Blog Posts from July and August 2014

Wednesday, July 2, 2014

Washington DC

Memento

Over ten years ago my son took me to see the movie *Memento*, which he'd seen several times already and was sure I would enjoy. It was an intentionally disjointed story that I couldn't follow completely, so, while it was interesting, I'm not sure I
enjoyed
it. One theme of the film, however, was an exploration of memory.* At the beginning of the movie, we see Leonard, the story's protagonist, killing Teddy, whom he believes murdered his wife. Leonard, however, has anterograde amnesia, meaning that he can remember nothing except the last few minutes of his past. He's compensated for his impairment by keeping a record of his past in notes, photos, and tattoos. The movie proceeds with the scenes leading up to the killing in reverse order, which puts us, the viewer, in the same mental place as Leonard: As we watch each scene, we, too, know nothing of the past.

I turns out that Leonard has completely misunderstood the implications of his notes, photos, and tattoos. Later in the movie, we learn that the person he eventually kills is actually innocent of the murder. At the end of the movie, we find out that Leonard's diabetic wife was not even murdered but died of an accidental insulin overdose.

Memory is the foundation of rational action, of course. But it's more. As we follow Leonard backward in his life, we get some sense of the utter confusion, the disorientation and, in this case, the horror of being able to remember only the most recent past.

My loss of memory is, of course, in nowhere near the same category as Leonard's. Nevertheless, I get glimpses of what it's like to be him. For instance:

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I don't know this person standing in front of me is; but should I?

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Have I already told this story to my son-in-law during his two-day visit or was it someone else I told?

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As I talk, is my line of reasoning based on a fact I'm sure of or on a speculation I've seen on the Internet?

At our leadership team meeting after church this week, I had only the foggiest idea of what had happened in the previous meeting. The other three people had each brought a paper they'd clearly read in advance, so I must have received it, too. Had I just forgotten to read it and bring it; or did I somehow not obtain it; or had I thrown it away altogether? Although the others have mostly gotten used to my impairment, I was still embarrassed that I'm not creating more memory aids to make sure things like this don't happen. What bothers me most is this low-level disorientation. Am I throwing things away that I should keep or just forgetting them? Why don't I get around to creating the memory aids? How many of my questions are things I should already know? Should I even participate in the discussion?

I'm not really confused, just sometimes a little lost. I'm sure lots of other people experience some of this same disorientation. Nevertheless, my questions to myself can sometimes make me wonder just who I've been. It's just unnerving enough to give me images of what it might be like when memory really slips away.

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* Fair disclosure: I don't remember all of the following details; I looked them up in Wikipedia .

Wednesday, July 9, 2014

Washington DC

Racism in My Community?

This past Sunday morning I offered a teaching in our small Eighth Day Faith Community . We're a lay-led church and take turns preaching or teaching. I spoke about racism. It's not that racism, in the usual sense,* runs rampant through the church; quite the opposite. Most of us have worked for many years, in non-profits that have served impoverished African Americans within Washington's inner city, and many of those non-profits were founded by members of our community. But, like all white institutions in the United States, racism permeates our structures while our unconscious prejudices make change difficult.

During the past year or two, a number of us from the community have participated in anti-racism training and have become quite sensitized to the nature of American racism both personally and in our institutions, including Eighth Day. About ten percent of our fifty-member worshipping community is African American, but our leadership is completely white (and over fifty) and our style of worship is largely white … except for the singing, which has changed dramatically in the past several years, in part as a response to our increased exposure to African American worship and in part because it's just so much more lively and fun.

As we have struggled with the issue of racism, there have been conflicts within the community that have become heated and, in my opinion, have been creating some potentially serious divisions. On the other hand, I believe that many of those divisions are less real than they appear and are mostly due to different understandings of the meaning of some words we use. It's not that there aren't important disagreements among us, but we've allowed those disagreements to divide us rather than to help us understand one another and learn from each other. So my intent in teaching was to try to heal some of the division by sharing my perceptions.

