

Blog Posts from December 2012

Saturday, December 1, 2012

Several weeks ago, Dawn Longenecker, who supervises the Disciples House interns, asked me to come in mid January to do a presentation for the interns. I felt I needed to let her know there would be some uncertainty about my future capabilities. She, of course, expressed her concern and caring. Several days ago, she wrote me an email about some unrelated issue and then wrote, "I continue to be stunned about the news about your health." "Stunned!" That word expresses what I would like to hear from people. It's what I feel is often missing in others' reactions; it's why I was so grateful for Carol's and my children's responses.

Intellectually, of course, I know my expectations are not only silly but unfair. I can't expect other people to have any particular reaction, to find the exact word I'd like, or to express it immediately ... or ever. I know how deeply they care for me and how little the form of their reaction has to do with their love and concern. Nevertheless, my emotional sense of incompleteness from others' reactions has been part of the swirling mix of feelings as I try to accept this new reality.

Sunday, December 2, 2012

Washington DC

I watched the movie *Friends with Benefits*. It was typical rom-com stuff, but, about half way through, a new character was introduced: the father of one of the protagonists. He had Alzheimer's, but what was interesting is that I didn't immediately recognize it. For the first several scenes, the father was warmly welcoming and expansive, engaging in normal conversation with the son he hadn't seen in a while. There was no hint of cognitive impairment. Then the father invited everyone to go for a boat ride the next day, but his wife corrected him (with a we-have-to-go-through-this-all-the-time look), reminding him that the boat had been sold ten years previously. For a brief moment, he seemed impatient with himself, but then recovered. A few moments later, the camera panned, and it was obvious he didn't have any pants on. Still, I wasn't sure that he wasn't just an eccentric old man who wore his undershorts around the house. But soon it became clear that he had early Alzheimer's.

But he wasn't defined only by his Alzheimer's. Ultimately he played a very important role as father advising adult son in making the movie's crucial decision.

What I liked about the movie was that it was the portrayal of *early* Alzheimer's. He wasn't bed-ridden or violent or funny or in any way over-the-top. In most media portrayals, there's little sense that much of the person is unaffected after the diagnosis. Here he was a real person struggling with what was happening to him. Also interesting was that his shifts between normal ability and impairment were complete about-faces: one minute fine, the next into bizarre behavior or speech. The portrayal of the disease was richer; it gave me another picture of what lies ahead.

Wednesday, December 5, 2012

On the bus to Philadelphia

A month or so ago, the battery of the used iPhone I had purchased a number of weeks previously failed so I bought a new battery over the Internet and tried to install it. Following one set of instructions, I tried to open the phone but became impatient with my inability. I ended up breaking it just trying to get it open. I'm still not sure the Alzheimer's caused it or not. More significant, however, is that my impatience led me to try to force it. Ordinarily, I think I would have just stopped and taken it in for professional installation.

I then bought another used phone over the Internet but within weeks this battery needed replacing, too. (Apparently the iPhone 3G is notorious for a short battery life.) I decided to try—very carefully this time—to install the new battery again. I looked up a different set of instructions, which advertized the task as relatively simple for anyone with a little experience. I enjoy being able to do little tasks like this, especially when they save you \$30 or so. This time, though, I read the directions through thoroughly ahead of time. They were very clear but complicated. After reading through about 23 steps and eight different electronic connections that would have to be carefully disconnected (and the battery isn't even out, yet), I decided I wouldn't chance it. Under other circumstances, I would have considered it a challenge and taken it on. But I know that somewhere in the middle of those 23 steps or beyond, I would have lost my way. So I'll pay the \$30.

Marja and I are getting comfortable talking about the disease and our future ... and even joking about it. Unfortunately, I can't remember examples. I've bought a little pocket notebook that I'm beginning to carry around for jotting things like that down.

I'm on the bus up to Philly to see Karin and then will leave tomorrow AM for Boston to spend a few days with my sister Lois and her husband Fred. I haven't told her about the Alzheimer's and I wanted to do it face-to-face. Our last attempt to get together was short-circuited by Hurricane Sandy. I'm not sure what to expect. I think I'm looking forward to it as a way of tightening the relationship with Lois.

