

Blog Posts from May 2013

Tuesday, May 2, 2013

Washington DC

Embarrassment (1)

Rachel, who reads this blog regularly, recently emailed me about her father, a retired physician with “vascular dementia” ie, caused by small strokes. When her father first started having symptoms, Rachel and her mother refused to accept a doctor’s diagnosis and, until her father’s symptoms worsened a year later, never mentioned the word “dementia,” even though her father seemed to have significant insight into his intellectual limitations and got on with his life within those limitations. He’s now in a nursing home, confined to bed, and can’t walk or feed himself although Rachel still enjoys her visits. “Some days I might be his daughter, other days I might be ‘a girlfriend’ or just someone he knows. I get rewarded by this and his humor which helps my heavy heart.” But Rachel wonders why his many friends from his life before dementia have stopped visiting him.

Rachel’s mother developed symptoms about a year later, apparently from Alzheimer’s. Unlike her father, Rachel’s mother is still in “cover-up mode,” not yet acknowledging her diagnosis, hiding her symptoms skillfully from other people. She and Rachel collude with one another, ignoring the impact of the silence on their relationship.

Rachel met one of her mother’s friends in the store who asked, “What’s wrong with your mum? Has she been given a diagnosis?” Rachel was unable to tell her mother’s friend the truth. In fact, she covered up for her mother, making the usual excuses, because, she said to herself, she didn’t want her mother’s friend to stop visiting! The questions make clear, of course, that the friend already knew: There *was* something wrong and it was some form of dementia. The secret, however, though hidden in plain view, had to be kept secret. The friend knows yet has to pretend she doesn’t. Rachel herself feels the embarrassment to the point of shame. My own guess is that the friend would visit

more

often if things were out in the open.

The common theme throughout Rachel's experience is embarrassment and shame. In retrospect, Rachel can see the shame first descending when she and her mother refused to acknowledge her father's dementia—despite its obviousness to both of them, despite even her father's acceptance of his symptoms. When her mother began having symptoms, mother and daughter again continued the denial.

Shame and embarrassment hover like clouds over dementia, especially Alzheimer's. When Rachel did finally begin talking about her father's dementia, in fact, she noticed how much more comfortable it was to talk about her father's "vascular dementia" than "Alzheimer's." Rachel acknowledges that most of her mother's friends know that she "has lost it" (as they like to say), however not one of those friends has mentioned the word "dementia" to her. The word "Alzheimer's" is still not mentioned around their home. There's an overpowering taboo: We all know what's going on, but we don't want to acknowledge it or face it.

Why do her father's friends stay away? My guess is that they're afraid they won't know what to do in the presence of dementia, that they'll be embarrassed by Rachel's father's condition. What do you say, after all, when your old friend doesn't remember you or repeats himself every five minutes, or does something else embarrassing. (I certainly had those fears before my diagnosis and to some extent I still do.) We believe we'll feel uncomfortable, so we stay away, leaving our friend suffering not only from limited cognitive function but also from isolation and perhaps increasing shame, too.

I recently listened to a brief podcast in which several experts were asked to respond to the question of why people fear Alzheimer's so much. None of them mentioned embarrassment or shame as important factors, which seems astonishing to me! Isolation may be the worst part of the diagnosis, and shame and embarrassment are the primary causes of isolation. If we don't recognize the embarrassment, much less acknowledge it, we can't confront it and work it through. Through writing this blog and reading the comments and emails, I'm beginning to think that embarrassment and shame are among the worst parts of this disease.

There are over five million Americans with Alzheimer's, more if you include other forms of dementia. By the time we reach 85, half of us will have Alzheimer's. This is a common disease that almost everyone has some direct contact with, yet it's somehow become shameful. It's all around us, yet it remains hidden in the closet, causing so much isolation and fear. It's past time we got it out of the closet and into the light.

Monday, May 6, 2013

Washington DC

Embarrassment (2)

In my last post I wrote about the general embarrassment that surrounds Alzheimer's. Embarrassment may not seem like such a big deal, but I believe it has a lot to do with the isolation of people with Alzheimer's. And isolation *is* a big deal!

I think it may be helpful to break the embarrassment into two different pieces: the embarrassment that a person with Alzheimer's feels for her own behavior and the embarrassment that others feel in the presence of a person with Alzheimer's.

