

Blog Posts from April 2013

Monday, April 1, 2013

Napa CA

Helplessness

I'm on the train home from visiting my daughter and her family in Napa, CA. Friday I decided to walk the family dog and join my grandchildren at the nearby park. The dog sometimes slips out of her collar and needs a simple harness to keep her on-leash. But after at least ten minutes of confusion, trying unsuccessfully to figure out how to put the harness on, I had to settle for the collar, stuff the harness in my pocket and, after I'd reached the park, ask my 8-year-old granddaughter Madeline to put the harness on.

This would not have happened five years ago. Although my neurologist is virtually certain I have Alzheimer's, he tells me that I'm very early in the disease and that, in the average case, I would not yet have come to medical attention because no one else would have noticed or been concerned enough to push me toward help. But I know that something is wrong: I can't think as well. The confusion around the dog harness is only a minor thing, of course, but my previous IQ was high enough and my capacity to recognize spatial relationships strong enough to keep this sort of thing from happening. If it had, I'd have been pretty embarrassed.

What surprises me is that such little episodes of helplessness don't cause me much frustration or embarrassment anymore. I was the bookkeeper for our little church; in December I made a \$24,000 [mistake](#) in figuring out next year's anticipated income (ok, that's not a little episode), which created some havoc in the community. I recognize the seriousness of the mistake (and I've therefore given up the task), but I feel no [shame](#) [or humiliation](#)

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This would not have been normal emotional behavior for me. Before my diagnosis, I took such pride in my ability to do such things that a mistake like that would have devastated me emotionally. But it's different now.

Before my diagnosis with this disease, I rarely even contemplated the possibility of Alzheimer's, and, when I did, the thought of this helplessness terrified me. Especially in our country, it seems to me, feeling helpless is not culturally acceptable and frequently occasions shame. We disparage the "learned helplessness" of the poor, for instance, as almost the worst of all sins and blame for their own poverty. Our native optimism convinces us that people aren't really helpless: There's always some way out, and it's their job to figure it out.

Some time ago, a student in a class of nursing students to whom I was speaking challenged me. "Aren't you accepting your limitations too easily; you don't seem to fight against them. If you fought it a bit more, maybe your symptoms would be less intense." Left unsaid was, "You're not as helpless as you think."

We do sometimes make exceptions for those with unavoidable and obvious mental disability such as mental retardation, traumatic brain injury from war, post-traumatic stress disorder (but notice how long it took us to recognize both of the latter diagnoses) ... or Alzheimer disease. And even then, we're not comfortable around those people. Helplessness is embarrassing.

I've been through this before: I suffered from a severe depression for decades before I realized the cause was an organic brain disease. During that period, I was ashamed of my inability to enjoy life; I considered a character defect that I should have been able to overcome. After I understood that the cause of my depression was an unavoidable chemical imbalance in my brain, however, the shame disappeared. I was still helpless, but I didn't have to "try harder" to get over it.

It's the same thing now. I'm not embarrassed when I can't remember ever meeting a person with whom I had a long conversation recently. I'm not frustrated when I can't fix a simple problem with my [file drawers](#). My helplessness is unavoidable. I am not going to get better no matter what I do; my capacities will decline further. This is not my fault.

So I don't fight my inabilities. I can accept this part of myself as real. The sadness continues but not so much the pain of helplessness.

Perhaps part of my symptoms are just my apathy and it *would* be better to fight more. But even if that were true, fighting my plight has its problems, too: more frustration and tension, less ability to talk so openly about my disease, less capacity to notice the fine differences in my condition, and so on. I fought my depression vigorously and ultimately it made me feel worse.

Furthermore, I've discovered a vocation in this sharing my experience wherever I can, and I can't tell the story if I don't accept the realities of Alzheimer's. I'm old enough to understand my limitations, my helplessness in these situations. It may be that someone else who fought their disease would do better; I doubt it, but in my experience, at least, it's been more important to be completely straightforward with my limitations. Acceptance has its own rewards, and I value them highly.

Friday, April 5, 2013

Washington DC

What Happened to My Fears

Things have been crazy since I got back from my California trip!! There have been almost 50,000 page views on the site, over 70 comments, one interview from *CBS This Morning*, requests for six radio interviews, and lots of emails. It's been overwhelming but it's an exciting confirmation of the importance of bringing Alzheimer's out of the closet.

