ALZHEIMER’S DISEASE: CHALLENGES FOR THE PATIENT’S FAMILY/CAREGIVER

Carol Fedor, ND*

ABSTRACT

With any diagnosis of Alzheimer’s disease (AD), there are, in fact, 2 affected parties: the patient and the caregiver/family. During the journey of AD progression, the caregiver and family will be making decisions with the patient that gradually restrict the patient’s ability to manage his or her own life and make him/her increasingly dependent on the family and caregiver. Friends, extended family, and primary care practitioners all have an ongoing and essential role to play in ensuring that the patient with AD receives the best quality of care while maintaining the patient’s wishes and dignity throughout the disease process. Among the healthcare team, the primary care nurse often has an important relationship with the patient because she acts as care manager, information and education resource, and advocate. Thus, nurses are in a critical position to educate and assist caregivers through their myriad struggles during the course of AD illness. This article reviews some of the major challenges that the family of a patient with AD will face, such as losing driving privileges, deciding on the patient’s ability to live alone, managing finances, the healthcare and psychosocial needs of caregivers, and financial burdens. Although it is important for all care providers to try to understand what the patient experiences, healthcare providers need to also understand what the family/caregiver of a patient with AD experiences.


DRIVING

One of the more difficult decisions a family has to make regarding their loved one with AD is whether the patient can continue to drive safely. This decision is complex because it removes one of the primary sources of independence for the patient. Because our communities are designed to rely so heavily on the automobile, removal of driving privileges has the potential to render the patient homebound if alternative means of transportation are not provided. However, the fear of dependency or sympathy for the

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patient should not outweigh the potential risks of injury or even death if signs indicate that driving is impaired. Although it is very common in our society, driving requires a complex set of skills.

Some of the signs of diminished driving skills that families should look for include unexplained dents in the car and the patient taking an unusually long time to run errands (indicating that he/she is getting lost). When possible, family members should take the opportunity to ride along with the patient to closely monitor driving skills. Obviously, patients showing clear impairment in driving skills should stop driving. The ethical dilemmas arise in those patients who do not yet show these signs. For the clinician, legal implications are also a consideration. Laws requiring notification of the Department of Motor Vehicles about a person’s diagnosis with a dementia or mention of poor driving skills by a family member varies by state. However, if any identified potential for danger while driving exists, the clinician should discuss this with the patient and/or the family. One option is for mildly impaired patients with AD to continue driving with certain limitations, such as driving only during the day, only along familiar routes, and avoiding high-traffic areas. Restricting or removing driving privileges is easier if someone else is available to drive the patient, thus all options should be discussed. The American Academy of Neurology recommends that, for patients with a Clinical Dementia Rating (CDR) scale score of 1 (which is roughly equivalent to a Mini-Mental State Examination score of 20–24), the clinician should notify the patient and family that the patient has a substantially increased rate for accidents and driving performance errors, thus he/she should not drive an automobile. For patients with a CDR score of 0.5, clinicians should inform the patient and family that, in general, patients with possible AD pose a significant traffic safety problem when compared to other elder drivers. Clinicians should also consider referring the patient for a driving performance evaluation by a qualified examiner. Importantly, clinicians should reassess the dementia severity and appropriateness of driving every 6 months for these patients, and all of these recommendations should follow state laws.²

**ABILITY TO LIVE ALONE**

Subsequent to discussions and decisions on driving, analysis of the patient’s ability to live alone is also sensitive, perhaps more for the family than the patient. Some patients with AD realize that they are no longer able to live by themselves and, in fact, may be relieved when that is suggested. As the patient and family consider independent living ability, the family should look for certain signs. For example, does the patient continue to know his way around the neighborhood or does he get lost? Can the patient prepare his or her own meals (ie, are there signs of burned pots or spoiled food in the refrigerator)? Can the patient recognize an emergency situation and call 911? Is there someone who can “keep an eye” on the patient, preferably a close neighbor? If the answer to some of these questions is no, there are intermediate options between living alone and nursing home placement, such as a home companion, adult day care centers, small group homes, or assisted-living facilities (discussed in more detail later in this monograph by Danielle Arends, RN, MSN, GNP). Although signs of inability to live alone may be obvious to family and patient, this subject should always be approached delicately. It still represents another enormous loss for the patient and can be humiliating as the patient must forfeit yet another part of his/her life to someone else. For example, when broaching the subject of moving to another type of living arrangement, patients are more likely to respond to a set of options (Would you prefer to live with us or move into a group home with people your own age?), rather than a negative statement (eg, You can’t live alone anymore.).

