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A pproximately 80% of dementia patients are cared for by family members. That’s millions of family members who provide care for a parent or relative, many of whom must balance these duties with the demands of their full-time jobs and other family members.

With our population aging and the number of Alzheimer’s disease patients in this country predicted to steadily increase over the next two decades from 5.5 million today, the number of caregivers will have to increase as well. If you are not a caregiver already, the chances are high that you will become one at some point.

Studies that measure depression or distress in caregivers report that rates of these symptoms are two to three times higher in dementia caregivers than in the general population. Other studies reveal that social isolation and family disagreements are more prevalent in Alzheimer’s caregiver families than in similar families who are not caring for someone with dementia. What kinds of emotional problems do caregivers of Alzheimer’s patients have? Many experience a mixture of feelings, including frustration, sadness, anger, irritability, helplessness, guilt, and depression.

Being a caregiver for a family member or friend with Alzheimer’s disease can be so stressful that doctors often think of caregivers as “hidden patients.” Because caregivers are often faced with overwhelming day-to-day responsibilities, many stop going in for medical checkups, self-medicate their anxieties with alcohol, don’t exercise, and eat poorly.

Not surprisingly, Alzheimer’s disease caregiver stress takes a heavy toll. Caregiver stress and burnout symptoms are very similar to those of depression. They include:

- **Denial** . . . about Alzheimer’s disease and its effect on the person affected. “I know Mom will get better. They must have made a mistake.”

- **Anger** . . . at the person with Alzheimer’s disease and others. “If he asks me that question once more, I will scream!”

- **Withdrawing socially** . . . you no longer want to stay in touch with friends or participate in activities you once enjoyed. “I don’t care about getting together with the neighbors anymore.”
• Anxiety . . . about facing another day with the Alzheimer’s patient and what the future holds. “I’m worried about what will happen when I can no longer provide care.”

• Despair . . . you feel sad and hopeless much of the time. “I don’t care anymore.”

• Exhaustion . . . you barely have the energy to complete your daily tasks. “I don’t have the energy to do anything anymore.”

• Sleeplessness . . . you wake up in the middle of the night or have nightmares and stressful dreams. “I rarely sleep through the night, listening to hear if Dad is out of bed.”

• Emotional reactions . . . you cry at minor upsets; you are often irritable. “I cried when the grocery store was out of my favorite cereal. Then I yelled at the clerk.”

• Lack of concentration . . . you have trouble focusing, and you find it difficult to complete complex tasks. “I used to do the daily crossword. Now I am lucky if I can concentrate enough to solve one quarter of it.”

• Health problems . . . you may lose or gain weight, get sick more often (colds, flu), you may develop chronic health problems (backaches, headaches, high blood pressure). “Since the spring, I have had either a cold or the flu. I just can’t seem to shake it.”

If you’re experiencing any of these symptoms, consider contacting an Alzheimer’s disease support group, talking with your religious or spiritual leader, consulting with your primary care physician, or making an appointment with a counselor.
People with dementia often exhibit behaviors that are frustrating, embarrassing, and sometimes even dangerous to the caregiver and others. These may include angry outbursts, agitation, aggression, wandering, vocalizations, hoarding or hiding things, and inappropriate sexual behavior.

For many caregivers, these difficult behaviors are the most challenging and exhausting aspect of caring for a person with dementia. Unfortunately, the available medications to treat Alzheimer’s disease have little effect on behavioral problems.

In their groundbreaking book on Alzheimer’s caregiving – *The 36-Hour Day* – Peter Rabins, M.D. and Nancy Mace discuss the six R’s of managing difficult behavior in people with dementia. They are:

- **Restrict.** First, calmly attempt to get the person to stop the behavior, especially if the behavior is potentially dangerous.

- **Reassess.** Consider what might have provoked the behavior. Could a physical problem (toothache, urinary tract infection, osteoarthritis) be behind the agitation or anger? Is a particular person or the noise level in the room triggering the negative reaction? Could the time of day and fatigue be contributing to the problem?

- **Reconsider.** Put yourself in the dementia patient’s shoes. Try to imagine what it must be like to not understand what is happening to you or to be unable to accomplish a simple task. Consider how frustrating or upsetting the current situation or environment might be for a person with dementia.

- **Rechannel.** Try to redirect the behavior to a safer, less disruptive activity. For example, if the person constantly disassembles household items, try finding simple unused devices, such as an old telephone or a fishing reel, that can be taken apart and put back together repeatedly. For someone who hoards or hides things, put away valuables and replace them with an array of inexpensive items. Distraction often works well to curtail disruptive repetitive
behaviors and restlessness. For example, try asking the person you’re caring for to “help” with simple tasks, such as holding spoons or potholders while you cook.

**Reassure.** The demented person’s brain injury and the resulting confusion and frustration can lead to anger, anxiety, and outright fear in certain situations. Calmly reassure the person that everything is okay and that you will continue to take care of him or her.

