Blog Posts from December 2013

Tuesday, Dec 3, 2013

On Amtrak coming through eastern Washington State

Changing Course

I've just returned from Seattle where I was visiting my son. On the train trip back, I became repeatedly confused trying to locate my seat. Here's the process in some detail. Although I had a seat in one of the coach cars, I usually spend most of my time in the lounge car writing or reading at one of the tables. I have to return to the second coach back to my seat occasionally, however, for one reason or another. Several times, however, I got confused about which way to turn to get from the lounge car back to my seat. (Just to be clear: on a train there are only two directions to choose from.) One end of the lounge car has tables and the other swivel chairs, but during these episodes I couldn't remember which end of the car I'd entered. I would take a few seconds and then head in the direction I guessed my seat was located. I'd walk a few steps, however, and then realize I wasn't sure. So I'd have to concentrate on the logical connections between each step in the entire thinking process. It went something like this:

- I would remember watching the lounge car being physically hooked up at the very end of the train; therefore,
- the lounge car must behind my coach car; therefore,
- if I want to go from my coach seat to the lounge car, I have to walk toward the rear of the train; therefore
- if I want to go back to my regular seat from the lounge car, I have to walk toward the front of the train; therefore,
- I have to look out the window to recognize which direction the train is going. In my confusion, even if I looked at the scenery as it passed by I had to consciously decide which way the train was going. Therefore,
- I should walk in that forward direction; and
- while I walked through the coaches I should double check that I was going in the same direction that the seats were facing.

I actually had to go through each step consciously and deliberately, step by step. I was especially startled when the direction the train was going wasn't intuitively obvious as I looked out the window; I'd have to decide which way the scenery was going and remember that the train would be heading in the opposite direction. But the bigger problem was that I couldn't

simultaneously keep in my mind the several needed bits of information. I would remember, for instance, that the lounge car was at the end of the train, but as I was trying to decide which direction the train was going, I'd forget where the lounge car was in relationship to the train. Or I'd figure out where the lounge car was relationship to the rest of the train, but get confused about the relationship between my car and the lounge car. It was very weird. And, then, on the way to my seat after having actually reasoned it all out, I'd get confused, stop, and have to go through the entire process again. One time I walked almost completely through one car, reversed direction, walked back almost to the lounge car, and then reversed direction again before I had it right.

And then other times, even when I got the direction right, I'd just forget where my seat was within the car. So I'd have to walk through the car looking for my suitcase in the overhead rack. A couple of times I went right past my seat it without recognizing it.

I felt confused, of course, but I was surprised that I wasn't more frustrated. Part of it was that on the train, there's no hurry with anything, so the confusion doesn't cause a problem. But the other part (and I find this difficult to believe myself) was that I found the episodes fascinating: How, for instance, was it possible to look out the window yet have to consciously reason out which way the train was going? I did get embarrassed wondering what people thought of me wandering up one direction, stopping and walking back, and then changing again, but in reality, of course, no one was paying attention or would have cared.

And then just as quickly as it came on, it would be over until the next time. Mostly I'm fine and then something like this will happen. It is so intermittent.

Amazing!

Friday, December 6, 2013

Washington DC

Flowers for Algernon

On the train home from Seattle, I read *Flowers for Algernon* by Daniel Keyes. The novel is written as a series of journal entries written by Charlie, a mentally challenged man who has been selected to participate in a clinical trial of a surgical procedure designed to double or triple his IQ. Impatient scientists choose him as the first human subject after only one experimental mouse, Algernon, exhibits signs of increased intelligence. Indeed, the surgery is successful, and we experience Charlie's increasing intellectual brilliance: he develops a photographic memory, learns ten languages, quickly becomes an expert in several different unrelated fields, and so on. However, we also watch, as Charlie becomes more isolated, not only because nobody can follow him intellectually but also because—in his emotional naïveté—he doesn't recognize how he alienates others with his aloofness and lack of empathy.

But then Charlie notices that Algernon has begun to regress and is soon having trouble with the simplest mazes. Charlie, of course, recognizes his likely future: he will lose his newly acquired IQ and may even lose more than he had originally gained. He returns to the experimental lab and works feverishly, not to change the course of his own disease but to discover the metabolic pathways that doomed the surgical experiment from the beginning.

Meanwhile he chronicles his own decline. Knowing what's coming, he has to watch himself deteriorate. Sound familiar?

It's a good read, but I found two lessons particularly important. Charlie's intellectual descent doesn't seem to bother him as much as one might expect. He has succeeded in finding the medical reason behind his decline and feels satisfied with his life. Second, as he loses his intellectual brilliance, he opens up emotionally, and old, withered friendships become rich again, perhaps richer than before.

In this brief summary, the novel sounds Pollyannaish. It isn't. It is, however, hopeful. Regardless of what too many of us in the culture believe, intellectual intelligence is not the be-all-and-end-all of life. There are, of course, intellectual geniuses who are also empathic and compassionate, so the issue is not intelligence *per se*. But there is *something* in his declining intelligence that allows a richer emotional life.

This rings true for me . I can't really explain it, but at least I am finding that the increasing emotional openness and deeper friendships more that match what I'm losing cognitively.

As I've written before, there are caveats. First, I'm only mildly cognitively impaired and I may be watching through rose-colored lenses. In a sense, I have the best of both worlds: increasing emotional intelligence and still persistent intellectual intelligence. Secondly, *Flowers for Algernon*, like *Still Alice*, is a novel, a story, by a cognitively intact author who can only imagine the inner life of a mentally challenged person. Third, the story describes little about the suffering of others close to him and nothing about the suffering of caregivers.

Nevertheless, while it may or may not be an accurate depiction of intellectual decline, I found it deeply meaningful. I will eventually become profoundly impaired myself and will certainly die, but the journey does not, apparently, have to be the culturally expected suffering.

