

## Blog Posts from May 2014

Tuesday, May 6, 2014

Washington DC

### Life-Long Teachers

My wife Marja is an adult educator. Almost thirty years ago, she and another teacher founded [Academy of Hope](#) to provide high-school-equivalency education for those who had not finished high school. They started with four students in the former guard's room of a low-income housing building. They earned the \$50 monthly rent with bake sales. Academy of Hope has now expanded into the largest adult education program in the city. Several years after the founding, Marja handed over the administration of the school so she could devote her time to her real love, one-to-one teaching and tutoring. After her retirement several years ago, she has continued to volunteer as a tutor at the school.

Marja still gets called back to deliver lectures "from the founder" to occasional groups. She'll be speaking at Georgetown University next month. Public speaking is not her favorite activity, and she usually has to go through her own personal hell to prepare a lecture. What she comes up with, however, is a reflection of her own self: straightforward, simple, humble and meaningful.

She's plans to speak about the "life-long learner," a concept familiar to anyone in adult education. We don't stop learning just because we've completed high school or college or graduate school. Our formal education can continue indefinitely or pause for a while and then resume. At Academy of Hope, adults from their twenties to eighties continue their formal education. For some it's wanting to be able to help their children with homework, for others it's a matter of qualifying for job advancement, and for still others it's the simple desire for knowledge. For all it's a source of deep pride.

But we may not recognize that we are also "life-long teachers." We teach specific skills to our children and other adults, too. We teach from our experience. We teach from our presence. We teach from wisdom gained over years. Most of us are not aware of the teaching we do. None of us really knows its long-term impact.

In this blog, of course, I'm teaching in a more formal sense about cognitive impairment in order to bring it out of the closet and into the light. I also teach in my writings, lectures, and seminars. But much of my teaching is less formal, although, perhaps, more important. People have told me that just talking openly about my impairment cuts through some of the stigma attached to the disease. When I remain active within my community and take on whatever responsibilities I can handle, others learn that Alzheimer's or any cognitive impairment is a gradual process during much of which the impaired one can still participate in daily life. Others begin to recognize that one can live with this diagnosis without fear.

In the same way, each of you who reads this blog, or is cognitively impaired yourself or cares for a person with cognitive impairment, each of you teaches others about Alzheimer's or other cognitive impairment. The teachings may be very specific, for instance, passing on some medical knowledge you've gained or the availability of a website or an Alzheimer's organization.

Or the teachings may be less well defined. The willingness of you who have an impairment to "out" yourself neutralizes some of the embarrassment and shame that makes people afraid of the disease. Your participation in the regular activities of daily living gives others a more realistic picture of what it means to live with Alzheimer's and reduces some of the fear. Your willingness to talk with another person who is worried about his or her own cognitive impairment can be very important.

The readiness of those of you who are caregivers to join support groups helps other people who are earlier the journey. When you dare to ask others for help, you teach about community and diminish the anxiety that others may have about the isolation they fear. And when you include even your moderately demented loved one in activities she or he enjoys, you teach people to be less afraid.

Those of us who are in the middle of the struggle with this disease may forget that we have learned a lot that we can teach others. We are a relatively small group of people. We have wisdom and unique expertise that is profoundly important in our society. In a culture in which Alzheimer's is still deeply misunderstood, the education we provide is a vital piece in the effort to dispel longstanding ignorance and shame.

Monday, May 12, 2014

Washington DC

## **Elderly at 69?**

It's not just my mind that makes me feel old. It's my body, too. For the last several years I've had a permanent numbness in my feet caused by a neurological condition known as "peripheral neuropathy." It makes it difficult for me to sense anything on the skin of my feet. It's as if I were sensing through a thick piece of cloth, as if I were wearing socks.

Fortunately, it's not a progressive disease and mine has been stable for a number of years. The worst part is that the nerves responsible for telling my brain just where my foot bones are in relation to each other (the proprioceptive nerves) are also affected, so I don't quite know where my feet are, which means I stumble constantly and lose my balance easily. I don't know if the worst part is falling into somebody I'm talking to or swinging wildly for a couple of steps as I regain my balance.

So in addition to this declining memory, I feel physically unsteady, too. I sometimes feel elderly, especially when the person I'm talking to reaches out and steadies me or when I stumble over nothing. (Marja and I hold hands on our evening walk. It's not just cute; it would also protect if I tripped.) Just to be clear, I *know* I'm not elderly in either my mind or body. Marja and I backpack into high mountains, carrying our supplies as we hike for a week. Despite the city traffic, I still bicycle everywhere I go (my overall balance is fine; I just can't find my feet). I do over thirty push-ups most mornings, and so on. And I still teach, lecture and lead groups well. But in a society that seems to value youth over everything else, it's a struggle not to feel less-than.

Mostly it's the same old problem: I'm still hanging on to a picture of myself from twenty years ago when I was an athlete and could calculate most everyday math problems in my head. As I've written in this blog several times before ( [here](#) , [here](#) and other places), however, a sure path to unhappiness is to hang on to the self I used to be.

I'm sixty-nine, my memory is shot, I'm confused from time to time, and I stumble over cracks in the sidewalk. And unless I think I'm *supposed to be* different, I'm fine with it.

