

ALZHEIMER'S DISEASE CAREGIVING ADVISORY GROUP

Convened by the National Alliance for Caregiving

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April 8, 2009



Represented Organizations

Alzheimer's Association

American Association of Geriatric Psychiatry

American Association of Homes and Services for the Aging

Cleveland Clinic Neurological Institute

Georgetown University Memory Disorders Program

National Alliance for Caregiving

National Family Caregivers Association

National Medical Association

Towson University Department of Gerontology

University of Utah Center for Alzheimer's Care

**Alzheimer's Disease Caregiving Advisory Board
April 8, 2009 Meeting Summary**

Introduction

On April 8, 2009, the Alzheimer's Disease Caregiving Advisory Board, convened by the National Alliance for Caregiving, met to discuss how family caregivers and the medical community can work together to work in partnership with primary care physicians and neurologists in understanding the diagnosis and progression of Alzheimer's Disease. To this end, a primary focus is the development and execution of feasible treatment strategies and working to improve the situation for Alzheimer's patients. The facilitated discussion was focused around the three questions. Responses to each question are summarized below.

1. How can family caregivers and physicians best work together to develop and carry out therapeutic strategies for patients with Alzheimer's?
2. What can nurse practitioners and other allied health professionals do, in concert with family caregivers, to improve the diagnosis and treatment of patients before they can be seen by a neurologist?
3. Through what type of formal process can family caregivers most effectively provide direct input into the development of a caregiver's perspective into the Alzheimer's treatment guidelines?

Question 1: How can family caregivers and physicians best work together to develop and carry out therapeutic strategies for patients with Alzheimer's?

- a. Make the patient/caregiver/physician office visit more productive through advance preparation, partnering, and a consultation of adequate length (at least 30 minutes).**

There is a great deal of support for educating and preparing both family caregivers and physicians as to what each group can do to improve the effectiveness of the patient-doctor visit that take place. One recommendation is for the family caregiver to come prepared with information about the patient (perhaps even a checklist) and know what questions to ask prior to the office visit. The physician is best able to assist the caregiver when notified about key issues in advance of the office visit. An effective resource includes the Alzheimer's Association's "Partnering with Your Doctor"¹ workshops, which offers the following recommendations:

- ◇ Encourage all family caregivers to be present at the medical visits of their loved one.
- ◇ Train caregivers of people with Alzheimer's disease how to have the most productive, partnering relationship with their physician:
 - Manage office visit expectations – particularly the time a physician is able to spend
 - Maintain a log of activities, observations and medications that can be shared with the treating physician, especially as new symptoms appear
 - Utilize a checklist of questions to guide discussions with physicians and allied health professionals.

¹ Representative of the Alzheimer's Association

- ◇ Encourage caregivers to communicate areas of concern to the physician in advance of the patient visit, through a separate office visit, a phone call, or an email. This helps prepare the physician for the nature of the visit and can serve as a more appropriate means to convey information that might be sensitive to discuss in the patient's presence—particularly around the sensitive issue of Alzheimer's.
- ◇ Provide an AD dementia-specific checklist that physicians can use to help assess the holistic needs of the patient's care.
- ◇ Utilize nursing staff to organize weekly telephone calls for caregivers of Alzheimer's patients or facilitate support groups based out of the physician offices. This would address several variables, including support to caregivers that minimizes one-on-one education and addresses provider concerns regarding non-reimbursed time.

b. Support the primary care physician for faster/better diagnosis

Advisory board members suggest the following:

- ◇ Expand and refine efforts to train primary care physicians to diagnose and treat Alzheimer's disease. One option: partner with the Alzheimer's Association² through its established physician education program for practice training, offering CEU's in partnership with neurologists. The focal point of the education would include the implementation of standard AD screenings and basic assessments related to dementia care.
- ◇ Give primary care physicians a list of specialists who diagnose and treat Alzheimer's so they can make good referrals and ensure that patients get the appropriate care in a timely manner.
- ◇ Give family physicians resource materials to give to caregivers, including educational materials, information on supportive programs and services, and names of organizations and resources of information.
- ◇ Develop easier, reliable assessment methods for diagnosing Alzheimer's that could be used by primary care physicians.

c. Effect policy change so that insurance reimbursements cover services that are essential to diagnosing and treating Alzheimer's patients.

