

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

Webinar 2: After the Diagnosis of Alzheimer's Disease: Preparing the Patient and Caregivers

*Participants asked these questions during the August 12, 2015, webinar on preparing the patient and caregivers after the diagnosis, webinar 2 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: After the Diagnosis of Alzheimer's Disease: Preparing the Patient and Caregivers](#)

### Featured Speakers:

- Debra L. Cherry, PhD, Alzheimer's Association California Southland, Los Angeles
- Lisa Gwyther, MSW, LCSW, Center for Aging and Human Development, Duke University
- Robert Schreiber, MD, Harvard Medical School

### Diagnosis and Cause of Alzheimer's Disease and Dementia

#### Q1: What is the screening tool mentioned by California staff?

**Gregg Warshaw:** Some common screening tools for cognitive impairment include: the Mini-Cognitive; the St. Louis University Mental Status (SLUMS) Examination; the Montreal Cognitive Assessment (MoCA); and the Folstein Mini-Mental Status Examination (MMSE).

#### Q2: Is the AD8 Dementia Screening tool available without a license, for example, is it in open access?

**Debra Cherry:** Yes, it is currently available without a license. We provided a reference on the slide to the original article on it and I believe it also appears on our [www.alz.org/socal](http://www.alz.org/socal) website. In fact, which was one of the reasons we picked the AD8 tool. There were some other validated tools, but we needed one that was available for use without a licensing fee, available for use by telephone, and one that had been translated at least into Spanish, which is true for the AD8. It was translated to Spanish from Spain, which isn't optimal for our population, but it was one of the best options we could find for telephone care management assessment.

**Q3: Will you mention how many forms of dementias there are? Are there differential diagnoses for Alzheimer’s Disease – please address a few?**

**Gregg Warshaw:** Dementia is a general term to describe several diseases that cause a significant decline of cognitive function that result in overall functional decline. The major diseases that can cause the dementia syndrome are Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia, Frontotemporal Dementia, Parkinson's Disease, and Normal Pressure Hydrocephalus. All adults with the dementia syndrome should have a careful evaluation to clarify the actual cause of their brain disease. This evaluation will include excluding clinical problems that could mimic the dementia syndrome, e.g., adverse medication effects, depression, HIV/AIDS. Some patients with Alzheimer’s Disease will die from other illnesses, heart disease, and cancer. If a patient survives to later stage Alzheimer’s Disease, death is usually associated with weight loss, declining ability to swallow, and recurring infections, such as, pneumonias.

**Communication and Support for Caregivers**

**Q4: The Alzheimer's Association has found that 50% of physicians are not disclosing the diagnosis to patients and/or caregivers. How can we as professionals work more collaboratively with physicians about diagnosis and to help promote other services?**

**Gregg Warshaw:** It is essential that the patient and caregivers/families of every adult with Alzheimer’s Disease or a related dementia be fully informed about the diagnosis. When asked, most adults with Alzheimer’s Disease will provide permission for sharing the diagnosis with a family member. If the adult with Alzheimer’s Disease is at a stage in the illness where they no longer have the necessary incite or ability to provide consent, clinicians can share the diagnosis with family without violating confidentiality regulations (HIPAA). If a clinician caring for a family member with Alzheimer’s Disease will not discuss the diagnosis with the family, the relatives should identify a new clinician.

Office based primary care clinicians may not be familiar with the resources available in their community to assist adults with Alzheimer’s Disease and their families. To promote a better awareness of these services among clinicians, ongoing outreach by community-based service providers with staff in office-based primary care practices is a needed.

**Q5: How do you provide long-distance support to family caregivers that live afar?**

**Lisa Gwyther:** There are a number of ways to do that. Sometimes I try and share the same information long distance that I share with family members who are here. I can do that by phone. I have in many cases done conference calls with family members in two or three locations. I can send written information or emailed information or refer them to websites. And

then I also encourage long distance family members to get involved with support groups wherever they live, Alzheimer's Association or otherwise, because they will find in those groups many people who have similar difficulties living at a distance, feeling guilty and wanting to be there, but not knowing how to support. And then I try and teach families how to support the people who are on the front lines by offering to do things that they can outsource like handling the money or making phone calls or looking up information or calling the person with dementia regularly. All of those things can help a local family member.

