

## Blog Posts from August 2013

Thursday, August 1, 2013

Washington DC

### My Disease Progression

I've noticed some symptoms getting worse; it's not *much* worse but still I notice it.

Some symptoms don't bother me much. Several days ago I was looking for two specific files in a list. I knew what was in each file, but I couldn't remember or even guess the file names. All my file names have some relationship to the subject of the file, however, so that I knew that if I checked through the long list of files, I'd find it eventually. Since there were two different files I was looking for, I decided to look for both at the same time. But I couldn't. I couldn't keep in my mind the subject of both files while at the same time looking through a list in which I had to match a name to the subject. I had to keep three things in my mind and I could only manage two. I went through the list one at a time, however, and had no trouble.

Other symptoms are more unusual. I was wearing a very light nylon backpack as well as my usual belt pack when I came home from a long bike ride. I'd put my keys in my belt pack, but as I stood at the front door with my bike leaning awkwardly up against me, the keys weren't where I'd put them. I searched through the four compartments of the beltpack repeatedly. Repeatedly. I kept searching—it may have been five full minutes—because they *had* to be there. Finally I remembered that I had the nylon backpack on, so I reached back, felt the keys in the backpack and started to take it off to retrieve them. The next thing I remember was that I was searching through my belt, unaware that I'd already found the keys in the backpack. Again, I perseverated with the beltpack for what felt like five minutes, then thought (as if it were a *new* thought) about the possibility that the keys were in the backpack and only then realized that the backpack was slung half-way off one shoulder with the keys in it. I'd completely forgotten what I was doing halfway through taking the backpack off.

And other symptoms are just strange. The other day I was in the kitchen and heard a symphony being played outside in the alley. Boom boxes travel frequently through the alley but

I don't remember any symphonies. And the music stayed in one place, seemingly outside our window. I looked out and couldn't see anyone or any source of music. I asked Marja, "What's that music?" "I don't know," she said, "I don't recognize it." "No, I'm asking where it comes from."

She looked confused so I said, "What's the source of the music; it seems like it's coming from the alley."

With some puzzlement, she said "It's coming from the radio." Of course, it was coming from the radio that has been in the same place for years, that is always tuned to classical music on public radio, and that I had had to lean over to see into the alley. But I'd not recognized it. Bizarre.

On the other hand, there are some things I haven't lost. I'm noticing again that what I might call "wisdom" has not really declined, at least not that I can notice. I can still participate meaningfully on the church leadership team, provide mentoring to some other people in the church, offer opinions that friends seem to value. I just returned from giving a talk about Alzheimer's to a group of social workers, and I doubt that they would have noticed if they hadn't known my diagnosis. I'm aware of intellectual, cognitive slipping but not loss of wisdom.

I've always wanted to be a "wise old man" and I was getting there. After my diagnosis, I grieved the potential loss. Now, it seems, I can keep the role, at least for a while longer.

It's a fascinating process. Intellect gradually disappears but relationship can flower.

Sunday, August 4, 2013

Washington DC

## **What's Going On?**

Now I'm confused! In the past few months, I've been part of two separate research studies in which [Positron Emission Tomography](#) (PET) scans to look for [amyloid plaques](#) (one of the presumed causes of Alzheimer's) were normal, even though the two scans used different methods of measuring the amyloid.

I also had a PET-glucose scan which ought to document damaged areas in the brain where the cells are not fully functioning. That, too, was normal. In other words, I've had three different brain scans, none of which indicated that I had Alzheimer's. I've just reviewed the results with my doctor.

What is going on?

One possibility is that I needn't take the results too seriously. Medical tests are never perfect, and these particular tests have only recently been used to diagnose Alzheimer's. We still don't know enough about their accuracy to know anything with certainty. But three different tests, using different methods and looking for different mechanisms, are unlikely to be wrong simultaneously. My very rough statistical calculations is that, if I have Alzheimer's, the likelihood that at least one of scans would show something is in the neighborhood of 99.75%

A second possibility is that my symptoms are due to something else. Although Alzheimer's is by far the most usual cause of dementia, there are two other fairly common causes, [temporal-frontal dementia](#) (TFD), where the damaged cells are in a specific area of the brain, and [Lewy Body dementia](#) (LBD) where a protein different from amyloid gums up brain functioning. But I would think that the PET-glucose scan should show problems in each of these diseases, too. Vascular dementia (a series of small strokes) is also fairly common, but the scans, including the CT and MRI, should have ruled that out. Further, according to the doctors, the specific combination of my symptoms doesn't fit any of the three dementias. And—given the other examinations, blood tests, and CT scans that I've had—there are no other reasonable possibilities causing dementia.

