

Blog Posts from September 2013

Tuesday, September 3, 2013

Washington DC

Weeping in Church

I've been more emotionally open since my diagnosis of Alzheimer's, and I like it. I've written about this deeper emotional experience [before](#) , but I continue to be amazed and grateful for this new part of my life.

I am enjoying contact with people more, especially the brief contacts with people I know well. I'm physically touching people more, feeling their concern for me, feeling actively grateful for their friendship. As an introvert I still don't like trying to make conversation with people whom I don't know (at a party, for instance), but it's been a bit easier and more enjoyable.

Frequently the beauty or depth of an experience will bring tears to my eyes, especially during our Sunday worship services. Our faith community is fairly small, perhaps forty in attendance every week, so we know each other well. Several mentally retarded people come to our services as do several with mental illnesses in various stages of control.

Every week, we have communion and members of the congregation serve one another. Sometimes, when one of these folks offers me the bread or the juice, I am overwhelmed by profound feelings ... of gratitude. Part of it, I think, is the experience of communion itself, the sense that there is something more than friendship or acquaintance that binds our community together. Part of it is the recognition that we—this man or woman who is serving me communion and I—belong to the same human community. In this moment the barriers that I too often put between us drop away. Our commonalities far outweigh our differences. I feel gratitude that this *particular* person and I come together to share something meaningful with each other. And joy wells up within me.

I don't know quite how to describe this experience of joy; perhaps, it's indescribable, but it

seems to be physical. It's as if I'm being broken open to a deeper reality. I feel tightness rising in my throat. My face twists up as if to cry. Tears fill my eyes (but aren't enough to spill over onto my cheeks). If I'm saying the words of communion, I have to stop for a second or two, almost choking on the words. When I am again able look back at the person, I often experience a moment of peace and sense of deep spiritual connection with him or her.

We also have five or six good singers and musicians who lead the music in the church with creativity and energy. We often sing songs we know well: spirituals, music that one of the musicians has written, beautiful classic hymns. For one of the songs recently, Connie asked those who could to sing the descant. I've forgotten the particular song already (no surprise there!), but I won't forget the welling up of joy in listening to "angel voices."

On balance, I'm surprised to find, the increase in emotional openness more than compensates for the loss of cognitive function. I don't expect that that will continue as my impairment gets worse, but for now I'm grateful.

September 9, 2013

Washington DC

Yes, Get Yourself Tested

Last Friday I visited the Montgomery Hospice in nearby Maryland to speak to a group of fifty staff and volunteers who work with patients with Alzheimer's disease or some other dementia. For twenty minutes I described my [history](#), my equanimity (so far) in the face of the disease, and my paradoxical [joy](#) in the call I've been given around Alzheimer's.

I was surprised (again) by the energy and intensity of the questions. In a past career of public speaking, I've presented about poverty, or American politics and economics, or matters of faith. Usually the questions go on for about ten minutes and then peter out. But this past Friday, the questions were still coming, some with considerable intensity when after a full hour and a half together, time ran out. Something similar has happened in every such conversation so far.

A most common question is some version of “I may be having symptoms; should I get tested for cognitive impairment?” Most of the time the underlying question is probably, “Do I really want to know?” Alzheimer’s disease seems so frightening and there’s no treatment, anyway, so what’s the use of dealing with it before I have to?

I’m beginning to believe strongly that, if you’re having symptoms (other than a mild slowing in your thinking or some difficulty in remembering names and faces, which may be normal), it’s important to get tested and find out whether you have some cognitive impairment ... whether you want to or not.

The most important reason is that not all cognitive impairments are Alzheimer’s or on their way to becoming Alzheimer’s. Many are due to some other disease that is treatable or even reversible. While not curable, vascular dementia (due to small strokes) can be stabilized by stopping cigarette smoking, lowering cholesterol, reducing high blood pressure and controlling diabetes. [Normal pressure hydrocephalus](#) can sometimes be treated. And some other dementias—such as [Parkinson’s disease](#), [Lewy Body disease](#), [Frontotemporal dementia](#), [Pick’s disease](#) and other rarer forms—will have courses different from Alzheimer’s that might be helpful to know about.

And there are some causes of dementia that can actually be cured:

- thyroid disease,
- depression,
- over-medication or side effects from even appropriate doses of certain medications,
- some vitamin deficiencies and
- abuse of alcohol.

The second reason for knowing is that it’s important to be able to plan for the future with spouse, children and close friends. These people will need to know how you want to be treated when you can no longer guide them. A related reason is that [financial planning](#) needs to be done early, especially planning for long-term care.

