STATE HEALTH IMPROVEMENT PLAN

Priority Area Workgroup 1

Caregiver ToolKit

Supporting Your Caregiving Journey With Alzheimer's Disease

Elder Affairs FLORIDA

ELDERAFFAIRS.ORG

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Introduction

Introduction

Dear Florida Caregivers

This toolkit is here to help you find answers to your caregiving questions. The resources included are from non-profits, businesses, and government agencies that specialize in dementia, senior care, aging, and end-of-life issues. You will hear real caregiver testimonies throughout the toolkit. Our goal is to make caring for loved ones less stressful by helping you become a more confident and well-informed caregiver. We wish you success throughout your caregiving journey!

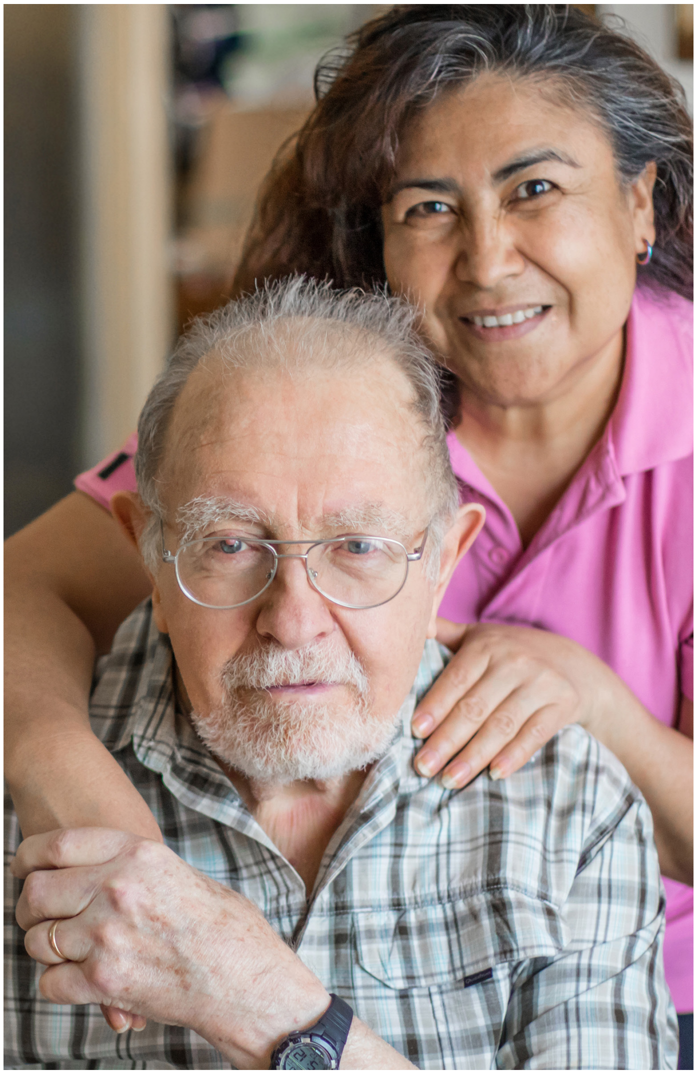
Who Can Be a Caregiver?

Many individuals are caregivers without even realizing it. Caregivers are responsible for the physical care and emotional support of someone who can no longer care for themselves due to illness, injury, or disability. This often includes providing support with financial and legal affairs.

Caregiving comes in many varieties – including from afar. Long-distance caregivers support a loved one who lives an hour or more away. Many types of support are possible from any distance: assistance organizing appointments and in-home services, medication reminders, financial and legal assistance, emergency preparedness, and a growing number of telehealth options make it possible to assist a loved one no matter where you live.

You Are Not Alone

Today, Floridians are expected to live longer than the average American life expectancy. However, many are facing chronic health problems that can develop in later years. Families are stepping up to help. Caring for a person with Alzheimer's disease or related dementias (ADRD) sometimes requires a team of people. If you provide daily care, participate in decision-making, or simply care about a person with the disease, this toolkit has resources to help.



Getting Started

People step into caregiving roles with widely varying needs and resources. As you work with your loved one to develop a care plan, consider the following helpful first steps:

- **Ask your loved one how you can be supportive.** Be respectful of their right to make decisions about their care needs and protect their dignity.
- **Call your local Area Agency on Aging (AAA) helpline (see map, page 70).** Their helpline operators can share more about the programs and services your loved one may be eligible to receive. The AAAs act as the gateway for all state services, and their helplines serve as the primary entry point for all needs.
- **Start early.** Get to know the types of resources that are available before your loved one develops a critical need for the service.
- **Learn more about their illness or condition.** Many of the resources within this toolkit offer education programs and support groups that can help you prepare for future needs and make informed decisions.
- **Share responsibilities** with your loved one's inner circle of caregivers and maintain open communication with everyone whom your loved one wishes to include.
- **Develop a support system for yourself.** Connect to a support group or share your caregiving experiences with a few close friends. Caregiving is hard work. Take care of your mental and physical health and practice self-care.

