

Blog Posts from July 2013

Wednesday, July 3, 2013

Washington DC

The last couple of posts have been a bit heavy, so I'm sharing something lighter today. I first heard the former poet laureate of the US, Billy Collins, recite "Forgetfulness" on Garrison Keillor's *A Prairie Home Companion* several years ago, long before my diagnosis, but it felt familiar then, anyway. A reader recently reminded me of it.

FORGETFULNESS

The name of the author is the first to go
followed obediently by the title, the plot,
the heartbreaking conclusion, the entire novel
which suddenly becomes one you have never read,
never even heard of,

as if, one by one, the memories you used to harbor
decided to retire to the southern hemisphere of the brain,
to a little fishing village where there are no phones.

Long ago you kissed the names of the nine Muses goodbye
and watched the quadratic equation pack its bag,
and even now as you memorize the order of the planets,

something else is slipping away, a state flower perhaps,
the address of an uncle, the capital of Paraguay.

Whatever it is you are struggling to remember,
it is not poised on the tip of your tongue,
not even lurking in some obscure corner of your spleen.

It has floated away down a dark mythological river
whose name begins with an L as far as you can recall,
well on your own way to oblivion where you will join those
who have even forgotten how to swim and how to ride a bicycle.

No wonder you rise in the middle of the night
to look up the date of a famous battle in a book on war.
No wonder the moon in the window seems to have drifted
out of a love poem that you used to know by heart.

-- Billy Collins

If you're interested in listening to Billy Collins read his poem, go to

<http://www.youtube.com/watch?v=wrEPJh14mcU> . I found the animation that went with his reading annoying, so I just didn't watch it.

This poem is about dementia in general, not necessarily about Alzheimer's, but it could still be interpreted as making light of a disease as serious as Alzheimer's (or any other dementia for that matter). So I'm sorry if anyone is offended. I hope it's clear that I don't take Alzheimer's lightly or minimize its terrible impact on the lives of so many. But in our society we can hardly say the *word* Alzheimer's. It needs *some* lightening up.

Saturday, July 06, 2013

Washington DC

A Paradise Built in Hell

In *A Paradise Built in Hell*, Rebecca Solnit writes about that special sense of community, of altruism, of love, even of joy that can arise out of disaster. We're all familiar it. It's quite obvious in major disasters but happens here in Washington even when we get a big snowstorm that locks down the city. People are friendlier on the street, young people shovel off the sidewalks of older people, people with four-wheel drive vehicles make them available for emergency transportation, and so on. We who can wander by each other in the neighborhood without even saying "Hello" suddenly recognize a sense of community with each other; we pause and marvel with each other at the beauty. Time can stop. Our day-to-day concerns drop away; our schedules are put on hold. We can move into the present moment, and life is, for the time being, different, richer, more joyful.

It can happen when someone dies even, when someone is very sick, when any tragedy strikes, really. Not always, of course, but out of tragedy can come joy.

I wonder if that isn't part of the explanation for this joy I've felt since my diagnosis with Alzheimer's last September. It's felt bizarre to write about these last months as one of the happiest times in my life, but that's been the truth. Perhaps it's the tragedy itself that has created the joy.

Certainly when I received my diagnosis last September, normal life stopped. Suddenly I found myself in a tragedy that had previously invoked terror. Many of the concerns of routine life, of my schedules, of my responsibilities became suddenly of secondary importance. I moved into the present, which can be a place of richness. From the [responses of other people](#), too, I could tell that something was different; many sought deeper relationships, richer than before. My children and I experienced (and still experience) a closeness ([here](#) and [here](#)) we had not previously known. Marja and I [moved closer](#) to one another ... and have remained there. My relationships with people from my faith community are stronger.

Perhaps, as Solnit suggests, Hell can birth paradise, when suddenly community deepens and the humanity of both others and ourselves is revealed.

Alzheimer's could never be called good. Like Hurricane Katrina, or 9/11, or a tornado, or an earthquake, Alzheimer's could not be wished on anyone. Yet out of it can come a joy that has taken me by surprise.