I bring all of this up here in this blog because my role in our community has subtly changed over the past two years, in large part due to my original diagnosis of Alzheimer's and the lingering cognitive decline. I now feel much more emotionally and spiritually bonded to the community. I take real joy in my relationships with others, which was often not the case in my past. As I wrote several weeks ago, I've become more comfortable with myself and more accepting of my gifts. I've been able to "lead from behind," which is far more comfortable for me than the painful anxiety I experience with the usual kinds of more direct leadership.

One implication is that the nature my leadership in our community has changed. In becoming more joyful and less intense, I listen more. In developing strong relationships with people, I know more profoundly what is happening in the community. Through our anti-racism training and our small " mission group " that has been exploring racism and trying to educate our various communities, I've developed special relationships of real trust with the African Americans in our faith community and others I now connect with. All of this allows me to speak with some authority to both "sides" of the issues and to be trusted by most to seek the common good rather than speak from one perspective or the other.**

I'm sure my role in our community is not only the result of my cognitive decline but also of the many years of my presence and leadership, but, paradoxically, my cognitive decline has strengthened my emotional intelligence and interpersonal connections. Once again I find myself more grateful to my cognitive changes than disappointed by them.

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* Racism re-defined as (often) unconscious, undesired prejudices plus institutional power may not be familiar to most people. I've explained it much more fully in my teaching .

** After the service two different people said I was probably the only person in the community who could have given the teaching. Be that as it may, it does indicate something of my role in our little fellowship.

Monday, July 28, 2014

Washington DC

Where have you been?

I realize I haven't written anything for almost three weeks. One kind soul even emailed me inquiring after my health. It's true that I was out of Internet range for a week and I've been

struggling with a smashed collarbone [1] for the last ten days that has made typing difficult. But the reality is that I haven't had much to say.

I'm fine. Physically the pain from the collarbone injury doesn't bother much except at night. I continue to struggle with the mild cognitive decline that impairs my memory and makes certain intellectual tasks more difficult. But I've gotten used to the limitations; there doesn't seem to be much (if any) progression; and my life is otherwise so much better than before my decline that I don't think about it much anymore.

I appreciate the little community that has sprung up around this site, and I want to stay in touch. I'll continue to write if I have anything to say. I will, however, be out of town for the next month with limited Internet access. If I am inspired, I'll find some way to publish the results here on the blog while I'm away. Otherwise, I'll be back in September.

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[1] For those of you who drive in cities and use on-street parking, I beg you to look for bicyclists before you open the door on the driver's side. If you open your door without looking, a bicyclist has no chance. A week ago Saturday I was riding in a bike lane on a side street. Without warning (I suspect I was checking my rearview mirror for traffic), I crashed into an open door and the edge of the door hit me in the middle of my collarbone. I wear a helmet of course, but if I'd been five inches closer to the car, it would have smashed my face in. Since "being doored" (as it's known in the trade) also spills the rider out into the traffic lane, the consequences would have been much worse if there had been any traffic. I've ridden in the city for years and intend to continue to do so (for convenience, health, financial and ecological reasons). So please watch out for me and my brothers and sisters as you're getting out of your car.

Monday, August 4, 2014

Washington DC

Disappointment

A close friend, blogger and author Carol Marsh recently wrote of her fear of a treatment

that might alleviate the worst of the migraine headaches that have disabled her for years. She was scheduled to undergo the new treatment the following day and was noticing her anxiety and fear about the procedure:

- the possibility that she might have negative reactions to the medication,
- the pain of the procedure itself,
- her disappointment if the treatment didn't work.

But she also noted another cause of her anxiety: the fear that the treatment might work and relieve much of her pain.

- If she were no longer disabled, could she, at 60, get a job after her disability check was cut off?
- Others admire her for getting a university degree in Creative Writing while suffering almost constant pain. If she were no longer disabled, what would there be to admire?
- She feels sometimes that her whole life has revolved around coping with her pain. What was she going to do as an able person?
- Silly as it may sound, she even fears not getting enough sleep if she can't take to her bed anytime she feels tired.

If she's no longer disabled, who is she?

She well understands that her fears of getting well might seem ridiculous to most people. Nevertheless, they are real.

