

Dementia-Informed Advocacy

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Housekeeping

- All on mute. Use Questions function for substantive questions and for technical concerns.
- Problems getting on the webinar? Send an e-mail to NCLER@acl.hhs.gov.
- Written materials and a recording will be available at NCLER.acl.gov. See also the chat box for this web address.

About NCLER

The National Center on Law and Elder Rights (NCLER) provides the legal services and aging and disability communities with the tools and resources they need to serve older adults with the greatest economic and social needs. A centralized, one-stop shop for legal assistance, NCLER provides Legal Training, Case Consultations, and Technical Assistance on Legal Systems Development. Justice in Aging administers the NCLER through a contract with the Administration for Community Living's Administration on Aging.

About ABA COLA

The ABA Commission on Law and Aging is a collaborative and interdisciplinary leader of the American Bar Association's work to strengthen and secure the legal rights, dignity, autonomy, quality of life, and quality of care of aging persons.

The Commission accomplishes its work through research, policy development, advocacy, education, training, and through assistance to lawyers, bar associations, and other groups working on issues of aging.

Key Lessons

- The ways dementia can change the communication and responses of persons living with dementia
- Strategies for communication with persons living with dementia to provide quality, person-directed legal assistance and advocacy
- Understanding changes in behavior by persons living with dementia and ways to work through unexpected behaviors and remain a strong advocate for the person

Dementia Basics for Advocates

What is Dementia?

- Dementia is a global term for illnesses that result in a decline in neurocognitive function.
- There are some causes of neurocognitive decline that are reversible.
- Alzheimer's and other causes of dementia are terminal and progressive.

• From: <https://www.nia.nih.gov/health/alzheimers/basics>

Poll #1

- Have you had a close family member with dementia?
 - a) Yes
 - b) No
 - c) Not sure

Diagnosing Alzheimer's

- Alzheimer's is diagnosed based on two factors,
 1. Amyloid plaques—a form of protein deposits in brain tissue
 2. A decline in cognitive ability
- It is possible to have an accumulation of amyloid plaques and not have a noticeable decline in cognitive ability.
- It is also possible to have a decline in cognitive ability and not have amyloid plaques.
- 15 years ago, diagnosis during lifetime was impossible

From: "The Problem of Alzheimer's" by Dr. Jason Karlawish and nia.nih.gov/health/what-alzheimers-disease

Alzheimer's and Other Causes

- There are an estimated 6.3 million persons living with Alzheimer's-caused dementia in the United States
- There are other causes of dementia, and different causes result in unique changes in personality and behavior
- Currently incurable
 - The best treatments currently available slow the progression of symptoms in some people for some causes

As Advocates We Need to Know

- The fundamentals of dementia
- Progressive decline in cognitive ability, including:
 - Memory
 - Language
 - Decision making
 - Organizing and sequencing information
 - The ability to learn
 - Social judgement
 - Personality
 - Behaviors

Person-Centered Approach

- The impact on or changes experienced by each person will be different
- Accommodations and support allow most persons to live full lives until later stages of the illness
- A diagnosis is not destiny
- Is it a loss of ability to form a thought, or a loss of ability to communicate those thoughts?

Learning More

- Understanding the basics of what causes changes in cognitive decline prevents overgeneralization or mischaracterization
- Reliable sources of information & resources:
 - [National Alzheimer's and Dementia Resource Center](#)
 - [NIH National Institute on Aging: Alzheimer's Disease & Related Dementias](#)
 - [U.S. Department of Health & Human Services: Alzheimers.gov](#)
 - [The Alzheimer's Association](#)

Poll #2

- Have you had training in the various causes of dementia in later life?
 - a) Yes
 - b) No
 - c) Some, but I would like to learn more

Forming & Maintaining an Attorney-Client Relationship

Attorney-Client Relationship (1 of 2)

Model Rules of Professional Conduct 1.14

- Changes in cognitive function or a diagnosis does not prevent the formation of an attorney-client relationship or end an attorney-client relationship.
- Changes in cognitive function heighten awareness of the need to communicate effectively, to work with the client, and meet the client where they are cognitively.

Attorney-Client Relationship (2 of 2)

Model Rules of Professional Conduct

1.14

- Rule 1.14 of the Model Rules of Professional Conduct direct lawyers to “as far as reasonably possible, maintain a normal client-lawyer relationship with the client.”
- The comments to the rule 1.14 should be read in detail to fully understand how to apply rule 1.14.

