Caregiver Kit

Support for those who care for others

Dementia
&
Alzheimer’s Disease

NorthWest Senior & Disability Services
Created in partnership with Northwest Regional Council/Area Agency on Aging
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Ten Warning Signs of Alzheimer’s Disease

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Memory loss that disrupts everyday life is not a normal part of aging. It is a symptom of dementia, a gradual and progressive decline in memory, thinking, and reasoning skills. The most common form of dementia is Alzheimer’s disease, a disorder that results in the loss of brain cells.

The Alzheimer’s Association, the world leader in Alzheimer research and support, developed a checklist of common symptoms to help recognize the warning signs of Alzheimer’s disease.

1. **Memory Loss.** Forgetting recently learned information is one of the most common early signs of dementia. A person begins to forget more often and is unable to recall the information later.

2. **Difficulty performing familiar tasks.** People with dementia often find it hard to complete everyday tasks that were once so familiar, they were nearly automatic. Individuals may forget the steps to prepare a meal, use a household appliance, or participate in a lifelong hobby.

3. **Problem with language.** People with Alzheimer’s disease often forget simple words or substitute unusual words, making their speech or writing hard to understand. They may be unable to find the toothbrush, for example, and instead ask for “that thing for my mouth.”

4. **Disorientation to time and place.** People with Alzheimer’s disease can become lost in their own neighborhoods, forget where they are and how they got there, and not know how to get back home.
5. **Poor or decreased judgment.** Those with Alzheimer’s may dress inappropriately, wearing several layers on a warm day or little clothing in the cold. They may show poor judgment about money, like giving away large sums to telemarketers.

6. **Problems with abstract thinking.** Balancing a checkbook is a task that can be challenging for some. But a person with Alzheimer’s may forget what numbers are and how they should be used.

7. **Misplacing things.** Anyone can temporarily misplace a wallet or key. A person with Alzheimer’s disease may put things in unusual places: an iron in the freezer or a wrist-watch in the sugar bowl.

8. **Changes in mood or behavior.** Someone with Alzheimer’s disease can show rapid mood swings – from calm to tears to anger - for no apparent reason.

9. **Changes in personality.** The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful, or dependent on a family member.

10. **Loss of initiative.** A person with Alzheimer’s disease may become very passive, sitting in front of the TV for hours, sleeping more than usual, or not wanting to do usual activities.

If you or someone you know is experiencing these symptoms, consult a physician today. Early and accurate diagnosis of Alzheimer’s or other dementias is an important step in getting the right treatment, care, and support.

The Alzheimer’s Association, the world leader in Alzheimer’s research, care, and support, is dedicated to finding prevention methods, treatments, and an eventual cure for Alzheimer’s.
The Stages of Dementia

Stage 1: No cognitive impairment
An individual who is not impaired does not demonstrate memory problems and none are evident to a health care professional during a medical interview.

Stage 2: Very mild decline (Age Associated Memory Impairment)
Individuals at this stage may report forgetting names or where they have placed familiar items, such as keys, eyeglasses, or other everyday objects. These problems, however, are not evident during a medical examination or apparent to friends, family, or co-workers.

Stage 3: Mild cognitive decline (Mild Cognitive Impairment)
Memory deficits become more evident to family and co-workers at this stage. Memory problems become evident during an intensive interview. An individual may have problems with one or more of the following:

● Getting lost when traveling to an unfamiliar location
● Performance issues in social and work settings are noticeable to family, friends, and co-workers
● Word and name finding problems become more evident to family members or close associates
● Retaining little information after reading a passage
● Difficulty remembering names when introduced to new people
● Losing or misplacing a valuable object
● Denying that there is a cognitive impairment
● Mild to moderate anxiety
Stage 4:  Moderate cognitive decline (Mild Dementia)
At this stage, individuals remain oriented to time and place, recognize familiar people and faces, and are able to travel to familiar locations. However, a careful clinical interview will detect clear-cut deficits in the following areas:

- Decreased knowledge of current and recent events
- Reduced memory of personal history
- Impaired ability to perform challenging mental arithmetic, such as counting backwards from 100 by 7’s
- Decreased ability to travel, handle finances, etc.
- Inability to perform complex tasks
- Denial is a dominant defense mechanism
- May seem subdued and withdrawn, especially in socially or mentally challenging situations

Stage 5:  Moderately severe cognitive decline (Moderate Dementia)
At this stage, individuals can no longer survive without some assistance and there are major gaps in memory. They retain knowledge of many major facts regarding themselves and others and know their own names and their spouses’ and children’s names. They do not require assistance with eating or toileting. There are deficits in the following areas:

- Inability to recall a major relevant aspect of their current lives, such as an address or telephone number of many years, the names of close family members (such as grandchildren), or the name of the high school or college from which they graduated
- Some disorientation to time (date, day of week, season, etc.) or to place
- An educated person may have difficulty counting back from 40 by 4’s or from 20 by 2’s
- Difficulty choosing the proper clothing to wear
Stage 6: Severe cognitive decline (Moderately Severe Dementia)
Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with daily activities. At this stage, individuals may:

- Forget the name of the spouse whom they are entirely dependent on for survival, but generally can distinguish familiar from unfamiliar faces
- Will be largely unaware of all recent events and experiences in their lives
- Generally recall their own name and retain some knowledge of their past lives, but this is very sketchy
- Generally be unaware of their surroundings, the year, the season, etc.
- Demonstrate difficulty counting from 10, both backward and, sometimes, forward
- Require help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)
- Have increasing episodes of urinary or fecal incontinence
- Need help with getting dressed properly (without supervision, may make such errors as putting pajamas over daytime clothes or shoes on the wrong feet)
- Experience disruption of their normal sleep/waking cycle
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an imposter); hallucinations (talking to imaginary people or to their own reflection in the mirror); compulsive, repetitive behaviors (such as continually repeating simple cleaning activities); anxiety symptoms, agitation, and even previously nonexistent violent behavior; or loss of willpower

Stage 7: Very severe cognitive decline (Severe Dementia)
This is the final stage of the disease process when individuals lose the ability to respond to their environment, the ability to speak, and ultimately, the ability to control movement. Speech is often unrecognizable. They need help with eating, toileting, dressing, walking, transferring, hygiene, and grooming. The brain appears to no longer tell the body what to do. Reflexes become abnormal and muscles grow rigid. Swallowing also becomes impaired.

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Compassionate Communication with the Memory Impaired
By Liz Ayres
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DON’T

- Don’t reason.
- Don’t argue.
- Don’t confront.
- Don’t remind them they forget.
- Don’t question recent memory.
- Don’t take it personally.

| Don’t reason |  |  |
|-------------|  |  |
| Patient     | “What doctor’s appointment? There’s nothing wrong with me.” |  |
| Don’t        | Reason | “You’ve been seeing the doctor every three months for the last two years. It’s written on the calendar and I told you about it yesterday and this morning.” |
| Do          | Short explanation | “It’s just a regular check-up.” |
|             | Accept blame     | “I’m sorry if I forgot to tell you.” |