As you've probably figured out if you've been reading this blog, I haven't felt embarrassed or ashamed of my Alzheimer's disease ... at least not yet. It's true that my disease is early and my behavior not yet too gross, so things may change. But I think the reason I don't feel embarrassed is because I've told most everybody I'm around.

I've *always* had trouble remembering names and faces and, in the past, it's caused me lots of embarrassment. I felt stupid and I worried the other person was offended.

Shortly after my diagnosis in September, I started slowly telling people: my family and closest friends, our small faith community, my email contact list, and finally the whole world through this blog and the *Washington Post*.

My memory has now gotten much worse, of course, but now we all know why. I know that there's a reason beyond my control for my declining memory and I don't worry the other person is offended.

When I forget names or get confused in conversations or forget to do things I've promised to

do, I now make some reference to the Alzheimer's disease, we all shrug our shoulders and we continue on. In December, I made a [\\$24,000 mistake](#) in figuring out our faith community's next year's budget. Before I discovered the mistake, we'd already allocated the money to various missions, so it was a mess. Previously, I would have felt hugely embarrassed and ashamed and it would have taken me weeks to get over it. This time, none of us was very happy, of course, but, because everyone knew my condition, no one was resentful, and I wasn't embarrassed. (Yes, it was clear that I shouldn't continue as bookkeeper, however.)

The other evening at a reception, I was talking with a woman I knew socially about Alzheimer's in her family and about her concern over her own symptoms. Because there's a big difference in heritability between autosomal dominant ("early onset") Alzheimer's and the normal later-onset disease, I was curious about her age and said, impulsively, "You're about 55, right?"

Umm ... it is it highly unacceptable in American culture to suggest to a forty-four-year-old woman that she looked like she could be fifty-five. Under other circumstances, I would have been mortified and would have spent the rest of the evening trying to make excuses. But I wasn't embarrassed. We lose some of our inhibitions with this disease, and—despite the fact that I'd just steamrolled a social norm—I just rolled my eyes, as if to say, "What do you expect?" As the evening went on, she mentioned my *faux pas* several times; I just kept rolling my eyes. I knew that in the normal social context it was unacceptable; but both of us knew that Alzheimer's had changed that context. She may still have been offended, but I wasn't embarrassed.

So at this early stage in the disease, I don't feel very embarrassed because I'm aware of a new context. At some point, of course, I'm going to get to the place where I won't be embarrassed because I won't realize I ought to be. Other people, like my wife Marja, may be embarrassed, but I won't be.

It seems to me, then, that the isolation that plagues so many people with Alzheimer's is not because of *their* embarrassment, but the embarrassment (or fear of embarrassment) of friends or family that threatens them and drives them away. I'll look at that in a future post.

I'd be very interested in getting comments from any of you with relatively early disease who have made a deliberate point to inform other people. What has been your experience with your own embarrassment? Have you regretted going public?

Thursday May 9, 2013

Washington DC

Embarrassment (3)

For the past two posts I've been trying to circle around this terrible stigma that hangs over Alzheimer's disease and creates so much isolation and suffering. I've been trying to figure out what the stigma is. Why do people draw away? Why is this common disease such a mark of disgrace that brings shame and embarrassment to so many who are associated with it?

But after spending many hours on this post, I've decided I don't really get it. I don't personally experience the stigma or shame myself, and I don't think I know much more than anyone else about why other people feel that way. I've gotten lots of comments, each offering different perspectives that may be part of it. As I wrote about in the first post of this series ([Embarrassment \(1\)](#)), people feel embarrassed because they don't know what to say or do; they imagine themselves in similar situations and become afraid; perhaps they detest a human being who has lost control over himself. I don't know any more than I've already written.

But let me tell you just one story about the stigma.

Even the word, apparently, is unspeakable.

A week after a lengthy feature article about my Alzheimer's came out in the *Washington Post*, I was at a large function with many people who knew me fairly well, hadn't previously known about my diagnosis, and yet had seen the paper.

Perhaps thirty people approached me to talk about "the article in the *Post*." They referred to "your condition," they asked "how are you doing," or said to me "how courageous you are," but not a single person among the thirty mentioned the word "Alzheimer's." I knew I had

Alzheimer's; they knew I had Alzheimer's; I knew that they knew; they knew that I knew, but the word itself remained unspoken.

