# **Blog Posts from June 2013**

Monday, June 3, 2013

Washington DC

# Why Not Try This (2)

Ever since writing Why Not Try This (1), I've remained curious about why I refuse to try alternative treatments, so this post is a supplement to that one. With this somewhat abstract essay, I don't expect to convince anybody else, but I do want to understand myself.

I'm a doctor. I'm not naïve about the many problems in medicine and medical research,\* but ultimately I trust them. If there were an effective treatment for Alzheimer's, I believe researchers would already be studying it and neurologists would be using it. What ambitious young researcher wouldn't want to win the Nobel Prize for discovering a cure for Alzheimer's?

I know well that pharmaceutical companies refuse to fund research from which they can't profit. It's also true that the decades of cutting federal funding for medical research has made independent studies more difficult. Nevertheless, the government and some independent groups (eg, the <a href="Alzheimer&rsquo;s Disease Cooperative Study">Alzheimer&rsquo;s Disease Cooperative Study</a>) still fund research into treatments with no profit potential, for instance, studies

of Vitamin E, Vitamin C, generic ibuprofen and several others have found no evidence of improvement and even some suggestion of harm to people with Alzheimer's.

Scientific method

In order to make sure it's the treatment that's responsible for any improvement, the scientific method requires studies that are:

- Placebo-controlled: Somebody gets the drug and the others get sugar water to make

sure it's the treatment that's improving things and not just the subjects' desire for it to work.

- Randomized: Subjects are placed randomly into a treatment group and a placebo group to make sure the two groups are starting from the same place.
- Double-blind: To limit bias, neither patient nor researcher knows who's in what group or what the test results look like until after the study is completely done and reported.
- Large enough so that they're statistically valid. A couple of anecdotes don't prove anything.

If a treatment doesn't prove effective in such studies, I'm not going to waste my time with it.

What's Wrong With an Anecdote?

So why would a treatment that has been effective for a number of people not pass scientific tests?

- The diagnosis may have been wrong in the first place, so a cure doesn't imply anything about the impact on Alzheimer's. The husband of a friend became quite suddenly demented; he was helpless to care for himself and stayed that way for weeks. With no real treatment, he returned to normal over several months. Nobody knows what he had or why he's better.
- People with incurable diseases *want* to believe that a treatment will work. The power of such faith can be staggering. Improvement (or the belief in improvement) may have nothing to do with the actual treatment.
- We know that the symptoms of Alzheimer's can vary considerably from day-to-day or week-to-week. If a treatment coincides with one of those upswings, people may credit the treatment.
- Something else could be causing the improvement. We already have drugs that improve the *symptoms* of the disease but don't affect the underlying course. Alternative treatments may also improve symptoms without affecting the disease process itself.

Why Not Try This?

All right, say my friends, why not try something anyway? How can it hurt? Well, any choice

has side-effects.

- Many alternative treatments take significant time away from family, work, and life.
- Some of the drugs and other treatments are expensive.
- Other treatments have potential side effects: coconut oil, for instance, has high levels of saturated fat which may lead to heart attacks and stroke.
- Chasing after rainbows can become an obsession (for instance, my patient with MS in Why Not Try This (1)
- Especially since I'm a physician and a blogger on Alzheimer's, my using a treatment just reinforces the unwarranted belief that there are cures out there.

I've always tried to avoid actions that don't make sense to me. To try a treatment because "it can't hurt" would be for me a form of denial. Perhaps that's just pride; maybe so.

To be clear, I don't want to deter anyone else from pursuing a treatment that gives them hope or comfort. I'm just writing to explain my rationale for refusing to consider the many treatments continually suggested to me.

\* For a devastating critique of medical research, read " <u>Lies, Damned Lies, and Medical Science</u> " by doctor, researcher, and statistician, John Ioannidis.

Thursday, June 6, 2013

On Amtrak to Napa CA

# Variability (1): We're Not All the Same

The silence and taboo that surround Alzheimer's prevent our understanding that its symptoms can vary enormously from person-to-person and even from hour-to-hour within the same person. This ignorance can lead to frustration, depression, isolation, and confusion on all sides.