My doctor said that he still believes I have Alzheimer's. But he's certainly puzzled by the negative results. The other possibility, he said, was that I was so early in the disease that both scans were negative. If that's the case, of course, it's very good news. But it seems to me highly unlikely. I've had symptoms for perhaps five years and serious symptoms for three

years. In addition, plaque deposition in Alzheimer's begins at least fifteen years before symptoms appear. Being too early in the disease doesn't seem to me a reasonable explanation for all the normal tests.

Another (unspoken) possibility is that my symptoms are due to normal aging and that I'm among the "worried well," a polite way of saying that my more severe symptoms are imaginary. I have a difficult time believing this (although, of course, no one who's just imagining symptoms is going to believe it). The neurologist hasn't mentioned this possibility, but it has to be on his mind. If it's all in my imagination, then I'm not sure I'm relieved. I've blanked out an entire day, lost my ability to do more complex calculations on a spreadsheet, gotten lost three times, have had to give up my usual writing and teaching, and had other major episodes.

As a part of the NIH study, I've been scheduled for a full (4 – 6 hour) [neuropsychological](#) exam at the end of the month. When I asked the doctor at NIH to give me the results of the scans before the neuropsych exam, he hesitated. Doctors don't like to give patients partial results because people can worry or jump to weird conclusions. I reassured him that as a physician I understood the problem. So he gave me the results of the scans, and here I am worrying and jumping to weird conclusions.

I'll wait for the results of the neuropsych tests.

The specifics of my situation feel unique, but many people with mild cognitive impairment (MCI) find themselves confused and anxious because of the uncertainty involved. I've written about some of the issues with MCI in early Alzheimer's [before](#). As I [read more deeply](#), however, it seems that medical thinking about MCI is changing. I've assumed that if a mild cognitive impairment is progressing, then it's really just an early phase on its inevitable way to one of the dementias. And this is certainly true much of the time. But some doctors believe that MCI may be more complicated. In some cases, they believe, it may be a specific diagnosis with its own cause that may stay stable or even improve over time. But details are sketchy.

People now come to medical attention much earlier in the disease process. Unfortunately, the appropriate tests, diagnostic criteria and medical understanding have not kept up. When a person is diagnosed early in the disease, uncertainty is inevitable. This isn't a question of ignorance or incompetence: It's just the nature of the disease.

No wonder I'm confused.

Tuesday, August 6, 2013

Washington DC

## **A Change in Identity ... Again**

Wow! My anxiety has sky-rocketed! I realize that this blog is not about the neuroses of David Hilfiker, but surely there is something here that many with Alzheimer's experience. One of my readers recently emailed me. She'd been diagnosed with Alzheimer's in 2008. Recently, though, she was thoroughly retested and the results were completely normal! The previous diagnosis had been in error; her symptoms then had been significant but temporary, caused by something else. She didn't have Alzheimer's. She wrote, "The news is wonderful for me and my family, but I feel as if I have lost my moorings again."

After almost a year of believing that I have Alzheimer's and now finding myself with some [normal test results](#), what if I'm not heading for dementia? Or, worse, what if my symptoms are imaginary, all in my head? Then I lose my sense of self. My identity created over many months, accepted by friends, readers, and myself, fades away. What if I'm not who I thought I was?

Since I found out about the test results last week, I've been more anxious about *not* having Alzheimer's than having it, which doesn't make any logical sense. A more appropriate reaction might be:

I don't have Alzheimer's? How wonderful!! The sentence I've been living under has disappeared. Hallelujah!

But, no, I feel anxious. My situation is different from my reader's in that there's no evidence, yet, that my cognitive impairment has changed. Nevertheless, I also feel unmoored.