Sunday, May 12, 2013

Washington DC

A Longer Life

Several people with early Alzheimer's disease have left comments on this blog. They've known their diagnosis for several years and their symptoms often go back a year or two before their diagnosis. They're all still able to use the computer, obviously, and, according to their reports, are functioning pretty well in day-to-day life. I'm beginning to realize that this early phase of the disease can go on for quite a while.

Jim Landry, for instance, lives in nearby Maryland, so we got together a couple of days ago to meet and compare stories. He has known of his diagnosis for over two years. We talked for two hours, and he told me about a number of examples of his cognitive impairment, for instance, the inability to calculate even fairly simple arithmetic, difficulty in word finding, and his reluctance to drive anywhere except very locally. (He gets confused too easily if the traffic is at all heavy). I was, of course, looking for impairments as we talked, but the only one I actually noticed was the trouble with word-finding. He was skilled enough at substituting other words, however, that I wouldn't have noticed unless I'd been specifically listening for it. Even paying attention, I noticed only that his substitutions were not always exact synonyms for the words he was looking for. Ordinarily no one would notice his impairment.

So in most situations, he, like me, can "pass" in day-to-day interactions with other people. He has been completely "out" (the vocabulary around homosexuality is quite intentional) about his diagnosis and can't imagine doing it any other way. He's found no reason to regret his openness. He did have to leave his professional job because of his difficulties with memory, but that was before his actual diagnosis; his job loss was from his impairment not from his going public.

A person who comments here frequently, "meganthemegan" reports that she gets lost quite easily but is quite comfortable asking people for help; she has trouble with social etiquette (eg

using the F-word inappropriately); she can't do basic arithmetic, and so on. But she's also developed a number of coping mechanisms that help her get about: becoming a "neat freak" so she can find things, writing very explicit notes to remember things, recording voice notes on her smartphone, and so on. (The voice notes have been a wonderful suggestion that I've taken up; I'm not fast enough on the smartphone to write things down in a reasonable amount of time, but when something comes up in a normal conversation that I need to remember, I can dictate it pretty quickly. When I get home, I process my notes.)

Her comments to this blog are written with no evidence of cognitive impairment. She obviously gets around in her environment and can relate well to her friends. By her own report, she's impaired but she's fully with us. She writes,

I've given up on names and math and being a well-behaved woman. I have become better at rolling my eyes and shrugging my shoulders while smiling. ...

I have also experienced the incredible fullness of "present moments" -- love and fear, expansion and contraction. I am reminded of Rilke's words:

"Let everything happen to you
Beauty and terror
Just keep going
No feeling is final"

I'm writing about these two people in part because theirs are just beautiful stories. But they are also an indication that "real life" can go on for a long time after diagnosis. I talked on Skype to a guy who's had Alzheimer's for *ten years* and I couldn't detect *any* impairment. I myself have declined so gradually since my diagnosis last September that daily functioning seems even to me almost normal.

The implication is that the progression of my Alzheimer's will probably be slower than I'd originally thought: I may be around for a good long time.

So that's good!

Initially, this realization brought up the question: So now what do I do with the rest of my life? I've gotten to thinking of myself as a "professional Alzheimer's patient" (with this blog, media coverage, speeches, and so on). I've been subconsciously assuming that that role and my calling to "out" Alzheimer's would occupy the rest of my life, and that would be enough! But now there's much more life to occupy.

But the question of what I'll do is really unnecessary. This is a waiting period, and the future will show itself of its own accord. (One of the joys of this disease, actually, has been much freedom from worrying about what I "should" do.) I have the diagnosis; I know the basic outline of what's coming. I have the truly important things—relationships, community, love, meaning, an appreciation of the world's beauty—and they will remain. I've entered into a strange world as an increasingly mentally challenged person. Apparently it's going to drag out longer than I thought, but I'm still very curious. It's quite a journey.

I'd be greatly interested in hearing from you with a relatively early diagnosis. If you ever think about it, what do you envision for the next few years?

Wednesday, May 15, 2013

Washington DC

Driving

When I was a family doctor in a small town, one of the most difficult tasks was telling an elderly or seriously ill person that his driving was no longer safe and he would have to give up his license. In our culture, losing one's driving privileges is a significant blow to the ego, especially for men.

As I was driving this past Saturday, I had a disturbing experience. Every three or four months I drive 3½ hours to southern Virginia and 3½ hours back to Washington to visit my friend Jens Soering, who has served 26 years of a life sentence for a crime that I believe he didn't commit. It's a long trip and I have to get up much earlier than usual and, since I don't sleep well anyway, I don't get much sleep.

