

Alzheimer's Care:

**Person Centered Strategies for
Communication and Challenging
Behaviors**

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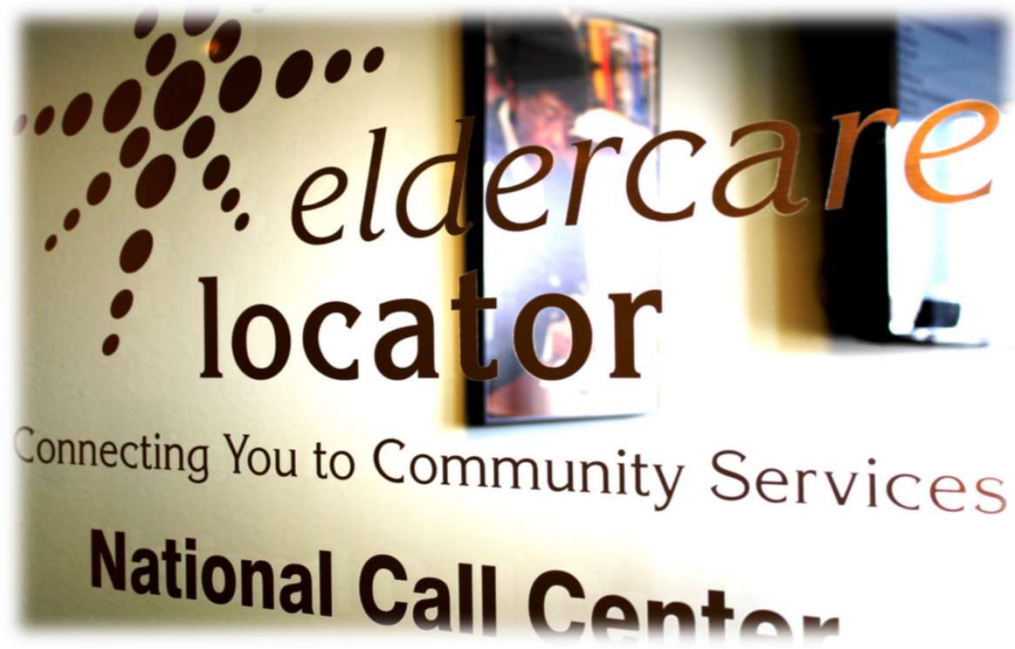
Atlanta Regional Commission, Area Agency on Aging

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**The Eldercare Locator
National Call Center
1-800-677-1116**



National Association of Area Agencies on Aging

Area Agencies on Aging & Title VI Native American Aging Programs



advocacy | action | answers on aging

National Association of Area Agencies on Aging



The National Aging Service Network



622 Area Agencies on Aging

National Association of Area Agencies on Aging

All AAAs Play A Key Role In...



All AAAs offer five core services under the OAA:



The average AAA offers more than a dozen additional services.
The most common non-core services offered by AAAs are:

- Insurance Counseling (85%)
- Case Management (82%)
- Senior Medicare Patrol (44%)

The Eldercare Locator National Call Center



1-800-677-1116

eldercare.acl.gov

National Association of Area Agencies on Aging



Call Statistics Major Findings:



Call Volume
Call Complexity

Emerging Issues

Transportation needs continues to be the most requested service and there has been an increase in help with supportive in-home services. Combined these two service requests comprising 41% of the calls into to the Eldercare Locator.



Emerging Issues

Caller need complexity continues to increase. This includes escalated calls regarding reporting of suspected elder abuse, emergency housing and crisis calls.



The Eldercare Locator Eldercare.acl.gov Online Resources



[Home](#) [About](#) [Resources](#)

1-800-677-1116 

Find help in your community by entering your zip code OR city and state.

Zip Code

City/State

Enter zip code

Search



Welcome to the Eldercare Locator, a public service of the U.S. Administration on Aging connecting you to services for older adults and their families. You can also reach us at [1-800-677-1116](tel:1-800-677-1116).

Have A Question?