It sometimes crosses my mind that perhaps I'm taking the Alzheimer's too seriously by needing to travel 800 miles and take five days. I also worry that making the disease so important in relationships is just narcissistic: Lots of people have Alzheimer's, but you don't hear them trumpeting it about. I'm even trying to figure out some way of visiting my other sister Laurie and her husband Paul on our way back from our Christmas in Napa. It would involve getting off in Chicago and taking the bus to Minneapolis.

I realize that things will almost certainly change, but these few months have made me happier and more content than I have been in a long while. Gone is the sense that I should be doing *more*

It's okay to take some time off, to give up some projects that don't seem appropriate. I think what I find most freeing, though, is that I don't feel the same necessity to live in the future, fearing the judgment that will come if I don't do it right. I have felt much better, for instance, just responding to the tasks that come before me rather than having a set idea of what I should be doing ahead of time.

Relationships are closer, especially with people whom I've told. Before our leadership team meeting on Sunday, Kent asked how I was. It was not just a greeting. He wanted to know how things were going for me in the light of the disease. Dawn Longenecker wants to get together ... just to talk. I'm aware of the gift of being in the Eighth Day community, even among those who don't know my diagnosis yet; I feel closeness, support, love that have always, I'm sure, been there. When I talk with my children, it's deeper. It feels sometimes like I'm in a different, better world.

Amazing.

Thursday, December 6, 2012

On the bus to Boston

I was sitting in daughter Karin and her husband Gabriel's kitchen last night on my way to visit my sister Lois. Gabriel filled a Sippy-Cup for their 2½-year-old Jai. On his way to Jai's chair, he passed by me and, by mistake, put the cup down before me. He realized his mistake and picked the cup back up almost immediately and said something like, "That's not for you." "Not yet," I said; "I'm not that far gone, yet." I'm not sure that Gabriel got the joke (although I think he did), but I wonder if he felt constrained not to treat something "so serious" as humorous.

Little events like that, certainly no one's "fault," make me wonder whether others are even interested in dwelling on my Alzheimer's. I'm interested in those experiences, of courses, but is my listener? I asked Karin to stop me from talking about my disease when it got to be more than she wanted. I doubt she will; I doubt very few people will be able to stop me even if I request it explicitly. Another potential for isolation.

Again, I notice how it's my fantasies about the future that are painful, not the present.

I called Lois to ask directions to where we would meet in Boston. She was giving me detailed but ultimately uncomplicated instructions. Nevertheless, I couldn't keep them in my head. I think the internal problem was that once I was concentrating on the second part of the description, I couldn't remember the first part and make the visual connection. I'm going to have to write more and more down.

"Only the person who loses his life will find it." It's a Christian version of the Buddhist idea of non-self. I will have to lose my attachment to images of myself if I'm to be truly alive during this period of illness. One way of looking at non-attachment is a willingness to give away my desires and put in place the laws and disciplines of YHWH. (I wish I knew for sure what that meant!) Only the willingness to detach myself from my image will allow me to be led through

the Spirit into responding to exactly what is in front of me.

In an important way, then, the Alzheimer's is a teacher about detachment, about losing self. If I try to keep my life, I will constantly be trying to *be* who I *was*. All those things—intelligence, competence, prophetic vision—will gradually go. Exactly what will replace them is not clear. So far, what I've gained is greater than what I've lost, so I can't really complain yet about having to give up things.

Friday, December 7, 2012

Martha's Vineyard

Lois picked me up at the bus station yesterday evening and we drove directly down here to Martha's Vineyard. On the way down, not knowing about the diagnosis, she asked what I was doing these days; the answer, of course, was that I was coping with this diagnosis. It seemed a good lead-in to the weekend, so I told her. She was silent for a while as we drove the highway and then, "Jesus, David." A little later, "I am so sorry." There were some tears. Shortly thereafter, she said, "I knew you had some bad news if you were coming up here just to 'visit.'"