In the last month or two, some of that special feeling—my ability to live in the present, my sense that my life is worthwhile even if I can't accomplish that much, my sense of joy in living—has been diluted, and I've wondered why. Had I slipped back into old patterns, lost the new sense of emotional richness? I wonder now if much of that loss comes from my recognition that the course of my disease will be slower than I'd anticipated. My symptoms don't interfere much with everyday life. I'm getting used to having Alzheimer's. It doesn't shock me into the present. I've become again more emotionally invested in day-to-day events and responsibilities. Some of the usual pressures return. It's a normal response, I guess: my day-to-day life now contains Alzheimer's.

Some of that special feeling has declined but not all of it. Life is more precious. I still have closer relationships with my family, my friends and my community. Solnit suggests that tragedies can change who we are, give us more compassion, bring us into the present, make our experience of life deeper. I am very grateful.

Tuesday, July 9, 2013

Washington DC

Contented Dementia

I've just finished James Oliver's *Contented Dementia*, a book that describes a teachable method for caring for people with moderate to severe dementia.

The emphasis is on reducing the "client's" (Oliver's word, even if it's your mother) fear and anxiety by discovering the context to which they are responding and then entering into that

context as completely as possible. Imagine *our* context as a series of pictures in a scrap book. If all the pictures are there, we respond out of “reality.” The primary “difference between the person with dementia and the person you used to know is a single disability: they can no longer store information [the pictures] efficiently” and must often, therefore, respond based on the few pictures that remain. So as the person with Alzheimer’s tries to respond to the question, say, “What did you have for lunch?” but can’t find the picture for today’s lunch, some other picture has to be chosen. And in that other picture lies the problem. But if the caregiver can discover the set of pictures from which the client is acting, problems can be avoided and wonderful opportunities for new life can arise.

Out of that understanding come three rules:

1. *Don't ask questions.* Almost *any* question requires the client to retrieve new information. If they’re unable to do so, they can become anxious and fearful.
2. *Learn from them as the experts on their disability.* Assume that everything the client says or does has meaning within their world of limited memory and perception. If we don’t understand the pictures they’re acting from, their responses won’t make sense, but if we enter into their world with them and discover the meaning of their behavior, then we can act in a way that responds to their needs as they perceive them.
3. *Always agree with everything clients say, never interrupting them.* First of all, disagreeing with clients requires them to access the pictures they no longer have, which can arouse significant anxiety. Second, it precludes our entering into their world, preventing us, the caregivers, from gathering information about their reality.

I noticed a simple example in *Quartet*, a movie about a nursing home for retired professional musicians. At the movie’s decisive moment, when they’re about to go on stage, the quarter’s demented member heads for the door because she “has to catch her train.” Two of the others try to dissuade her by telling her how important the moment is, pleading with her, reminding her how much they need her. But she becomes increasingly agitated and insistent on leaving. The fourth member of the quartet, however, recognizes what’s happening, enters into her world and tells her simply that she has plenty of time to catch the train.

My immediate reaction was that never contradicting the client is just enabling her disoriented behavior. But my reaction, I think, is based on my judgment that she has some control over the pictures that go missing and, that if I just insist she find them, she can. There’s too much of the parent in me: I shouldn’t let her “get away with it,” I think. It’s just plain dishonest and

disrespectful of her, my judgment tells me, to pretend that her world makes sense. And I don't want to look silly to others by entering into a farce.

My initial reaction, however, ignores the fundamental fact that she perceives her current-day world within pictures that I can't see. The opera singer is desperately trying to understand what's happening to her (the other members of the quartet are holding her back) in the context of her other pictures (the need to get to the train). They can help her make sense of her experience only by entering it, acknowledging its validity, and offering her a response that simultaneously satisfies both the "real" world and hers.

It is a remarkable book, detailing unique insights and their implications for the care of a person with moderate Alzheimer's. I can imagine some point in my journey when I will appreciate a person who can join me in my world and see *my* pictures rather than insist I respond to pictures I don't have.

Sunday, July 14, 2013

Washington DC

I Take It Back ... sort of

About twelve hours after I'd put up the [previous post](#), I wished I could take it back (which was the first time that's happened). I realized it was too simplistic and I expected readers to call me out on it. The author of

Contented

Dementia

seems to be working from the same assumption that most of our culture does: People with Alzheimer's are basically out of touch with reality and need constant guidance. The author explicitly states that it's never too early to put these rules into practice. Well, I have Alzheimer's and I, at least, want questions from others, realize my reality is incomplete, and want to be challenged on things.