Speak with an
Information Specialist
Monday - Friday
9am - 8pm ET

Caregiver Corner



National Association of Area Agencies on Aging

**Service Listings in the
Eldercare Locator
Database
Eldercare.acl.gov**

1. Information and Assistance
2. Aging and Disability Resource Center
3. Area Agency on Aging
4. Title VI American Indian, Alaskan Native and Native Hawaiian Program
5. State Unit on Aging
6. **Elder Abuse Prevention**
7. Health Insurance Counseling
8. Legal Service Program
9. **Long Term Care Ombudsman**



The Eldercare Locator

Eldercare.acl.gov

Online Resources

[Home](#) > [Resources](#) > Caregiver Corner

Caregiver Corner

Caregivers play a critical role in the health and well-being of their loved ones. The Caregiver Corner is here to help with [useful links](#) and resources. Everyone's caregiver story is different, but below are some common questions received at the Eldercare Locator.



1. Who can help me with transportation, in-home care (bathing, dressing, sitter services, preparing meals) and other local services such as respite care that I may not even know about?



2. My father is a veteran. What programs could he or his spouse be eligible for now that they need help in the home?



3. Can I get paid for caregiving?



1-800-677-1116

9:00 am – 8:00 pm EST Monday – Friday



Information Specialists



Local Resources/National Resources

National Association of Area Agencies on Aging

Types of calls received and handled

- Transportation
- In-home care
- Housing options
- Caregiver Resources
- Health insurance and supplemental insurance
- Nutrition programs
- Legal Assistance
- Elder Abuse
- Home and Community-based services



Local and national resources provided by the Eldercare Locator

- Area Agency on Aging (AAA)
- Aging & Disability Resource Centers
- Adult Protective Services (APS)
- Local Social Security offices
- Local SHIP offices
- Housing and Urban Development
- Medicare and Medicaid
- FEMA
- **Alzheimer's Association Helpline**
- VA Caregiver Support Line



Learn More About



Support Services



Housing



Elder Rights



Insurance and Benefits



Health



Transportation

National Association of Area Agencies on Aging

**Connecting Older Adults
and Their Caregivers
to Local Resources**



1 (800) 677-1116 • www.eldercare.acl.gov



**Conecta a los adultos mayores
y a sus cuidadores con
recursos locales**



1 (800) 677-1116 • www.eldercare.acl.gov



Caring Across the Miles

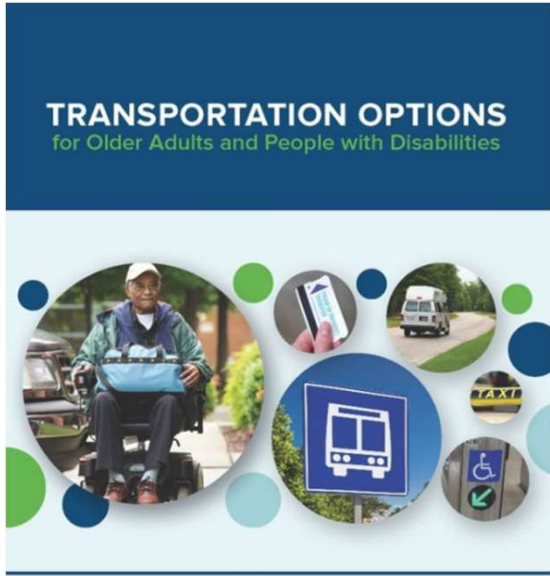
Resources for Long-Distance Caregivers



Connecting You to Community Services

1 (800) 677-1116
eldercare.acl.gov

National Association of Area Agencies on Aging



**Dementia, Caregiving
and Transportation**

Living Well With Dementia in the Community

Resources and Support



National Association of Area Agencies on Aging

Mariam Schrage

Alzheimer's Association

Communication changes throughout Alzheimer's disease

Early Stage (Mild)

- Convey thoughts and feelings through language
- Able to make decisions about future care
- May misinterpret what others say
- Difficulty finding the right words
- Taking longer to speak or respond
- Withdrawing from conversations
- Struggle with decision-making or problem solving

Middle Stage (Moderate)

- Use basic words and sentences
- Rely more on tone of voice, facial expression and body language
- Continue to need emotional connection and meaningful activity
- Increased difficulty finding the right words or even inventing new words to describe familiar things
- Speaking less frequently
- Communicating through behavior rather than words

Late Stage (Severe)

- May still respond to familiar words, phrases or songs
- Communication is reduced to a few words or sounds
- Use body language and the five sense to connect

Communication in the early stage

To connect:

- Ask directly how to help with communication
- Keep sentences clear and straightforward
- Leave plenty of time for conversations
- Include the person in conversations that affect him or her, including planning for the future.