**MANAGING FINANCES**

Alzheimer’s disease is a progressive disease and the rate of cognitive decline can vary from patient to patient. Therefore, the important decisions regarding driving, finances, and legal issues need to be addressed soon after diagnosis, while the patient is still able to make his or her own decisions. Financial planning can be complex, even for healthy adults. The Alzheimer’s Association has created a brochure that outlines the important financial issues and types of planning the patient with AD, along with the family, will need to make.³ In brief, the patient should identify someone they trust implicitly to whom they can discuss and ultimately delegate their financial affairs. They should also be prepared to work with (and pay for) financial planning professionals and thus locate important financial documents. These documents will be neces-
DISAGREEMENTS WITHIN FAMILIES

Because the issues that families must face as AD progresses are so complex and emotionally charged, disagreements within families as to what is best for the patient are to be anticipated. It is not uncommon for primary care providers to serve as mediators to achieve resolution. Karlawish et al proposed a consensus-building approach to providing care for patients who lack decision-making capability (which was ultimately endorsed by the American College of Physicians and American Society of Internal Medicine). Although initially designed for decisions regarding palliative care, the principles can be applied to any care issue that has to be made for a cognitively impaired patient (Table 2). The decision-making process should be structured as a consensus-building process grounded in dialogue among the family members, the immediate caregiver, the patient (if possible), and the healthcare team. The goal is to achieve consensus regarding the current situation, available options, and likely outcomes, including the meaning of emotionally charged terms, such as “quality of life,” “competent,” and “dying.” As reviewed by Rabins et al, if the patient is incapable of making his or her own decisions, the family should make substituted judgment, unless there is reason to suspect that they are not acting on behalf and in the best interest of the patient.5 The challenge is if the decision involves acting on behalf of the patient, which may not be a life-prolonging decision. For the clinician, the challenge is to balance these 2 priorities and to determine what being “treated with dignity and respect” means to the family.

Karlawish et al also provide a series of steps to walk the clinician and family through the consensus-building process.4 Even for clinicians with long-standing relationships with the patient and/or family, each of these steps should be performed to ensure that everyone understands all of the facts and all of the options (Table 3).4 First, the clinician must identify all parties that will be involved in the decision-making process. Second, the participants must explain in their own words how they are experiencing the patient and the disease. Third, the clinician teaches the family about the expected clinical outcomes of AD, followed by a reaffirmation of advocacy for the patient’s quality of life and dignity. Finally, when all parties’ needs have been aired, the clinician can provide guidance on the decision based on existing data and clinical experience.4

<table>
<thead>
<tr>
<th>Table 1. Important Definitions</th>
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<tr>
<td><strong>Trusts</strong></td>
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<td><strong>Wills</strong></td>
</tr>
</tbody>
</table>
| | • Awareness of making a will  
| | • Knowledge of the extent of property to be bequeathed  
| | • Ability to formulate a reasonable plan for distribution of the property  
| | • Ability to understand the relationship between oneself and the recipients of one’s belongings* |
| **Durable Power of Attorney** | Durable power of attorney is the delegation to another person (the attorney) the ability to sign papers and carry out other legal processes, which remains active after the person becomes incompetent, thus durable power of attorney is preferred for dementia patients. This transfer of power begins only at the time that incompetency develops. It is often recommended that a person have a separate power of attorney for health and financial issues. |
| **Living Will** | A living will states a person’s wishes should he or she become terminally ill. They are not recommended for patients with AD because many of the difficult decisions surrounding AD care occur well before the patient is deemed to be terminally ill (ie, feeding tubes and ventilators) but long after they are capable of making decisions. Also, it is difficult to predict what will happen during the course of AD and to include all possible contingencies in a living will. |
| **Advanced Directives** | An advanced directive allows the patient to designate someone to make their health decisions for them should they become incapacitated. Advance directives are recognized in all states. |

AD = Alzheimer’s disease.

As Karlawish et al note, consensus building will vary depending on the patient’s clinical condition, the family dynamics, and the level of pre-existing trust or conflict in the provider-patient-family relationships. If a consensus cannot be reached, outside persons may need to be invited into the discussion, such as clergy, social workers, or medical/ethics consultants. To this end, the Alzheimer’s Association has begun an educational campaign targeting newer audiences, among them religious leaders, with the recognition that families often turn to their clergy in times of crisis.