Lois hadn't missed anything a month or so ago when I'd called up to invite myself for a visit. When she returned my call, Marja picked up the phone and, in the course of the conversation, told Lois that I was concerned about some "cognitive issues." That was "back in the day" (six weeks ago) when we had decided to break the children in gently by mentioning concerns but not going so far as to name the diagnosis. It was a useless strategy, of course. Anyone in our family would pick up on those words immediately and press for clarification. Even if they didn't push for more information, they would be waiting for the next shoe to drop.

Advice to others with Alzheimer's: Do not try to break anyone in "gently" unless you're prepared to tell a bald-faced lie to keep the conversation from going to the end. They are going to worry. (That probably won't stop me from trying to postpone telling my other sister Laurie before I visit her.)

After we'd arrived on the island later yesterday evening, Lois and I told her husband Fred. Given his career as a psychiatrist, I was hardly surprised that he had no visible emotional reaction, although I'm beginning to find such matter-of-fact responses more and more helpful. It's good to be able to talk easily and frankly about what's going on. We talked mostly about Alzheimer's from a medical point of view, and I got some new information. He said that there were new drugs in Phase II testing (to see if a drug is safe) that showed some hope for preventing the deposit of "beta amyloid," the protein that is deposited around the neurons. The resulting dysfunction of those neurons is considered the primary cause of the cognitive decline. Although there's no clinical evidence yet, the possibility that medications might ultimately be able reverse (or at least stop the progression of) early disease seems reasonable. Lois, of course, was very interested in getting me into a drug trial, but since the current phase is multi-national, taking a total of 200 patients and tens of thousands probably clamoring to get in, the chances are minuscule. There will undoubtedly be Phase III trials (to further test for whether a drug is effective). I find myself curiously (even irrationally) resistant to the idea. Part of Alzheimer's symptoms is apathy. Is that what's keeping me passive? Well, it's certainly a part of it. Truth is, I just don't want to be bothered with pushing for inclusion into a trial that I don't stand much of a chance of getting into anyway.

Saturday, December 8, 2012

Martha's Vineyard

For a while last evening, Lois couldn't find her credit card. She said something about having heard that she should memorize the number of at least one of her credit cards, but that would be impossible for her. I said somewhat arrogantly that I had memorized mine. (I should add that I have worked on it for a long time and still reverse some digits.) She said, "So which one of us has Alzheimer's?"

It seems to happen frequently. I'll mention a symptom, and Lois (or Marja) will complain of having the same symptom.

We older people are very afraid of this disease. Normal ageing does sometimes lead to similar symptoms. And we're worry. Lois and I were talking about the intelligence test Kong gave me to make the diagnosis; Lois asked what questions I missed. I told her about forgetting the date.

“The date!? The date?!” Who doesn’t forget the date?! She sounded incredulous, especially when I said that the diagnosis of dementia was made after missing only five questions like that. I don’t think Lois or Marja or others are making their concern up. She probably does have similar symptoms. Partly, it’s denial: “If I don’t have Alzheimer’s, but I have the symptoms of Alzheimer’s, then maybe David doesn’t have it, either.” But the opposite is probably also a factor: “Maybe I have it, too.”

We’ve laughed a lot here. Much of it has to do with the increasing comfort with my diagnosis. There are lots of jokes or just light-hearted comments to be made.

It’s frustrating that I can’t remember any specifics now as I write. I’ll need to use my notebook for even the little things. It makes this blogging more difficult, too. I know that stories are by far the best way to tell the tale, but I forget the details almost immediately. What’s interesting is that—even though I can’t remember the details of the incident—I remember the emotions quite well. The dark humor is comforting for me. We don’t have to deny the disease. I don’t have to feel guilty or so frustrated by my mistakes. I suppose it will be harder when my symptoms are much worse.

Fred is a psychiatrist. I asked him if he thought that medical students might find interviewing me or my lecturing them interesting. Once my symptoms are a little worse, knowing that I’m so impaired in one area but so competent in another (talking with them, for instance, or being able to handle a blog) may teach them a lot about the disease and become more comfortable with it. We talked about lots of possibilities: Lecturing to medical audiences—especially medical students—in small groups and allow them to see my limitations clearly even as they see other areas that have not diminished; having first-year medical students assigned to follow me every six months or a year to watch the progression of the disease; making a video (or even a documentary) at periodic times that would show the progression of the disease.