Just to be clear, I still believe that my cognitive impairment is real and progressive and either is, or will progress to, Alzheimer's. But the uncertainty itself has unmoored me.

I'm sure I'm not alone in my feelings. As I wrote in the [previous post](#), anyone with [Mild Cognitive Impairment](#) experiences a similar disorientation, in large part because of the uncertainty about exactly what their diagnosis will mean for them. And all of us with progressive disease will experience continual changes in who we are.

The emotional/spiritual question that we face is: Can I retain equanimity in the face of such shifting in the sense of self. Can I recognize at a deeper level that my self is always changing and let go of my attachment to whatever the current sense of self is? I've written about this before ( [here](#) and [here](#) ), but this feels more wrenching. So, it's an even greater opportunity for spiritual growth, for learning to let go.

Wednesday, August 21, 2013

On the Train Back from the BWCA

## **It's Not Denial**

(For those of you interested in what I've been doing over the past two weeks, the Boundary Waters Canoe Area in northeastern Minnesota was its usual beautiful self. The weather was ideal. All of our children, grandchildren, and sons-in-law canoed and portaged together through unspoiled wilderness. [Even the signs marking the portages were taken down a number of years ago.] I'm grateful that each of us enjoys one another enough to have taken on the considerable logistical challenge to get us all together. We'd been planning such a trip for when the grandchildren were a little older, but we moved it up because of my diagnosis.)

Quite a few comments over the past several months have mentioned the difficulties for caregivers when the person with dementia "refuses" to recognize his impairment. Understandably, it can drive some caregivers absolutely crazy. The patient with considerable financial resources persists in disastrous judgments. The now-dangerous driver insists on

driving. Important issues about the future can't be addressed. Both caregiver and patient get frustrated and angry.

The term for this lack of insight is "anosognosia," from the Greek words *nosos*, "disease" and *gnosis*

, "knowledge" while the prefix

a

- changes it to a negative: "no knowledge of the disease." It's a condition in which a person suffering from neurological disability seems unaware of it. From my medical training, I'm familiar with this condition when caused by a stroke: victims remain unaware of their affected side and will deny that they're hemiplegic. But it's also common in Alzheimer's.

Most caregivers understandably interpret this condition as psychological denial, but it's not. A blogger on the Alzheimer's Disease International website [writes](#) ,

Denial is a strategy used to reject something that a person wants to ignore or avoid because it is too difficult to face. Anosognosia, on the other hand, is being unaware of a decline in cognitive skills.

Research has shown that this condition is due to physical damage to specific areas of the brain. The patient has no more ability to recognize her symptoms than she does to lift her arm.

When Alzheimer's damages these areas of the brain, the patient simply *cannot* recognize her impairment. The importance to the caregiver of understanding the cause of this lack of awareness is obvious. Trying to cajole or therapize or intimidate a person into recognizing her disability will fail and will lead only to frustration and anger in both caregiver and patient.

Recognizing that the patient has no control over his denial, of course, won't change the practical problems, but it might help prevent the blaming and mistrust that so often results. Realizing that your loved one *can't* see that his mind is failing and that no amount of reasoning or nagging is going to make any difference might increase compassion and decrease frustration.

Although the problem may decrease as the Alzheimer's worsens, there is no known treatment. But, as the author of [Contented Dementia](#) suggests in the context of other problems, trying to see the world from the perspective of the person with Alzheimer's will help. How might it feel to have others harping on your incompetence when you *know*

yourself to be unimpaired? What's it like to be unable to accomplish something important when you see no good reason why?

Is it possible for you, the caregiver, to create an alliance with the patient to reduce his frustration? Can you find a way to "agree to disagree"? Can you feel less of a sense that you're betraying the person with Alzheimer's when you arrange for authorities to take his driver's license away (ideally without letting the patient know that you were responsible).

No amount of understanding, of course, is going to make it easy for you to respond to this condition, but it may make it possible to stay in a better relationship with the person you love.

Saturday, August 24, 2013

Washington DC

## **Betrayal?**

In response to my [last post](#) on people unable to recognize their cognitive impairment (anosognosia), one reader described the dilemma of wanting "to include in social settings a loved one who demonstrates anosognosia about [his] cognitive impairment." I have gone ahead, she says, and "confidentially shared with a few folks in my Christian community, yet am uncomfortable with others knowing something my loved one doesn't about himself. Yet if I don't share, then I am worried others won't know how to lovingly respond to him."

