

Chris and Mark Donham

Since Chris was diagnosed with Alzheimer's, the couple have taken numerous cross-country motorcycle trips.

Avoiding Caregiver Burnout

How to not lose your wits when cooking, cleaning, driving to doctors, putting pills in little boxes, and taking care of someone you love.

BY PAT OLSEN

ver since Chris Donham first started showing signs of Alzheimer's disease, her husband Mark has taken her on motorcycle trips around the country to visit friends and family. A year and a half ago, he left his job as a sales representative to become a full-time caregiver for Chris. The couple, from Lake Oswego, OR, may seem young to be in this situation—Mark is 45, and Chris, who has early-onset Alzheimer's, is just 51—but they are not alone. Caregiving is equal-opportunity employment, if also a labor of love.

And if you aren't careful, it can burn you out.

SOURCES OF BURNOUT

Mark's devotion to Chris is obvious: A few months ago, he hung family photo collages throughout the house to keep memories alive for her. Not only does he make sure they go on walks every day, he's also taken her cross-country to visit friends. Mark's strong religious beliefs and a local Alzheimer's support group have helped him cope with a difficult situation, but he knows he has to take care of himself, too.

"You don't realize how much stress and strain there is," Mark says. "If you look at the statistics for caregivers of Alzheimer's patients, 50 or 60 percent have health problems." In a study reported in the September 2007 issue of the *Journal of Immunology*, researchers found that caring for an Alzheimer's patient can shorten a person's life by four to eight years. Over 40 percent of these caregivers report high levels of emotional stress, according to a 2007 report from the Alzheimer's Association.

There are two potential sources of caregiver burnout, says Lisa Shulman, M.D., associate professor of neurology at the University of Maryland, who conducts studies on caregiving in Parkinson's disease. "There's both emotional strain and physical strain," she notes. "Although we usually think of the emotional

When it comes to making **big decisions** about care, don't wait until a crisis hits.

strain of caregiving, providing for the needs of a person with disabilities also takes a physical toll."

"Physical symptoms can include exhaustion, difficulty sleeping, changes in appetite or weight, and a tendency to get sick more often than in the past," says Robert Heinssen, Ph.D., clinical psychologist and researcher at the National Institute of Mental Health.

The importance of self-care was brought home to Mark recently. After dropping his wife off at her once-a-week respite care at a local community center, he ended up in an emergency room with signs of a possible heart attack. He was fine, but it was the wake-up call he needed. He is increasing Chris' respite care to twice a week and plans to get in-home care once a week. He is also wise to have sought out a support group, according to a recent study in the journal *Neurology*. Researchers found that when Alzheimer's caregivers get support and counseling, it benefits them and can keep the patients they care for out of a nursing home longer.

CAREGIVING 101

"It's so easy to get burned out caring for someone," warns Janet Jankowiak, M.D., a geriatric and behavioral neurologist at Radius Specialty Hospital in Boston. Her father has Alzheimer's and is in an assisted living facility. Dr. Jankowiak finds that keeping her dad organized and on a schedule, and providing as much structure as possible—from writing his activities on a calendar to arranging his clothes for the week—helps them both immensely.

One holiday, she thought that having him visit with the family the entire day would be enjoyable, but he "sundowned," becoming anxious as evening began. Dr. Jankowiak realized they both would have been better off had she just invited her father for dinner like always, she says, which is in keeping with a suggestion from the Alzheimer's Association to try and maintain the person's normal routine during holidays.

Dr. Jankowiak sets an example for others in situations like hers by exercising and getting assistance. "If you're the primary caretaker and something happens to you, there's no one else to do it," she says. She has also enlisted her teenage son in the caregiving process, and he has been an enormous help with her father, she says. Dr. Jankowiak also hires additional aides to help her dad at the facility.

Depending on the disease, says Dr. Shulman, your loved one has two competing needs: one for assistance, and the other for independence. If a caregiver provides too much assistance, it can result in an adverse consequence—the patient may do less than he is able. This can lead to the patient "giving up" and allowing himself to be treated like a child. But it's also a priority to be fully attentive to the patient's needs. Caregivers "walk a tightrope," Dr. Shulman explains.