I, for instance, am quite early in the disease. Since my cognitive impairment doesn't yet interfere with my daily life, I don't even qualify for the formal diagnosis of Alzheimer's (although there's virtually no doubt that that's where I'm headed). Sometimes I have no obvious symptoms at all. Most of the time, you probably wouldn't recognize my impairment. Sometimes, however, I get pretty confused. A few days ago, I came home from an hour's exercise on my bike. I was wearing my beltpack and a nylon backpack that is so light I can forget it's there. I had put my keys into my beltpack, but as I stood at the front door, trying clumsily to get my bike inside, I couldn't find the keys. I searched through the four compartments of the beltpack repeatedly. Repeatedly. I kept going over and over it—it may have been a full five minutes—because they just had to be there. Finally I remembered the backpack. I reached back, felt the keys through the nylon, and only then could I vaguely remember putting them there. I started to take the backpack off. The next thing I knew, I was looking through my beltpack again. Again, I perseverated with the beltpack for what felt like five minutes, then thought (as if it were a new idea) about the backpack, and only then did I realize that it was hanging on my shoulder with the keys in it. I had completely forgotten what I was doing halfway through taking the backpack off and had started looking for the keys from the beginning again. Now, that's pretty confused.

I've had a few other periods of confusion. Three years ago an <u>entire day disappeared</u> from my memory. Last September I

### got lost

riding my bike through a very familiar area and there have been two other similar episodes. When I'm writing or am otherwise at the computer, I have difficulty holding several things in my mind at the same time and can get confused.

But most of the time, I'm not impaired except for my memory. Sometimes even my memory kicks in. Talking with a friend the other day about an event several years ago, I was able to remember the name of the person involved, even though that had been the only time I'd met him. "Your memory is lots better than mine," said my friend.

Alzheimer's symptoms also vary greatly from one person to the next. For me, the affliction is primarily in the area of medium term memory loss and loss of the ability to calculate and occasional confusion; it's not (yet, anyway) in the area of intellect, personal relationships, reading, and so on. For other people with Alzheimer's, personality changes may dominate: outbursts of rage or paranoia, hypersexuality or accusations of infidelity while they can still function in most other areas of daily living.

Other people have so much trouble with word-finding that they seem almost unable to speak, yet their intellect remains intact and they crave good conversation. For still others it's getting lost easily.

This variability doesn't fit into Alzheimer's public image, which is of advanced disease, so other people's reactions can be difficult to deal with. I'll explore some of those reactions in the next post.

Monday, June 10, 2013

Napa, CA

## Variability (2)

In the <u>previous post</u>, I described how my symptoms come and go and how symptoms—especially in the earlier stages—can vary greatly from person to person. This variability can be confusing to others.

The Public Image

The public image of Alzheimer's disease is the blank face of the old person, unable to recognize her family, wandering away from the nursing home, slumping in a wheelchair drooling, or lying like a vegetable in a nursing home bed while medical people try to prolong her life indefinitely. That public image doesn't include the person like myself who has only mild cognitive impairment or the person with significant symptoms who is able to hide his impairment well. And it doesn't include people who have profound difficulties in one area but are only mildly affected in others.

The result is a series of misunderstandings. On the one hand, other people tend to doubt the diagnosis of a person with only mild symptoms that aren't really noticeable. On the other hand, people tend to treat those with noticeable symptoms as if they were more profoundly impaired than they actually are. The public image has no middle ground, no place for the wide expanse of impairment within which the person with Alzheimer's may live.

## Mild Cognitive Impairment

To take an example, my Alzheimer's can so far be recognized only by a careful observer, yet, as I wrote in <a href="Variability">Variability (1)</a>, I am myself aware of intermittent confusion and difficulty word-finding. Many others who have written me in response to this blog have had a similar situations. If we mention our symptoms to other people, they frequently discount them, ascribing them to other things: to normal old age or inappropriate concern about old age, to normal forgetfulness ("I know just what you mean; I have the same thing"), to anxiety or depression. Sometimes, they will acknowledge the changes are abnormal but be reluctant to accept the diagnosis: It's "just one of those weird things that can happen to anyone." When I described my

# \$24,000 bookkeeping error

, my friend replied that that wasn't so bad, suggesting that it may have been just poor concentration or sloppiness in my work.

These responses are well-intentioned. People want to be empathetic and comforting, to assuage our fears, and to include us in their circle. The issues of  $\frac{\text{embarrassment}}{\text{embarrassment}}$  ( $\frac{2}{2}$ ) ( $\frac{3}{2}$ ) and

#### fear

that are associated with the disease also play a role, of course, but the reality is that we don't

fit the image most others have of Alzheimer's. It's hard to blame them for misunderstanding.

The conclusion a person with mild impairment may come to, however, is that others won't really listen to his confusion and pain over what's happening to him. How can this be happening to me? What do these symptoms mean? How fast is this going to progress? If my friends and family have trouble believing that I have Alzheimer's, where is the place for my pain? We become needlessly isolated ... our worst fear.