It is, I suspect, a common dilemma. The problem arises most seriously in the issue of driving. (I've explored the issue in other [posts](#), but anosognosia significantly complicates the problem.) There are at least two sets of issues: first, the practical ones that will arise if he finds out that you have spread what he considers a lie about him and, second (and much more difficult) the feelings you may have of having "betrayed" him. I have a couple of thoughts, but I would certainly welcome comments from those who have faced the problem.



First, would arranging to have his license taken away or even letting other people know about his diagnosis be a “betrayal” of the person you love? I don’t think so. The person you love is now different in an important way from the person he has been: He can no longer recognize reality and act appropriately. Remember, anosognosia is an injury to the brain that makes him *incapable* of recognizing his impairment. He doesn’t have the capacity to make a good judgment about himself. You *must* do it because he can’t. The only real question is whether in any particular instance the choice is actually a loving response, done in the best interests of everyone. Fulfilling your responsibility in a loving manner cannot be betrayal ... regardless of what the patient feels and believes, regardless even of what you feel.

Second, a dangerous driver must not be allowed to continue driving. Period. That outweighs any other consideration, including any of his feelings that you have betrayed him and any of yours. If the patient will not stop on his own, someone has to interfere and make it happen, even if it requires informing the authorities. This doesn’t have to be the caregiver directly, but if no one else does it, the caregiver must at least arrange for it to happen, perhaps by asking someone else to make the call.

The issue of whether to inform friends is obviously much more ambiguous because no one is directly in danger of injury. As any regular reader of this blog will know, I believe strongly in telling other people about one’s own diagnosis (see [here](#) and [here](#) ). I assume that friends who are at all close will have already noticed the symptoms or will soon. Discussing the disease frankly will probably decrease embarrassment and isolation. But the choice to let other people know might appropriately be outweighed by the likely consequences (if he finds out) or even by one’s *feelings* of betrayal.

Another possibility, however, would be to determine whether the friends already know something is going on. If they do, you might tell them about the physical nature of anosognosia over which no one has any control. This doesn’t give them any new information about your loved one (the friend already knows) but it does add objective information that may help in any given situation.

If I were a caregiver, I think I would probably tell a trusted small circle of friends, not so much

to help *them* but to help *me* in dealing with a difficult situation. My loved one might reasonably expect me to keep confidential his problem but not to keep me from getting the help I need.

Don't forget that the nature of progressive dementia is that the caregiver has gradually to take over more and more of the decision making (and lots else) that the patient has always done. You might as well get used to it early.

These are only my thoughts, however. Some of you readers will have certainly faced these questions. What do you think?

Wednesday, August 28, 2013

Washington DC

## **Who Will Care for Us?**

I mentioned in a [previous post](#) an incident in which Marja uncharacteristically didn't get home until after midnight and I didn't know where she was. Terror moved into a place just under the surface of my emotions. I realized then that a crucial reason I've been able to live without much fear of the future is my assumption that Marja will be there to accompany me through this illness.

What if Marja isn't here? I have an extraordinarily supportive faith community. We frequently devalue the importance of close community. I hope I'm not being a Pollyanna here, but I have some confidence that if Marja is not here to care for me, then my community will surround me.

My children would certainly be available and would do their best, but I obviously don't have the same relationship with them as with Marja. I'm sure I could live with them for quite a while, but I could not (and would not) expect them to keep me as far into my illness as Marja. And since my children live far away, I'd have to leave the community here.

There's no particular reason to expect Marja to be unavailable, and I really don't think about it much, but sometimes the possibility scares me.

I read an [article](#) in the *Washington Post* on Monday about an AARP report predicting a severe shortage in the number people unable or unwilling to provide unpaid care. The number of potential caregivers (defined by AARP as those aged 45-64, ie our children) available in the next few decades for the elderly, demented, and otherwise fragile people of the baby-boomer generation will be falling. The shortage will be due to:

- the increasing numbers of baby boomers,
- the increasing longevity of Americans, and
- the decreasing number of those younger caregivers available because baby boomers have had fewer children than their parents.