There are a number of other reasons to get tested that are more individual. In my own case, *worrying*

is always worse than

knowing

. I'd much rather be dealing with a known enemy than wondering whether he might be lurking around the corner. I also want time to prepare friends and family to move through this journey with me, to alert them to what's coming, so that we can avoid some of the stigma and embarrassment that too often accompanies this disease. If

I'm

noticing symptoms, friends and family are going to notice them sooner or later, too ... whether I get tested or not. If I get tested and everybody knows, we can work consciously on our changing relationships rather than feel embarrassment and pretend that nothing is wrong.

The question becomes much more difficult when the patient himself is mentally incapable of recognizing his symptoms ([anosognosia](#)) or is in psychological denial. In the former case, he may be willing to trust his spouse or children to go for a neurological exam, anyway. The person in psychological denial may be the most difficult. In such cases the better part of valor may be retreat.

[In [early August](#) I mentioned I would have a neuropsychological evaluation at the end of the month. I had the evaluation two weeks ago but am still awaiting the results. I suspect that the tension I'm feeling as I await results may unfortunately be keeping my well of material from which I usually draw pretty dry; hence, no post in the past week. I expect I'll have lots to say when I know more about what's going on.]

Friday, September 13, 2013

Waiting

It was exactly one year ago today that the neurologist told me I had "mild cognitive impairment" (MCI) that would almost certainly progress to Alzheimer's. Shortly afterward, I got lost a couple of times while biking, made several major mistakes in the bookkeeping I was responsible for, and noticed increasing difficulty in keeping more than one or two things in my head at the same time. It was bad news, but it all seemed consistent and pretty straightforward.

But then in late spring and early summer, I had a series of [brain scans](#) looking for physical evidence of Alzheimer's, and they were completely normal. 2½ weeks ago, I had an extensive neuropsychological examination of which I'm awaiting results. During the examination, it seemed to me, my memory wasn't as bad as it had been. For the last couple of months, it has seemed to me that I've been somewhat sharper than before.

Last year's clarity about what I have and where I'm heading has become murkier.

It may not be mysterious at all. Perhaps I've gotten so used to the memory impairment that I don't remember anymore what it was like to have a normal memory. Alzheimer's is a disease that is better some days and worse others; perhaps I'm just in one of the better phases. Perhaps I'm one of those people whose disease progresses very slowly (as people with Alzheimer's but normal brain scans tend to be).

Or could I be even getting better. The negative brain scans have opened up the possibility that my symptoms have been due to something other than Alzheimer's. The problem is I don't know for sure, and I don't like the uncertainty.

Is it possible that I'm actually improving and could return to normal? I've been doing some reading about mild cognitive impairment (MCI), but it hasn't clarified an answer to that question. As I mentioned in the [last post](#), there are a number of treatable, even curable causes of dementia: thyroid disease, alcoholism, vitamin deficiencies, depression, and medication side-effects. So if I had MCI from one of those, it would be possible to improve. A thorough medical examination can diagnose any of those diseases, however, and I've had a very thorough medical exam which was normal for all of them.

If my MCI were due to little strokes (vascular dementia), then if the strokes stopped, my MCI could remain stable, too. But the brain scans I've had (the CT scan and the MRI) should have picked up little strokes, and they were normal.

So are there other forms of MCI that might remain stable or even get better? The Alzheimer's Association's recent report, [2013 Alzheimer's Disease Facts and Figures](#), states that some people with MCI don't seem to progress onto dementia and even improve, but research scientists don't really know why. And, apparently, if your MCI is, like mine, an impairment

mostly of memory, then it's unlikely to improve.

All of that leaves me feeling just a bit confused. I'd like to have a long discussion with one of the neurologists, but they, understandably, want to wait for the results of the neuropsych exam.

So I wait and try to learn about uncertainty.

Tuesday, September 17, 2013

Washington DC

Abstractions

I was reading a book on Christian spirituality last night before bed when I realized that I was understanding very little of it. I got the general principles, I suppose, but much of what the author was writing was too abstract, and I found myself just reading along, understanding all the words, all the sentences, but not really getting anything out of the reading. I hadn't read much by this author before, so I blamed it on his writing style.

Then I picked up another book on my nightstand, this one on Buddhist spirituality by a neuropsychologist who writes about brain structure and function, how they are involved in happiness and suffering and their relationship to Buddhist practice. I was fine (even found it very interesting) as long as he was writing concrete descriptions of the brain: its gross anatomy; the 100 billion neurons, each with 5000 connections to other neurons; the relationship between the structure and function of the brain to our suffering or happiness; and so on. I understood these concrete details, but, as soon the chapter veered into the abstractions behind them all, I recognized again that I was getting nothing out of the reading.