So I've been surprised to have no negative comments or emails; in fact, I've had a number of caregivers very grateful for it. That's meant I've had to reflect more deeply and with more nuance. What I've come to is that *Contented Dementia* can be a very helpful book for caregivers, but the advice needs to be re-interpreted.

Here again are the three rules with my re-interpretations.

Don't ask questions.□

This rule simply doesn't apply to earlier stages of dementia. But we need to recognize that any question requires anyone to access previously acquired information. As dementia progresses and the memories and pictures gradually fade away, questions requiring memories that are no longer accessible may arouse considerable anxiety and fear. Once the particular pictures disappear, avoid those questions that depend upon them.

Properly understood, the second and third rules, far from being simplistic are actually important principles that I try always to follow in any interaction.

Learn from them as the experts on their disability.□

If the last word is changed to from "disability" to "context," this is just good advice for anyone. The person with whom I'm talking is the expert on the context out of which their thoughts and opinions arise. If I don't understand something of that experience, I won't even know what the person *means* by their words much less how to respond to them. I, for instance, am a political leftist and tend to favor big government to provide the institutions and services best provided by all of us acting communally (ie through government). Much of that opinion, however, is based on my 25 years of working with impoverished Americans. But if I'm talking with a person who pulled himself up by his own bootstraps, who had his business destroyed by government regulations and high taxes, and who knows only of poor people who have abused the system, then I need to know about his context if we're going to have a meaningful conversation.

Mostly when I talk with people, I ask a lot of questions trying to understand where they're coming from. I assume that what they're saying makes sense in their context. That doesn't mean I agree with them or vote with them, but it does mean I'll be able to respect them and to live with them.

It's the same in my conversations with people with Alzheimer's. Unless I know their reality, my responses won't make sense and we're not likely to get along very well.

Always agree with everything clients say, never interrupting them.

This sounds ridiculous, but it is in fact what I try to do with everyone I meet. I can't contradict the pictures that comprise their reality. In any conversation, I usually find myself fascinated by the context of another person's experiences. And when the other person is interested in my reality, we can have wonderful conversations. Even when we come to different conclusions and, say, vote on opposite sides of the issues, I can't disagree with their pictures. My response to the "big government" issue is often to tell my own stories of impoverished people I know or of living in Finland where "big government" clearly "works."

It's the same principle for people with Alzheimer's. I'm not going to have much luck arguing with how they experience reality; it's probably only going to make things worse. Helpful interactions, therefore, are going to come from entering into their world and responding to it, not contradicting it.

Contented Dementia does over-simplify at times, but, understood properly, its recommendations still hold. Most helpful are the book's many, many examples that build upon its basic understandings.

July 17, 2013

Accepting It With Grace

A guest post

Some of the many letters and emails that I've been receiving over the months have told the stories of the writers' journeys with Alzheimer's. I can't begin to share all of those stories, but so many bear repeating that I'm sharing a part of one story that's touched me.

I found out about your blog through the Phi Beta Kappan newsletter. My wife was the PBK member, and she is now in the advanced stages of dementia. Since dementia "creeps up on cats' feet," it's difficult to say when it actually began, but she's probably eight years into it with a normal expectance of maybe two more years. Since we're both well into our 80s, that's about all either of us would normally get anyway.

Like you, it wasn't something that we (or our family) wanted, but we don't get to select our late-life maladies. Since you probably have a 10-year expectancy and a seemingly bright mind (like my intelligent, upbeat wife), you still have an extended period in which your mind will function reasonably well. And your family will travel the journey with you at whatever level. One of the good things about filling up a reservoir of good will with your family and friends is that they come together in love and compassion when you need it, as you so correctly wrote in your post "[A Paradise Built in Hell](#)."

