

Blog Posts from January 2013

Tuesday, January 1, 2013

Napa CA

My spiritual director reminded me that my vulnerability will only grow as the disease progresses. She expressed the hope that the Eighth Day community could not only see the vulnerability but also see the richness and opportunity in it. It's not *exactly* the biblical aphorism ("He who loses his life for my sake will find it") since the Alzheimer's is a natural phenomenon that I did not decide upon. But I am deciding to

show

my vulnerability and that

is

a conscious decision. In freely sharing my diagnosis, I am acknowledging it and baring my vulnerability

before

I would actually have to. If that turns into a positive experience for the community, we may be able to learn something about the sharing of our inner realities.

Acknowledging one's own and others' vulnerability is itself essential to community. Claims of human invulnerability are always lies that damage the possibility of truly human relationship. The hope is not only that the importance of vulnerability will become clearer as the disease progresses but also that we could begin to share that gift with one another. For that I would be very grateful.

Sunday, January 7, 2013

Telling My Youngest Sister Laurie

Lois, my oldest sister, and I went to Minnesota over the weekend to spend time with my other

sister Laurie. It is getting less surprising to me, but spending time with people with whom I've just shared that diagnosis was a wonderful time, a deep closeness between the three of us, including Laurie's husband Paul. I had a much briefer time with Alex and Abbey, their grown children, but that time also was rich. The richness, I believe, comes from the increased sense of vulnerability we all feel. Both Laurie and Lois have their own sufferings that confront them. Both Laurie and her husband have been disabled for many years, she with multiple sclerosis and he with incapacitating back pain. Lois is still grieving the loss of her daughter fifteen months ago. Pain is additive, it seems. This ongoing loss of their brother adds to their vulnerability. Aside from the hours we spent watching all of the NFL play-offs (who would guess that my sisters would become rabid football fans?), we spent almost all of our time together, talking and just being present to one another.

I've mentioned it before but this increasing vulnerability is a great gift to me. I've been intellectually aware that I am vulnerable to the vicissitudes of life just like anyone else. During some of my bouts of more severe depression, I've known it experientially, too. However, I've basically considered myself a person who doesn't need much from others. Our American myth is that such independence is the bedrock of the culture. But it's based on a lie. None of us is independent; all of us have deep needs that can only be met by other people. While I may have recognized my vulnerability intellectually, there is all the difference in the world between my striving to overcome it in order to prove my independence, on the one hand and welcoming that vulnerability and experiencing its gifts, on the other.

Laurie, Lois and I have decided to get together more often. I hope it happens, but we'll see.

I still marvel at the reality that these last several months have been the richest period in my life.

Wednesday, January 9, 2013

There are still periods of several days in which I don't really notice any cognitive symptoms. Strangely, I find myself almost wishing there were some symptoms to anchor me. It's sort of like pressing on a sore spot to make sure it still hurts. It's not that I don't have doubts about the

diagnosis, although I do irrationally consider the possibility that the diagnosis is wrong. As I've explained before, my first reaction to such thoughts is not anticipatory joy but actually anticipatory disappointment. My identity has gotten so wrapped up in my disease, that I would regret losing the immediate future I've been planning for. This is just one more symptom, I think, of my needing a "self" to anchor me. I need to keep reminding myself that as natural as that need seems to be, I quite agree with the Buddhist recognition that hanging on to self is a cause of deep suffering. Let go. Let go. Let go!

Saturday, January 12, 2013

Yesterday, we met with a lawyer to talk about the details of the issues with Medicaid. She mentioned that the cost of nursing home care was now between \$100,000 and \$120,000 a year, which is an extraordinary figure it seems to me. Since the majority of people with Alzheimer's will eventually end up in the nursing home and most of those will run through their resources fairly quickly, the cost to the government is extraordinary. Most people think of Medicaid as a program only for poor families with single moms. But in reality two-thirds of Medicaid funds go to care for people who had been middle class, but just burned through whatever funds they had. If only those people who want to shrink the size of government to the point where it can be drowned in a bathtub could recognize how important Medicaid and lots of other government programs are to our country, perhaps we could have intelligent discussions about the role of government and taxes in our country. Oliver Wendell Holmes, the Supreme Court justice once wrote: "Taxes are what we pay for civilized society." Amen.

It's one of the reasons I feel okay about trying to avoid having to pay for my nursing home expenses ourselves. Our government should be doing far more to encourage a civilized society, especially creating the conditions for justice, which means a redistribution of resources to make our society livable for the poor. Since Marja and I are giving the lion's share of our resources to that very purpose, I have no reluctance in having Medicaid pay my nursing home expenses if our money will be used for what government ought to be, but isn't, doing.

