

Blog Posts from November 2012

Friday, November 2, 2012

It's getting worse ... and much more frustrating. Trying to work out what should have been solutions to some spreadsheet problems that I thought should have been pretty easy were not.

Similarly, I realized that I had misprinted and wasted two batches of bookmark strips printed with the year's lectionary scriptures (which I've been making for the church for many years) and printed another set in which the front was mistakenly identical to the back. Eventually, I caught all of the mistakes, but only after wasting much ink, expensive card stock, time, and patience.

Now, I could have made perhaps one of those mistakes before my impairment, perhaps even two. So I can't attribute any one mistake to the Alzheimer's, but taken collectively, it's obvious. Trying to know which mistakes are really due to the illness is a useless task (that I nevertheless keep attempting). It's sort of like attributing any specific weather event to global climate change. Any single event, no matter how extreme, might have happened without climate change but the aggregate cannot be misinterpreted. Any particular one of these mistakes I'm making could be just a normal mistake, but the aggregate points pretty decidedly toward progressive disease.

How long can I responsibly hold on to these responsibilities I've carried at church? In most cases, like the lectionary strips, either I or someone else will discover and correct the mistakes without important consequences. But, especially in bookkeeping, mistakes can be more serious. I don't want to give the responsibilities up because they are important elements of belonging to the community, but at some point it will obviously become necessary.

The same thing is true about my driving. At what point will my capacity to drive be so limited that I can't drive well enough to keep my license? Over the weekend I drove a 3½-hour trip into Virginia. I thought I might be feeling a little but spacey, but that may have been due to the lack of sleep and all the Coke I'd been drinking to stay awake. But I noticed nothing unusual on the way back. When I do have to give up my license, it's going to be very painful.

How will I decide these things? For something like driving, I certainly can't wait until other people start noticing. For other things, like bookkeeping, the mistakes might be relatively serious but ultimately correctable. For others, like printing lectionary strips, there's no real reason not to wait until others notice. I certainly want to forestall giving up some activities as long as possible. So far I've had confidence in my judgment. But a loss of judgment is itself another of the symptoms of Alzheimer's.

Tuesday night, I took another trip into Virginia, driving down to Richmond to do my annual talk to a college class at Richmond University. The professor who invites me down always asks for the same talk: a brief discussion of my medical mistakes article, a description of my work in the inner city, a description of the history of the ghetto, and a discussion of the criminal justice system and its impact on the poor. Rather than depending upon a lecture (which has never worked as well with this particular group), I decided this year to spend most of the time in discussion, so I broke my usual speech into a number of different parts, shortened each of them, and developed some pretty good discussion questions.

I thought it went well. The students seemed very appreciative. The professor later confirmed my judgment from her point of view. I wasn't nervous and I felt very much "on my game." It was a great ego booster in the midst of all this unpleasantness. It won't last forever, of course, but that area of my mind doesn't seem to have been affected yet. It's not a little thing! And I'm very grateful.

Sunday November 4, 2012

Gratitude

There's a passage in the book of Romans that has always irritated me ... especially as it's commonly used to somehow dismiss the suffering of others:

In all things God works for the good of those who love him, who have been called according to his purpose. Rom 8:28

Taken in isolation, the passage has always seemed so naïve, such a statement of privilege. Have all things worked for the good of those who love Lord if they happened to be Tutsis in Rwanda 1994, who happened to be tortured in Uzbekistan, or who happened to be abused as children?

And how about me? Are all things working together for me? Well, maybe. I refuse to accept the straightforward implication as most people understand it. But, in my case, it seems to be doing just that, working together. For those who have to just watch me deteriorate, no, it's not working together. But for myself ... well, it just may be.

This diagnosis has brought me much deeper into my relationships with all sorts of other people. It's certainly been true for Marja and me but also, so far, for our kids and for the few close friends I've told.