In response to some of the emails and comments, this post and the next will be about the cultural fear of Alzheimer's. Curiously, I'm not afraid of this disease, but why not? What is it, exactly, that I should be afraid of?

What was I afraid of before I knew my diagnosis? It's hard even to remember. I don't think I ever put it into words. So let me imagine what I would have been afraid of a year ago.

Helplessness and dependency: I've always been independent and can take care of myself. It would be awful to have to depend upon another person to tend to my needs. I would hate imposing on them—especially Marja—unfairly, becoming a burden. I don't want to be helpless.

Loss of intellectual capacity: What I've done in my life has been dependent on my intelligence and intellect. To exaggerate a little, I've always been the smartest guy in the room. Who would I be if I lost most of my intelligence? How would I spend my time, if I couldn't use the computer, couldn't write, couldn't even read? Everything that gives me joy would be gone. What would I actually do?

Embarrassment: How would I survive the embarrassment of diminishing memory and intelligence? It would be terrible to forget a friend's name or to repeat myself over and over because I couldn't remember what I said five minutes ago.

Rage: What if I became one of those people who flies into a rage at the drop of a hat, who yells obscenities, who causes pain to others?

Isolation: How would I tolerate the isolation? People would react the way I've usually reacted to people with diminished intellectual capacity, with the embarrassment, even the shame that Alzheimer's carries. They wouldn't know what to say. And so they'd abandon me and I'd be alone.

What would it be like to be *incontinent of feces*? to have to be wiped after every bowel movement into my diapers? How could I tolerate that?

What would it be like to *lie there in a nursing home* unable to carry on a conversation, unable to relate to anyone, unable to remember who anyone is?

So I was afraid then. Why am I not afraid now? I'm not completely sure but:

- Before I would have feared that even this first level of symptoms would be painful, but instead it's been rewarding and positive. What does that say about the rest of my fears?
- My fear was based on my assumptions *as a non-demented person* thinking how awful it would be. But I now realize that because of the stigma and silence that surround the disease, I didn't actually know

what the experience of a demented person was. (I'll write more about that in the next post).

- If I examine closely each of my fears, what exactly am I *afraid* of? Isolation is really the only one I *fear*. The rest of it would be embarrassing or unpleasant, but I'm not afraid of them?

- I've had no embarrassment in telling others and the response of people close to me has been overwhelmingly positive. My worst fear—of isolation—has been put to rest.

- It seems to me quite possible that as things become worse, my dementia itself will change my reaction to what's happening. With increasing cognitive impairment, I may not find my symptoms as painful as I feared. Obviously I can't be sure about that now but, given my experience so far, it seems to me quite possible.

So for me at this point, there is no fear. But I want to read more comments about the inner experience of Alzheimer's. If you have Alzheimer's what's your inner experience? If you don't have Alzheimer's but have asked people with the diagnosis about their subjective experience, tell me what you've heard. And finally I'd like to hear from people who don't have dementia but are afraid of it: What are the *specific* reasons you're afraid?

So far I've received lots emails and comments from people with positive experiences with the disease. I've been surprised that I haven't heard from more people who have experienced the disease from the inside who think I'm naïve, who are saying to themselves, "Just you wait! Tell me in 3 years that it's not so bad." So help me out with your comments.

The next post will be about why the fear is so strong in the culture. How do most others perceive the disease and how does that contribute to their fear? I have some ideas.

Sunday April 7, 2013

Washington DC

Why Might We Fear

Several people responding to the Washington *Post* [article](#) last Sunday have expressed their deep fear of having Alzheimer's. In his comment to my post "

[Adventure](#)

," Richard Fox bluntly asks why more people don't commit suicide after learning their diagnosis.

Where does the fear come from?

Most of the sources of fear that I can think of don't come directly from the experience of people with Alzheimer's at all but from those looking on from the outside.

Our fears may come from the images of Alzheimer's in popular culture, which are almost exclusively of advanced disease: The patient has bursts of anger and paranoia; she wanders aimlessly and can't even recognize members of her own family; he lies mute and helpless in a nursing home bed.

Our fears may come from our observation of severely demented people, staring blankly into our faces, embarrassing us as we don't really know what to say.

Our fears may come from the stories of exhausted caregivers who have been traumatized not only by the terrible emotional and physical stress of caring for utterly helpless invalids but also by the gradual loss of comfort and support from the one they have loved and depended upon for decades. These sources tell us of deep suffering on the part of the caregiver but may not say much about the actual experience of the demented one being cared for.