The best solution to keeping our money away from Medicaid, it seems, is to create a trust that Marja and I no longer have control over and then to put most of our money there. Our trustee, probably our eldest daughter, could then disburse the money to the causes that we consider important as well as a certain amount to us for living expenses beyond Medicaid. It's hard to

believe it's that simple and that everyone in our situation doesn't choose it, but, according to the lawyer, most people don't trust anyone else with control over their money, even a family member. What does *that* say about our culture?

Monday, January 14, 2013

After meeting with the lawyer on Friday, we met with our financial adviser on Saturday to talk about the issues arising from the Alzheimer's. The details probably aren't relevant here, but I was impressed by two things. The first was our process. I'd told him previously about my Alzheimer's; Saturday we acknowledged it again at the beginning of our meeting and he expressed his sympathy appropriately. But after that, we moved directly into the meeting and were able to talk easily about the nursing home I'll probably need, my death, and Marja's needs during and after my illness. It was a straightforward discussion, and I was grateful.

The second thing was that he mentioned was that his mother-in-law had Alzheimer's and she's currently at the stage where she is quite confused about many things (for instance, they can't leave her at home alone) but when she is in conversation with them, she is still present. While I'm sure there are limitations to what she can understand, nevertheless, they are still in what feels like full relationship with her.

Somehow I'd forgotten this stage and that I unconsciously saw myself as going directly from a somewhat confused and ambulatory old man to a bed-ridden vegetable in the nursing home. If I'd thought about it consciously, of course, it would have been obvious that there are several long stages in between. On the one hand, his mother's story is hopeful: Even well into the disease, it's possible to still be in relationship with people close to me. On the other hand, it's likely that the point will come that my family won't be able to meet my needs even though I'm still ambulatory and "present" to myself and to others; this could happen, for instance, if I wandered uncontrollably. Perhaps I will need to be in a nursing home well before I lose consciousness of myself and those who love me. That thought is scary.

January 17, 2013

Washington DC

Joseph's House and Its Interns

My first class with the Joseph's House interns met this afternoon. It was wonderful.

[Joseph's House](#) is a home and hospice for homeless people with terminal diseases. My family and I founded it in 1990 as a home and community for homeless men with AIDS and we lived there together for three years. It was a wonderful place, an experiment in deep community between white and black, rich and poor, sick and well. We took men in when they were just becoming ill, so they could participate fully in the community until they became sick and died, usually about a year after coming in. It was easily the most intense period of my life. I haven't been director there for years and I left my position as the finance person about five years ago. I still keep in touch as a founder connected with fundraising and as a friend to Patty Wudel, the Executive Director who has shaped Joseph's House into a profoundly beautiful place of silence, presence, care and love. Now that my disease has allowed me to look back over my life, Joseph's House is one of those things in which I take great deal of pride. It was a great privilege to have been involved in its creation.

The most important contribution I currently make to the house is to teach the year-long volunteers, most of whom are just out of college. They learn about presence and compassionate care quite naturally by working there, so our class emphasizes the social injustice that brought these men and women into the house. We meet once a week for an hour and a half, studying some history of early oppression of African Americans, reading [Urban Injustice](#), my book on the history of the ghetto, and reading Michelle Alexander's [The New Jim Crow](#) to discover the profound injustice of the American criminal justice system. It's usually a wonderful class.

As is usually true, this group of young people seems bright and eager, and we seemed to establish a bond immediately. I had been a bit reluctant to teach this year because of my diagnosis, but Patty and I decided I would teach as long I could. But I felt it was only fair to let

the interns know about my diagnosis. I'm glad I did. I think I'll be able to handle things okay, but, since we're going to be spending almost five months together, I wanted them to understand my memory lapses (and whatever other symptoms came along) to give them permission to talk with me or Patty if my behavior started affecting the class. As with others I have told, these moments have been full of respect, caring and love. Yet again, the moment felt beautiful: a great sense of spiritual connection.

I fear I'm sounding like a broken record, stuck in la-la land, telling everyone how wonderful this is, denying the realities of this disease. But I'm quite aware of what's coming. And that doesn't change the beauty of the present moments.