Emmajane Valpicelli Pictured here with her instructor Emmy

her instructor, Emmy has taken ballroom dancing lessons to reenergize herself.

DON'T WAIT TO MAKE DECISIONS

Mark has learned another important lesson about caregiving: When it comes to making the big decisions, don't wait until a crisis hits. He borrowed the mantra "Sooner rather than later" from a woman in his support group and is starting the search for long-term care now. Years ago he and Chris prepared for the possibility that she'd fall ill; her family carries the gene for early-onset Alzheimer's and several of her family members died of the disease before age 55. First came investment planning so that Mark could care for Chris at home when the time came. Then the couple took care of wills and other legal documents and bought long-term care insurance for her. Investigating nursing homes now helps ease his mind.

EMOTIONAL CAREGIVING:

▶ BE HONEST WITH THE PERSON RECEIVING CARE:

Acknowledge that it's not an easy decision, but that you need it for your own well-being. Be sensitive to the person's feelings about being a burden, spending money, and having a stranger help with care. You might say "I wish I could continue doing _______, but I just can't. You're very important to me and it would be a great relief if I knew your needs and my needs were being met."

- ▶ **LEAN ON FRIENDS:** Friends who listen and offer advice only when asked are invaluable. Ask outright if you can use your friend as a sounding board when you need to. If just one person can do this, try not to overburden him or her.
- ▶ TRY A SUPPORT GROUP: Support groups are good ways to blow off steam and share ideas with people facing similar situations. An online support group is good for homebound caregivers. Hot lines can help when a crisis strikes.
- ➤ **CONSIDER THERAPY**: If you frequently feel depressed, overwrought, or overwhelmed, get help from a psychiatrist or therapist. If you don't know where to turn, ask your doctor for a referral.

Source: Caregiver's Handbook: A guide to caring for the ill, elderly, disabled...and yourself (Harvard Health Publications, updated 2007)

Stephen Sergay, M.D., president of the American Academy of Neurology, seconds Mark's advice about decision-making. Although he was living in the U.S., thousands of miles away from his parents in South Africa, Dr. Sergay experienced many caregiver challenges. When their health declined to the point where they needed assisted living, he traveled to their home to tour assisted living facilities with them. Invariably, his father would put down a deposit and call Dr. Sergay as he was boarding a plane back to the States to say he had changed his mind. It took visits to about 10 facilities before his father accepted the change he was about to make.

ATTITUDE IS EVERYTHING

Understand that caretaking is a process that may involve everything from changing where your loved one resides to revising what you accept as normal. The timeline requires that you be gentle and have patience. If you understand this, Dr. Sergay says, you'll be calmer and better equipped to deal with your role. For example, you might choose respite daycare within a larger, long-term facility to introduce your loved one to the idea of long-term care. If you know your family member is comfortable with a facility, then you'll feel more comfortable, too.

To reduce your anxiety, don't hesitate to include your family doctor and neurologist in conversations about long-term care for your family member, advises Dr. Sergay. His patients and their families often make an appointment with him to chat about a family member's future, and it's not unusual for them to have several additional meetings.

Finally, try to be tolerant, Dr. Jankowiak suggests. Realize that your loved one isn't deliberately trying to annoy you when he does things that seem to make no sense. If you've told him something 10 times, take a deep breath and have faith that he's trying to do his best.

HANDLING GUILT

Probably all caregivers feel guilty at one time or other. Maybe you feel you're not providing enough care, or the right kind of care, for your loved one, or maybe you're upset that you've lost patience occasionally. You may feel bad about wanting more time for yourself, or you may be having a hard time with all that's involved in caregiving. This is natural, but it also may be a sign that you need a break.

You can't be a good caretaker if you don't take care of your-self. A commonly-used analogy is the advice given to airline passengers on takeoff: in an emergency, fasten your own oxygen mask first before attending to a child's mask. The same principle applies to caregiving. You've got to tend to your needs first if

Your loved one has **two competing needs:** one for assistance, the other for independence.

you're to be responsible for another person.