2025
ALZHEIMER'S DISEASE FACTS AND FIGURES

Over

7 MILLION

Americans are living with Alzheimer's

1 IN 3

older adults dies with Alzheimer's or another dementia

IT KILLS MORE THAN

breast cancer + prostate cancer

COMBINED

Between 2000 and 2022 deaths from heart disease have decreased

2.1%

while deaths from Alzheimer's disease have increased

142%

In 2025, Alzheimer's and other dementias will cost the nation

$384 BILLION

By 2050, these costs could rise to nearly

$1 TRILLION

The lifetime risk for Alzheimer's at age 45 is

1 IN 5 for women

1 IN 10 for men

NEARLY 12 MILLION

Americans provide unpaid care for people with Alzheimer's or other dementias

These caregivers provided more than 19 billion hours valued at nearly

$413 BILLION

UP TO 4 IN 5

Americans feel optimistic about new Alzheimer's treatments in the next decade

of Americans would want a medication to slow the progression of Alzheimer's following a diagnosis

For more information, visit alz.org/facts

ALZHEIMER'S ASSOCIATION®

2025
FLORIDA
ALZHEIMER'S STATISTICS

PREVALENCE

Number of People Aged 65 and Older with Alzheimer's (2020)

579,900

% of Adults Over 65 with Alzheimer's

12.5%

WORKFORCE

of Geriatricians in 2021

418

Increase Needed to Meet 2050 Demand

168.2%

# of Home Health and Personal Care Aides in 2022

72,410

Increase Needed to Meet 2032 Demand

22.6%

CAREGIVING

of Caregivers

870,000

Total Hours of Unpaid Care

1.4B

Total Value of Unpaid Care

$29.4B

Caregivers with Chronic Health Conditions

66.4%

Caregivers with Depression

28.6%

Caregivers in Poor Physical Health

13.6%

HEALTH CARE

of People in Hospice (2017) with a Primary Diagnosis of Dementia

19,897

Hospice Residents with a Primary Diagnosis of Dementia

15%

# of Emergency Department Visits per 1,000 People with Dementia (2018)

1,552

Dementia Patient Hospital Readmission Rate (2018)

23.0%

Medicaid Costs of Caring for People with Alzheimer's (2025)

$3.7B

Per Capita Medicare Spending on People with Dementia in 2024 Dollars

$35,223

MORTALITY

of Deaths from Alzheimer's Disease (2022)

6,397

More than **7 million Americans** are living with Alzheimer's, and nearly **12 million** provide their unpaid care. The cost of caring for those with Alzheimer's and other dementias is estimated to total **$384 billion** in 2025, increasing to nearly **$1 trillion** (in today's dollars) by mid-century.

For more information, view the *2025 Alzheimer's Disease Facts and Figures* report at **alz.org/facts**.

ALZHEIMER'S IMPACT MOVEMENT
ALZHEIMER'S ASSOCIATION

Stages of Alzheimer's

Stages of Alzheimer’s

Alzheimer’s disease typically progresses slowly in three stages: early, middle and late (sometimes referred to as mild, moderate and severe). Since Alzheimer’s affects people in different ways, each person may experience dementia symptoms — or progress through the stages — differently.

Disease Progression

The symptoms of Alzheimer’s disease worsen over time, although the rate at which the disease progresses varies. On average, a person with Alzheimer’s lives four to eight years after diagnosis, but can live as long as 20 years, depending on other factors. Changes in the brain related to Alzheimer’s begin years before any signs of the disease. This time period, which can last for years, is referred to as preclinical Alzheimer’s disease.

This information has been developed to walk you through the below stages so you can feel more prepared to assist your loved one. The stages below provide an overall idea of how abilities change once symptoms appear and should only be used as a general guide. (Dementia is a general term to describe the symptoms of mental decline that accompany Alzheimer’s and other related dementias.)

Throughout this toolkit, the three stages will be referred to as early – stage (mild Alzheimer’s disease), middle – stage (moderate Alzheimer’s disease), and late – stage (severe Alzheimer’s disease). Be aware that it may be difficult to place a person with Alzheimer’s in a specific stage as stages may overlap.

Communication

Alzheimer's disease and other dementias gradually diminish a person's ability to communicate. Communication with a person with Alzheimer's requires patience, understanding, and good listening skills. The strategies below can help both you and the person with dementia understand each other better.

Changes in communication

Changes in the ability to communicate can vary and are based on the person and where he or she is in the disease process.

Things to expect to see throughout the progression of the disease include:

- Difficulty finding the right words.
- Using familiar words repeatedly.
- Describing familiar objects rather than calling them by name.
- Easily losing a train of thought.
- Difficulty organizing words logically.
- Reverting to speaking a native language.
- Speaking less often.
- Relying on gestures more than speaking.

