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Treating an Alzheimer's patient? 6 tips from a patient's spouse

The author's wife struggled with Alzheimer's disease for 10 years. The insights he provides here are drawn from his experience—and the literature.

What's it like to be the caregiver for an Alzheimer's patient? In my case, it was like being both married and widowed at the same time. Or as a person in my support group once put it: It's a life filled with grief on the installment plan.

My wife, Clare, struggled for nearly 10 years with Alzheimer's disease before passing away in April 2016—just one month shy of her 70th birthday and 2 months shy of our 49th wedding anniversary.

Our experience was gut-wrenching, but not unique for families coping with Alzheimer's disease. Life as a caregiver is one of non-stop daily stress, with much sadness and anxiety, often accompanied by periods of mild or serious depression. Doubt, guilt, frustration, and many other emotions lead many caregivers to take anti-anxiety or antidepressant medication, meet regularly with therapists, take sleeping pills, or experience significant weight gain or loss. Stress drove me to my comfort foods, and I gained nearly 100 pounds while caring for Clare. Only in the

last few months have I been able to start taking off that weight.

Helping a loved one who has Alzheimer's with even the basic activities of daily living—hygiene, dressing, eating—becomes progressively difficult. Caring for a loved one who is confused, no longer remembers your name or who you are, or can occasionally become aggressive, is emotionally painful.

After being Clare's 24/7 caregiver for 6 years, I agreed that placement in an assisted living facility was in her best interest. My role morphed from primary caregiver to primary care advocate, but the stress did not lessen. I met regularly with facility staff to ensure proper care because many staff members were not sufficiently motivated, educated, or trained to consistently provide proper care for individuals with Alzheimer's disease.

Financial stress weighs heavily on caregivers. Unless one qualifies for Medicaid, is very wealthy, or is lucky enough to have outstanding long-term health care insurance and prescription drug coverage, caregiving

costs can be astronomical. For someone with Alzheimer's in a community such as Long Island, NY, assisted living facilities charge between \$7000 and \$10,000 per month, and nursing homes between \$15,000 and \$18,000 per month. Home health aides working 24/7 also cost around \$15,000 per month. Caregiving costs can drain not just the patient's bank account, but can wipe out the retirement life savings of the surviving caregiver.

Once Clare went into assisted living, I dealt with the daily loneliness and the enormous lifestyle changes. Being alone in my bed those first few nights after placement was painful beyond words, and learning to live alone for the first time after many years of marriage brought incredible sadness. It is no surprise to me that research points to caregiver stress as an independent risk factor for elderly caregiver mortality.¹

My experience navigating the health care system with my wife included numerous challenges and instances of unnecessary frustration. My hope in providing the following suggestions is that they will help you help other families like mine.

1. Listen carefully to caregivers

When Clare first exhibited symptoms suggestive of Alzheimer's, I started logging them and presented written summaries to doctors at each visit. But unless Clare exhibited those same symptoms in the presence of her doctors, my observations were routinely ignored. I'd try to discuss concerns—eg, Clare getting lost while driving to familiar locations, experiencing increased aphasia—but the doctors didn't read my logs or listen carefully to what I was trying to tell them. The January/-February 2017 AARP Bulletin² noted studies showing that doctors listen for about 23 seconds before interrupting patients, but it also cited a 2001 South Carolina study³ that found patients spoke, uninterrupted, for an average of 12 seconds before being interrupted by a resident.

I eventually did learn that early Alzheimer's symptoms can be easily misinterpreted as signs of stress, anxiety, or depression. But that underscores the need for doctors to listen carefully to caregivers, especially spouse caregivers who observe behaviors 24/7 that

may not be present in a quick office visit or revealed on a brief cognitive screening test.