More Severe Symptoms

The other side of the problem caused by the public image is that the extent of a person's disease can be overestimated. He may get lost repeatedly, or forget familiar names, or become otherwise confused yet retain a normal sense of self and capacity for relationship. Others may

nevertheless treat him as if he were far more demented than he actually is and, often, avoid him, afraid they would be unable to relate to him.

In *Speaking Our Mind*, Lisa Snyder tells of a man whose impairment was an extreme difficulty finding words. He was almost incapable of responding verbally. It was easy to interpret his inability to respond as proof of advanced disease and believe that real communication was impossible. Yet the man was still hungry for intellectual interaction, in which he *was* 

able to participate in as long as Snyder was patient enough to let him find the words on his own time.

Another example: Unless you knew that personality changes could be a primary symptom of the disease, it would be easy to assume that, say, the very paranoid person in the nursing home is just out of it. And if that person's mind were actually fairly clear yet she's been treated as completely demented, she would then have good reason to be paranoid.

As Lee Ann Gerleman <u>reminds us</u>, the *person* is still in there, often aware of much more than we think she is, hungry for love and attention. She may have forgotten that the little girl who comes to visit is her granddaughter, but she loves that little girl who visits and laughs with her, anyway.

But too often we treat them as children, speaking overly slowly or very loudly or, worse, just ignoring them and talking only to the caregiver.

## General Misunderstanding

The faulty public image of the disease, then, can lead to frustration not only for mildly impaired people who are treated as if everything is okay but also for people who are only moderately impaired and treated as out of it. Either can lead to frustration, depression, isolation, and confusion. It's important we lift the taboo and get the disease out of the closet, so that all of us can understand better what's going on. It could at least mitigate the isolation that is such a painful part of Alzheimer's disease.

Thursday, June 13, 2013

Napa CA

I'm spending a week in Napa with my daughter Laurel and her family. Last evening I helped Laurel put together fifteen 100-page training manuals for her work. The job was fairly simple: punch three holes in each of the pages, insert tabbed dividers between the pages to create ten different labeled sections, and put them all into a three-ring folder.

As I worked, I found myself increasingly confused, forgetting where I was in the process, combining two sections without a divider, or removing a section divider from one manual and inserting it into the other, duplicate. Then once I would notice the mistake, it took me forever to figure out what I'd done and correct it. But eventually I could figure it out.

I'm used to this level of impairment by now, so it wasn't terribly frustrating. Nevertheless, I was grateful for Laurel's response: She noticed my confusion and said something about the task being more difficult than she'd expected. She wasn't pretending my confusion was completely normal ("the old I-know-just-what-you-mean-that's-happening-to-me-too trick"), yet she was comforting me by acknowledging that I didn't have to be completely demented to be having some trouble. I was happy that we'd developed a comfort with acknowledging my cognitive impairment.

I'm reading Lisa Snyder's <u>Speaking Our Minds</u>, a series of fascinating interviews with people at various levels cognitive impairment. Commenting on one interview, she writes, "[The person with Alzheimer's would not be made to feel inferior by Alzheimer's." My emotional reaction, of course, was to make it all about me: "Who are you kidding? Of course, I'm going to feel inferior: my mind is going while everyone else's is not." But a little reflection changed my mind. Obviously, my skills and abilities will become inferior to other people's, but that doesn't have to make me feel inferior as a person.

I used to be a competitive cross-country ski racer. Now, due to a numbness in my feet (unrelated to Alzheimer's), I can hardly stand on skis. I'm clearly an inferior ski racer, yet, given my condition, no one would think it reflected on my inherent worth as a person. The same would be true for cancer or almost any other non-mental chronic disease.

But it's different with Alzheimer's or any other cognitive impairment (just ask any mentally retarded person). There's a temptation to see cognitively impaired people as less worthwhile, to feel comfortable avoiding or ignoring them.

So far, I'm actually feeling better about my worth than before my disease. I have the best of both worlds: My symptoms are hardly noticeable to others, yet I get lots of credit from other people who think I'm handling it so well emotionally.

Will that change as I lose my capacity to drive and, thus, my independence; as I lose my capacity to speak cogently about my illness; as I can't really take part in the normal life of the community?

Probably ... at least to some degree. On the one hand, so much of my image of myself has been wrapped up in my sense of intellectual superiority. What will happen to my image as that disappears?

