

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

Webinar 4: Understanding and Responding to Behavioral Symptoms Among Individuals with Alzheimer's Disease and Related Dementias

Participants asked these questions during the November 3, 2015, webinar on understanding and responding to behavioral symptoms among individuals with Alzheimer's disease and related dementias, webinar 4 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: Understanding and Responding to Behavioral Symptoms Among Individuals with Alzheimer's Disease and Related Dementias](#)

Featured Speakers:

- Geri Hall, PhD, ARNP, Clinical Nurse Specialist, Banner Alzheimer's Institute
- Beth Spencer, MA, LMSW, University of Michigan School of Social Work
- Gregg Warshaw, MD, Professor Emeritus of Geriatric Medicine, University of Cincinnati

Behavioral Symptoms

Q1: Are there differences in the specific kinds of behavioral changes associated with each type of dementia? For example, is there a certain type of behavioral symptom that's more common with vascular dementia as compared with the others?

Dr. Gregg Warshaw: The key thing to remember is early in the disease there are certain symptoms that are much more common in atypical dementia other than Alzheimer's disease. As Dr. Hall pointed out in her presentation, in people with Lewy Body dementia they might have more hallucinations, or they might have more personality changes. In frontotemporal dementia individuals might have more personality changes early on. In vascular dementia one of the things that we notice early on is some neurologic findings and some physical findings on exam. Behavior will vary based on where the stroke disease is, because vascular dementia is really a stroke-related dementia.

Early in the disease, providers can make some of these distinctions. As the disease progresses, it becomes a little harder because late-stage Alzheimer's disease has a lot of these similar findings. It is important that we don't use dementia as a term without characterizing it by

cause. I think of it like congestive heart failure. There are a lot of causes of congestive heart failure. You can have congestive heart failure because of vascular disease and coronary artery disease, or you can have congestive heart failure because of valvular disease. It's important to describe the cause. When I see on a diagnostic list the word dementia, I always want to understand what the clinicians think the actual cause of the dementia is. If we think it's Alzheimer's, we should say probably Alzheimer's disease. If we think there is mostly a vascular component, we should say vascular dementia. If we're not sure and we think there is a mixture, we should state that as well. If we're more precise in diagnosis, then we can be more precise in looking for behaviors that are associated with that diagnosis.

Q2: If a family member is coming to you with concerns about their family member exhibiting behaviors like a urinary tract infection -- for example, being forgetful, wandering and aggression -- what approach would you suggest being used with the family if they keep mentioning the UTI instead of any other rationale for this behavior?

Geri Hall: That's probably the most common call that I get from my patients who are confident that something has changed or suddenly happened. They know when it's been a period of a day or two days or even a week, that something is wrong. I send them instantly to their general physician, primary care physician, or if it seems more acute to what they're saying, to a local emergency room so that they can get treated medically. We're very careful to use a lot of patient education, and it centers on these triggers. Many of our patients and families are on Internet support groups, so everybody knows about UTIs, but they forget about pneumonia and pain and all the other things that need to be looked out for.

Q3: When an individual expresses dangerous behavior symptoms in a community environment, who would you recommend we contact for help when family members are not present?

Dr. Gregg Warshaw: Larger cities and all states have Adult Protective Services agencies that will accept referrals, from any concerned person, regarding adults who are abused, neglected, at risk, or have behaviors that are not being adequately addressed and may place the person in danger. More information can be found on the [National Adult Protective Services Association website](#).

Management of Alzheimer's Disease and Dementia

Q4: A brother who has early dementia symptoms has extreme anger issues towards his sister. He has excluded her from his life and is verbally aggressive to her. How can a mending of their relationship occur?

Dr. Gregg Warshaw: In trying to understand relationship problems in the context of a

dementia, it is helpful to gather information about the affected adult's previous personality and family relationships. In the case you are describing, what can be determined about the brother's prior relationship with his sister? It is useful to try and find a neutral party who can confirm if a real basis for the anger exists. If the relationship was always difficult, then this could become exaggerated by the dementia. If this is a total change of behavior, then it may represent a personality change caused by the dementia. In either case, as the dementia progresses the brother may forget about the source of his anger, and this could improve the relationship with the sister. A geriatric psychiatrist may be able to help in this situation.

