

Blog Posts From March 2013

Friday, March 1, 2013

Washington DC

Public Vulnerability

A reporter and photographer visited yesterday. They are considering a substantial article in a local paper about my Alzheimer's, with the possibility of following me through the remaining years of my disease. Several years ago they spent a lot of time at Joseph's House, the home and hospice for homeless men and women that we founded twenty-three years ago. And, although I only vaguely remember our interactions, they wrote sensitively about the house in a long article accompanied by beautiful, grace-filled pictures. So I trust them not to take advantage of me. (For all the ways the media are savaged for breaking trust and writing sensationally, they've never treated me that way in almost thirty years of occasional interviews.)

They stayed for two hours. I must admit it was wonderful to be the center of attention, especially of two attractive, intelligent and gracious women. We enjoyed ourselves, and I felt I got to know them well. In fact, I talked so freely and we laughed so much that I wondered if my volubility was indication of a growing loss of judgment. I do want to let as many people as possible know what it's like to experience this disease. On the other hand, I don't want to make a spectacle of myself.

I've had a lot of experience with public vulnerability. When I made a serious medical mistake over thirty years ago, I wrote about it in the best medical journal in the country. The article was then picked up by *Harper's* magazine and became probably the single most important writing of my career, eventually helping to break the profession's taboo against public discussion of our mistakes. (For a long time, in fact, I was primarily known within the medical community as "that doctor who made those mistakes.") Another example is my referring frequently to my depression in my writing, speaking and teaching; it led many people to share with me their own experience with depression, grateful to hear the subject talked about publicly.

In both cases, people had cautioned me about the inappropriateness of my openness, but, in retrospect, that public vulnerability has been perhaps my most significant contribution to our

society.

Truth be told, however, I've been enjoying myself and my interactions with people so much since my diagnosis in September that I'm not willing to let that question of inappropriateness spoil the fun. Being open is a good thing to do, and I don't trust the naysayers.

And if my judgment does become so impaired that I can't distinguish appropriate from inappropriate, then I trust my circle of friends and family to help me figure it out. So, at this point I don't care. This has been too much fun!

Monday, March 4, 2013

Washington DC

Emotional Openness

I find myself enjoying this increasing emotional openness that seems to be part of my Alzheimer disease.

Saturday night, Marja and I went to the Kennedy Center to see a play presented by a Finnish troupe in Finnish (with subtitles) as part of a month-long Nordic Festival. Marja is from Finland and the long periods of time our family has spent there have given me a real sense of connection to the place and to the culture. The setting of the drama is under a bridge somewhere in Finland where a number of homeless people are camped. An extended family there decides to put on a Christmas pageant in gratitude for some distant relatives who live nearby who have allowed them to use their shower. So the climax of the play begins with the homely pageant, introduced by a reading of Jesus' birth from the Gospel of Luke. That reading is part of any Christmas celebration there. It is beautiful in Finnish and full of emotional richness for me, a symbol of my happiness there, I suppose. This time the reading began abruptly, and I wasn't expecting it. Immediately as the character began to recite it, however, a profound sense of longing overcame me. I choked up with tears of gratitude.

Then Sunday morning in our little church community, we had a wonderful service. Every part

of it from prayers of gratitude to prayers of confession, to our (always prolonged) sharing of the peace gave me deepening awareness of my belonging. The music was energetic and rich. Our teacher for the morning was a professor on sabbatical who's been part of our community for only seven months. One aspect of her teaching was a recounting the richness of our community and its importance for her spiritual journey. One of the events she recounted was my acknowledging my Alzheimer's and the community's welcoming my vulnerability with obvious caring. Another person prayed for Marja and me. There was a powerful sense of community.

In our church we offer each other communion. When the time came, Marja was right in back of me in line, so, after I'd taken communion, served by the person in front of me, I turned to offer the bread to Marja. I choked up so much that it took me, perhaps, a full minute to get the words out, "This is the body of Jesus broken for you." Each time, I was overcome each time by tears of joy, of gratitude, and of connection.

(I thought it was pretty funny, however, when Marja and I talked about it later over supper. She had thought I was crying because I was frustrated from not being able to remember the words. Oh, well, so much for soulful communication between the marital partners brought close by this terrible disease.)

For my entire life until now, I've been particularly unemotional, due, I believe, to clinical depression. I felt few emotions, and crying during communion was certainly not normal behavior for me. Perhaps it's the loosening of inhibitions that's common to Alzheimer's. Whatever is causing it, it feels rich.

