

Living with Alzheimer's, A Disease Without Boundaries

BY DAVID GOODMAN AND FRANK ESPOSITO

SENIOR MOMENTS

FOR ANN, THINGS ALWAYS CAME EASY. Pretty and smart, she was homecoming queen in high school. At the top of her class academically, Ann earned honors as a musician (the flute) and an athlete (equestrian). She went on to a highly selective all-girls' college in New England, and after graduation moved to Manhattan, where she worked as an editor and writer at a well-known national magazine. At a party one night, she met a handsome and charming man, Peter, who was several years older and already a partner in a successful law firm. The two married, had two beautiful children and soon moved to a huge house in a tony New Jersey suburb.

Once her children were in school full-time, Ann returned to work as an editor and wrote several nonfiction books. She loved her work and continued to gain prominence in her field. She maintained her passion for riding horses, an interest her daughter inherited, and became a competent golfer and skier. The family bought a weekend house in upstate New York, and often went on adventure vacations that involved hiking, kayaking or deep sea fishing.

After her children finished school, married and moved out of New Jersey—her son becoming an attorney outside Denver and her daughter a pediatrician in Chicago—she and Peter began to discuss early retirement. Although she planned to continue working, the thought appealed to her. She liked the idea of having more time to travel, indulge her hobbies and visit their children (and, eventually, their grandchildren).

Her fairy tale life, however, came to an abrupt end. For it was around this time that Ann began to notice that Peter was beginning to exhibit some difficulty recalling words. This seemed especially disconcerting because her husband had always been extremely articulate and for many years was a forceful courtroom orator. Soon, he began repeating himself, asking the same questions over and over again. A prodigious reader, he would stare for hours at the same page in a book or newspaper. He became increasingly forgetful, sometimes not remembering why he had gone to the store or how to drive home on streets he had known for years. She knew this was not



a case of normal aging.

Ann took him to see a doctor, although she already knew the diagnosis—Peter had Alzheimer's disease. He was still in the early stages, the doctor confirmed, but eventually the illness would rob him of his mind and change their life forever.

It didn't take long. In addition to losing his cognitive faculties, his personality and behavior began to change. He became more contentious and demanding. He required more and more attention, eventually acting as dependent as a young child.

The responsibility fell 100% on Ann. It became her burden and, although she never complained about waking up at all hours of the night, worrying whether Peter had left the oven on or walked out of the house, it was slowly killing her.

Ann's story is hardly an unusual one. Alzheimer's is a disease that does not discriminate. It affects people of all backgrounds, ethnicities, socio-economic status, and education. What many families fail to focus on, however, is not just the person with the disease, but like Ann, the family member who serves as the caregiver.

Many caregivers experience such symptoms as denial, anger, social withdrawal, anxiety, depression, sleeplessness, and irritability. In short, caring for a spouse or parent with



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Alzheimer's, often leads to burnout.

Since Alzheimer's is not a disease like cancer or diabetes that is necessarily visual, other members of the family may not know what the caregiver goes through. Even in the later stages of the disease, Alzheimer's patients can manage to cover up so well that even adult children or siblings may see a totally different side when they visit or call. Yet, caring for a loved one with Alzheimer's can be an all-consuming 24-hour-a-day, seven-day a week grind.

What can caregivers do to reduce the burden? The Alzheimer's Association and other experts offer the following recommendations:

Manage your stress level. High levels of stress, which are very common with primary caregivers, can cause physical problems. Use various relaxation techniques to ease the stress and consult your doctor.

Take care of yourself. Caregivers can't ignore themselves in the process of helping their loved one. Watch your diet, exercise and get plenty of rest. Take time out for shopping, entertainment and getting away.

Become an educated caregiver. Find out where there are support groups or contact your local Alzheimer's association to learn more about how to cope.

Be realistic. Many of the behaviors that occur with Alzheimer's disease are beyond your control and the control of your loved one. Yes, you can grieve, but you must also focus on the positive moments.

Do legal and financial planning. Consult an attorney and other specialists to discuss legal, financial and medical issues. These decisions need to be tied up sooner rather than later.

Give yourself a break. This is considered the most important step – and the one that you can least ignore. It may mean exploring home care, adult day care options or respite services. Home care may

include companion services, a home health aide who can assist in helping with the activities of daily living (bathing, dressing, toileting and feeding), homemaking services to help around the house, or skilled care to assist with medication and other medical services. It can be live-in or hourly. Adult day care may offer music and art programs for the Alzheimer's patient. Respite services can allow the caregiver to re-fresh her batteries by going away for the day or taking a much-needed weekend break.

Don't be a martyr. If at all possible, don't do it alone. You can't live like this for too long. Seek the support of family, friends and community resources.

Alzheimer's is an insidious disease that slowly destroys a person's life. Yet, it will also destroy the life of the caregiver. It took awhile for Ann's children to realize this. Having finally reached the conclusion that "we have already lost dad, we can't lose mom too," her children convinced her last year to hire a live-in home health aide. With a dedicated person taking some of the responsibility off her shoulders, Ann can now sleep at night. She works several days a week, and occasionally goes out to see friends. She has taken long weekends to visit her children. Her plans for the future have been dramatically altered, and the loss remains, but she is slowly getting back to being herself again.

David Goodman and Frank Esposito run Expert Home Care in New Brunswick, which specializes in live in and hourly home care, and Companion Connection Senior Care, an organization of non-medical home care agencies with over 175 members in North America. They can be reached at 800-270-6949.