<p>| Don’t argue |  |  |
|-------------|  |  |
| Patient     | “I didn’t write this check for $500. Someone at the bank is forging my signature.” |  |
| Don’t        | Argue | “What? Don’t be silly! The bank wouldn’t be forging your signature.” |
| Do          | Respond to feelings | “That’s a scary thought.” |
|             | Reassure | “I’ll make sure they don’t do that.” |
|             | Distract | “Would you help me fold the towels?” |</p>
<table>
<thead>
<tr>
<th><strong>Don’t confront.</strong></th>
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<tbody>
<tr>
<td>Patient</td>
<td>“Nobody’s going to make decisions for me. You can go now and don’t come back!”</td>
<td></td>
</tr>
<tr>
<td>Don’t</td>
<td>Confront</td>
<td>“I’m not going anywhere and you can’t remember enough to make you own decision.”</td>
</tr>
<tr>
<td>Do</td>
<td>Accept blame or respond to feelings</td>
<td>“I’m sorry this is a tough time.”</td>
</tr>
<tr>
<td></td>
<td>Reassure</td>
<td>“I love you and we’re going to get through this together.”</td>
</tr>
<tr>
<td></td>
<td>Distract</td>
<td>“You know what? Don has a new job. He’s really excited about it.”</td>
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<table>
<thead>
<tr>
<th><strong>Don’t remind them they forget.</strong></th>
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<tbody>
<tr>
<td>Patient</td>
<td>“Joe hasn’t called for a long time. I hope he’s okay.”</td>
<td></td>
</tr>
<tr>
<td>Don’t</td>
<td>Remind</td>
<td>“Joe called yesterday and you talked to him for 15 minutes.”</td>
</tr>
<tr>
<td>Do</td>
<td>Reassure</td>
<td>“You really like talking to Joe, don’t you?”</td>
</tr>
<tr>
<td></td>
<td>Distract</td>
<td>“Let’s call him when we get back from our walk.”</td>
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<thead>
<tr>
<th><strong>Don’t question recent memory.</strong></th>
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<tbody>
<tr>
<td>Patient</td>
<td>“Hello, Mary. I see you’ve brought a friend with you.”</td>
<td></td>
</tr>
<tr>
<td>Don’t</td>
<td>Question memory</td>
<td>“Hi, Mom. You remember Eric, don’t you? What did you do today?”</td>
</tr>
<tr>
<td>Do</td>
<td>Short explanation</td>
<td>“Hi, Mom. This is Eric. We work together.”</td>
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<table>
<thead>
<tr>
<th><strong>Don’t take it personally!</strong></th>
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<th></th>
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<tbody>
<tr>
<td>Patient</td>
<td>“Who are you? Where’s my husband?”</td>
<td></td>
</tr>
<tr>
<td>Don’t</td>
<td>Take it personally</td>
<td>“What do you mean, who’s your husband? I am!”</td>
</tr>
<tr>
<td>Do</td>
<td>Go with the flow, reassure</td>
<td>“He’ll be here for dinner.”</td>
</tr>
<tr>
<td></td>
<td>Distract</td>
<td>“How about some milk and cookies? Would you like chocolate chip or oatmeal?”</td>
</tr>
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**Do repeat exactly.**

<table>
<thead>
<tr>
<th>Patient</th>
<th>“I’m going to the store for a newspaper.”</th>
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<tr>
<td>Don’t</td>
<td>Repeat differently</td>
</tr>
<tr>
<td></td>
<td>“Please put your shoes on.”</td>
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<tr>
<td></td>
<td>“You’ll need to put your shoes on.”</td>
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<tr>
<td>Do</td>
<td>Repeat exactly</td>
</tr>
<tr>
<td></td>
<td>“Please put your shoes on.”</td>
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<tr>
<td></td>
<td>“Please put your shoes on.”</td>
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**Do eliminate “but”, substitute “nevertheless.”**

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<thead>
<tr>
<th>Patient</th>
<th>“I’m not eating this. I hate chicken!”</th>
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<tbody>
<tr>
<td>Don’t</td>
<td>Say “but”</td>
</tr>
<tr>
<td></td>
<td>“I know chicken’s not your favorite food, but it’s what we’re having for dinner.”</td>
</tr>
<tr>
<td>Do</td>
<td>Say “nevertheless”</td>
</tr>
<tr>
<td></td>
<td>“I know chicken’s not your favorite food (smile), nevertheless, I’d appreciate it if you’d eat a little bit.”</td>
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**DO**

- Give short, one sentence explanations.
- Allow plenty of time for comprehension, then triple it.
- Repeat instructions or sentences **exactly** the same way.
- Eliminate ‘but’ from your vocabulary; substitute ‘nevertheless.’
- Avoid insistence. Try again later.
- Agree with them or distract them to a different subject or activity.
- Accept blame when something’s wrong (even if it’s fantasy).
- Leave the room, if necessary, to avoid confrontations.
- Respond to feelings rather than words.
- Be patient, cheerful, and reassuring. Do go with the flow.
- Practice 100% forgiveness. Memory loss progresses daily.
- Please elevate your level of generosity and graciousness.
You can’t control memory loss, only your reaction to it. Compassionate communication will significantly heighten quality of life.