Marja has mentioned several times that we have so much to be grateful for in our lives. And she is speaking in the context of this disease, too. Other than my depression, our lives have been charmed, without significant suffering. In terms of our external lives, we could have asked for nothing more. Our marriage has been loving and supportive for both of both of us and we have become even closer with age. Our children are great gifts. As adults they have become good friends to us and to each other. (We actively enjoy being together). They lead happy and productive lives. Both Marja and I have been able to spend our adult and professional lives, doing what we most wanted to do yet earn enough money and be appreciated. We have a community. And the list goes on.

All of those have pure grace and, although I previously found gratitude hard to come by, we were at least aware of the gift. Part of that lack of gratitude has been that I've always put myself in the place of never being satisfied with myself. I can't rest on my laurels; I need to be doing something now! The judgment inherent in that has made gratitude hard to come by. But now I've been freed from the need to prove. I can look back and be grateful. The Alzheimer's has given me much freedom from "shoulds."

Even the things that would seem to drive me away from God haven't. I am certainly declining in my mental functioning. I'm becoming more confused and frustrated by not being able to do the more complicated tasks of my life. I know I still have gifts that others don't and that people still depend on me for things, but the circle is tightening. Paradoxically, however, the freedom to let those things go, to loosen commitments has been positive ... for which, again, I'm grateful.

Thursday, November 8, 2012

Marja's friend from her childhood in Finland arrived last night. I didn't expect to have to "tend" to her at all, but Marja had to work this morning. She doesn't speak a word of English, and she's difficult to speak to even in her native tongue. What has bothered me the most is that I'm really having trouble communicating in Finnish. Our family has lived in Finland for two separate year-long periods and many summer vacations, and I've studied Finnish intensely. My Finnish is not perfect, but under normal circumstances, I'm pretty fluent. And Marja and I spend some time almost every night talking in Finnish so as not to lose it. So my Finnish isn't rusty. But I'm finding it very difficult to speak Finnish with our guest. The easiest words are difficult or impossible to find. I can't use the (admittedly complex) grammar well.

I understand what Marja or her friend is saying just fine, but I'm losing the active vocabulary. Is this from my Alzheimer's? I can't be sure, but I have always enjoyed speaking with Finns. Will I have to let this go, too? I've said it before, this is a disease of constant losses ... and it's hardly started.

Saturday, November 10, 2012

Hope

I was at a meeting yesterday when an old friend came into the kitchen next to the room we were meeting in. I'd heard that he was "declining" mentally. That seemed obvious from fifteen feet away. He smiled at us but his face was immobile, almost as if he had Parkinson's disease. He moved slowly and without really acknowledging us. This is probably a picture of myself in a few years. I've been hearing about his decline for a long time, so once again I'm being forced to accept the fact that this disease goes on for *years*. Somehow, I'd taken refuge in the idea that the period of real dementia would only last four or five years and much of that time I wouldn't have much consciousness of where I was. But it will probably be more drawn out. Will I be able to tolerate this long process? It's not so much fear that I feel now but the tragedy of a long, slow slog, unpleasant without hope.

Without hope. Hmm. I've been dealing a lot with this question of hope for several years. I've been thinking, writing and teaching for more than two years (much of it is on my website, www.davidhilfiker.com

) about our response to the ecological crisis when there can be no reasonable hope of “fixing things.” The reality is that we are not going to slow this process of, for instance, global warming, for a long time, and for the foreseeable future, the impact on civilization is going to get worse and worse. I’ve been impatient with people when they can’t recognize the hopelessness of even keeping the damage from getting worse. In our culture, most of us don’t know how to deal with hopelessness. While it can’t be *fixed*

we can learn to live in the present, to act upon the universal principles expressed in the Gospel, to recognize that no one can completely fix what’s happened, and to recognize that whatever happens I can contribute to the work of building a new society when the system-as-it-is collapses to one degree or another.

