

Blog Posts from September 2012

The following are posts from my [blog](#) .

Friday, September 14, 2012

Now It Begins

Yesterday, the cliché goes, was the beginning of the rest of my life.

My neurologist's diagnosis of Alzheimer's stuns me. While he never said he was certain, I'm familiar enough with doctor language to know that he's almost sure. In the first few moment after he told me, there were a few minutes of confusion, but then I realized I was not surprised, especially after I'd not been able to reproduce the drawing of the cube.

One small part of me actually felt relief. Finally the meaning of all my symptoms made sense. At an unconscious level, I suspect, I had known. The uncertainty had been relieved. I felt a kind of calm in my soul.

But for another part of me, an abyss had just opened. My life would be forever changed. I wasn't in denial: I knew exactly what was going on and what the ramifications could be.

I asked some pertinent questions, made a follow-up appointment for six months and left without demonstrating much emotion.

As if to confirm the diagnosis, I got lost on my way home from my appointment with the doctor. "Lost" may be too strong a word. I knew approximately where I was and which direction I wanted to go in. The north-south streets in Washington are numbered in order and the east-west in alphabetical order. This should not have been difficult. I went back and forth confused about how the street names worked. Things didn't really clear up until I meandered into familiar territory. From there I found my way home without trouble.

Last night I emailed the doctor, mostly to get into writing what he's thinking and to make sure I didn't misinterpret what he said. Is the disease progressive? Is it Alzheimer's?

As Kaiser doctors usually seem to do, he responded promptly this morning. He's pretty confident that I'm "transitioning" gradually into dementia. Since the radiology, blood tests and physical exam haven't picked up any other causes of dementia, it's "most likely" Alzheimer's. Given doctors' usual reluctance to commit themselves unless things are quite certain, he's giving me a clear message. There isn't much doubt.

I'm alternating between among periods of a) almost forgetting about the diagnosis, b) suddenly remembering it and c) feeling terrible sadness. I don't feel scared. I've never consciously felt afraid of death. I don't usually get worried about future pain. I'm not afraid of physical illness that leaves me significantly impaired. I wouldn't *invite* any of those in, of course, but I've been around death and dying much of my professional life and I've done formal meditations on my own dying and my body's decomposition after my death. But Alzheimer's has always seemed like the worst way to go out. So I don't think I would be scared of cancer or another physical disease leading to death. Curiously, I feel more sad than scared: sad that I'll not see much of my grandchildren's growing up, sad that people's last memories of me will be of a body unable to recognize anyone or speak cogently, sad that Marja and I won't grow old together and that she'll be burdened with taking care of me. That last thought almost brings tears.

What will happen to my relationship with Marja? It will change dramatically, of course, and eventually she won't be able to depend on me for much of anything. She's very independent, though, and will probably do okay. I have no fear that she will abandon me, but what will it be like when I see her depending on others the way she now depends on me? Will I feel the pain of jealousy as if she were deserting me for someone else?

I'm sad that I'm going to be foisting off a severely demented husband on her. She's had over twenty-five years dealing with the unpleasantness of my severe depression. I feel awful—even irresponsible—that after less than twenty years of my emotional stability she will have to deal with this, too. It's too early to worry about these things, I know, but somehow it's the undefined combination of all this coming pain that creates the deep sadness.

Saturday, September 15, 2012

Spiritual Questions

I have always identified my “self” with my intellect. And now it appears that this self is going to change radically. Buddhists suggest that suffering arises just here in this identification with “self.” My identity is as an intellectual and I’m going lose it.

I can’t tolerate the prospect of a declining intellect. What am I then if I’m not the brightest one in the room? How will I respond to people with that embarrassed look in their eyes as I say something stupid? What do I *do* if I can’t have “meaningful” conversations or exchange emails on the topics of the day?

On the other hand, much as I hate to acknowledge any positive side to this illness, I suppose it will intensify my spiritual journey. I have never really been aware of *needing* another person or needing God, for that matter. I’m sure that’s an exaggeration, but one part of that identity will surely disappear is the “independent one.” Can I allow myself to need, to be really vulnerable, to depend on others? Can I allow others to help me? If I can’t, the future is going to be painful. I will now *have*
to
learn to live one way or another without my analytic mind.

I remember a documentary of a daughter caring for her demented mother. She said that her mother used to be so stiff and judgmental, always obsessed with the past or the future, and they’d never had a close relationship. But now, she said, they were fully in the present together, laughing a lot and playing a lot. I can’t imagine myself letting go like that. Can I learn to?