It wasn't that these books were too complex for me to understand. The concrete details of the neurology, for instance, were just as sophisticated and complex as the abstractions of the spirituality (if not more so). But the neurology was tangible and material; the spirituality intangible and conceptual. It was the abstractions behind the Buddhist practice (and Christian spirituality) that got me.

I'm very familiar with both Christian and Buddhist spirituality and have enjoyed such books before with no trouble understanding the concepts. Something in my brain has changed. This change is not just about the impairment of memory, at least not directly. This is about the impairment of comprehension.

Another example of my impairment showed itself on Sunday. In our small faith community, as I've [mentioned before](#), we serve each other communion. We line up in one of four separate queues, and each of us receives the bread and the juice from the person in front of us. After each one finishes, he turns and serves the person behind him. This past Sunday I received communion from Wendy in front of me but then walked directly back to my seat without serving my wife Marja who was behind me. I've certainly never done that before! Marja told me later that Wendy and she just looked at one another, tacitly acknowledging that each understood the source of my confusion.

A few minutes after I'd returned from the line and sat down, I realized what I'd done. I noticed that I didn't feel embarrassed by what would have otherwise been very embarrassing for me. I knew that Wendy already knew what was behind my forgetting. She didn't have to wonder what was going on, to check in with other people to see if they had noticed anything, to be a little embarrassed the next time our eyes met. Both she and Marja understood; they could shrug and move on. I could shrug and move on. I was once more grateful that I'd shared my diagnosis with the community before things like this started to happen.

Sometimes I wonder if I'm just [imagining](#) or at least exaggerating this cognitive impairment. Sometimes it's obvious I'm not.

Either way, a friend has reminded me, I will not find equanimity in getting caught up in the debate.

Saturday, September 21, 2013

Washington DC

Invisibility

People like me don't fit the image of Alzheimer's disease, and we're usually invisible to the media, the medical system and the public.

I've commented on this before (for instance [here](#) and [here](#)), but I had an especially powerful experience of our invisibility a few days ago. I'd been invited to participate in a large panel discussion in a press conference announcing the formal release of the

[World Alzheimer Report 2013](#)

. The fourteen-or-so panelists were each given an embargoed copy of the report a few days before the conference and asked to comment. As I looked through the 92-page document, however, I didn't find a single reference to mild cognitive impairment (MCI), to people who look like me. True, the

conference conveners

should be recognized for giving me and one other person with Alzheimer's a place on the panel and the Associated Press recognized for its

[article](#)

. Still, as far as I could tell, we were left out of the report itself.

Since the emphasis in this year's report was on caregivers, I was especially surprised at being left out. People like me, of course, don't need care yet, but I would guess that the help and attention we get *now* will make a considerable difference in how difficult it is to care for us *later*.

These are a few of the questions I asked in my allocated two minutes on the panel:

I'm at an early stage of my disease and still mentally competent. If I talk openly with family and friends about my diagnosis and come to some internal peace with it, will that change how difficult it will be to care for me later on? What can doctors or nurses or social workers do now that might make it easier for person to find that internal peace and so reduce the future burden on caregivers?

If I include in the conversation my wider circle of friends and community, will they be able to give me more support now and to give my wife Marja the support she'll need later on, reducing her exhaustion and allowing me to be kept at home longer? What can we do now to help Marja, other family members and friends to be more able to care for me later?

Will making financial plans now (while I'm still competent) make later care less agonizing for my family? Is there inexpensive or *pro bono* help available?

If my family and I discuss now how I would want those difficult, end-stage questions, to be answered, will that ease their stress when the time comes?

Each of those questions becomes more difficult when the person with Alzheimer's is *incapable* of recognizing their own symptoms (

[anosognosia](#)

). How is that different from psychological denial and how do we tell the difference between the two? Does the difference matter to our care later on? What can we do now to help in the care or preparation for care in the case of someone who doesn't recognize that anything's wrong?

The unfortunate fact is that we don't know the answers to any of those questions. No one has done the research. And we won't know until our image of Alzheimer's changes to include people along a wide continuum of disease. The staggering amounts pain to caregivers and of money from all of us (\$200 billion a year for long-time care of Alzheimer's alone) are shouting at us to wake up.