On the other hand, I have a solid confidence in my self-worth. I have a brain disease, and intellectual loss is simply what happens. It doesn't reflect on self-worth any more than my incapacity as a cross-country skier. Will that be one of the things I can remember that as the lights go out?

And, if I can't remember my self-worth, won't my increased ability to express love and affection (that's been generated by this disease) buoyed by the love and support of my family and community sustain it? No one, of course, can predict much in this unpredictable disease, but I have some confidence that they will ameliorate my sense of inferiority. It's one of those things I'm curious about.

Friday, June 21, 2013

Kansas City, MO

# Do I Really Want To Know?

I was visiting Elsie, a friend with moderate dementia, the other day. I was curious to know whether she had Alzheimer's and, if so, how she was dealing with it. Elsie had been very important in my life for almost twenty years before I moved to a different faith community about ten years ago, and I hadn't seen her in while. I'd heard reports that she'd become forgetful; she things she'd said a few minutes ago; she sometimes didn't recognize people who should have been familiar to her. She remembered me because our relationship went back thirty years. (Alzheimer's affects short-term memory much more than it doesn't long-term memory.)

Elsie greeted me warmly. She'd always been an energetic, gracious and humble presence, and that hadn't changed at all. It was almost as if we were continuing our relationship from where we left off so many years ago. Elsie is certainly not in denial about her memory loss; she refers to it easily, with good humor and without self-pity. In the context of talking about her memory troubles, I told her that I had some memory problems, too, and that I had a diagnosis of Alzheimer's. (I have to admit I was trying to manipulate her a little to see if she'd mention "Alzheimer's" in reference to herself.) Perhaps Elsie knew what I was getting at, for she interrupted me and said, "Oh, I don't think it's that important to know the diagnosis, do you?" (For Elsie the "do you?" at the end of a sentence is not so much a question as a restatement of her belief.)

What an interesting response! Elsie has no trouble acknowledging her impairment, but doesn't want her diagnosis pinned down. Does she suspect it's Alzheimer's and doesn't want to think about the implications? Does she want to avoid a label that would spread through the community and stereotype her? I interpreted her rhetorical "Do you?" as a desire not to continue that discussion, at least not then.

That conversation came back to mind this afternoon. I'm in Kansas City and gave a talk at a medical conference about my Alzheimer's. After the conference wrapped up, I met with Ron, a friend from Minnesota I hadn't seen in thirty years. We spent a couple of hours reminiscing and talking theology. As he dropped me off at the hotel, Ron mentioned that he, too, had been bothered by his increasing forgetfulness and wonders whether he ought to get it checked out.

He was implicitly asking the question Elsie didn't want to ask: Was there any reason to get tested to find out if he had Alzheimer's?

My response is equivocal. The one reason that argues strongly for getting checked out is that only 80% of people with dementia have Alzheimer's. A primary purpose of an early neurological exam is to rule out the causes of the other 20%, some of which are treatable. Parkinson's disease, for instance, is at least partially treatable. Small strokes can also mimic Alzheimer's, and in that case aggressive treatment of cardiovascular disease might prevent progression.

Personally, I wanted to know right away. My impairment—not only in memory but also in computation and some degree of confusion—had become obvious to me. If there was an explanation, I wanted to pin it down rather than fantasize or worry that I was going nuts.

Other reasons for early testing I've thought of—the need to do long-term planning, wanting to know before others begin to wonder what's going on, wanting to make sure I'm not a danger to self or others—seem less important to me than they originally did.

I was aware of my symptoms <u>well</u> before anyone else noticed. And I doubt I'm unique. It seems to me that anyone who is interested and open to knowing about Alzheimer's and who is paying attention to his cognitive state is going to notice symptoms very early. Ron's already worried about his memory. If other symptoms develop, he'll undoubtedly notice early and get tested.

At one point, I thought an early diagnosis was important to making future plans. Financial decisions for <u>Medicaid</u>, for instance, must be made five years before application. One should certainly not wait too long before making plans, but I've been having symptoms for over three years, and it seems there will still be plenty of time before I need nursing home care.

I was also originally concerned because I wanted an early diagnosis that I could share with friends before my symptoms became noticeable, before they were reduced to whispering behind my back. I wanted to be able to ask a professional (my neurologist) help determine whether I could safely drive. But it's now pretty clear that I've been aware of symptoms *long* before others noticed and that

#### my concern

about my own ability to drive is higher than the state's or the insurance companies'.