I worried out loud that the ability to talk cogently about my experiences might disappear, too, but Fred thought that it might take quite a while. I didn’t press him for details, but perhaps that ability might come from a different part of the brain. I need to ask him why he thought that might be true, so I’ve written the question down.

Tuesday, December 11, 2012

Washington DC

Last night, in the course of a conversation about how much we tend to forget as we get older, a friend mentioned her concern that she might well have Alzheimer's disease. Her mother and sister had it. A while ago she was at training for her work, and the trainer asked her to enter her password into her computer to begin. Not only did she not remember the password but she also didn't remember she even *had* password. She had to leave the training. When she got back to her office, she realized that, of course, she had a password and remembered immediately what it was ... As she told me, I didn't display any emotion. I asked her some questions. I wanted to make sure that I demonstrated empathy by staying with the conversation so that she knew that I was accepting of her disease and not shocked or about to abandon her. It's only now that I see that my response was just the same clinical, professional response that has been so unhelpful for me all along. I have wanted something more from others, but I didn't even offer it to my friend. Perhaps she wouldn't have wanted anything more, but I didn't even give her the opportunity. I didn't offer her my real empathy. I don't have much reason to be surprised about the reactions of others to *my* disease. And, in fact, there have been more empathetic and helpful responses than I should have expected.

Alzheimer's is a common disease. Lots of people have been through this process before; many are going through it now. I'm not so special, yet I keep expecting that people will respond to me as if mine were a unique suffering. And some do. But as the disease progresses and I become more typical, as my friends become accustomed to my behavior, as I develop the usual empty appearance of an Alzheimer's patient, there will be even fewer who see me as "special." I guess I need to prepare for that, too.

Wednesday, December 12, 2012

Washington DC

I think about what this increasing memory loss will mean. I am human, I exist in community, I know myself through my memory. What will it be like not to be able to remember Marja's name or what I just said? Will I still feel "normal" like I do now? So do I feel normal now? Currently, I

feel just as much a person as ever. I forget a lot of things and I get confused sometimes, but those external symptoms don't seem to change my consciousness. In terms of self-perception, I am just as much David Hilfiker as I have ever been. Things that I forget, of course, just disappear. I may know I *should* be able to remember them, but I don't. Fortunately, I suppose, memory has never been my strong suit, so it's not really part of my self-image. It's almost the opposite of the Buddhist non-self: even as I change drastically, my consciousness is of the same "self."

So mostly I worry about the future. What will it be like when ...? But I am not given to know the future, especially in a disease like this where no one can really tell me what is was like even for them. It's a little like death because no one can know what it's like to die before they die, and then it's too late to tell anyone else. Similarly, you can't tell anyone else what it's like when you're confused about what's being asked or can't remember long enough to put it together.

All this is speculation, of course. I've noted several times before that staying in the present is not particularly painful, and the future isn't here, so this worry doesn't help anything. But if I want to share with you who are reading this what's actually happening now, this useless speculation and worry about the future are what's happening now.

Am I *worrying*, though? Actually, I don't think so. I just looked it up: The dictionary defines "worry" as a state of anxiety, being troubled by something. I certainly think a lot about the future, but I don't feel real anxiety about it. Am I "troubled"? Again the dictionary defines "troubled" as being in distress or being afflicted. I don't obsess about the future. I've said frequently that it doesn't do any good to dwell upon the future, but it does help, I think, to *imagine* it. Imagining prepares me for what's coming. Obviously, I can't know for sure what's coming. So if my imagining the future were worrying about the future, then it might be well to curtail the worrying. As it is, its primary value is to get me ready for what's coming.

The elder lawyer we'd visited a month or so ago contacted us to let us know he couldn't take our case because he was just too busy. So I asked around and last night a friend, Debi, gave me the name and email address of another elder lawyer I could contact. After I'd finished composing the email and sent it. Debi mailed me back to tell me I'd sent the email to *her* and not the other lawyer. I had apparently clicked Reply when I wrote the email and unintentionally sent it back to Debi. OK, that's a mistake probably everyone has done at one time or another. So I pulled up what had sent to her and put it in to my Outbox to go to the other lawyer. A few moments later—fortunately before the email actually left my computer, I noticed I had done exactly the same thing again, almost sending it to Debi a second time. Fortunately I caught

myself and sent it to the lawyer.

