

My Alzheimer's **

In June of 2013 I spoke at the Second Annual Bioethics, Spirituality and Humanism in Medicine Conference in Kansas City MO. The participants were a select group of health care specialists (social workers, nurses, chaplains and doctors) who were particularly interested in the ethical and spiritual issue in medicine. One section of the conference invited health professionals to talk about their own chronic diseases and what it was like to be on the other side of the stethoscope. I was asked to give the keynote for that section.

I have Alzheimer's disease. It's been quite a journey; and this morning I'd like to share part of that with you.

The onset was insidious, but I mark the beginning as June 5th of 2010, the day I lost a day. I drive several times a year from Washington down to southern Virginia to visit a friend in prison, Jens Soering. Jens had recently been transferred from one prison to another, and this would be my first drive to the new prison.

During my visit, the prison chaplain stopped by to say hello. I introduced myself. "Yes," he said, "I remember you from last time."

"No," I said, "this is the first time I've been here. But he insisted we'd met, and I let it pass.

After he'd moved on, I asked Jens about the chaplain's comment. "Yeah," he replied with concern, "you were here last December."

Well, I was absolutely certain I'd never been there before. The new route there was complex. It was a 3½-hour trip down, four hours there and 3½ hours back. Visits with Jens were usually memorable. I couldn't possibly have forgotten it!

But I had. To this day I remember nothing about that forgotten trip. Nothing remotely similar

had ever happened before (or since, actually).

I decided, though, not to get it checked out. If it was important, there would be further symptoms. There weren't, so I pushed it to the back of my mind and it became just a weird story I told friends.

Months later, I was working on a spreadsheet for my church's budget. I needed a relatively complicated formula that I'd developed in previous years. I tried to recreate the formula from scratch. Not only was I unable to do it, but—when I went back to old spreadsheets and looked at the formula I'd previously created myself—it was too complex for me even to understand! I just couldn't follow what I'd done.

What was going on? I asked my wife Marja and several close friends if they'd noticed any symptoms of impaired mental function. They hadn't. To this day, almost no one notices anything.

Just to put my mind at rest, however, in late summer of 2011, I saw a neurologist for a work-up. My score on the Montreal Cognitive Assessment was 27 out of 30. Given my previous IQ, I shouldn't have missed any. The neurologist said I had "mild cognitive impairment"—and he didn't seem concerned either by my history or the result of the cognitive assessment. He didn't mention Alzheimer's.

Somehow I was reassured. I'm not usually much into denial, but a label of "mild cognitive impairment" should have set off alarm bells all over. A little background: My IQ had been something north of 140. I'd been valedictorian of a large high school class, Phi Beta Kappa in my junior year at Yale, a successful doctor, and a well-recognized writer. I was used to being the smartest guy in the room. Yet I'd just tested as cognitively impaired, and I didn't even press the neurologist for what he thought was going on. At least consciously I just let it go. The neurologist asked me to come back in a year "just to check."

Things didn't change much over that year. I was finding my writing and teaching more difficult, although I made no connections with my cognitive impairment. I became less interested in my writing, which suffered accordingly. I found it more and more difficult to hold several themes in my mind at once. In one class that I was teaching, I realized I couldn't handle

the challenging back-and-forth that had always been my forté.

I see now that my memory was also gradually deteriorating. More and more I had to depend on written records to remember past events. Even with a handheld digital calendar, I missed appointments. But I'd learned long ago to brush off my forgetfulness with a self-deprecating or humorous remark. No one noticed.

A month before my follow-up, I got temporarily lost while visiting my daughter in Philadelphia. I'd always had an excellent sense of direction, but I figured I just hadn't paid enough attention in an unfamiliar environment. I forgot about it.

So I walked into my follow-up appointment with my neurologist a year later without much concern ... though I can't really explain that. I got to the place on the cognitive assessment where I was supposed to copy the skeleton of a cube from a model drawn right next to it. I couldn't do it; I couldn't get the lines to meet together correctly. "Now, that's disturbing," I said as my heart sank. I proceeded to have trouble repeating five unrelated objects immediately to say nothing of five minutes later. I could come up with only eleven words beginning with "f" in one minute, compared with twenty-one the year before.

The diagnosis was still mild cognitive impairment, but this time I pressed the neurologist to tell me what he *really* thought. My symptoms, he said, were almost certainly due to Alzheimer's; my impairment just wasn't enough to meet the formal diagnostic criteria yet. I wasn't yet *officially* demented.

I can't say that I was blind-sided by the diagnosis; subconsciously, I guess, I was emotionally prepared. My heart stayed sunk for the rest of the visit, but I was typically stoic. I asked a few clarifying questions and left.