HEALTH AND PSYCHOSOCIAL NEEDS OF CAREGIVERS

The healthcare and psychosocial needs of AD caregivers have traditionally been overshadowed by the more acute concerns of the patient. However, it is clear that caregivers suffer from significant medical and psychological needs during the progression of AD. Because most AD caregivers are spouses of patients with AD, they naturally tend to be older and many have their own health problems typical of a geriatric population, such as asthma, arthritis, diabetes, cardiovascular disease, hypertension, peripheral artery disease, and vision and hearing limitations. Schulz and Beach showed that spousal caregivers of patients with disabilities who were experiencing caregiver strain had mortality risks that were 63% higher than noncaregiving controls. The mortality risks were also adjusted for sociodemographic factors, prevalent disease, and subclinical cardiovascular disease.

Psychologically, AD caregivers also frequently suffer from depression and anxiety, which can exacerbate medical conditions. The psychological burden can be affected by many risk factors, including (in the patient) severity of AD and presence of neuropsychiatric symptoms and (in the caregiver) female gender. In fact, caregiver burden screening tools have been developed for quick, reliable screening in clinical practice. Musil et al studied the physical and mental health of AD caregivers over a 2-year period and showed a significant increase in stress and depressive symptoms, along with increases in cardiovascular and musculoskeletal problems. Increasing dependency of the patient and increasing age of the caregiver were associated with worse physical symptoms. Of note, roughly 50% of the participating caregivers were younger than 65 years. Thus, caregiver burden can happen even in the younger group of older adults and will most likely worsen with time and disease progression.

An interesting study of caregiver strain was conducted in 150 community-dwelling caregivers, of whom 80% were African American with a wide range of income. Analysis of specific patient, caregiver, and support characteristics on role, personal, or emotional strain revealed interesting trends that are noted among other studies of more generalized populations. As summarized in Table 4, behavioral disturbances cause significant role, personal, and emotional strain for the caregiver. A patient’s inability to perform activities of daily living (ADLs) or instrumental ADLs and poor support from the healthcare team caused significant personal strain. Higher income was associated with significant role strain. Although this at first may be surprising, the authors offer 2 possible interpretations:

Table 2. Principles of Consensus Building for Caregivers/Families of Patients with Dementia

- Structure the decision making as a consensus-building process grounded in dialogue among the family members, the caregiver, and the healthcare team
- The goal is to achieve consensus about diagnosis and prognosis, the benefits and burdens of different treatment options, and the meaning to each party of emotionally charged terms
- Decisions should be based on the patient’s preferences and a balance of the burdens and benefits of each option


Table 3. Steps to Achieving Consensus for Caregivers/Families of Patients with Dementia

1. Identify the main participants in the decision making
2. Allow the participants to narrate how the patient has come to the illness
3. Teach the decision makers about the expected clinical course of the patient’s disease
4. Advocate for the patient’s quality of life and dignity
5. Provide guidance on the basis of existing data and clinical experience

many higher-income caregivers are still employed and thus struggle with work and caregiving responsibilities while managing other roles, such as parent or spouse; or higher-income individuals are less likely to qualify for free or low-cost community services that might help these caregivers.18 Importantly, this study also suggests that the challenges of caregivers are not limited to the typical clinical study participant, but apply to many types of caregivers.

Left unchecked, the physical and psychological toll of caregiving can lead to elder abuse. As reviewed by Coyne, several studies have identified risk factors for elder abuse by family members and other caregivers, many of which are present in AD caregivers.19 These risk factors include excessive physical and psychological demands with caregiving; advanced age; poor health; physical frailty; impaired ADLs and behavioral disturbances in the care recipient; care recipient and caregiver living together; depression; and dementia.19 Other risk factors include alcohol and substance abuse by the caregiver, caregiver psychopathology, and family history of abusive behavior.19-25

Given the almost certain strain that will be placed on the family, and notably the primary caregiver, and the long process of AD progression, there is a great need for regular respite. Table 5 provides a list of resources for caregivers that can provide respite care or sources of information on respite care.