Advisory board members recognize that part of the reason that Alzheimer's patients do not get what they need is that they may need services that are not currently reimbursed, and reimbursements affect what medical professionals choose to do for a patient.

- ◇ Work toward reimbursements for:
 - Longer patient consultations
 - More time with family caregivers for consultation about AD patient care and ancillary services
 - Office visits that do not involve medical testing – an AD wellness visit
 - Chronic disease and coordination management
 - Health education.

² Representative of the Alzheimer's Association

Medicare will pay for certain types of caregiver education when it is provided as part of a patient's medically necessary face-to-face visit. A tip sheet of information about the caregiver education Medicare codes is attached to this summary.

d. Educate caregiver for treatment awareness and doctor selection.

Advisory group members believe that family caregivers would be more effective if they received education about treatment for Alzheimer's. One meeting participant explains that the caregiver's knowledge and expectations can significantly affect the kind of care offered and the sustainability of AD patient outcomes. Further, the caregiver's knowledge and active involvement helps ensure that decision-making about treatments is active rather than passive, particularly when a patient is approaching the stage when additional treatment may be futile.³

In addition to helping them become more knowledgeable about the disease itself, caregivers need to be helped in finding a physician who is both capable and interested in treating the disease of their loved one.

- ◇ Teach caregivers about the course of the Alzheimer's disease, its science, and its treatment.
- ◇ Teach caregivers about the neurological tests and any other steps that should be done for the patient. Then, if they see their physician is not following through on specific strategic recommendations, they can either speak up or use this as an "exit strategy" to find another physician.
- ◇ Identify primary care physicians who are capable and interested in treating dementia
- ◇ Educate caregivers that not just any physician will be right for handling their loved one in case of dementia. Empower them to find the right physician.

An advisory group member points out that the education of the caregiver should be linked to the patient's medical care needed at that time; if not, it may not be timely or dependable. However, it is recognized that physicians cannot provide this information without assistance, and it is suggested that pharmacists and health educators can play a role, assuming payment mechanisms can be put in place.

e. Foster faster recognition of signs of dementia.

Dementia, especially in the early stages, is not always recognized quickly by the healthcare system. Advisory board members speculate that this is partly because caregivers may not always think about bringing their loved one to a doctor for memory issues, they may be reluctant to mention them when at the doctor's, especially in front of the patient, and they may be concerned that his/her opinion may not be taken seriously by the doctor.

- ◇ Receptionists and other medical and non-medical staff in primary care doctors' offices should all be trained on signs of dementia and be encouraged to report them to physicians. This could be as simple as having the receptionist mention to the nurse if visits are missed frequently. Alternatively, non-physicians in medical offices could administer quick assessment checklists and report the results to the physician.

³ This explanation was provided by an advisory group member after the meeting in writing.

- ◇ Caregivers and the general public should be educated about the types of changes that signal dementia or its progression, and the importance of discussing these signs with physicians should be emphasized.
- ◇ Along these lines, everything should be done so that patients and families get to treatment, including to psychiatrists as well as primary care doctors or neurologists, before the situation becomes a crisis.

f. Consider reconfiguring models that work for identifying depression to work for Alzheimer's disease.

Question 2: What can nurse practitioners and other allied health professionals do, in concert with family caregivers, to improve the diagnosis and treatment of patients before they can be seen by a neurologist?

a. Conduct a range of educational programs targeting allied health professionals, community programs, and the public at-large about Alzheimer's disease.

Create awareness campaigns and training programs to alert individuals who encounter aging populations (at Meals-on-Wheels, elder day care, community pharmacies, etc.). These varied target groups can serve as advocates to recognize early signs and to encourage caregivers to seek out a medical consultation for their loved one.