What I noticed was difficulty following the thread of conversation on National Public Radio while simultaneously paying attention to my driving. I couldn't follow any concept that required concentration. It seemed that I could only pay attention to one thing at a time, either the driving or the radio. I was concerned that if I tried to pay enough attention to the radio to understand, I wouldn't be able to drive as well.

I didn't have the same trouble driving back to DC that afternoon, so I assumed my trouble had just been my tiredness from too little sleep, but it got me to thinking about driving in the face of my diagnosis. Ordinarily, I feel no deterioration in my driving ability compared with my skills before my Alzheimer's diagnosis (but, as we'll see below, it turns out that my own rating of safety doesn't mean much). My neurologist—using the nationally recognized neurology standards—isn't concerned. But if I did have a serious accident that was judged my fault, would I be risking my insurance company refusing to cover me? Or even that I would face criminal charges for negligence? I could just imagine myself in a court room as the prosecutor intoned: "Dr Hilfiker you *knew* you were cognitively impaired and yet you put yourself behind the wheel of a car. What can you say to this family of the little girl who died as a result?" OK, a little melodramatic but you get the point.

Should I be driving? It's obviously an important question, but it doesn't feel like a particularly powerful emotional issue for me (we'll see about that when it's time to stop, of course). In practice it will certainly be difficult for Marja and me. Even though we don't have a car and can get around Washington quite well with a combination of good public transportation and our bikes, it will still mean that Marja will have to drive those short trips around the city (for which we borrow friends' cars) and the occasional long trips in rental cars to places we can't get to by public transportation. I've always done most of the driving; Marja doesn't enjoy it and becomes anxious and tense while driving, so it will be an adjustment for her. But we'll deal with it.

Should I be driving?

I emailed my neurologist to get advice and he wrote back essentially advising me not to worry

about it, yet.

He wrote that the American Academy of Neurology has published guidelines for auto safety for people with Alzheimer's (<http://www.neurology.org/content/74/16/1316.full.html>). (The following a bit technical but stay with me.)

There are six useful factors to consider in determining how safe a person is driving. The most important is the Clinical Dementia Rating scale, which requires a professional neurological exam (but the criteria can be found at <http://www.neurology.org/content/74/16/1316/T1.expansion.html>)

The other five can supplement the dementia rating:

1. a *caregiver's* rating of a patient's driving ability as marginal or unsafe
2. a history of crashes or traffic citations in the last five years
3. the patient deliberately reducing driving mileage or avoiding driving in certain situations
4. a [Mini-Mental State Examination](#) score of 24 or less and
5. aggressive or impulsive personality characteristics.

As I mentioned above, research indicates that your own rating of your safe driving ability isn't correlated with the results of an on-road-driving-test.

(Note: This same webpage says that insurance companies and licensing agents have a demerit point system based only on previous crashes or citations, but I couldn't find a description of the exact criteria.)

I was a little surprised that the implication on the Academy's website was that any person who can pass an on-road-driving-test is judged safe, which seems a little loose to me. I would think that the biggest issue in safe driving would be distractibility, and I doubt a routine driving test would measure that very well.

My neurologist believes my dementia score to be essentially zero, so, according to the criteria, I can still consider myself safe to drive, which fits with my subjective conclusion. But I know it's only a matter of time. Alzheimer's is a disease of constant losses. Losing one's driver's license is, in our culture, a highly symbolic event. I only hope I have the grace to accept that loss when it comes.

May 18, 2013

They're Still In There

Washington DC

Lee Ann Gerleman is a nurse who's worked for many years in long-term Alzheimer's care units and has been making frequent comments on this blog. I've collected and (heavily) edited some of them here .

Through the months, I've written about my curiosity about consciousness in moderate stage Alzheimer's. (For the definitions of the various stages, see http://www.alz.org/alzheimers_diasease_stages_of_alzheimers.asp .)

Lee Ann has responded:

People with dementia are still just regular people. Their reality, however, seems spread out

over time. If you know the patient for a long period of time, you can get the full story. It just seems as if things have gaps between them. And the patients are just as loving and needing of love as anyone else. They soak up love like a sponge. For someone like me caring for patients with dementia, a locked unit in a nursing home is a love place. You can hug more, love more, and it is gratefully reciprocated. So this disease is just a continuing part of the journey.