None of these sources asks the patient directly what it's like to be in his or her mind. And, due to the fear, embarrassment, and shame that surround the disease, no one with Alzheimer's is going to volunteer their stories, either. So we know little about the *experience* of the disease at all.

We know little about the *stages* of the disease (many of which are not so scary).

- Early on, at my stage, no one notices the subtle symptoms and most people aren't

going to volunteer anything, either, so we don't hear about early Alzheimer's.

- As things get worse and memory deteriorates, people learn to hide their disability by faking normalcy (often quite well) or avoiding interactions completely, so we don't know that part.
- At a more severe stage, the person with Alzheimer's may stay (or be kept) out of sight even though she is still able to contribute.
- And after still further decline when the patient's memory has gone, it may be very difficult for the patient to be in public despite her capacity for meaningful interaction with others.

The end result is that our fears rarely come directly from the experience of an actual patient but from our imagination, an imagination that has had little real contact with Alzheimer's. What could be more terrible, we imagine, than forgetting the name of a person you know well; repeating the same thing you just said five minutes ago and five minutes before that; standing there mute and unable to join the general conversation; or vegetating in that nursing home bed? But those are our projections *now* (as people without dementia) of how we *would* feel *if* we were demented. But since we aren't demented, we don't actually know what we would experience or how we would feel. Perhaps we have a distorted picture of the experience of Alzheimer disease.

Here are some counter-examples that do show each of these stages but the images are far different from what we'd expect.

- I am myself early in the course of the disease and I can still write a blog of my experiences and find my way downtown to go bike-riding to the library with my grandchildren.
- One delightful movie *Friends With Benefits* provides [images](#) of a later stage of the disease. The father is indeed sometimes confused, but not always, and he ends up playing an important and positive role in his son's life.
- Joy ([Joy at Joseph's House](#)) is a significantly demented woman not really able to interact socially with others, yet she brings meaning and happiness when she visits our hospice.
- Years ago I saw a documentary in which a daughter and demented mother were dancing joyfully around the room. The daughter later explained that her mother and she had had a terrible relationship most of their lives. Now her mother had forgotten those difficult times (indeed, had forgotten who her daughter even was), and for the first time they could enjoy each other.

Many of the comments in this blog and emails that I'm now receiving write of relationships with people in much more advanced stages, in which companionship, love, humor, closer relationships, and deeper meaning have become possible *because of* the Alzheimer's (see, for examples, Lee An Gerleman's comment after my

[last post](#)

or Tim R's comment after “

[State of Consciousness](#)

.”) Several people have told me of reconciliation with estranged parents as old hurts are forgotten and both people stay completely in the present.

In fact, we don't know what our experiences of this disease might be.

Tuesday, April 9, 2013

Washington DC

Trying Not to Be a Success

The Washington *Post* carried a significant article on me on Easter Sunday and its web homepage. Since then this blog has received well over 50,000 page views (compared with a daily average of 80 before that.) I'm overwhelmed. The blog is still getting over 2,000 page views a day and 420 people have signed up to receive each post in their email. For now, the blog is “successful.” As I result, I notice myself worrying about how to keep the “readership.”

But trying to make the blog “successful” carries an unacceptable risk.

As I wrote [last month](#) , “The concern that I have is that all the editing [I do] will result in my censoring in order to prioritize 'interesting' and 'well-written' material over the raw experience from inside the world of Alzheimer's.” In the face of 50,000 page views, I can feel that temptation very strongly to write more carefully to make it “worth it” to those of you who read it. I'm a writer, and this temptation is powerful.

I'll do my best to resist. I thought briefly I could partially solve the problem by just typing spontaneously in my journal and then, when I write the post, go back and show you what I've changed. (As you can see from the following paragraph in which I've tried, that doesn't work. It's not only unreadable, of course; but doesn't show much of anything about Alzheimer's: Strikethroughs are deletions and I've capitalized typos *within* the strikethroughs.)

I will do my best to resist that temptation refuse that temptation at least in my hjournal from which this post my these posts are written. Already this morning I've noticed this morning Even now I'm carful as I compose this journalmyself going back and correcting as I type. THIS IS A PARA The problem is that I've always ediGted my work. and as you can see from this paragraph in which i've stricknI'm TYP Part of this is just correcting typos and grammar (before this disease, I was a good typist) but part of it isW making sure it sounds right to you. Aand i'm ging going to continue correcting the typos a and the problem is that my paragraphs The One solution would be to show you each time I correct a tptypo, fix, edit the grammar, or go back and write things nbetter. As you can see from this parapgraph in which I'cve tried to do that, the post would be utterly unreadable.

