

Dementia-Informed Advocacy

CHAPTER SUMMARY • April 2022

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ABA Commission on Law and Aging

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.

Introduction

Changes in cognitive function that are the symptoms described as dementia require changes in attorney-client interaction to facilitate the relationship most effectively. Dementia is a term used to describe a decline in cognitive ability due to changes in the brain structure, or body or brain chemistry. Cognitive function includes memory; the ability to understand; the ability to make informed choices; the ability to communicate ideas, thoughts, memories, and feelings; and ability to learn. Dementia often impacts short- and long-term memory differently.

This Issue Brief provides a framework for dementia-informed lawyering and advocacy, built from the model of trauma-informed advocacy. Advocates and attorneys working with older adults living with dementia can use this model to deploy dementia-informed strategies to provide quality, person-directed legal and elder rights assistance to individuals.

Understanding Dementia

The first step to providing dementia-informed advocacy is to understand the basics of dementia. The most common cause of dementia is diagnosed as Alzheimer's disease. Alzheimer's is diagnosed based on two factors: the presence of amyloid plaques—a form of protein deposits in brain tissue, accompanied by a decline in cognitive ability. It is possible to have an accumulation of amyloid plaques and not have a noticeable decline in cognitive ability. And it is possible to have a decline in cognitive ability and not have amyloid plaques. Other illnesses cause dementia, generally affecting fewer people. Fully understanding the changes in a person's cognition and behavior is essential in diagnosis of a cause, as some causes result in recognized patterns of behavior.

Dementia affects each person differently. Evaluating the limits of what the person can understand, decide, and communicate needs to be done individually with each person. NCLER's [resources on decision-making capacity](#) provide more information and tips for advocates.

The ability of a person with cognitive impairment may vary from day to day, and from morning to night. If the person is having an "off" day, talk with them again before determining what the person can understand and what they cannot. "Sundowners syndrome" is the classic explanation for a person with dementia experiencing a decline in ability later in the day. However, it is not universal. Just as some people are morning people, and some people are night owls, the time of day when each person will be at their best will vary and is sometimes predictable. Often, if you ask, the person or their trusted caregivers will tell you when the individual is at their best.

Learning More About Dementia

Understanding the basics of what causes changes in cognitive decline prevents overgeneralization or mischaracterization. Attorneys and advocates working with clients with specific diagnoses will benefit from doing research and background reading to improve understanding of how the illness may affect the attorney-client relationship. Some reliable sources and resource centers include:

- [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](#)

Forming & Maintaining an Attorney-Client Relationship

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

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. Resources include [Issues in Capacity: Balancing Empowerment and Protection](#) and [Practice Guide and Worksheet on Understanding Legal Capacity & Ethics](#).

Communication and Behavioral Accommodations

Individuals living with dementia may experience communication barriers and behavioral changes that require accommodations to maintain an effective attorney-client relationship. This section discusses strategies and practices for continuing person-directed representation when the client is experiencing common behavioral changes.

Aphasia

Aphasia is a technical term for having difficulty finding the right word.¹ Word finding is a challenge for many persons living with dementia. This may result in long pauses as the person struggles to put their thoughts into words. Attorneys and advocates should give the person time and may want to plan for longer meeting times with the client to accommodate the need for word finding. Sometimes the words will come more easily when the person relaxes, and advocates can apply [trauma-informed strategies](#), such as making sure the person feels comfortable in the space the meeting is being held and previewing what the meeting will cover. If the person uses the wrong word, the attorney or advocate can take steps to figure out in context what the person means, politely rephrase, and confirm understanding. Difficulty finding the right word does not mean a lack of ability to understand.

Delusions

Delusions are strongly held beliefs that have no basis in fact and cannot be verified by outside evidence.² Some individuals living with dementia develop delusions. The belief is often a part of the person's perceived reality, and they will hold the belief, despite evidence to the contrary. Facts or reasoning will generally not change the person's belief.

1 NIH National Institute of Neurological Disorders and Stroke, [Aphasia Information Page](#).

2 Alzheimer's Association, [Suspicious and Delusions](#)

Advocates and attorneys should engage in a careful balancing of respect for the client with a lawyer's obligation to the truth. One strategy is to acknowledge the person's belief as being real to them, while not agreeing or confirming the belief as true. Reasoning or arguing with the person will likely not change the person's beliefs and may damage the relationship of trust.

Hallucinations

Persons living with dementia sometimes experience hallucinations, and may see, hear, smell, taste, or feel things that don't exist outside their mind.³ The perception is very real to the person, and it is part of their reality. The most common hallucinations are the presence of persons who are not there or having sensations that aren't experienced by others they are with, such as hearing a crying baby or music, smelling smoke, or perceiving that a taste is off. Similar to addressing delusions, presenting facts or arguing may not be effective in changing the person's perceptions.

Often the best option is to acknowledge what the person is perceiving, apologize for not being aware, and asking the person how they want to proceed. Some additional options that may be helpful include:

- Move to another room to get away from the person or sound that is disturbing the client;
- Provide time to allow the sound they hear to stop or for the person they see to go away; and
- Make a change in the setting by opening or closing windows or doors, or move the furniture around to help dispel the hallucinations.

There are options for medical treatments for some individuals who experience hallucinations. If the person or their caregivers are concerned, they should consult an expert who fully understands the person's health.

Memory

Often the first change that is noticed in a person living with dementia is a decline in short term memory.⁴ People with dementia may start to lose things that they never lost before, forget to deposit income, pay bills, or pay the same bill more than once. They may get lost in familiar surroundings, especially if there has been a change.