**Review.** After an unsettling experience with your loved one, take time to review how you managed the problem and what you might have done differently. Think about what may have triggered the problem, how it might have been avoided, and what you might try the next time a similar situation arises. It also helps to create a patient-friendly environment. This might include soothing music in the background; pictures, words, or arrows to help orient the person in the house; or a secure place to sit outside or walk in the backyard.
Wandering is a common behavior in people with Alzheimer’s disease and other types of dementia. Many dementia patients will simply get up and walk away from their homes for the same reasons that healthy people do—to release pent-up energy.

Unfortunately, when people with dementia leave home alone, they can end up lost, confused, and unable to communicate vital personal information. Ideally, the dementia patient will always carry identification.

The Medic Alert + Safe Return program offered by the Alzheimer’s Association is a reliable, inexpensive way to safeguard the dementia patient’s identification. Initial enrollment costs $19.95 and there is an annual fee of $30. Members receive a medical alert ID bracelet or pendant engraved with their medical conditions and the Safe Return phone number. Members are listed in a national database that anyone can call at any time to report someone missing or found.

Another nonprofit organization called Project Lifesaver provides dementia patients who wander with wristbands that emit tracking signals and works with local law-enforcement agencies to find someone who is lost.

Microchip protection is another option for the dementia patient. If you have ever waved an ID card over a sensor to gain access to a restricted area, you’ve used Radio Frequency Identification (RFID) technology. In its latest incarnation, an RFID implant known as VeriChip is helping to manage a serious consequence of wandering: needing medical attention but being unable to communicate. The use of RFID technology for medical identification is in its infancy. Health insurance policies do not cover VeriChip; however, its cost is relatively low.

Safeguards at Home

• First, consider why the dementia patient might be walking off: Is he or she physically uncomfortable, agitated, or bored? Keeping people with dementia engaged can help control impulsive actions like wandering.
• Ask the doctor if medications could be causing restlessness.
• Keeping clocks in plain view can limit confusion about time.
• You can bolt outside doors or install safety locks, but this practice can be dangerous in case of a fire or another emergency.
• Attempting to stop the dementia patient in the midst of wandering can be difficult. Instead, follow them and gently lead them home when they are ready.

For more information:

• Alzheimer’s Association Safe Return
  888-572-8566
  www.alz.org/we_can_help_safe_return.asp

• Project Lifesaver International
  877-580-LIFE (5433)
  www.projectlifesaver.org

• VeriChip
  800-970-CHIP (2447)
  www.verimedinfo.com
Memory White Paper
A dramatic increase in the number of people affected by Alzheimer’s disease has heightened the urgency of the research into Alzheimer’s and other dementias. The Memory White Paper brings you state-of-the-art information on how to tell the difference between Alzheimer’s, another form of dementia, or ordinary age-related memory loss, and the best ways to keep your memory sharp as you get older. You will also learn about important new research in identifying, treating, and preventing memory disorders, as well as new drugs for Alzheimer’s and other dementias that can help slow memory decline.

The Johns Hopkins Memory Bulletin
Edited by Dr. Peter V. Rabins, Professor of Psychiatry at the Johns Hopkins University School of Medicine and co-author of the best-selling guide for caregivers, The 36-Hour Day, The Johns Hopkins Memory Bulletin brings timely, in-depth information for anyone facing Alzheimer’s disease, dementia, or another memory problem. In each quarterly issue, you’ll read about the latest scientific breakthroughs, research findings from the world’s foremost medical journals and conferences, medications, caregiver support and relief, plus breakthrough medical discoveries for safeguarding your brain against aging and memory loss. Subscribe today at the special web-only discount and get 4 FREE special reports to download instantly.

Diagnosing and Treating Alzheimer’s Disease
Written by Dr. Peter V. Rabins, Director of the Division of Geriatric Psychiatry and Neuropsychiatry at the Johns Hopkins School of Medicine and Medical Editor of the Johns Hopkins Memory Bulletin, Diagnosing and Treating Alzheimer’s Disease is an indispensable resource for anyone concerned about Alzheimer’s disease. This new report provides all the facts you need to make informed decisions if you have to confront Alzheimer’s disease. You’ll learn how Alzheimer’s is currently diagnosed … the existing drugs that are used to treat it … and various new therapies that may some day provide better treatment.

Caring for a Loved One with Alzheimer’s Disease: A Guide for the Home Caregiver
Written by two world-renowned Alzheimer’s specialists, Dr. Peter Rabins and Dr. Ann Morrison, this practical 134-page guide provides detailed advice on how to successfully manage your day-to-day responsibilities – to your patient and to yourself. Chapters include: When It’s Time to Take Away the Car Keys, Personal Care for the Dementia Patient, Dealing with Alzheimer’s Troubling Behavior Problems, Dealing with Alzheimer’s Troubling Behavior Problems, Deciding to Move a Loved One into Residential Care. And when you order now, you’ll also receive a free bonus report, entitled Caregivers Ask the Expert: Questions from Alzheimer’s Caregivers Answered by Johns Hopkins Expert Peter V. Rabins, M.D., M.P.H.

For more information, or to order, go to:
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