What so many people don't realize is that even quite demented patients are just the same as the rest of us. They may be forgetful, but inside their consciousness, down where it really counts, they still have their inner conversations going, just like we all do.

Lee Ann sent me an email with her thoughts on the subjective experience from within Alzheimer's.

Some people talk about how it would be such suffering to be lying in bed, incontinent and so on, about how we "might as well just shoot 'em." They're equating a different way of interacting as being a bad way. But if patients are comfortable and no longer embarrassed by incontinence, they sleep and remember good times and bad. Maybe their memories are not as deep as ours, but the love and memories are still there. Like the patient whose great granddaughter comes and walks her around outside. She doesn't know who that little person is, but she knows she loves that little girl. That is true happiness, being deeply in the moment with a little girl who is taking very good care of you. All the little friend wants you to do is smile and be happy.

She continues in commenting upon my post "[Why Not Suicide?](#)"

If we indeed "go backwards" in our cognition, then being the two-year-old child in our minds wouldn't be any worse than being a two-year-old 83 years ago. There's wonder in everything around us. And someone with the cognition of a two-year-old would enjoy things just as much as anyone. With a two-year-old, of course, there's joy in watching the child grow and mature. With an 83-year-old "child," it's heartbreaking for family and friends to see their loved one going down and down. But that 83-year-old lives in the present, and there are things to see and do. Watching a 3-year-old picking a tomato is no different in awesomeness from watching an 83-year-old pick a tomato with the same amazement. Someone with AD is just going the wrong way on the highway of life. But for them, it's still the same highway. They experience love, caring, amazement, seeing wonderful things, happiness, just as anyone does.

And then there are the truly amazing events that leave you scratching your head:

One little woman used to steal my nurses notes—all of the little scribbles that a nurse would make to remember things. She would take my scribbles over to the grand piano, sit down with a flourish and play for hours from my nurses notes as if they were sheets of music. She never missed a note, played probably four or five different sonatas—Bach, Beethoven, and others. If I tried to take my papers back, she would get all upset, so I'd let her keep them as long as she played. When she was done, she'd bring the papers back to me and put them on my cart with a quiet little thank you.

And other surprises are just humorous:

One woman was discussing with me how wonderful her husband, Tom, had been for 65 years, never a mean word, always loving; she looked like a bride, thinking of her loved one. So ten minutes later, her husband came in to visit and I hoped she was still on the same wonderful bride-journey, so I said, "Tell this man about your wonderful life with Tom." She looked at me in shock, and said, "OMG I married him?" So much for giving him a pat on the back.

Care givers are sometimes understandably bitter about all the patient's friends disappearing as the disease worsens, abandoning patient and caregiver to the disease. Lee Ann had a different take.

Alzheimer's is, after all, "The Long Goodbye." When patients initially go into a special care unit, their families are usually very supportive, and come for all of the fun activities, etc. But about half the families then begin to come less and less, and I think it's because that as the patient begins to move away more, the family adapts by moving away also. They are adapting to the changes in the relationship. Which is good for them. Family members naturally begin to withdraw somewhat, as they spend more time out in the world. It's hard to explain. They don't love the patient any less, but they learn to change with the times and go out into the world more.

And other times, Lee Ann seems to feel deeply privileged just to be present to the moment.

I sometimes find it very touching to be sitting with an AD patient and their adult child. Of course, the son or daughter is upset that they aren't being remembered. But then I ask the patient about her children. It is amazing to watch the patient glow, talking about her child, the school work, the play, Christmas when he was five, the smiling and obvious love. The adult children were focused on losing Mom, but when they can see their Mother's obvious love for them, it does help, I think.

In the end, of course, we don't know the subjective experience of the person with moderate to severe Alzheimer's. But, at least for Lee Ann Gerleman, the potential for rich relationship remains.

Thursday, May 16, 2013

Washington DC

Do I *Really* Have Alzheimer's?

When, in conversation with another person about my Alzheimer's, I mention one of my particularly frustrating symptoms, they'll often respond with something like, "Yeah, I know what you mean; I've been getting a lot more forgetful, too."

It drives me nuts.

Usually, I just let the comment pass, but it most often feels like a dismissal of my diagnosis, as if to say, "Everybody gets like that sometimes; don't take it so seriously." It irritates me, so I list a few of my more abnormal symptoms to shut the person up. But sometimes they'll respond to that by saying something like, "Well, you said you're not 100% sure you have Alzheimer's, didn't you? It could be something else, right?"