Wednesday, December 11, 2013

Washington DC

What Happened to the Laundry?

A few days ago, I was doing our laundry in the basement of our small apartment building. After washing one load, I put it in the dryer, filled the washer with a second load, and went back to our apartment. I came down an hour later, expecting to find both washer and dryer cycles finished. Instead, I found them still going. The LED on the washer indicated that there were still forty-seven minutes remaining in its cycle. I interrupted the dryer cycle and found that the clothes were still very damp. What was going on?

My first thought was that I'd forgotten to turn both the dryer and the washer on after loading. I had previously done so occasionally on one machine or the other but never both at the same time. Since both machines were now running, of course, there was no logic to my thinking, but it took a while for that to sink in.

It took me a bit to realize I should open the washer to see what was in there. I was surprised and a little confused to find clothes belonging to someone else. How did they get there? Then I noticed a basketful of our dry laundry on top of the washer. Where did that come from? Had I forgotten even to put the clothes into the washer? Had I forgotten to turn the washer on, which

encouraged another person to empty our dirty laundry from the machine and start washing his? The best way to figure that out, I thought, was to check the dry clothes in the basket to see if they were clean or dirty. It wasn't obvious to me. These were the dark clothes and I couldn't remember whether I'd put the light clothes or the dark clothes into the washer first, so that didn't help me figure out whether they were clean or dirty. I then reasoned that the clothes in the basket should be warm if they'd just come out of the dryer, but they were only slightly warm in the middle of the basket, so what did that mean?

I see now that, as I tried to make sense of the situation, I somehow couldn't keep these few bits of information simultaneously in my mind.

- I'd waited an hour, but both machines are on.
- The washing machine indicates forth-seven minutes left in the cycle.
- The clothes in the dryer are still damp.
- A basketful of our dry clothes sits on top of the washer.

I stood there going back and forth in my mind, checking the dry clothes, trying to figure it out. Slowly, bit-by-bit, I realized: Someone else had come down, taken my dry clothes from the dryer and put them into my empty laundry basket, then put my wet clothes from the washer into the dryer and finally started washing his clothes. Even after I thought of that possibility, however, I wasn't sure; it seemed a little complicated. I left the dryer going to finish its cycle and took the dry clothes to our apartment, but the uncertainty cleared only slowly.

I had been confused, of course. In previous episodes of confusion, however, I'd realized I was confused *during* the confusion. This time I became aware only gradually after it was clearing.

In reflecting on this, I notice how episodic my confusion is. I'm lucid the overwhelming majority of the time: Over the weekend, I gave a short talk without notes and led a discussion for an hour and a half without trouble; I can usually figure out computer complication or keep our finances in order. At our church yearly budget meeting on Sunday, I was helpful in clarifying some complications. I haven't had much trouble writing this post and explaining (in a hopefully unconfused way) the state of my confusion. As a general rule, I'm not confused at all, and then suddenly something like this happens.

As usual, my laundry-room episode didn't bother me emotionally. Things like this are still more fascinating than troubling. In addition, episodes of obvious impairment resolve those fragments of uncertainty that still bother me after all the tests that were normal .

I'm having these episodes more often, though: putting the cabinets together with my son Kai, confusion on the train , and now this. It's nothing dramatic like getting lost and it's a very slow and uneven process, but the impairment does seem to be worsening.

Saturday, December 14, 2013

Washington DC

The Roller Coaster

Over the last several weeks, I've written about three episodes of confusion:

- when I was following directions to put a cabinet together with my son,
- when I was finding my seat in the train , and
- when I was figuring out what happened to the laundry .

It's starting to sink in that these episodes are, indeed, getting more frequent. I'm beginning to get some sense now of what it might be like to be confused much of the time and, even more difficult, not be able to snap out of it on my own.

I have a baseline level of mild impairment that I'm used to: I lose things constantly. I frequently can't find the right word. I not only forget to keep appointments but, when reminded, forget I ever made them. That baseline level of impairment is slowly increasing certainly but very slowly and only over a period of months.

The episodes of confusion are completely different: One minute I'm at baseline, the next minute I'm bewildered by what's happening around me; and five minutes later I'll be just fine again, even curious about what just happened to me. The episodes always seem sudden; they come out of the blue with no precipitating events. I've never noticed myself sliding gradually into one. By the time I notice, the confusion is full-blown. Returning from the deeper confusion to baseline, however, seems to take a bit longer, perhaps a few minutes.

I'm getting used to these spells and they haven't bothered me much so far. But as they get worse, I wonder if it won't be much more difficult for my family, friends or caregivers who will have to relate to me and respond to me without being sure of my level of confusion. This variability in symptoms is a hallmark of Alzheimer's. So if you were to experience me during one of my episodes, you'd have a tendency to relate to me the next time as if I'm always so confused. On the other hand, if you experience me only at my good, baseline times, can you be prepared for my cognitive level suddenly dropping through the floor? Can you trust me to handle money or the finances or to take the vacuum cleaner apart to fix it? The underlying question will be: Do you treat me and trust me as if I were at my day-to-day level and, if so, how do you factor in the fact that I may become suddenly more confused? Life together may be a real roller coaster.

In this context, think of the decision about when to stop driving; it may be the most difficult one in the entire illness, especially for men. Right now, I'm a competent driver; people are comfortable riding with me and no one would think to suggest giving up my driver's license. But what if I'm in the middle of traffic going 70 mph on the Interstate when I have an episode of confusion and I don't know quite how to handle it? Should I be evaluating my driving ability on the basis of my baseline impairment or on the basis of how I am at my most confused? All logic tells me to that I should evaluate myself for driving as if I were at my worst.

That's a scary thought!! But maybe I need to face it without flinching.

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