I've always been intellectually aware of the profound privilege of my life: I was given a sharp intellect; I'm in good physical shape; Marja's and my relationship is wonderful; my children are doing well; I've always had meaningful work for which I've been well compensated and appreciated; I have a supportive community; we have no financial problems, and on and on and on. So I've always known how good I had it but have never *experienced* the gratitude that our good fortune would usually evoke. Perhaps my happiness and contentment over the past months have not been so much new as old, never-before-experienced *feelings* of joy and contentment. Perhaps this Alzheimer's is allowing me to enjoy my life for the first time, not because things are any better, but because I'm more emotionally in touch with the goodness.

I feel rooted, grounded. I'm where I'm supposed to be. I'm not looking for something else, something better. And this gift comes through my disease.

March 6, 2013

Washington DC

This is a guest post from Patty Wudel, Executive Director at [Joseph's House](#), the home and hospice for formerly homeless people with AIDS where I worked for many years.

David [wrote last week](#) about a recent Joseph's House staff meeting where he shared his experience with Alzheimer's disease and about Joy, who was there that day and is in her seventh year with Alzheimer's.

Joy and her partner Grace normally volunteer at Joseph's House on Tuesday mornings, arriving early enough to join the silence that begins our weekly staff meeting. Along with our other volunteers and staff, they sit in deep quiet as each "finds a place of rest in the middle of things." When the bell sounds to end the silence, Grace heads for the kitchen to prepare the hearty lunch she'll serve after our meeting.

Joy usually stays with the rest of us for the meeting. She used to keep Grace company in the kitchen, but often she became restless and would wander in and out of the room during our meeting. Her restlessness was distracting for everyone.

Several Tuesdays ago, Helen, our 86-year-old community elder, shifted into Grace's chair when the meditation ended and extended her hand to Joy, who took it. That day Joy stayed for the whole meeting with Helen beside her. Since then Joy has remained with the rest of us for our staff meeting while Grace cooks in the kitchen. Joy listens intently when someone speaks and responds to the emotional tone of voice, especially if the speaker is seated close to her. Sometimes she chuckles or raises her eyebrows, punctuating what is being said. Other times she asks a question. If what is being shared brings tears to the speaker, Joy will cry a little also. Our staff and volunteers take all this in stride easily and kindly.

Right now Joy's presence at our staff meetings feels effortless. Actually, because we so much love to have both Grace and Joy at Joseph's House, our community is simply doing everything we can so they can both be with us. It's good, and it's not really difficult at all. It feels natural.

Friday, March 8, 2013

Washington DC

Why Not Try This?

A good friend was quite excited to tell me about new research being done in which certain brain exercises can actually re-wire the brain. He gave me a book on the topic, which, out of deference to him, I will at least look at. His thought, of course, is that I should get involved. "It's only an hour or two a day," he said.

But I'm not inclined to spend much time evaluating the treatment, even though I have heard that it might be effective in the case of certain types of stroke. To re-wire a brain in which specific neurons have been knocked out while leaving all others untouched—as happens in a stroke—seems to me quite different from rewiring a brain with Alzheimer's generalized damage.

But my reaction certainly begs the questions: Why not? What can I lose? Why not try everything? My reluctance seems strange even to me.

Perhaps it's just apathy, a well-known symptom of Alzheimer's. But there are more objective reasons for my hesitation, too.

First, deciding to do one thing means deciding, if only passively, not to do others things. One or two hours a day of brain exercises is a significant diversion from living the limited time I have left.

Second, this research is in its very early phases with no actual evidence of effectiveness in Alzheimer's. So the chance of this approach having a positive effect is tiny. There are many such untested treatments out there. Already in my emails I've had at least three others suggested to me, each one with its small chance of success. Why not try this one, or that one, or the one over here?

But it's more. Spending time and energy trying to fix myself seems to me like a form of denial of my disease and its terrible future.

I've been in this position before. During my public teaching or lecturing or writing, I've often referred briefly to my depression. It's a way of bringing depression out of the shadows and reducing the stigma that sticks to it. Almost invariably after such a lecture, someone would come up and suggest a "new treatment" that usually seemed at least reasonable and was purported by someone to be effective; there were dozens of them. Each person, I'm sure, meant well but behind their "suggestions" I felt the implicit challenge: How could you not do absolutely everything possible to treat this disease?