Yes, it *could* be something else. But it's not. I can't blame my friends; they're just trying to be optimistic or make me feel better or, perhaps, shield themselves from the fear of the disease.

Or maybe they're just trying to make sense of the disease, to understand what I'm going through and I'm just being overly sensitive.

As I've written before, a definitive diagnosis of Alzheimer's disease can only be made at autopsy. In clinical practice, however, the diagnosis is made by testing for dementia using a cognitive function test and then ruling out other causes of that dementia (see my post "[Research](#)"). For some of us with early disease, however, we don't even meet the official criteria for dementia, which, in practice, usually means a score of less than twenty-five out of thirty questions on the Montreal Cognitive Assessment (MoCA). Those of us who score between twenty-five and thirty are given the diagnosis of "[mild cognitive impairment](#)" (MCI). If the other causes of dementia have been ruled out, however, MCI virtually always progresses to Alzheimer's.

So do I always feel absolutely certain? Well, mostly I do. My personal neurologist believes my MCI will progress to dementia, as does the research neurologist I've asked. At an intellectual level, I'm convinced this is Alzheimer's disease. But am I absolutely, 100% certain? No.

And that little bit of uncertainty makes this difficult disease even more difficult. As a doctor, I understand that in medicine almost nothing is certain. Sometimes we just have to wait and see. But, even so, the three years since my first symptoms feels like a long period to wait.

Most neurologists, I suspect, don't mention Alzheimer's to people with early MCI unless they ask. At my first visit almost two years ago, my neurologist told me about my score of twenty-seven but—perhaps noting that I hadn't asked—didn't specifically mention Alzheimer's. That I—a guy who always wants the details—didn't ask specific questions after missing three questions on the MoCA surprises me. Perhaps it indicates my own fear of the disease at that time.

I have a lot of confidence in my neurologist, and, when I asked about Alzheimer's at my visit this past September, he was candid saying that he thought my MCI would progress to Alzheimer's.

There's really no way around this dilemma of uncertainty, but it raises uncomfortable issues for those of us with mild cognitive impairment. We ask ourselves questions like:

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What's really going on?

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If it's not Alzheimer's, what else is it?

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If I'm not 100% sure, do I inform my friends, anyway (much less go public with a blog and newspaper interviews)?

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Do I go into all the details of MCI vs Alzheimer's every time someone questions my diagnosis?

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Do I take the major steps to reorganize my finances (see [Medicaid](#))?

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If my job requires a high level of cognitive ability, do I quit now or wait to make a serious mistake or have my boss fire me?

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Should I apply for disability?

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Should I get started on my "bucket list"?

-

What kind of advance directives should I make?

Obviously, some people would rather not know and deliberately avoid the diagnosis. Others move into active denial, perhaps never facing their reality. But for those of us who want to know what's happening to us, why we're forgetting so much, why we've declined intellectually, the uncertainty can wear us down.

I'd be interested whether others with who are in the early stages of Alzheimer's find this limbo nerve-wracking.

May 24, 2013

Washington DC

Normal Aging or Alzheimer's?

A number of people have commented here written me directly, asking how to tell the difference between the symptoms of Alzheimer's and normal aging. As I wrote in my previous post, "[Do I Really Have Alzheimer's](#)," it's not that easy. There are no foolproof answers.

The Alzheimer's Association does have a [helpful web page](#) laying out ten early signs of Alzheimer's and how they differ from normal aging. If you're wondering whether you have the disease, reading them can be a little frustrating because early in the disease the distinctions are matters of degree and not easy to be sure about. Nevertheless, they can give us some comfort about normal changes in aging or help us decide when we need to get ourselves checked out. The following are taken largely from that page but somewhat edited; occasionally I include my own reflections.

Memory Loss

Changes in memory are the most common initial symptoms in Alzheimer's, but normal aging changes memory, too. A normal person might forget names or appointments but will usually remember them later on, perhaps with a little prompting.

In early Alzheimer's, however, memory loss begins to disrupt daily life. We forget recently learned information and important dates or events. We may have to ask for the same information and over again and/or rely on notes or electronic devices to remember.

Challenges in Planning or Solving Problems

In normal aging we might make occasional errors when, say, balancing a checkbook or figuring out a tip. But in mild cognitive impairment, there may be trouble following a familiar recipe or keeping track of monthly bills. You may have difficulty concentrating or take much longer to do things than you did before.