Well, here I am facing another kind of hopelessness. There is no significant chance that I can be “fixed” and recover. But, at least so far, when I can stay in the present, my life has actually been richer than before and I can sense my contribution to the community more. At least one of my contributions will be to teach my community not to be afraid of this disease. I won’t be able to do that if I’m always thinking about the future and all the unpleasant possibilities. Can I find legitimate hope in just being present to the community?

Monday, November 12, 2012

At the end of our Eighth Day covenant members meeting yesterday, I talked about my Alzheimer’s. It was a small group, but—as I guess I should expect by now—it was a very good, close time. People listened carefully and we talked some about that this would mean for the community.

An older friend was sitting one person over from me, obviously upset and then beginning to cry. I had not anticipated her reaction but quickly realized her husband died several years ago of a different (but symptomatically similar) dementia. I had actually noticed the symptoms before I had heard about the problem, but was told that the family didn’t want to talk about it. Things were different twenty years ago, however, and there was not the same opportunity for such sharing.

But at yesterday’s meeting, I very willingly interrupted my story and she did share her pain. I had mentioned how much closer Marja and I were becoming because of the disease. I had also mentioned the “interesting adventure” aspect of my disease. At that point she broke down

completely, sobbing. She said that had been one of her husband's reactions, too. Her sobbing seemed to be a real catharsis for both her and the community

I told everyone about my fear of abandonment and about how I hoped that naming the disease and my fear of abandonment now could help at least some of them to not abandon me. I gave some specific examples of how naming things might help. I realized that I hadn't defined them even for myself before.

For instance, whenever my memory fails or anything else happens, I hope the other person (or persons) and I will all be able to acknowledge freely that, given the disease, it's only to be expected. We won't have to ignore the elephant in the room or retreat into embarrassment.

I hope that I will be able to acknowledge and express my feelings whenever it's appropriate. I'll feel less isolated than I might if I felt I had to hide or repress the feelings.

It won't be perfect, of course, but I will save me the embarrassment of having to explain away my symptoms, for instance, my difficulty in remembering. I won't have to make up some excuse; it might even give me the courage to let go of my anxiety and embarrassment over whatever dumb thing I just did.

The community's response was really wonderful. Almost everyone responded. I talked about the paradoxical blessings: the closeness between Marja and me, my conversations with Kai, the opportunity to let go of analytic thinking. People seemed to be able to understand the paradox. We talked about the support that I would need and, even more, that Marja would need. People thought we could do it together.

As we were closing the meeting, I realized that we may have others in our small community who are undergoing the same process although it hasn't been obvious or mentioned publicly. If so, it will be a heavy burden for the community to carry all of us. I would not be surprised if my public announcement and its positive reception didn't encourage some similar response from others in the community who could begin to acknowledge the issue and work with it.

My immediate reaction to that scenario is not something I'm particularly proud of. As I thought of our having others in a similar situation, I actually resented the possibility that they would lessen the specialness of my situation. If several of us are demented or heading that way, how can any of us be seen as unique, as having a special place in the community? It harkens back to the fact that I was not really so disappointed with my diagnosis, for it made me special. It seems to me bizarre, but that was my reaction.

My other reaction was to think about the larger community. We've been working hard to bring younger members into the congregation. How many are going to be interested when they know about demented people among the members?

Friday, November 16, 2012

I totally blanked on my 3 PM weekly meeting with my closest friend Fred Taylor at Columbia Heights Coffee yesterday. The appointment was already on my calendar. Around 1:30, I noticed the appointment and made a mental note that I'd have to leave soon. Then I completely forgot about it until about 4:30. I was embarrassed, so I called Fred, and launched into this long, convoluted apology. But he interrupted me and said without any rancor, "So, in the future, I'll just have to call you the day before."

"It was already on my calendar," I complained. "It's not going to do much good to be reminded." So he replied, "Well, I guess I'll have to call you an hour before."