When I was practicing as a rural physician, I had a patient, Peter, a man with Multiple Sclerosis (MS). At the time there was no effective treatment for the disease. Peter would come in every month or so having heard about or read about a new treatment that he wanted me to facilitate. In medicine the number of "possible" treatments is inversely proportional to the effectiveness of accepted treatments: If there are a hundred treatment options out there, you can be pretty sure that none of them is effective. I had no confidence at all in these new treatments for MS, but I wasn't about to interfere unnecessarily with Peter's path of hope. But as I watched him chase one mirage after another, I wondered whether he could ever come to peace with his illness.

Might not one of these new treatments for Alzheimer's actually work? Of course. But which one and with what likelihood? I prefer accepting my future and dealing with it as best I can. I could see that following these leads could bring mostly frustration and tension, inability to talk so openly about my disease, decreased ability to notice the fine differences in my condition, and less time enjoying the newly emotional and loving connections I'm making with family and friends.

I have a particular vocation around this disease: to share with others my experience of it in order to reduce the fear it produces, puncture the stigma, point out the positive sides, help others to accept their disease and reduce their isolation. And part of what that means is to accept what's happening, pay attention to it and chronicle it. Others will choose to fight the disease; more power to them; perhaps they will find an effective treatment; perhaps trying it out will further our knowledge. But I know that this is my path, which may very well not be right for others. Certainly many people will judge my decision as crazy. I could come to regret it, too. But after living with myself these past decades, I know that I must recognize my limitations and not struggle against them.

I fear this post will make no sense to anyone. But I'm clear about what I'm doing.

Monday, March 11, 2013

In the Chicago Amtrak station

Hyperbole?

I offered what we call a "teaching" at our Eighth Day church on Sunday. The subject was my Alzheimer's and my "theological learning" over the past five months. As with so many experiences I've had with other people since September, this was a wonderful sharing that felt rich and beautiful, deepening the bonds of community. I posted the teaching on both the [Eight h Day site](#) and [my own](#), and (as I usually do with my writings) sent it out to my mailing list of over 300. Within hours a torrent of emails began to flood my Inbox. This suggests not only support for me but also the hunger people have to learn about this disease. It's well-matched by my desire to write and teach.

As I review the sermon, however, I see I'm using the terms "beautiful," "wonderful," "rich," "gift" so often that it begins to feel like a soap advertisement out to convince myself and others about the wonder of the product. Reviewing my posts over the last several months, I get the same feeling. At an intellectual level I understand what the [future](#) has in store for me: It's not pretty. And my friends and old readers will know that I'm hardly a Pollyanna: My usual response is to dwell much more in dark side of things than the light. Indeed, this experience of joy over the past five month is unique, as great a surprise to me as it may be to those who know me well.

But the richness and beauty are so real that I can hardly write about it without using these overused terms that smack of hyperbole or, worse, just trying to put a pretty face on suffering. I do sometimes wonder whether these current feelings aren't some kind of euphoria that will eventually reveal itself as just another way of coping with feelings of fear, anxiety, depression, etc. Given some of the emotional pain I've suffered several times in my life, however, I know that denial is not my style.

Perhaps what sometimes seems like hyperbole is just the loosening of inhibitions that goes with this disease.

At this point I don't know. Wherever this joy comes from, it's real, and it's part of what it has meant for me to live within the reality of my Alzheimer's disease. And I'm grateful.

And, as [I've written before](#) for a writer everything is material.

Tuesday, March 12, 2013

Washington DC

State of Consciousness

I'm curious about what will happen to my state of consciousness as I enter more deeply into this disease. At present that consciousness feels no different from any other time in my life. Toward the end, however, I'll be lying in a bed apparently unconscious. But will I be unconscious? If I *am* conscious then, what is *that* experience? If I'm not conscious then, what are the gradual changes in consciousness that will happen between now and then?

On the Saturday before the Oscars, Marja and I went downtown for a showing of the five films that were nominated as the best "short films." A French film, *Henry*, made a deep impression on me. From the beginning, the film felt confused, almost surreal. It flipped back and forth in time and was full of strangers who kept acting as if they knew Henry, the main character. But they kidnapped him, forcibly injected him with drugs, and kept him helpless in restraints. He met earlier versions of himself and of his wife.

It was all very bizarre until, over half-way through the film, I finally tumbled to the fact that Henry was demented, and the film was showing his world from his point of view, his own experience of the world. Mostly he was in his own demented world, but his sense of himself didn't seem to change as he passed back and forth. As far as Henry could tell, he was the same person whichever state he was in.

Of course, this was only a film, and Henry's sense of himself was only fiction. But how does the inner state actually change as the disease progresses?