My wife and I could still go to films and plays up to a year ago and she could stay with the plot. She's now pretty much bed-ridden and we watch repeating versions the same evening news -- local and national on two channels and then last night's reruns of Steven Colbert and Jon Stewart. Since the three hours of TV news and faux-news involve short segments that she can comprehend and since we hear pretty much the same set of segments upwards of six times, she can get a sense of what's happened. A former avid reader of newspapers, magazines, and books, she's now switched to TV. Even half-hour dramatic shows are too long for her to maintain the plot, so she likes things such as the current "America's Got Talent" because the segments are no more than a few minutes at the most.

We have a large family -- 30 with our children, spouses and grandchildren -- and I've kind of done for them what you're doing with your blog: I keep them informed about the nature of dementia and about the current life of their female patriarch. In "A Paradise Built in Hell," you mention the here-and-now world you're moving into, and I've also stressed that with our family. Keep the conversations to about what's occurring right here and now, and then she can, and will join, in. The challenge for us as a family is to not think of dementia in terms of embarrassment. It's what happened to us and it can also happen to them later on. So accept it with grace.

Over three years ago, we hired one of our much-loved, local daughters-in-law to provide us with home care during the Monday – Friday daytime, and that was a good idea. The assistance will not be so much for you as for your wife, who will need to develop a life of her own as your condition worsens. For example, it's allowed me to continue to participate in a weekly lunch with long-time colleagues. One significant advantage of hiring help from within the family is her knowledge of our previous life. They can converse about things that are still of significance to my wife.

Each of our stories is different. I'm grateful to this reader for sharing a bit of his and his wife's journey.

Saturday, July 20, 2013

Washington DC

Pride

Earlier this week, the covenant members of our small faith community met for our monthly members' meeting. I've been part of the four-person leadership team for a number of years. In our community, commitment to membership in anything—the church, a mission group, the leadership team—is made for a year at a time, after which each one of us re-evaluates to discern whether we're called to continue that commitment.

Sunday, I shared with the community some of my ambivalence about renewing my commitment. I said I was concerned that my cognitive impairment wouldn't allow me to continue to participate meaningfully, especially for a full year.

But it's complicated.

At this point in my illness, I'm aware of cognitive losses that have led me to give up, for instance, the bookkeeping at church or the writing of complex articles and commentary that was my vocation prior to this disease. But I haven't yet noticed a decline in my ability to be actively and helpfully present in small groups or in mentoring relationships with individuals. Perhaps I can call that capacity "wisdom," which, surprisingly, doesn't yet seem compromised.

So, at this point, I still have a role on the team that's important to me. But I'm concerned about the losses that might be just around the corner, disabling me more quickly than I'd anticipated and making me a burden to the team. I may or may not recognize my need to relinquish responsibilities before others do. My community has reassured me that they'll speak up if my abilities are compromised, and they encouraged me on Sunday not to allow that concern to keep me off the team. We've talked enough as a community about my Alzheimer's that I do have some confidence that they'll be able to tell me if I am not contributing.

And that may be the problem.

As I've reflected on it since Sunday, my ambivalence actually rests on my fear that they **will** have to tell me it's time to leave before I recognize it myself. It's been a value inculcated since childhood:

Do not think too much of yourself; never allow your self-assessment to outrun others' assessment your capacity.

If I don't leave on my own initiative, I fear, I will be humiliated by their request to leave. So the real issue is not my concern about being a burden but about my pride.

I want to be on the team. I have an important role there. My capacities in that area are not yet impaired. Most importantly, perhaps, my presence there connects me tightly to our community, which is central to my sense of meaning and my happiness. This is a community that knows my illness, that loves me, and which I trust. Yet I am contemplating giving all that up, not because it may be time to do so, but out of pride that fears the humiliation of being told I must.

As our pastor lay dying a few months ago, he told me he was learning about the supreme value of weakness and vulnerability. In our weakness is our strength, wrote the apostle Paul. Yet my pastor said he could only accept that fundamental truth as he was dying. I'm not sure I believe Paul yet, but I can see that my weakness from Alzheimer's disease is helping me confront issues I could not have otherwise confronted and given me a deep gratitude and a heightened capacity for relationship. It's giving me permission to allow my community to gather around me without my humiliation. My weakness has given me new life.

