

Questions and Answers (Q&A): Caring for Individuals with Alzheimer's Disease and Related Dementias

Webinar 1: Presentation and Diagnosis of Alzheimer's Disease

Participants asked these questions during the August 5, 2015, webinar on presentation and diagnosis of Alzheimer's disease, webinar 1 in the Geriatric Competent Care Webinar Series, Caring for Individuals with Alzheimer's Disease and Related Dementias. We have edited speakers' responses for clarity. The panel discussion recording, slides, and transcript can be found on the Resources for Integrated Care website by clicking the following link:

[Caring for Individuals with Alzheimer's Disease and Related Dementias: Presentation and Diagnosis of Alzheimer's Disease](#)

Featured Speakers:

- Chris Callahan, MD, Indiana University, Director, Center for Aging Research
- Beth Galik, PhD, CRNP, School of Nursing, University of Maryland
- Irene Moore, MSW, LISW-S, University of Cincinnati College of Medicine

Diagnoses and causes of Alzheimer's Disease and Dementia

Q1: Would you recommend imaging (e.g., MRI vs CT) as routine part of diagnostic testing in someone with cognitive impairment?

Dr. Gregg Warshaw: Brain imaging studies may be especially useful in the following situations: (1) onset occurs at an age <65 years old, (2) symptoms begin suddenly or progress rapidly, (3) there is evidence of focal or asymmetrical neurologic deficits, (4) the clinical picture suggests normal-pressure hydrocephalus (e.g., onset has occurred within 1 year, gait disorder or unexplained incontinence is present), or (5) there is a history of a recent fall or other head trauma. In general, a non-contrast CT head scan is adequate to exclude intracranial bleeding, space-occupying lesions, and hydrocephalus. If vascular dementia is suspected, MRI is often performed, but not recommended. If performed, white-matter changes revealed by T2-weighted MRI images should not be over interpreted.

Q2: With Frontotemporal dementia - can it be secondary to TBI?

Dr. Gregg Warshaw: Research has linked moderate to severe traumatic brain injury (TBI) to a greater risk of developing Alzheimer's Disease or other dementias. It is possible that the symptoms would be consistent with a frontotemporal dementia. There is no evidence that one

mild TBI event increases the risk for dementias. Athletes with repeated mild head trauma can develop a dementia syndrome named chronic traumatic encephalopathy (CTE).

Q3: Is diabetes a condition which affects dementia and going forward what are the implications for dementia and healthcare costs?

Dr. Gregg Warshaw: There is a form of dementia that is caused by vascular problems in the brain. Diabetes can lead to vascular disease in the brain, and a resulting dementia. Alzheimer's Disease is not associated with diabetes mellitus. Yes, more diabetes could mean more vascular disease, which could lead to more dementia.

Q4: The speakers did not mention urinary or kidney issues and thyroid issues. Why is that?

Dr. Gregg Warshaw: Renal failure or thyroid disease could lead to cognitive changes that can mimic Alzheimer's Disease. These problems are part of the differential diagnosis. Urinary tract infections can result in an acute confusion state (delirium).

Q5: Do you have information and guidelines to differentiate between Delirium and Alzheimer's?

Carol Goodwin: The concept of differential diagnosis between delirium, dementia, and depression can be misleading because these conditions can co-exist and are risk factors for each other. To distinguish, the clinician needs to determine the person's baseline status and the timeframe in which cognitive changes occurred. Delirium is typically of a sudden onset. Information from family members, caregivers, and others who know the person can be essential.

Q6: Are there best practices for PCP practices to partner with other agencies if they do not have additional staff to assist with information gathering?

Dr. Gregg Warshaw: It is always useful to have a working relationship with a social worker and/or nurse who is familiar with Alzheimer's Disease. These professionals could be found at the local Alzheimer's Association chapter or the Area Agency on Aging.

Q7: Given all the actions to go through in diagnosing and supporting the individual, which of the innovative models of primary care (e.g., patient centered medical home) appear to work best for Alzheimer's Disease?

Dr. Gregg Warshaw: The basic guidelines for diagnosis and management of Alzheimer's Disease in primary care are listed below. They can be part of any number of clinical models. They do require that the primary care practices work closely with community-based resource providers.

Guidelines for diagnosis and management of Alzheimer's Disease:

- Active screening for cognitive impairment coupled with a second stage assessment to diagnose the specific type of dementia
- Evaluation for reversible causes of dementia
- Referral to patient and caregiver educational programs and/or community support agencies
- Consideration for specialty referral
- Active case finding and treatment for depression, psychoses, behavioral disturbances, and hazardous activities
- Active case finding and treatment for excess disability due to comorbid medical conditions
- Consideration for treatment with cholinesterase inhibitors
- Facilitated communication among the clinicians both within the health care system and the community
- Active surveillance and tracking of patient outcomes with feedback to the health care team
- Active monitoring and support of the caregiver's emotional and physical health

Q8: Out of the assessments you mentioned (Mini Mental State Examination, Montreal Cognitive Assessment, St. Louis University Mental Status), are there any benefits to using one assessment over the others?