I've always edited my work as I go. I've always corrected typos and grammar, editing for content and style as well as developing my thoughts as I write. Again, this is what all writers do.

It turns out that as I was in the middle of writing this post, David L Smith left a very thoughtful comment on my "[State of Consciousness](#)" post. He points out that the purpose of this blog is to show what this disease is like from inside my own mind, but any editing I might do creates

a coherence of thought and elegance of prose of someone who doesn't have [Alzheimer's], and that will mislead your readers into thinking the disease is more benign than it really is.

It's an important issue, but the consequences for me at this point in the disease *are* pretty benign. I have Alzheimer's
and
I still have a "coherence of thought and eloquence of prose" (such as it is). I'm not *giving* that up; it will be *taken* from me soon enough.

My task in this blog is to show how Alzheimer's appears from inside my head. The shame and embarrassment that keep Alzheimer's in the closet do great harm. Since the image too many people have of Alzheimer's is a person wandering around, getting lost and speaking nonsense or lying mute in a nursing home bed, it's important to show that in the early stages of the disease, symptoms are quite mild and there are often years of incremental, almost unnoticeable decline in functioning that the public rarely recognizes because the diagnosis is so rarely public. (See the previous post "[What Happened to My Fears](#) ?")

If I were consciously to dumb myself down (which I won't), it wouldn't really show you anything except a good writer dumbing himself down.

The much more difficult question is the unconscious censoring that is inevitable. To retain your trust, I will do my best to show you who I am through my uncensored writing, warts and all? I will be as rigorously careful as I can not to aim for success.

Ultimately, as I said in that earlier post, the issue is integrity.

Thursday, April 11, 2013

Washington DC

Confusion

At this early stage in my disease, I sometimes feel embarrassed describing my symptoms. They feel so prosaic. I can't mention a particular symptom without someone (often my wife Marja) saying, "I know what you mean; I have just the same thing." What I want to say in return is, "Well, no ... you don't." Usually, however, I hold my tongue.

The deficits I notice in my cognitive functioning are sometimes major, like [getting lost](#) or [misestimating the church budget](#) by \$24,000, but more often they're losing things or being slow on the computer or just plain

confusion. The confusion isn't necessarily obvious to anyone else, but I can feel myself getting lost in a process.

This morning, for instance, I got really confused just writing in my journal. A single page took me an hour and a half to write (without even going back much to edit). Ordinarily it would have taken me twenty minutes or less. But this morning I made several typos perhaps every line. I constantly left out words or phrases that I'd intended to write but didn't. I'd go back to fix it and would shortly thereafter noticed that the way I fixed it was wrong, too. Sometimes it took me several minutes to finally fix a misplaced word or phrase.

I was sure that at one place in that journal entry, I'd written four bullet points onto the page. A few seconds later, though, I looked up and there were only three bullet points. I could have sworn there were four; apparently I'd gotten confused between *deciding* to write something and actually *doing* it. What I can't describe very well is the sense of confusion, like living in a fog, not quite connecting with the world about me.

A couple of days ago, I wanted to insert some of the stories I'd written a few days earlier into the blogs I was currently writing. Because my memory is now so poor, I needed to make sure I hadn't used those stories in previous posts. It meant reviewing a couple days worth of posts on the blog, several stories I was currently working on and several stories that were in my journal but not yet used.

I keep the journal, the working files and the posted files in three different folders. As I went back and forth between the three folders trying to compare the stories, I kept getting lost between the folders, getting confused about what I was trying to do, reading some files over and over and not reading others at all. There were only six or eight stories among eight or so short files, but I couldn't remember which story was where. A ten-minute job took me at least half an hour. What was most difficult for me, again, was this sense of being lost in a familiar area. Why can't I do this?

Another confusion: Some of the radio interviews scheduled for the coming weeks asked for Marja's participation, too. When I'd written down the interviews on my calendar, however, I'd forgotten to indicate whether Marja had been invited. Only when Marja asked to which she should come did I realize I needed to keep track of it. So I went back and found the emails containing the requests; in one case I had to call the interviewer. Now I have to remember to

write it down with future requests. It seems a little thing ... and perhaps it is. But the little things build up.