Communication in the early stage

Keep in mind:

- Avoid making assumptions
- Speak directly to the person
- Communicate in the way that is most comfortable for the person.
- Laugh together
- Be honest

Communication in the middle stage

To connect:

- Approach from the front, say who you are and call the person by name
- Maintain eye contact and get at eye level if seated or reclining
- Avoid criticizing, correcting and arguing
- Pay attention to your tone
- Take your time

Communication in the middle stage

Keep respect and empathy in your mind, then:

- Join the person's reality
- Assess the person's needs
- Let the person know you hear his or her concerns whether they are expressed through words, behavior, or both
- Provide a brief answer
- Respond to the emotions behind the statement

Communication in the middle stage

To connect, keep it slow and basic:

- Use short sentences and basic words
- Speak slowly and clearly, one person and one question at a time
- Limit distractions
- Be patient
- Offer a guess or fill in words if acceptable

Communication in the middle stage

To connect, give multiple cues:

- Provide visual cues and gestures
- Avoid sudden movement
- Write things down for the person
- Put answers into your questions
- Repeat as needed
- Turn negatives into positives
- Avoid quizzing

Communication in the middle stage

To connect, respond empathically and reassure:

- Join the person's reality
- Provide reassurance that you hear and understand
- Focus on the feelings, not the facts
- Validate and redirect the person if necessary

Communication in the late stage

To connect:

- Listen for expressions of pain and respond promptly
- Help the person feel safe and happy
- Continue to bring respect to each conversation
- Keep talking to the person with dementia
- Use all five senses to communicate

Communication in the late stage

Connect through touch:

- Feel different fabrics
- Identify shapes by touch
- Give lotion hand massages
- Identify everyday items in a bag by touch
- Visit with animals
- Hold the person's hand or stroke his or her arm or back

Communication in the late stage

Connect through sight:

- Laminate brightly colored pictures to look at together
- Watch videos of animals, nature, or travel
- Look at photo albums together
- View photos of famous paintings, favorite settings, or prominent people from the past
- Go bird-watching
- Go outdoors or sit by an open window together

Communication in the late stage

Connect through sound:

- Listen to familiar music
- Listen to recordings of the sounds of nature, farms, cities, or animals
- Identify musical instruments by sound
- Listen to songs or speech in the person's native language
- Read books, poetry, scripture, or newspaper articles to the person
- Let the person hear the gentle tone of your voice

Communication in the late stage

Connect through smell:

- Make small plastic bags containing items for the person to smell, such as:
 - Herbs or spices
 - Cotton balls dipped in essential oils
 - Grass clippings or fragrant flowers
 - Teas or coffee beans
- Use fragrant lotions for hand massages
- Cook or feed the person foods that smell good such as apple pie or chicken soup

Communication in the late stage

Connect through taste:

- Favorite foods
- Home-baked goods
- Popsicles
- Flavored drinks
- Ice creams and puddings

Behavioral Changes

Triggers

- Pain or discomfort
- Over-stimulation or boredom
- Fear or frustration
- Unfamiliar surroundings
- Complicated tasks

Understanding and addressing the behavior

- Detect and connect
- Address physical needs first
- Then address emotional needs
- Reassess and plan for next time

Aggression

- May be verbal or physical
- May occur suddenly with no apparent reason or result from a frustrating situation
- Usually is upsetting but not dangerous
- There are some times when the person is a danger to themselves or others and safety measures are necessary

Aggression

Possible causes:

- Physical discomfort
- Environmental factors
- Poor communication

Aggression

How to respond:

- Try to identify cause
- Rule out pain
- Focus on feelings, not facts
- Don't get upset
- Limit distractions
- Shift focus to another activity
- Speak with the person's doctor about medical interventions
- Call 911 when help is urgently needed

Repetition

- Includes repeating a word, question, or activity or undoing something that was just finished
- Typically occurs because person is looking for comfort, security and familiarity

Repetition

Possible causes:

- Deterioration of brain cells
- May not remember that she or he has just asked question or complete a task
- Environmental influences can cause or make worse

Repetition

How to respond:

- Look for a reason behind the repetition
- Focus on the emotion, not the behavior
- Turn the action or behavior into an activity
- Stay calm and be patient
- Provide an answer
- Engage the person in an activity
- Use memory aids
- Accept behavior and work with it

Wandering

- Six in ten people with dementia will wander
- May not remember his or her name or address and can become disoriented, even in familiar places
- Anyone who has memory problems and is able to walk is at risk

Wandering

Warning signs:

- Returns from a regular walk or drive later than usual
- Forgets how to get to familiar places
- Tries or wants to “go home” even when at home
- Is restless, paces, or makes repetitive movements
- Acts nervous or anxious in crowded areas (mall, restaurants)

Wandering

Tips for prevention

- Have a routine
- Identify the most likely times of day that wandering may occur
- Reassure the person if they feel lost or disoriented
- Ensure basic needs are met
- Avoid busy places that are confusing
- Place locks out of the line of sight
- Use devices that signal when a door is opened
- Keep car keys out of sight

Wandering

Make a plan:

- Keep a list of people to call on for help
- Ask neighbors, friends, family to call if they see the person alone
- Keep a recent, close up photo and updated medical information to give to police
- Know your neighborhood
- Keep list of place where the person may wander
- If they wander, search immediate area for no more than 15 minutes and then call the police

RESOURCES: ALZHEIMER'S ASSOCIATION

alzheimer's  association®

Working with people living with dementia and their families



Accepting the Diagnosis

Accepting a diagnosis of Alzheimer's or a related dementia requires time to absorb information.



Early-Stage Caregiving

Early-stage Alzheimer's and related dementia symptoms are mild and the main role of a caregiver is support.



Middle-Stage Caregiving

During the middle stages of Alzheimer's, the person living with dementia will need a greater level of care.



Late-Stage Caregiving

The late stage of Alzheimer's usually requires intensive care. As caregiver, your role focuses on preserving quality of life and dignity.



Aggression and Anger

Aggressive behaviors can occur suddenly, with no apparent reason, or result from a frustrating situation.



Anxiety and Agitation

A person with dementia may become restless or upset in certain places when focused on specific details.



Depression

Identifying depression in someone with Alzheimer's can be difficult, since dementia can cause some of the same symptoms.



Hallucinations

Some hallucinations may be frightening to a person with Alzheimer's, while others may involve ordinary visions from the past.



Memory Loss and Confusion

Those with Alzheimer's may not remember familiar people, places or things in the later stages of the disease.



Repetition

In most cases, a person with Alzheimer's is probably looking for comfort, security and familiarity when repeating information.



Sleep Issues and Sundowning

Like changes in memory and behavior, sleep changes somehow result from the impact of Alzheimer's on the brain.





Suspicions and Delusions

Suspicions and delusions — firmly held beliefs in things that are not real — may occur in middle- to late-stage Alzheimer's.