Friday, January 18, 2013

Washington DC

***Sojourners* Interns**

I led a seminar with the *Sojourners* interns this morning. *Sojourners* is a Christian magazine committed to peace, justice and discipleship. It's a good publication and has done much to bring Christians—especially evangelical Christians—into the movement for peace and justice. Internships are very competitive and these are very bright and committed young people. This was my usual seminar on the history of the inner-city black ghetto, and I know the material well. But I was nervous, perhaps because I thought I would be telling these accomplished young people what they already knew. My fears were unfounded, but I was still nervous and I found myself much less fluent and having much more difficulty finding words than usual.

So was this just one of those dissatisfying good sessions that every teacher goes through? Or was it my disease? I'm beginning to realize that I pop in and out of being affected. Yesterday at Joseph's House with the interns was great; this morning at Sojourner's not so much. In Alzheimer's symptoms come, I understand, but it's confusing. Should I continue to accept these invitations to work with groups or mentor individuals? I'll keep going for now. I hope I'll recognize when to stop.

Saturday, January 19, 2013

Washington DC

Memory

I spent an evening at [Joseph's House](#) last evening. I occasionally visit for the Friday evening meal, which is open to guests. Last night as we ate, I was seated close to two Ethiopian refugees who'd come to the house in the past few months. One I had talked to several times in the past months, but I could remember almost nothing of our conversations, even his name. As he described a talk we'd had a year or two ago about the possibility of living with us, I could only vaguely remember it. Clearly I'd been a somewhat important person to him ... and I could remember little of it.

It's really embarrassing. These several times we'd met, I'd been surprised by his instant welcome and warmth toward me. After the first time or two, I knew each time that I had met him but not the contexts. It wasn't appropriate in that situation to tell him about my Alzheimer's, but I worried that he'd felt slighted when I didn't recognize him for the fourth or fifth time.

The same thing happened with the other Ethiopian, a woman that I can now vaguely remember meeting and talking with at our church's Thanksgiving dinner. She too was friendlier than a stranger would be, and as we shook hands, she recognized that I didn't remember her and mentioned it. I apologized, but again I felt really embarrassed.

This is just the beginning of many such meetings. A part of me wishes the disease would progress faster so that my condition would be more obvious and I less embarrassed. (Well, ok, it's a really, really small part of me that wishes for a faster progression.)

My memory is increasingly being shredded; there large holes through which more and more is

falling. My symptoms are becoming more noticeable, and I'm glad that I will be sharing with my entire community at [Eighth Day](#) tomorrow and beginning to publish all these [blog entries](#) in a week or two.

Sunday, January 20, 2013

Washington DC

Constant Losses

Yesterday, the drawers in my old file cabinet locked. We've never had a key and never locked it. I enjoy and am used to fixing things around the house, but after two hours of putzing, smashing and removing the old lock, and breaking the thin closet door next to the cabinet, I gave up. Only then did I recognize that the file drawers had never been locked in the first place; I just hadn't noticed the latch! This is one of a number of things in the past few months that I haven't been able to do, several times breaking something in the process. It should have, but hadn't, occurred to me that I would be losing that skill, that joy, too. It's a disease of constant losses.

In all of this, of course, lies the opportunity for spiritual growth, to find rest and gratitude within the suffering. I'm doing okay with it, I think. I don't get too frustrated with myself, I don't blame myself, or feel guilty. I understand that this is just what I've been given at this time in my life, and the task (and adventure) is to make peace with it. And to a great degree I seem to be able to ... at least for the time being.

As the disease progresses, I keep thinking that I'm going to *feel* differently, experience myself somehow as a different person. But so far that doesn't seem to be true. Yes, my limitations are becoming more and more noticeable. Yes, they are affecting my life practically. So I

am

different, but

I

am not different ... if that makes any sense to you. It seems contrary to the Buddhist notion of "[not-self](#)"

.” I recognize that I’m different intellectually, but the difference doesn’t seem to be in my *self*

. It’s almost as if I’d lost an arm: It’s obviously gone; I can’t do what I used to do, but there’s something within me left unchanged. “Illusion,” I suspect the Buddhists would say. But it is certainly my experience at this point.

Monday, January 21, 2013

Washington DC

Vulnerability

In my previous thinking and writing about the vulnerability of the poor, I’ve emphasized that we people of privilege can never really give our privilege away. We can take on voluntary poverty by moving into the ghetto, or sharing the poverty of a remote African village, but our privilege always goes with us. We have our education, we have our vocabulary that opens doors, or we have family that in a pinch will help out. At the very least we know what privilege is and in which direction it lies. Usually, when I’ve talked or written about this, I’ve added the caveat, “... unless we develop a mental illness that takes our privilege away.” Alzheimer’s will, in this sense, eventually take my privilege away.

