

Supporting Patients & Families with Dementia

THE PHYSICIAN'S ROLE

By David Troxel, MPH

In 1901, Dr. Alois Alzheimer met a new patient, a German housewife named Auguste Deter, who presented with profound forgetfulness, delusions, and other cognitive problems. Mrs. Deter was just 51 years old.

Medical historians in 1996 unearthed Alzheimer's actual clinical notes from his session with Mrs. Deter. Here is an excerpt:

She sits on the bed with a helpless expression. What is your name? Auguste. What is your husband's name? Auguste. Your husband? Ah, my husband. She looks as if she didn't understand the question. Are you married? To Auguste. Mrs. D? Yes, yes, Auguste D. How long have you been here? She seems to be trying to remember. Three weeks. What is this? I show her a pencil. A pen. A purse, key, diary and cigar are identified correctly. At lunch she eats cauliflower and pork. Asked what she is eating she answers spinach. When she was chewing meat and asked what she was doing, she answered potatoes and horseradish. When objects are shown to her, she does not remember after a short time which objects have been shown. In between she always speaks about twins. When she is asked to write, she holds the book in such a way that one has the impression that she has a loss in the right visual field. Asked to write Auguste D., she tries to write Mrs. and forgets the rest. It is necessary to repeat every word. Amnesic writing disorder. In the evening her spontaneous speech is full of paraphrastic derailments and perseverations.

Dr. Alzheimer was a beloved member of his medical community, and like many during that time, he was fascinated by the connection between mind and body. Was Auguste's profound forgetfulness and behavior some expression of mental illness? Could there be a biological basis for this behavior within her brain? Dr. Alzheimer followed Mrs. Deter until her death in 1906; then an autopsy of the brain revealed two abnormal structures called plaques and tangles, which today are the prime suspects that damage and kill nerve cells in Alzheimer's disease.

The rest, as they say, is (medical) history, and Auguste Deter was the first person described as having Alzheimer's disease in what was then thought to be a rare condition. Dr. Alzheimer advocated for Mrs.

Deter, but she nevertheless died in a lunacy asylum. Dr. Alzheimer died long before his name became famous—and long before the disease named after him became a global public health concern.

Today, the numbers are staggering. According to the Alzheimer's Association, a person is diagnosed with Alzheimer's disease or another dementia every 70 seconds. One in four families will be touched by dementia, and 5.4 million Americans have dementia, 500,000 of them under the age of 65.¹

As baby boomers now enter their 60s, dementia is becoming a major crisis. Cases will double or even triple in the coming decades, and there is still no truly effective treatment. The four FDA-approved medications for dementia including the cholinesterase inhibitors may enhance memory and functioning for a short period of time, but as a family member recently told me at a presentation in Wenatchee, current dementia medications "are like parachutes... they slow you down but you still eventually hit the ground."

For every person with dementia, there is a caregiver, and the Alzheimer's Association says that this number is more than 15 million and growing.² Most of these caregivers will seek out advice and support from a physician. In preparation for this article, I asked several physician friends and colleagues about their experiences working with families coping with dementia. Here are some of the responses:

"Families are hungry for information... I wish I knew more about local resources."

"Very challenging. The dementia patient and his or her family demand more time than I can reasonably give."

"Frustrating... medications don't help all that much with symptoms and behavioral meds can make matters worse."

"Because my mom had Alzheimer's, I try to walk a mile in their shoes. A hopeful attitude helps."

The above comments are reflective of my own experiences working with physicians and the medical community during my years with the Alzheimer's Association and in university settings. Alzheimer's and other dementias represent a perfect storm for many practicing

1 Alzheimer's Disease Facts and Figures, Alzheimer's Association, www.alz.org/downloads/Facts_Figures_2011.pdf

2 World Alzheimer Report 2010: The Global Economic Impact of Dementia, Alzheimer's Disease International, www.alz.co.uk/research/files/WorldAlzheimerReport2010ExecutiveSummary.pdf

physicians. Dementia doesn't have a ready cure or a long-lasting treatment, requires time-consuming family and caregiver education, involves complex family dynamics, and may trigger behaviors that are upsetting, challenging, and even dangerous. How does the physician find the time for all of this? How can he or she best support patients?