**FINANCIAL BURDENS FOR THE FAMILY**

There are important financial considerations for the family of a patient with AD, in the short term after diagnosis and long term. If the patient will remain at home with informal care provided by the family, there may be economic implications, such as loss of or reduction in income for the caregiver and perhaps also the patient. In an Alzheimer’s Association survey of caregivers, most caregivers who were employed (70%) say caregiving has interfered in one way or another with their job (Figure 1).26 Families will also need to consult with an attorney specializing in elder law regarding issues, such as durable power of attorney, advance directives, and living wills (which are defined in Table 1).

As the disease progresses, programs such as in-home care, adult day care, and respite will need to be paid directly by the family or patient, as most private and government health insurance policies do not cover these services.

Any type of long-term care incurs significant financial commitments. As part of the decision-making process for long-term care, caregivers and families should identify their financial resources, and then look to see what their community has to offer. This will allow them to more realistically determine what type of care is an option for their loved one. Although Medicare pays for brief stays in skilled nursing facilities for certain types of acute illnesses or conditions, most long-term care for AD is not covered and AD is not considered to be an acute condition. Medicare Part A will pay for home health services if the patient is homebound and has other conditions requiring the services of a licensed healthcare professional. It also

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**Table 4. Selected Predictors of 3 Subtypes of Caregiver Strain: Regression Analysis of AD Patient-Caregiver Dyads**

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Adjustment or role strain (n = 150)</th>
<th>Personal strain (n = 150)</th>
<th>Emotional strain (n = 150)</th>
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<tbody>
<tr>
<td></td>
<td>Beta</td>
<td>t</td>
<td>Beta</td>
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<tr>
<td>Patient characteristics</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Behavior</td>
<td>0.34</td>
<td>3.10*</td>
<td>0.44</td>
</tr>
<tr>
<td>Cognition</td>
<td>0.16</td>
<td>1.53</td>
<td>0.00</td>
</tr>
<tr>
<td>Depression</td>
<td>-0.04</td>
<td>-0.04</td>
<td>0.01</td>
</tr>
<tr>
<td>Pain on average day</td>
<td>0.06</td>
<td>0.70</td>
<td>0.03</td>
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<tr>
<td>ADL/IADL</td>
<td>0.16</td>
<td>1.73†</td>
<td>0.31</td>
</tr>
<tr>
<td>Caregiver Characteristics</td>
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<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>-0.07</td>
<td>-0.61</td>
<td>0.06</td>
</tr>
<tr>
<td>Adult child</td>
<td>0.07</td>
<td>-0.64</td>
<td>0.07</td>
</tr>
<tr>
<td>Income</td>
<td>0.27</td>
<td>2.83*</td>
<td>-0.02</td>
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<tr>
<td>Race (1 = black, 0 = other)</td>
<td>0.02</td>
<td>0.29</td>
<td>0.04</td>
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<tr>
<td>Support Characteristics</td>
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<tr>
<td>Formal services</td>
<td>0.03</td>
<td>0.34</td>
<td>0.06</td>
</tr>
<tr>
<td>HC team support</td>
<td>-0.02</td>
<td>0.29</td>
<td>-0.21</td>
</tr>
<tr>
<td>Informal support</td>
<td>0.16</td>
<td>1.75†</td>
<td>-0.01</td>
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<tr>
<td>Models</td>
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<tr>
<td>R²</td>
<td>0.41</td>
<td>0.41</td>
<td>0.31</td>
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<td>F (df)</td>
<td>4.5 (12.78)</td>
<td>4.5 (12.78)</td>
<td>2.9 (12.78)</td>
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<tr>
<td>P value</td>
<td>.001</td>
<td>.001</td>
<td>.002</td>
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</table>

*P <.01; †P <.10; ‡P <.05.
AD = Alzheimer’s disease; ADL = activity of daily living; HC = hospice care; IADL = instrumental activity of daily living.
pays for hospice for the terminally ill. Medicare Part B pays 80% of approved charges for (among other things) medical equipment, such as walkers, hospital beds, and wheelchairs. Importantly, Medicare does not cover custodial care for people who need help with ADLs, such as bathing, dressing, toileting, and walk-