Monday, September 17

I’m interpreting so many mistakes I make in light of the dementia: typing mistakes, skipping words when I write, forgetting where I put stuff. In the past, I have sometimes used my diagnosis of depression as an excuse to avoid things, to pull back from life’s challenges. I don’t want to repeat that mistake here by interpreting everything through the eyes of this illness.

For instance, I'm scheduled to give a talk to a big audience at the International Street Medicine Conference. I've been more anxious than usual. It's not so much the speech itself; I'll write that out ahead of time and have Fred Taylor and Maria Barker read it carefully. It's the question-and-answer session afterward and the later conversations with interested people that precipitate my anxiety.

So should I push myself regardless of the anxiety as a way of keeping my mind sharper? Or should I remove such stress from my life?

I've already decided not to take any more of the large speaking assignments, though. The level of anxiety is greater than I want to handle. I'm okay now but will I be okay in three months to give a speech? Will I feel too much pressure to continue against my better judgment?

The more difficult question is whether I should cancel the classes I teach or should I wait until the diagnosis becomes obvious to other people? Should I resign from my position as the bookkeeper at Eighth Day? The questions are all a jumble now; I think I'll wait to decide those things, but it's unclear.

Tuesday, September 18, 2012

What's hardest now is the level of uncertainty. I think of all these possibilities down the road and follow them on out despite the uncertainty. I look at each little event in which something seems a little off and wonder whether that's normal or a symptom of my illness. Am I using the illness as an excuse to avoid doing what I just don't want to do? Or not?

I had my weekly session with my spiritual director yesterday.

She immediately picked up my reluctance to tell people about my condition "too early." She asked what I meant by "too early." Her question made me realize that I'm mostly afraid of "crying wolf" and then being embarrassed if the diagnosis turns out to be wrong, a false alarm.

After a few of her questions, it became clear that what I was doing was holding on to an image of myself as a careful good thinker, a cool guy who wouldn't rush in and worry others unnecessarily.

But is it worth keeping the secret from my community if it means that I can really ask them for support? As for it being a false alarm, I don't need to state my diagnosis as a known fact ... because it isn't. What I'm really going through now is the struggle with the uncertainty about all of this and the fear of the future. I don't need to say any more than that. I won't be misleading people if I'm having trouble precisely because of the uncertainty. I want to share *that* suffering with those who can comfort me. So even in the unlikely event that the diagnosis were wrong, we could all celebrate together. I want the community to understand how painful my uncertainty and my fear are here in this present moment.

I talked with Patty Wudel this morning and got a taste of telling someone without fear that I was crying wolf. She is an intimate friend, and I love her. I told her everything especially the uncertainty and my fear of "crying wolf." She was quite willing and able to listen thoroughly to my pain, and I didn't fear the possibility of being wrong about the diagnosis. I also appreciated her willingness not to feel the need to dwell on my troubles throughout the entire conversation. We could move easily on to other things that were important to us.

I still don't see the need to share it with people who are not among my immediate support circle (ie make a general announcement to the church). My spiritual director's insight also gives me the "permission" to talk with the family over Christmas, which is far better than having to wait until spring when the diagnosis will be clearer.

Wednesday, September 19, 2012

Is my fear of Alzheimer's bringing me closer to or further away from the fundamental realities of life, from God? Could it be that the vulnerability that I'm feeling (for the first time in my life) will make it possible for me to recognize for God at the emotional level, too. Will my fear anchor me more deeply in the present?

What is the fear? Is it actually a fear of death? I suppose ultimately it is, but I've never been conscious of any fear of death. Perhaps it's a fear of non-being, but what's to fear about

non-being? As much as I'm hate to think of myself lying in a nursing home bed, I'm not aware of fear. Disappointment and sadness? Yes. Fear? I don't think so.

Every day I notice something more that is amiss in my mind. I'm typing slower and with many mistakes; I'm so easily distracted; I'm so slow in getting things done; my memory seems to be getting worse by the week. Are those things evidence of worsening disease or am I beginning to imagine things in order to conform to the diagnosis?

At what point will my impairment become obvious enough to me that I internalize the diagnosis? Or is it already obvious to me? What would I say if I were my own physician? Probably the same ambiguous things that my doctor is saying: "Well, it looks pretty convincing; we can't be sure, of course, without more data points, but it is beginning to look that way." If I were my own physician, I'd share my deep concern. But I wouldn't be any more definite.