- ◇ Part of this education, particularly education of the public, needs to establish new "peer expectations" for what should be done when signs of dementia emerge. Currently, it is expected that someone who has chest pain is taken to the hospital. It is essential to patients' well being that the public also thinks that a person with Alzheimer's symptoms needs to be diagnosed and treated.
- ◇ To support this type of education of the public and to give the public a resource they can consult with initial questions about dementia, informed mental health professionals could be placed in community centers, senior centers, community clinics, and other places where seniors congregate..

b. Improve the education of nurse practitioners and empower them assist in the Alzheimer's patient evaluation and diagnosis.

Because of their level of interaction with patients, nurse practitioners can play an essential role in the early diagnosis of Alzheimer's and can monitor disease progression.

- ◇ Increase the focus on Alzheimer's and dementia in nursing school, in in-service education, and in professional meetings. Educate primary care nurse practitioners to recognize symptoms and on what they can do to intervene when signs and symptoms become prevalent.
- ◇ Nurse practitioners can help translate the science of dementia to family caregivers, to help them understand the biological basis for the disease progression and provide needed resources for support.

c. Assign nurse practitioners the role of helping Alzheimer's patients and their family caregivers navigate the health system, ensuring continuity of the patient's care.

- ◇ Nurse practitioners may be able to "triage" patients, order appropriate tests and partner with Neurology in advance of a full neurological evaluation.
- ◇ The nurse practitioners and nurses should build relationships with physicians and clinics that are responsive and generally serve as advocates for the patients.

An underlying assumption, felt by many of the advisory board members, is that it is not acceptable for a patient to have to wait several months to engage in the specialty care segment of the health care system.

d. Educate pharmacists more about Alzheimer's disease so they can play a more active role in getting patients to diagnosis and treatment.

Every day, neighborhood pharmacists see a wide range of individuals who are filling or refilling prescriptions, but who also may be showing initial signs of dementia. Pharmacists can be a great community based resource as well as an advocate for patients with Alzheimer's Disease and their caregivers. An easy step is for pharmacists to encourage treatment and provide a resource list for AD patients and physicians.

- ◇ Include education on Alzheimer's disease in the pharmacy school curriculum.
- ◇ Offer continuing education credits for pharmacists to take seminars about Alzheimer's Disease and the importance of maintaining a dialogue with AD caregivers

e. Primary care practices can implement peer-to-peer caregiver mentor programs for individuals who care for someone with Alzheimer's Disease. Family caregivers of people in later stages, for example, could mentor caregivers of AD patients in the earlier stages.

Question 3: Through what type of formal process could family caregivers most effectively provide direct input into the development of Alzheimer's treatment guidelines?

Advisory group members suggest that caregivers should play a role in evaluating the Alzheimer's treatment guidelines not just for neurology, but for geriatric psychiatrists, primary care, and other specialties involved with the disease. They note that caregivers would contribute several types of input:

- ◇ Adding guidelines or caregiver principles for the AD patient. Examples include (1) Evaluating patients in a timely manner from the "first initial demonstration of dementia-like symptoms" and (2) Maintaining patients in the least restrictive environment.
- ◇ Assessing current guidelines so that they respect the caregiver's experience and can realistically be implemented.

- ◇ “Translating” the guidelines into laymen’s terms so caregivers can understand practical ways to implement them.

Beyond gathering caregiver input into treatment guidelines, advisory group members suggest also that each individual practice obtain feedback from an advisory group of family caregivers recruited from their practices.

Suggested methods for including caregiver input in the development of treatment guidelines are as follows.

a. Include caregivers on the panel that makes the treatment recommendations

b. Conduct research with caregivers so that the guidelines are based on empirical data reflecting caregiving experiences and needs.

- ◇ In particular, conduct research on caregiver goals, especially analyzing the differences and similarities among goals of family caregiver, early on-set AD patients, and health care providers: Are caregivers interested primarily in quality of life, or reducing the rate of the disease progression, or is a cure the only thing that is important to them?
- ◇ Include research on whether caregivers believe existing guidelines are effective (e.g., should primary care physicians or neurologists deliver ongoing Alzheimer’s dementia care?)
- ◇ Conduct research by surveying caregivers who attend support groups, e.g. those affiliated with the Alzheimer’s Association⁴

c. Create a public comment period for treatment guidelines with lead medical associations and societies so that caregivers and organizations working on behalf of caregivers can provide feedback.