He most likely recognized that this was my Alzheimer's acting up. And so, he wasn't really disturbed, that is, he didn't *blame* me. But, of course, I blamed myself. And there are a couple of things I'm going to have to learn:

First, my inability to do what is normally expected of a person is going to happen to me over and over. Especially when I feel as normal as I do, I'm always going to wonder whether it's the Alzheimer's or just my carelessness. So I will tend to feel embarrassed. I'm just going to have to let that go. Mostly, it's not going to be my "fault." I'll have to stop worrying, for instance, that others will blame a carelessness on my part .

Now that's going to be hard. The emotional imperative my entire life has been: YOU DO NOT MAKE MISTAKES. And making mistakes is going to be a huge part of this illness. It will not be easy to let it go, to acknowledge each time what's happened without feeling upset. But that's going to be the challenge.

One other thing is that my friends will mostly make allowances for me; most of the time they're not going to be pissed off, for they know about the disease. They won't need a long apology to reassure them. So I can allow myself real gratitude for their care. It's hard to be grateful, of course, if you're embarrassed. So I'll have to learn to be grateful.

This is another of the blessings of this illness. Perhaps it will be easier to let some things go, to have my friends help me let things go.

Sunday, November 18, 2010

We had an Eighth Day budget committee meeting this afternoon after the church service. I realized during the night that I had to fix a couple of minor things on the suggestions for the budgeting process. So I got up early to work on it. This should not have been a difficult process. Ordinarily it would have taken, perhaps, half an hour. But I knew that I would have some mental slowing, so I allowed for an hour and a half.

But it took me *five* hours! I missed church and was half an hour late for the meeting. And still I wasn't sure. These should have been simple changes, but I kept getting confused. I would figure out how to fix something but before I could actually finish doing it, I couldn't remember the details of my reasoning. I kept trying to simplify the process, writing each step on a piece of paper, but I kept having to go further back in the reasoning process just to remember, for instance, the obvious fact that total income equaled past income plus future income. I knew why this was happening, of course, so I didn't really blame myself, but it was frustrating anyway. Eventually, I got answers that I thought were probably correct, but even now I'm not sure.

After I'd arrived at the meeting, I told the other committee members that I wasn't sure of my estimate of how much was going to be left over at the end of the year (that we could then use for next year's budget). I could be way off, I said. If so, we'd have to go through the entire several-week process again. Ultimately, I suggested that we use the figure I'd provided but

emphasized its tentative nature. There was really nothing else to do, so we soldiered on with the difficult task of allocating income, knowing that we might have to do it again. Again, as we went through the process with only tentative allocations, no one seemed to harboring negative feelings toward me.

At the end of the afternoon, Maria volunteered to come back to our apartment and review my calculations to make sure they were right. So she did and they were. As she was leaving, I told her how appreciative I was of her willingness to come over. She said something like, "Well, I'm going to be available to you through this whole thing." It was really wonderful, a moment of deep connection.

I was very grateful that I'd informed the church membership about my impairment and its implications for the community. Since I knew they knew, I didn't have to apologize over and over or make up some reason or be really embarrassed. Everyone knew what was going on. No words were spoken and none were needed.

My own reaction was also positive. Even as I was working on the spreadsheet in the morning and frustrated with my inability to do it right, I didn't blame myself or get angry or become afraid. I understood what was going on and just treated my confusion as a fact of life, frustrating certainly, but nothing I had to guilty about.

In the entire process, I had much to be grateful for.

Sunday, November 25, 2012

It's not only asking for help that's difficult but also accepting that which is freely offered. On Friday, we went to the Natural History Museum to see a wonderful IMAX film on the monarch butterfly. Leaving the museum afterwards, I tried to put my jacket on. After putting my right arm into the jacket, I was having some trouble swinging the jacket around to get the left arm in. The problem was only that the jacket was bunched up behind me. So I needed to take the jacket off, straighten out what was wrong in back and put the jacket on. Marja saw me struggling and moved over to help me. I was annoyed and pulled away from her help. In this particular case, my difficulty had nothing to do with the Alzheimer's and I was able to take care of it by myself.