**Q6: Can you discuss how an individual can accomplish the need to share information across the continuum of care, considering the HIPAA barrier and no method to bypass the barrier/HIPAA requirements when there is no one specified caregiver?**

**Lisa Gwyther:** That's really tricky because you have to respect the privacy of the individual and often the person with dementia will refuse to have a family member in the room with them with the physician or refuse for information to be transferred. What I usually recommend to families is that they try and work it out for themselves and talk with each other about what they've heard from the healthcare professionals, try and get on a sort of level playing field about what they've heard or what they've been told. But it can be incredibly tricky. If somebody is resisting or if someone can't be there, or if the physician doesn't understand that there are these multiple caregivers in many families, or they may spend hours talking to the wrong person, as Debra pointed out, who is not the decision maker. So, I urge families in the very beginning to get powers of attorney for healthcare established early and to use those effectively in getting releases of information.

**Q7: Our plan serves many dual-eligible beneficiaries from diverse communities who have dementia or Alzheimer's Disease. You mentioned Spanish language fact sheets which sound quite helpful. Do you have other advice for working with culturally diverse members and their families?**

**Debra Cherry:** Each culture is very different. And within a family, there is not only culture, but there is acculturation, so you have parts -- and you may have generations that are very Americanized and others who are very traditional. And you may also have variation in socio-economic status and in literacy level. In general, a more person- and family-centered approach is a good one to take. You have to understand where the family is at, try to get a sense of their personal and family values, what do they want to accomplish in the dementia care, and then support them and educate them as you go.

**Q8: How do you prepare for end of life?**

**Gregg Warsaw:** Communication about serious illness is enhanced when clinicians spend sufficient time getting to know their patients and adopting a goal of exploring their patients' life values and aims. Discussing a patient's preferences and goals of care will help guide treatment recommendations.

For adults with Alzheimer's disease, it is important to speak with family and friends to determine if the patient had documented advance directives for end-of-life care prior to developing Alzheimer's disease. Clinicians need to understand what was important to the patient and the family. One key aspect to these dialogues is determining if the family understands the current medical situation. It is then important to assess the family's willingness to talk about what to do next. A clinician might first inquire if the family members have thought about what he or she would do at this point in the disease, or what he or she is hoping for or worried about. Based on these discussions, a provider may offer to make a recommendation for care that is consistent with the goals and values the patient and/or the family has expressed. This often will include the suggestion to enroll in hospice or make a referral to palliative care.

After making the recommendation, the clinician may explore what the patient and family think about the proposal. The provider might emphasize the expertise of a palliative care team to improve symptom management and to help address the physical and practical changes brought on by the disease. When discussing hospice, it is important to specifically describe what hospice can do to meet the patient's articulated goals and needs. Providers should also emphasize their continued involvement with the patient regardless of hospice and/or palliative care involvement, because families caring for an adult with late-stage Alzheimer's disease often fear abandonment by their providers at end of life. Families also often have misconceptions about hospice and palliative care, which should be elicited and addressed to ensure that the goals and procedures of hospice and palliative care are understood.

### **Clinical and Pain Management of Alzheimer's Disease, Technology and Medication Options**

**Q9: How can the physician help make families aware of medical issues, such as patients in pain, which could lead to an involuntary admission to a mental health treatment center?**

**Gregg Warsaw:** It is very important to assess for pain in older adults with Alzheimer's disease. Pain can lead to changes in behavior that may be reversible if the pain is well managed. Caregivers are frequently able to recognize pain if they are familiar with the usual facial expressions of the adult with Alzheimer's disease. Also, during the provision of personal care, (e.g., bathing, dressing), it may be possible to recognize pain. Over the counter medication such as: Acetaminophen (Tylenol) is often used to treat pain, and generally is well tolerated. Massage, music, physical therapy, may also help with pain.