What was astonishing to me was the estimated cost of the unpaid care currently provided by caregivers. In 2009, it was the equivalent of \$450 billion, more than the cost of Medicaid and approaching the total cost of Medicare! The national political terror of budget deficits and increasing taxes (a different topic about which I have strong feelings but won't get into here) makes it unlikely that the huge government financing necessary to fund the increase in paid caregiving will make it through the political process.

Perhaps the greatest fear of Alzheimer's is abandonment. I have my children, so I'll be okay through most of the journey. But what about those who don't have unpaid care available? Where will the money come from to care for them either at home or in an institution? We will have more reason to fear.

Thursday, August 29, 2013

Washington DC

## **Tips for Communicating**

A number of caregivers who have left comments or emailed me have asked for my advice on dealing with their loved ones' dementia. Since I have absolutely no personal experience in that

area, I can only offer second-hand advice that I can't personally vouch for. In two previous posts ( [here](#) and [here](#) ), however, I did review the book *Contented Dementia*, which offers a good general framework for thinking about the issue. I've also recently come across a set of "[Tips for the Caregiver](#)" from the [Bureau of Geriatric Psychiatry](#) in Tuscaloosa, AL. The tips are taken from a larger "[Caregiver Packet](#)"\* which is also well worth reading.

Here's a bit of a summary (in no particular order): I've used the masculine pronoun throughout to keep clarity.

- Non-verbal cues may be as important as what you say, so try to be calm and reassuring, speak slowly and distinctly, and use simple words. Use gestures when appropriate. Point to objects or demonstrate an action, such as brushing your teeth.
- Remember that the patient is dealing with confusion, anxiety, loss of self-esteem, irritability and feeling of depression.
- Before asking the patient to do something, address him by name to get his attention and maintain eye contact. Ask only one question at a time and give him time to respond. He is having to think a lot harder than you would to answer the same question. Allow him adequate time to respond in conversation or perform an activity. Rushing him will only increase his confusion.
- An Alzheimer patient has difficulty coping with change. Try to maintain a regular daily routine; it will help the patient maintain his abilities and may also save you time and energy.
- Performing his own daily tasks (eg dressing) helps to maintain his self-esteem. If you help him before he really needs it, he may forget how to do it for himself.
- Break down all tasks into simple steps. Tell the patient slowly, one step at a time, what to do. Giving too many directions at one time, or giving them too quickly, will increase the patient's confusion. If the patient gets upset and becomes uncooperative, stop and try again later.
- Keep your expectations of what the patient can do realistic given his degree of impairment.
- Use humor whenever possible, though not at the patient's expense.
- Do not disagree with made-up stories or mistaken impressions. Do your best to understand his reality and respond to it. Do not contradict him. (See my posts on *Content ed Dementia* ( [here](#) and [here](#) ).

- Be consistent. If you say that you are going to do something, follow through with it.
- If the patient repeatedly asks a question, remember that he cannot remember the answer you have just given him. Reassure the patient that everything is fine and that you will be with him and will help him.
- Repeating the same act may be meaningful for the patient and provide relief of tension; if he spends 20 minutes contentedly wiping the kitchen counter, let him continue.
- If you do get angry, use "I" statements as opposed to "you" statements. Example: "I'm feeling angry, I need to rest now," instead of "You make me so angry, I can't stand to be here." Remember, he can't change his behavior for you. Also, he is frightened to see you angry at him when he feels so helpless. Talk to a friend when you need to blow off steam. Support groups are a great place for this.
- Always remember the importance of love and affection. Sometimes holding hands, touching, hugging and praise will get the patient to respond when all else failed.
- When he can no longer communicate verbally, keep talking to him about those things that were important to him, such as yourself, family member, etc. Speak clearly, say names of people he loved, touch him, massage his arms, feet, head and back. Touching is the greatest communicator of love.

Modified from [Caregiver Packet AlzBrain.org](http://Caregiver Packet AlzBrain.org) \*

Again, I have no personal experience, but these suggestions make a great deal of sense to me and may help some of you caregivers.

*\* Clicking on this link will produce a pop-up asking whether you trust the link. I believe it trustworthy and you can proceed .*

[September 2013](#)

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