Even with this disease, of course, I will never really experience the vulnerability of the poor and oppressed, of say an oppressed person who also has Alzheimer’s. But this will get me closer. Similar to the worst time of my depression when I had to face the possibility that I would never be well, the Alzheimer’s means that I will be more and more vulnerable to the needs and desires of others. If am not able to participate in a conversation (or if other people think that I can’t), then I will be excluded. At some point I will be dependent on others to get me what I want or need. I will become susceptible to scams or frauds.

I don’t feel that vulnerability yet, but it is certainly coming. It will take a certain spiritual strength to exist in that vulnerable space. But what kind of spiritual strength will I have as my cognitive impairment worsens?

Thursday, January 24, 2013

Washington DC

A Life Changes

I've had a disquieting, indefinable sense of things being not quite right. It's part apathy, part a mental fuzziness, part anxiety, part a sense that I've not been doing my best, part a loss of confidence. On the one hand, I've accepted one, possibly two new engagements to speak with students and I think my class this afternoon with the interns will go well. At the same time I'm anxious about both of those things. I feel like I'm wasting time, yet I'm not sure how I could have been more efficient.

Perhaps it's mostly loss of confidence. I want to update both my own [website](#) and [Eighth Day's](#) (which I manage), yet I'm a little scared that I won't be able to handle the update and will have wasted the \$1000 that it will probably cost. I'm not sure; I can't define this feeling well.

I want to spend a lot more time with my family over the next couple of years, both my children and my siblings. Because of the long distances involved, it will mean fairly long absences from Eighth Day, and I'm wondering about what that will mean for the level of my participation in the community.

If I think of it, taking time with family really isn't negotiable so the real question is which church responsibilities to let go. Recently, as we talked during our weekly coffee, Fred affirmed the priority of visiting family, which is certainly my desire.

My life has changed dramatically; I and others will have to expect significant changes in what I do with the time that I have left.

Fred and I also talked about making good use of the time that I have here. He said that part of his theology is that “nothing is wasted.” What I understand from what he said is that any experience can become, in Garrison Keillor’s word, “material.” That is, I can take whatever I’ve been given and use it for good in the world. I’m certainly hoping that I can do that. I’m hoping, for instance, that my experience with this disease can give young people a different perspective on this aspect of aging. They don’t, of course, think much of their own dying and I would imagine that Alzheimer’s is at the top of their list of horrible ways to die. So if the young people in my classes, at church, and perhaps at medical schools or colleges, will allow me to enter their lives a little bit, I might be able to do some good.

Saturday, January 26, 2013

Washington DC

Accommodation

I guess I’m accommodating to the diagnosis. I go through days or even weeks when I notice no symptoms ... at least no new symptoms. I suppose I’m getting used to picking up a new magazine and reading half way through an article only to realize that I’ve not only read the magazine previously but that I also read this same article just a few days ago. Or blanking on a word in every conversation. Or spending five minutes looking through our tiny apartment for my hat or shoes or backpack several times a day. I *am* used to it and it doesn’t feel abnormal. I catch myself thinking what I’m going to say to friends or those who read my blog if this whole thing turns out to be a false alarm.

I shouldn’t blame Marja, then, for flipping back and forth in how she thinks of me, too, one night concerned that I’ve just fallen for a telephone scam, the next cautioning me about publishing this blog because it might be something else, not Alzheimer’s. We both go back and forth.

I continue to be amazed at the wonderful conversations I’m having with people. I’ve had good

conversations with people before this disease, of course, but it now happens repeatedly. My second discussion class with the interns at Joseph's House was very rewarding. What a gift!

Monday, January 28, 2013

Washington DC

Little Things

A Presbyterian pastor visiting yesterday from New Jersey introduced himself to me in church. He seemed to think we'd met before. I shrugged and probably looked at him pretty blankly, so he started describing several occasions where we'd seen each other, what we'd talked about and that he'd come to Joseph's House. Clearly, it had been important to him; I couldn't remember a single bit of it. So I was embarrassed that I didn't remember a thing about this man who knew me so well; he was embarrassed to think that the conversations had meant so little to me. I considered cutting through the bilateral embarrassment by mentioning the Alzheimer's, but that would have trapped us both in one of those too-much-information moments with 15 seconds left. In this case, embarrassment seemed the best choice.

