



THE AGING & ALZHEIMER'S UPDATE

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Caring for a Family Member with Alzheimer's: Barb Sloop's Story

This issue of the Aging & Alzheimer's Update is dedicated to the enduring love and caring by wives, children and others who care for persons with dementia. Here is one caregiver's story...

by David Matthews

Caring for a family member with Alzheimer's disease is a long, hard road. Barbara Sloop went down that road with her husband, Dick, who was diagnosed with Alzheimer's in 2002. Now she wants to share her experience to help others who are struggling with the care of a family member. Dick Sloop was a surgeon by profession. He had a fulfilling career, but being a surgeon was only one aspect of the person his wife describes as an encyclopedic man with boundless energy. Dick became an avid white-water boater after a boat



Barbara and Dick Sloop enjoyed visiting family and other activities before Barb took the difficult step of finding a care facility for Dick, who died in 2007.

trip on the Deschutes River. "Barb," he exclaimed, "I'm going learn to run rivers!" He built four drift boats and made extensive repairs on them over the years, as he and Barb ran rivers together throughout the great Northwest. They had a wonderful family, four sons, a daughter, and 11 grandchildren. Life was good.

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Caring for a Family Member with Alzheimer's . . .

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Alzheimer's took that away. Barb calls "Alzheimer's" her four-letter word. "But," she says, "out of everything bad something good comes. If you can help other people, that's something good that's come out of your experience."

The very first advice she would give anyone caring for a family member with Alzheimer's is to find a support group. Seek out access to friends and professionals. Don't isolate yourself from the resources available.

The disease is a moving target. The caregiver never knows what is going to come next. It is important to be able to walk with someone who experiences the same problems and difficulties, someone you can communicate with in a meaningful way.

Alzheimer's is an isolating disease that cuts people off from family and friends. Public places and ordinary social gatherings can be very difficult for someone with Alzheimer's. Barb found that she needed to keep things quiet for Dick, to avoid loud noises and surprises, which are hard for people with Alzheimer's because of its debilitating effect on understanding and judgment.

She also found that even with the difficulties, even though the road is hard, quality of life is still possible during the early and middle stages of Alzheimer's disease. She and Dick discovered that another couple in the neighborhood shared their situation. The husband had also been recently diagnosed with Alzheimer's. For a year and a half the four of them could do things together in their homes.

Don taught Dick how to play pool. Dick enjoyed this because he was very analytical and could figure out the angles. A problem developed as they progressed in the disease. They could not remember who had which balls, but they figured it out for themselves. They wrote something down. The men would play pool for a couple of hours while their wives visited upstairs. After the pool games, the four of them ate lunch or dinner. Barb's experience gave her reason to believe that if researchers can find a way to get a diagnosis in the

earliest stages and develop treatments that delay progression of the disease so it plateaus for five or ten years, this would have tremendous implications for quality of life for patients and their caregivers.

Dick's symptoms worsened as the disease progressed. He asked the same questions over and over. He checked for the mail and paper many times a day. Barb managed to connect with him most of the time. Through many trials, she realized that not only was she strong, she was strong enough.

Advanced Alzheimer's is another chapter. It is crucial for the caregiver to understand that there will come a time when the job becomes too much for one person to handle at home. Barb advises going with someone to look at different care facilities when it becomes obvious that one is needed. Let someone, preferably a friend, drive so you don't have to worry about parking or finding directions. Let your focus be on finding the very best place, asking the questions you need to ask, and taking notes.

She never felt a moment of guilt once she found the right care facility for Dick. She says without hesitation, "It's not valid to feel guilty unless you have the ability to cure them and don't do it. None of us has that ability." She adds that it is important to nurture the caregivers at the facility. "Help them get to know you as well as the patient. And remember, they are doing good work."

Dick Sloop was in a care facility for two-and-a-half years before he passed away in the fall of 2007. Now Barb is rediscovering parts of her life she put aside while caring for Dick. She explains, "You don't have your own life until death or total care, and you are still not released until death. I'm not complaining when I say this. That's just reality."

The heart of Barb Sloop's message to an Alzheimer's caregiver is that you are strong enough. You can face the reality of Alzheimer's and do what you must. But you don't have to do it alone. Part of being strong is giving yourself permission to accept help. ❁

“DELIRIUM”

Sudden confusion or agitation can signal a potentially serious medical problem. People with dementia are at high risk for developing delirium when they are in unfamiliar and stressful places such as a hospital.

