentation without really thinking through whether I had any other options. I have previously committed myself to a smaller environmental foot print when I travel so I haven't flown in years, but I can certainly bend my principles and fly home in time for to offer the lecture. Fortunately, my email to the sponsor didn't get through and I was able to make new travel arrangements without panicking her.

These are the sorts of little personal indignities that come with my cognitive impairment. Friends tell me that they have memory lapses like this all the time; it's normal for them. But it wasn't normal for me before this impairment. On the other hand, the major impact of my lapses is that usually, they only embarrass me. It's not a big deal. I can live with it.

Monday, March 31, 2014

Napa, CA

My confusion when trying to perform multi-step tasks continues. It seems a bit worse than it used to be and certainly more frequent.

My granddaughter Madeline was mildly ill Friday, so we canceled our plans for an excursion into San Francisco and she, her brother, and I spent much of the day inside playing board games, one of which was *Yahtzee*, which was new to me. If you know poker, however, the rules are not complicated. One of them involved the conditions under which you could roll the die additional times during your turn, and the kids tried to explain it to me. After a while, it became clear that I wasn't getting it. Madeline, nine years old, looked at me brightly and said, "That's okay, grandpa, we can explain them to you as we go along."

Madeline had noticed my inability and frustration but showed no hint of surprise, condescension or impatience. She just decided to comfort me: "That's okay, grandpa." We proceeded with the game and, indeed, we had no problems.

A similar difficulty occurred in a cooperative game Laurel, her husband, the kids and I were playing yesterday. Each player gets four "actions" in each turn, but the other players can help figure out which actions should be taken. Needless to say, everyone contributes their ideas one on top of each other, but a consensus usually arises quickly. I'd played the game with them before and knew the rules. Nevertheless, I just couldn't follow the discussions. Once we got beyond the first or second action, I couldn't keep them all in my head simultaneously, nor could I figure out how one suggestion was better than another in helping us win the game. It was like trying to follow scientists discussing a new and complicated theory; I was in over my head. But this was a conversation the children easily understood about a family game. I could only sit and watch, a new experience for me.

Trying to make simple calculations in my head has gotten difficult, too. How many tablespoons are in a cup? There are three steps:

1. I know that there are 15 milliliters [ml] in a tablespoon and 240 ml in a cup.
2. I don't know without a pencil and paper how many times 15 goes into 240, but I do know that 30 (twice 15) goes into 240 8 times.
3. Multiply 8 by 2 to get back to tablespoons and you get 16 of them.

It seemed simple to me. On paper it took me perhaps fifteen seconds. But I just couldn't keep all three steps in my head at the same time.

The impairment is annoying, but, fortunately, I don't feel embarrassed or get angry with myself. Although [I don't have Alzheimer's](#), I know that the chances of my cognitive decline worsening are high (see [here](#)

). If I don't dwell on how much I've lost compared to my past and if I don't dwell on what's coming in the future, things are just fine.

Most religions seem to recognize the same truth, for instance,

Do not worry about tomorrow, for tomorrow will worry about itself. Each day has enough trouble of its own. Matthew 6:34

I've always known this intellectually, but my intellectual impairment seems to have inscribed it in my heart, too.

It's a wonderful gift.

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