



Resources for APS: Working with People with Dementia

Background on Dementia

5.8 million Americans are living with Alzheimer's disease. By 2050, this number is projected to rise to nearly 14 million. APS workers may encounter both alleged victims and alleged perpetrators who are living with dementia in their cases.

Dementia and Abuse

According to the [National Center on Elder Abuse](#) (NCEA), nearly half of all people with dementia experience some form of abuse by others. People with dementia are particularly vulnerable to abuse by their caregiver, self-neglect, or financial exploitation. These statistics make it imperative that APS workers understand the impact of dementia on caregivers. Knowing the signs of dementia, the relationship between dementia and capacity, behavioral issues related to dementia, and resources to assist clients and their families is critical for workers.

The Impact of Dementia on Caregivers

Before a diagnosis of dementia, caregivers may not understand what is happening with their family member or be well-equipped to manage behavioral changes they are seeing. The Alzheimer's Association notes that family relationships may become tense or argumentative and the person with dementia may have more aggressive or inappropriate behaviors as the disease progresses and cognitive ability declines. Helping caregivers understand what to expect early on can help all involved.

The Importance of Providing Dementia Education to Prevent Abuse: A Case Example

APS received a report that the family of a client with dementia were restraining the client to change her diaper, leaving bruises on her wrists and ankles. When the APS worker interviewed the family, they reported the client became combative when they tried to change her diaper so they felt they had to either restrain her to change her diaper thereby physically assaulting her, or skip changing her diaper, thereby neglecting her. The worker explained to the family how they could give the client more control (e.g. letting her choose who would change her and clean some areas herself) thereby decreasing her combativeness and reducing the abusive interactions.

Providing Help to Caregivers

APS workers can play an important role for families caring for someone with dementia by listening to their concerns. By providing caregivers with a “reality check,” and information and access to resources, APS may help prevent possible abusive or neglectful behaviors from occurring. The Alzheimer's Association has fact sheets on what to expect as an individual with dementia moves through the stages of the disease ([Stages and Behaviors](#)) and glossaries and checklists to help new caregivers make sense of the new terms and jargon they encounter ([Community Resource Finder Glossary](#)). Safety concerns related to caring for people with dementia include issues related to home safety (e.g., securing stove tops, preventing wandering), driving and transportation, medication safety (e.g. preventing overdoses) and traveling (e.g., minimizing anxiety during trips). The Alzheimer's Association also provides [safety checklists](#) and information about [wandering prevention and support programs](#).

Training and Other Resources

Caregivers and people with dementia have access to many online and in-person trainings to learn more about the diagnosis and care needs. APS workers may also help caregivers find and access resources they are not aware of to help with daily caregiving responsibilities (e.g., respite care, transportation).

- The [Alzheimer's Association](#) provides free, online trainings ranging from basics of dementia to planning for the future. There are offerings targeting people with dementia and caregivers.
- [Powerful Tools for Caregivers](#) is a six-week in person class teaching caregivers how to care for themselves and their families. The class is available in multiple languages.
- [REACH VA](#) is a program from the US Department of Veteran Affairs targeting the specific challenges faced by caregivers of veterans. The trained coach provides four individual sessions with the caregiver over two to three months with a possible extension. Sessions can be in person or via telephone or video conferencing. The caregiver must be a veteran or caring for a veteran.
- The [Savvy Caregiver](#) is a program developed for individual caregivers or workshops to teach basic knowledge, skills, and attitudes around caring for someone with Alzheimer's Disease. The Eldercare Locator's publication entitled [Living Well With Dementia in the Community](#) that discusses both dementia and areas where supports are needed, can be ordered through the [Eldercare Locator](#).
- The Federal Transit Administration funds a [National Aging and Disability Transportation Center](#) with resources.
- The [National Respite Network and Resource Center](#) addresses respite care across all ages. It includes information describing respite and useful webinars.

Dementia and Minority Populations

Minority populations are disproportionately affected by dementia. In the study [Diversity and Disparity in Dementia: The Impact of Ethnoracial Differences in Alzheimer's Disease](#), it is postulated that difference in biological factors may explain disparities in the incidence and prevalence; and cultural factors, such as difference in definitions of

“normal aging” and accessibility to medical care, may influence diagnosis and treatment. Caregivers in these populations may benefit from information specific to them such as:

- Learn more about Older Americans Act programs for American Indians and Alaska Natives at the [National Resource Center on Native American Aging website](#).
- The Centers for Disease Control and Prevention's [Roadmap for Indian Country](#) supports discussion about dementia and caregiving in tribal communities.
- [Savvy Caregiver in Indian Country](#) is an adaption tailored to address the needs of American Indian and Alaskan Native caregivers who are caring for an elder with dementia.

Encouraging Self-Care for Caregivers

Caregivers should be encouraged to take care of themselves as well. The NCEA [flyer](#) on ways to practice self-care while caring for someone with dementia is available in multiple languages and includes a place to add local resource numbers.

Training for APS Programs

In addition to the resources and trainings for caregivers above, APS agencies should develop their own staff capabilities and resources for working with people with dementia and their caregivers. The NCEA, Alzheimer’s Association and Department of Justice’s [Elder Justice Initiative](#) provide research and information around dementia and other issues. Talk to multi-disciplinary team agencies to learn about their programs and challenges, and [share that information](#) with the APS TARC!

Additional Resources:

- Alzheimer's Association & AARP's [Community Resource Finder](#)
- Family Caregiver Alliance's [Family Care Navigator](#)
- National Respite Network and Resource Center's [National Respite Locator](#)
- National Resource Center on LGBT Aging's [State by State Resource Locator](#)
- National Resource Center on Native American Aging's [Native Service Locator](#)