If you're involved in long-distance caregiving, you're likely dealing with the guilt of not being physically present. You may not feel as physically drained as a caretaker who's present all the time, but that doesn't mean you're not worried and anxious. The National Institute on Aging suggests that you remember you're doing the best you can in your situation, and to take comfort in knowing that you're not alone. Support groups can also help long-distance caregivers.

BEYOND LONGTERM CARE: WHAT ABOUT YOU?

Emmajane (Emmy) Valpicelli, 59, of Tinton Falls, NJ, is testimony to the depression that can hit caretakers after a loved one enters a nursing home. When her husband Tony, 61, had

PRACTICAL CAREGIVING:

- ► GET ORGANIZED: File paperwork under key topics: medical care, benefits, resources, assisted living, etc.
- **▶ KEEP THE PERSON'S MEDICAL HISTORY AND MEDICATIONS LIST HANDY:** Store these in a binder in which you log conversations—to whom you spoke, when, and what was suggested.
- ► COORDINATE MEDICAL CARE: Each doctor should know what the others suggest and what medications the patient is taking.
- ► ASK UNTIL YOU HAVE ANSWERS: Don't be afraid to ask for simpler explanations, a breakdown of the risks and benefits of a particular treatment, or a second opinion.
- ▶ BE INFORMED: The National Institutes of Health's MedlinePlus Web site (medlineplus.gov) offers reliable information on hundreds of conditions.
- ▶BE PRESENT: At the hospital, it helps to have an extra set of eyes and hands. Tell staff if you notice confused or erratic behavior.
- ▶ NETWORK: Get recommendations on nursing homes or home health care from social workers, doctors, nurses, friends, family members, and co-workers.

Source: Caregiver's Handbook: A guide to caring for the ill, elderly, disabled...and yourself (Harvard Health Publications, updated 2007)

a stroke a few years ago, she left her job as a medical biller to care for him full-time. The petite brunette tried hiring aides but felt that no one could care for her strapping husband quite like she did, even with their size difference.

Like Emmy, half of all caregivers care for a loved one alone, according to the Caregiver's Handbook: A Guide to Caring for the Ill, Elderly, Disabled...and Yourself (Harvard Health Publications, updated 2007). If her husband's stroke was the first blow to Emmy's serenity, having to move him to a nursing home when he developed additional medical problems was the second. Not only was she wracked with guilt, she felt empty.

"Since I was no longer caring for him, I had no identity and I didn't know what to do next," she says. Worried at seeing their mother sitting around moping, her two grown daughters pressed her to find something that excited her. Years earlier Emmy loved to go out dancing, so she decided to take ballroom dancing lessons as a refresher. Now she advises all caregivers to find something they love to do.

"It changed my life," says Emmy, beaming. "I have confidence now," she adds, explaining that dancing teaches you to hold yourself erect and present a self-assured image that affects your whole outlook. She's 15 pounds lighter, she feels great, and she has acquired a whole new group of friends. She even enters dance competitions.

And if she had one thing to do over in caring for her husband? Emmy's answer is instructive for other caregivers. "I think I would take all the help I could get," she says. "Whether you do something better than someone else or not, it still gets done."

FINDING THE IOY

As a devout Christian, Mark feels it's an honor and privilege to care for his wife, regardless of the stresses that come with the job. He has one last thought for caregivers. "For all the negative things about being a caregiver, there are some times that are just amazing," he muses. "We tend to forget the joy of the moment, where things are vivid and real."

He describes watching a sunset over the water with his wife one day. Chris was exuberant on catching sight of the brilliant red and orange sky, and then she glanced away. When she turned back, it was as if she were seeing it for the first time. There is joyfulness in those moments, Mark says—joy that comes with letting go of expectations and cherishing the relationship that is still very much alive.

Pat Olsen (patolsen.com) has written for publications such as Remedy, Diabetic Living, and Bipolar magazine. Like many people, she has caregiving experience herself.