And knowing that my cognitive functioning is impaired can create doubt about my thinking, for instance, did I lose my coat on the train coming back from Napa or was it stolen?

Nowadays, I lose things pretty often, for example, my sunglasses while in Napa or misplace things many times a day, so it no longer bothers me so much. But if I actually lost my coat (as opposed to having it taken), I've reached a much worse level of impairment than I was aware of. I remember taking the coat off the overhead rack exactly once on the trip, during a rest stop when it was drizzling. I specifically remember putting it back in its place, slightly damp. Then it was gone.

I searched for it everywhere, asked the conductors and at lost-and-found. So if I had lost it, it wasn't in the train, which meant that I would have had to have taken it outside, taken it off, set it down, and left it there when I got up. I don't remember doing anything like that. To lose something by misplacing it is one thing, but to have taken all those steps and not remember any of them is quite another.

I'd like to believe it was stolen. But it was an old coat, valuable only to an indigent person without a coat, and those folks don't usually travel by train. More importantly, I've been on many 3-day Amtrak trips across the country and I've never even heard of any theft of any kind, despite the fact that computers, luggage, and other things are commonly left in plain view. Things just don't get stolen on Amtrak.

It's not so much the value of the coat that bothers me; I'll get a new one from Value Village. It's not that I don't know this sort of thing will eventually be happening a lot. What bothers me is the uncertainty, the not knowing where I'm at. Did I blot the whole thing out? If I'm that far gone, what kind of precautions should I be taking? Should I be traveling alone? Should I be driving? Perhaps losing the coat shouldn't matter, but it matters to me! How far along am I?

April 15, 2013

Why Not Suicide?

Washington DC

I've been surprised that the question of suicide has come up only once in this blog's comments, even after the two recent posts on fear ([here](#) and [here](#)). As I write there, I think that for me life will retain too much meaning to want to leave it early. But given the attitude of most people towards Alzheimer's, why don't more choose suicide?

Certainly many think about it. On seeing an Alzheimer's patient (or any other person) lying terminally ill and comatose in a nursing home bed, almost everyone thinks, "I don't want to die like that!" Others will feel the same when a person can't remember family or wanders babbling. But when they gets to that point, they rarely suicide. Why not?

For some, of course, the first and overriding issue is that suicide is morally wrong and can't be considered.

Second, while people might want to commit suicide "before I get that bad," very few people will choose suicide while their lives still retain meaning. Some people might choose to kill themselves while they're suffering greatly, but the *prospect* of future suffering is not enough of a motive. If life is worth living now, we hang on to it. We are, after all, attached to life.

Third, many people with Alzheimer's lose their *ability* to suicide before they're ready to go through with it. The novel *Still Alice* depicts an intellectual college professor with early-onset Alzheimer's who decides she'll suicide when it gets "too bad." She places into the medicine chest a bottle of pills strong enough to kill her and writes herself a note with exact instructions on when and how to use the pills. As she gradually declines, she gradually loses the capacity to remember or figure out what she meant. Ultimately, she wonders who this person is who is trying to kill her by writing this note to her.

Fourth, the experience of the person with Alzheimer's may not be as bad as we—who are looking in from the outside—think it would be. When we get there, we may find no reason to suicide. As unimpaired people or as people earlier in the disease, we project how we will feel in the future but, in fact, we have little idea what our experience will be then. In the Comments

section of this blog and in emails to me, I've read beautiful stories about the happiness of patients with very advanced disease. Maybe most of them aren't suffering much at all.

Finally, one values life differently as one gets sicker. I worked for many years in a home and hospice for homeless men with AIDS. Most of them were admitted when their symptoms were relatively mild; they'd see other patients about to die and vow to overdose before they got "that bad." As far as I know, none ever did or even tried to. As we approach the end, to have a "meaningful life" requires less and less.

Human beings generally value their lives deeply. We may think that when we reach such-and-such a condition, our lives will lose that value. But, apparently, that's very seldom true. My understanding is that the suicide rate for people with Alzheimer's is low. I'm not surprised.

For my own part, I think I'll be just too curious about what the future holds to consider walking out.