Those of you who have followed this blog for a while know that I've experienced similar difficult feelings while gradually learning that I didn't have Alzheimer's. I've written about it in previous posts (for instance, here) but never quite so clearly and succinctly as Carol has.

- As a "professional Alzheimer's patient" with a popular blog and invitations to speak, I had a satisfying vocation that contributed to the well-being of others. I didn't want to give it up.

- I had learned to let go of difficult tasks without feeling selfish.
- My life-long anxiety about not doing enough lost its power over me.
- I felt gratitude for my life, for my friends, for my community that I'd never felt before.

- With that gratitude and with the security in my vocation, I'd become a nicer person.

How much of that would I lose?

I was relieved and grateful of course that I no longer had Alzheimer's. But my disappointment seemed often to outweigh my gratitude. I felt like a fraud who had duped interviewers, audiences and suffering people for my fame. I was no longer the person I had thought I was. Who was I?

We depend on our identities—including the painful ones—to order our lives, even to give them meaning. For the first half of my adult life, for instance, I suffered from untreated depression. I thought of myself as a "depressed person." Then new medication dispelled virtually all my depression. I was ecstatic without any sort of disappointment, not even a sliver … or so I thought.

Nevertheless, even after twenty years, I've never quite given up being a "depressed person." There were little benefits:

- I had a ready excuse to decline social invitations I wouldn't have wanted anyway.

- I could finally admit that I was unhappy as a doctor and give myself permission to leave the profession.
- The reality of my depressions had become an important part of the lectures I gave.

In ways I didn't recognize then, I actually *missed* my depression.

Identity is a huge part of us. Even the painful threads of our identity haven been woven into the fabric of ourselves. Regardless of the pain a part of our identity has previously brought, we can understand and forgive ourselves for that little sliver of disappointment when we're forced to shape a new one.

Wednesday, August 6, 2014

Why Windfarms Kill Absent-Minded Geese

West on Amtrak

Ok. So Marja and I are traveling by train across the plains of North Dakota on our way from DC to Seattle to go hiking and to see our West Coast children. We see a large wind farm, the blades revolving so slowly that Marja wonders out-loud why they sometimes kill migrating birds. I think, well, the ends of the blades are probably moving more quickly than they seem. How fast, I wonder?

There being nothing better to do after staring out the window at corn and grass and sky for a couple of hours, I decide to figure it out. (For those of you who don't care how fast they're going or don't follow math easily, you might skip to the last four paragraphs.)

I google the size of a wind-turbine blade: 116 feet long (Holy smokes! I thought maybe 40 feet long). I time one revolution of the blades: six seconds.

(Five years ago I could have gone from here and figured the speed of the tips in my head, but I can't come close now, so I take a scrap piece of paper and write each step down.)

I'm happy that I remember from my basic geometry that the circumference of a circle is πr (pi [3.14] times the radius), so I calculate that the distance the tip travels in one revolution is 364 feet. Now I need to translate the feet into miles. I dig out from my memory that one mile is 5280 feet; so the number of *miles* traveled in one revolution is 364 divided by 5280 (364/5280). Since there are 60 seconds to a minute and 60 minutes to an hour, there are 3600 seconds in every hour. So the time of one revolution per hour is 6 divided by 3600 (6/3600). Therefore, the speed in miles per hour is the result of 364/5280 (the distance expressed in miles) divided by the result of 6/3600 (the time expressed as a fraction of an hour).

Now I realize that this may sound complicated when you read it. If you write out the numbers and if you know basic geometry and algebra, however, it's really pretty straightforward.

(It would have been a whole lot simpler, of course, if I'd done the long division of each of the separate fractions into their decimal equivalents before proceeding, but in my confusion I didn't see that until I'm writing this blog post and checking it over several times.)

The answer as a complex fraction is 364/5280 divided by 6/3600. This should not be difficult for a high-school valedictorian, Yale-graduate physician, whose best subject was math. But I can't do it, even on paper. The source of my problem is a usual one for me: it's a multi-step process. I should translate the feet traveled into miles traveled; translate the time of one revolution per second to the time per hour; make them into a complex fraction; and do the arithmetic. But by the time I finish with the first step and begin the second, I'm already confused about where I am in the process. I keep flipping each of the fractions, multiplying and dividing and getting thoroughly confused. My scrap paper is covered with the four numbers (364, 5280, 6 and 3600) in various combinations plus others I can't remember the source of.