Q5: Could you explain more options or alternative treatment plans, such as reading out loud, yoga, and spiritual talks?

Beth Spencer: Yes. I would say that certainly one of the areas where there is increased interest in research going on is with mindfulness practice--not only for caregivers--but also for people with early-stage dementia. Sometimes it's simple. I will say that I had my mother with dementia living with me for six months this year and got a big wake-up call about what it really feels like to do this 24-7. I spent a lot of time with her when she was starting to get upset just having her take a deep breath. We would just count down together; do a little bit of breathing. I would put on some music. I think music is often a distraction but also a calming agent for people if you know what kind of music they like.

As for more alternative treatments, there is research going on looking at Tai Chi for people in the earlier stages of dementia to help with balance and to help with calming. A lot of people use massage and aromatherapy is big. However, as Dr. Hall said, many people with Alzheimer's lose their sense of smell, so that doesn't work for a lot of people. Art therapy is one that's being used more and more. A lot of adult day programs and assisted living programs are developing innovative creative arts approaches to making the quality of life better for people. If their quality of life is better, they're likely to not be as distressed a lot of the time.

Geri Hall: I'd add one thing, and that is exercise is also good to really help with behavioral control and prevention.

Q6: The suggestions for alternative treatments are helpful. Do you have suggestions for alternative treatments for people that have macular degeneration (visual impairment) and Alzheimer's disease?

Dr. Gregg Warshaw: Sensory loss (hearing or vision) is a common and serious co-morbid condition that may be present in adults with Alzheimer's disease or related dementias. An occupational therapist can be helpful in adjusting the home environment for a person with visual loss. They may recommend changes in colors or lighting. The family can be educated to

cue their relative to who is the room and objects in the environment. Music or audio books may be helpful ways to engage the visually impaired adult with a dementia. Visual hallucination that is distressing to the adult with Alzheimer's disease should be evaluated by a physician.

Q7: How do you recommend most caregivers strategize around providing a system with activities of daily living if they disagree with each other on how to provide the assistance?

Beth Spencer: If you are talking about multiple family members who are in conflict, which is certainly challenging for all of us in the healthcare profession. I've done many, many family meetings with families where there was conflict. I would say that typically what I do in that kind of situation is start by trying to understand what everyone understands of the disease and of the medical situation of the person. Often people don't have the same understanding and so you kind of need to start there.

For example, in people with Lewy Body dementia there are such huge fluctuations from day to day that it's terribly confusing to families, because the person may seem very normal one day and extremely confused the next day. That makes it hard for families to understand what's happening. It is important to talk about expectations each person in the family has. After going through how everyone feels, we start looking at how tasks are getting done. Again, whether I'm working with a group of staff or of family, I always start with what are the feelings of the person. What do you think is going on inside that person? That's where we must start because our job is to support them in whatever ways we can to make their life as stress-free as possible and their quality of life as high as possible.

Dr. Gregg Warshaw: I think one of the things that is distinctive about Alzheimer's disease is that even in the mid stages, patients frequently look healthy. Depending on how much time family members spend with their relative with the disease, they may not understand the degree of damage that's occurred in the brain. They may look at the at their parent or loved one and see them as they always have been. Another characteristic of Alzheimer's disease is that people with the disease may lose insight and may not actually recognize their deficits. The family members who are listening to their parent, for example, say, "I can do this. I don't need any help with this." Normally, children do what their parents say, and so they assume that their parent knows what they're talking about. I think in these conversations and in these sessions, like Beth described, it's important to make sure everybody understands the degree of difficulty the person is having and what their capabilities are in this issue of loss of insight. Otherwise, people will be coming at the problem in completely different perspectives.

Q8: At what point in the trajectory of Alzheimer's disease is it the right time to use medication such as Aricept or Donepezil?

Dr. Gregg Warshaw: These are medications that may help with the brain chemistry so that the chemicals that communicate between the brain cells will be increased and maybe improve memory. Generally, although these drug effects are variable and usually not too dramatic, they're best used early in the disease.

The class of drugs that Donepezil is in generally has been tested early in the disease. If it has beneficial effect on the patient's memory, they can be used for a period until the brain disease progresses to the point where additional chemistry doesn't help because the neurons are too damaged. Figuring out when to stop those medications is always a challenge for the clinician, the patient, and the family. If the medications don't work early in the disease, then they can just be stopped and not be used.