Thursday, December 13, 2012

Washington DC

I realized last night that I'd made a huge mistake that will probably create havoc for the community. I've written of the beginning of this mistake before on Nov 18, 2012. In order to create a budget for Eighth Day, I had had to estimate how much money we would have left over at the end of the year. I went back over the figures in QuickBooks and—after a very difficult, prolonged and confusing process—I estimated that it would be about \$24,000. As I wrote then, I gave that figure to the budget committee, we created a recommended budget on the basis of my estimate, and two weeks ago the entire community passed the budget.

It now turns out that my estimate was grossly in error. We will have almost no money left over at the end of the year, which means that the extra \$24,000 we put in the budget and have allocated to the various ministries is imaginary. The budget would have to be cut down by about 15%, but process would be enormously inconvenient for the community. I've emailed the Eighth Day leadership team and the budget committee and recommended that we not go back and rewrite the budget. For complicated reasons that aren't relevant here, Marja and I will owe about that same amount in tithe by the time we bring my mother-in-law's inheritance to the States. So I'm recommending that at the end of 2013 we see how much is needed and Marja and I pay that tithe early.

Regardless of how we solve the problem, I've now made a mistake with relatively serious implications. It's pretty clear that I need to stop doing the books for Eighth Day. Since I want to be able to continue contributing my time and energy to the community, having to give up doing the books would be a real blow. Actually, doing the bookkeeping (as opposed to the computational error I made leading to this mistake) is relatively easy to do, and I think I would be able to keep that task for, but, given this mistake and the community's knowledge of my Alzheimer's, I doubt they would want me to continue.

It's strange, but I didn't (and don't) feel the panic that I ordinarily would if I made a mistake of this magnitude and had to acknowledge it to other people. Perhaps it's apathy; more likely it's

the combination of knowing that it's really not "my" fault (but the Alzheimer's) and trusting the community to accept me as I am. I am certainly glad I told them earlier.

Friday, December 14, 2012

On the train to Napa

I sent an email yesterday to the budget committee and the Leadership Team about the mistake I'd made, suggesting that I give over the duties of bookkeeper. I got the following response from Fred that he copied to all the others:

[I] reckon the dilemma you describe as a piece of God's humor (I mean this seriously) and move along trusting that things will work out in a way we can handle either by 8th Day receiving more than we have anticipated or by our needing to make cuts in the fourth quarter which we have to do any year income is short of projections. I think we have done our job—both as finance committee and [church] members—on this budget and we should let things proceed and not worry about it ... definitely not worry about it! In doing so I think we will honor our dual grounding as faith-based and responsible. Most of all it is critical that you or you and Marja not take this on as your responsibility. Stuff happens! And sometimes it gives and sometimes it takes. That's my piece of wisdom.

I'll probably go with my original plan since it's only modestly inconvenient, but Fred's response certainly helps me recognize how much support he is offering me.

As I write this, Marja and I are on the train to Napa, CA, to visit our family. Coincidentally, Fred is on the same train with us as far as Chicago. As Fred and I talked, our conversation turned to my decision to give up the Eighth Day bookkeeping job. He pointed to the difference between *accepting* the limitations that come with the disease and "*dropping out*" of community by giving up too soon on a task that keeps me connected to the community. It's a fine line and I've faced it before, for instance in trying to decide whether to continue my professional writing about political/economic matters.

I told him that it *would* make me feel that I was contributing less to the community. The bookkeeping itself is not that difficult, and I think I can do it well for a while, but I'm afraid that it wouldn't be acceptable to the community. On the other hand I could ask the community and not assume I know what they want. The best might be to talk it over with leadership team. I will decide then about informing the covenant members and getting their feedback.

In trying to write this blog entry this morning, I've had to go back and forth between my journal entries and my letter to my spiritual director to get clear what I've already written about in previous posts. This should be a relatively simple task but I found myself getting confused. After more than an hour, I had to stop and come back to it later. When I came back to it, I was able to complete the task but it was still not easy.