Symptoms of delirium include:

- **Disorientation that is sudden and different from the usual confusion of a person with dementia**
- **Hallucinations**
- **Difficulty maintaining attention**

If any of these symptoms appear in someone you care for, alert a doctor or other clinician right away.

OTHER HELPFUL RESOURCES

The Alzheimer’s Health Care Handbook: How to Get the Best Medical Care for your Relative with Alzheimer’s Disease in and out of the Hospital by Mary Mittelman and Cynthia Epstein.
Paperback available on amazon.com.

“**Hiring In-Home Help,**” a guide to assist in hiring and managing private help in the home. For information about this and other helpful resources and services, email Legacy Caregiver Services at caregiver@lhs.org.

“**Lotsa Helping Hands**” website (www.lotsahelpinghands.com) is a free, easy-to-use, private calendar, specifically designed for organizing helpers, where everyone can pitch in with meals, visits, rides, and others tasks necessary for life to run smoothly when a family member needs care or during times of medical crisis.

Hospitalization Happens

A trip to the hospital with a family member or friend who has a memory disorder can be stressful for both the patient and the caregiver. The tips provided here can relieve some of that stress by helping you prepare for both unexpected and planned hospital visits.

Planning ahead is key to making an unexpected or planned trip to the hospital easier for both the person with a memory disorder and the caregiver. What you can do now:

- Think about and discuss hospitalization before it happens
- Let the person with dementia take part in the planning of the hospital stay as much as possible.
- Know whom you can depend on. Make a schedule with family and friends to take turns sitting with your relative during the entire hospital stay or helping you out at home.
- Shortly before going to the hospital, decide the best way to tell your family member that the two of you are going to spend a short time in the hospital.

Pack an “emergency bag” with important information:

- The person’s name, nickname, address, insurance policies, Medicare and Medicaid cards, doctors contact info.
- Current and updated list of all illness conditions, medicines and dosage instructions.
- List of medicines or foods that have ever caused a bad reaction.
- Copies of important papers such as Durable Power of Attorney, Health Care Power of Attorney, Living Will, POLST (Physicians Orders for Life-Sustaining Treatments).
- A small bag or suitcase with: change of clothes, toiletries, and extra adult briefs (e.g., Depends) if the person uses them.

Pack comfort items too: Things that help your loved one feel safe and secure such as favorite clothes, blankets, or pillow; a clock or calendar to help the patient stay oriented to time and date; a tape or CD player.

Things that might be helpful for the caregiver:

- Cell phone
- Small amount of cash
- Notepad
- Change of clothes, toiletries, and personal medications
- Pain medicine such as Advil, Tylenol or aspirin – this is for you, the caregiver, not the patient

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During the Hospital Stay

- Have someone be with the patient at all times if possible – even during medical tests
- Ask doctors to limit their questions to your relative. Arrange to answer questions from the doctor in private, outside the patient's room
- Ask the staff to avoid using physical constraints
- Help your relative to fill out the menu and to open food containers
- Remind your relative to drink fluids

If anxiety or agitation occurs

- Remove street clothes from sight
- Turn off the television, telephone ringer and intercom. Listen to soothing music
- Post reminders or cues if this comforts your family member
- Talk in a calm voice and offer reassurance. Repeat answers to questions when needed
- Give a comforting touch or distract your loved one with offers of snacks.
- Consider “unexpressed pain” (e.g., furrowed brow, clenched teeth or fists, kicking). Assume your relative has pain if the condition is normally associated with pain. Ask for pain evaluation and treatment every four hours without the patient having to ask for it – especially if he or she has labored breathing, loud moaning, crying or grimacing, or if you are unable to console or distract him/her.
- Help staff understand what your relative’s “baseline” is (his/her level of functioning before coming to the hospital) to help differentiate between dementia and acute confusion or delirium.

Remember that not everyone in the hospital knows the same basic facts about memory loss and Alzheimer’s disease. You may need to help staff understand what approach works best with your relative or friend; and ways to reduce his/her distress. Thinking about and planning for these things now can help to reduce the stress of hospital stays for both the patient and caregiver. ❄

Adapted from a booklet produced by the North Carolina Division of Aging in conjunction with the Joseph and Kathleen Bryan Alzheimer’s Disease Research Center. You can obtain a copy of the original booklet and download other helpful materials at www.nia.nih.gov/alzheimers.

