Thoughts on the Experience of Alzheimer’s

Editor’s note: The following reflections are the words of Betty, revised from the book “Speaking Our Minds – What it’s Like to Have Alzheimer’s” by Lisa Snyder.

I think it’s just within the last year that I’ve noticed I have a memory problem. As a social worker, I dealt with people who had memory problems, so now it’s a matter of being honest about my own.

I’ve been in the same swimming class for two years, and I don’t remember everyone’s names. They just escape me. I have to listen to people calling other people by name so I can catch on. I find all kinds of ways of doing that! I’ve learned many ways to get around not knowing someone’s name by relating to the person first and seducing them into doing more talking. If they talk about five minutes, pretty soon I have enough clues. I can usually identify more quickly with what people do, and where they come from, than their actual name.

There is always a startled feeling when I forget something that I could have talked about yesterday. If I sit with it a while, maybe it will come back. An hour later the whole thought may return, but it’s too late because the moment has passed.

Sometimes I can say, “Oh, I forgot to tell you this.” But it’s all a matter of timing. Also, I know that I may take something away from home, put it in my pocket, and then be completely unable to determine what I did with it. I just don’t recollect. Things like that happen sometimes. It’s there. I’m aware that my memory doesn’t work as well as it used to.

It helps that I’m not alone in this. For the time being, Kurt is there to correct me on things, and I also correct him sometimes. But as long as Kurt can stay one step ahead of me, I’m not going to worry. We’ve been a team for a long time, so I guess I don’t have much choice in the matter and neither does he.

I’m more dependent now, and I’ve never been particularly dependent. I’m not glad about the fact that this is happening. But I know that I have no choice at this point.

Sometimes when I forget something, Kurt has to get hold of himself and not get all uptight about it. Obviously, he’s having to

(continued on page 2)
Reflections
(continued from page 1)

learn this over a period of time. It irritates me that he gets ticked off over something that I’ve forgotten, and every once in awhile I blow up. I’m sorry about it, but I just forget things.

In the past, people never uttered the word Alzheimer’s for fear that they would catch it. They were defending against it. It used to be that way around cancer. But now Alzheimer’s disease has a lot of attention, and the symptoms that are described scare people— that we’ll walk blindly into a car because we’re lost and wandering. It isn’t necessarily true, but people get an idea.

When it comes to Alzheimer’s, you’re not sure how people will respond to you. None of us like unexpected responses. People may brush you away because they are afraid of the disease. They may feel uncomfortable because they don’t know what to say to you. It’s very different if you know that you are talking with someone who is familiar with the disease; there is a safety net when you talk with people who understand and care about your condition — people who don’t step on your feelings or minimize your problem. When you forget something and somebody says, “Oh well, it’s not important,” maybe it was important. It shouldn’t have been forgotten, but it was, and you need an explanation for yourself.

People may deny that they have Alzheimer’s disease because they don’t have the opportunity to talk with other people who are sympathetic and understanding and who will help them along in the whole process. That’s a sad state of affairs. Anyone who has this diagnosis needs to have others with whom to talk.

In a way, Alzheimer’s is a learning experience. I used to be able to retain a lot of information that could easily be recalled at any time, and that ability is diminishing. I’m learning that I can’t always rely on that information. So instead, I may answer someone’s question with another question. We all do that. It’s a process of trying to help ourselves.

Also, I’m observing myself and other people a little more closely. I’ve always been very sensitive to body language, emotions, and attitudes. I can tell from how a person moves whether it was a good thing or bad thing that I said. I have to use my intuition a lot more than I used to in order to pick up on the meaning of what people are saying to me. These are skills that I had training in as a social worker, so at least I’m prepared.

I think the most urgent issue for everyone is to learn the whole business of acceptance. I’ve seen too many health care
Experience of Alzheimer’s  
(continued from page 2)

professionals who have never made it to that phase. They know the diagnosis, but they don’t take time to find out what it truly means for that person. This casualness with which professionals deal with Alzheimer’s is so painful to see. A person with Alzheimer’s disease is many more things than just their diagnosis. Each person is a whole human being. It’s important to be both sympathetic and curious and to have a real interest in discovery about who that person is. You have to really be willing to be present with the person who has Alzheimer’s. But there are some people who don’t want to learn, and it’s the looking down on and being demeaning of people with Alzheimer’s that is hard to watch.