As I look over these blog posts, so much of it is a simple recounting of all the symptoms of the Alzheimer's I've experienced and not so much *reflections* on what's happening. On the one hand, I want to talk about them, to process them. On the other hand I'm not sure that this kind of cataloging is helpful to my readers.

Monday, December 17, 2012

Visiting family in Napa CA

So many of the lessons I'm learning with Alzheimer's would be important at any point in anyone's life. Learning to let go of self, to laugh at myself, to recognize my dependence on others and accept their concern and help, to see myself as ordinary, and so on are life-skills we could all use, regardless of our capacities. So, for instance, I'm learning not to blame myself for my mistakes but to believe that I'm doing the best I can under the circumstances. Intellectually, I have long believed that all people do the best they can under the circumstances, but it's only now that I can believe it for myself and not feel guilty for my stupidities, to let them go as life's inevitabilities.

So many of the lessons I'm learning with Alzheimer's are life-skills that we can all use at any point in our lives, regardless of our capacities: understanding the pain in hanging on to my "self" and then learning to let go; laughing at myself, gently and without judgment; recognizing my dependence on others and graciously accepting their concern and help; acknowledging that I'm

much more ordinary than I often think; learning the boundary between acceptance and pushing forward; and not blaming myself for my mistakes but believing that I'm doing the best I can under the circumstances.

Thursday, December 20, 2012

Visiting family in Napa CA

I'm going to be driving to the San Francisco airport to pick up Kai, Karin and Gabriel who will be coming in around midnight. I've become somewhat anxious: Am I in good enough condition to be making such a drive over California freeways at midnight? I sent an email to my neurologist who was fairly reassuring that—at this stage in the illness, before there's even a formal diagnosis of dementia—I'm probably okay. Waiting to make a mistake before I give up doing the books for Eighth Day is one thing; waiting to make a mistake driving until I give it up is quite another.

Although it hasn't made a big difference yet, I've begun trying to pay very explicit attention to where I put things. I need to make a mental note when I put things down or have a specific, routine place for things where things belong. It's a little aid to help me compensate for what I cannot do. (When I was an intern at St Mary's in Duluth, all of us carried around a "peripheral brain" that contained details about drugs, procedures, evaluations and so on. This is just an extension of that concept into a new situation.)

Friday, December 21, 2012

Visiting family Napa CA

Last night as we sat around the fireplace, Laurel's husband James asked what my first symptoms were. I talked about the various episodes. Laurel said she'd noticed for quite a while that I was taking longer to do things and that I was losing things. I'm realizing that this disease has been having an impact for a much longer time than I've been aware of. I'm now beginning to believe that the difficulty I've had in writing and a general mild apathy—both of which have

bothered me quite a bit—are due to the illness. Perhaps that's too convenient an excuse, but it seems to be true nevertheless.

Monday, December 24, 2012

Napa CA

We went to an annual San Francisco “Dickens Fair” yesterday. It was the Cow Palace, a huge place just packed with various stalls, stages, actors running around playing period characters, and food, all in a Victorian theme. There was an astonishing number of fair-goers in full costumes with all the accouterments, eg several men with chimney-sweep equipment. So it was pretty neat. Although the birds-eye map of the floor was pretty straightforward, it was confusing for me to wander around by myself. And when I did spot something and wanted to show it to the family, I had trouble remembering where I had seen them. That's a significant increase in impairment of spatial memory.

During this Christmas vacation, I've thought intermittently about how long it will be until I see the family again. I've decided to come much more frequently to see Laurel and her family so it will be only March. But Karin and Gabriel will be in India for as long as a year and a half as he does his PhD dissertation. They will be back in August but then not until mid-2014. The changes in cognitive ability don't seem to be happening very quickly, but they are certainly happening. I don't know who I'll be when I see them again. In some important way this and other times are opportunities for saying good-bye, for recognizing that things will be significantly different when we are together again. Perhaps that's too dramatic! Perhaps it will be so gradual that we don't ever really say goodbye but the relationships just fade away. If so, when is the time for mourning? Probably I just have to accept the fact that each saying goodbye will have more significance than it has before this disease. Maybe that's enough.