They are not crazy or lazy. They say normal things and do normal things for a memory impaired, dementia individual. If they were deliberately trying to exasperate you, they would have a different diagnosis. Forgive them...always. For example: they don’t hide things, they protect them in safe places...and then forget. Don’t take stealing accusations personally.

Their disability is memory loss. Asking them to remember is like asking a blind person to read. “Did you take your pills?” “What did you do today?” Don’t ask and don’t test memory! A loss of this magnitude reduces the capacity to reason. Expecting them to be reasonable or to accept your conclusion is unrealistic. “You need a shower.” “Day care will be fun.” “You can’t live alone.” Don’t try to reason or convince them. Give a one sentence explanation or search for creative solutions. Memory loss produces unpredictable emotions, thought, and behavior, which you can alleviate by resolving issues peacefully. Don’t argue, correct, contradict, confront, blame, or insist.

Reminders are rarely kind. They tell the person how disabled they are – over and over again. Reminders of the recent past imply, “I remember, I’m okay; you don’t, you’re not.” Ouch! Refer to the present or the future. If they’re hungry, don’t inform them they ate an hour ago. Offer a snack or set a time to eat soon. They may ask the same question repeatedly, believing each time is the first. Graciously respond as if it’s the first time. Some days may seem normal, but they are not. They live in a different reality. Reminders won’t bring them into yours. Note: for vascular dementia, giving clues may help their recall. If it doesn’t work, be kind...don’t remind.
Ethical dilemmas may occur. If, for instance, the person thinks a dead person is alive, and truthful reminders will create sadness, what should you do? To avoid distress, try these ways of kindness: (1) distract to another tropic, (2) start a fun activity, or (3) reminisce about their loved one. “I was just thinking about _______. How did you two meet?” You might even try, “He’s gone for a while. Let’s take our walk now.”

Open-ended questions (“Where shall we go?” What do you want to eat/wear/do?”) are surprisingly complex and create anxiety. Give them a simple choice between two items or direct their choice. “You look great in the red blouse.”

They are scared all the time. Each person reacts differently to fear. They may become passive, uncooperative, hostile, angry, agitated, verbally abusive, or physically combative. They may even do them all at different times, or alternate between them. Anxiety may compel them to shadow you (follow everywhere). Anxiety compels them to resist changes in routine, even pleasant ones. Your goal is to reduce anxiety whenever possible. Also, they can’t remember your reassurance, but keep saying them.
Caring for a loved one who has dementia can be overwhelming and frustrating, especially if he or she becomes agitated, anxious, or verbally or physically aggressive. Other challenging behaviors may include resisting care, becoming suspicious, hallucinating, or wandering. It is important to keep in mind that he or she is not acting this way on purpose. Behaviors occur for a reason and you may need to become a detective to figure out the cause.

Behaviors may be related to:

► **Physical discomfort**  
  *Illness, pain, or medication*

► **Overstimulation**  
  *Loud noises or a busy environment*

► **Unfamiliar surroundings**  
  *New places or the inability to recognize home*

► **Complicated tasks**  
  *Difficulty with activities or chores*

► **Frustrating interactions**  
  *Inability to communicate effectively*
Use this three-step approach to help identify common behaviors and their causes:

1. Identify and examine the behavior
   ► What was the behavior? Is it harmful to the individual or others?
   ► What happened just before the behavior occurred? Did something trigger it?
   ► What happened immediately after the behavior occurred? How did you react to it?
   ► Consult a physician to identify any causes related to medications or illnesses.