Tuesday, July 23, 2013

Washington DC

Invisible in the Medical System, Too

Several months ago, after reading this blog, [Jim Landry](#) emailed me. He lives in the Washington area, and he, too, has early Alzheimer's. We got together, enjoyed a walk in the woods near our apartment, and promised to get back together. A couple of weeks ago, Marja and I along with Jim and his wife, Nikki, went down to the annual Folk Life Festival on the National Mall. We found much in common. I was especially happy that Marja and Nikki—both

spouses of men with cognitive impairment—could spend some time together.

Several days ago, I received an email from Nikki informing me that Jim had had a bike accident, breaking a collar bone and several ribs—which can be very painful—and causing internal bleeding. The bleeding was probably not serious but deserving a couple of days observation in the hospital.

Nikki wrote:

When medical professionals ask about medical conditions and medications, I tell them what he's on and that he has early onset Alzheimer's. There's a moment's pause as they take this in, ignore it, and carry on with what they were saying. When I brought it up again yesterday (because they were expecting Jim to manage his own pain medication schedule and that wasn't working), the medical personnel overreacted in the other direction. Now, Jim says, twenty people accompany him to the bathroom and he is being fed with a spoon!

The ignorance of what having Alzheimer's means among medical professionals and how they should adjust their behavior is shocking and awfully frustrating.

The next day Nikki emailed me again:

I've had many conversations with the doctors, nurses, nurse supervisor, and social worker and they are *all* abysmally ignorant about how to treat and help a person with a cognitive disability like Alzheimer's.

The numerical scale (1-10) for example, that they use as the standard protocol for determining pain level baffles Jim, especially when the pain is increasing. Even the alternative scale of "happy faces" is difficult for him to answer at times. Last night, he went from 12 midnight to 9 am with *no* pain medicine! When I arrived, he was frantic with pain: it seemed to have crept up on his brain [unrecognized until it was severe], another symptom of Alzheimer's. We negotiated that he'll be given meds regularly without having to ask for them—with some extras he can get for breakthrough pain. I plan to set an alarm to check on his status through

the night.

The ignorance *is* shocking, but it's also completely understandable to me as a physician because I know how little training medical people receive in recognizing and treating cognitive impairment. We learn in our training to take care of the seriously demented but not to care for people with less severe levels of cognitive impairment, especially the early stages.

Let me guess what was going through the doctors' minds: Nikki tells them that Jim has Alzheimer's. They take one look at him sitting on the examining table, responding normally to their questions, looking like everybody else. "Looks okay to me," they tell themselves. So they essentially ignore Nikki's comment, perhaps not even mentioning it to the nurses. Nothing is done to determine the level of Jim's impairment and how his care needs to be tailored, because they aren't skilled in it or perhaps don't even recognize the need for it.

Later, Jim has some difficulty with his medications. Nikki explains again about the Alzheimer's, and the nurses spring into the kinds of action they've been trained in: put the side rails up, accompany him everywhere, talk slowly in loud voices, spoon feed him, and all the other things they believe appropriate to a severely demented person.

As a person with early Alzheimer's, Jim is invisible within the medical system. Most of the nurses and doctors literally don't know how to recognize him, much less care for him. I don't blame the individual medical people; they've not been trained, and they are subject to all the same constraints of fear and embarrassment as the rest of us. Nevertheless, it's simply bizarre that most medical people don't know how to deal with a disease more common than heart disease and more common than all the cancers taken together.

Friday, July 26, 2013

Washington DC

It's Not Necessarily What It Seems

There have been many responses to my last [post](#) about Jim and Nikki's experience at the

hospital after Jim's bike accident. The emotional intensity of these comments has encouraged me to think a little more deeply about this disease. Living with Alzheimer's is more complicated than I've thought. Early dementia is not that easy to spot, and more advanced dementia may seem very different from day to day. It can be difficult for other people to know what's going on.