Dr. Gregg Warshaw: These are each well standardized screening tools for the assessment of cognitive function in adults with dementia symptoms. I would emphasize, these are not diagnostic tests, and the results should be used along with a careful history from the patient and family, a physical examination, and selected laboratory tests. In some cases, more in-depth neuro-psychological tests will also be required to determine the diagnosis.

Q9: In terms of the examination of the patients, including the medical and nursing and social work examinations, these seem beyond the scope of what most primary care doctors feel that they can do at this moment in history. Do you have any thoughts about that? Dr. Callahan has done a great deal of work on care management, but is there do you have anything to share about the pragmatics in the world we're living in today?

Elizabeth Galik: In a busy primary care practice you bring up a good point; it can be quite challenging to try to squeeze a lot of this assessment in in a short visit. It's fine to parse things out over time. You don't necessarily have to cover everything in one visit. You can always ask the patient and the family member to come back in for another visit. The other thing is that a lot of practices have history forms that they'll either send ahead of time to be filled out electronically or paper copies to be brought in. If you include questions for the patient or

questions that the caregivers can answer in those forms, you can gather some of that information ahead of time. So, those are some strategies that you can use but you can also break this out over the course of several visits.

Q10: When gathering preliminary history, how can the family member or caregiver avoid HIPAA violations when working with the office receptionist to provide the information?

Dr. Gregg Warshaw: In most cases, the individual with a dementia wants their family members to be part of the assessment and planning. Sometimes people with dementia prefer to see their clinician alone, or it may not be possible for anyone to go with them. If this is the case, a family member may wish to talk to the clinician afterward. When a caregiver relative contacts a clinician with concerns about a person, the clinician may decline discussion on the grounds of breaking patient confidentiality. It is generally agreed that clinicians should listen to the concerns of caregivers, relatives, friends, or neighbors because they may have valuable information that can help their patient. The clinician should make it clear that they may tell the patient about the conversation. HIPAA guidelines should not be allowed to interfere with providing optimal care to a patient. As long as clinicians are gathering or sharing information to provide the best care to a patient, they will be within the HIPAA guidelines.

Q11: Will biomarkers for Alzheimer's Disease be used to understand the risk of disease for direct family members of a patient diagnosed with the disease? Could you speak to the molecular imaging technologies that are being used?

Dr. Gregg Warshaw: Several potential biomarkers are being studied for their ability to indicate early stages of Alzheimer's Disease. Examples being studied include beta-amyloid and tau levels in cerebrospinal fluid and brain changes detectable by imaging. Recent research suggests that these indicators may change at different stages of the disease process.

Molecular imaging technologies, utilizing positron emission tomography (PET). PET scans are among the most active areas of research aimed at finding new approaches to diagnose Alzheimer's in its earliest stages. Molecular strategies may detect biological clues indicating Alzheimer's is under way before the disease changes the brain's structure or function, or takes an irreversible toll on memory, thinking and reasoning. Molecular imaging also may offer a new strategy to monitor disease progression and assess the effectiveness of next-generation, disease-modifying treatments. Several molecular imaging compounds are being studied, and two have now been approved for clinical use.

Before a biomarker can be used in medical clinics, it must be validated, in which multiple studies in large groups of people establish that it accurately and reliably indicates the presence of disease. Furthermore, the laboratory methods used to measure the biomarker must be

shown to be stable and reliable. Eventually, adults with a family history of Alzheimer's Disease would be able to be tested prior to symptoms to determine their risk for developing symptomatic Alzheimer's Disease. This is a rapidly evolving area and the [Alzheimer's Association website](#) is a good source of reliable information.

Intellectual Disability

Q12: Can you please speak to dementia in individuals with Down syndrome or those who have intellectual disability?

Dr. Gregg Warshaw: As with all adults, advancing age also increases the chances a person with Down syndrome will develop Alzheimer's Disease. Because people with Down syndrome live, on average, 55 to 60 years, they are more likely to develop younger-onset Alzheimer's (Alzheimer's occurring before age 65) than older-onset Alzheimer's (Alzheimer's occurring at age 65 or older). Autopsy studies show that by age 40, the brains of almost all individuals with Down syndrome have significant levels of plaques and tangles, abnormal protein deposits that are considered to be hallmarks of Alzheimer's disease. But despite the presence of these brain changes, not everyone individual with Down's syndrome develops Alzheimer's symptoms. In people with Down syndrome, changes in overall function, personality and behavior may be more common early signs of Alzheimer's than memory loss and forgetfulness.