I’m all for support groups for people with Alzheimer’s disease. That’s one of the best ways to find out how varied this disease is. The primary value is in sharing experiences about a common issue without having to put up a wall because you’re concerned about how people are going to respond. The main issue is to help people to be open about Alzheimer’s—not to privatize it, especially within the family. Very often the tendency with something like this is to hold it in and suffer with it. But it isn’t necessary to suffer alone. People with Alzheimer’s are curious about what all of this is going to mean to their lives, and if they can get some sense of this through a support group, then they can move into this process more at ease. That’s very important.

Reprinted with permission. To read more reflections from individuals with Alzheimer’s, see “Speaking Our Minds – What it’s Like to Have Alzheimer’s” by Lisa Snyder. Baltimore: Health Professions Press, Inc., 2009.

MAILBOX

Editor’s note:  
We heard from many readers, including the following, who appreciated our Summer issue cover article on gratitude that was written by Angela Lunde:

Hi Lisa,
A recent focus theme in our Mind Matters Group was Gratitude. We discussed the ways you can show gratitude to someone including a thank you card, a phone call, flowers, a meal, or a smile. I put together a group poem using some of the thoughts expressed by our group regarding things they are grateful for.

Gratitude

I am grateful for the career I had as a teacher
For good health for myself and my family
I’m blessed to have the men in my life, my husband and sons
I’m grateful for being alive and to be able to walk and smell the roses
For music, kisses, jokes, chocolate, sun, smiles and church
I’m grateful for my sweet wife of 60 years, and I thank God for every minute of it
For the opportunity to be a teacher and a coach and to have a wife who supports me
For the ability to travel
I’m grateful for friends who stand beside me in all instances
I’m grateful for being part of this group.

Barb Brandt, LCPC, Program Manager
North Shore Senior Center
House of Welcome Adult Day Services
Mind Matters Early Memory Loss Program
Northfield, IL

http://www.healthpropress.com/
Question and Answer

Q With holidays coming up, I know we will be going to some gatherings with lots of family and friends. I’m nervous mostly because I can’t remember names! Do you have any advice?

A We asked people with memory loss to answer this question and here are some of the replies:

“The connection is more important than the name. Connection is something that happens between people and maybe that’s what we need to focus on and not the name.”

“If you are concentrating on someone’s name and trying to remember it, then you are missing the whole conversation you could be having because you’re obsessed with the name.”

If the name doesn’t come up right away when you see someone, find some other way to connect – comment on something else about them or the day or something. Maybe there is something you remember about them that you can talk about even if you don’t remember their name.”

“My kids and I have an agreement that if someone comes up to me at a party, one of my family members will try to address the person by their name so that I can hear it. Not that I’ll remember it, but it spares me that awkward moment.”

“Don’t let the fear of forgetting someone’s name keep you from socializing. We’re social beings and we don’t want to become hermits. If you keep the groups smaller, you can rehearse the names ahead of time. I do better in smaller groups. But in big groups, I just give it up and just say, “Hey – good to see you!”

“Look, I’d rather forget the name and remember something about the person than remember the name but not anything about who it is I’m talking to. Just focus on what you CAN remember, not what you can’t.”

Q I sometimes drink a little more over the holidays because of all of the parties. Is alcohol bad for my dementia?

A Alcohol consumption affects each person differently. Although a history of mild alcohol intake may actually help to prevent Alzheimer’s, many physicians recommend that people who do develop Alzheimer’s should limit or eliminate their alcohol intake. Alcohol can temporarily worsen symptoms by impairing concentration, memory, speech, problem solving, and judgment, as well as physical coordination and balance. This balance concern is especially important for persons with Lewy Body dementia who have greater risk of falling. Alcohol intake can also increase irritability, contribute to depression and difficulties with sleep, and interact dangerously with some medications.

Consult with your physician about alcohol consumption. Any recommendations may depend on your alcohol use history, the medications you are taking, and the impact of alcohol on your dementia symptoms. Although a toast of champagne at New Year’s is not likely to be harmful, if your physician recommends abstaining from alcohol, consider switching to non-alcoholic beverages or sparkling juices that are available in most supermarkets.
RESEARCH UPDATES

The Importance of Sleep

There has been growing interest in researching the relationship between poor or limited sleep and the risk for developing Alzheimer’s disease (AD). This fall, two separate reports about sleep reveal its important in brain health and the risk for AD. The first paper is from Johns Hopkins University where researchers found that poor sleep quality was associated with greater amounts of beta-amyloid in the brain. Beta-amyloid “plaques” are a hallmark of AD and are destructive to brain cells. Participants reporting more than seven hours of sleep had the least beta-amyloid in the brain. Those reporting less than six hours of sleep had the most, and those reporting between six and seven hours have an intermediate effect.