Hold onto your Memory Conference on Aging & Memory in the African American Community

Over 150 African American elders and their families attended the 2nd annual Aging & Memory conference held on September 6th at Portland Community College Cascade Campus. Keynote speaker, Monique Williams, MD, from the Washington University Alzheimer’s Disease Research Center, spoke on “Quality, Culturally Competent Care for Older Adults.” Sessions were offered on Depression; Nutrition, the Heart and Diabetes; Communicating with your Doctor; and Alzheimer’s disease. An afternoon of activities provided resource information and the opportunity to sample a variety of healing practices including massage, meditation, acupuncture, and aromatherapy. Urban League of Portland, Volunteers of America, Providence Elderplace, Loaves and Fishes, The Links, and others partnered with the Layton Center to plan this conference. ❄



High school volunteers helped out at the Aging & Memory Conference and served as “listening posts” to gather attendee responses to the conference



Dr. Patrick Ethel-King’s popular session on “Depression and Stress” at the Aging & Memory conference. (photos by Tory Campbell, Beany Dion Photography. Used by permission.)

FRONTO-TEMPORAL DEMENTIA (frontotemporal lobar degeneration)

- An umbrella term for a diverse group of rare disorders that primarily affect the frontal and temporal lobes of the brain — the areas generally associated with personality and behavior.
- Some people with frontotemporal dementia undergo dramatic changes in their personality and become socially inappropriate, impulsive or emotionally blunted, while others lose the ability to use and understand language.

PRIMARY PROGRESSIVE APHASIA

- A relatively rare form of dementia caused by a disease process in the brain that results in degeneration of nerve cells in the parts of the brain that control language.
- Begins with the slow decline of the ability to use language in speaking, understanding, reading and writing.
- Other types of mental processes are relatively normal initially and may remain normal for years, but begin to decline with time.
- This form of dementia is more common in younger individuals, with symptoms usually starting in the 50's, and is more common in males than females.

Support groups are also offered in Oregon by:

The Alzheimer's Association:
1-800-272-3900

Legacy Caregiver Services:
503-413-7706

You can invest in the brain health of future generations by making a charitable gift to OHSU Layton Aging & Alzheimer's Disease Center through the OHSU Foundation. Gifts and pledges are welcomed by check or credit card. You can give online at www.ohsufoundation.org, or contact Lori Sweeney at 503 494-7455, sweeneyl@ohsu.edu.

Support Group for Family Members of Patients with Fronto-Temporal Dementia or Primary Progressive Aphasia

There is not always time during a regular clinic visit to adequately discuss the changes and problems in patient behaviors. **Fronto-temporal dementia** and **Primary Progressive Aphasia** are two forms of dementia that are often accompanied by challenging behaviors. A support group expressly for spouses or relatives of patients who have either a diagnosis of fronto-temporal dementia, primary progressive aphasia or a related disorder, has been holding monthly meetings at OHSU under the auspices of the Layton Aging and Alzheimer Center. Support groups can ease the job of caregiving by allowing participants to share successful strategies and receive emotional support.



This group is open to patients and research participants at OHSU. For more information, please contact Kathy Wild, Ph.D., at 503-494-6975.

What is the relationship between dementia and Primary Progressive Aphasia (PPA) and Fronto-temporal dementia?

- “Dementia” is a general term for a disorder of the brain usually caused by the degeneration of brain cells.

Symptoms of dementia consist of a gradual, often initially unnoticed decline in an individual's customary mental abilities and/or personality. They progress and worsen over time. Eventually, assistance is required even in routine activities of daily living.

- “Primary Progressive Aphasia”, and “Fronto-Temporal Dementia” are specific diagnoses of the cause of dementia. Each of these and other forms of dementia have different characteristics. “Alzheimer's Disease” is the most common form of dementia.



The Layton Center welcomes our new Clinic Coordinator, Teri Gilmore, RN. Teri comes to us from Providence Health system where she worked for 15 years with oncology clinical trials and more recently in patient care. Teri replaces Joyce Lear, RN, who has served as Clinic Coordinator since 1990. We will miss her!

To find out about research studies at the Layton Aging & Alzheimer's Disease Center, check our website (www.ohsu.edu/research/alzheimers) or call Teri at 503-494-7615. If you have questions about your clinic appointment or wish to schedule an appointment, please call 503-494-6976.

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OHSU

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