2. Explore potential solutions
   ► What are the needs of the person with dementia? Are they being met?
   ► Can adapting the surroundings comfort the person?
   ► How can you change your reaction or your approach to the behavior? Are you responding in a calm and supportive way?

3. Try Different responses
   ► Did your new response help?
   ► Do you need to explore other potential causes and solutions? If so, what can you do differently?

10 Quick Tips to Responding to Behaviors

1. Remain flexible, patient, and calm.
2. Respond to the emotion, not the behavior.
3. Don’t argue or try to convince.
4. Use memory aids.
5. Acknowledge requests and respond to them.
6. Look for the reasons behind each behavior.
7. Consult a physician to identify any causes related to medication or illness.
8. Explore various solutions.
9. Don’t take the behavior personally.
10. Share your experiences with others.
Aggression

Aggressive behaviors may be verbal (shouting or name-calling) or physical (hitting and pushing). These behaviors can occur suddenly, with no apparent reason, or can result from a frustrating situation. Whatever the case, it is important to understand what is causing the person to become angry or upset.

How to respond:

1. **Try to identify the immediate cause.**
2. **Focus on feelings, not facts.** Consider the person’s emotions.
3. **Don’t get angry or upset.** Be positive & reassuring.
4. **Limit distractions.** Examine the person’s surroundings and adapt them to avoid a similar situation.
5. **Try a relaxing activity.** Use music, massage, or exercise.
6. **Shift the focus to another activity.**

Anxiety or Agitation

A person with Alzheimer’s may feel anxious or agitated. He or she may become restless and need to move around or pace. He or she may also become over-reliant on a certain caregiver for attention and direction.

How to Respond:

1. **Listen to the frustration.** Find out what may be causing it.
2. **Provide reassurance.** Use calming phrases and let the individual know that you’re there for him or her.
3. **Involve the person in activities.** Try using art, music, or other activities to help the person relax.
4. **Modify the environment.** Decrease noise and distractions, or move to another place.
5. **Find outlets for the person’s energy.** He or she may be looking for something to do. Take a walk or go for a car ride.
Confusion

The person with Alzheimer's may not recognize familiar people, places, or things. He or she may forget relationships, call family members by other names, or become confused about where home is. The person may also forget the purpose of common items, such as a pen or fork. These situations are extremely difficult for caregivers and require much patience and understanding.

How to Respond:

1. **Stay calm.** Although being called a different name or not being recognized can be painful, try not to make your hurt apparent.
2. **Respond with a brief explanation.** Don’t overwhelm the person with lengthy statements and reasons.
3. **Show photos and other reminders.** Use photographs and other items to remind the person of important relationships and places.
4. **Offer corrections and suggestions.** Avoid explanations that sound like scolding. Try “I thought it was a fork,” or “I think he is your grandson, Peter.”
5. **Try not to take it personally.** Alzheimer’s causes your loved one to forget, but your support and understanding will continue to be appreciated.

Suspicion

Individuals with Alzheimer’s may become suspicious of those around them, or even accuse others of theft, infidelity, or other improper behavior. Sometimes the person may also misinterpret what he or she sees and hears.

How to respond:

1. **Don’t take offense.** Listen to what is troubling the person and try to understand their reality. Then, be reassuring and let the person know you care.
2. **Don’t argue or try to convince.** Allow the individual to express the idea. Acknowledge his or her opinion.
3. **Offer a simple answer.** Share your thoughts with the individual, but keep it simple. Don’t overwhelm the person with lengthy explanations or reasons.
4. **Switch the focus on another activity.** Engage the individual in an activity, or ask for help with a chore.
5. **Duplicate the lost items.** If the person is often searching for a specific item, have several available. For example, if the individual is always looking for his or her wallet, purchase two of the same kind.
Repetition

A person with Alzheimer’s may do or say something over and over again, like repeating a word, question, or activity. In most cases, he or she is probably looking for comfort, security, and familiarity.

