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What About You?

By Luciana Cramer, Educator and Care Specialist

Soon after Janet and her husband Paul moved to a lovely beach-front condo in Central California, Paul was diagnosed with Alzheimer's disease. Janet arranged her activities around Paul's increasing need for care, companionship and supervision. She took him to his doctors' appointments; she cooked, washed and cleaned up after him; she routinely accompanied him to the only restaurant he was willing to grace with his presence, Taco Bell. She frequently stayed in with him otherwise he would become frantic in her absence; she watched the weather channel—his favorite channel—with him day in and day out; she was up with him in the middle of countless nights, calming him down during his restless episodes of insomnia.

In the meantime, Janet neglected to follow-up with her own doctors' appointments. Attending to Paul's care-needs became her top priority, leaving her with little time to do the things that SHE used to enjoy doing. In order to appease him she had to stop going to the places she loved. She no longer went out with her friends, who in turn stopped inviting her. Paul's isolation slowly became hers. She seldom found herself without Paul by her side, and he followed her as closely as a shadow around the house, allowing her no privacy. Janet was fatigued but kept on going, plowing through stress and sleep deprivation.

She felt an intense sadness for Paul's condition. Caring for him was the only thing that mattered to her. This went on for years until the day that Janet collapsed, paralyzed with dread, grief and exhaustion, and sobbed for hours. She cried, "I can't do this anymore."

Janet's experience is not unique.

Many family caregivers fail to realize that they are caring for two people: their loved one with dementia and themselves. Both need care, both need their needs met.

Caregivers must be aware of all the stressors under which they are living. There are **physical**



stressors related to the demands of providing assistance with personal needs, i.e. hygiene, housekeeping, lifting and cleaning. There are **financial** stressors—dementia costs are estimated to be three times higher than other conditions! There are **environmental** stressors: the home must be modified to accommodate the unique needs of dementia patients, and companion caregivers may find themselves living in uncomfortable settings. There is also the **social** stressor of isolation. The caregiver often becomes isolated from society and from their own loved ones with dementia. Relationships in dementia caregiving are chronically single-sided. Finally, there is **emotional** stress, related to juggling multiple responsibilities while experiencing every stage of grief at once, every day, month after month... with no end in sight.

Stress has consequences: dementia caregivers are at elevated risks of developing certain health conditions, such as high blood pressure, anxiety, shingles, heart attack and, most ironically, Alzheimer's disease.

Caregivers commit their time, energy and financial resources to provide for their loved ones and to compensate for all that dementia

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Tips

1. Find time for yourself.

Take advantage of respite care so you can spend time doing something you enjoy.

2. Take care of yourself.

Watch your diet, exercise and get plenty of rest. Staying healthy will make you a better caregiver.

3. Manage your level of stress.

Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, change in appetite). Note your symptoms. Use recreational and relaxation activities that work for you, and talk to your doctor.

4. Reevaluate changes as they occur.

People with Alzheimer's change and so do their needs. They may require care beyond what you can provide on your own.

5. Make legal and financial plans.

Plan ahead. Consult a professional to discuss legal and financial issues including advance directives, wills, estate planning, housing issues and long-term care planning.

6. Visit your doctor regularly.

Make time for your regular checkups, and listen to your body. Pay attention to fatigue, stress, sleeplessness or changes in appetite or behavior. Ignoring symptoms can compromise your physical and mental health.

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continuously takes away. They are deeply affected by the stressors of caregiving. They live with a persistent grief, which small daily losses to dementia continue to reload and renew. Dementia takes away in small bites. Every bite hurts. Although not afflicted with dementia themselves, the stress and the hurt may cloud a caregiver's judgment.

Sadly, as a result, the needs of people with dementia are often allowed to obscure the needs of their family caregivers. Caregivers must be diligent in making sure their own needs are met, otherwise they may become collateral damage to dementia. A damaged caregiver, a beaten down caregiver, a caregiver depleted of his energy, joy, resilience and eventually his health is unfit to provide care.

In Janet's case, she neglected to do things that brought her joy and dedicated herself instead to that which gave Paul joy. As dementia eroded his activity range little by little, the things he enjoyed doing dwindled down into a repetitious, monotonous routine, which is very soothing for people with dementia, but torturous for others. The beautiful beach in front of her home became not an invitation, but a gloomy reminder of the life she and Paul had intended to live. She failed to appreciate the toll her style of caregiving (without self-care) was taking on her until she collapsed, exhausted by Paul's dementia.

Do not become dementia's collateral damage.

Make sure your own needs are high within your priorities. Get rest and plenty of sleep. Continue doing the things that give you joy. Keep your hobbies, find time for yourself, get assistance and support. Help is available and you need all the help you can get.

Perhaps Janet's biggest mistake was to keep Paul's dementia a secret. She was embarrassed

by his diagnosis. She tried to preserve his legacy and shelter him from the judgment of friends and extended family. In doing so she deprived herself of their support and assistance. Unaware of Janet's caregiving predicament, friends did not understand why she had stopped returning calls and slowly began distancing themselves. Janet's self-imposed isolation, although not intended as such, contributed to her ultimate meltdown.

Caregivers who are open about their experiences with dementia and share them with friends and family often receive waves of loving support. Most people want to help. All they need to proceed is an open door to reach out to you and a little direction from you—not everyone knows how to deal with dementia.

Allow those who want to help you to do so. Friends can provide rides, companionship, respite, humor and affection, things we all need here and there. They can give you a break. Your safety and well-being depend on it.

Service agencies and associations can also provide assistance. In-home helpers are trained to provide every level of care in the home, according to what you and your loved one require. Day centers provide much needed respite for caregivers, and care specialists at the Alzheimer's Association can keep you informed about the disease and the resources available in your area. Support groups can provide you with emotional support and practical advice for dealing with dementia-related challenges. Reach out. Get help.

Help yourself. Ask for help. Allow those who can help to do so. Remember you are caring for yourself as well. You are valuable, and your safety and well-being are important. There is a lot of help available. Make good use of it.



Tools:

alz.org/communityresourcefinder - Know what community resources are available. Use our online Community Resource Finder to find Alzheimer's care resources in your community.

alz.org/care - Become an educated caregiver. Visit the Alzheimer's and Dementia Caregiver Center to learn more and access care training resources, including free e-learning workshops.

alzconnected.org - Get help and find support. Seek the support people who can relate to your situation. Use our online social networking community and local support groups for finding comfort and reassurance.

alz.org/alzheimersnavigator - Use Alzheimer's Navigator™ to help assess your needs and create a customized action plan.