



Support for Alzheimer's Caregivers

Caring for a loved one with Alzheimer's? It's just as important that you take good care of yourself. Learn about the many kinds of caregiver support available to you.

By Elizabeth Shimer Bowers, Medically reviewed by Farrokh Sohrabi, MD, 12/10/2013

A mother changes her baby's diaper, never thinking that her son or daughter will be doing the same for her 60 years in the future. Such is the circle of life for families affected by Alzheimer's disease, where sons and daughters, nieces and nephews, and others become full-time caregivers for their loved ones.

Alzheimer's caregiving can take a serious toll on your emotional and physical health. Finding support is essential both for your own well-being and to be the best caregiver you can be.

Alzheimer's Caregiving: Know That You're Not Alone

Alzheimer's disease is a type of dementia that causes problems with thinking, memory, and behavior that affects an ever-increasing number of people. About 5 million Americans are living with Alzheimer's today, but as the U.S. population ages, that number is expected to balloon to more than 7 million by 2025 and to nearly 14 million by 2050. This also means that more people are becoming Alzheimer's caregivers each day. According to the Alzheimer's Association, 15.4 million caregivers provided more than 17.5 billion hours of unpaid care for loved ones with Alzheimer's in 2012 — care valued at \$216 billion. And there's also the emotional cost of being a caregiver, a burden that cannot be quantified.

"Being a caregiver for a loved one with Alzheimer's disease can be taxing physically, emotionally, and mentally — it's truly a 24 hour-a-day job," says Ashley Gorman, PhD, a board-certified neuropsychologist with Morris Psychological Group in Parsippany, N.J.

Because being an Alzheimer's caregiver is so tough, finding caregiver support is extremely important. "Caregivers need to take care of themselves for two main reasons," says Kathy Kniepmann, OTD, MPH, EdM, OTR/L, a researcher and occupational therapist at the Washington University School of Medicine in St. Louis. "First, they deserve to stay healthy and enjoy life, even if most of their time is spent helping their loved one with Alzheimer's," she says. "And second, if the caregiver's health declines, he or she will no longer be able to help their loved one."

Because you devote so much time and effort to your loved one, it's important to consider multiple types of caregiver support. Support may come in the form of help from friends and family members, formal support groups geared toward helping Alzheimer's caregivers, and time spent doing activities you enjoy.

Finding Alzheimer's Caregiver Support

“The Alzheimer’s Association offers many forms of support,” says Katie White, early-stage coordinator for the Central Ohio Alzheimer’s Association. “For example, at our chapter, in addition to educational materials and support groups, we offer care consultations and programming designed for individuals living with Alzheimer’s.” Other resources include adult day care, in-home assistance, Meals on Wheels, and visiting nurses. “The services offered provide a safe and supportive environment for caregivers to share, learn, and prepare for the future,” White says. To find these and other resources, start with your local Alzheimer’s Association, call the Alzheimer’s Association’s 24-hour help line at 800-272-3900, talk to your doctor, or contact your local hospital.

Other options for Alzheimer’s support include:

Access Alzheimer’s educational materials. “From a medical standpoint, caregivers can do a better job of being an advocate for their loved one with Alzheimer’s if they’re educated on the disease,” says Joyce Fogel, MD, chief of geriatric medicine at Beth Israel Deaconess Medical Center in New York City. As the disease progresses, you’ll be able to better cope and care for your loved one if you know what to expect in terms of behavioral and personality changes. “As a caregiver, you want to make sure to treat your loved one with respect and not like a baby, and finding that fine line involves being properly educated on Alzheimer’s,” Dr. Fogel says. “The Alzheimer’s Association is a great resource for educational materials, as is the National Institute on Aging.” Fogel also recommends asking your doctor or local hospital for educational materials on Alzheimer’s disease. “Hospital social workers can be a tremendous resource for caregivers,” she adds.

Connect with family and friends. “If it’s possible, as a caregiver you should sit down with other family members and divide care responsibilities in a realistic way,” Dr. Gorman says. “Family members can offer caregiver support by being there to lend a hand or simply to talk and listen.”

Beyond family, friends and neighbors can also provide a means of support for caregivers. “There are also day programs for people with Alzheimer’s disease that can give caregivers a few hours of break time during the day,” Fogel says.

If you’re reluctant to ask for help, start by asking for a little support here and there. “Ask a family member or friend to stay with the person with Alzheimer’s disease for an hour once a month or once a week so you can go to the grocery store or attend an appointment,” Kniepmann suggests.

Join a support group. Caring for a loved one with Alzheimer’s disease can be very isolating, but realizing you’re not alone as a caregiver can help. “Support groups specifically for Alzheimer’s caregivers can help caregivers feel connected and learn from others’ experiences,” Gorman says. To find an Alzheimer’s caregiver support group near you, call your local chapter of the Alzheimer’s Association, inquire at your local hospital, or talk to your doctor.

See a mental health professional. “It’s not uncommon for Alzheimer’s caregivers to experience feelings of grief, anxiety, and depression,” Gorman says. According to the Alzheimer’s Association, warning signs of caregiver stress or burnout include anger, social withdrawal, anxiety, irritability, problems concentrating, sleep issues, and exhaustion. “If you experience any signs of caregiver stress, tell your doctor, or if you already have a connection with a mental health professional, consult that person,” Gorman says.

Pursue favorite leisure activities. According to research done by Kniepmann and published in *The British Journal of Occupational Therapy*, female caregivers (of stroke survivors, in this case) who cut back on or quit activities they enjoy are more likely to feel burdened and have poorer mental health. "Taking care of yourself includes taking time for fun because leisure activities support well-being by providing an escape, a diversion, and social interaction," Kniepmann says. "Some Alzheimer's caregivers feel guilty about taking time for fun, but they need to realize that leisure time can refuel them."

Make healthy choices. Alzheimer's caregivers can become so focused on their loved ones that they neglect their own physical health. "Eat healthfully, try to exercise every day, and see your doctor regularly," Gorman says.

Overall, it's important for you to take good care of not only your loved one, but of yourself as well. "Go easy on yourself, keep your expectations realistic, and stay positive," Gorman says. "Feel good about all the things you're doing for your loved one, and don't feel guilty about the things you aren't doing. Go for a walk, read a book, or have coffee with a friend. Make sure to do the things that make you feel rejuvenated so you can be the best possible caregiver for your loved one with Alzheimer's."