When my own mother, Dorothy, was diagnosed with Alzheimer's disease in 2001, her physician Dr. Robert Harbaugh, a neurologist in private practice in Santa Barbara, California, navigated this storm brilliantly. When he gave us her diagnosis, he was honest and direct but upbeat, "Dorothy, welcome to the memory-loss club," he said. "You have Alzheimer's disease. One in four people your age have this problem. Thank goodness you have a supportive family. Make the best of this, stay active, go to Macy's more often and spend your husband's money." Dr. Harbaugh also encouraged my father to go to a support group or to contact the Alzheimer's Association for further assistance. Mom left the doctor's office smiling and with a sense that we were all in this together—even as my father worried about the next Macy's bill!

Recommendations

Here are some tips and recommendations for working with dementia patients and their families:

For the Patient

- **Be direct and honest about the diagnosis.** Families will often ask the physician to not disclose a diagnosis of Alzheimer's disease or other dementia. They worry that the bad news will be devastating to Mom or Dad. This puts the physician in an untenable position, and indeed most physicians will rightly overrule a family request and go ahead and tell the patient his or her diagnosis. When secrets are kept, it makes it harder for families to openly use services. Patients have the right to know. We should model the right way of talking about this disease.



Jack and Jean Sorensen. Jean is a resident at Expressions of Enumclaw, a Prestige Memory Care Community. Also pictured is Expressions Director, Cindy Detrick

- **Encourage neuropsychological testing.** Many persons with dementia can give Academy Award-winning performances that fool professionals and family members with their remaining cognitive reserves. This may be one reason why many family members remain in denial—and why conflict between siblings is common; one sister feels mother is fine, and the other is convinced she needs to move into residential care immediately. A neuropsych evaluation lays out a clear picture in a comprehensive, written report. Even the strongest case of family denial will waver when the report (usually covered by Medicare or insurance) quotes mother as liking President Eisenhower and stating her age as 40 instead of 80.
- **Recast the illness.** Dr. G. Allen Power, a geriatrician in Rochester, New York, recently published an excellent book called *Dementia Beyond Drugs*.³ In an interview for this article, Dr. Power said his best advice for his fellow physicians was to "think of dementia not as a fatal disease, but as a chronic disability. When we view dementia purely from the standpoint of disease and decline, we drastically lower our expectations for the person's abilities and overall well-being. But when we focus on their strengths [it is still possible to] enable them to grow and find meaningful engagement throughout life. This simple change in mindset can significantly improve the well-being of millions of people living with cognitive difficulties." It's unconventional, but one "treatment" for dementia may be to volunteer at an animal shelter, continue playing the piano, or plant a garden.
- **Suggest positive lifestyle changes.** Supporting Dr. Power's remarks, recent research suggests that exercise is good for the brain and may even slow dementia.⁴ Social engagement fights depression and keeps the person cognitively active. The Alzheimer's Association has supported findings about heart health and diet to suggest that what is good for the heart is good for the head. These are positive action steps we can recommend to persons with dementia, certainly cause no harm, and may have ancillary benefits such as building muscle strength and lowering the risk of falls.

For the Family Caregiver

- **Be sure you hear the "testimony" or story of the caregiver.** Even in this high-tech age of brain scans, many physicians would agree that the family's story is still the most influential piece of information needed for diagnosis. Make sure that the caregiver is

continues

3 Power, G.A., *Dementia Beyond Drugs*, (Baltimore, MD: Health Professions Press, 2010).

4 Reynolds, Gretchen, "A Memory Tonic for the Aging Brain," Health and Wellness, Well Blog, *NYTimes.com*, <http://well.blogs.nytimes.com/2011/05/25/a-memory-tonic-for-the-aging-brain/?ref=health>

with the patient in your office during your examination or interview (persons with dementia are very poor reporters, and left to their own devices they won't deliver your recommendations to their family), and encourage them to keep notes or diaries noting behavior and changes. This will help you make the most of your office visit.