Learn More

- NCLER resources on legal capacity are available to help attorneys and advocates navigate the ethical issues that may arise when working with a client living with dementia:
 - [Issues in Capacity: Balancing Empowerment and Protection](#)
 - [Practice Guide and Worksheet on Understanding Legal Capacity & Ethics.](#)

Tips for Working with a Person with Cognitive Impairment

Differences and Timing

- Dementia effects each person differently
 - Avoid assumptions
- Assess understanding each time
- Best time of the day—ask:
 - The person
 - Trusted family members
 - Trusted caregivers
 - Be aware of impact of medication

Preparing for Meetings

- Before you meet, take a few minutes to prepare:
 - What are the most critical issues
 - How best to communicate
 - Have a back-up plan if the person is having a bad day
 - Prepare yourself to slow down and move at the client's pace

Assessing the Space

- Talk where the person is most comfortable.
 - This may be your office, or it may be their home. Ask the client and their family or caregivers where they are most comfortable.
- Reduce distractions:
 - Turn off background noise
 - Turn off glaring lights

Communication

- Slow down—talk slowly and clearly.
 - Simple direct questions and explanations
- Maintain an adult tone and communications style.
 - Avoid being patronizing or “baby talk”
- Limit the agenda—focus on one issue
 - Switching from one issue to another is difficult for many persons living with dementia

When to Stop

- End the meeting when the person shows signs of being tired, confused, or frustrated, and seems unable to refocus
- You may need to break an issue up into multiple meetings
- Take a break and make it clear when you are changing the subject

Sometimes It Takes Time

- Allow the person to talk
 - May need time to warm up to the subject
- Talking may help the person organize thoughts or focus communications
- The stories they tell are important to them
 - And will help you understand what is important to the person and what they want in their case
- A helpful book on this:
 - [How to Say It to Seniors: Closing the Communication Gap with Our Elders](#), by David Solie

When Finished

- Recap what you have covered
- Provide the person with brief notes on key points
 - Written notes are helpful (be mindful of literacy)
 - Provide lists of things you need
- Ask if there is someone helping or supporting them
- Send follow up questions and reminders of the next meeting
- Call the day before and the day of the next meeting
 - Don't let no-shows end the relationship

Poll #3

- Do you meet with clients (choose all that apply):
 - a) In your office
 - b) In their homes
 - c) In care settings
 - d) Virtually
 - e) Other

Cultural Considerations

- In some cultures:
 - Cognitive change is seen as progression into an advanced state of consciousness or wisdom
 - Changes in mental health are seen as a failure or viewed with great shame
 - Delusions or hallucinations are seen as evil spirits
- Always ask how the person and family view this
- Honor strongly held cultural beliefs

Communication and Behavioral Accommodations

Memory

- A decline in memory is a classic symptom of dementia
- Short-term memory is often impacted
 - Long-term memory is often the least effected
- Expect that persons with dementia are going to forget things
- Repeated questions
- Repeated stories or statements
- Misplacing things

Accommodations for Memory Loss

- Answer repeated questions, change the subject, and move on.
 - Avoid saying, “we already answered that.”
- Written reminders
- Phone reminders
- Note taking, calendars, organizers
- Supportive family and friends
- Allowing the person to talk—telling stories can sometimes result in recall
- Stay steady and even

Case Example

You asked Bill where he lived before moving here, and he answers, “oh you know, that city, down near the end of the Mississippi River, with the big Mardi Gras parades.”

Aphasia

- A technical term for finding the right words
 - Most people have some minor challenges
 - Some normal increase with age
- Dementia increases difficulty with word finding
- Allow more time for responses
- When necessary, assure the person that this happens to everyone
- The harder we try, the harder it is—relax
 - “it will come to me/you in a minute”

Word Finding

- Find meaning in context when the wrong word is used
- Encourage the person to describe what they can't find the word for
- Talk about other aspects of the issue, and see if the word comes to them
- Feed it back to confirm understanding
- Thought formation and communication are not always tied together
 - The person may know what the answer is but struggle to communicate it

Delusions

- Delusions are strongly held beliefs that have no basis in fact and cannot be verified by outside evidence.
- Some persons living with dementia develop delusions.
- The person will hold the belief despite evidence to the contrary.
- The belief is a part of the persons perceived reality.
- Facts or reasoning will likely not change the person's belief.