Elsie is almost ninety. She's well aware of her impairment. I agree with her that there's no

reason she needs to use the A-word.

Ron's only symptoms are memory problems. If they are due to Alzheimer's, he'd be very early in the disease and there would be little objective reason to get tested while his symptoms remain limited. It would be a while before others noticed or he became a danger to anyone. In my own case, I just wanted to know what was going on. Ron's enough like me that he'll probably have an early evaluation, too. But if another person wasn't particularly interested, I'd certainly not push her to be evaluated until symptoms became far more obvious than Ron's.

Monday, June 24, 2013

Washington DC

# **Fellow Traveler**

I've just returned from visiting my daughter and her family in Napa, CA. On the train trip there, I met Kalju (pronounced "Kal-you"), a seventy-nine-year-old immigrant from Estonia who regaled me with stories of his past.

Kalju was seventeen when, early in World War II, the Soviet army occupied Estonia. He was about to be shipped off to Siberia when his Soviet employer notified authorities that he'd been servicing army trucks and was therefore vital to the war effort. Shortly after, when the Germans drove the Soviets out and occupied Estonia, Kalju was sent to a work camp in southern Germany. After the war, he immigrated to Winnipeg, Manitoba, where he worked as a laborer. He was transferred for a while to Churchill in the far north on Hudson Bay. He worked his way through high school until he immigrated to Chicago, where he was educated as a social worker and ultimately worked with African-American children in a Chicago ghetto for twenty years. During the 1968 riots, young African American men rolled his car over 1½ times and left him upside down in the car; on another occasion he was almost hammered to death until others intervened.

He was accompanied on the train by Judy, a 46-year-old author, and her daughter. Judy had known Kalju for decades and recently decided to write his biography. They've become close friends. Judy and her daughter accompany him in his frequent travels, in part because they

enjoy his company, in part because he needs their help.

I had talked with Kalju for an hour before I recognized his dementia. We'd been on the train for over 24 hours, yet he asked Judy for the directions to the bathroom, which was on the first level of the same car. A few minutes afterwards, he came back to ask directions again.

I later talked with Judy. Kalju's symptoms, she said, can be pronounced but are extremely variable. He recognizes his poor memory and his reliance on Judy and her daughter for orientation, yet he denies any general cognitive impairment. When I mentioned my Alzheimer's to him, he said he was glad he didn't have anything like that: His head simply had too much information, and there wasn't room for anything new.

Shortly after meeting Kalju and deciding to write his biography, Judy realized that, while he told wonderful stories, he repeated them frequently. She's now heard each of his few stories many times and realized she can't write an autobiography with so little material.

Kalju can be quite disoriented indoors, she tells me. In a hotel room, for instance, Kalju has to ask every day where the bathroom is. Outdoors, however, he can go for long walks, even in unfamiliar environments, and never get lost. Judy has witnessed personality changes too, like when Kalju explodes in anger for no apparent reason. Often he apologizes but may later deny that the incident happened.

His judgment is sometimes impaired. They were once on a city bus riding through a poor, inner-city ghetto. Although the bus was full of African Americans, Kalju began talking loudly about the two times in Chicago he'd been attacked by young black men.

She has also noticed that, in the moment, he'll recognize his poor memory, his disorientation and his need for assistance, but, when the moment is past, he doesn't seem to remember these episodes of confusion, adamantly denying any impairment.

As I discovered when I engaged him in conversations, his impairment is not immediately evident and he can be quite lucid: I might never have realized he had dementia had I not

witnessed his repeated asking for directions to the same place. He doesn't fit into the stereotype of Alzheimer's. He is able to maintain good relationships. He can go on long walks outdoors without getting lost or disoriented. His life appears full.

He helped me to see that life with Alzheimer's – even when symptoms are becoming more evident – does not have to lead to early isolation. It's comforting.

Thursday, June 27, 2013

Washington DC

## **Decline**

I originally started writing today to review how slowly the symptoms of my Alzheimer's have progressed and what that's meant for me. But after reviewing where I thought I was, I decided to take an Internet IQ test to get another perspective.

In my review, it was clear that some of my symptoms haven't progressed at all since my diagnosis

last September. I haven't

gotten lost

again. I actually notice improvements in my relationships. I'm still losing lots of things, but it's not much worse than before. My

lecture in Kansas City

last week went well.

Some things have gotten worse. The confusion and blank-out during the <a href="keys-at-the-front-d">keys-at-the-front-d</a>
oor
incident were

new. I'm less able to do arithmetic in my head, reconcile the checkbook or handle complicated data

Yes, there are some changes, but not as many as I expected by now.