The second paper is from researchers at the University of Rochester, New York, where researchers explored the purpose and benefits of sleep. Through their work in laboratory mice, they demonstrated that during sleep, the brain cleans itself and removes waste that accumulated during waking hours. This “waste” can include the removal of fragments of beta-amyloid that could ultimately become damaging plaques.

Both studies shed light on a possible way in which sleep may remove beta-amyloid from the brain and reduce the risk of developing AD. These studies do not suggest that better sleep can remove amyloid plaques that have already deposited or that good sleep can cure AD. However, for overall brain health and for better quality of life for those living with AD, it is important to have any sleep problems or disturbances evaluated by your physician to ensure that you and your loved ones get a good night’s sleep on a regular basis.

We are grateful to Michael Rafii, MD, PhD for this summary of sleep revised from his blog at: http://www.adcs.org/Blog/ADCSBlog.aspx

Having a Sense of Purpose

Findings from a study at Rush University Medical Center in Chicago reveal that having a sense of purpose in life, or believing that what you do matters, may help to offset some of damage to the brain caused by AD. Rush researchers have studied more than 1,500 seniors since 1997 and all were free of dementia at the start of the study. The participants all had yearly evaluations to determine their overall wellbeing, including their sense of purpose in life. In the study, 246 participants ultimately died, and their brains were autopsied for signs of the plaques and tangles found in AD. The researchers found something very interesting. Those who reported a high sense of purpose during life were just as likely to have plaques and tangles in the brain as those who reported little sense of purpose. But despite having the same amount of plaques and tangles, those who had reported a strong sense of purpose during life had generally scored higher on tests of memory and other areas of thinking despite the plaques and tangles.

The researchers, led by Patricia Boyle, PhD, suggest that purpose in life may help to protect against the harmful effects of plaques and tangles on memory and other thinking abilities. Participating in meaningful and purposeful activities may promote greater cognitive (thinking) health. Although having a sense of purpose cannot reverse symptoms of AD, putting remaining social and cognitive skills to use through meaningful activity may play an important role in living your best with AD.
The Buddy Program - Individuals Living with Alzheimer's Mentor Medical Students

By Darby Morhardt, PhD, LCSW

Editor’s Note: In our cover story, Betty discusses her concern with healthcare professionals who aren’t interested in understanding the whole person behind the Alzheimer’s diagnosis. The following article presents an inspiring remedy to this problem and is revised and reprinted with permission from The Caregiver newsletter (Fall 2013) of the Duke Family Support Program. See http://www.dukefamilysupport.org/. For more information about The Buddy Program, contact Dr. Morhardt at: d-morhardt@northwestern.edu.

First year medical students paired with a mentoring “buddy” with early-stage dementia

“I think that as doctors, it may be easy to have the disease state overshadow everything else – and forget the reality of a disease as it effects the patient’s life – and the lives of their loved ones. I truly believe that a program like this has enabled me to see the other side of the diagnosis – and will only enhance my ability to practice later on.”

- Buddy Program Medical Student Participant

There is a growing concern over who will provide for the care of our aging population. Unfortunately, studies show that healthcare professionals and physicians in particular, tend to have a negative attitude toward older patients and a lack of awareness regarding early diagnosis of dementia. In an effort to change medical student perceptions while providing a meaningful role for persons with dementia, the Northwestern University Cognitive Neurology and Alzheimer’s Disease Center (CNADC) developed The Buddy Program, an experiential learning and mentorship program for persons with dementia and first year medical students.

The Buddy Program is rooted in the value and belief that persons with early stage dementia have the continued capacity to make meaningful contributions to society and others. The person with dementia receives companionship, social interaction, and the opportunity to mentor the student, while the student has an opportunity to have their image of persons with dementia shifted and transformed through this mutual relationship. The program originated as a result of a physician who, after being diagnosed with Alzheimer’s, was no longer able to practice medicine but believed he was still able to impart valuable experience and knowledge and ‘mentor’ a medical student.