Thursday, April 18, 2013

Washington DC

Crazy-making

Monday was my first day in a Georgetown Hospital research study of a drug so new it has no name, only numbers. It's a double-blind study so neither the local research team nor I will know whether I'm getting the real drug or a placebo (25% chance). The drug is an antibody that is supposed to attack and dissolve the [amyloid that gums up the synapses](#) between the neurons in Alzheimer's. The drug's real effectiveness may not be so much in treatment of symptomatic disease like mine but more in

very early Alzheimer's, that is, decades before symptoms arise. It might even prevent Alzheimer's if given early enough. And there's the possibility that this study could even lead to a vaccine that confers life-long immunity to the disease! But that's probably long after I'm dead.

Today was only the first day of five or six weeks of testing to see whether I even qualify for the study; but it's already stirring things up for me emotionally. I suspect I'll be writing a few posts over the next months as the study continues.

The emotional impact today came from the preliminary cognitive testing. The study is looking at the effectiveness of the drug in "mild" cognitive impairment. If your score is too low (too much cognitive impairment) or if it's too high (too close to normal), then you'll be excluded from the study.

What astonished me was that my results were so close to normal that I barely qualified for the study. I was stunned! I have lost so much of my thinking compared to several years ago, yet it barely registered on the tests. When I asked the nurse about it, she acknowledged that there were problems with testing "highly intelligent people" (her words not mine) who apparently have a "cognitive reserve" that allows for normal results on the usual screening test even in the presence of significant impairment and disease.

The testing had two parts. The first was a basic screening test used in neurologists' office to indicate whether there's any level of impairment at all. Because the study is double-blind, I don't know the exact results (except that I barely qualified for the study). I believe I had a perfect score on the first test. The second one was more sensitive than the first and meant specifically for the memory loss of Alzheimer's. My memory for the objects I had to remember was indeed terrible, and I'm sure that test made my score bad enough to qualify ... yet I almost did too well, anyway. If I'm right that I had a perfect score on that first test, then I could have gone into a neurologist's office with my current level of impairment, been given the appropriate screening test, and told there was no objective indication that anything was wrong.

It would have been utterly crazy-making! I *know* I'm significantly impaired. [Getting lost](#) , being unable to [figure out spreadsheets](#) (that I myself created several years ago), or making a [\\$24,000 error](#) in bookkeeping are not simply little exaggerations or deficits everyone has. If I were told nothing in was wrong, I would fear that I was *imagining* things, which would have frightened and isolated me.

So how could I be almost too normal to qualify for the study? Isn't there something wrong with testing if it can't recognize my level of impairment? Perhaps finding very mild impairment in "highly intelligent" people is more difficult, but it can't be impossible. To avoid such crazy-making, it seems necessary to try.

On the other hand, the tests did, in the end, pick up definite cognitive impairment. With all the publicity and the number of people hitting this blog, my wife Marja has been concerned that I'd gotten too far out front with the public attention. "What if you *don't* have Alzheimer's?" she said. How embarrassing would that be?!!" But the research center tests confirm the diagnosis. Marja is much relieved.

April 23, 2013

Washington DC

A Spectrum of Disease

My symptoms rise and fall in no distinguishable pattern. Some days are good days; some days are worse. At this point in my disease, I have really no reason to complain. As far as I can tell, I'm still intellectually intact and enjoy good conversations. Last week I spoke about my Alzheimer's to a group of people training to be hospice chaplains. I talked for about twenty minutes, sharing a bit of my previous history, what it's been like since I noticed symptoms and where I am now. After that I led a discussion that went well. Yesterday I read my [spiritual autobiography](#) to our small faith community and again led an energetic discussion filled with personal sharing on all sides. In some ways, then, I feel completely unimpaired.

The constant difficulty at this point is losing things ... all the time. It's not that they stay lost for very long; they're usually hiding in plain sight. At Sunday's church service, I couldn't find my backpack; I asked around and nobody had seen it. I searched around the (small) room for three or four minutes and finally found it in an absolutely obvious place. It was not, however, a place where I usually leave the pack nor did finding it jog my mind of having put it there. Shortly thereafter, a friend asked why I didn't have my glasses on; I hadn't noticed they were gone. I nearly panicked, thinking I might have left them before church at a coffee shop. I was about to run over when I noticed the glasses lying on the table next to which I'd been sitting. I rarely remove my glasses outside our house and never without a specific reason. I have no memory of taking them off or even why I might have taken them off.

These are tiny things. They happen to everybody. But they are happening to me many, many times a day. Several times a day, I will roam through the apartment, looking for my jacket, my backpack, my belt, or my slippers. Such little episodes are less frustrating than they might be because I am conscious of my Alzheimer's and expect things like this to happen. I'm more curious than anything else. Having shared my diagnosis with people close to me, I'm not embarrassed when I have to ask them for the third time whether they've seen my notebook.