When working with a client living with dementia, attorneys and advocates should take steps that can accommodate memory loss. Clients may ask the same question that were already answered and may forget the information that was provided to them in previous meetings. Some practices that can be helpful to a client with dementia include:

- When a question is repeated, politely answer and move on. Avoid pointing out that it was already discussed.
- Provide a list of key points or a list of follow-up items to bring to their next meeting.
- Provide reminder calls the day before and a several hours before scheduled meetings.
- Help the individual make notes. Many persons with early to moderate dementia or mild or moderate cognitive impairment develop coping strategies such as maintaining calendars with detailed notes, post it notes, stacks of paper, or calendar reminders.
- Engage with trusted family or friends, as directed by the client. The client may rely on family or friends to support them, such as by keeping track of paperwork and appointments. Advocates may ask the client if it is okay to talk with a family member or friend to help with the appointment.

³ Alzheimer's Association, [Hallucinations](#)

⁴ Alzheimer's Association, [Memory Loss & Confusion](#)

Long-term memory can be deep and is often the last to fade. An important tool is to let the client talk. While they are telling stories of things long past, they can also provide insight on the direction of their case and share information that may be helpful for their case.

Emotions

Persons living with dementia may experience changes in emotional responses. The person may laugh at things others find tragic or experience sadness and tears in times of joy. Changes in brain structure and brain chemistry cause behaviors to change. Advocates and attorneys should be aware of and prepared for potential emotional responses and remain emotionally level and accepting when possible.

A person living with dementia may experience a lowering of inhibitions and say or do things that are considered inappropriate. This can include changes in language, such as swearing, making comments that are out of character for the person, and displaying physical acts of aggression or anger.⁵ Physically aggressive behavior is rare, but not out of the realm of reality. Dementia can reduce the normal level of restraint. While this is rare, advocates should always keep personal safety in mind with physical barriers and routes of escape. Advocates should maintain professional demeanor but evaluate when they may need to take steps to secure their own safety and avoid vicarious trauma. Written workplace violence policies can help advocates navigate potential violent situations and identify unacceptable behavior.

Late-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. They may lose the ability to eat without assistance. They may sit and stare—sometimes described as a catatonic state.

At this stage, it is unknown what the person can understand, and advocates should not assume that the person cannot hear them. Talking to the person can be comforting and assuring. Familiar voices and often music may be comforting at this stage. Maintaining an established, normal attorney-client relationship can include visiting the client. Advocates may observe the environment and care the person is receiving and monitor how they are being treated.

Self-Care & Addressing Vicarious Trauma

Advocates and attorneys working with individuals living with dementia will want to give these clients extra time for meeting and may need a little time after the meeting to decompress. Working with clients with dementia can be emotionally draining. Effectively communicating across barriers can take significant attention and energy. Taking a few minutes to go for a walk or recharge and refresh can be helpful before getting back to work.

Deploying strategies to address vicarious trauma or burnout, can be useful. Talking through the experience in a trusting environment can help restore advocates' ability to help others. NCLER [resources on secondary and vicarious trauma](#) provide strategies for advocates and organizations.

Alzheimer's and many other causes of dementia are progressive and terminal. Working with clients through the progression of the illness can be difficult. Be aware of your grief and engage in practices that help you heal.

Takeaway Tips for Working with a Person with Cognitive Impairment

- Before a meeting, take a few minutes to prepare and determine the most critical issues, how best to communicate, and develop a back-up plan if the person is having a challenging day. Prepare to slow down and move at the client's pace.

5 Alzheimer's Association, [Aggression & Anger](#)

- Talk where the person is most comfortable. This may be the office or it may be the person's home. Ask the client and their family or caregivers where they are most comfortable.
- Reduce distractions. Turn off background noise or glaring light.
- Slow down and talk slowly and clearly.
- Maintain an adult tone and communication style.
- Talk about one issue or one question at a time.
- Limit the agenda.
- End the meeting when the person is tired—multiple meetings may be needed.
- Allow the person to talk and provide insight on their preferred direction of their case.
- Recap what you have covered in a meeting or call.
- Provide the person with brief notes on key points.
- Send follow-up questions and reminders of the next meeting.

Additional Resources

- [National Alzheimer's and Dementia Resource Center](#)
- [National Institute on Aging, National Institute on Health](#)
- [ACL Support for People with Dementia, including Alzheimer's Disease](#)
- NCLER Recording: [Assessing Legal Capacity: Strategies for an Elder Rights-Centered Approach](#)
- NCLER Chapter Summary: [Assessing Legal Capacity: Strategies for an Elder Rights-Centered Approach](#)
- ABA Commission on Law and Aging: [Assessment of Older Adults with Diminished Capacities: A Handbook for Lawyers, 2nd Edition](#)
- [Becoming a "Dementia-Capable" Attorney](#), Elissa Meyer
- [How to Say It to Seniors: Closing the Communication Gap with Our Elders](#), David Solie
- [The Problem of Alzheimer's](#), Dr Jason Karlawish

Case consultation assistance is available for attorneys and professionals seeking more information to help older adults. Contact NCLER at ConsultNCLER@acl.hhs.gov.

This Issue Brief was supported by contract with the National Center on Law and Elder Rights, contract number HHS75P00121C00033, from the U.S. Administration on Community Living, Department of Health and Human Services, Washington, D.C. 20201.