But, of course, there was no way Marja could read my mind and know for sure what I needed. So what she did was appropriate. What bothered me was thinking that she thought that I was helpless when, in fact, I wasn't. So it's going to be a delicate dance in which we both have to offer each other a lot of grace. I'd better learn to find a gracious place to receive help both when I need it and when I don't.

I was reminded this morning that I'll have to learn to laugh at myself. As treasurer for the church, I usually pick up the offering basket right after I've taken communion, bring it into the kitchen, and do the initial processing. After taking the offering, the liturgist is supposed to put the basket on the altar near where I take communion, so I can remove it. But sometimes they don't, putting the basket in different places. Sometimes I fantasize they've purposely hidden it. At our services we give each another communion. After receiving the bread and juice we turn and offer them to the person behind us in line. This morning, I'd just taken communion from the person ahead of me and was turning around to give the bread to the woman behind me. But I was also looking to make sure that the liturgist had put the offering basket in the right place. As I turned and offered the bread to Carol, I looked down and instead of the bread I was holding the offering basket. I gave a look of chagrin, hurriedly exchanging the basket for the bread. At another time in my life it would just have been one of those funny things that happen. But for me such events are going to happen more and more frequently. It's still funny, I suppose; at least Marja thought so when I told her at home. So I'd better learn to laugh at myself as this worsens.

Wednesday, November 28

Marja went out with her friend Eve last night; I expected her home about 10 PM. About 11:00 or so, I began to notice that she wasn't home yet. After midnight, I began to worry. Marja is well able to take care of herself, and she's sometimes forgotten to call me when coming home late. And I've always told her that I don't worry easily and that events like that were more annoying than worrying. (True, the previous episodes were during the day and not after midnight.) I knew that if anything serious had happened, the police or hospital would let me know quickly. And, above all, I knew I couldn't do anything about it then.

I couldn't sleep, though. Awhile later I began to fantasize about what it would mean for me if Marja *were* gone. And that was a scary thought. Who would take care of me as I declined? I couldn't imagine putting that burden on the children, at least not for very long. So it would mean, I imagine, loneliness, early nursing home admission, and so on.

It really is the fantasies about the future not the realities that are most painful.

Friday, November 30, 2012

I keep forgetting that this disease can go on for a very long time. Over such long periods of time, one's self-image changes; I can feel it to a tiny degree already. I stopped being a doctor in 1993, but it took me a number of years before I had left the doctor-self behind. And until I did leave it behind, I didn't realize how much strength it had given me. By three or four or five years from now, this current confident and competent, sense of self will be atrophying. Right now, I can recognize my symptoms and realize that I have Alzheimer's, but I don't yet identify myself as demented. That will change: the losses will pile up.

One of the futures that scares me is the rages that sometimes accompany mid-stage Alzheimer's that scare and puzzle caregivers because they seem so uncharacteristic of the patient. They can be violent and require restraints. I worry about the suffering those rages would inflict on Marja and others and how that would, therefore, isolate me. I've always been under the impression that these extreme, unwarranted bursts of anger were simply intrinsic and unpreventable. But an Internet article suggested these rages are frequently from anger that has been repressed during the course of the disease and not from some programmed, organic inevitability. If those with this disease don't allow themselves to work through their emotional responses, if they have to deny it, if they become confused about what's happening, and or they are given no permission to express their perfectly normal anger, then the emotional lability that is intrinsic to the disease is eventually much more likely to manifest as rage. But I'm starting in a very different direction, letting friends and family know, trying now to build support for later, talking about it a lot and trying to imagine what future scenarios might be like. And I have a lot of people who are willing to go on the journey with me. Hopefully, that will at least keep my anger manageable.

It does seem, however, that emotional lability is programmed into this disease and the question is how it will manifest itself. Avoiding the rages may be wishful thinking. It's one more reason, I think, to stay on this path of sharing my experience.

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