

Blog Posts From September and October 2014

Sunday, September 7, 2014

Sudoku

[Written: August 27, 2014]
Iowa

Amtrak,

Marja and I are on the train home from visiting our children and grandchildren on the West Coast. While in Napa playing with my grandchildren, I got addicted to the puzzle game Sudoku, downloaded it to my computer and have playing it on the train-ride home

Without going into the intricacies of Sudoku, I need to copy an 81-cell grid that's on my computer screen right in front of me onto a piece of paper also in front of me. The grid is divided up into nine squares of 9 cells each, and I need to mark with an X the cells I've completed and leave the others blank. It's a simple task: copy a design that is right in front of me.

I just can't do it; not even close; I become repeatedly confused. I've posted about other experiences of getting confused; for example, [here](#), [here](#), and [here](#), although in those situations I was confused about much more complicated matters. But this is straightforward copying, and I can't do it.

Immediately afterwards, I was editing an essay I'm writing and I got confused again, too confused to continue. Then I tried reading a simple novel and got mixed up there, too.

Have I suddenly gotten worse? What can have caused it? If the cause of my cognitive decline is vascular (little strokes), have I just had another shower of the tiny clots? It seems that my life has turned again.

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Several hours after the episode above, however, I came back to my reading and then to editing, and I was able to do both without difficulty. Just yesterday, a week after the events above, I had no difficulty in copying a similar pattern from a Sudoku game.

So it was a temporary event. It could have been something akin to a transient ischemic attack (TIA), but I doubt it. I suspect it was something much simpler. I don't sleep well on the train (to say the least) and was extremely tired. I was also wired on caffeine, which I ordinarily don't drink much. I'm beginning to think that the physical stress I was under from the tiredness and from the caffeine significantly exacerbated my cognitive decline.

Come to think of it, my [trouble calculating the speed](#) of the tips of the wind generators occurred on the train out West, when I'd also been short of sleep (and probably wired on caffeine, too).

Hard as it may be to believe, I've never thought of this possibility. Could other exacerbations of my underlying cognitive decline have been similarly affected by physical distress?

If physical stress is a major contributor to my episodes of worsening confusion, then I need to think seriously about decreasing that stress. It's the lack of sleep that is the most likely culprit. I've never slept well and can say that I've been chronically tired a great deal of my life (except during certain vacations). Part of it is anxiety, part of it is my history of depression, but much of it, I suspect, is that I just enjoy the late night so much and can't discipline myself to go to bed. This kind of change could be very problematic.

In certain ways I've taken good care of my body throughout my life: lots of exercise, reasonably good diet, normal weight, and so on. I have not, however, ever given much thought to my chronic tiredness. It's time to re-examine things.

Friday, September 19, 2014

Washington DC

A Gift of Community

When I [first thought I had Alzheimer's](#), I was given the gift of community. I'd been part of my small church for over a decade, but I'd never been aware of the love that its members held for me. I knew that they admired me for what I'd done and could do; I knew they respected me for my integrity; but I had not been aware of their love for me. This wasn't, I now perceive, because they didn't love me earlier but because I couldn't take their love in, or even recognize it.

What had previously frightened me most about Alzheimer's had been the anticipation of the [isolation](#) that so often descends as friends, relatives, and even family turn away. Alzheimer's is often seen as embarrassing, frightening, leaving other people uncertain how to respond. Many, even most, just gradually drop away, or so readers of this blog have written me. Isolation was really the only fear I had ... especially late one night when my wife [Marja didn't come home](#) at the time I expected her, and I began to have fantasies of living the rest of my life without her..

When, shortly after my diagnosis, I [announced](#) it to the church, I could feel that fear of isolation begin melting. Immediately a circle of prayer formed around me. I must admit to not believing that prayer changes things supernaturally, but those prayers certainly changed my relationship to my community. I *felt* their love and concern.

My relationships with many people from the community changed profoundly (or at least my perceptions of them did). Friends came up to me and assured me that they wanted to stay in

relationship, to care for me when I needed caring for. (I knew, of course, that not everyone would be able to keep that commitment; Alzheimer's is too frightening. Yet I knew that some would. And I knew that all of them sincerely wanted to.)

Throughout the next year, my sense of the community's love for me only deepened. When I couldn't remember names or made [serious mistakes](#), people not only forgave me but worked with me and had compassion (without pity) for me.

Most of the love and compassion that the community felt for me had been present, I'm sure, all along. But I was too independent and closed off to sense it, to let it in, until I found myself so vulnerable. At that point I needed it so much that I opened up. My vulnerability, I suspect, melted that protective shell around me, and allowed the love in. Similarly my vulnerability gave the community opportunities to do some things for me, which brought us closer. (If you really want to demonstrate your love for a friend, ask him or her to do something for you that you really need.) My vulnerability gave them appropriate opportunities to express their love.

What has been amazing to me is how that change has persisted. When I discovered a year later that I [did not, in fact, have Alzheimer's](#), our deeper relationships endured. They were still offering me love and acceptance, and I was still able to open myself to it.

It seems to me nothing short of miracle. Suddenly at age 67, the self-protection that I had held onto all of my life melted away almost overnight, and I was able to allow in a kind of joy that I'd never experienced.

The gift has stayed with me. I'm very grateful.

The Last Post ... (?)

Sunday, October 19, 2014

Washington DC

Some of you will have noticed that I haven't written in almost a month; you may be wondering what's happened to me. I'm fine, but I just haven't had anything new to say. My cognitive lights are no longer winking out. True, some are still burned out and unlikely to return, but it seems I've written everything I've had to say about them. So it's time to end this chapter in my life and close "Watching the Lights Go Out."

This journey since my initial diagnosis of Alzheimer's two years ago has been a wild and amazing ride. As I've written before, I have been and still am grateful for this ongoing experience; I've become a better and more joyful person. Writing here has given me the opportunity to share the journey with others, thereby clarifying my own experience.

More important, however, has been the joy I've felt in the growth of this community created by you who have been reading it. Many of you have used the comments section of the blog. At least as many others have written me privately [through my website](#) . And I suspect there are others who, for many different reasons haven't written but still feel part of this community. All of you have given me many gifts for which I am, and will remain, deeply grateful for each one of you.

This blog has been explicitly about my own personal experience with cognitive decline, "watching the lights go out." It's been that first-person, intimate story that has captured people's interest and sometimes even their hearts. It's important to me that I maintain the integrity of that purpose.

I'm going, therefore, to close the blog. I will be writing, however, about the process of aging in much the same personal style. Perhaps I will create a new blog for that ... or another topic. Perhaps, after a time to make a clear break with the past, I will re-open this one. But for now I'm done.

I am deeply grateful.

[Jump to my blog](#)