

## Blog Posts from October 2013

October 3, 2013

Kalispell MT

*During the 1980s, Lois Wagner was my boss and colleague at Community of Hope Health Services, a small inner-city clinic that she had founded. In 1990, she joined us at [Joseph&#39;s House](#) living with and caring for homeless men with AIDS. We have remained close friends even as she moved to San Diego to become a professor of nursing at Point Loma University and then retired to Kalispell, MT where she has lived with and cared for her mother who has Alzheimer's.*

### Guest Post: The Journey of Caregiving

By Lois Wagner

I am a 72-year-old living with and caring for my 95-year-old mother. I am also a nurse by profession and have spent many years caring for and teaching about caring for people at the end of life. As I've been reading David's blog while mother's cognitive abilities diminish, I have become more reflective on my journey.

Moving from companion to caregiver

I have now been with my mother for six years as companion/caregiver. We have slowly moved from being primarily companions to my being her caregiver. However, the caregiving has to be done with some finesse. It truly is like a dance. Sometimes I need to move in close and help her a lot and sometimes I need to back off and let her do things herself. Which means sometimes it seems like I'm stepping on her toes because I moved in too closely and other times I pull away and she almost falls--either literally or figuratively. The transition from companion to caregiver is not always clear or consistent.

## Not asking questions

The idea of not asking questions as mentioned in [Contented Dementia](#) has been a very helpful one for me. I have found that mom gets very anxious if she is put on the spot with a question even about what to eat. But if I muse out loud, for example, "I'm thinking about either soup or salad today; can't quite decide; well, maybe we'll have soup," she will often either agree or say she'd rather have the salad. It's been really kind of fun to see if I can reduce the number of questions to as few as possible as a means of increasing her sense of well-being and decreasing times of "ill-being."

## Learning to wait and be late

I am learning to wait and to be late. No matter how much time we plan, it seems that there are always last minute needs that arise and it does not work to try to rush or hurry. In the big scheme of things it's not so important to always be on time.

## Reducing stress

If I get too busy or stressed, mom reflects that in both cognitive and physical symptoms. She's a gauge of my stress level.

## Routine and ritual

We have instituted a couple of daily routines that bookend our days. In the morning I read out of a little meditation book and she reads corresponding Bible scriptures. Her Sunday School training is still there and she can even find those obscure books in the Bible and seems quite pleased with herself when she does. Often she will read a scripture that is a little more abstract and she will grin and say "Whatever that means," and we will laugh and move on. In the evening I was finding it difficult to get her to go to bed. She would say she was going to bed but would just sit there. So, I stand in front of her and put out my hands and say, "Let me help you get to the bed." She looks up at me with a smile and we walk down the hall hand in hand. I put lotion on her feet and pull the covers up and we look each other in the eyes and say, "I love you."

Sleep well. See you in the morning.” I put on her music and leave her to sleep, which she does well.

I continue to learn about change, acceptance, expectations, frustration, flexibility, silence but most of all about love as we make this journey together.

Monday, October 7, 2013

Washington DC

## **In the Fog**

Sometimes there are tiny views of what my future holds. The view last week was more disturbing to me than usual.

A friend who volunteers regularly at [Joseph's House](#) had invited me to have breakfast there, help him clean up and talk a little. To help with clean-up, I took my place at the sink to wash dishes. The drill is to wipe excess food off the plates, wash them in soapy water, stack them near the sterilizer, put them into the sterilizer as each load is finished and then put them away. Pretty straight forward!

However, I found myself at each stage in the process uncertain what to do. If the little place designated for stacking the soapy dishes filled up, where else should I stack them? If there was coffee in the cup, did I need to wash it or was it enough to toss the coffee and put the cup directly into the sterilizer? When it was time to put the cups away, where were they stored? (Answer: right in front of me). How much dish soap should I pour into the basin?