Friday, December 28, 2012

Napa CA

Wednesday evening all of us—Marja and I, our children Kai, Karin, and Laurel and our sons-in-law, James and Gabriel—sat down to talk about money in the light of my illness. The issues were a) the very practical one of transferring money to them in order to sequester it from Medicaid and b) the bigger issue of the financial future for all of us. The conversation felt good. I felt in them a quiet recognition of what was coming and why the conversation was necessary. I was surprised to find that Kai and others were specifically interested in my end-of-life desires. As I articulated them then they are pretty simple: I don't want to be kept alive artificially after I can no longer recognize people; by "artificially" I would include treatment of even treatable infections (for instance, urinary tract infections) that left untreated would probably end my life. And I want the family to feel okay about putting me in a nursing home when they can no longer *easily* care for me. Especially if Marja were to die before I did, I don't want the children putting their own lives on hold after I can't at least mostly take care of myself.

Marja and I already both have wills and "Five Wishes" documents that go over this, but I will need to review them to make sure they take into account our new situation.

We mostly talked about the disposition of our money after both of us died. We've already talked to them about the fact that most of Marja's inheritance will be going to work for justice. [\[1\]](#)
We haven't yet decided on the details but some portion will defray college tuition costs for the grandchildren; most, however, will be going to work against poverty. While each of the children supports our decision at an intellectual level, it's only natural that there is some unhappiness at an emotional level that the bulk of the inheritance will not go to them and their children. I'm glad we had the conversation.

I've thought again how it will be when I can no longer actively participate in family conversations and decisions like this. I think I'll be aware of it and feel sadness (and most likely some resentment) at the distance. Once again, these are thought about the future. The present is filled with positives.

During this visit, Karin, Laurel and Kai have been intentionally making decisions to spend time together with me, and I've been very appreciative. I'm happy that my children want to be with me before they feel like they have the responsibility to care for me. An issue like this makes us all more appreciative, I expect, of how tenuous our lives are and how important it is to take advantage of the moment when it's here. I've been very grateful for this vacation and the desire of every member of the family to spend time together. It's clear that I will have a lot of support during this illness.

In reading to my grandson Otto last night, I noticed I had forgotten most of the previous chapter that I'd read the night before. Otto has a phenomenal memory for the book, so it's not reasonable to compare myself with him, but even reading last night's chapter through a second time, the memory of the previous reading was not clear.

Sunday, December 30, 2012

Napa CA

I'm noticing for the first time that my confusion is now interfering with my life in ways that are obvious to others. We've been playing the game *Rummikub*, which, though basically simple, has room for some complex moves. I can only carry those moves out to a limited degree of complexity. And when we switched from

Rummikub

to

Skip-Bo

, it took me a significant period of time to make the transition between the games, getting constantly confused between the rules for each game. More importantly, I noticed Laurel helping me without much hesitation as she noticed my confusion. It's the first time, I think, that I've actually needed help, another person has noticed it, and they've done something about it.

And I was pleased at how I was able to receive the help. I was grateful for it and not embarrassed or resentful. Because we've talked about everything, she felt free to jump in and without my experiencing it as paternalistic. This will obviously begin to happen more and more and my ability to respond to it well will be tested repeatedly. We have a good beginning. It also reinforces my decision to make the diagnosis completely public.

The manifestations of the disease are increasingly frequent. The other day walking with Laurel, I got disoriented, and it took me a while to recognize where we were. I'm limiting my driving out here, not so much because I feel unsafe driving, but because Laurel and Kai are safer ... at least their reaction times are much better. I am just astonished at how quickly Laurel can type on her cell phone; I mean I literally don't see how she can do it. I wonder if my brain has slowed down so that other things just seem quicker.

So it gets deeper and deeper. It's deep enough that I'm ready to share the diagnosis with the rest of the community and with my extended mailing list...perhaps on Jan 20.

It feels very much that this adventure is truly beginning. I will become very different both in consciousness and in relationship to others. And I have a great deal of curiosity (and, of course, fear, too) about how this whole thing will work out.

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