EARLY STAGE
Mild Alzheimer’s Disease

MIDDLE STAGE
Moderate Alzheimer’s Disease

LATE STAGE
Severe Alzheimer’s Disease

Early-Stage Alzheimer's

In the early-stage, a person may function independently. He or she may still drive, work, and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.

Symptoms may not be widely apparent at this stage, but family and close friends may take notice and a doctor would be able to identify symptoms using certain diagnostic tools.

During the early-stage, it's possible for people with dementia to live well by taking control of their health and wellness, and focusing their energy on aspects of their life that are most meaningful to them.

At this stage, individuals may have difficulty:

- Coming up with the right word or name.
- Remembering names when introduced to new people.
- Performing tasks in social or work settings.
- Forgetting material that was just read.
- Losing or misplacing a valuable object.
- Experiencing increased trouble with planning or organizing.

Communication in Early-Stage

In the early-stage of Alzheimer's disease, sometimes referred to as mild Alzheimer's, an individual is still able to participate in meaningful conversation and engage in social activities. However, he or she may repeat stories, feel overwhelmed by excessive stimulation, or have difficulty finding the right word.

Tips for successful communication:

- Don't make assumptions about a person's ability to communicate because of an Alzheimer's diagnosis. The disease affects each person differently.
- Don't exclude the person with the disease from conversations.
- Speak directly to the person rather than to his or her caregiver or companion.
- Take time to listen to the person express his or her thoughts, feelings and needs.
- Give the person time to respond. Don't interrupt unless help is requested.
- Ask what the person is still comfortable doing and what he or she may need help with.
- Discuss which method of communication is most comfortable. This could include face-to-face conversation, email or phone calls.
- It's OK to laugh. Sometimes humor lightens the mood and makes communication easier.
- Don't pull away; your honesty, friendship and support are important to the person.

Source: Alzheimer's Association alz.org

> *"Keep conversation focused on the present, clear and direct messages, and made sure I had his attention in front of him so he could see me."*
>
> *-Mr. K*

TrialMatch: Find Clinical Trials for Alzheimer's and Other Dementia

Alzheimer's Association TrialMatch® connects individuals living with Alzheimer›s, caregivers and healthy volunteers to clinical trials that may advance Alzheimer's research. The free, easy-to-use service allows you to see which studies are a good fit for you or a family member. Search for studies, receive email notifications about new opportunities, or connect with research teams.

Start TrialMatch

Find Potential Studies in Three Easy Steps

TrialMatch makes it easy to identify studies you may qualify for in a location near you. The continually updated database contains hundreds of studies being conducted at sites across the country and online.

1. **Start TrialMatch.** Get started by calling 1-800-272-3900 or emailing TrialMatch@alz.org.
2. **Answer a few simple questions.** This information will refine the list of recommended studies to those that best apply to you or the person you are helping sign up. All information is kept completely confidential unless you choose to share it with a study team.
3. **Review your study matches.** You're under no obligation to participate. You can reach out to researchers directly to sign up, or let researchers know that you are open to being contacted with more information about their study.

You can also browse available clinical studies by location, type and language, or sign up to be notified when new studies are posted that are relevant to you.

Get Started

If you have questions about TrialMatch or your clinical study matches, please call the Alzheimer's Association at 800.272.3900, visit their website at TrialMatch - Free Clinical Trial Matching Service | alz.org or email TrialMatch@alz.org.

Source: Alzheimer's Association alz.org

"The absolute biggest lesson learned - and the best possible advice I could give anyone dealing with this disease, is to bring in professionals AS EARLY AS YOU CAN! Of course, it costs money to do so, and I completely understand people wanting to keep things in the family as long as they can but that only leads to conflict and messy situations. As far as finances are concerned, because something you notice early on is the loved ones lack of ability to pay bills on time and manage money appropriately. When this happens, please allow someone outside of the family to take over the finances. This will eliminate stress, accusations, and worry. Secondly, this is no situation to be selfish. You are their support, just as they've always supported you. You are their light, their guide, their biggest fan - just as they always were to you. So aside from what you think you want for them or what a family member insists is best; stop. think. And ask yourself, but what is the absolute best for my loved one who is going through this horrible, scary disease? If you have people in your family that you aren't seeing eye to eye with, SEEK HELP! There are licensed counselors that can help you not only sort of untangle your biggest stressors, but also alert you if any malpractice or mistreatment is going on in the home. The hardest part might be building up the courage to advocate for this person you love but trust me it will be worth it."