Difficulty completing familiar tasks at home, at work or at leisure

In normal aging we might need occasional help in using the settings on a microwave or recording a TV show, but in early Alzheimer's you may find it hard to complete daily tasks, drive to a familiar location, successfully manage a budget at work or remember the rules of a favorite game.

Confusion with time or place

Any older person may get confused about, say, the day of the week or the date, but we can usually figure it out later. But with Alzheimer's you may lose track not only of dates but also of seasons or the passage of time in general. You may sometimes forget where you are or how you got there.

Trouble understanding visual images and spatial relationships

There are some vision problems that are just signs of normal aging, like those related to cataracts or the need for reading glasses. But for some people, vision problems are a sign of Alzheimer's. A person may have difficulty reading, judging distance or determining color or contrast, which may cause problems with driving.

New problems with words in speaking and writing

As we age, most of us have occasional trouble finding the right word, but it's worse in early Alzheimer's. You may have trouble following or joining in a conversation; you might find yourself stopping in the middle of a conversation and having no idea how to continue. You might have to repeat yourself or struggle with vocabulary; you might have problems finding the right word or call things by the wrong name (eg, calling a "watch" a "hand-clock").

Misplacing things and losing the ability to retrace steps

Normally, in getting older we may misplace things from time to time, but we can usually retrace our steps to find them. In Alzheimer's, however, you may put things in unusual places or lose things and be unable to retrace your steps to find them again, sometimes even suspecting others of taking them (because you can't believe you just lost it). Losing things becomes a regular habit.

Decreased or poor judgment

Anyone makes a bad decision once in a while, and it may happen a little more frequently as we age. But in Alzheimer's you may experience regular changes in judgment or decision-making, for example, poor judgment when dealing with money like giving large amounts to telemarketers. We may pay less attention to grooming or keeping ourselves clean.

Withdrawal from work or social activities

As we get older, anyone can feel weary of work, family, or social obligations. But people with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. You may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. You may also avoid being social because of other changes you've experienced.

Changes in mood and personality

As we age many of us get more rigid, developing very specific ways of doing things and becoming irritable when a routine is disrupted. But in Alzheimer's, the mood and personality changes can be more pronounced. You can become confused, suspicious, depressed, fearful or anxious. You may be easily upset at home, at work, with friends or in places where you're out of your comfort zone.

Unfortunately, none of these is precise; the borders between normal and abnormal are blurry. Something that might be normal for one person may be a sign of Alzheimer's for another.

Furthermore, there's no set number of symptoms that indicates disease. If we find ourselves in between, it's hard. Personally, I wanted to know, but I still found myself waiting even after some changes that should have prompted me. If you're seriously wondering whether or not you have Alzheimer's, my own advice is to see your physician and get a referral to a neurologist. The worse that can happen is reassurance you're normal.

Tuesday, May 28, 2013

Washington DC

Preparing Our Hearts

Several comments on this blog have referred to this disease as "the long good-bye," during which the person with Alzheimer's gradually moves away toward a land into which friends and family cannot follow.

As the one with Alzheimer's who will eventually move away, however, I experience a different sort of long good-bye ... from the other side of the relationship, from a much earlier stage in the disease, and with joy rather than sorrow. I have the privilege to attend my own prolonged memorial service, so to speak, and receive from friends and family their gratitude, admiration and love while I'm still here and can drink it in. A good friend whom I see now only rarely sent me a long email last week, recounting several periods in our lives together in which my presence had been important to her and her husband, expressing her gratitude for my work with the impoverished and its impact on her life, and affirming the depth of our mutual relationship. In reading it, I was transported toward one of those "thin places" between our material world and the world of spirit and mystery.

Her email was especially beautiful, but others have written to express similar feelings and to reaffirm their sense of our belonging together over many miles and many years.

Strangers have written to describe the impact of my writings on their lives. Physicians who read my first book, [Healing the Wounds](#), about the emotional and spiritual contradictions of doctoring have written me about how deeply the book shaped their careers. Some are twenty-five years into their practice and have read of my Alzheimer's, which has impelled them to write; others are college students in pre-med wondering if medicine is their calling.

Similar emails arrive regarding my other books, some of my writings, even speeches I gave at their medical school. Thirty years ago I wrote an [article for *The Other Side*](#) magazine about my depression and how it cast its black shadow over my search for God. After all these years, people have written to thank me for it.