These were minuscule decisions, and they didn't matter. If the spot for stacking the dishes filled up, put the dishes anywhere. If I don't know whether to wash the coffee cups or not, go ahead and wash them; it's not a big deal. What did it matter if I put in too much or too little soap?

I was in a mental fog, detached from the place and the others in the kitchen. What was most distressing was a sense of dependency on others; I felt I needed to ask someone about almost everything, yet I felt weird about asking. I felt others' eyes on me (although I don't know if that was true or just a subjective sense.) My world contracted to the tiny space around me.

I am ordinarily treated with deference at Joseph's House. New volunteers, especially the [year-long interns](#), know of my role as founder and have at least heard of [my books](#) if they are not already reading them. The deference has always been embarrassing so my response has been a bit self-deprecating. The truth, however, is that I also enjoy the deference and am willing to put up with my discomfort.

So were the volunteers noticing my confusion? As I worsen, will their opinion of and respect for me change? (Of course it will, especially as the volunteers change every year.) How will that feel to me? And what will it be like to visit at Joseph's House as I lose that place of special respect? Will I even want to visit as I worsen? For the first time, I felt some of the isolation that is probably coming ... not because others isolate me but because—in my embarrassment—I isolate myself.

Thursday October 10, 2013

Washington DC

## **Confusion ... Again**

Marja and I visited friends the other night. They're a small group of twenty-somethings who live near-by in community, and each volunteers at an anti-poverty ministry in the city. Our conversation turned to the role of the Millennials in the politics of the next generation. I mentioned [The Fourth Turning](#), a book quite relevant to the conversation and tried to give them a synopsis. But I got lost in my own words. When I realized I couldn't find my way through to an adequate description, I said to the volunteers, "I can't do this! I'll just have to stop." I'd told them earlier this year about my Alzheimer's, so I acknowledged my confusion, and we went on with the conversation.

I noticed three things. First, I believe this is the first time I've gotten confused enough that I had to give up half-way through a conversation. It feels like a further step down the ladder.

Second, I was gratified not to feel embarrassed by the episode. The conversation just continued on as if it were normal for someone to get confused by his own thoughts. Nobody seemed weirded out.

Third, I wonder how this will affect my willingness engage in complex conversations. Will I be comfortable with trying to explain *The Fourth Turning* again? But the reminder is: "Use it or lose it!" If a person with moderate Alzheimer's, for instance, has trouble buttoning her blouse and her husband jumps in to help and then proceeds to take over every time a blouse needs buttoning, his wife will quickly lose the skill altogether. Better to let her struggle for awhile until it's clear that she can't do it.

Mine, of course, is a cognitive, not a muscle-coordination problem. But the principle is the same. It will be better for me to continue engaging in such discussions, even of *The Fourth Turning*, until I'm sure that the capacity is really gone. That will probably result in a few more potentially uncomfortable times before it becomes clear that I can no longer do it, but I also don't want to shut down any earlier than I have to.

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In my [previous post](#) I described my confusion washing dishes at Joseph's House. I wondered whether it would cause the interns' "opinion of and respect for me [to] change." I received several comments and emails from readers who thought it unlikely I'd lose the interns' respect as I worsened. They're probably right. Actually, even as I wrote the post, I struggled to find an appropriate word and used "respect" because I couldn't find just the right one.

One reader suggested that what others might lose is not respect for but interest in me. That feels accurate. Even as people continue to feel respect for me, it's only natural that some will feel little interest in spending time with me. I had exactly that reaction to Robert Greenleaf, an author I greatly admire, when he visited us here in Washington. Once it became clear that he was cognitively impaired and that it would keep him from meaningful discussion, I saw no

purpose in remaining and left as soon as I could without being grossly impolite. I don't feel proud of that, but it certainly seems a normal reaction and I can't see any reason it should be different in my case.

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In case any of you is wondering, I won't be getting the results of my [neuropsych evaluation](#) until after the government shutdown is over, and the National Institutes of Health can reopen. Given that the latest suggestion from the Republicans to extend the debt ceiling debate for another six weeks or so *while keeping the government shuttered*, my results may be a while. Other people's problems with the shutdown are certainly greater than mine, but I'm still frustrated.