-Ms. H

EDUCATIONAL PROGRAMS AND DEMENTIA CARE RESOURCES AVAILABLE 24/7.

alz.org/education

Alzheimer's and dementia don't come with an instruction manual, but there are resources available to help. Use these free education programs to learn more about what to expect and how to prepare for the future:

- *Healthy Living for Your Brain and Body: Tips from the Latest Research*
- *10 Warning Signs of Alzheimer's and Dementia*
- *Understanding Alzheimer's and Dementia*
- *Living with Alzheimer's: For People with Alzheimer's*
- *Living with Alzheimer's: For Caregivers (Early, Middle and Late Stage)*
- *Effective Communication Strategies*
- *Understanding and Responding to Dementia-Related Behavior*
- *Dementia Conversations: Driving, Doctor Visits, Legal and Financial Planning*
- *Managing Money: A Caregiver's Guide to Finances*

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DON'T JUST HOPE FOR A CURE. HELP US FIND ONE.

alz.org/TrialMatch

Alzheimer's Association TrialMatch® connects individuals living with Alzheimer's, caregivers and healthy volunteers to clinical trials that may advance Alzheimer's research. The free, easy-to-use platform allows you to see which studies are a good fit for you or a family member. Search for studies, receive email notifications about new opportunities or connect with research teams.

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Middle-Stage Alzheimer's

Middle-Stage (moderate) Alzheimer's is typically the longest stage and can last for many years. As the disease progresses, the person with Alzheimer's will require a greater level of care. In the middle stage, the person living with Alzheimer's can still participate in daily activities with assistance. It's important to find out what the person can still do or find ways to simplify tasks. As the need for more intensive care increases, caregivers may want to consider respite care or an adult day center so they can have a temporary break from caregiving while the person living with Alzheimer's continues to receive care in a safe environment.

Also, during the middle-stage of Alzheimer's the dementia symptoms are more pronounced. The person may confuse words, get frustrated or angry, and act in unexpected ways, such as refusing to bathe. Damage to nerve cells in the brain can also make it difficult for the person to express thoughts and perform routine tasks without assistance.

At this stage, individuals may experience:

- Being forgetful of events or personal history.
- Feeling moody or withdrawn, especially in socially or mentally challenging situations.
- Being unable to recall information about themselves like their address or telephone number, and the high school or college they attended.
- Experiencing confusion about where they are or what day it is.
- Requiring help choosing proper clothing for the season or the occasion.
- Having trouble controlling their bladder and bowels.

- Experiencing changes in sleep patterns, such as sleeping during the day and becoming restless at night.
- Showing an increased tendency to wander and become lost.
- Demonstrating personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like handwringing or tissue shredding.

Communication in Middle-Stage

The middle-stage of Alzheimer's, sometimes referred to as moderate Alzheimer's, is typically the longest and can last for many years. As the disease progresses, the person will have greater difficulty communicating and will require more direct care.

Tips for successful communication:

- Engage the person in one-on-one conversation in a quiet space that has minimal distractions.
- Speak slowly and clearly.
- Maintain eye contact. It shows you care about what he or she is saying.
- Give the person plenty of time to respond so he or she can think about what to say.
- Be patient and offer reassurance. It may encourage the person to explain his or her thoughts.
- Ask one question at a time.
- Ask yes or no questions. For example, "Would you like some coffee?" rather than "What would you like to drink?"
- Avoid criticizing or correcting. Instead, listen and try to find the meaning in what the person says. Repeat what was said to clarify.
- Avoid arguing. If the person says something you don't agree with, let it be.
- Offer clear, step-by-step instructions for tasks. Lengthy requests may be overwhelming.

- Give visual cues. Demonstrate a task to encourage participation.
- Written notes can be helpful when spoken words seem confusing.

Source: Alzheimer's Association

Late-Stage Alzheimer's

In the late-stage (severe) of the disease, dementia symptoms are severe. Individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases, but communicating pain becomes difficult. As memory and cognitive skills continue to worsen, significant personality changes may take place and individuals need extensive care.

The person living with Alzheimer's may not be able to initiate engagement as much during the late stage, but he or she can still benefit from interaction in ways that are appropriate, like listening to relaxing music or receiving reassurance through gentle touch. During this stage, caregivers may want to use support services, such as hospice care, which focus on providing comfort and dignity at the end of life. Hospice can be of great benefit to people in the final stages of Alzheimer's and other dementias and their families.

At this stage, individuals may experience:

- Require around-the-clock assistance with daily personal care.
- Lose awareness of recent experiences as well as of their surroundings.
- Experience changes in physical abilities, including walking, sitting and, eventually, swallowing.
- Have difficulty communicating.
- Become vulnerable to infections, especially pneumonia.

Communication

The late stage (severe) of Alzheimer's disease, sometimes referred to as severe Alzheimer's, may last from several weeks to several years. As the disease advances, the person with Alzheimer's may rely on nonverbal communication, such as facial expressions or vocal sounds. Around-the-clock care is usually required in this stage.

Tips for successful communication:

- Approach the person from the front and identify yourself.
- Encourage nonverbal communication. If you don't understand what the person is trying to say, ask him or her to point or gesture.
- Use touch, sights, sounds, smells and tastes as a form of communication with the person.
- Consider the feelings behind words or sounds. Sometimes the emotions being expressed are more important than what's being said.
- Treat the person with dignity and respect. Avoid talking down to the person or as if he or she isn't there.
- It's OK if you don't know what to say; your presence and friendship are most important.

