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Improving Communication With Physicians

Key Strategies You Can Use During the Middle Stage of Alzheimer's Disease

by Kim DeHart, Program Director, Michigan Great Lakes Chapter

Physicians are usually the first, and often only, contact for those with Alzheimer's disease and their family caregivers. They are in a unique position to provide education about Alzheimer's disease, advice on how to manage symptoms, and links to community service providers. However, many caregivers feel they are not receiving the information and support they need from physicians to provide adequate care for their relative (Fortinsky, 2001). There are many factors that contribute to gaps in communication between physicians and caregivers. In this article, we will address some of the strategies family caregivers may use to improve communication with their relative's physician beginning with the next visit.

Normally, when people visit the doctor, they go alone, ready to discuss their own complaints and concerns. This changes with Alzheimer's disease due to the progressive decline in the person's cognitive abilities. When first diagnosed with Alzheimer's disease or another dementia, your relative may be fully able to communicate verbally with her physician. However, as time goes on, she may not retain the ability to express her own feelings, symptoms, or behaviors. As someone who spends a significant amount of time with this person, you may become an "expert"



on her behavior and health condition. Therefore, it is important for you to accompany your relative to the physician's office, and to be prepared to communicate directly with the physician.

You are at the physician's office for two reasons. Your primary task is to help your relative by acting as an advocate. Being an active participant by reporting changes and addressing concerns helps to ensure that your relative receives proper care. However, you are also there to help the doctor. Physicians need caregivers to help monitor treatment plans and report changes in behavior. Both of these individuals truly rely on your presence and participation in the medical encounter. The health care relationship relies on involvement of three parties - the person with Alzheimer's disease, the caregiver, and the physician. Each member of this triad is crucial to providing the best care for the person with Alzheimer's.

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Education Programs Focus On Communication

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The Michigan Great Lakes Chapter will present "Improving Communication With Your Physician," a two-hour program focusing on how to communicate more effectively with physicians and get the most out of office visits, in both Adrian and Ann Arbor this summer. Program dates and times can be found in our most recent issue of the Community Calendar; call (800) 337-3827 to request a copy or visit our website at www.alzmgreatlakes.org.

Recently, the chapter applied for a grant from the Michigan Department of Community Health in collaboration with the Michigan Alzheimer's Disease Research Center (MADRC) to develop a train-the-trainer program for professionals who provide education to family caregivers through the Alzheimer's Association or

Community Mental Health affiliated agencies. If funded, the grant will enable programs on "Improving Communication with Your Physician" to be offered throughout the chapter area in the coming year. Look for more information in future issues.

Another program that offers support with communication issues during the middle stage of Alzheimer's is the Caregiver Education series entitled "Building Caregiver Skills." This program addresses the challenges of communicating with someone with dementia and coping with difficult behaviors. In recent months, this series has been offered in the Southwest and South Central regions. Three sessions will be presented this summer; call the chapter office nearest you for more information, (800) 337-3827.

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What to Ask Physicians to Get the Answers You Need

Asking questions is probably the most important thing to do when you accompany your relative to the doctor's office. Your questions will help clear up doubts, concerns, and misunderstandings. Don't just worry about something; ask!

- Ø What is the diagnosis?
- Ø Which tests must my loved one undergo?
- Ø What are the treatment options?
- Ø Should my loved one avoid any kinds of food or activities while being treated?
- Ø What is the future course of Alzheimer's?
- Ø Do you have written information about the disease?
- Ø Are there services available to provide support and assistance to our family?
- Ø Where can I get more information, education and training about Alzheimer's?
- Ø How will my family members be affected over time?
- Ø Do I need to see another physician or specialist?
- Ø Can we schedule a follow-up visit?
- Ø Under what circumstances can I contact you when I have concerns or questions, or when I need to inform you of changes?

Excerpted from the Caregiver Kit, 2000, Michigan Alzheimer's Disease Research Center-Education Core and Alzheimer's Association, Michigan Great Lakes Chapter.

Improving Communication

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As a caregiver, there are certain things that you have a right to expect from a physician. You deserve answers to your questions, easily understood explanations, kind treatment, appropriate referral to specialists, and referrals to community resources. If your relative is not receiving the care she deserves, you can change that.

For you to provide the best care, you need to be informed about the disease, what to expect, and how to manage symptoms. (See accompanying article on page 2 for ideas on what to ask physicians to get the answers you need.) Most physicians will understand your concerns as a caregiver and can help guide you to the resources that you need. In fact, many will already be aware of the troubles caregivers often encounter, but you must share any concerns you have with the physician and let him know that you need education and training that recognizes your emotional attachment to your relative. Most likely, the doctor will appreciate the attention you have paid to your relative's health.

Strategies to Improve

Physician-Caregiver Communication

Strategy 1: Keep a log of signs and symptoms. This will help the physician identify behaviors/symptoms that occur outside the office, when your relative is engaged in normal, daily activities.

Strategy 2: Ask for a diagnosis. This will help you develop the right treatment plan; plan for the future with regard to long-term care and legal/financial issues; and obtain outside assistance/guidance.

Strategy 3: Define Your Role. Let the physician know that you want to form a partnership, in order to provide the best care

for your relative. Once the doctor realizes that you share the same goal, he will be more willing to include you in discussions about treatment and care.

Strategy 4: Be Clear and Concise. Be as organized and clear as possible during the visit. Bring a list of items you would like to discuss with the physician, with the three top concerns highlighted. This will make it easier to address your priorities in a short time frame.

Strategy 5: Increase Assertive Behavior. When you don't understand something the physician has said or when you feel an explanation wasn't adequate, just ask! When you become more assertive, you will convince him you are an important part of the physician-patient-caregiver triad.

Strategy 6: Seek and Reveal Knowledge. Inform the physician that you need information about Alzheimer's, both written and verbal. Also, let him know how much you already know about the disease, so he can correct any misconceptions.

Strategy 7: Be prepared. Be prepared to both ask and answer questions. A written summary of behaviors, medications, and medical conditions can help you and the physician make the right choices about a treatment plan.

Strategy 8: Remember that every member of the triad is important. While it's critical that you establish a partnership with the physician, it's also important to acknowledge the contributions of your relative with Alzheimer's. She should be encouraged to participate in all decisions, because she will be the one most affected by those decisions.

Excerpted from the Caregiver Kit, 2000, Michigan Alzheimer's Disease Research Center-Education Core and Alzheimer's Association, Michigan Great Lakes Chapter.

Resources

Tools to help you prepare for your next office visit:

Care Log - Helps you record your observations regarding the symptoms and behavior of the person with dementia. This information will help you and the doctor better care for your relative.

Next appointment - This document will help you to be clear and organized at your next doctor's appointment.

Commonly Asked Questions - A guide to help you ask critical questions.

Caregiver Checklist - This checklist reminds you of everything you need to know, remember, and bring to your next office visit.

Additional Resources for Middle Stage Alzheimer's Disease

"Steps to Understanding Challenging Behaviors"
Alzheimer's Association, 1998

"Best Friends Approach to Alzheimer's Care"
Bell & Troxel, 1997

"Understanding Difficult Behaviors,"
Spencer & White, 1989

To obtain these and other resources, call the chapter office nearest you at (800) 337-3827.