- **Encourage education.** I predict that caregiver education will soon be seen in the same light as diabetes education or education surrounding self-management of arthritis. As Dr. Power suggested, Alzheimer's has become a chronic condition; families are in this for the long haul. We need to teach them the importance of getting what I have coined "the knack of caregiving." The knack is the "art of doing difficult things with ease or clever tricks and strategies." The knack includes learning patience and acceptance, remaining flexible, keeping your sense of humor, keeping patients busy and engaged, creative communication, and learning ways to redirect individuals away from challenging behaviors.
- **Encourage legal and financial planning.** Patients with capacity and caregivers should execute a power of attorney to a trusted party and complete their durable powers of attorney for health care.
- **Encourage early use of services.** Even the best caregivers sometimes wait too long to take advantage of services. One way of encouraging them to seek help is to remind them that socialization is, in many ways,

the treatment for dementia. We want our patients to participate in adult day care center, have a supportive and friendly home worker, or live in an activity-rich assisted-living memory program. Not using services tends to keep the patient isolated, contributing to a more difficult caregiving experience.

The go-to organization for caregivers is the Alzheimer's Association (www.alz.org). Based in Seattle, the association's Western and Central Washington chapter partners with physicians and other health care professionals to support persons with dementia and their caregivers. A 24-hour helpline is available at 800-272-3900. There, anybody, including physicians, can ask questions, receive information and referrals, and request resources. The association sponsors more than 100 support groups, ongoing workshops and conferences, and will send or deliver brochures and materials to any physician's office upon request.

One suggestion I can make is to "prescribe" services. Take your standard prescription pad and jot down "Adult day care center three times a week," or "Support group," or "Contact the Alzheimer's Association at 206-529-3886." This can be a powerful way to reinforce your recommendations. Even better, you can be the "bad guy" if the patient or a family member doesn't want to move forward. An adult son or daughter can say to his or her father, for example, that it is "doctor's orders" that he attend a support group or that mom attend a day care center!



At a recent conference, I heard a prominent researcher say, "Our field of knowledge about Alzheimer's disease and dementia is doubling every 18 months." Despite this impressive statement, a cure for Alzheimer's disease and other dementias is proving elusive. Many drugs in the research pipeline have failed, and some of the core theories about Alzheimer's causation have come under attack.

We don't have a treatment, but I would argue that we do have a strategy. We can create a therapeutic environment that fosters happiness and reduces challenging behaviors. This is achieved through meaningful activities, music, nutrition, exercise, and socialization. It is supported by well-educated caregivers who don't wait to use services. It also is supported by physicians who give good information and offer encouragement that Alzheimer's can be a journey instead of a destination. We can travel that route and come out at the end feeling good about having given our family members a life with as much dignity as possible. ■

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An Alzheimer's Disease Bill of Rights

Every person diagnosed with Alzheimer's disease or a related disorder deserves:

- To be informed of one's diagnosis.
- To have appropriate, ongoing medical care.
- To be productive in work and play as long as possible.
- To be treated like an adult, not a child.
- To have expressed feelings taken seriously.
- To be free from psychotropic medications if at all possible.
- To live in a safe, structured and predictable environment.
- To enjoy meaningful activities to fill each day.
- To be out-of-doors on a regular basis.
- To have physical contact including hugging, caressing, and hand-holding.
- To be with persons who know one's life story, including cultural and religious traditions.
- To be cared for by individuals well-trained in dementia care.

Virginia Bell & David Troxel, *A Dignified Life: The Best Friends Approach to Alzheimer's Care*. Health Communications Press, 2002. www.bestfriendsapproach.com