The Alzheimer's Association is here
all day, every day for people facing
Alzheimer's disease through our free

 24/7 Helpline **800.272.3900**

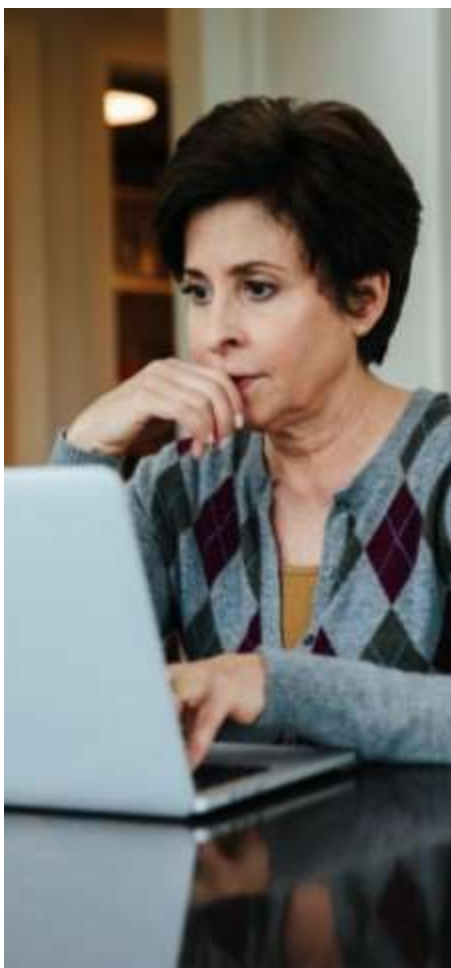
 website **alz.org**

alzheimer's  association®

Highly qualified Helpline team

- Helpline Specialists provide disease information, caregiver education, referral to local resources, triage complex calls to care consultants
- Masters prepared Care Consultants provide: problem-solving, care planning, crisis assessment and intervention
- 100+ hours new-hire training in classroom & hands-on
- Clinical supervision weekly
- On-going in-service training
- Quality monitoring, 1:1 coaching





The Alzheimer's Association offers free **online** and **in-person** education sessions for those living with the disease and their caregivers.

[alz.org/education](https://www.alz.org/education)



Online Resources: Caregiver Center

Resources for:

- Personal care
- Medical care
- Behaviors
- Safety issues
- Care options
- Legal & financial planning
- www.alz.org/care

Alzheimer's & Dementia Help & Support Research Get Involved Your Chapter Search Q

Caregiving

Caregivers for Alzheimer's and dementia face special challenges.

Caring for a person with Alzheimer's or dementia often involves a team of people. Whether you provide daily caregiving, participate in decision making, or simply care about a person with the disease — we have resources to help.

What to Expect

As Alzheimer's progresses, your role as caregiver changes. Learn what to expect and how to prepare.

Early-Stage Caregiving

Early-stage Alzheimer's and related dementia symptoms are mild and the main role of a caregiver is support. [Learn More](#)

Late-Stage Caregiving

The late stage of Alzheimer's usually requires intensive care. As caregiver, your role focuses on preserving quality of life and dignity. [Learn More](#)

Middle-Stage Caregiving

During the middle stages of Alzheimer's, the person living with dementia will need a greater level of care. [Learn More](#)

Stages and Behaviors

Learn about what to expect and what resources are available for each stage of Alzheimer's disease. [Learn More](#)



ALZConnected[®], powered by the Alzheimer's Association[®], is a free online community for everyone affected by Alzheimer's or another dementia.

alzconnected.org

Community Resource Finder

- Access comprehensive lists of resources, services and community programs (including ADRC's, AAA's)
- Search by category and proximity
- Sort by specific needs and preferences
- www.communityresourcefinder.org

The screenshot shows the Alzheimer's Association Community Resource Finder interface. At the top, there's a navigation bar with 'Search', 'Learn More', 'Help', and 'My List'. Below this is a main heading 'Get easy access to resources, community programs and services.' followed by a sub-heading 'Get started below by choosing the type of care and the location.' A grid of six category buttons is shown: 'alzheimer's association PROGRAMS AND EVENTS', 'AARP Family Caregiving PROGRAMS AND EVENTS', 'CARE AT HOME', 'COMMUNITY SERVICES', 'HOUSING OPTIONS', and 'MEDICAL SERVICES'. A 'Distance (closest first)' dropdown and a 'VIEW ON MAP' button are at the bottom right of the grid.