One small part of me actually felt relief. All those symptoms—difficulties writing and teaching, episodes of confusion, losing things—finally made sense. At an unconscious level, I suspect, I had known. Now the uncertainty had been relieved. I felt a kind of peace.

Since then, there's been some progression of the disease, though not as much as I'd anticipated. Riding my bike, I got quite lost once in a very familiar part of town, unable to make sense of the street signs I saw. I'd lived in Washington for thirty years. If you know DC's carefully numbered north-south streets and carefully alphabetized east-west streets, you know a native should not get lost.

I've become highly distractible. I'll finish a report that needs to be submitted immediately and neglect to email it. I'll start one task, begin another that occurs to me, switch over to an email that just came in, and skip to renting a car for next week. It all gets done but in twice the time.

A few days ago, I couldn't find my keys in my beltpack where I'd put them. As I stood before our door, I searched through the four compartments of the beltpack repeatedly. Repeatedly! It may have been a full five minutes; they just *had* to be there. Finally I remembered the light nylon backpack I was also wearing. I reached back and felt the keys through the nylon, only vaguely remembering that I'd put them there. I started to take the backpack off. But then I was searching fruitlessly through my beltpack again. After what felt like five minutes, again, I remembered (as if it were a new thought) about the backpack and reached for it; only then did I realize that it was hanging off one shoulder with the keys in it. Halfway through taking the backpack off, I'd forgotten what I was doing and had started looking for the keys in my beltpack from the beginning again.

Such episodes are still infrequent. Losing things as often as I do is certainly inconvenient. Getting confused playing with my grandkids in simple games is sometimes embarrassing (although *they* seem to enjoy it). Mostly my symptoms don't bother me. You probably wouldn't recognize my impairment unless you knew me well. The progression of my disease has been very slow since 2010. Even after years of confusing symptoms and increasing cognitive impairment, I still don't meet the formal criteria for Alzheimer's.

One of the immediate questions was: Whom do I tell? There was no question that I would share with my family and good friends. I wasn't about to suffer with this in complete isolation. So I told Marja and my three closest friends. Whatever they felt internally, Marja, and two of the friends responded with appropriate concern, good listening, and obvious compassion, just as any other psychologically sophisticated person would. They didn't freak out. I had myself been stoic about the whole thing, too. But the third friend did freak out and responded with shock and tears. I was surprised to find this "unsophisticated" response so consoling. It helped me begin acknowledging my deep grief.

A similar thing happened with my children. Two of them lived on the west coast so I had to tell each of them by phone ... and I hate talking about anything important on the phone. They, too, were shocked, with tears and sadness. And even over the phone, I had perhaps the most intense, wonderfully intimate conversations with each of them that we'd ever had. We told each other how important we were to each other and how much we loved one another; we cried together from our deep grief for the relationship we would gradually lose. It was beautiful actually, and I was filled gratitude.

Embarrassment and isolation were the two things I feared the most, so I decided to tell everyone with whom I would have significant interactions. I hoped that—if I were open with my diagnosis, shared frequently about how it was affecting me, and shared my fear of isolation—I hoped the community would support me and we could deal with the embarrassment and isolation together.

And, I wanted to tell others about my impairment before they started whispering among themselves about it.

It's worked out. Since sharing with our small faith community, I've been far more open emotionally to them and they to me. Relationships have deepened. We've begun to work through our mutual embarrassment when I've made mistakes or forgotten things. I blame my Alzheimer's, they nod, I roll my eyes, and we just soldier on. The community has come together around me. Granted, my impairment is not yet very noticeable; nevertheless, I have some confidence that my community will be a real source of support, for me ... and eventually for Marja.

The question of going public was not difficult, either. I'd made something of a career previously by publicly violating certain taboos. I wrote in the *New England Journal of Medicine* thirty years ago, about a serious mistake I'd made in my rural practice because I believed we doctors needed to bring mistakes out of the closet.

Twenty years ago, I wrote about my struggle with depression and then deliberately mentioned it in my public lectures.

Sharing these experiences with others was important for me and sometimes helpful to them.

Alzheimer's, too, needs to be brought out of the closet. After a few months I sent an email to the 300 people on my list, and I started my blog.

The big change occurred when the *Washington Post* did a major feature. For two months my blog was swamped with supportive comments and emails. More importantly, many have expressed gratitude for my breaking the silence about something that's affected them so deeply. It has been highly gratifying.

What anxiety I did have around being so public was not so much because I *had* the disease but because of the minuscule chance I

didn't

. Alzheimer's is a diagnosis of exclusion, made by ruling out other causes of cognitive impairment. But my diagnosis is still "mild-cognitive-impairment-

probably

-Alzheimer's."

In fact, it's almost *certainly* Alzheimer's ... but not yet officially ... and never definitively (until autopsy). Marja was, until recently, in some stage of denial, so she hung on to the tiny chance that the diagnosis was wrong and was quite anxious about my going public. "You've become a professional Alzheimer's patient, David. What if you *don't* have it? How embarrassing would that be!" Her anxiety was contagious.