An older friend once told me of an event shortly before her husband died with Alzheimer's. He had been completely out of it, intellectually unresponsive for a long time. My friend visited her husband at the nursing home and during the middle of her visit, his dull eyes seemed unexpectedly to find their focus, and he began a normal conversation that lasted some minutes. He seemed lucid and in those few moments they re-kindled their emotional bond. He was cognitively present to her.

What happened? Presumably we'll someday be able to describe physically what happens in the brain to bring about such wild swings. But what was his *experience*? Was he conscious of himself during their conversation? Was he in some way conscious of himself when he was out of it? What changed as he went into his wife's world and then out of it again?

In Henry's fiction world there was no real change in his sense of consciousness as he moved between the two worlds. Is that what happens?

Several people have said that emotional presence is one of the last lights to go out as the disease progresses. The experience of the staff at Joseph's House is that there are moments when Joy, the woman afflicted with Alzheimer's (["Grace and Joy"](#)) is still sometimes emotionally present. What is her experience in those moments?

How little we know about this disease. [50% of people eighty-five years and older](#) have Alzheimer's yet we know almost nothing about what the experience is like.

I was surprised that the movie didn't frighten me. Henry's experiences seemed mostly "interesting." But it did help me to realize how little I know of what's coming, how naïve this blog may later seem. And Henry's experiences and those of his care givers—along with the questions that the film raised in me—strengthened my determination to bring a bit more light to this disease.

Thursday, March 14, 2013

Washington DC

Vulnerability (2)

Patty Wudel, the executive director for Joseph's House, the home and hospice for formerly homeless people, recently [wrote here](#) about the role that Joy, a volunteer with Alzheimer's, plays in the house.

Patty has also told me the story of a Mr Bumbridge who was a resident at Joseph's House a number of years ago. Although he'd been employed all his life, he had never found a place of belonging and had been completely disconnected from family. Then he'd developed cancer and was on his way home to Philadelphia by bus. By the time he reached the Washington Greyhound station, however, he was too sick to continue and Travelers Aid called Joseph's House.

Patty remembers Mr Bumbridge as a tiny, jockey-sized man. He was a good conversationalist, a much appreciated gift at Joseph's House. At dinner he would often sit between the same two, much larger, much more muscular men, bantering and joning ¹ with them. As Mr Bumbridge deteriorated and became too sick to come down to dinner, however, these two younger residents at Joseph's House would go up to his room, coax him out, and carry him downstairs to the big Joseph's House dinner table. Whether one can eat or not, dinner at Joseph's House is a central place of connection and community. Even when he was unable to eat, Mr Bumbridge continued to offer his gift of conversation. Even after Mr Bumbridge became so feeble that he couldn't take part in the conversation or even sit up at the table, but these two big, formerly homeless men with AIDS still went upstairs and carried Mr Bumbridge down to include him in the community. Patty has an image of the three of them, Mr Bumbridge unable to hold himself up and leaning against one of his younger friends, who had

his arm around him. Even in his helplessness and weakness, Mr Bumbridge helped to create community.

I've been thinking a lot more since my previous two posts ([here](#) and [here](#)) about helplessness and vulnerability as compared to strength. The power of vulnerability is something I've believed, intellectually, to be an important Christian insight, but I've never really internalized it emotionally as truth that I could rely on in my life. But in Joy and in Mr Bumbridge we find two people, each bringing the community together through their helplessness.

I'm not helpless, yet, but it's my vulnerability, not my strength, that has awakened compassion and intensified the community around me. And it's awakened other people to their own vulnerability, too. In my previous condition of emotional strength, I couldn't have played such a role.

When we compare vulnerability to strength, we too often can't see the importance of vulnerability because we're measuring both against what strength can do. But that's the wrong metric and misses completely the power of powerlessness. Weakness has its own gifts, the value of which is measured on a different scale from strength.

These stories encourage me. Joy is quite far along in her dementia and is really "out of it" from the usual societal point of view. Yet—in her humor and sensitive emotional radar—she is still contributes to the community. She's included and helped to feel useful, not only because she needs it but also because in her helplessness she binds the community more tightly together. Mr Bumbridge, too, offered his gifts.

It's a reciprocal relationship. When the Joseph's House community can welcome and include them in their helplessness, their gifts bind the community more tightly together. It gives me hope that as I can *do* less and less for others, my helplessness can offer strength to a community, too.