Source: Alzheimer's Association

> *"I needed help in how to navigate this and I worked full time to support us."*
>
> *-Mr. B*

Food and Fluids

One of the most important daily caregiving tasks during late-stage Alzheimer's is monitoring eating. As a person becomes less active, he or she will require less food. But, a person in this stage of the disease also may forget to eat or lose his or her appetite. Adding sugar to food and serving favorite foods may encourage eating; the doctor may even suggest supplements between meals to add calories if weight loss is a problem.

To help the person in late-stage Alzheimer's stay nourished, allow plenty of time for eating and try these tips:

- **Make sure the person is in a comfortable, upright position.** To aid digestion, keep the person upright for 30 minutes after eating.
- **Adapt foods if swallowing is a problem.** Choose soft foods that can be chewed and swallowed easily. Thicken liquids such as water, juice, milk and soup by adding cornstarch or unflavored gelatin. You can also buy food thickeners at a pharmacy or health care supply store, try adding pudding or ice cream, or substitute milk with plain yogurt.
- **Encourage self-feeding.** Sometimes a person needs cues to get started. Begin by putting food on a spoon, gently putting his or her hand on the spoon, and guiding it to the person's mouth. Serve finger foods if the person has difficulty using utensils.
- **Assist the person with feeding, if needed.** Alternate small bites with fluids. You may need to remind the person to chew or swallow. Make sure all food and fluid is swallowed before continuing on with the next bite.
- **Encourage fluids.** The person may not always realize that he or she is thirsty and may forget to drink, which could lead to dehydration. If the person has trouble swallowing water, try fruit juice, gelatin, sherbet or soup. Always check the temperature of warm or hot liquids before serving them.

- **Monitor weight.** While weight loss during the end of life is to be expected, it also may be a sign of inadequate nutrition, another illness or medication side effects. See the doctor to have weight loss evaluated.

Minimize Eating and Nutrition Problems

In the middle and late stages of Alzheimer's, swallowing problems can lead to choking and weight loss. Be aware of safety concerns and try these tips:

- **Prepare foods so they aren't hard to chew or swallow.** Grind foods, cut them into bite-size pieces or serve soft foods (applesauce, cottage cheese and scrambled eggs).
- **Be alert for signs of choking.** Avoid foods that are difficult to chew thoroughly, like raw carrots. Encourage the person to sit up straight with his or her head slightly forward. If the person's head tilts backward, move it to a forward position. At the end of the meal, check the person's mouth to make sure food has been swallowed.

Learn the Heimlich maneuver in case of an emergency.

- **Address a decreased appetite.** If the person has a decreased appetite, try preparing some of his or her favorite foods. You may also consider increasing the person's physical activity or plan for several small meals rather than three large meals.

Swallowing Problems in Adults

Learn about swallowing problems from the American Speech-Language-Hearing Association at asha.org/public/speech/swallowing/swallowing-disorders-in-adults

Incontinence

As Alzheimer's disease progresses, it is common for incontinence of the bladder and bowels to occur, particularly in the middle and late stages. There are many causes, as well as ways to help manage incontinence. How you respond can help the person living with dementia retain a sense of dignity.

Tips for Managing Incontinence

Although incontinence typically occurs in the middle or late stages of Alzheimer's, every situation is unique. The following tips can help caregivers of people living with Alzheimer's who are experiencing incontinence.

Understand

- Bladder and bowel accidents can be embarrassing. Find ways to preserve dignity. For example say, "Anyone can have an accident" instead of saying, "You wet yourself."
- Be matter-of-fact; don't scold or make the person feel guilty.
- Respect the need for privacy as much as possible.
- Get more help if you are affected by this issue. Call us at (800) 272-3900 or join ALZConnected, our online support community where caregivers like you share tips for managing incontinence.

Communicate

- Encourage the person to tell you when he or she needs to use the toilet.
- Watch for nonverbal cues, such as restlessness, making unusual sounds or faces, pacing, sudden silence or hiding in corners. These cues may indicate the need to use the toilet. Use adult words rather than baby talk to refer to using the toilet.
- Learn the person's trigger words or phrases for needing to use the toilet. The person may use words that have nothing to do with toileting (e.g., "I can't find the light"), but to that person, it means going to the bathroom. Communication challenges often increase in the late stage of the disease.
- Some people do well when they are reminded to go to the bathroom on a regular schedule, perhaps every two hours.

Make it Easy to Find the Bathroom and Use the Toilet

- Keep the bathroom door open so the toilet is visible.
- Put a picture of a toilet on the bathroom door.
- Paint the bathroom door with a color in contrast to the wall.
- Make the toilet safe and easy to use. For example, raise the toilet seat, install grab bars on both sides of the toilet and use night lights to illuminate the bedroom and bathroom.
- Consider a portable commode or urinal for the bedroom.
- Remove plants, wastebaskets and other objects if mistaken for a toilet.