Monday, October 14, 2013

Washington DC

## **Win Some, Lose Some**

I attended a three-day anti-racism seminar last week. Our Eighth Day faith community is discovering that to truly invite people of color into our community we must do more than put out a welcome sign and be well-intentioned and friendly. There are also institutional structures within our community that are barriers to true fellowship. Furthermore, within those of us who exercise power in the community (almost all white), there are unconscious attitudes and beliefs that maintain racism within the church. The path to changing these structures and attitudes goes through minefields of history, anger, privilege and blindness, but a group of us (half black, half white; half male, half female; half from Eighth Day, half from other communities) met with a trainer to explore the issues more deeply and make plans together about how we could facilitate change in our communities.

Five of us had a significant three-hour conversation one evening about some specific issues within the community. It was intense, emotional, complex and difficult. I felt I needed to be at the top of my game to contribute helpfully to the conversation; to avoid the most dangerous of those mines scattered throughout our discussions; to help clarify some of the subtle, complex

issues; and to be open to the pain, anger, and feelings of betrayal while emphasizing the good will, the possibilities for hope, and the importance of our task. And it did happen! I was not only extraordinarily grateful that the five of us could trust and care for one another, but I was also aware that despite my cognitive impairment I was just as sensitive, just as creative, and just as helpful as I have been at any time in my life. And the expressions of gratitude I received afterward confirm that the others felt my presence helpful, too. At the end of the conversation, in fact, one of the African Americans among us chuckled and shook his head, saying to me something like, "I thought you had Alzheimer's!" He meant it as a compliment and gratitude for my participation.

I don't want to exaggerate my role or suggest that the courage, the sensitivity and the dedication to our community that each the others brought to that conversation were not equally essential to what we accomplished. I mean only to say there are significant parts of me that Alzheimer's has not yet hobbled.

The two previous posts here have been about significant cognitive impairments that will inevitably worsen. Much of the time—even in conversations like those last weekend—I forget important details within a few minutes after they are described. Yes, that impairs to some degree my participation any conversation, but what has remained, and possibly even sharpened, is my capacity to listen deeply, to hear another person's pain, to understand the larger picture out of which that pain comes, and to clarify the issues and possibilities.

Am I impaired? Most definitely! But certain gifts remain. They too, of course, will eventually be gobbled up. But for now, I and those who love me can be grateful.

I keep hearing from caregivers who write me that the capacity to relate to another person may be one of the last to go in Alzheimer's or any dementia. That, it seems to me, is a great blessing.

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A lighter moment: Our community was on a separate retreat this past weekend. I mentioned to a friend that I've been greatly enjoying *Discovering of Witches*, a delightful novel about witches and vampires. My friend recognized that witches and vampires were not exactly the

usual subjects of my previous reading habits; he was so amused that he went around telling others in the community. After hearing about it, one of those told said seriously: "It's such a tragedy, isn't it?" He meant, I suppose, that reading about vampires and witches represented a major decline in my capacities. Me? I'm grateful I can now explore new worlds.

Friday, October 18, 2013

Washington DC

## **Is It Always My Fault?**

I'm having more of these good-days/bad-days experiences.

Monday, evening I met with a Gettysburg College class on homelessness that had come to Washington for some direct contact with poverty. In preparation, they'd read [Not All of Us Are Saints](#), my book of stories about my providing care to the poor in Washington. I gave them a brief lecture on the origins of poverty in the inner city, and they had lots of questions. After an hour and a half, the students were flagging a bit, but I decided to tell them about my Alzheimer's. That seemed to re-energize everyone, and we had a good discussion. Once again, I had no trouble in a small-group setting. It was rewarding for me and, I think, helpful for them. I was gratified.

