A Comprehensive Approach to Managing Dementia Patients: Considering the Caregivers

A Q&A with Richard Isaacson, MD

An estimated 5.4 million Americans have Alzheimer’s Disease, according to the Alzheimer’s Association, and 5.2 million of these are age 65 or older (www.alz.org/downloads/Facts_Figures_2011.pdf). By 2030, the number of Americans age 65 or older with AD could reach 7.7 million. In 2011, the association reports, nearly 15 million Americans provided unpaid care for a person with AD or other dementias. The vast majority—80 percent—of home care for dementia patients is provided by family caregivers, the majority of whom are themselves over age 55.

Collectively, those providing unpaid at-home care to a person with AD administer the equivalent of $202.6 billion worth of care. This care can lead to various forms of stress and negatively impact the physical health of caregivers. In fact, the association reports, caregivers are at increased risk for chronic illnesses.

Clinical neurologists are aware of the critical role that caregivers play in the lives of their patients, yet they may feel unprepared to assist caregivers in their duties. Surely it can be a challenge to assess and meet the needs of a caregiver, but it should be part of the comprehensive approach to patient care, says Alzheimer’s specialist Richard Isaacson, MD. Below, Dr. Isaacson, author of the book *Treating Alzheimer’s, Prevention Alzheimer’s: A Patient & Family Guide*, offers an overview of his approach AD care.

What non-pharmaceutical interventions (including community services and resources) should clinicians think about and be prepared to recommend to the AD patient’s family? How much, if any, responsibility does the clinician have for the health of the caregiver?

I cannot stress enough the importance of non-drug approaches as part of the comprehensive management of Alzheimer’s disease. These include specific vitamins (Folic Acid, B6, B12 and D), dietary changes (e.g., decreasing carbohydrates and saturated fats, increasing omega-3 fatty acids), the FDA-regulated medical food (Axona), physical exercise, mental exercise (including music therapy), and caregiver support.

The benefits of physical exercise for patients with Alzheimer’s disease have been suggested in a variety of

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<th>TABLE 1. CAREGIVER ACTIVITIES</th>
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<td>In addition to assisting with general healthcare and activities of daily living, unpaid caregivers report the following activities, according to the Alzheimer’s Association Report:</td>
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<td>• 50% live with the affected patient</td>
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<td>• 64% advocate for their care recipient with government agencies and service providers</td>
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<td>• 46% arrange and supervise paid caregivers from outside community agencies</td>
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studies, including research in mice that supports this. The aspect of brain exercise for which I most strongly advocate is learning something new. Taking classes (e.g., adult education) and learning a new language or a new skill (like how to play an instrument) may be especially important. Listening to music (especially classical) and music therapy for memory programs have been shown to improve memory in patients with Alzheimer’s disease. There are even music activity and educational programs on CD that patients and caregivers can use together to stimulate the mind and exercise memory.

Caregiver support is essential. If the stress and fatigue of being a caregiver begins to affect his or her own health and well-being, not soon after will the patient’s condition also decline. I advocate for support groups (try the Alzheimer’s Association at www.alz.org, Alzheimer’s Foundation of America at www.alzfdn.org, or a local memory disorders center), a social worker to get involved early, and I spend a great deal of time with patients to ensure the caregiver has adequate support. Since I have a family history of Alzheimer’s and have seen first-hand the toll this disease takes on the family, I think clinicians do have a responsibility for caregiver and family health and well-being.

How should clinicians approach new therapies and how does one weigh the potential promise of new therapies against the realities of disease progression?

Considering my family history, I take a fairly comprehensive approach and offer the same therapies to my patients as I would for my own family. My philosophy is to offer anything and everything as long as it is grounded in scientific evidence and balanced in safety. While patients will inevitably decline, in 2012 it is nearly impossible for clinicians to know exactly which patients will respond more optimally to which therapies. Even a relatively small chance (<50%) of a positive response is higher than zero, and as such I will offer a variety of safe and evidence-based therapies to patients. There are several therapies that have shown preferential benefit in patients with specific genes, and in the future clinicians may be able to make treatment decisions based on pharmacogenomic considerations.