Friday, March 15, 2013

Washington DC

Apathy ... or Common Sense

Recently, I reneged on my commitment to co-teach a course at the [Servant Leadership School](#), the “street seminary” of our Church of the Saviour community. I’ve taught there regularly for years. The content of one particular course that I consider important has, however, been difficult for me to present, frustrating, and anxiety provoking. A friend had suggested we teach it together, and I thought he might well make up for my deficiencies. But, although the first class is still four weeks away, I’m already fearful, realizing that I won’t be able to pull together even the part of the course I’d agreed to take on without feeling anxious for the next three months of my life.

Ordinarily the thought of reneging on such a commitment would have provoked guilt and embarrassment. But I’m different now. Given the amount of clear-thinking time I have left, I’m not willing to spend so much of it in needless anxiety. In addition, my limitations mean I’m less likely to teach it well. My friend, I’m sure, is disappointed; I am, too. But both of us know I’m limited now.

This disease is always thought of as a tragedy. And I suppose it is, especially for those who have to observe and even more so for caregivers. But I wonder how much the Alzheimer’s patients themselves suffer. At my stage in the disease, of course, it’s all just speculation, but so far the disabilities—confusion, uncertainty around teaching, and especially loss of memory—aren’t causing real suffering. I’m sometimes frustrated, of course, until I recognize that it’s the disease that’s caused me to forget such-and-such. But then I just let it go and the frustration dissolves. Perhaps the [apathy](#) that accompanies Alzheimer’s blunts my motivation to care so much. Regardless, I don’t compare my current incapacity to my former capacity and, to the extent that I don’t compare, I don’t suffer.

So hop ahead several months or several years and you see me sitting on a bench just staring or responding inappropriately to your attempts to talk with me. Certainly it would be painful for you, especially if you knew me well, but would it be painful for me? It seems quite possible that the very losses I will experience will make me cognitively less capable of recognizing them or caring about them. (See “[Out of the Frying Pan Into the Freezer](#) .)

For now, it’s all just speculation. I hope I’ll still be able to communicate some of the discoveries as the lights go out.

Sunday, March 17, 2013

Washington DC

Denial and Such

This is a guest post from my wife Marja Hilfiker.

Most of the time, I have been in denial of some sort or another.

True, David lost his belt pack twice on the same trip to see the grandchildren. The first time it was returned by strangers, minus the cash. The second time it just seemed to evaporate. A few months later, while we were on a backpacking trip, I salvaged his new belt pack from an outhouse, which I just happened to visit before we continued our hike. When I first told our daughter Karin about David's cognitive impairment, she said, "Yeah, Dad seems a little weaker every time I see him." Last fall, David suddenly had a rash of missed appointments and meetings, but some extra precautions brought those problems generally under control.

Otherwise, many of the symptoms David complains about seem all too familiar. Can't remember names. Same here. Can't find words. Me too. Typing has gotten terrible. So what else is new? Aren't we just getting older in tandem? We are senior citizens after all. We should be grateful we are still ambulatory. Unless, of course, I have Alzheimer's as well. In one test of cognitive functioning, we both got a perfect score, so who is going first?

I didn't go to David's appointment with his neurologist, but our recollections of what David had reported from that appointment have varied enough for us to argue about them. I clearly recall that the doctor had said, "I have a hunch that you may be moving toward dementia." That seemed drastic enough to me, but now David insists that he never used the word "hunch" but diagnosed progressive cognitive impairment that was likely to be Alzheimer's disease. However, it was later verified that the medical record did not include the word Alzheimer's.

The denial definitely cushions the blow. I have never felt shocked or terrified or overcome by grief. We always thought that this would be the worst possible way to go, but the reality is sinking in very gently. Or is it reality? After David made what I thought was a premature announcement of his condition, he got so much loving attention from the community, including *The Washington Post*, that I started worrying that he does not have Alzheimer's.

The good part of it is that whatever it is, we're in it together. Out of the ruts of our parallel lives, we reach toward each other more in affectionate gestures or offers to spend time together. Since last fall we have enjoyed some remarkable free concerts, and I even made an effort to find David a birthday present. All that in addition to our evening walks, hand in hand, down Columbia Road seems to have taken on a sense of urgency.

Tuesday, March 19, 2013

Seattle WA

No Regrets

I'm visiting my son Kai in Seattle, and for the past three days I've been watching him referee soccer games. From the time Kai was six and on through high school, I watched almost every one of the hundreds of soccer games he played, but I've never seen him ref. It's been a real treat!