Friday, September 21, 2012

I was biking down to Kennedy Center last night and rode into Washington Circle. It was dusk, but I could see clearly enough. Suddenly, everything looked unfamiliar. I tried to figure out where I was. In retrospect, it felt like I had just biked through the back of the wardrobe and into Narnia, and the doorway back was no longer available. The ambient light seemed soft, almost dream-like. I knew I had to find New Hampshire Ave, but I was at a multi-street intersection that confused me. I could see the street signs for I St and for K St, but somehow they didn't orient me. I kept thinking that those streets didn't come this far south. I got confused about which direction the numbered streets went. New Hampshire Ave was less than 100 feet away, but eventually I had to ask someone to help and, even after that person gave me directions, I had to ask another person after I'd walked a little way.

This is the confusion-event that nails down for me the diagnosis of "progressive cognitive impairment." I'm ordinarily good at directions, and I've passed through that circle hundreds of times. I got lost when there was no reason to get lost.

It doesn't *seem* real to me yet, but it's time to stop pretending that it only *might* be; the days we can say "we're not yet sure of the diagnosis" are over. I have a progressive cognitive impairment, which is almost certainly Alzheimer's Disease.

O my! The physical sense of anxiety soaks through me and settles in the core. My mind is numb. I've done just fine preparing this paper for the talk at Salt Lake City next week (both Fred and Marja have read it). Details and nuances are clear. But I get confused riding into Washington Circle! I feel so normal. How can I have such a disease?!! I don't feel different from before; these confusion events must be happening to someone else. But, no! This is me and this is Alzheimer's.

I'm already thinking ahead to the embarrassment I (and, more importantly, others) will feel as this worsens. Will I be shunned as (I'm ashamed to admit) I have usually shunned "such people"? What will I do? My spiritual director suggested in mid-summer taking a sabbatical from analytic thinking (talk about irony), but my conscious efforts have accomplished little. Now the sabbatical will feel more like retirement.

But I'm not only an "analytic thinker." I experience myself as all kinds of awareness. My self-image is of a person who usually understands what is going; who is curious to understand more; who can share with others, listen to them, empathize with them;. But those senses of self will change, too.

The emotional work I have to do is to sit with the Buddhist sense of "no-self." It is not "I" that will gradually deteriorate but only my current experience of myself. And as I worsen, my demented sense of self will not be "I," either. It will still be only my *current* experience of myself. Contrary to Christian belief as usually understood. there is no permanent self or soul. Some sort of experience of "I," I suppose, will still be here, but that won't be the "real me," either. There is no "real me."

I must let go, let go, let go.

Saturday, September 22, 2012

I've only told a few friends about the diagnosis. Up until yesterday, the reactions had been muted: expressions of concern, good listening, questions and time for me to talk it through, but not very emotional. But yesterday during our regular monthly lunch, Carol Marsh had a very

different reaction. After we'd talked for a while about her and her writing classes, I told her about my dementia. She was stunned and could hardly talk. I started to tell her almost immediately about some of the practical questions I was facing (preparing for our future, taking care of finances, and so on), but she quickly silenced me, saying she needed just to take the time to let it sink in. (My launching into all the practical details would have avoided having to face Carol's immediate pain.)

We were together for about an hour, not saying much except the pain of it, how much it hurt and how she and I were going to face the future in our relationship. She promised she would be with me, even after the "me" she knew was no longer there. It was a sorrowful time, of course, but one that brought me closer to the incarnated reality of what's happening. My tears started coming up (but not *out*) for the first time, I felt deep sadness and a sense of loss. Spiritually, I felt in different space, closer, perhaps, to the deeper reality of God.

Marja and I talked last night about telling our grown children. She thinks rightly that we should talk with them before we go out to Napa for Christmas. She suggested giving only an "introduction" over the phone, telling them about some "concern" about my cognitive function but not really telling them outright about what it is. Trouble is, once the conversation starts, I will probably not be *able* to confine my talk to preparing them .

Sunday, September 23, 2012

Standing Out

There are parts of me, I find it hard to admit, that are actually excited about this diagnosis, parts of me that are not really disappointed, parts, in fact, that even want it. It's not the prospect of real dementia or lying drooling in a nursing home bed, of course, but there is something titillating about the present, about being that person who can shock others, who talks honestly about his illness and helps others relate better to it. It's sort of like when I shared publicly what my doctor mistakes had been and meant or the fact of my depression and its meaning. My willingness to talk openly about mistakes and depression—including when I spoke in medical schools and medical conferences—was a contribution to those there. I got lots of positive feedback. Others saw it as a special spiritual maturity.

I've always liked standing out from others, doing things that few others dare (or want) to do. It's been part of my sense of self. This is such an occasion.

How strange!