September 24, 2013

Washington DC

The Difference Between Mild Cognitive Impairment and Alzheimer's Disease

As I've written before ([here](#) , [here](#) , and other places), diagnosing Alzheimer's disease gets complicated and causes significant confusion. I'm now stuck in the middle of that confusion. My primary neurologist diagnosed mild cognitive impairment (MCI) that would almost certainly progress to Alzheimer's. But what does this "almost certainly" mean? When I pressed one of my research doctors, on the other hand, he assured me that I

had
Alzheimer's.

How does a doctor make the diagnosis? A definitive diagnosis can only be made after autopsy of the brain. In clinical practice, however, the criteria for diagnosis of Alzheimer's are impairment in memory and impairment in one of six other areas of cognition, [#**](#) but the impairment has to be severe enough to be dementia, which means they must interfere with normal activities of daily living. So since my symptoms don't yet interfere with day-to-day life, my diagnosis is not Alzheimer's but "only" MCI.

But this creates a problem. Alzheimer's is a progressive disease that begins as long as thirty years before symptoms develop. Autopsies of people with either MCI or Alzheimer's will show the same pathology. In fact, a person can be cognitively normal and still have the pathological changes found in Alzheimer's. So the disease—whatever you *call* it—has symptoms along a wide continuum, and it doesn't make sense to name it Alzheimer's only when it reaches a certain severity. The medical community, of course, recognizes this problem and is moving toward a new definition based on a whole new set of criteria of specific physical changes in the brain that eventually develop into Alzheimer's dementia. Those criteria will include even those who are years from any impairment. So people will be classified as "preclinical Alzheimer's," or "mild Alzheimer's," or "Alzheimer's dementia."

But that definition won't be useful in practice until there are reliable tests, such as brain scans or spinal fluid analysis, that reliably detects and measures those physical changes in the brain. And, so far, the tests haven't been proved to be reliable.

We're still stuck with the problem that you don't have Alzheimer's until you have developed dementia, that is, until your symptoms interfere with your daily life.

Why should I care?

The statistics for how large a problem Alzheimer's is count only those with dementia, which means that they grossly underestimate the numbers affected with the disease, unless the reader understands it all. There are probably twice as many people with some degree of cognitive impairment from Alzheimer's than is usually reported. And that's misleading.

The current definition also makes it difficult for those with early symptoms to know what's going on. If somebody is told that he "only" has MCI, will he be falsely comforted? Do I, for instance, have Alzheimer's or don't I? Using the current criteria, I don't. Using the more inclusive criteria, I probably do. What do I tell others? The subtitle of this blog is: "A Memoir from Inside Alzheimer's Disease." Is that misleading? Or should I go through the whole spiel every time I give a talk or lead a discussion? And if I did, wouldn't that confuse people even more?

Can MCI sometimes be a separate diagnosis? It's unclear. Certainly the vast majority of time, MCI develops into Alzheimer's or one of the other known dementias. But, for instance, the Mayo Clinic [writes](#) that "some people with mild cognitive impairment never get worse, and a few eventually get better." But that doesn't make sense unless MCI is a separate, non-progressive disease, and I can't find scientist suggesting that.

As Alzheimer's loses its stigma, more patients with MCI will present themselves to medical people, renewing interest in the questions around MCI. Let's hope that that murkiness around mild cognitive impairment will clear up soon.

*** In addition to dementia, the diagnosis of Alzheimer's requires an impairment in memory and at least one other cognitive deficit:

- aphasia (abnormal speech),
- executive function impairment (difficulty with planning, judgment, mental flexibility, abstraction, problem-solving, etc),
- agnosia (impaired recognition of people or objects), or
- apraxia (impaired performance of learned motor skills).

September 27, 2013

Washington DC

Genetic Testing

As part of a recent research study, I was tested for the Apolipoprotein E (ApoE) gene, which is linked to the development of Alzheimer's. There are at least three different forms of ApoE, one that seems to protect somewhat against the development of Alzheimer's, another that seems neutral, and another (the $\epsilon 4$ variant) that increases the chances of developing Alzheimer's. I had one copy of ApoE- $\epsilon 4$, that is, I received one ApoE- $\epsilon 4$ gene from one parent and the other parent gave me one of the others. Having one copy of ApoE- $\epsilon 4$ about doubles the chances of developing the usual (old-age) Alzheimer's; if both copies are present, your chances of developing Alzheimer's are [10 to 30 times higher](#) than a person with no copies.

Should you get genetic testing for Alzheimer's? A [factsheet](#) from the Alzheimer's Association (from which much of this post is taken) recommends against routine testing except for research purposes and for a particular, rare kind of Alzheimer's.