These are the kinds of things we *could* tell each other any time, any day as we live our usual lives, but most of us don't; it's almost taboo ... at least among men. I don't think I speak only for myself when I say that we can go for years of deep relationship with another person without ever articulating our gratitude for who we are together, for our love for one another. So often we wait until the person is close to death—or, more often, perhaps, until that memorial service—before we dare articulate these beautifully human feelings of love and connection.

The taboo seems to extend to the one on the receiving end, too. Prior to my diagnosis, I was well defended, good at protective humility, at deflecting, at denying, or escaping these embarrassing moments of praise, or admiration, or love.

This long good-bye of Alzheimer's, however, seems to weaken the taboo on both sides, evoking those expressions of closeness from others while I am still very much here and permitting me to allow the gratitude, admiration, and love to wash over me. My heart seems to have grown. I can listen gracefully. It is part of the wonder and joy of these months since my diagnosis.

In some ways I'm now in the best of both worlds: not much intellectual diminishment; yet lots more emotional openness. I'm very aware that profound intellectual loss will come later, but I wonder if this long good-bye is preparing us for those later times. I wonder if this period allows the softening of hearts—mine *and* those of friends and family—so that when I can no longer respond to their words or even understand them, when I don't even know who they are, our hearts will then be prepared to love without concepts.

There is a mystery here, for which I am very grateful.

Wednesday, May 29, 2013

Washington DC

A Delicate Dance

This past Memorial Day, our faith community spent the weekend at a camp in rural Pennsylvania. It was just a time of play with virtually no program: unscheduled hiking, laying in the sun, watching a movie, playing board games, swimming (in pretty cold water) and so on. What I noticed during the weekend was how seldom my cognitive impairment was even an issue. I still refer to it, usually obliquely, when I get a little confused or lose yet one more thing, but I was surprised and pleased over the weekend to notice that my community is now quite comfortable with my diagnosis. There's no need to belabor it.

The progression of my Alzheimer's has been slow. Although I've certainly noticed some worsening over the eight months since my diagnosis, it hasn't even reached the point where other people notice unless they're looking for it. The reality is gradually settling in for me that I have a lot of life left that will not be significantly impaired by disease.

The first months after my diagnosis, the emotional impact of having Alzheimer's disease was so powerful for me that it became the primary focus of my life. It tended to overwhelm other parts of me and became almost my *identity*. I suspect that period of identifying myself as an Alzheimer's patient was important to me in order to accept my diagnosis, and the powerful emotional responses of family and friends seemed to encourage that focus, so I don't regret it. Once I became public with this blog and other media coverage (among which were an

[article](#)

in the Washington

Post

and a

[segment](#)

on the CBS Morning Show), my role as a professional Alzheimer's patient and informal spokesperson for the disease further cemented my identity as a person with cognitive impairment, a special case deserving of special attention.

But as with diabetes or heart disease or even cancer, it's not an identity; Alzheimer's is one of those things that happens in real life.

It's true that Alzheimer's is a little different from other serious chronic diseases in that it's still a taboo subject that needs to be brought out of the closet. Our cultural fear of the diagnosis makes it more difficult for family, friends and others to see it as normal, as not so different from any other ultimately fatal disease. But, of course, it is normal! If almost fifty percent of 85-year-olds have Alzheimer's, then we're not talking about something abnormal.

Over the weekend, my primary identity wasn't an Alzheimer's patient but a member of my community enjoying the countryside and each other. I then returned from the weekend to a comment on my post "[Normal Aging or Alzheimer's?](#)" by a reader, a.b.w. "Beware of the trap of self-indulgence," she wrote. It reminded me not to take myself and my illness too seriously, not to get caught up in a special identity. (That's a little harder for me since I've taken on this vocational role in order to bring attention to the disease and its taboo. But the danger of self-indulgence is clear.)

It's important, however, to acknowledge that having a name (a "label") for my impairment (as compared to wondering what the hell is going on) has been comforting to me. It's given me some sense of the future and allowed me to make necessary plans. Also, my "coming out" to friends and acquaintances has made it easier for them and me to get past my diagnosis. We hardly mentioned it this weekend.

Nevertheless, a.b.w.'s warning against self-indulgence is well put. For me that temptation comes in the form of allowing the name to define me. I do have cognitive impairment, yet my self is far more than that. It's a careful dance.

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