Then I came home to discover another of my screw-ups. We've been trying to get rid of bedbugs in our apartment (long story). The last time we'd used the vacuum cleaner was to suck up any lingering critters. Marja had wanted to throw the vacuum bag away so that any of the bugs swept up wouldn't escape back into the apartment. But I decided we could just take off the bag, seal it in plastic and reuse it the next time. Then I stored it in its usual place inside the vacuum cleaner without even a note anywhere to remind us what I'd done. Monday, Marja had spent much of the day scouring the apartment to get rid of the bugs, including a fair amount of vacuuming. When I came home, I took over, only to eventually discover the disconnected, sealed-up bag. We'd both spent a long time vacuuming with a machine that sucked things up but then leaked them back out again.

Unfortunately, I didn't remember anything about what I'd done with the bag. So I blamed Marja. She, naturally, blamed me. After a little bit of the typical husband/wife back-and-forth, I



felt angry and blurted out something like: “So anything that happens is now automatically my fault?!!” Only gradually did I begin to remember and recognize it was, indeed, my fault. It was humiliating.

But, given my Alzheimer's, when something ridiculous happens and neither of us knows why, doesn't it make sense to assume that I was responsible? Occasionally, of course, it will be Marja's fault (her memory isn't perfect, either), but by far the likeliest candidate is going to be me. That's just the reality. And that means that I have to come to terms with it.

I would like to get to the place where I can, even in the moment, acknowledge that I've probably done whatever ridiculous thing that just happened. I would like to get to the place where I don't feel defensive or humiliated. Perhaps both Marja and I can get to the place where we don't need to waste emotional energy pinning down who did what. Perhaps we can get to the place together where we even laugh at the ridiculousness (if it is, in fact, funny).

I think we can get there, but it will take work on both of our parts.

Thursday, October 17, 2013

Washington DC

## **Cushion?**

I've begun to read Daniel Kuhn's *Alzheimer's Early Stages*. The book is directed toward “care partners” (his word, as opposed to “caregivers”) and not particularly toward the people with Mild Cognitive Impairment (MCI) themselves, but my reading has so far stimulated my thinking. He writes about hearing the diagnosis:

[T]he person with the disease usually receives the diagnosis with little or no emotion and few if any questions. ... Those with AD [Alzheimer's disease] seldom grasp the full implications of the diagnosis. Even those who are well aware of their symptoms ordinarily do not appear overwhelmed by the news. It seems that the ability to understand the magnitude of the situation may be blunted by the disease itself. Those with AD typically do not share the same

perceptions of the disease as others close to them. In a sense, the disease is often accompanied by a cushion that softens its meaning for the affected person.

This raises the question, of course: Where does this cushion come from? Kuhn suggests that it's because the person with Alzheimer's does not grasp the full implications of the diagnosis as well as a person without impairment might receive a diagnosis of, say, terminal cancer.

In my case, at least, I would argue the point. It's certainly true that upon [receiving the diagnosis](#) I showed little emotion and had no immediate questions. It's true that I didn't share the same level of grief as others close to me. But I don't think it was because I failed to grasp the "full implications" of the diagnosis. No one *really* understands the full implications, of course, until he or she begins to experience them. But I knew what was coming as well as anybody!

So what does explain why the diagnosis caused me so much less shock than it seemed to cause others around me? I don't have a good answer. I suppose it could be that my deep introspection precipitated by my previous depression and consequent decision to leave medical practice left me more prepared for an overwhelming diagnosis like Alzheimer's. Perhaps it had to do with my history of meditation and the recognition that as long as I was able to remain in the present, I had no reason to fear. Perhaps it was because I hadn't experienced anything frightening yet, and was more *interested* in the diagnosis than *afraid* of it. Perhaps I realized subconsciously that the experience of the disease is worse for others than for the affected person.

Or perhaps I'm just an inexplicable exception. That seems unlikely, so I wonder if others have had similar experiences of a cushion upon hearing their diagnosis.