Monday, May 19, 2014

Washington DC

## **Surprise!**

A week ago Friday, over seventy people crowded into a friend's house for my wife Marja's surprise seventieth birthday party. She actually had no idea it was coming and was flabbergasted when we walked in, especially when she saw her brother who had traveled from his home ninety miles north of Toronto. Two of my stepsisters and a brother-in-law from Cleveland also showed up. It was lovely, even for me who seldom enjoys parties.

The number of people was staggering. We're not part of large communities: our small church of perhaps fifty people, our families, and a few of Marja's former students. But Marja means much to so many people, and a large percentage came. Ten days later both of us are still basking in the joy of that gathering. Marja still mentions it at least daily

In the two days before the party, we also surprised Marja with the arrivals of our two children who weren't already in the area. Laurel flew in from California and Kai from Seattle. Our younger daughter Karin had returned earlier in the week from her fifteen-month stay in Delhi, and we were still elated by that. It was delightful to have our little nuclear family together again for a few days.

The most beautiful aspect of the party for me was the several weeks before as I combed through our photo albums and loose stacks of pictures to find photos of Marja from different phases of her life. Especially wonderful for me were the pictures from her adolescence and early adulthood. I'd forgotten how beautiful she was. A gentle yet powerful spirit emanates from those pictures. I kept thinking: How could a woman so beautiful have been interested in me? I don't remember realizing at that time the depth of her spirit, so the pictures were my own surprise party. I scanned the pictures into digital images and sent the files to Laurel. She created a beautiful slide show that looped continuously throughout the party. Every time I looked, there was a cluster of people gathered around the monitor.

I suppose we become used to the beauty that surrounds us and it ceases to be startling or, too frequently, even apparent to us. Marja and I have been together almost forty-five years, and so often I forget the beauty between us. Every once in a while, though, it will suddenly break through. Each time it comes as a wonderful surprise, although never so powerfully as when I was selecting those pictures for the show.

My ongoing wonder—at both the numbers that showed up and at Marja and my relationship—reminded me again how much my cognitive decline has opened me emotionally. I doubt that this depth of joy could have broken through to me before. Oh, I'd been intermittently aware of and grateful for the gifts I've been given. Intellectually I would have known the importance of the party and recognized its joy. I would not, however, have experienced it so intensely. The depth of the joy has been a miracle.

Thursday, May 29, 2014

Washington DC

### **“A Fate Worse Than Death”**

In a recent [column](#) in the *NY Times*, physician-author Danielle Ofri described an incident in which she and another doctor were examining a patient with Alzheimer's. “A fate worse than death,” the other doctor murmured. Dr Ofri, too, felt uncomfortable.

There was something almost shameful in bearing witness to a fellow human being's profound indignities.

The patient had been a prestigious artist and intellectual and to see him with only a sliver of his former intellectual capacities was, Dr Ofri wrote, “beyond heartrending.”

It's also heartrending, however, to be in the presence of a person dying painfully from cancer or of a person with a severe stroke that leaves her immobilized. These diseases, too, are accompanied by indignities, for instance, having to be wiped clear after defecating. These other diseases, however, do not create shame. Alzheimer's does. Why?

Dr Ofri writes,

I was embarrassed *for* him, for how embarrassed *he* would likely be, if his former self could see his current self. That his current self lacked the capacity to be aware of his state offered little comfort.

Yes, we are embarrassed because his former self would have been embarrassed. That doesn't get us anywhere, though; it still doesn't answer the question of why he would feel embarrassed.

I'd like to suggest that we feel shame because we are looking at our future self *as if* we had our full mental faculties  
*and*  
were still behaving that same way.

After I became aware of my cognitive decline (and [believed for a year](#) that I had Alzheimer's), I did not feel embarrassed for myself even though I had the capacity to be aware of my mistakes. I was fully cognizant of my memory deficits and the problems it caused, and I was aware of my intermittent confusion. I had  
["lost" the \\$24,000](#)  
through no fault of my own but because my cognition was impaired. I might have been embarrassed if I hadn't told everyone I knew about my cognitive decline, but we all knew what was going on, so there was nothing to be embarrassed about.

True, my decline has been minimal compared to what others suffer. Nevertheless, I do forget names and faces I should remember; I miss appointments, even those I've written on my calendar; I have to ask others to take over more complicated intellectual tasks I can't manage any more. I'm rarely embarrassed, however, and certainly not ashamed. It's not that I lack the capacity to feel shame; it's that we all know that there's a good physical reason I'm incapacitated.

I'm not alone. I've talked with another Alzheimer's patient who is in a somewhat more

advanced state than I who also reports that he feels little embarrassment or shame. Of the hundreds of people who have written me, no one has even mentioned embarrassment or shame on the part of the person with Alzheimer's (and I look forward to some responses to this post). Why don't we experience embarrassment?

I can only speak for myself, of course, but it seems to me quite possible that, with increasing cognitive impairment, I will still be unembarrassed. Also, as Dr Ofri mentions, as the disease progresses, I will become incapable of feeling embarrassed. So it's entirely possible that at no point in the course of this disease will I feel embarrassment.

Perhaps Alzheimer's is not a fate worse than death. What would happen if we began to realize that when we get embarrassed or feel shame in the presence of a person with dementia we are really imagining a future we cannot actually imagine? Perhaps we could stop scaring one another and allow ourselves to relate more naturally to another person's cognitive impairment.

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