Plan Ahead

- Observe and recognize the person's routine toilet schedule.
- Provide a reminder to use the bathroom just before his or her usual time.
- Try setting a regular schedule for toilet use. For example, help the person to the bathroom first thing in the morning, every two hours during the day, immediately after meals and just before bedtime.
- Identify when accidents occur, then plan for them. If they happen every two hours, get the person to the bathroom before that time.

Follow Up

- Check the toilet to see if the person has used it.
- Help the person wipe and then flush the toilet as needed.
- Regularly wash sensitive skin areas.

Monitor Fluids

- Encourage overall fluid intake, but limit the fluid intake before bedtime.
- Cut down on drinks that stimulate urination, like cola, coffee or tea.

Adjust and Innovate

- Choose clothing that is easy to remove and to clean.
- Consider using padded undergarments or adult briefs. Even if a person doesn't need them ordinarily, they can be helpful when you're in a place where getting to a toilet might be difficult.
- Give the person plenty of time to empty his or her bladder and bowels.
- If the person has difficulty urinating, run water in the sink or give the person a drink for stimulation.
- Use waterproof mattress covers, incontinence pads or both on the person's bed to help keep fluid from soaking into the mattress.

Source: Alzheimer's Association alz.org

Common Responsive Behaviors

Common Responsive Behaviors

People living with Alzheimer’s may express their needs, feelings, or discomfort through what are often called “responsive behaviors.” These behaviors are not random-they’re meaningful responses to the person’s environment or unmet needs. Recognizing these behaviors as forms of communication can help you respond with empathy.

Anxiety and Agitation

A person with Alzheimer's may feel anxious or agitated. He or she may become restless, causing a need to move around or pace, or become upset in certain places or when focused on specific details.

Possible Causes of Agitation

Anxiety and agitation may be caused by a number of different medical conditions, medication interactions or by any circumstances that worsen the person's ability to think. Ultimately, the person with dementia is biologically experiencing a profound loss of their ability to negotiate new information and stimulus. It is a direct result of the disease.

Situations that may lead to agitation include:

- Moving to a new residence or nursing home.
- Changes in environment, such as travel, hospitalization, or the presence of guests.
- Changes in caregiver arrangements.
- Misperceived threats.
- Fear and fatigue resulting from trying to make sense out of a confusing world.

Tips to Help Prevent Agitation

To prevent or reduce agitation:

- **Create a calm environment.** Remove stressors. This may involve moving the person to a safer or quieter place, or offering a security object, rest or privacy. Try soothing rituals and limiting caffeine use.
- **Avoid environmental triggers.** Noise, glare and background distraction (such as having the television on) can act as triggers.
- **Monitor personal comfort.** Check for pain, hunger, thirst, constipation, full bladder, fatigue, infections, and skin irritation. Make sure the room is at a comfortable temperature. Be sensitive to fears, misperceived threats and frustration with expressing what is wanted.
- **Simplify tasks and routines.**
- **Provide an opportunity for exercise.** Go for a walk. Garden together. Dance to music.

How to Respond to Agitation

Do: Back off and ask permission; use calm, positive statements; reassure; slow down; add light; offer guided choices between two options; focus on pleasant events; offer simple exercise options, try to limit stimulation.

Say: May I help you? Do you have time to help me? You're safe here. Everything is under control. I apologize. I'm sorry that you are upset. I know it's hard. I will stay with you until you feel better.

- **Listen to the frustration.** Find out what may be causing the agitation, and try to understand.
- **Provide reassurance.** Use calming phrases such as: "You're safe here;" "I'm sorry that you are upset;" and "I will stay until you feel better." Let the person know you are there.
- **Involve the person in activities.** Try using art, music or other activities to help engage the person and divert attention away from the anxiety.
- **Modify the environment.** Decrease noise and distractions, or relocate.
- **Find outlets for the person's energy.** The person may be looking for something to do. Take a walk or go for a car ride.
- **Check yourself.** Do not raise your voice, show alarm or offense, or corner, crowd, restrain, criticize, ignore or argue with the

person. Take care not to make sudden movements out of the person's view.

- **See the doctor.** See the person with dementia's primary care physician to rule out any physical causes or medication-related side effects.

Anger and Aggression

Aggressive behaviors may be verbal or physical. They can occur suddenly, with no apparent reason, or result from a frustrating situation. While aggression can be hard to cope with, understanding that the person with Alzheimer's or dementia is not acting this way on purpose can help.

Causes

Aggression can be caused by many factors including physical discomfort, environmental factors and poor communication. If the person with Alzheimer's is aggressive, consider what might be contributing to the change in behavior.