I've always been interested in how a referee handles the game, especially the fouls about which there's some disagreement from a player or coach. So I've watched with interest and been impressed with my son. Never having played soccer, however, I don't notice the fine points of the game very well; I don't see as, for instance, Kai does. I often can't tell whether there's been a foul or not. This has always been true for me, even when I watched Kai's games twenty-five years ago.

But over the weekend, I've been startled by my inability to remember what just happened on the field. Even when I do sometimes recognize the foul that's just happened, within seconds I

can remember almost nothing of the specifics. If a player were to ask *how* he fouled the opposing player, I would have no idea. I'd remember

that

a foul happened but not

how

it happened or

why

I thought it was a foul. The immediate memory is just gone. It's spooky.

Kai and I went out for pizza last night and talked quite a bit about my Alzheimer's. He said that if he had Alzheimer's he would have lots of regrets about not being able to do all the things that he'd planned to do with the rest of his life. He wondered whether the cause of my lack of regret or resentment results is just that, at sixty-eight, I'm twice as old as he is, or whether there was some special reason I seem so at peace.

So I tried to tell him. I've written about some of this several times before, for instance in my [sermon](#)

a couple of weeks ago and in posts about being able to

[live in the present](#)

or being

[more open emotionally](#)

. But perhaps the most important factor is that I don't have any significant regrets about how I've lived my life. I've been privileged to be able to do pretty much what I've wanted to do.

Unlike most people, Marja and I never really had to worry about money. When we were younger, we lived frugally, not out of necessity but because it seemed a better, more wholesome life. We've had very little need for what passes for luxury in our culture. That financial freedom and security allowed us to follow our true vocations and take time to do the other important things, too. Physicians ordinarily have high salaries, so I could work wherever I wanted to (in my case with the poor), take a low salary for a physician and still make enough. (Far more constraining for me has been not knowing what I *wanted* to do.) But the end result is that I have no bucket list.

So when I discovered I had Alzheimer's, I could look back at my life without regret that I didn't choose to do this or dare to do that. Marja and I have had a good life. And far from preventing me from doing things, so far this disease and its process have given me a richer life. I now have a well-defined call and a fulfilling vocation (writing and speaking about this illness). Sure, I'm younger than I hoped I would be when I contracted my last disease. Certainly I would like to

live longer, see my grandchildren grow up. But we all have to die, and I've been given much more than most people.

And now I've been given this adventure!

This has been a good weekend with Kai. Our future together is now limited and both of us want to use it well. There's been no pressure to have "meaningful conversations," but we've both wanted to be vulnerable and open ourselves up to the other in ways never possible before. I feel very grateful.

Wednesday, March 20, 2013

On the train from Seattle WA to Napa CA

Spontaneity vs Clarity

As I write these posts about Alzheimer disease, I'm becoming increasingly aware of how much my disease affects my ability to write well. Recently I reviewed several posts I'd already published here and found some confusion. (I would quote it here except that I corrected it on the spot and now can't remember even what the post was about, much less the difference between the corrected and uncorrected versions.) I notice a tension between wanting to be a good writer and wanting to write as a patient who's declining with Alzheimer's. On the one hand, I want my writing to be as clear and easy to understand as possible ... as I'm sure my readers want, too. On the other hand, to the extent that I rewrite and polish, I'm losing some of the immediacy of my experience within this illness. The tension can't be completely resolved, but this blog is to be a journey through Alzheimer's and I will err on the side of reflecting what it's like to live within these confines, confusion and all.

Perhaps it's important to tell you of my process in writing, so that you know what you're getting. This is not a raw journal. I do try to journal every day and then select whatever seems appropriate for these postings. I then email it my close friend Carol Marsh, who is also a blogger and writes on [Chronic Pain and Spirituality](#). Although she does some editing for clarity, I most need her help in two areas: First, since my memory is deteriorating, I ask her to keep me from duplicating something I've recently written; and second, I want her to check that what I'm writing actually makes sense to a reader. (As my dementia progresses, we will have to

figure out how to present to the reader the writing that doesn't make much sense in a way that is nevertheless meaningful ... which may prove tough to figure out). Carol then emails her corrections and suggestions back to me. I read through and make other editing changes and then post it both here and on my [blog](#) .

So these are edited posts and not as spontaneous as they might seem. And the date of posting is at least a day or two and as much as a week after my initial journal entry. The concern that I have is that all the editing will result in my censoring in order to prioritize "interesting" and "well-written" material over the raw experience from inside the world of Alzheimer's. In my journal I do write spontaneously and try to mirror my actual experience without editing. As a writer, I've always edited continuously, looking for the best writing I could create. But now I have to balance that with what it's actually like to be in this intermittent confusion.