This morning I poured cold milk into a cup with the intention of putting the milk carton back into the refrigerator as soon as I put the cup into the microwave to heat. But I forgot to put the carton back and only noticed it standing there on the counter when I returned to the microwave a minute later. Before taking the cup out of the microwave, I made a definite mental note to return the carton of milk to the refrigerator as soon as I got my cup. It was only a few minutes later as I was returning with my milk to my room that I remembered the milk carton.

Twice I forgot the very same intention seconds after I'd made it, even after making a conscious mental note of the intention.

It may not seem like much but things like this that would have seemed just funny when they were rare events now happen over and over.

Tuesday, January 29, 2013

Research

Washington DC

I received a call from a research department at Georgetown University that is studying a treatment for Alzheimer's. The hope for the drug is that it will actually change the progression of the disease rather than just improve cognitive function while the pathology of the disease progresses undisturbed. I told my neurologist several weeks ago that I'd like to be part of such a research project, he informed the people, and a nurse at Georgetown telephoned me. I've read the particular research protocol. While it's intense, it's something I'd very much like to take part in.

The truth is that I only pursued the research possibility because my sisters [pushed me](#) into it. But now I'm very interested in the possibility. It may be difficult to qualify for and only a few hundred people from around the country will be invited in. There will actually be four or five interviews and SOME testing to determine eligibility. One of the tests will be a [Positive Emission Tomography](#) (PET) scan that can further confirm my diagnosis and lay to rest any lingering doubts. My neurologist offered me the test [several months ago](#), but I declined for cost reasons; now it will be part of the protocol.

As a physician I always felt that research protocols were the best way to get detailed care from doctors with sub-specialty interest, and I always recommended them to appropriate patients. Often, there won't be any benefit from the medication being studied, but the process itself leads to deeper understanding of the disease, attention to minor symptoms, and a sense that "everything is being done." So my [previous reluctance](#) doesn't really make any sense. Perhaps it was part of an unconscious need to slow down the acclimation process and better integrate Alzheimer's into my self image.

As scheduled, I spoke to about 40 Georgetown medical students this morning about inner-city poverty. I was nervous. I'm very familiar with the basic outline, but I needed to change the introduction. In rehearsing it before my talk, I realized that I could not speak fluently about something I wasn't intimately familiar with, so I had almost to memorize the introduction. It went well. Speaking with young people is one of my favorite things to do. The students were attentive, and my presentation was fairly fluent, although my memory for something quite familiar failed me at one point and I had frequent trouble word-finding.

Afterwards, I spoke with the professor. She apparently hadn't noticed anything wrong with the presentation, which relieved me. I then told her about my Alzheimer's, and asked whether there was any possibility of breaking into the medical school to share this process with doctors-in-training. She seemed positive and promised to talk with the relevant professor within a day or two.

I'm all set to announce my diagnosis to the world. All my previous posts are online both on my [website](#) and on my [blog](#).

Wednesday, January 30, 2013

Now It Begins

Washington DC

I have been diagnosed with a progressive "[mild cognitive impairment](#)," almost certainly Alzheimer's disease. The neurologist told me the diagnosis last September, but I've waited to begin this blog until now when my symptoms are becoming noticeable to others. (You can find all the previous posts in the blog's archives [bottom left] or by going to my [website](#) where I'll keep all the posts in a few documents for those who want to read the whole story in chronological order.)

Actually, I'd been noticing symptoms for a while but was still surprised by my doctor's diagnosis. Over the past several years, my memory has significantly declined. This is a common complaint for people as they age. For 20 years before he died, for instance, almost every time we visited, my father asked again for reassurance that he didn't have Alzheimer's. His memory loss, like many other older people's, was mostly for names and faces. I've always had that kind of poor memory, but I began losing memory in other areas as well. Two years ago, an entire trip to a rural area southern Virginia disappeared from my memory. I drove down to visit my friend Jens Soering in the prison to which he had previously been moved. I could have sworn I was going down for the first time. In fact, I'd been there before several months earlier.

I chalked it up to a single bizarre experience that would probably not mean much to a doctor, so I didn't do anything except tell the story to friends.

Some months later, I couldn't recreate a computer spreadsheet formula that I'd written several years earlier. In fact, when I went back and examined the formula from an old spreadsheet, I couldn't even understand what I'd done. Such calculation difficulties persisted. I went to a neurologist in the fall of 2011 for testing and he said that I did have a cognitive impairment but that it wasn't severe and the relevant point was whether it was progressive. I returned last fall (2012) and, yes, the impairment had progressed. There aren't too many likely candidates for causes for progressive cognitive impairment. The neurologist performed tests for them: they were all negative. There is no certain test for Alzheimer's except to rule out these other candidates, so the overwhelming likelihood is that I have early Alzheimer's disease.