Jim's impairment, for instance, is not obvious. In the several hours I've spent with him, I've noticed only a little trouble word-finding that he compensates for easily. When Nikki emailed me that Jim couldn't manage his own pain medication schedule or even use a scale of one-to-ten to indicate his pain level, I was surprised. I certainly wouldn't have expected that this man—who seems so bright and energetic, who can ride his bicycle without getting lost, who can carry on a stimulating conversation for several hours—would have trouble communicating the severity of his pain. If I'd been Jim's doctor, what would I have done with Nikki's warning about Jim's Alzheimer's when he seemed so competent? It's a confounding disease

It's problematic at the other end of the spectrum, too. A person with much more advanced disease may seem quite impaired overall yet be quite intact in other specific areas, for instance, playing the piano. Another patient, under the stress of a urinary tract infection or a hospitalization, may today seem completely confused about where he is or even *who* he is while tomorrow he'll seem almost unimpaired.

The symptoms of Alzheimer's aren't a smooth downward curve beginning at normal and descending to deeply impaired; they jump around in an almost random pattern. The specifics of the impairment will be unpredictably different from one patient to the next or even from day-to-day in the same patient.

What's the take-home lesson for me? I need to talk with family and friends often about my disease if I expect them to be able to respond appropriately to me. My friends aren't mind-readers; they need to be told as clearly as possible what I can and cannot do on any given day ... and to be prepared for surprises.

I can't assume that even a good friend will know how to respond to me in any particular situation unless I keep them up-to-date on what's going on. And even then there may be [misc](#)
[ommunication](#)

. If I don't talk about it, friends and family who expect a daily consistency will be confused and may begin to avoid me out of uncertainty or embarrassment. If we intend to break the cycle of ignorance and isolation, we need to bring Alzheimer's out of the closet ... over and over again.

Monday, July 29, 2013

Washington DC

Privilege

I've written [before](#) about privilege and losing privilege. After I came to Washington thirty years ago and began working in the inner city with impoverished African Americans, I became aware of the social rankings. Poor, undereducated, African Americans were on the bottom rung of privilege and power. I—white, highly educated, economically secure, and male—was near the top.

It's not possible for me to give up my privilege voluntarily. I can give my money away, but voluntary poverty is fundamentally different from life-long, imposed poverty. I can't give my middle-class upbringing away: In my family I will always have a safety net. I can't give my education away or my white skin. I have had a secure place in our society. People tend to believe what I say and listen to my opinion. When I was young, they didn't perceive me as threatening when I walked down the street or into a store. As a college kid, I had almost no chance of being imprisoned for the marijuana I smoked. I was given preference in job selection. And so on.

I'm not complaining. Privilege certainly makes life easier. But I didn't *earn* the essentials of my privilege; they were given to me.

I may not be able to give my privilege away. But it can be taken away by mental illness or addiction.

Or dementia!

As we with Alzheimer's (or other dementias) become increasingly impaired, other people will drop away, embarrassed or afraid. We won't be believed or [trusted](#). We won't have the power

to convince people to do this or do that. We won't be able to drive and may have to live in a locked unit.

Just to state the obvious: On a relative scale, I will still maintain some of my privilege. African Americans begin with less privilege than I and, on top of that, get dementia, too. The same is true for the poor of any race: Poor people get dementia and are still poor. I have dementia and am still relatively wealthy. Even with Alzheimer's, I still come out better, closer to the top.

These past three weeks, as I have experienced how deeply my African-American friends have been impacted emotionally by the verdict in the Travon Martin case, I've been more aware of the privilege I start with. The verdict didn't touch me at an emotional level for it doesn't affect me personally. I have long known about the vast differences in privilege between blacks and whites: how differently we are treated by the criminal justice system, for instance. Without having to know the legal details of the Travon Martin case, it has been for me just another example in a long line.

I can't speak for my African American friends, but for them this is not just another example. President Obama spoke of the *context* in which the case has taken place, a long history of African-American oppression. For African Americans, the verdict is, at the very least, a powerful symbol that evokes their outrage at a lifetime of injustice.

Dementia is not the same, of course, as the American black experience, not even in the same league. It's not based on a lifetime of second-class status. Only so much will be taken away from me.

Nevertheless, it's enough to grieve over. I will no longer have the privilege that I've taken for granted. I'm not obviously impaired yet, so I haven't felt the loss of privilege. But it's coming, and I will know something of my friends' experience. I hope I can be as gracious to the still-privileged as my African-American friends have been to me.

[August 2013 Posts](#)

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