The more frustrating difficulty is the decreasing inability to synthesize bits of information from various sources. Sometimes it's quite simple stuff like stories from several computer files (see "[Confusion](#)"); other times it's listening to reports in a meeting and not being able to pull everything together. Most days it doesn't come up, but it's frustrating when it does. Usually, though, I can just remind myself: "You have Alzheimer's, David. What do you expect? Usually, I can let it go."

Monday morning I biked downtown to a reception of the Alzheimer's Association Advocacy Forum that is meeting here in Washington to lobby for better funding for research. I attended one of their sessions. Some of the speakers had Alzheimer's and some didn't. Unless they mentioned their diagnosis, however, I couldn't tell which was which. Yet our predominant cultural image of Alzheimer's is the old woman babbling in the corner or the man lying almost comatose in the nursing home bed.

In fact, those of us with Alzheimer's range across a wide spectrum of symptoms. There are a lot of us out here with early-stage disease who are still actively living our lives. Unless I die earlier from something else, I will live for many years with this disease. Right now, I have memory loss that seems significant to me, but you wouldn't notice it unless I mentioned it or you were paying strict attention. I still teach and engage in deep conversation. Later, I expect I'll have more significant memory loss but will still be able to function meaningfully in my family and community. Still later on, I may be quite disoriented yet still live with and contribute positively to those around me. And later I will move toward those disturbing cultural images that bother us. (Even then, I've been told by caregivers, I may be able to have real relationships with those who care for me.)

The general public would be a lot less scared of this disease if more of us with mild impairment "outed" ourselves as having Alzheimer's and talked openly about it.

Thursday, April 25, 2013

Washington DC

My IQ does not measure my worth.

Martti, my Finnish father-in-law, suffered from dementia—not from Alzheimer’s but as a result of a series of small strokes, each of which chipped away step-wise at his mental abilities. He had been a highly respected math professor at a teacher’s college. He was a reserved man, committed to propriety, yet he also loved the tango and would occasionally roll up the rug to dance in the living room with his daughter, my wife Marja.

Finnish men and women of his generation were expected to make formal speeches at special occasions, and Martti prided himself on being able to speak well. As his 80th birthday approached, however, he was increasingly aware of his decline, yet he knew he would be expected to speak at the gathering in his honor. He was uncharacteristically anxious and asked Marja to listen to his speech to reassure him it was appropriate.

In that 80th birthday speech, Martti said, “I have had seventy-nine good years; the last year has not been so good anymore.” He was very aware of his cognitive impairment and much pained by it. Shortly after that, he told his family he wanted people to remember him as he *had been* rather than as he was now. In his last years he saw very few people outside the immediate family.

Martti did not reach an advanced stage of the disease before he died; he always knew who we were and could basically take care of himself. At one point in his disease, he said to Marja, “I used to be the head of this family but now I can’t do anything.” It wasn’t a complaint, just a statement of fact. While he bore it without self-pity, Martti suffered from his dementia.

Before my diagnosis with Alzheimer’s, I thought I would feel the same way my father-in-law

did, wanting people to remember me as I was at the height of my powers and not as I would become as a result of my dementia. My greatest fear was that I would lose that which I treasured the most: my intelligence and my independence. To some extent I still feel that way: Perhaps my greatest sadness is that my grandchildren will likely know me mostly as a doddering old man.

Surprisingly, though, that fear of intellectual loss has diminished greatly; my attachment to what I used to be is decreasing. It's becoming obvious that such attachment to who I used to be at a particular time in my life only leads to unhappiness. This is true even if we don't have Alzheimer's disease. When I was in my thirties and forties, for instance, my self-image included being a good athlete: agile, strong, and able to run or cross-country ski for hours. As my body aged and I was no longer so agile or strong, I found myself sometimes depressed because I no longer fit my image of myself. It was a while until I recognized that hanging on to that athletic self-image was not a recipe for happiness or contentment for a man who was, in fact, going to get older.

Similarly, attachment to my IQ is not going to bring much happiness as the Alzheimer's slowly but methodically clogs up my brain.

Buddhist teachings remind us that there is no constant "self." (See my "[Letting Go of Self](#) .") The Western idea that our self stays the same throughout our life just isn't very accurate. In fact, our self changes continuously and dramatically throughout our life. The Buddhist teachings point out that clinging to any particular self-image is sure to bring suffering because the self will not fit the desired image forever. Let it go!