So I finally remember to calculate the decimal equivalents by dividing the fraction in the numerator (364/5280) into its decimal equivalent, but I get confused even doing that. (*Divide the numerator by the denominator, right? Or is it the other way around? How do I do the long division of 364 divided by 5280? C'mon, David; long division is elementary school arithmetic!*) I figure out one of the decimals and now I can't remember where I am in the process, which of the fractions on the paper means what? My brain feels parboiled.

Finally, I have either to give up or "cheat" using the calculator on my phone. I calculate the 364/5280 into a decimal (0.069 of a mile) and write it down on a fresh piece of paper. Then I

calculate the 6/3600 into its decimal form (0.00166) hour and write that down. Finally, I divide the nominator decimal by the denominator decimal and get 43 mph.

I then decide that you might be interested in reading the whole debacle. But as I write the fifth paragraph above about my calculations, I notice that in my first step I used the wrong formula: The circumference is supposed to be pi times the **diameter** and not pi times the **radius**.

Does that make my result twice as large or half as large?

I have to work that out on paper, too. And now I can't remember what my initial result was nor can I find it in the jungle of numbers on the papers, so I recalculate the whole thing on my calculator, getting confused again along the way. I make so many mistakes that it takes me perhaps twenty minutes just to repeat the simple process. And checking all the calculations again takes me another half an hour, and I'm still not sure I'm right. So far, I've gotten three different answers, but the final one seems right.

T o those of you who wisely jumped here after the third paragraph or tried and didn't make it through the preceding paragraphs, I don't mean to imply that *anyone* should be able to figure this out easily. The point is that

I

used to be able to get an approximate answer to something like this in less than a minute in my head; With pencil and paper I could get the exact answer in two or three minutes. And now it takes me well over an hour and the use of a calculator to work out an answer I'm only shakily confident in.

If ever I need clear demonstration of my decline, something like this is it. I have no idea why my decline doesn’t show up on cognitive testing, but the reality is obvious.

For about a minute I notice myself getting depressed about it, but that lifts pretty quickly. I already know that I'm cognitively impaired. Do I really care how fast the tips of the propellers are moving? No, I don't. (It's 83 miles an hour if you're interested, probably fast enough to clobber a goose who's blindly following the goose in front of him while daydreaming about his mate and not paying enough attention to the blades.) Perhaps I used to care about impressing and amazing my friends by figuring out the approximate answer in less than a minute, but I'm actually happier now not being so hooked on the need to be superior.

Values change. I enjoy most of my new values better than the ones they've replaced. I'll

put up with the occasional confusion.

Wednesday, August 20, 2014

The Oregon Coast

A Treacherous Landscape

Last week while Marja, our son Kai and our grandson Otto were exploring the Oregon coast, we walked out to see the towering plumes of water created by the crashing surf at high tide. To get there we had to walk perhaps 50 meters over volcanic rock. The rock was uneven, of course, and we had to hop around the shallow pools of water from one island of rock to another. It should certainly not have been a problem; nobody else seemed to be having trouble moving around.

I'm used to my mild difficulties with balance caused by my peripheral neuropathy . Now, unable to use my left arm (which was in a sling from my broken collarbone), my balance was even worse. All of this was exacerbated by the sandals I'd chosen to wear rather than the hiking boots I should have worn. The cumulative impact on my sense of balance made it extraordinarily difficult to navigate around the small pools of water, and I almost fell several times onto the sharp surface of the rock. My flailing left arm and misstep into one of the small pools to maintain my balance made me feel foolish … and old!

However, I noticed something else. The landscape itself began to seem treacherous. I was aware that everyone else was navigating easily, but I noticed myself wondering: In such a dangerous place, how do they do it?