Table 5. Resources for Caregivers

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
<th>Phone Numbers</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Association</td>
<td>225 N. Michigan Avenue, Floor 17</td>
<td>P: (800) 272-3900</td>
<td><a href="http://www.alz.org">www.alz.org</a></td>
</tr>
<tr>
<td></td>
<td>Chicago, IL 60601-7633</td>
<td>P: (312) 335-8700</td>
<td></td>
</tr>
<tr>
<td></td>
<td>P: (312) 335-1110</td>
<td><a href="http://www.alz.org">www.alz.org</a></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Myths</td>
<td><a href="http://www.alz.org/AboutAD/Myths.asp">www.alz.org/AboutAD/Myths.asp</a></td>
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<tr>
<td></td>
<td></td>
<td>• Safe Return Program</td>
<td><a href="http://www.alz.org/Services/SafeReturn">www.alz.org/Services/SafeReturn</a></td>
</tr>
<tr>
<td>Alzheimer’s Disease Education and Referral</td>
<td>ADEAR Center</td>
<td>PO Box 8250</td>
<td></td>
</tr>
<tr>
<td>Center (ADEAR)</td>
<td>Silver Spring, MD 20907-8250</td>
<td>P: (800) 438-4380</td>
<td></td>
</tr>
<tr>
<td></td>
<td><a href="http://www.alzheimers.org">www.alzheimers.org</a></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• AD Centers</td>
<td></td>
<td><a href="http://www.alzheimers.org/adccdir.htm">www.alzheimers.org/adccdir.htm</a></td>
</tr>
<tr>
<td>Alzheimer’s Research Forum</td>
<td>600 Beaver Street</td>
<td>P: (781) 375-2277</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Waltham, MA 02452</td>
<td>Fax: (781) 373-2388</td>
<td></td>
</tr>
<tr>
<td></td>
<td>P: (814) 863-9423</td>
<td><a href="http://www.alzforum.org">www.alzforum.org</a></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Resources</td>
<td>Penn State University Gerontology Center</td>
<td>P: (814) 863-9423</td>
<td></td>
</tr>
<tr>
<td></td>
<td>405 Manon Place</td>
<td>Fax: (814) 863-9423</td>
<td></td>
</tr>
<tr>
<td></td>
<td>University Park, PA 16802</td>
<td>E-mail: agingpa.psu.edu</td>
<td></td>
</tr>
<tr>
<td></td>
<td>P: (814) 863-7903</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td><a href="http://agingpa.psu.edu">http://agingpa.psu.edu</a></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Society of Canada</td>
<td>20 Eglinton Avenue West, Suite 1200</td>
<td>P: (416) 488-8772</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Toronto, ON M4R 1K8</td>
<td>E-mail: <a href="mailto:info@alzheimer.ca">info@alzheimer.ca</a></td>
<td><a href="http://www.alzheimer.ca">www.alzheimer.ca</a></td>
</tr>
<tr>
<td></td>
<td>P: (416) 488-8772</td>
<td></td>
<td></td>
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<tr>
<td>American Association of Retired Persons</td>
<td>601 E Street NW</td>
<td>P: (888) 687-2277</td>
<td><a href="http://www.AARP.com">www.AARP.com</a></td>
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<tr>
<td></td>
<td>Washington, DC 20049</td>
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</tr>
</tbody>
</table>

American Health Assistance Foundation     22512 Gateway Center Drive  
                                           Clarksburg, MD 20871  
                                           P: (800) 437-2423  
                                           P: (301) 948-3244  
                                           Fax: (301) 258-9454  
                                           www.ahaf.org

ClinicalTrials.gov  
8600 Rockville Pike  
Bethesda, MD 20894  
P: (888) 346-3656  
P: (301) 594-5983  
Fax: (301) 402-1384  
www.clinicaltrials.gov

Cognitive Neurology and Alzheimer’s Disease Center  
Northwestern University  
Feinberg School of Medicine  
320 East Superior  
Chicago, IL 60611  
P: (312) 908-9339  
Fax: (312) 908-8789  
E-mail: CNADC-Admin@northwestern.edu  
www.brian.northwestern.edu

Eldercare Locator  
P: (800) 697-1116  
www.eldercare.gov

Family Caregiver Alliance  
690 Market Street, Suite 600  
San Francisco, CA 94104  
P: (415) 434-3388  
www.caregiver.org

National Adult Day Services Association  
2519 Connecticut Avenue NW  
Washington, DC 20008  
P: (800) 558-5301  
Fax: (202) 783-2255  
E-mail: info@nadsa.org

National Alliance for Caregiving  
4720 Montgomery Lane, 5th Floor  
Bethesda, MD 20814  
www.caregiving.org