For the past several years I've been restless, even bored. During most of my adulthood, I've moved or otherwise changed my work every seven years or so. I left Yale for Germany. I left medical school and went to a tiny, remote town. I took a year's sabbatical from medicine to be a house-husband in Marja's home town in Finland. We moved to the inner city of Washington so I could practice medicine with the impoverished. I founded Joseph's House, a home for homeless men with AIDS, where our family lived for three years. I left medicine and took another sabbatical to Finland. I left Joseph's House to become a full-time advocate and writing. But now it's becoming seven or eight years, and I'm restless again. I've known this for several years but haven't really known what to do, what kind of choice to make. But now the choice has been made for me. For these two weeks since the diagnosis, at least, it's been interesting. I can write this blog, speak to audiences, perhaps counsel others. It's a new life, and some parts of me look forward to it ... despite the tragedy that I know is coming.

Friday, September 28, 2012

I've been away all week at the Salt Lake City International Street Medicine Conference. My talk went as well as I could expect ... even a standing ovation. Many of the older participants and even some of the younger ones had read my books and some even mentioned my positive influence on their careers. I felt something of a rock star.

On the other hand, I became even more aware of my increasing disability. The brief question-and-answer period after the talk went well enough. That's ordinarily my favorite part of these speaking invitations, but this time I was anxious ahead of time. But I really felt out of it in the social events afterwards. I just wasn't able to participate in the conversations. Given the anxiety this whole process has engendered, I don't think I should accept speaking engagements to large groups anymore although I still feel like I can work with smaller groups.

I couldn't easily find my way around the college campus where the conference was held. The lecture room was probably no more than a seven-minute walk from the hotel, but I had to ask for directions on perhaps six different trips before I got the route straight.

Someone yesterday mentioned his mother who had had Alzheimer's for ten years. I had somehow been thinking two years or so of being aware of what was going on, a year or two of needing help and then perhaps death in the fifth year. To live so much of my life with this progressive disease seems intolerable. Sometimes the recognition of what is happening to me is a knife wound in my chest. Tears aren't particularly close, but I wish they were.

Saturday, September 29, 2012

Walking around the Denver Amtrak station on the way back home from Salt Lake City, I saw the full moon rising; the "old man in the moon" was just so clear, so three-dimensional, as obvious to me as I can remember. It was beautiful! Is it my desire for God that is opening to non-cognitive beauty? Or is it my cognitive impairment, or is it just a beautiful evening moon when the train trip and my sleep deprivation make my mind more open to newness? It doesn't matter, I guess. It was beautiful!

The present moment in this disease isn't actually difficult, nothing like my depression. The symptoms I'm experiencing now are mildly frustrating. My current suffering, at least, stems primarily from aversion to what's coming in the future and from attachment to a self that I believe will soon be no longer available.

Sunday, September 30, 2012

I was with friends on my way back from Salt Lake City and had really looked forward to talk with them about my diagnosis. I don't know why I expected more, but their response was little different from that of most others. They weren't really able to take the information in or respond to my suffering in a way that was helpful. They listened attentively, they asked some questions about why I was so sure about the diagnosis, and they shared some of their experience of being with others who had the disease. In short they did all the things I would probably have done under the circumstances. But somehow they didn't feel present to the suffering I feel.

Since I would have responded the same to my friend with the diagnosis, I can't blame them. We're close friends. I suppose like everyone else they were overwhelmed by the news of the diagnosis and needed some time to work with it. *They* were the ones who needed the most help, not I. This disease, I'm coming more and more to understand, is not just about me. In

fact, at this point at least, my suffering is probably less than the suffering of those close to me. Like everyone else, I suppose, I would have expected to be devastated under these conditions. But I'm not. Others are. At least for now, it's not about me.

They are both physicians. He mentioned that people don't actually die of their disease but of complications, for instance, pneumonia or severe bed sores. Those who are in better physical shape at the beginning live longer. I'm in good physical shape. I'll live longer.

I'm beginning to hear all sorts of stories about people who live a long time Alzheimer's. I could easily have ten or more years of the disease (especially since I've recognized it as early as I have). That's a good long chunk of life! Jai, my grandson who's two and a half now, will grow up with me—I imagine—as that vacant old man sleeping on the couch, like my alcoholic grandfather. Ten-year-old Otto will probably remember who I used to be but still his dominant image of me will be as demented. I will not spend my last years as the person I have known or as the person I thought I would be.

I'm facing a collapse of so much of what has given me meaning. What is it actually going to be like? I will have to find a way to "live with" this disease. It's different from an auto accident, most cancer, and heart attacks we view as killing the "real me." But demented is how I will be for the last 20% of my life. Dementia *is* my life. Like the quadriplegic, I have to learn how to live a new life. Can I discover other possibilities for finding meaning?

[October Posts](#)