Summary of Overarching Themes

1. Identify principles for Alzheimer’s Disease Caregiving as core recommendations for policymakers on Capital Hill.
2. Formalize a partnership with lead AD medical associations/ societies – particularly the American Academy of Neurology, American Academy of Family Practice, the American College of Physicians, the Association of Geriatric Psychiatry and the Association of Neurological Nurse Practitioners—to educate caregivers about what to expect from the disease, from the health care system, and how best to work with physicians’
3. Educate primary care physicians, nurse practitioners, pharmacists, and allied health professionals about the diagnosis and treatment of Alzheimer’s, and the importance of referring patients and caregivers to support networks and community resources.
4. Expand the role of allied health professionals to facilitate greater awareness in improving the diagnosis and care of people with Alzheimer’s Disease.

⁴ Representative of the Alzheimer’s Association

5. Build greater public education and awareness to augment the recognition of signs of Alzheimer's Disease.
6. Improve public policy-- specifically financing and reimbursement of services that are critical to Alzheimer's patients, including care coordination, imaging, infusion and other innovations required for AD patients
7. Streamline the diagnostic process for physicians and advocate for integration of care between the specialty (Neurology) and Primary Care.

APPENDIX

Presented by the Centers for Medicare and Medicaid Services. Tip Sheet for Providers: Caregiving Education

Medicare will pay for certain types of caregiver education when it's provided as part of a patient's medically-necessary face-to-face visit. Caregiver education is not separately payable in Medicare Part B; however, it can be billed as part of the counseling and coordination of care services you provide during a patient visit as long as it directly involves the patient and is medically necessary. Medicaid coverage policies for these services vary by state, so you should check with your Medicaid state agency for guidance.

In general, you must submit Medicare and Medicaid claims using HIPAA-compliant codes, such as the Current Procedural Terminology (CPT) codes developed and maintained by the American Medical Association. CPT codes for patient evaluation and management (E/M) visits include three key elements:

- Patient history (includes the patient's problem/complaint, any past, family and social history and a review of body systems)
- An examination
- Medical decision-making

CPT code descriptions for patient visits may also include counseling and/or coordination of care as contributory components, but these are not required to be part of every visit.

Billing for Caregiver Education Under Medicare Part B

An E/M patient visit is typically billed based on the key elements needed to support a specific level of service. But in certain circumstances, billing can be based on the time needed to support a specific level of service. You can bill an E/M visit based on time when more than 50 percent of the physician/patient face-to-face time in the office or on the hospital floor is dominated by medically necessary counseling and/or coordination of care.

When you bill for Medicare Part B services, your documentation in the medical record must support the level and amount of work you provided to the patient in that visit. For example, to report a Level 5 visit based on the three CPT key elements (history, examination and medical decision making), you must perform a comprehensive history, a comprehensive examination, and make highly complex medical decisions. Your documentation must support the level of work you performed: how extensive was the patient's history? Was the examination a less extensive assessment or did it involve a comprehensive single organ system or multi-system examination? How complex were the medical decisions required to make your assessment and complete a treatment plan?

The following is an example of how a visit for counseling based on time may be billed:

During a 40 minute patient visit, you spend 15 minutes taking the patient's history, performing the examination, and making your assessment. You spend the other 25 minutes of the visit counseling the patient and his family. The total time you spent on this encounter can be used to determine a specific CPT code level, as code levels have typical time associations.

The CPT code you use is also determined by where the patient E/M visit took place. Examples of settings where visits that may involve caregiver education can occur include the following:

- Doctor's office or other outpatient facility (CPT codes 99201-99215)
- A patient's home or private residence (CPT codes 99341-99350)
- An assisted living facility or other domicile (CPT codes 99324-99337).

Billing for Caregiver Education Under Medicare Part A

Medicare Part A covers home health services that include skilled nursing care and medical social services, both of which may involve caregiver education. For example, medically-necessary training activities that require skilled nursing personnel to teach a patient and his caregiver how to manage treatment regimens can be considered a skilled nursing service covered under the home health benefit.

CMS Publication No. 11390-P