National Family Caregivers Association  
10400 Connecticut Avenue, #500  
Kensington, MD 20895-3944  
P: (800) 896-3650  
www.nfca.org

National Institute of Neurological Disease and Stroke: Alzheimer’s Disease Information Page  
NIH Neurological Institute  
PO Box 5801  
Bethesda, MD 20824  
P: (800) 352-9424  
P: (301) 496-5751  
www.ninds.nih.gov

National Respite Locator Service  
Chapel Hill Training-Outreach Project, Inc.  
800 Eastovne Drive, Suite 105  
Chapel Hill, NC 27514  
P: (919) 490-5577  
Fax: (919) 490-4905  
TDD: (919) 490-5577  
www.respite locator.org

The Alzheimer’s Store  
12633 159th Court North  
Jupiter, FL 33478-6669  
P: (800) 752-3238  
P: (561) 745-0210  
Fax: (561) 744-9572  
E-mail: cs@alzstore.com  
www.alzstore.com

The American Red Cross—developed a training program for family caregivers that covers the following topics:  
• Home safety  
• General caregiving skills  
• Positioning and helping your loved one move  
• Assisting with personal care  
• Healthy eating  
• Caring for the caregiver  
• Legal and financial issues  
• Caring for a loved one with Alzheimer’s disease or dementia  
• Caring for a loved one with HIV/AIDS  
http://redcross.org/services/hss/care/

US Administration on Aging (AoA)  
Washington, DC 20201  
P: (202) 619-0724  
www.aoa.gov
ing, respite care for caregivers or adult day care, or medical supplies (eg, incontinence pads). Currently, the average cost for nursing home care is $42,000 per patient with AD per year.27,28 Thus, the brunt of the financial burden falls on the shoulders of the patient and his/her family, and long-term care costs ultimately constitute the major cost driver for AD.29,30 Therefore, families need to plan carefully for their loved one’s future.

**Role of the Nurse in Caring for the Caregiver**

Besides the more practical information on caregiving issues, the nurse can best help the caregiver by reframing not only the patient’s limitations and distressing behaviors, but also the caregiver’s response to them. As a first step, the current or potential caregiver should make a realistic assessment of himself or herself and the patient. What can the patient realistically still do by him/herself? What are the caregiver’s physical and emotional coping skills? What are the caregiver’s financial or time limitations? Who else is available as a backup for when the caregiver may not be available? Importantly, caregivers need to be able to say “I can’t do this.”

**Helping the Caregiver Help the Patient**

Once the caregiver’s and patient’s capabilities and limitations are defined, it is important for caregivers to understand the patient’s experience of AD as much as possible. The Progressively Lowered Stress Threshold (PLST) model was developed 20 years ago to help caregivers understand why patients with AD with cognitive symptoms and distressing behaviors do not respond to traditional care measures, such as reality orientation, maximum sensory input, and re-education for lost skills.31 The model postulates that a person’s stress threshold is set in adulthood, but changes in response to biological mechanisms, including brain damage. Distressing behaviors are responses to overwhelming stress. As AD progresses, lower doses of stressors produce stress responses, indicating a progressive lowering of the threshold. In AD, stressors can include fatigue; change in routine, caregiver, or environment; internal or external demands that exceed the patient’s capability; multiple and competing stimuli; physical stress (eg, illness and medication reaction); and affective responses to perceptions of loss. Interventions are then based on understanding the cause of the patient’s reaction and should be imple-

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**Table 6. Elements of Caregiving with “Knack”**

- Being well informed
- Having empathy
- Respecting the basic rights of the person
- Maintaining caregiving integrity
- Employing finesse
- Knowing it is easier to get forgiveness than to get permission
- Using common sense
- Communicating skillfully
- Maintaining optimism
- Setting realistic expectations
- Using humor
- Employing spontaneity
- Maintaining patience
- Developing flexibility
- Staying focused
- Being nonjudgmental
- Valuing the moment
- Maintain self-confidence
- Using cueing tied to the Life Story
- Connecting with the spiritual
- Taking care of oneself
- Planning ahead

mented before the patient's stress level reaches its threshold (ie, proactively rather than reactively).\textsuperscript{32}