To a much smaller degree, I have noticed a similar phenomenon as a result of my cognitive decline. Certain aspects of the environment seem perilous in themselves. I find myself checking out immediately from of any disagreement about what happened in the past, even when I'm quite sure of my memory. I defer to others' sense of direction or decisions about how to find our way to wherever we're going. I want to avoid Scrabble after noting the decline in my ability to play.

These are not disabling. Most of the time my sense of direction is perfectly serviceable. I only lose my way in new environments (like driving to the Napa Library this morning with Otto and his sister Madeline) and even then it's only temporary. I still make some stab at arguing with Marja about memory. I'm definitely going to play Scrabble with Otto and Madeline again. Nevertheless, these situations create a certain apprehension.

I suspect that people with significant impairments experience similar (although much worse) anxiety. As their abilities wane, it's not just a question of avoiding those particular situations. It's also that the entire environment becomes more and more frightening and fear itself exacerbates their impairment … and their isolation.

There's a tendency, I suspect, for the caregiver to get a bit frustrated when the person with Alzheimer's refuses to do something that the caregiver knows that he really could do. Perhaps we underestimate the fear that makes their forays into the environment seem impossibly treacherous.

Wednesday, August 27, 2014

Amtrak, somewhere in Iowa

Terror

Where am I? What's throwing me around so roughly? Which way is up?

It's pitch black. Noise as if the world is ending surrounds me. I'm completely disoriented. What's happening? More than my worst nightmare, primal terror fills my consciousness. Where am I?

Oh, yes. Laurel's house, sleeping with Marja on the pull-out futon in their den. Of course … an earthquake. We need to get under a door frame. I try to stand up. What's this stuff on the floor blocking my path? I have to crawl toward the door over whatever it is on the floor. My

terror begins to subside but the adrenaline rush keeps me shaking. Marja has woken: “Where are we?” She sounds less terrified that irritated by the interruption to her sleep. I reach the door; the light switch doesn’t work. I move out into the hallway and finally my son-in-law’s flashlight pierces the darkness.

My daughter Laurel lives in Napa, about 6 miles from the epicenter of Monday’s 6.0 earthquake, the most powerful in northern California since 1989. It struck at 3:20 am. I had fallen asleep only an hour earlier, and the shuddering earth woke me abruptly from deep sleep. No wonder I was so disoriented. I can still find no words to describe the terror.

The house suffered no structural damage. The worst was the mess: fallen pictures, toppled shelves, computer monitors, all thrown to the floor. Glass shards lay everywhere: from wine glasses on shelves (this is the Napa Valley, after all), from Mason jars stored above the cabinets, and from the glass protecting pictures. In our room, which Laurel normally uses for her small Internet business, two computer screens and all sorts of supplies spilled across the room. Near the door had been five fairly heavy wooden boxes stacked loosely one on top of the other, unattached to a wall. The crashing and banging that had awakened me was the whole stack’s toppling and spilling its contents over the room. Fortunately, our bed wasn’t in its path.

Given the power of the earthquake, the Napa area also got off relatively lightly. Three people were critically injured but none killed, gas and water lines broke causing some fires, some buildings were damaged as were some roads. More immediately for us, no trains would be moving until railroad inspectors approved the tracks, bridges and tunnels within a hundred-mile radius. We rescheduled our trip home for the next day.

My thoughts keep returning to that initial minute of terror. The terror had no object, nothing I could identify as dangerous. It was just a moment of sheer chaos, disruption, and unknowing unlike any I’d ever known. For the past several days, I’ve searched for words to describe the feeling but have found nothing remotely up to the task.

I wonder if some people, upon learning their diagnosis Alzheimer’s or other dementia, experience a similar terror, a nameless dread. Perhaps long after the diagnosis, some still

wake in the middle of the night to that visceral panic even beyond the rational fear of the disease. Words of comfort cannot sooth the terror, much less dispel it.

It's painful for the rest of us to remain physically and emotionally present to the terror of another. We, too, are afraid of the helplessness and may pull away, unable to bear it when our ministrations are ineffective or, worse, rebuffed. At such moments we can only share in the agony of the one we love ... and remain present.

Posts from September-October 2014

Jump to my blog