Communication

Q13: What's the rule when speaking to the patient's family or caregiver? Should we speak to them without the patient present or without asking consent beforehand?

Dr. Gregg Warshaw: The best approach to communicating the diagnosis or to discussing the course of illness will vary based upon the patient's degree of cognitive impairment. It is important to always do your best to ensure the patient consents to discussing their condition or treatment with their family members or caregivers. With the patient's consent, it is beneficial to have time to talk with family members or caregivers. As a rule, at the end of an assessment or office visit, it is best to have the patient and family together to ensure everyone is hearing the same information.

Q14: Is it always necessary to share the diagnosis with the person with dementia? Often, they are in denial of their symptoms, rationalizing that everyone their age has memory problems, for example, and attesting that they are fully capable.

Dr. Gregg Warshaw: Clinicians ought to share diagnoses with their patients. Alzheimer's disease is a special situation that requires a careful assessment of how well the patient can utilize the diagnostic information. I would always answer a patient's question about the diagnosis, but I do

not always directly use the term Alzheimer's Disease unless asked. The family members and caregivers need to be fully informed.

Q15: How do you communicate to a patient that it may not be safe for them to continue to drive?

Dr. Gregg Warshaw: Recommendations to stop driving should not be given lightly, because driving cessation can lead to a decreased activity level and increased depressive symptoms. Referral for a formal driving evaluation by a skilled occupational therapist may be helpful in confirming unsafe driving behaviors, or perhaps in suggesting interventions such as adaptive equipment to correct for specific physical disabilities. In the interest of public safety, clinicians should know their state's law on reporting impaired drivers. In most states, clinicians are encouraged, and in some states mandated, to report their concerns to the licensing agency. To assist clinicians caring for older drivers, an excellent resource has been developed by the American Medical Association in cooperation with the National Highway Traffic Safety Administration: The Physician's Guide to Assessing and Counseling Older Drivers, available here: <http://www.nhtsa.gov/people/injury/olddrive/OlderDriversBook/pages/Contents.html>

Q16: There is importance for care managers to understand how to communicate with patients and their families. What type of training would you recommend for care managers to help them support these patients and family members?

Irene Moore: The Alzheimer's Association, if you're able to attend a family caregiving support group and listen to what family members say, would give you the best first-hand experience, along with lots of written information about going forward with this.

Clinical Management of Alzheimer's Disease, Consideration of Risks and Medication Options

Q17: This type of clinical management is being accomplished throughout Wisconsin through the Wisconsin Alzheimer's Institute Memory Clinics. There are 48 currently in Wisconsin. Are there any other types of independently managed clinics in the United States?

Carol Goodwin: Memory disorder clinics can be affiliated with universities, academic medical centers, community hospitals, or privately run, usually through specialty practices (neurology/psychiatry geriatrics). Some are state-designated and receive state funding.

Q18: Are Alzheimer's disease patients at high risk for suicide?

Dr. Gregg Warshaw: The answer to this question is still under investigation. It is known that early in the course of Alzheimer's disease, depression is common and could lead to suicidal ideation or suicide attempts. Later in the disease, the mental health of the caregivers is of

greater concern. The answer to this question is complicated by the fact that older adults without Alzheimer's disease are also at risk for depression and suicide.

Q19: What kinds of medications are administered for Alzheimer's disease, and what doctors are the one who can make this diagnosis.

Dr. Chris Callahan: One of the points that we try to make with patients and families is the important but the limited efficacy or effectiveness of medications that are available. There are a couple of classes of medications that are specifically prescribed for the cognitive symptoms. Studies have found that these are not tolerated by as many as one out of four patients. And so, if you imagine this in clinical practice, this should involve a discussion with the patient and with their caregiver about the pros and cons of these medications. Donepezil is an example of this for the cognitive symptoms. There is some evidence, although it's controversial, that those medications that were developed for the memory disturbance and the other cognitive symptoms might help with other behavioral symptoms.

We have strongly encouraged families that when they're dealing with behavioral symptoms that using non-drug approaches is probably more effective, safer, and less expensive. But it's time-intensive, and it requires a patient caregiver that is willing to have these in-depth conversations. That is part of what the dementia care team is doing. Over time, they aim to provide information and support the caregiver to be able to handle many of these behavioral symptoms without the need for medications, bringing the patient to the emergency room, or other harsher interventions.

There are no drugs that are specifically developed and tested to treat any specific behavioral symptoms. They're strategies to help the caregiver to deal with a myriad of behavioral symptoms that cannot be treated with medications. Medications are quite controversial right now in the context of dementia. We certainly do use them, but it's a discussion with the patient and the caregiver about their pros and cons.