**Q10: Do you have much experience with telehealth? Are you finding benefits from the telehealth technology to keep in contact with the caregivers and the patients to make sure everybody is not track and safe?**

**Lisa Gwyther:** I don't have much experience, so I can't be an expert, but I'm very aware of it. I think it will eventually be helpful, but I think what we forget is that people with Alzheimer's disease may not adapt well to new technology, it may be scary, and they may need human intervention and touch sometimes. So, trying to do things via Skype or via some telehealth platforms could pose a problem. I have found it very helpful to use old-fashioned technologies, with families and with people with Alzheimer's Disease. Some of them respond really well to just the old-fashioned telephone.

**Q11: Have you considered the benefit of using home telehealth technology to keep in contact with the patient, their family, and/or their caregiver to make sure they are on track and safe? Have you looked into using technology to observe a patient's movement and activities?**

**Gregg Warsaw:** This is a rapidly evolving area. Home monitoring and safety technologies are available commercially. Robotics and telehealth are being used in home and nursing home settings. GPS tracking devices are available to help locate adults with Alzheimer's Disease. I recommend contacting the [Alzheimer's Association](#) to obtain up-to-date information.

**Q12: How many years do any of the medications used to slow the progression of Alzheimer's have a therapeutic impact?**

**Gregg Warsaw:** The available prescription medications used to treat the memory problems associated with Alzheimer's Disease do not slow the progression of the underlying damage to the brain. They may improve memory and behavior for a period of time, especially early in the illness. The benefits of these medications vary among adults with Alzheimer's Disease. Some patients will not respond at all, while other may benefit for a few years.

**Robert Schreiber:** So, in terms of therapeutic impact, we're talking about people's ability to maintain their function and hopefully there may be some evidence of some behavioral improvement. This is variable for all individuals. There are people that seem to really do well on a medication. In that instance, we maintain that medication because they seem to be progressing slower than what we would expect. And then there are others that we put them on medication don't experience much of a difference. It's really important to do standardized assessments on where people are at. And there are a lot of variables that can impact people's functional abilities.

We talked about healthy lifestyle behaviors and a lot of caregiver stress. Providers must have a holistic approach, but in general, with people with advanced dementia, we do not continue

medications and we will oftentimes stop them. For people who are rapidly progressing, where it does not appear the medication is making a difference, we oftentimes will give it a trial for several months, and then if it's not working, we'll back off on it. These individuals may have multiple other medications and you want to avoid any adverse drug-drug interactions. This is a question that providers should continue to ask. There is no fast and tried rule, its trial and error. There are always some concerns that if you take somebody off that they may rapidly decline. There have been case reports of that, but in general, it's a matter of individually looking at the person and taking an assessment.

**Q13: Are any of you familiar with Pill Pack, a pharmacy that packages pills in a unique way, which may serve people with cognitive deficits?**

**Gregg Warshaw:** This is a commercial, enhanced pharmacy service that is covered by some insurance plans. A key aspect of the service is the packaging of multiple pills into individual packets labeled for the date and time they should be taken. Although this appears to be a very useful service, there is no evidence that I have seen to suggest that this service would enhance the medication adherence for adults with Alzheimer's disease.

**Q14: Is targeting aggression common in Alzheimer's disease?**

**Robert Schreiber:** Yes, I think it was Lisa who mentioned the fact that usually the person who is most around the individual oftentimes becomes the target for aggression and especially if it's somebody who's the one primarily responsible as the primary caregiver. So, this does occur, and it is important to understand who is the care giving network and how can you diffuse this aggression? What can you do behaviorally? Oftentimes individuals that are the target of aggression need significant support. But we see that very, very commonly and I would advise that individual to seek out support through the Alzheimer's Association, to talk to the doctor but really be proactive with that.

## Resources

**Q15: CareFirst has many members but a lack of resources or accepting facilities, will some of the resources that you listed help with placement?**

**Gregg Warshaw:** I recommend contacting a local or national chapter of the [Alzheimer's Association](#) to obtain information on facilities accepting adults with Alzheimer's disease.