More than one hundred different genes are suspected of making you more susceptible to Alzheimer's, although only a few have been *clearly* linked. But genetics is only one cause of the disease. Even an identical twin (exactly the same genes) of a person with Alzheimer's has only a 25% chance of getting the disease.

Of all the genes, the ApoE- $\epsilon 4$ is the most prominent, but having it does not mean you have or will develop the disease; it only means that your chances are higher than average. Even two copies ApoE- $\epsilon 4$ just increase your chances. Many who have the gene will never get Alzheimer's; many who don't have the gene will. Outside a research context, the presence or absence of the gene changes nothing; it's medically useless.

There are three rare genes that are different. If you have one of those genes, you will definitely develop Alzheimer's, and, since the genes are "autosomal dominant," half your children will get the gene and thus the disease, too. The onset of this kind of Alzheimer's can be very young, even in the late twenties or thirties. In these rare cases, however, the family will be well aware of its tragic history, and testing for the gene earlier in life can be very important in

making life decisions, like whether or not to have children.

In the vast majority of cases, however, testing settles nothing. If you just want to know, go ahead and get tested, but be aware that the best you'll get is a false sense of security or an unjustified sense of dread. If you do choose to be tested, you should have careful pre- and post-test counseling so that you don't misinterpret the results.

A potential problem in knowing your genetic status is that the results may be used (legally or illegally) to discriminate in providing insurance (for, say, long-term care) or in hiring. People who choose to get tested, therefore, should find a way of doing so anonymously.

The cause of Alzheimer's is at present unknown. There are a number of risk factors, the most important of which is age. The impact of other risk factors, including genetics, is relatively small in comparison. Except in those rare families with autosomal dominant disease, there is no test that will predict who will or will not develop Alzheimer's.

September 30, 2013

Washington DC

Panties in the Refrigerator

I'm reading mostly novels these days. For most of my adult life, I've read serious non-fiction: politics, religion, economics, philosophy, and so on. I might have read two novels a year if someone pressed them on me. I still do read an occasional non-fiction, but I'm trying to spend most of my reading time with novels.

Part of it is that I have a little trouble staying with fairly abstract readings (as I mentioned in [Abstractions](#) a couple of weeks ago). Another part is that I just don't find myself as interested in the intellectual world any more. (It doesn't help, of course, that our national politics has become so dysfunctional, corporate power so overwhelming, media so subservient, the free market so dominating, and consumerism so unexamined ... whoops, there I go again. Perhaps I'm not so

disinterested.) Intellectual work is getting to be less and less a part of my self-identity. That phase of my life seems to be over: Been there, done that! I'm not even reading much about Alzheimer's.

But perhaps the most important part is that I just *want* to read novels. They're usually less abstract, of course. They tell stories of people who are different from me. They speak to my heart, not just my head. It's part of the increasing emotional openness I'm experiencing. I greatly look forward to my reading time just before bed. Fortunately, I don't have a set time to get up every day: A novel can keep me up hours past my bedtime.

I don't ordinarily read children's books. But seventeen-year-old Max Wallack sent me the little book he authored: [*Why Did Grandma Put Her Underwear in the Refrigerator?*](#) It was short, so I looked at it.

It's a great book! Seven-year-old Julie is the narrator, but even older children who are faced with someone who has Alzheimer's will find it helpful, I think. Grandma comes to live with Julie's family. Not too long after, Julie notices that Grandma is starting to lose things. Julie's worried she might be responsible for Grandma's trouble; maybe Julie's own messiness has caused the problem. Her mom explains simply that Grandma can't remember because she has Alzheimer's disease. After Julie finds Grandma's panties in the refrigerator, she asks her mom about it. She's afraid Alzheimer's might be contagious. Her mom reassures her and describes very briefly the neuronal dysfunction in Alzheimer's. The rest of the book follows the deepening and wonderful relationship between the Julie and her grandmother.

Although I'm much earlier in the disease than Grandma, the book reminds me of my relationship with my grandchildren. My [daughter told them](#) I was having trouble with my memory, which didn't seem like a big deal to them. When I'd lose something or forget how to play a game, they'd sometimes ask me matter-of-factly: "Is that your memory problem?" I'd say, "Yes" and that was pretty much the end of the discussion.

We don't need to protect our children from Grandma's diagnosis. If *you're* okay with it, *they'll* be okay with it. And, at least for the younger children, *Why Did Grandma Put Her Underwear in the Refrigerator?* might be a good way to start the conversation.

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