To what extent should the caregiver and his/her needs influence treatment decisions? What is the neurologist’s role/responsibility in recommending community resources and programs as adjuvant interventions for the patient? How about resources for the caregiver?

When you are treating a patient with Alzheimer’s, you are really treating their entire family. As my mentor Dr. Louis Caplan taught me, neurologists should ideally spend sufficient time getting to know family situations, psychosocial and economic stresses, thoughts, fears, biases and wishes. Referral to community support groups through a variety of local and national organizations and other online educational resources can also be quite helpful (see www.therapy-formemory.org/Resources.html for more information).

To what extent, if any, should the caregiver’s needs affect choice of a therapy? For example, should dosing decisions be made with the caregiver in mind?

I often try to simplify the treatment plan based on caregiver needs. If a caregiver is overwhelmed, it is helpful to use a slow and step-wise approach when recommending new therapies, and I routinely type out new medication recommendations with detailed instructions. I also prefer to use once daily thera-

ANOTHER BOOK RESOURCE FOR FAMILIES

New from Ronald Devere, MD (editor of Practical Neurology’s “Dementia Insights”) is Memory Loss: Everything You Want to Know But Forget to Ask. The book, written specifically for patients and caregivers, provides information on aging, memory, and memory loss. Additionally, there is discussion about testing, diagnosis, and treatment options. Finally, the book provides insights on crucial caregiver and patient decisions, including issues such as driving.

According to Dr. Devere, a key goal in writing the book was to provide scientific, fact-based information about memory loss in a format that is as honest and hopeful as possible. Much of the information provided to patients and families via the mass media can be frightening, emphasizing the worst aspects of dementia and its effects on individuals and caregivers.

Memory Loss: Everything You Want to Know But Forget to Ask is available through Amazon.com.
pies and consider options like a patch over an oral form, or vice-versa, depending on caregiver preference.

**Symptomatic therapies may be indicated, and there may be alternative therapies to consider. To what extent should the caregiver help direct these decisions?**

Patients and caregivers should be informed about the available FDA-approved drugs (cholinesterase inhibitor medications like the Exelon patch, Aricept or Razadyne ER, and the NMDA-antagonist medication Namenda), the FDA-regulated medical food (Axona), and evidence-based vitamins (B6, B12, Folic Acid and D), and supplements (e.g., the Omega-3 fatty acid DHA). They should also be instructed on the lifestyle modifications that also have evidence, like diet changes (e.g., decreasing carbohydrates, decreasing saturated fats, increasing antioxidants and fish high in omega-3s), physical exercise, mental exercise and music therapy.

In my practice, I always ask my patients and family members present during the initial visit how aggressive they would like me to be on a scale of one to 10. Based on their answer, and after a discussion of the risks, benefits, and costs of available therapies, I offer them a tailored and step-wise approach.

**There are investigational therapies and alternative management strategies. Do neurologists have a responsibility to inform patients and caregivers about these? How does one bridge these topics?**

Once maximized on the standard therapies, the decision about whether or not to be evaluated for a clinical trial should be discussed in detail with the patient and family members. In my practice, roughly 20 percent of my patients are currently enrolled in a research study trying to determine the effectiveness of a new therapy for Alzheimer’s. Patients and family should understand that with almost all clinical trials that a certain number of participants (usually 50-66 percent) will receive the investigational agent and the rest of the patients will get a placebo. To learn more about these, clinicians and patients/caregivers can visit www.clinicaltrials.gov, which keeps a list of ongoing and recently completed studies. The Alzheimer’s Association has a website called TrialMatch™ (www.alz.org/trialmatch, Phone: 800-272-3900) that provides individualized matching services for patients with Alzheimer’s, mild cognitive impairment and related dementias, as well as information for their caregivers, family members and healthcare providers.

Richard S. Isaacson, MD is Associate Professor of Clinical Neurology, Vice Chair of Education, and Education Director of the McKnight Brain Institute in the Department of Neurology at the University of Miami (UM) Miller School of Medicine. His new book is *Treating Alzheimer’s, Prevention Alzheimer’s: A Patient & Family Guide*, in which he answers the most common patient and caregiver questions on the treatment and prevention of Alzheimer’s disease.

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