But then I took that Internet IQ test. Surprised by the results, I took another, just to check.

(Now, before anybody comments on how unreliable Internet IQ tests are, I know, I know. But I'm not looking for a precise score, and I don't need the test to be as comprehensive as a more sophisticated exam. And although the items in each of the two tests were quite dissimilar, statistically the results were the same in each test.)

What was more revealing to me than the final numbers, actually, was my difficulty in completing some of the tasks in the tests. I've always been good at the kinds of abstract tasks that were on the tests. This time, however, I was astonished at what I could no longer do.

I wasn't surprised, of course, that my memory was shot.

But I was surprised at my limited ability to recognize the logic in the progression of patterns. This is a task I've always been good at. As an example, there will be 3 different patterns in each of three rows. The first row might have 1 *circle* in the first box, 2 circles in the second box and 3 in the third. The next row has one square

in the first box, 2 squares in the second and 3 squares in the third. The third row has 1 *triangle* 

in the first box, 2 triangles in the second and the task is to pick from a group of ten choices what comes next, in this case 3 triangles. The patterns become progressively more difficult, of course, but—very early on—I just couldn't recognize them. Wow! I thought, that's a big change.

I had a similar problem with a task in which I was instructed to pick out which of the ten digits was *missing* from a row of the other nine digits and to pick out from a second row of letters, which letter was *repeated*. Those should be easy, quick tasks, but I was slow ... really slow.

My IQ used to be something over 140, not "genius" but "superior." But I was shocked that, according to the two Internet tests, it's now slid to about 100, normal. While there's something to be said for finally being normal, sliding from the 99<sup>th</sup> percentile to the 50<sup>th</sup> a big drop. This

formal testing makes it clear that I'm more cognitively impaired than I thought

As has been usual during this whole illness, however, I feel a strange equanimity. What did I expect? To get smarter? For whatever reason, the decline just doesn't bother me. What's more curious to me, however, is that I don't notice any change in my <a href="experience of my self">experience of my self</a>. Surely that experience changes at some point in this disease. But it hasn't yet.

More on that in the next post.

Sunday, June 30, 2013

Washington DC

### Self

Many caregivers have commented in this blog or in personal emails that—even in quite severely demented people—the essential "person" seems to remain. Lee Ann Gerleman writes that the people she cares for are <u>still in there</u>, even though we only get a glimpse of them from time to time.

What it's like for them? Who is that person behind the mask of severe dementia? How do they experience themselves?

In the novel <u>Still Alice</u>, Alice Howland, a 50-year-old internationally-known college professor, tells (from her own point of view) the story of her journey into dementia. As she loses more and more of her memory, there is no sense that she experiences herself differently. Eventually, her husband becomes the "kind stranger" who walks her home and her daughter becomes "the woman in the red dress." It's a powerful story ... and believable, but the question remains: What is her experience of her self as memory fades?

As I described in my last post, I've lost more of my ability to think than I'd previously thought,

but I don't, as yet, experience my "self" any differently. Self is tricky to define, but, to be academic for a moment, the dictionary takes a crack at it, defining self as my essential being

- . It's completely subjective; only I can know my essential being. Cognition, on the other hand, includes knowing, remembering, judging, and problem solving. My self is what I am
- ; cognition is my abilities, which can be roughly measured objectively.

It's the sense of who I am that hasn't changed. It's as if my self looks out at all the cognitive limitations from behind a curtain, is aware of them, but doesn't have any sense that this "I" behind the curtain has changed. Here in the present moment, I seem no different than I ever was.

True, I am early in the disease, but since I've already lost so much cognitive ability, you'd think that I'd already be experiencing myself as at least somewhat changed. Will my essential being seem any different when I can't remember Marja's name? Who will this "I" be then? And if my self is going to be different, will that change be abrupt or gradual?

I thought about it again this afternoon as I walked with a friend I'd known for thirty years. Although we hadn't been close, she seemed to know me (probably because I come from her more distant past). Four times within a few minutes she asked me how old I was. Each time I answered, 68, she stared at me with a twinkle in her eye and said, "You look so young." Clearly she was still there but it also seems to me that she experienced herself as she always had.

I suspect that much of the cultural fear of Alzheimer's is that we'll lose our selves. But what if we won't? What if the I persists beyond memory and mental capacity? Wouldn't that be interesting! Would it decrease our fear? What might it reveal about the nature of human consciousness?

July 2013 Posts

Jump to my blog