A Theology Out of My Life with Alzheimer Disease **

February 24, 2013

The following is a teaching I presented at our Eighth Day Faith Community. I'd previously made my diagnosis public, so there were very few who were surprised that I chose to preach about it. I felt that I'd been taught enough about Gospel values through my disease that I wanted to share it. We're a small community, so it was an intense morning.

As most of you know, in September, I was diagnosed with progressive cognitive impairment that's almost certainly Alzheimer disease. Living with Alzheimer's has helped me to internalize a lot of theology in these past five months, and I want to share some of that with you this morning. Actually, I can't attest to it really being theology, but Fred has assured me that when we talk about the deepest human issues, we're talking about theology.

As I've described to many of you, I've had symptoms for over two years but didn't recognize them as Alzheimer's until a visit to a neurologist in September. Since then there's been a slow but noticeable decline in my ability to remember and to think clearly. If you talk with me much and pay attention you'll notice my memory loss and my trouble finding the right words; I've made enough mistakes as treasurer in the past few months to ask Kate Lasso to take over the books within the next several weeks; and I've had a few episodes of confusion.

Assuming it's Alzheimer's--and there's no reason to think it isn't--I can expect ongoing mental deterioration: Loss of reasoning ability, trouble with judgment, memory loss so extreme I won't recognize even Marja, and, eventually, inability to care for myself. About 75% of people with Alzheimer's ultimately require institutional care.

It's not a pretty picture; it's the ending to my life that I most feared. I've myself never been able to relate well to folks with cognitive deficits, so I feared increasing isolation. I was afraid of my family becoming strangers to me. The likelihood that my grandchildren will remember me primarily as a doddering old man sickens me.

But that's not the entire story. Paradoxically--miraculously, really--these last five months have been almost the happiest time in my life. Relationships with friends and family have become more intimate; relationships with others have bloomed. I've received enormous support from my family, this community, and other friends, some of whom I haven't seen in thirty years. It's been exciting and joy-filled.

For this teaching, I want to share some of the theology that underlies this contentment and happiness of the past few months. Much of it I've known intellectually for years, but as my mind begins to go, it seems to me that these fundamental truths are rooting themselves in much deeper parts of me. I'm afraid that they may sound like a bunch of platitudes when I put them into words, but they've become especially rich for me since last September. So try to hear with new ears.

Jesus said that she who saves her life will lose it; he who loses his life will gain it. One of the things that this has come to mean for me is that hanging on to a particular sense of self causes suffering. Until perhaps ten years ago, for instance, a big part of my self-image was as an athlete. But as I got older and had to give up running and then cross-country skiing, it was painful, not so much because I was losing things I enjoyed (although that was true, too) but because I could no longer live up to the image of my "self." I felt as if I were losing my "self." If you're going to get older, being attached to an athletic self image is no recipe for contentment. Another part of my self-image is as an intellectual, but--if one has Alzheimer disease--clinging to *that* self is also a recipe for suffering. It's similar to the Buddhist idea of non-self: What we think of as the "self" is constantly changing; there is no single "self" that persists throughout life. Clinging to our image of self leads to suffering. Embracing the changes leads toward enlightenment.

And in my disease, I've somehow been given the possibility of letting my "self" go. Now, since I still have much of my intellect intact, I can't be certain yet, but I don't think I'm hanging on to that declining intellect as much as I might. This has been pure gift; I haven't *done* it. I have no idea how I got here, but I can vouch for the freedom that letting go of our self image makes possible. Letting go of self, even a little bit, is a great blessing.

And it feels like other things have let go of me without my doing much.

Even thinking about future kinds of control that I'll lose (having to let Marja make my important decisions, for instance) doesn't seem to bother me. Perhaps it'll be completely different when

the time comes, but it seems that now is the season of my life to give those things up, to live in a very different space that *allows* more to happen rather than requires me to *make* it happen. It's actually great not to be in charge of so much, a wonderful freedom.

It also seems that I've been more able to experience the love and support of this community as a gift rather than as something I need to earn. I've seen myself as one who does a lot of tasks for the community: being on the leadership team, keeping the books, maintaining the website, printing the name tags and orders of worship, teaching, mentoring young people and so on. Since I'm an introvert who usually feels awkward taking part in other aspects of community life--like potlucks or parties--this way of anchoring myself had felt important because I felt that it was all those *tasks* that connected me to the church. But that easily led to the feeling that my belonging here *required* performing those responsibilities. Already, I'm giving up the bookkeeping; gradually the other tasks will go, too; yet, I still feel more than ever a deep belonging to this community. I get the love and support without having to earn it, so it doesn't feel soscary to let the bookkeeping and other jobs go. I'm much more connected to the spirit of this community.

Another gift: How often do we urge ourselves to "live in the present"? It's something that most of us aspire to. It's a primary focus of prayer and meditation, the purpose of chants and other music and art. "The past is past," we say. "The future hasn't happened yet; the only place we're actually alive is in the here and now." We *say* all that. But most of us--at least I—have found it almost impossible to internalize it and live it out.