I also worry that this becomes too much a stream of consciousness that's interesting only to myself. And since my judgment will be increasingly compromised, it will be hard to make those decisions. So I'm trying to find my way through several contradictory tensions.

Ultimately, what's most important, I suppose, is integrity. I will write about what's significant to me and try not worry about where that leaves me in the eyes of my readers.

After reading this, Carol sent me the following quote from James Agee in *Now Let Us Praise Famous Men* :

And if there are questions in my mind how to undertake this communication, and there are many, I must let the least of them be, whether I am boring you, or whether I am taking too long...If I bore you, that is that. If I am clumsy, that may indicate partly the difficulty of my subject, and the seriousness with which I am trying to take what hold I can of it...I am interested to speak as carefully and as near truly as I am able.

Sunday, March 24, 2013

Napa CA

Grandchildren

I'm in the midst of a 3½ week trip west to visit my children, Kai and Laurel in Seattle WA and Napa CA, respectively; I arrived in Napa last Thursday. After my grandchildren returned home from school, I had a chance to talk with them about my Alzheimer's.

When we were here at Christmas, I didn't talk with them because I was under the mistaken impression that Laurel was going to wait until my symptoms were more noticeable before telling them about my diagnosis. In fact, after our [October conversation](#) in which I revealed my diagnosis to Laurel, she began crying. Eight-year-old Madeline noticed, so Laurel told her and 10-year-old Otto that their grandfather would have increasing trouble with memory. Madeline's two questions were, "Will grandpa forget how to eat?" and "Will he forget how to talk?" Laurel answered, "We'll have to see."

So I wanted to talk with them a little about it. I asked them whether they knew about my "memory problem." They said that they did, but they didn't follow up with any questions, so I didn't press any further.

The children haven't related to me any differently. When I mentioned something that happened to me in childhood, Madeline—always energetic and inquisitive—asked me why I could remember something from so far back. I told her that most of my loss of memory was for things that happened recently, and she seemed satisfied with that. When I've had to ask them about things I've forgotten, they've just answered simply without remarking. I've found their matter-of-fact attitude quite refreshing. I feel no sense of embarrassment: This is just one of those things that happen.

Madeline and I were playing *Rummicub*, a game with tiles and some of the features of the card game rummy; the purpose of the game is to play all your tiles, leaving none. Otto, quieter and more cerebral, was hovering over each of us, "helping" by pointing out our best moves. Toward the end of the game, I had three tiles left and could see only an obvious move that used one of my tiles. But Otto quickly rearranged the tiles around to show me a complex move that used all my tiles. Not only had I not seen the possibility of the move, but—even after he showed it to me and then returned the tiles in their previous position—I could not duplicate what he'd just done. I asked him to show me a second time, but I still couldn't follow it. Only after he'd showed me for the third time could I remember the steps long enough to duplicate it! He

seemed more pleased with himself than bothered by my disability.

True, the move was somewhat complicated, but seeing possibilities within chaos has always been my strength. I wouldn't have been able to imagine requiring three demonstrations to understand it.

There were two different cognitive losses involved. First, I couldn't see the move ahead of time, which is, I think, the loss the ability to hold several things in my mind at once and, therefore, not see the abstract implications of an action. Second, the memory loss (that I'm getting used to): I wasn't able to remember what Otto had *just* showed me. Like my inability to remember what had just happened in a soccer game with Kai in Seattle (

[here](#)), my immediate memory is very impaired.

Again, however, the kids seem to accept it as just the way it is. They'll say something like, "That's your memory, right," and life goes on.

I've felt no embarrassment with them at all; in fact, we feel more bonded.

Tuesday, March 26, 2013

Napa CA

Adventure

As a child I mourned the loss of frontiers. It seemed to me that there were no adventures into the completely unknown left, nothing where you met challenges never before encountered. During my career as a physician and especially during my fifteen years at [Joseph's House](#) (our hospice for the homeless), however, I began to recognize the last stages of death as a true adventure into the unknown, a frontier that never disappeared. It's not that no one has ever died before, of course, but no one has returned to give us a map, so in our own dying each of us enters into the unknown.