Acknowledge

- Acknowledge while not agreeing or confirming
 - “I understand you believe that.”
- Balance respecting the client and a commitment to verifiable truth
- Search for evidence or verification
 - Ask the client for help
 - Ask outside sources for help

Case Example (2)

During your meeting with Ted, he is convinced that someone is spraying poison under his house, making him sick. You consider reaching out to the county health inspector to make a visit, the local/state environmental protection agency to inspect, local law enforcement to visit, or have a friend or family member help secure openings into the space under his house.

Hallucinations

- Hallucinations occur when someone sees, hears, smells, tastes, or feels things that don't exist outside their mind.
- The perception is very real to the person, it is part of their reality.
- Facts or reasoning likely won't change the person's perceptions.
- The most common hallucinations are the presence of persons who are not there.
 - Often persons who had an important role in the persons life
- Sometimes people will perceive senses that aren't there, such as hearing a crying baby or music; smelling smoke; or believe that a taste is off.

Accommodations for Hallucinations

- Acknowledge without agreeing or confirming
- Go in search of—with the person/for the person:
 - Let's go look and see if we can find the baby
 - Let's go check to see if there is anything smoking
 - Let me make fresh pot of coffee, that one might be off
- Offer to change locations
 - Let's move to the other room so the person can't see or hear you

Emotions

- Anxiety – feelings of dread, fear, uneasiness
 - Acknowledge and talk about the persons feelings
 - Professional therapy may help
 - Seek expert advice on medication
 - Change the subject, change the setting, do something that brings the person joy.
- Emotional lability is a neurological condition that causes uncontrollable laughing or crying, often at inappropriate times.
 - Don't be shocked or surprised
 - Avoid embarrassment
 - Support the person

More Changes in Emotions

- Rapid changes in emotional state
 - From happiness to sadness, or sadness to happiness
 - Hear the person out
 - Allow the person to express how they are feeling
 - Acknowledge—then, if possible, move on—if the person is not ready to move on, hear them out and reschedule
- Depression
 - Feelings of sadness, tearfulness, emptiness, or hopelessness
 - Angry outbursts, irritability, or frustration, even over small matters
 - Loss of interest or pleasure in most or all normal activities
 - Sleep disturbances, including insomnia or sleeping too much

Behaviors

- Lowering of Inhibitions
 - May say or do things that are socially inappropriate
 - Outbursts of swearing or prejudice
 - Sexually explicit language or actions
- Don't engage in the same behavior
- Maintain a professional demeanor when possible

Physical Aggression

- Physically aggressive behavior is rare, but it can happen. Fight, freeze, or flight response to stress include:
 - Striking out in frustration
 - Violent acts—can happen
 - Ask family and caregivers if this has happened before
- Maintain your safety – office safety policy?
- Engage the person, family, and caregivers in safety planning

Late/End-Stage Dementia

- In the late stages of dementia, the person may be unable to respond to their environment.
- Some persons lose muscular control and have difficulty or become unable to walk or transfer without assistance.
- May lose the ability to eat without assistance.
- Some lose the ability to swallow due to a decline in neuromuscular control.
- They may sit and stare – often described as a catatonic state.

Working With and Around Persons With Advanced Dementia

- Avoid saying anything in the persons presence that would be upsetting
- Don't talk about the person in their presence
- Do talk with them or to them even if they are unable to respond
- Many find music comforting
- Avoid leaving alone in silence when awake
- For lawyers, visit your client, explain what is happening, why, and how it affects them

Dementia is Terminal

- Terminal means the person will die with or from Alzheimer's or similar dementias
- For families and caregivers (including lawyers and other advocates) the loss and grief are often two-fold
- The illness slowly takes away the manifestation of the person you knew

Prepare and Allow Time (1 of 2)

- Take time to prepare emotionally before engaging with a person living with dementia
- Make sure your office and colleagues know you are working with a person with dementia and may need extra time
- Effectively communicating can be exhausting

Prepare Yourself Emotionally

- Working with clients with dementia can be emotionally draining.
- The client may remind you of past experiences or raise anxiety about the future.
- Some clients will say things that are shocking, disturbing, or funny when it is not appropriate.
- Be aware of your reactions and responses.

Self-Care

- Take time and engage in activities that help you recover and restore.
- Many people find it helpful to have someone to talk with about experiences and feelings
- Beware of your own needs to grieve
 - Engage in practices that help you heal
- NCLER Resources: [Secondary Trauma](#)

Conclusion

- Dementia is complicated and a rapidly advancing area of medial and scientific research
- Being aware is essential, not being an expert
- Understanding the changes in memory, personality, and behavior is crucial
- Managing our response enhances our ability to be an advocate for the person living with dementia

Thank You!



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