Another method of instilling empathy in the caregiver is best outlined by Bell and Troxel in their book on the “Best Friends” approach to caregiving for a patient with AD.\textsuperscript{18} Although a thorough discussion of their program is beyond the scope of this article, their book is referenced for further reading. In brief, the Best Friends approach is designed to remind the caregiver that the relationship to the patient is that of a best friend, not provider-patient. It helps the caregiver to reframe their role from a burdensome and overwhelming responsibility to a rewarding and successful experience. This approach also suggests that knowing what is causing a behavior allows the caregiver to give the patient what he or she needs, when he or she needs it.\textsuperscript{13} The Best Friends approach uses strategies, such as creating the patient’s life story, creating meaningful activities for the patient based on their cognitive and emotional status at that particular moment, and caregiving with “knack,” which includes having empathy, using finesse, knowing it is easier to get forgiveness than permission, using humor, setting realistic expectations, and taking care of oneself (Table 6).\textsuperscript{13}

**HELPING THE CAREGIVER HELP HIM/HERSELF**

However, as mentioned at the beginning of this article, the caregiver is the “forgotten patient” of AD. Even for caregivers who find the strength within themselves to appreciate their role as rewarding, it is a stressful experience involving long hours, physical stamina, and emotional dedication to a loved one who is dying. Support from the primary care provider team is essential, if only for positive reinforcement. Several recent studies have examined the effects of interventions by healthcare providers with some mixed results. Gerdner et al implemented a psychoeducational nursing intervention to 237 caregiver/patient dyads that was based specifically on the PLST model.\textsuperscript{14} The results showed that the intervention benefited all caregivers (nonspouses and spouses) regarding their responses to memory or behavioral problems. Importantly, the intervention did not significantly influence the level of functional decline in ADLs for the patients because the intervention is designed to affect the caregiver, not the patient. Also, spouses reported more negative responses to behavioral and ADL problems than nonspouses, and caregiver

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**Figure 2. Caregiver Burden Index**

1. I feel resentful of other relatives who could but do not do things for my spouse
2. I feel that my spouse makes requests that I perceive to be over and above what s/he needs
3. Because of my involvement with my spouse, I don’t have enough time for myself
4. I feel pressured between trying to give to my spouse and other family responsibilities, job, etc
5. I feel embarrassed over my spouse’s behavior
6. I feel guilty about my interaction with my spouse
7. I feel that I don’t do as much for my spouse as I could or should
8. I feel angry about my interactions with my spouse
9. I feel that I have done too much for my spouse as I could have or should have
10. I feel nervous or depressed about my interactions with my spouse
11. I feel that my spouse currently affects my relationships with other family members and friends in a negative way
12. I feel resentful about my interactions with my spouse
13. I am afraid of what the future holds for my spouse
14. I feel pleased about my interaction with my spouse
15. It’s painful to watch my spouse age
16. I feel useful in my interactions with my spouse
17. I feel my spouse is dependent
18. I feel strained in my interactions with my spouse
19. I feel that my health has suffered because of my involvement with my spouse
20. I feel that I am contributing to the well-being of my spouse
21. I feel that the present situation with my spouse doesn’t allow me as much privacy as I’d like
22. I feel that my social life has suffered because of my involvement with my spouse
23. I wish that my spouse and I had a better relationship
24. I feel that my spouse doesn’t appreciate what I do for him/her as much as I would like
25. I feel uncomfortable when I have friends over
26. I feel that my spouse tries to manipulate me
27. I feel that my spouse seems to expect me to take care of him/her as if I were the only one s/he could depend on
28. I feel that I don’t have enough money to support my spouse, in addition to the rest of our expenses
29. I feel that I would like to be able to provide more money to support my spouse than I am able to now

This is a 29-item self-report inventory administered by the primary caregiver. The respondent indicates how much discomfort this concern causes by choosing the most appropriate phrase from “not at all” to “extremely.” A total burden score is calculated. Four of 29 items were scored in the opposite direction and subtracted from the total. Although this index was originally published using the term “spouse,” it can be used with any type of caregiver. Reprinted with permission from Zarit et al. Gerontologist. 1980;20:649-655.\textsuperscript{17}
response overall became increasingly negative as the level of cognitive impairment deteriorated. This study shows that educational initiatives of the PLST model affect caregiver responses, and individual caregivers will vary in their response based on the severity of AD and their relationship to the patient.17