I may be unique as a professional Alzheimer's patient, but I doubt I'm the only one for whom the uncertainty around the diagnosis is unsettling. It does seem to me that if other causes have been ruled out, we should be able to say without equivocation that even a mild cognitive impairment is Alzheimer's.

Obviously not everyone will choose to be so public. Some people may be afraid of losing a job or friends or being treated differently. But there is a price to silence, too:

- the embarrassment of a social *faux pas* without being able to explain
- having others avoid you out of their embarrassment
- dealing with an emotionally devastating, painful disease with no support from anyone

- Withdrawal and isolation for fear of others finding out
- Having no access to others with Alzheimer's.

Just yesterday a friend emailed to say how painful it is that her husband still keeps his diagnosis hidden. The price seems too high.

Planning for our future is important. Marja has my medical power of attorney. My advanced directives include not feeding me once I can no longer feed myself. The expense of long-term care, not infrequently over \$100,000 a year, is a bit thornier. If we were poor enough, Medicaid would pay for my care, but we're not. Our decision is to "impoverish" ourselves by giving our money away to our children, who are allowed to transfer the money back to Marja afterwards.

But Medicaid rules don't allow you to give your money away within the five-year period prior to Medicaid application; otherwise, that money will be deducted from any Medicaid payments.

But prior to that five-year look-back period, there's no legal restriction. One benefit of early diagnosis is that I should have at least five years before I need long-term care, so we are in the process of giving our money to our kids. The caveat is that it's *really* theirs; we have no control over it. We have to trust our kids.

There are ethical issues in exploiting governmental assistance when we have resources. I won't go into them here, but I'd be happy to discuss those issues in the Q&A or privately afterwards.

Before my diagnosis, I was terrified of this disease. Given how central the life of the mind had been to me, I am surprised to find myself less frightened than sad:

- sad that I'll miss my grandchildren's growing up;
- sad that I'll miss the role of "wise old man" within my community (a role I'm getting good at and looked forward to);
- sad that people's last memories of me will be as a doddering, embarrassing old man unable to recognize those I love;
- and, most of all, sad that Marja and I won't grow old *together* but that she will be

burdened with perhaps years of caring for me, when I no longer knows who she
i
s. That last thought can still bring me to tears.

There have been, of course, periods of some fear, when my stomach *has* dropped away. My greatest fear has been isolation as the disease progresses. People are *very* uncomfortable in the presence of cognitive impairment (just ask any mentally retarded person). People stay away; it's too awkward. What do you say to the person who's just asked you the same questions three times in ten minutes Or even if they didn't stay away, out of the same discomfort, I would isolate myself. Either way, I would be alone with my failing mind. But even this fear of isolation has been nothing close to the terror of Alzheimer's that I felt before my diagnosis.

Even then, I wasn't particularly afraid of death. 23 years ago, our family founded and lived in a home for homeless men with AIDS, so I'm familiar with death. But I did fear the losses:

- losing intellectual capacity,
- losing independence,
- losing family,
- losing dignity in a nursing-home,
- losing my future.

But the greatest terror was simply free-floating and non-specific.

I'm surprised to find that I feel quite a bit of equanimity in the face of it all. I'm not much afraid.

There *is* a great fear in the culture about Alzheimer's, but that fear, it seems to me, is largely based on one's assumptions *as a non-demented person* thinking how awful it *would* be. But very few of us have any idea—
any
idea—of the experience of the demented person him- or herself.

Previously, for instance, I would have feared even this first level of symptoms, but instead it's been rewarding and positive. There's nothing *here and now* that's so painful. What fear I have is of the future. But I don't live in the future. To the extent that I can stay in the here and now, there's no pain, no fear. So why couldn't the same be true in the later stages? I don't know, but I've decided that, to the best of my capacity, I will wait with curiosity rather than fear.

Prior to my diagnosis, as I said, I feared the loss of my intellectual faculties. But, in fact, I've enjoyed being freed of the responsibilities my intellect created. Been there! Done that! Will I also not care so much as I lose some other of my mental faculties. In fact, I don't know what my experience of the future will be. And for now, I'm fine with that.

There is one fear I can't shake: losing Marja. One night I didn't know where she was and she hadn't called. That, in itself, wasn't unusual; she's a resourceful lady and can take care of herself. But, when she didn't come home by midnight, I began to panic. Intellectually I knew she was probably fine. Emotionally, I was terrified. Without her presence in my life, my equanimity about the future would not be possible.

Alzheimer's was supposed to be the worst that could happen to me. Yet, so far, it's been pretty interesting. To tell a weird truth, I've been sometimes almost excited about what's coming. There are fewer and fewer real adventures in our lives. This feels like a real adventure ... even if a happy ending isn't guaranteed.