But Alzheimer's has taught me a lot. Almost all of the suffering that I've so far experienced in this illness lies completely in the future. The only real anguish now is when I dwell on that future. So, it's not the future that's causing me suffering; it's my image of the future. Thinking too much about it creates the misery; living more in the present alleviates it.

Certainly much of the good news of Jesus has to do with living in the present. Most of us recognize that truth, too, and--to one degree or another--we try to embody it, but in our culture it's very difficult. It feels almost irresponsible.

But I “get it” now, not only intellectually but also emotionally and spiritually. It's not been a "figuring it out." It's not perfect, of course, but it's been a gift that's been given.

I suspect that my diagnosis affects some other people similarly. Once we've had the initial discussion about my prognosis with Alzheimer's, there's not much point in dwelling on my long-term future (although I don't want to discourage anyone from asking questions. We don't know exactly how it's going to go, anyway. And my past takes on a very different hue in the light of the disease. We all become more cognizant, I think, of the shortness of our lives. So we can all stay much more present to each other.

Marja and I have to *plan* for the future, of course, but I really have been mostly free of worry about it. I'm grateful for the gift.

Another surprising freedom has been from shame and humiliation. (You know that sinking feeling in your gut when you really screw things up?) All of us make mistakes, screw things up, and create problems for ourselves and others. My Alzheimer disease has rather seriously compounded *that* issue. In the midst of it, though, I've found myself strangely at peace. I'm not happy with mistakes, of course, but I don't get angry with myself, condemn myself or insist to myself that I "do better." The Alzheimer's gives me the permission to say: "I've got this cognitive impairment so I'm *gonna* to be screwing up like this." The disability of the disease allows me to judge myself less harshly.

I've always believed that human beings are doing the best they can. Most people seem to disagree with me on this, but--at least in conversations with me--their arguments always refer to themselves as not doing their best. Especially when we know another person's history and circumstances, we can often see that, within his limitations, he's doing the best he can. But we can't believe it about ourselves. Somehow we think that if we don't transcend our own limitations, we're not "doing the best we can." If only we worked harder, we could do better.

With my Alzheimer's, my limitations are becoming more and more obvious, especially to myself, so it's actually easier not to judge myself. But is the situation really any different from before this disease? Back then I was doing the best I could, too. If I screwed up, either it was due to one of my physical, mental or spiritual limitations (just as it is now) or it was just one of those things that happen to everyone. Mistakes do happen! Was there any reason to judge myself or to feel ashamed or humiliated? Now, guilt--which is knowing that I've made a mistake or done something wrong--may be appropriate, but it's completely different from shame--which is believing that *I'm* the mistake or that it's my *self* that's wrong. It is possible to recognize our guilt without succumbing to shame.

One of the things I was afraid of with Alzheimer's was the humiliation that I would feel before others when I made a blunder in a conversation or didn't recognize someone I should have known. What do you say to a person, after all, who's just asked you exactly the same questions three times within ten minutes? But when the blunders have actually happened within this community—a serious my bookkeeping mistake, for instance--I've been given a great deal of acceptance … and love, actually. The mistake is noted, the Alzheimer's is acknowledged, if only with body language, and we move on to how to handle the aftermath. As my disease gets worse, I may not be able to hang on to this gift, but, so far, it's allowed me to accept the forgiveness and grace that's offered in the Gospel.

A couple of weeks ago, I spent a morning with Gordon. He talked several times about passages in the letters of Paul that refer to our strength being in our weakness. Gordon said he'd not really understood that within himself before this time of his dying. He mentioned the importance of vulnerability. I'm sure I don't know all of what Gordon meant, but I think my Alzheimer's has allowed me to experience something like it.

Actually, this isn't the first time I've experienced the power of vulnerability and helplessness. Writing in my first book about a terrible medical mistake made me vulnerable to the possible criticism and scorn of other doctors. Writing about that mistake and exposing myself, however, was one of the most important things I did as a physician; it broke a taboo and began an important conversation within medicine. Later, I wrote and spoke publicly about my depression, which again made me vulnerable, yet twenty years later I still get comments on that article. People have told me that it changed their lives.

And even after this short time, revealing my Alzheimer's diagnosis has given me an inner strength that's been wonderful. Apparently, I don't need to be the brightest bulb in the room; my weakness is enough. It's given me a powerful sense of connection with this community and bonded me deeply to you. As bizarre as it seems, it's been *through this disease* that I've become more connected to others.

Finally, what God's vision is for me now seems clear. I'm to be a voice of this illness in the present moment. To communicate it to the world. To stay in touch with my reality and share it with others. To invite people into less fear and embarrassment around this illness.

It's a very clear call.

I feel freer. Perhaps that's the easiest way to describe the impact of my disease. I've always known intellectually that I had the support of family, a few good friends, and my community. But much of my life I've felt, well, lonely. In binding me closer to my family, to those friends and to this community, this illness has alleviated much of that loneliness. I don't need to keep fighting.

I shouldn't be surprised, I guess. This freedom is promised by the gospel.

And I'm very grateful.

Amen

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