Musil et al studied the effect of perceived support from healthcare providers on caregiver stress and health.17 Numerical measures revealed essentially no effect, but the authors discuss the possible reasons. In fact, an effect may be hidden amongst the many variables that affect any 2-person relationship. For example, AD is a progressive illness and little is known about what types of provider-caregiver interactions are useful at different points along the disease trajectory. Also, as the disease progresses and caregivers turn to providers for suggestions on how to deal with distressing behaviors, the suggestions become more empirical than evidence based, perhaps causing the caregiver to perceive the advice as less effective.17

The Internet is now a source of community support for caregivers. Brennan et al recognized early the value of computer networking for caregiver support, primarily because the information or intervention can be accessed at any time.35 Computer networking is ideal for interventions that occur intermittently with unpredictable frequency, such as in-home care.35 They devised ComputerLink, a network that contained 3 functional areas for caregivers: an electronic encyclopedia, a decision support system, and opportunities for communication. The encyclopedia provided factual information on AD, the caregiving experience, clinical care, and local services. The decision support system used decision modeling to create questions that helped the user identify alternatives to the problem at hand based on the user's own values and preferences. Communication was through on-line forums, private e-mail with other users, or a private anonymous question-and-answer session with a master's level nurse moderator. The results showed significant impact in caregivers' decision-making confidence, but not decision-making skill. No change in experience of social isolation was noted, although comments posted by caregivers, in focus groups, and in final interviews indicated that the network was perceived as a social support. This study was conducted more than a decade ago when in-home computers were much less common and more difficult to use (eg, study participants connected to the network with a 1200 baud modem).36 The existence of myriad on-line support groups, including with Alzheimer's Association and Alzheimer's Disease Education and Resource center, indicate that computer/on-line technology is now part of our culture and the nurse would be well served to use the computer as a source of support and information for caregivers of patients with AD, particularly those in more remote areas.

Clearly, more research is needed to better define the needs of caregivers over the course of the disease, based on the relationship to the patient, their outside responsibilities, educational level, health status, and financial and family support. However, the primary care nurse should be prepared to monitor, recognize, and manage caregiver burden. Several caregiver burden assessment scales are now available; the Caregiver Burden Index is shown in Figure 2.37 Some shorter, modified versions have also been published. Some are also developing rapid screens for caregiver burden that can be used easily in clinical practice, such as that developed by Hirschman et al and shown in Figure 3.35

### Figure 3. Shortened 7-Item Screen for Caregiver Burden

For each of the following statements, please circle the answer that indicates the degree to which you believe the experience/event has caused you distress, such as being upset or nervous. If the event has not occurred, please circle “did not occur.”

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel so alone—as if I have the world on my shoulders.</td>
<td></td>
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<tr>
<td>Occur Not Cause Distress Distress Distress Distress Distress Distress</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. I have little control over my relative’s behavior;</td>
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<td></td>
<td></td>
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<tr>
<td>Occur Not Cause Distress Distress Distress Distress Distress Distress</td>
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<td>3. I have to do too many jobs/chores (feeding, shopping) that my relative used to do.</td>
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<td></td>
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<tr>
<td>Occur Not Cause Distress Distress Distress Distress Distress Distress</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I am upset that I cannot communicate with my relative.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Occur Not Cause Distress Distress Distress Distress Distress Distress</td>
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<tr>
<td>5. My relative is constantly asking the same questions over and over.</td>
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<td></td>
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<tr>
<td>Occur Not Cause Distress Distress Distress Distress Distress Distress</td>
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<td>6. I have little control over my relative’s illness.</td>
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<td></td>
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<tr>
<td>Occur Not Cause Distress Distress Distress Distress Distress Distress</td>
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<tr>
<td>7. I am totally responsible for keeping our household in order.</td>
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<td></td>
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<tr>
<td>Occur Not Cause Distress Distress Distress Distress Distress Distress</td>
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</tbody>
</table>

CONCLUSIONS

With the many different challenges that families and caregivers of patients with AD will face, multiple support structures will be necessary. Friends, extended family, and primary care practitioners all have an on-going and essential role to play in ensuring that the patient with AD receives the best quality of care while maintaining the patient’s wishes and dignity throughout the disease process. Among the healthcare team, the primary care nurse often has the most far-reaching relationship with the patient because he/she acts as care manager, information and education resource, and advocate. Although it is important for all care providers to try to understand what the patient experiences, healthcare providers need to also try to understand what the family of a patient with AD experiences.

REFERENCES