Physical Discomfort

- Is the person able to let you know that he or she is experiencing physical pain? It is not uncommon for persons with Alzheimer's or other dementias to have urinary tract or other infections. Due to their loss of cognitive function, they are unable to articulate or identify the cause of physical discomfort and, therefore, may express it through physical aggression.
- Is the person tired because of inadequate rest or sleep?
- Is the person hungry or thirsty?
- Are medications causing side effects? Side effects are especially likely to occur when individuals are taking multiple medications for several health conditions.

Environmental Factors

- Is the person overstimulated by loud noises, an overactive environment or physical clutter? Large crowds or being surrounded by unfamiliar people — even within one's own home — can be over-stimulating for a person with dementia.
- Does the person feel lost?
- Most people function better during a certain time of day; typically mornings are best. Consider the time of day when making appointments or scheduling activities. Choose a time when you know the person is most alert and best able to process new information or surroundings.

Poor Communication

- Are your instructions simple and easy to understand?
- Are you asking too many questions or making too many statements at once?
- Is the person picking up on your own stress or irritability?

How to Respond

- **Try to identify the immediate cause.** Think about what happened right before the reaction that may have triggered the behavior.
- **Rule out pain as the cause of the behavior.** Pain can trigger aggressive behavior for a person with dementia.
- **Focus on feelings, not the facts.** Rather than focusing on specific details, consider the person's emotions. Look for the feelings behind the words or actions.
- **Don't get upset.** Be positive and reassuring. Speak slowly in a soft tone.
- **Limit distractions.** Examine the person's surroundings, and adapt them to avoid similar situations.
- **Try a relaxing activity.** Use music, massage or exercise to help soothe the person.
- **Shift the focus to another activity.** The immediate situation or activity may have unintentionally caused the aggressive response. Try something different.
- **Take a break.** If the person is in a safe environment and you are able, walk away and take a moment for yourself.
- **Ensure safety.** Make sure you and the person are safe. If the person is unable to calm down, seek assistance from others. Always call 911 in emergency situations. If you do call 911, make sure to tell responders the person has dementia, which causes them to act aggressively.

Suspicion and Delusion

A person with Alzheimer's may become suspicious of those around them, even accusing others of theft, infidelity or other improper behavior. While accusations can be hurtful, remember that the disease is causing these behaviors and try not to take offense.

What to expect

Delusions (firmly held beliefs in things that are not real) may occur in middle- to late-stage Alzheimer's. Confusion and memory loss — such as the inability to remember certain people or objects — can contribute to these untrue beliefs. A person with Alzheimer's may believe a family member is stealing his or her possessions or that he or she is being followed by the police. This kind of suspicious delusion is sometimes referred to as paranoia.

Although not grounded in reality, the situation is very real to the person with dementia. Keep in mind that a person with dementia, with declining cognitive function is trying to make sense of his or her world.

A delusion is not the same thing as a hallucination. While delusions involve false beliefs, hallucinations are false perceptions of objects or events that are sensory in nature. When individuals with Alzheimer's have a hallucination, they see, hear, smell, taste or even feel something that isn't really there.

How to respond

- **Don't take offense.** Listen to what is troubling the person, and try to understand that reality. Then be reassuring, and let the person know you care.
- **Don't argue or try to convince.** Allow the individual to express ideas. Acknowledge his or her opinions.
- **Offer a simple answer.** Share your thoughts with the individual, but keep it simple. Don't overwhelm the person with lengthy explanations or reasons.
- **Switch the focus to another activity.** Engage the individual in an activity, or ask for help with a chore.
- **Duplicate any 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 — like repeating a word, question or activity — or undo something that has just been finished. In most cases, he or she is probably looking for comfort, security and familiarity.

Because people with Alzheimer's gradually lose the ability to communicate, it's important to regularly monitor their comfort and anticipate their needs.

How to respond:

- **Look for a reason behind the repetition.** Does the repetition occur around certain people or surroundings, or at a certain time of day? Is the person trying to communicate something?
- **Focus on the emotion, not the behavior.** Rather than reacting to what the person is doing, think about how he or she is feeling.
- **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.
- **Stay calm, and be patient.** Reassure the person with a calm voice and gentle touch. Don't argue or try to use logic; Alzheimer's affects memory, and the person may not remember he/she asked the question already.
- **Provide an answer.** Give the person the answer that he or she is looking for, even if you have to repeat it several times. If the person with dementia is still able to read and comprehend, it may help to write it down and post it in a prominent location.
- **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.
- **Use memory aids.** If the person asks the same questions over and over again, offer reminders by using notes, clocks, calendars

or photographs, if these items are still meaningful.

- **Accept the behavior, and work with it.** If it isn't harmful, don't worry about it. Find ways to work with it.
- **Share your experience with others.** Join ALZConnected, the Alzheimer's Association's online support community and message boards, and share what response strategies have worked for you and get more ideas from other caregivers.