There is another category of medication which is available that uses a different mechanism. It's called Namenda or Memantine. That drug can be used earlier or later in the disease, like Donepezil. Some physicians will use them together, although the benefits of using them together are not that well documented. Some people use Aricept early in the disease and Memantine later in the disease, but it varies from patient to patient and doctor to doctor how that works. Generally, the idea of these medications is to improve the brain chemistry, which implies that there are still enough functioning neurons that the patient can benefit. As the disease progresses, these drugs have less and less value.

Q9: Could you speak a little bit more about adverse drug events and how they can be prevented? How can home care staff, family caregivers, and care partners play a role in decreasing adverse drug events?

Dr. Gregg Warshaw: That's a good question. I'm very interested in medication lists in older patients and particularly ones with Alzheimer's disease. The first thing that I really pay attention to is "does the person have adequate support in managing their medications?" It's very hard for a clinician to assess medication effects on a patient if they're not sure how the patient is taking their medications. A lot of older people living at home with Alzheimer's disease or dementia are supervising their own medications. In those circumstances, we have no idea what's going on. They may be taking too little or too much of their medications. Families may come by and check occasionally, but they're not there watching what's happening with the medications. To begin the process of understanding medication issues in older adults, particularly with dementia, you must make sure people are getting the medications properly. That may require a caregiver responsible for making sure the patient takes the medications as needed.

The next step is to look at the medication list and to try to get it down to as few medications as possible. This is a good advice for any older adult, but particularly for people with dementia.

They do not need to be taking medications with only marginal benefit. They should be prescribed the simplest medication regiment as possible.

When there are problems that might be related to medication, providers can try to withdraw medications that they think might be causing the trouble and see the effect. Once again, it makes sense to me that when you're changing medications in any patient, particularly older adults with dementia, you change one medication at a time or reduce slowly, and not stop medications all at once. Providers shouldn't reduce them abruptly, but they should try to do it in an organized way so we can see which medications might be important.

Then finally, new medications are always the first thing I'll ask about when there is a behavioral change associated with medicines. Sedatives, medications with anti-colon-inducing properties, pain medications--particularly narcotic pain medications--and things that can interfere with brain function are the ones that generally will lead to behavioral problems in people with dementia. Providers should try to be aware of when those medications are started. Older people, even with Alzheimer's disease, may see multiple specialists and multiple doctors, who may not all be familiar with Alzheimer's disease. They may not all be careful about what they prescribe, and so I'm always looking to see if any new medications have been prescribed.

Q10: Could you explain more on how more rest during the day could help someone sleep better at night?

Geri Hall: When patients are excited, they become overtired. It's almost like a child before Christmas. Also, the less rest patients have during the day may lead them to go to bed earlier. So, they may go to bed at 7:00 p.m. and by 2:00 a.m. they've had a full night's sleep. What I suggest to families is to try it for 24 to 48 hours and see what happens. What we find is that the patients sort of automatically gets into those more restful behaviors because it's more comfortable for them, and it really does--trust me--help them sleep better at night.

Q11: Can you please provide an example for responding to changes in sense of time (e.g., individuals asking repeatedly what time it is, asking repeatedly if it's time to go home)?

Geri Hall: First, change, anything that disrupts the usual day-to-day routine, is very confusing. For our patients, admission to long term care is very confusing. With the repeated questions, what we tend to see is 'when are we going, when are we going, when are we going?' If you respond, "We're going at three. We're going tomorrow," that really has no meaning to the person with dementia. Basically, if you say, "Why are we going?" and the person says, "I want to make sure I get to church," then you can reassure them and answer their question directly saying, "I'll make sure that you get to church." We found this makes a significant difference.

Q12: Is a glass or two of wine, in general given there are no counter indications, harmful?

Dr. Gregg Warshaw: The use of alcohol by adults with a dementia diagnosis should generally be discouraged. Alcohol is centrally acting sedative and will further impair memory. On the other hand, if a dementia patient is requesting a small glass of wine (2 - 4 ounces) in the evening or before bed, it is reasonable to try this and observe for any adverse effects.

Q13: Are there similar scales as the Functional Assessment Staging Tool (FAST) scale used in Alzheimer's for other types of dementia to measure disease progression?