It may be harder for those of us who have prized our intelligence and seen it as the highest value. What else would there be, after all, if our intelligence faltered? How would our life have value? Those thoughts just reveal our arrogance, our prejudice against those with low IQs. We fear becoming those who we have not valued very highly.

But I am beginning to see that—in addition to the losses—there may be another kind of joy available as my mental powers decline. I'm reminded of parents and caregivers of the mentally retarded who talk frequently about the joy they find in the relationship with those whose intellect is deeply impaired. Feelings are more available; relationships are more immediate; the *person* is valued, not so much for what he can
do

but for who he
is

. Perhaps it's the quality of our hearts and not the number of our IQ that matters more.

I'm still early in the disease and haven't yet lost too many of my intellectual abilities. At this early stage, it would be naïve for me to insist that I'll live up to my words above. Maybe my equanimity in the face of this illness will collapse and I'll suffer like Martti did. I can, however, see the possibility of just letting this particular self go. So far, I haven't clung to the capacities that have already slipped away, and I can foresee accepting the next steps as just part of my journey, too. I won't have to try to be the brightest bulb in the room, anymore. Been there, done that! Now is the time for a new part of my journey. Perhaps that is my future.

I wonder about Martti. Could he have suffered less if he hadn't been so attached to his previous self? Would he have been so unhappy if he knew that his value and his worth did not depend on his IQ? I'd like to think so.

April 29, 2013

Love & Jealousy; Community & Isolation

Washington DC

My wife Marja and I were at a silent retreat with others from our faith community this past weekend. We entered the Great Silence after Friday dinner and remained silent until after Sunday morning worship. We slept at the Inn where each of us had a separate, simple room with a bed, desk, chair and sink. We had meals and met together in the Lodge, a separate building that has an almost sixty-year history of continual silent retreat. It is a place that invites one into silence.

I've meditated almost daily for at least fifteen years and have found quiet only in the midst of very long retreats, never in my daily meditation. With the diagnosis of Alzheimer's, I had hoped (illogically, I suppose) that the slowing of my thinking would make my mind simpler and quieter, my meditation deeper. No such luck! As my mental abilities have decreased, it's been just as noisy in there as ever. I had a small hope that over the weekend of retreat, I'd find a bit of inner silence, but all I experienced was the "monkey-mind" of constant chatter.

But there was something else both more beautiful and scarier.

I was sitting in the Lodge looking out the floor-to-ceiling windows just before evening worship when Marja walked down the path through the woods from her room. I was suddenly aware of deep longing. She radiated an inner light. Lean and strong, she walked gracefully as if she belonged to those woods and that path. She smiled easily at several of our friends. In those few moments, the fullness of her inner beauty was revealed to me in a way I'd never felt in over fifty years of our relationship. In that moment I felt extraordinarily grateful that we belonged to one another.

But then the future broke in. As I watched her exchange glances with some others, I felt strangely excluded from those relationships. Suddenly, it was five or ten years down the road, and Marja had relationships with others that I was *incapable* of sharing or even understanding. I felt immediately jealous: I wasn't able offer her what she needed and she had to look elsewhere. It was as if she were having an affair. In that moment, I felt jealous of *any* other relationship.

Although they became muted, the feelings stayed with me as Marja sat across the room during the short worship that evening. Afterwards, I went outside into the dusk, and sat on the steps overlooking the meadow and woods. As Marja came out the door, I caught her eye and she sat next to me. We clasped all four hands together. Feeling our bodies touch, holding one another, I was comforted and felt safe again.

The jealousy was "real," even if the imaginings that prompted it were not. I "know better" than to live in the future like that. But that's where I lived for those moments of jealousy. I was fearful of what the future might bring. Feelings of isolation are what I fear the most and what, I suspect, many with Alzheimer's suffer greatly from. And jealousy has the potential to isolate me from the one with whom I share so much, who will be there with me forever.

Everything that happened in those few minutes bordered on the mysterious. Part of me feels very grateful for the emotional openness that has occurred as my illness has progressed. Part of me is scared. Those feelings, both sublime and painful, would not have been possible for me two years ago.

In the end, of course, it's precisely this living in the future that causes so much of the pain of Alzheimer's. I've not been falling for it much, but I sure did this time.

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