2. Stay up to date on screening tools that detect Alzheimer's

The Mini-Mental State Examination, or MMSE, is the most frequently used cognitive screening tool, in part because it can be administered in less than 10 minutes. Although unquestionably valuable, a Cochrane review "did not find evidence supporting a substantial role of MMSE as a stand-alone single-administration test in the identification of MCI [mild-cognitive impairment] patients who could develop dementia."⁴

Time-pressured doctors might consider using the AD8 screening interview, an informant questionnaire that takes only 2 to 3 minutes to administer, but has demonstrated superior sensitivity in detecting early dementia compared with the MMSE.⁵ In addition, a study in the December 2016 issue of the *Journal of Alzheimer's Disease*⁶ confirmed the usefulness of the Sniffin' Sticks Odor Identification Test whereby patients try to identify 16 different odors. I can attest to Clare's rapidly deteriorating senses of taste and smell as her disease progressed.

"Results suggest that a simple odor identification test can be a useful supplementary tool for clinically categorizing MCI and Alzheimer's, and even for identifying people who are at the highest risk of worsening," according to principal investigator, David R. Roalf, PhD.⁷

Prompted by prior studies that have linked a weakening sense of smell to Alzheimer's, doctors in a few larger dementia clinics have already begun using smell tests in their assessments. One possible reason the practice has not yet become common, however, is that the tests take about 5 to 8 minutes to administer. Roalf and his colleagues are hoping to develop a shorter test that will work as well as the longer ones. "We're hoping to shorten the Sniffin' Sticks test ... down to 3 minutes or so ... We think that will encourage more neurology clinics to do this type of screening."⁷

Is 5 minutes too much time to take to administer a valuable screening test?



A simple odor identification test can be a useful supplementary tool for clinically categorizing MCI and Alzheimer's.

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➤ If caregivers have already observed issues with their loved one's driving ability and ask you to intervene, please help remove a major cause of caregiver stress while also making our roads safer.

3. Be candid when speaking with patients and their caregivers

A survey reported in *Time* magazine on March 24, 2015, found that as many as 64% of doctors do not share a diagnosis of Alzheimer's with their patients because of "fear of causing emotional distress in their patients" due to a lack of effective treatment or cure, and because of a "lack of time and resources to fully explain what the diagnosis means."⁸

But Alzheimer's patients and their caregivers need as much time as possible to plan accordingly, especially if they have not already discussed and finalized end-of-life planning (will, living will, health care proxy, durable power of attorney), preferences for staying at home with aides or being placed in a facility, or wishes to take final trips or enjoy final activities together before cognitive impairment worsens. Withholding a diagnosis can rob patients and caregivers of that valuable planning time.

4. Connect caregivers to resources and support groups

Information on the stages of the disease, available local support groups, and online resources are extremely helpful. Of the 15 people in my spouse support group, only one or 2 were referred there by a doctor. Become familiar with local support groups because that is where caregivers discuss common needs, learn and share helpful caregiving strategies and techniques, and find emotional support from others walking in similar shoes.

5. Help caregivers take away the car keys

When to take away the car keys is an extremely difficult emotional decision that often leads to heated arguments. People with Alzheimer's rightfully fear losing their independence and only reluctantly accept they can no longer drive safely. But their caregivers worry about them getting lost or causing an accident or, worse, a death. Even though some people with Alzheimer's can continue to drive safely for a while, the ever-worsening cognitive decline with the disease sooner or later leads to impaired judgment

and the inability to drive safely.

If caregivers have already observed issues with their loved one's driving ability and ask you to intervene, please help remove a major cause of caregiver stress while also making our roads safer. And please do not routinely refer people with Alzheimer's to driving test facilities. A person with Alzheimer's may do very well at the particular moment of the test, yet might fail that same test if it was given an hour earlier or later.

6. Manage expectations of what medications can do

None of the current FDA-approved medications have proven to have any long-term positive effects on Alzheimer's. Clinical trial data show that these meds may be able to slow the rate of disease progression for some people who take them, but even then the benefit is short-lived. Yet many doctors, year after year, renew these "expensive bottles of hope," as I call them, when the thousands of dollars needed to buy them could be much better spent on day-care programs or personal aides. A candid disclosure to patients and caregivers would enable better decision-making. **JFP**

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