I would like to hear from you, either as a comment or in an [email](#). What was your reaction to finding out? If it was similar to mine, do you have an explanation for the cushioning from the shock that you experienced?

Wednesday, October 30, 2013

## Washington DC Letting Go of Alzheimer's

Since my thorough neuropsychological evaluation for cognitive impairment in late August, I've been nervously awaiting the results, which had been delayed in part by the government shutdown, including the National Institutes of Health (NIH). Last Tuesday, I finally got them: the tests were completely normal; there's no sign of cognitive impairment.

This is, of course, wonderful news and should be a great relief. I tend, however, to be a glass-half-empty kind of guy, and I don't feel much relieved: I've traded a diagnosis (Alzheimer's disease) for a set of disturbing symptoms with no reasonable explanation.

In case you've been reading these posts only occasionally, let me summarize [my situation](#). About three years ago I started having symptoms of cognitive impairment (getting lost, inability to perform certain bookkeeping responsibilities, increasingly poor memory, losing things constantly, and so on). Two years ago I visited a neurologist who administered the usual cognitive testing, which revealed mild impairment. Repeat testing a year later also show a mild degree of impairment. Other major causes of cognitive impairment were ruled out, so I was left with a diagnosis of Mild Cognitive Impairment (MCI), probably Alzheimer's. This blog has been a description of my ongoing experience with this impairment.

As part of research studies that I've participated in, I have now had [three brain scans](#) over the past eight months, none of which has shown any sign of Alzheimer's disease. This most recent neuropsychological set of tests at NIH was very intensive and extensive, about four hours in length. Unlike the previous, less thorough tests of cognitive function, this more rigorous evaluation shows no sign of cognitive impairment.

So I now have a set of symptoms that have impaired me for several years but for which I can find no reasonable explanation. The reason I have avoided making entries in this blog over the past week is that I haven't known what to write; this has so stunned me that I've had to talk it through with family and some friends. So far, I can't explain it in any reasonable way. Here are some of the thoughts I've had.

- Perhaps my previously diagnosed cognitive impairment has resolved and I've gotten better.

Unlikely. My symptoms haven't gone away. Also, any cause of cognitive impairment (of longer than six months) that might improve with time (vitamin B-12 deficiency, for instance) has been medically ruled out. These things just don't get better.

- Perhaps all the brain scans and the neuropsychological tests have been wrong.

Unlikely. Any medical test, of course, can be normal even when the disease is present. In the case of the tests I've taken, this "false negative" rate is very roughly 10% for each. Mathematically, that means that there is more than a 99.99% chance that at least one of the tests would be positive if I had Alzheimer's.

- Perhaps it's some other form of cognitive impairment.

Unlikely: Not only have I been thoroughly evaluated to rule out the other reasonable causes, but the intense cognitive testing indicates no sign of impairment for any reason.

- Perhaps I'm imagining it.

Always a possibility, but people very close to me have also seen obvious evidence of impairment for several years and no one, including a trained psychologist who knows me well, finds this possibility credible. I don't either.

There are a number of other possibilities I'll explore in later posts, but for now, any explanation I've been able to come up with is highly improbable.

As I written [before](#) , all of this can be extremely unsettling. For several days last week, I felt quite unmoored. I'd [come to terms](#) with my identity as an Alzheimer's patient and now it had become, at the very least, uncertain. This life over the past year as an Alzheimer's patient had become very meaningful and fulfilling. What was I now? What was I going to do?

But after lots of conversation with friends and family, I no longer feel so unmoored. This is but one more twist in a bumpy, uncertain road. I can trust myself and my perceptions. I can simply wait for the next step in this strange journey. I feel ready to let go and see what exciting thing will happen.

These test results, whatever they ultimately mean, are good news. At the very least, the impairment I perceive is progressing very slowly. At the very least, this is another opportunity to learn to live with uncertainty, just as most people with mild cognitive symptoms have to. It's an opportunity to [let go of self](#) .

This wild ride continues.

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