Dr. Gregg Warshaw: Since the FAST scale is assessing function, not specifically memory, it is a useful scale in all types of dementia. On the other hand, Lewy Body, frontotemporal and vascular dementias do have a different array of symptoms and rates of progression. The Global Deterioration Scale (GDS) is widely used and is more specific to Alzheimer's disease. The Clinical Dementia Rating Scale is widely used in Alzheimer's disease research trials. A frontotemporal dementia rating scale has been developed.

Q14: Would you suggest that large nursing homes be divided, as it seems that smaller environments are better for dementia such as Greenhouse Model?

Dr. Gregg Warshaw: Specialized, smaller nursing units in nursing homes for adults with Alzheimer's disease and related dementias are now common. However, the research outcomes on these units' effects on the well-being of the patients are mixed. Even so, the environment has considerable impact on an adult with dementia, so a living space that creates a safe and supportive mood is helpful. Also, crucial to the quality of a nursing home unit, is the training for the staff in the care of adults with dementia.

Q15: How can we decrease unnecessary hospitalizations?

Dr. Gregg Warshaw: Adults with Alzheimer's disease should see their primary care physician (PCP) at least every 4 months. If the patient is otherwise healthy, they should receive appropriate preventive care: vaccines (e.g., influenza and pneumonia); medication reviews (including over-the-counter medications), and safety screening (fall risk and driving safety). If the adult with Alzheimer's disease has other chronic illnesses, they should be closely followed and have plans in place to ensure that the adult with the dementia has adequate support to manage self-care instructions and medication regimens. Caregivers should be instructed to notify the PCP if there is any sudden change in cognition.

Q16: What are ways to help families engage individuals with respite services when caregiver stress is excessive and behavior problems are present?

Beth Spencer: If the person is living at home, you really have two respite options, depending on where you live, obviously. One is in-home respite. Another is adult day programs or out-of-

home respite. There is very often the person with dementia is resistant to either option, feels that somehow, they are being told they need a babysitter, and it's demeaning and very uncomfortable.

When I was director of an adult day program, one of the things that I did was strategize with the family over the phone before they ever brought their relative for a visit about how they were going to present it. I don't have a general answer to this because it's very individual. It depends very much on the person and knowing the person. I usually spend some time with a caregiver helping them think about what the objections are to having either a home care or going to adult day program and whether we can figure out an approach that will make their relatives feel better.

For an example, when my mother was living with me, I continually said to her, "The home care people are coming to help me." In fact, which was true. I didn't have them initially help her at all. I had them help me do things, so that she got used to having them in the home. It was more acceptable to her to some extent. It's a hard issue. It's very hard to help people with this issue and, as I said, I think it's very individual, depending on the circumstances of the person and the family.

Induced Dementia or Alzheimer's

Q17: Is there such a condition as surgically induced dementia or Alzheimer's, is it common?

Dr. Gregg Warshaw: If an adult with normal cognition has a surgical procedure that results in prolonged oxygen deprivation to the brain, a dementia could be a side effect of the surgery. This would not be Alzheimer's disease, but rather a hypoxic brain injury that would not continue to worsen over time. Also, some people who undergo open heart surgery that involves a heart bypass machine may have resulting post-operative cognitive symptoms. These will frequently improve for several months after the surgery. Most commonly, adults with mild, frequently undiagnosed Alzheimer's disease, who undergo surgery, will develop an acute confusion episode (delirium) related to the procedure. This can appear as if the surgery caused the dementia, but the dementia was already present prior to the surgery, and the delirium episode draws new attention to the individual's cognition. Over time the delirium will improve, but the underlying dementia will still be present.

Resources

Q18: How can we receive the information on traveling with dementia? Can we get information re: the traveling booklet that Dr. Hall mentioned?

Dr. Gregg Warshaw: The [Alzheimer's Association](#) (Caregiver Center, Safety section of the website) has good general information on traveling with an adult with dementia.

Q19: What books are useful for social workers who work with caregivers of individuals with Alzheimer's and related dementia?

Dr. Gregg Warshaw: Many excellent books are available: I will recommend two books, but many others can be found in most bookstores, in libraries, and on the web.

- 1) The 36-Hour Day by Nancy Mace and Peter Rabins.
- 2) The Alzheimer's Action Plan by P. Murali Doraiswamy, Lisa Gwyther, and Tina Adler.