Alzheimer's, too, is an adventure, the last stages of which are shrouded in mystery, and each of us with this disease will explore an unknown wilderness. There are lots of people who've gone this way before, of course. Of the 40 million US residents over age 65, almost [5 million have Alzheimer's](#)

. And although I write this blog to dispel some of the mystery, ultimately neither will I be able to tell others what the last stages are like. In a [recent post](#) I wondered whether I'll be conscious toward the end when I appear to be completely out of it and, if not, what it will be like. We don't know.

My using the word "adventure" to describe my journey into the darkness might seem like a form of semantic denial, soft-peddling the likelihood of future suffering for me and people close to me. I don't believe I'm in denial, but even if I were, does that change the reality that this process will be an adventure?

Perhaps we don't think of Alzheimer's as an adventure because we want happy endings and believe that the word "adventure" applies only to *successful* adventures, where the hero faces enormous dangers and suffering but eventually returns to tell the exciting story. But what if the hero does not return from the mountain; or does, but without having reached the top; or does reach the top and returns, but emotionally scarred or physically damaged? Was it any less an adventure?

I'm grateful that I can still sense an excitement. Growing up, I felt cheated of uncharted territory. But each of us with this disease must explore it for the first time; each of us faces a unique adventure.

Monday, March 25, 2013

Napa CA

Why Don't I Read My Friends' Blogs?

Shortly after I began this blog, I received an email from a fellow writer, Ellen Painter Dollar, a

woman I knew almost two decades ago at [Potter’s House](#) when we attended church there together. Ellen has [ost](#)
[eogenesis imperfecta](#) (OI) or “brittle bone disease,” a genetic disorder in which bones break easily. In addition to the normal pain and disability of broken bones, OI also leads to bone deformities if some of the multiple breaks don't heal properly. Despite the fact that there was 50% chance that any child would have the disease, Ellen and her husband Daniel decided to have children. Their first child was born with the disease; the second two were not.

Ellen has written a book [\[1\]](#) about her journey. Her blog, [Parenthood, Disability, Ethics, and the Crooked Way of Grace](#) explores disability in the context of parenthood, spirituality, and ethics. I've known about her blog for some time but have never looked at it. And when she emailed me several months ago, I responded with only a short note. Then, a few days ago, Ellen wrote me again to re-establish contact. After this second email, I find myself feeling guilty for never having responded to the first or even checked out her blog.

It's not the first time. My good friend, Carol Marsh, who's been of immeasurable help to me with these posts, also has her own blog, [Chronic Pain and Spirituality](#) that has been born of her chronic debilitating migraine headaches. I have only skimmed it briefly two or three times.

My lack of interest is embarrassing. Why would I not be interested in the experiences of two friends who are also writing out of their severe disabilities? I've felt a vague sense of guilt, even a little shame, [\[2\]](#) although I know that neither Ellen nor Carol has any expectations. Perhaps it's just the apathy that is typically part Alzheimer's, but I think there's more. I suspect I didn't look at their blogs *before* my diagnosis because I didn't really want to look at such undeserved disability, the same way many people don't want to look at Alzheimer's. I also didn't want to feel obligated to respond meaningfully to them. I never thought about it consciously; I even intended to return Ellen's email with a more meaningful response and to look at Carol's blog some day.

But, now, even my own diagnosis has not prodded me to examine their writings.

Why have I continued to ignore the writings of my two friends, even when I know how important it is to me that others that share *my* situation? Part of it is probably not wanting to face more suffering. Perhaps I don't want to examine with different eyes this "

[most beautiful time](#)

“in my life for fear of tipping things off balance. Perhaps I am afraid that, if I read about my friends' suffering, I will discover more suffering in myself. It may very well also have do with wanting to maintain the self-deception of my own unique position. In Ellen's case, I probably don't want to face my envy of her wide readership. I don't want to read about their discoveries, perhaps thinking they would compete with my own.

I'm not sure of any of this, but my behavior still strikes me as self-centered although after this writing, it's perhaps more understandable. When I don't look at my friends' worlds, I'm certainly limiting my own. I know how important it is to me to have others read this: I don't feel so alone.

It's more than a little embarrassing, especially since I've asked both of them to read this before I posted it. Will my exploring these reactions here change my behavior? I hope it's not just my guilt that forces me to their blogs.

[1] [No Easy Choice: A Story of Disability, Parenthood, and Faith in an Age of Advanced Reproduction](#)

[2] I once read that guilt is the recognition that I did something wrong; shame is the sense that my whole being is wrong.

[1] Joning: a form of (usually) good-natured making fun of; it's been honed to an art form within parts of the African American community.

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