The 'Conduct a Search' modal is open, displaying a list of categories with radio buttons: 'Alzheimer's Association Chapters', 'Alzheimer's Early Stage Programs', 'Alzheimer's Association Programs', 'Alzheimer's Events', 'Alzheimer's Social Engagement Programs', 'Alzheimer's Support Groups', and 'Alzheimer's Support Groups'. The 'Alzheimer's Support Groups' category is selected. Below the list are input fields for 'City' (60601), 'State' (IL), and 'Zip code' (60601). A 'SEARCH' button is at the bottom right of the modal.

The search results section shows two results. The first is 'ALZConnected@' with a delivery method of 'Online' and an audience of 'Care Partners and People with Dementia'. The second is 'The Clare Adult Children Caregiver Support Group' with a date of 'Monday, December 03, 2018', a time of '06:00 PM - 07:30 PM Recurring', and a delivery method of 'In Person'. The audience is 'Caregivers'. A third result, 'The Clare Caregiver Support Group for partners and spouses', is partially visible below.

Online Resources: Safety Center

- Wandering
- Creating a safe home environment
- Driving
- Medication Safety
- Technology
- Traveling
- MedicAlert +Safe Return®
- Disaster
- www.alz.org/safety



Wandering

Wandering among people with dementia is dangerous, but there are strategies and services to help prevent it.



Home Safety

Home safety is critical for those with Alzheimer's and other dementias. Learn about potential safety hazards and get home safety tips.



Dementia and Driving

Guidance on driving safety related to dementia, vision & older drivers. Includes videos, tips & resources to help you deal with this difficult topic.



Medication Safety

Use these safety tips to help avoid medication-related problems.



MedicAlert + Safe Return

Learn about our 24-hour nationwide emergency response service for individuals with Alzheimer's.



Technology 101

Check out this run-down of common tracking technologies and information about emerging trends.



Traveling

Traveling with persons with Alzheimer's or other dementias requires planning. Get tips on how to travel safely with them.



In a Disaster

Disaster situations can be especially confusing for those with Alzheimer's and other dementias. Here, you'll find tips on planning in a disaster.



Abuse

Those with Alzheimer's and other dementias are vulnerable to abuse and neglect. Learn types and signs of abuse and how to report an incident or concern.

Alzheimer's Care: Person Centered Strategies for Communication and Challenging Behaviors

Amber Meadows-Dillard

BRI Care Consultant

Atlanta Regional Commission, Area Agency on Aging

AIRS Conference

June 5, 2019

Local Resources for Alzheimer's Care

Area Agency on Aging

- Older Americans Act Title III funded programs
- Medicaid Home and Community-Based Services
- Powerful Tools for Caregivers workshops
- Benjamin Rose Institute (BRI) Care Consultation

Local Resources for Alzheimer's Care

Aging Services Organizations

- County-Based Agencies
- Community-Based Agencies
- Programs of All-Inclusive Care for the Elderly (PACE)
- Private care providers
- Memory Assessment Clinics

Memory Assessment Clinics

- Georgia Memory Net
- Workflow
- Access to community resources
- Access to No Wrong Door grant funding



BRI Care Consultation

- Assistance for both caregivers and care recipients
- Contact via telephone and email
- One year service model
- This service does not provide:
 - Therapy
 - Mediation for family conflict resolution



Two Unique Services

BRI Care Consultation

1. Focus on Caregiver and Care Recipient
2. Long-term service
3. Action planning
4. Focus on current and future needs
5. Focus on informal support
6. Personalized relationship

Information and Referral

1. Focus on the caller
2. Short-term service
3. Information & Referral only
4. Focus on current information needed
5. No focus on informal support
6. Professional relationship

BRI Care Consultation Assessments

Most often completed by the caregiver

- Example: In the past four weeks, has there been more strain in your relationship with your loved one than there used to be?

Domains Assessed:

- Dyadic Relationship Strain
- Memory Problems and Difficult Behaviors
- Arranging Services
- Personal and Home Safety

Information and Referral Assessment

- Conduct with the person present when possible
- Inquire about the person's ability to participate

Assessment Tools:

- Determination of Need-Revised (DON-R)
- Financial Assessment
- Food Security Survey
- Nutrition Screening Instrument (NSI)

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Questions?

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