Since last fall, the disease has progressed. My memory is much less reliable. I've had trouble finding words, especially in Finnish as my wife Marja and I try to converse but also quite noticeably in English. Both my daughters, Laurel and Karin, recognized in retrospect that it took me longer to do certain tasks. That slowness in figuring things has gotten worse, too. While I can still eventually do most computer tasks, they can take a long time, and I can get confused easily. I've even had two experiences of being in locations that should have been quite familiar but, in fact, I didn't really know where I was or how to get where I was going.

I've been apathetic about writing and about my website these last several years. I'm somewhat less interested in politics; for example, I couldn't sit through the presidential debates last fall. (Some of you may feel that the only mentally healthy response to the debates is to turn them off, but it's never been true for this political junkie.) Perhaps I'm just looking for an excuse, but I'd like to believe that this disease is at least predominantly responsible.

So, while there is always a chance that it's something else, my neurologist and I are pretty certain that it's Alzheimer's. So far, the symptoms have been limited. I can still write well, although you may have noticed that my essays have been less frequent lately. When I type, I frequently leave out words and phrases (which I hope I'll edit out before I actually put my posts up). I'm still teaching in small groups, still doing the books for my church, still mentoring some others. Up till now, I've noticed my mistakes well before others do. My judgment seems unimpaired. My life goes on.

It seems paradoxical, but Marja and I are actually doing quite well. In fact, I've noticed some positive changes in my ways of thinking and acting. I'm more emotionally open. I'm less insistent on maintaining my image as prophetic voice or incisive writer. I don't need to prove myself with new accomplishments. For the first time, Marja and I have allowed ourselves to look back on our lives with satisfaction and gratitude. I'm more vulnerable to other people and have been experiencing an extraordinary closeness to some people that I would never have thought possible. While it seems crazy to say it, *so far* my life has been better ... happier ... than before this disease. I have no illusion about what's coming, but, up until now, it's been good.

Garrison Keillor said recently, "Nothing bad ever happens to writers; it's all material." So, at least for a time, this Alzheimer's disease will become material for my website and for this blog. I want to write about what Alzheimer's is like from the inside. What is the experience of losing one's mind? Do I still experience myself as the same "self"? Obviously, I don't know how long I can do this, although my good friend Carol Marsh has volunteered to keep it going with interviews when I can no longer write. We'll have to see.

I had a number of scenarios for my death. This wasn't one of them. But now, I have pictures in my mind of lying drugged and incontinent in some nursing home. I don't want friends and family to remember me as that old guy babbling on the couch. I'm afraid of the uncontrollable rages that sometimes accompany this disease. Mostly, I think, I'm afraid of abandonment as I become one who can't hold up his part of the conversation. I'm afraid that--except for Marja--my family or even very close friends will abandon me (even though I know intellectually that these are irrational thoughts), but it's not paranoia to think that the quality of relationship will isolate me.

But it's not only fear that we have about Alzheimer's. It's also embarrassment. What do we say to the guy has just repeated himself for the third time in five minutes? Several years ago

our community invited to Washington a writer whose books had brought great change to our lives. But he had Alzheimer's that had progressed significantly. I'm not proud to say that I had no use for him. Why had we invited a man who could hardly follow a conversation? (After my experience so far, I suspect he did understand at a non-cognitive level and honoring him was well worth our effort.)

So part of my reason for this blog is to address that fear and embarrassment. I've been frank and transparent with my family and my community because I want us to work together to teach each other about this disease and how to respond to it. I want to discover what friends (or even just acquaintances) can do to understand this illness and not have to abandon me. Perhaps I can take some fear away. .

I've been writing "posts" since September and they're all now on my [blog](#) , but haven't wanted to publish them until now. I'm not sure how many people will want to go back and read those many posts, but I think that just putting them on a blog will almost certainly bury them too deeply and discourage anyone from reading the whole story. So, here they are in chronological order. I will continue to do that as the archives expand. I've also written a short

[autobiography](#) that, I hope, will give you the chance to know who I was and, therefore, what I've lost.

These have actually been wonderful months! I want to follow it out. I hope some of you will want to join me.

[February 2013 Posts](#)

[Jump to my blog](#)