The goals of the Buddy Program are to:

• Educate medical students about Alzheimer’s by increasing their knowledge base, heightening their awareness of skills and strengths that remain in persons with Alzheimer’s and familiarizing them with care/support issues and effective communication skills.
• Introduce students to research and practice opportunities in fields related to aging and dementia.
• Provide persons living with dementia an opportunity to serve as a mentor to a future doctor.

Since 1997, the Buddy Program has paired 167 students and persons with dementia. The ‘buddies’ plan an academic year of regular meetings (four hours a month) around mutually satisfying activities, such as visiting museums, attending concerts, sharing a meal or simply going for a walk. The students write a journal entry of their (continued on page 7)
The Buddy Program
(continued from page 6)

buddy visit following each activity.

Resulting journal themes have included: students’ expressions of a heightened sensitivity and empathy toward persons with Alzheimer’s; a change in their preconceptions of dementia; and a growing awareness of how their communication impacts the person with dementia and their relationship. For example, one student wrote, “My interactions with my mentor and his wife afforded me my first opportunity to talk about the disease to someone who has it. I realize that I need to be much more conscious of the things I say about the disease and how they may make my mentor feel. This skill of putting myself in my patient’s place and trying to understand things from his or her perspective is something that I will continue to work on because I feel it will make me a more empathic physician.”

There was evidence of an increasing comfort over time as the friendship between student and mentor grew. For example, this student reflected, “The most important thing that I took from my time with my mentor was the idea that there is a benefit to slowing down the pace of one’s life from time to time. My mentor walked slowly, she spoke slowly. Our conversations certainly moved slowly; often, we would have the same discussion several times in one visit. And I began to adjust to her pace. I would like to say that I never minded this deliberate approach, and I was certainly never upset by it, but at times near the outset I would find myself moving a bit faster or trying to determine where her thoughts were going before she’d finished speaking, as if to move the walk or the conversation along at a speed closer to my own. But I soon realized that there was really no reason to do such things, and moreover, that in doing them, I was robbing us of a great benefit of our relationship.”

Students explained how they saw their buddy as a mentor through their expressions of all they learned from them and how they will apply what they’ve learned in their practice. One student stated, “My mentor has been an inspiration on how one should always view the good and positives in life…the buddy program has allowed me to gain a unique perspective and see a person, beyond a diagnosis or disease.” And another explained, “My mentor has primary progressive aphasia, but he is not defined by his diagnosis. He is a husband, a father, a grandfather, a teacher and an art aficionado. If you ignore these aspects of the patient you are doing both the patient and yourself a disservice… I will avoid making assumptions about how the diagnosis will affect a patient’s life. I will let the patient tell me how they view their illness and how it impacts their life.”

“I will avoid making assumptions about how the diagnosis will affect a patient’s life. I will let the patient tell me how they view their illness and how it impacts their life.”

Through the buddy program, first-year medical students have been exposed to the human side of medicine in addition to the science behind dementia. The program has given them an opportunity to interact with a patient outside of the clinical setting. It has provided for the diagnosed person, the opportunity to teach medical students the importance of seeing a “patient” as a human being, and not as a disease.

The Buddy Program has been replicated at Boston, Dartmouth, and Washington Universities. This fall, the University of Kansas and Albany Medical College launch their programs with plans for the University of Wisconsin-Madison to begin in 2014. The Buddy Program is sustained in part by a grant from the Glen and Wendy Miller Family Foundation.
SUBSCRIBE TO *Perspectives*

The annual cost of four issues of *Perspectives* by surface mail is a suggested $20.00 donation or **FREE by email.** Please complete and mail the information below to begin a print subscription, or email lsnyder@ucsd.edu to request an electronic subscription.

**Name**

___________________________________________

**Address**

________________________________________________________________________

________________________________________________________________________

**Phone/Email**

________________________________________________________________________

For surface mail, prepaid orders by check or money order only (**payable to UCSD ADRC**). International orders must be received payable in U.S. dollars on a U.S. affiliated bank. Please add $2.00 for postage for international subscribers. Mail to:

Lisa Snyder, LCSW  
UCSD Shiley-Marcos Alzheimer’s Research Center  
9500 Gilman Drive – 0948  
La Jolla, CA 92093  
Phone: 858-822-4800  Fax: 858-246-1282  email: lsnyder@ucsd.edu

---

**UC San Diego**

*SCHOOL of MEDICINE*

Shiley-Marcos Alzheimer’s Disease  
Research Center

9500 Gilman Drive – 0948  
La Jolla, CA 92093