How to respond:

1. **Look for a reason behind the repetition.** Try to find out if there is a specific cause for the behavior.
2. **Focus on the emotion, not the behavior.** Rather than reacting to what the person is doing, think about how he or she is feeling.
3. **Turn the action or behavior into an activity.** If the person is rubbing his or her hand across the table, provide a cloth and ask for help with dusting.
4. **Stay calm and be patient.** Reassure the person in a calm voice and gentle touch.
5. **Provide an answer.** Give the person an answer that he or she is looking for, even if you have to repeat it several times.
6. **Engage the person in an activity.** The individual may simply be bored and need something to do. Provide structure and engage the person in a pleasant activity.
7. **Use memory aids.** If the person asks the same questions over and over again, offer reminders by using notes, clocks, calendars, or photography, if these items are still meaningful to the individual.
8. **Accept the behavior and work with it.** If it isn’t harmful, let it be. Find ways to work with it.

Wandering

Those with Alzheimer’s disease are at risk of wandering, especially if they:

- Return from a regular walk or drive later than usual
- Try to fulfill former obligations, such as going to work
- Try to “go home” even when at home
- Are restless, pace, or make repetitive movements
- Have difficulty locating familiar places like the bathroom, bedroom, or dining room
- Check the whereabouts of familiar people
- Act as if they are doing a hobby or chore, but nothing gets done (e.g. move around pots and dirt without planting anything)
- Feel lost in a new or changed environment
How to respond:

1. Identify the most likely times of the day that wandering may occur and plan activities at that time.
2. When night wandering is a problem, make sure the person has restricted fluids two hours before bedtime and has gone to the bathroom just before bed.
3. Limit daytime naps, if possible.
4. Place night-lights throughout the home.
5. Use door alarms to alert you when the door is opened.
6. Secure trigger items: Some people will not go out without a coat, hat, pocketbook, keys, wallet, etc.
7. Use black tape or paint to create a two-foot black threshold in front of the door.
8. * Locks: Place out of the line of sight. Install slide bolts at the top or bottom of doors.
9. * Doors: Camouflage doors by painting them the same color as the walls. Cover them with removable curtains or screens.
10. * Hedges or fence: Put around the patio, yard, or other outside common area.
11. * Safety gates or bright colored netting: Use to bar access to stairs or the outdoors.
12. Develop indoor and outdoor areas that can be safely explored.
13. Provide the person with brightly colored clothing.
14. Enroll the person in the Safe Return program.
15. Ask neighbors, friends, or family to call if they see the person alone or dressed inappropriately.
16. Know your neighborhood. Are there dangerous areas near the home? Consider, for example, bodies of water, open stairwells, dense foliage, tunnels, bus stops, high balconies, and roads with heavy traffic.
17. Keep a list of places where the person may wander to, like past jobs, former homes, church, or a restaurant.
18. Keep a recent, close-up picture on-hand to give to police.

* These are meant to be suggestions only. Follow local, state, and federal laws & codes.
Alzheimer’s Association Fact Sheets

The Alzheimer’s Association publishes many informational and helpful fact sheets that offer effective strategies to care for a loved one with dementia. Please visit their website at www.alz.org.

You can find information about:

♦ Behaviors
♦ Bathing
♦ Communication
♦ Depression & Alzheimer’s disease
♦ Dressing
♦ Driving
♦ Early On-set Alzheimer’s disease
♦ Eating
♦ End of Life
♦ Hallucinations
♦ Home Safety
♦ Incontinence
♦ Late Stage Care
♦ Personal Care

The Alzheimer’s Association also has a 24/7 helpline that offers information and support to callers. Staff is able to answer questions about memory loss, medication & treatment options, safety issues, reducing caregiver stress, legal, financial, and housing options.

24/7 Helpline 1-800-272-3900