It's really Marja who will suffer the most. Not only will she have to shoulder the increasing burden of caring for me, but she'll also lose the source of the physical, emotional and spiritual support in our relationship. The greatest pain that I feel from this disease is knowing what awaits her. The only time I get really weepy is when I dwell on that.

What I have found very interesting, however, is that the majority of the comments left on my blog have been from caregivers, and almost all have written about some wonderful experiences during the last stages of the disease. As memory recedes and the person with Alzheimer's lives more and more in the present—because he *has* to—new possibilities for relationship can arise. One woman tells of caring for her mother. Their previous relationship had been very painful. As her mother declined and forgot who she was, however, they found a richness in the present. They laughed together; they danced together; they loved each other ... all in the present.

Even for Marja it won't all be pain.

I still find it bizarre to say, but these last nine months have been among the happiest of my life; I am more open, freer. My experiences are richer. Perhaps it's just the lowering of inhibitions. I actually don't care: My relationships with family have deepened, and I've never felt closer to my community.

Our religious traditions speak of losing one's life to save it, of letting the self go. Usually we're so attached to our self-image that we *can't* let it go. With Alzheimer's the suffering of hanging on is so obvious that I'm pushed into letting go. Trying to maintain control over my life is a losing proposition. I've felt relief at not having to be the smartest guy in the room. I no longer define my belonging to my community as what I *do* for it but how I *am* with them.

Another gift: How often do we (and our religious traditions) urge ourselves to "live in the present"? Alzheimer's pushes me into the present. The only real anguish *now* is when I dwell on the future. Again the choice is so obvious. It's better to live here, to live now. Marja and I have to *plan* for the future, of course, but I'm mostly free of *worry* about it. What a gift!

I've experienced a freedom from shame, that sinking feeling in my gut when I really screw things up. My Alzheimer disease has rather seriously compounded my capacity for screwing things up. In the midst of it, though, I've found myself strangely at peace. I don't much get angry with myself, condemn myself or insist to myself that I "do better." I have permission to remind myself: "Hey, you're cognitively impaired; it's normal to screw up like this." I can move on. There's real power in vulnerability and helplessness that I couldn't understand before; now it's clear. What a gift!

Just to acknowledge the obvious. First, all these wonderful changes have been pure grace. I haven't *created* them as much as accepted them. Second, there's a lot that's been given that I

haven't yet been able to accept; the freedom I'm experiencing, wonderful as it is, is very incomplete. Third, and most importantly, I'm in the very early stages of this disease, experiencing its *gifts* and not much of its *pain*. I'm not Pollyanna. No one knows how much, if any, of this richness will continue as the lights go out! Nevertheless, I'm grateful for the gifts this awful disease gives me now.

Let me finish with a story that may give some sense of the pain and the glory of this disease.

A month ago, Marja and I were at a silent retreat with others from our faith community. Just before evening worship, I was sitting in our chapel looking out the floor-to-ceiling windows when I saw Marja walk down the path through the woods. I was suddenly aware of a deep longing. She radiated an inner light. She walked gracefully—lean and strong—as if she belonged to those woods and that path. She smiled easily at several of our friends. In those few moments, the fullness of her inner beauty was revealed to me in a way I'd never felt in over fifty years of our relationship. In that moment, I felt extraordinarily grateful that we belonged to one another.

But then the future broke in. As I watched her make eye-contact with some of our friends, I felt strangely excluded from those relationships. Suddenly, it was five or ten years down the road, and Marja had relationships with others that I was now *incapable* of sharing or even understanding. I felt immediately jealous: I won't be able offer her what she needs and she'll have to look elsewhere. It was as if she were having an affair. In that moment, I felt painfully jealous of *any other* relationship she would have.

Although muted, both sets of feelings stayed with me as Marja sat across the room during the short worship. Afterwards, I went outside into the dusk, and sat—feeling sorry for myself—on the steps overlooking the meadow and the woods. As Marja came out the door, I caught her eye and she came to sit next to me. In silence, we clasped all four hands together. Feeling our bodies touch, holding one another, I was profoundly comforted and felt safe again.

The jealousy had been “real,” even if the imaginings that prompted it were not. I “know better” than to live in the future like that. But that's where I lived for those moments of jealousy: I was fearful of what the future might bring. Feelings of isolation *are* what I fear the most. And jealousy has the potential to isolate me from the one with whom I share so much, who will be there with me as long as I live.

But the love and beauty were real, too. That evening bordered on the miraculous, on the mysterious.

I am both grateful for the emotional openness this illness has given me ... and still just plain scared.

**** As of Oct 30, 2013, the diagnosis is much less clear. (Click [here](#) .)**