Source: Alzheimer's Association alz.org

> *"My turning point in my caregiving journey came about when I realized that my mom's illness was starting to become detrimental to my health and that it was absolutely not okay for me to be subject to caring for my mom in the way that I did. It was time to bring in professionals, something everyone should do from the very beginning."*
>
> *-Mr. C*

Sleep Issues and Sundowning

People living with Alzheimer's and other dementia may have problems sleeping or experience increased confusion, anxiety, agitation, pacing and disorientation beginning at dusk and continuing throughout the night (referred to as sundowning). Although the exact cause is unknown, these changes result from the disease's impact on the brain.

COPING STRATEGIES

Keep the home well lit in the evening.

Make a comfortable and safe sleep environment.

Maintain a schedule.

Avoid stimulants.

Identify soothing activities.

Plan activities and appointments in the a.m. or early afternoon.

Be mindful of your own mental and physical exhaustion.

Join a support group; call 800.272.3900.

TALKING WITH A DOCTOR

Discuss sleep disturbances with a doctor to help identify causes and possible solutions. Physical ailments, such as urinary tract infections, restless leg syndrome or sleep apnea, can cause or worsen sleep problems. For sleep issues due primarily to Alzheimer's, most experts encourage the use of non-drug measures rather than medication. In some cases when non-drug approaches fail, medication may be prescribed for agitation during the late afternoon and evening hours. Work with the doctor to learn the risks and benefits of medication before making a decision.

LEARN MORE
alz.org/care

ALZHEIMER'S ASSOCIATION®

24/7 Helpline 800.272.3900

Caregiving Tips & Strategies

Effective Communication Skills

According to the National Institutes of Health (NIH), communication is hard for people with Alzheimer's disease because they have trouble remembering things. They may struggle to find words or forget what they want to say. You may feel impatient and wish they could just say what they want, but they can't. The person with Alzheimer's may have problems with:

- Finding the right word or losing his or her train of thought when speaking
- Understanding what words mean
- Paying attention during long conversations
- Remembering the steps in common activities, such as cooking a meal, paying bills, or getting dressed
- Blocking out background noises from the radio, TV, or conversations
- Frustration if communication isn't working
- Being very sensitive to touch and to the tone and loudness of voices

Also, Alzheimer's disease causes some people to get confused about language. For example, the person might forget or no longer understand English if it was learned as a second language. Instead, he or she might understand and use only the first language learned, such as Spanish.

Help Make Communication Easier

The first step is to understand that the disease causes changes in communication skills. The second step is to try some tips that may make communication easier:

- Make eye contact and call the person by name.
- Be aware of your tone, how loud your voice is, how you look at the person, and your body language.

- Encourage a two-way conversation for as long as possible.
- Use other methods besides speaking, such as gentle touching.
- Try distracting the person if communication creates problems.

To encourage the person to communicate with you:

- Show a warm, loving, matter-of-fact manner.
- Hold the person's hand while you talk.
- Be open to the person's concerns, even if he or she is hard to understand.
- Let him or her make some decisions and stay involved.
- Be patient with angry outbursts. Remember, it's the illness "talking."

To speak effectively with a person who has Alzheimer's:

- Offer simple, step-by-step instructions.
- Repeat instructions and allow more time for a response. Try not to interrupt.
- Don't talk about the person as if he or she isn't there.
- Don't talk to the person using "baby talk" or a "baby voice."

Be Direct, Specific, and Positive

Here are some examples of what you can say:

- "Let's try this way," instead of pointing out mistakes.
- "Please do this," instead of "Don't do this."
- "Thanks for helping," even if the results aren't perfect.

You also can:

- Ask questions that require a yes or no answer. For example, you could say, "Are you tired?" instead of "How do you feel?"
- Limit the number of choices. For example, you could say, "Would you like a hamburger or chicken for dinner?" instead of "What would you like for dinner?"
- Use different words if he or she doesn't understand the first time. For example, if you ask the person whether he or she is hungry and you don't get a response, you could say, "Dinner is ready now. Let's eat."
- Try not to say, "Don't you remember?" or "I told you."
- If you become frustrated, take a timeout for yourself.

Helping a Person Who Is Aware of Memory Loss

Alzheimer's disease is being diagnosed at earlier stages. This means that many people are aware of how the disease is affecting their memory. Here are tips on how to help someone who knows that he or she has memory problems:

- Take time to listen. The person may want to talk about the changes he or she is noticing.
- Be as sensitive as you can. Don't just correct the person every time he or she forgets something or says something odd. Try to understand that it's a struggle for the person to communicate.
- Be patient when someone with Alzheimer's disease has trouble finding the right words or putting feelings into words.
- Help the person find words to express thoughts and feelings. But be careful not to put words in the person's mouth or "fill in the blanks" too quickly. For example, Mrs. D cried after forgetting her garden club meeting. She finally said, "I wish they stopped." Her daughter said, "You wish your friends had stopped by for you." Mrs. D nodded and repeated some of the words. Then Mrs. D said, "I want to go." Her daughter said, "You want to go to the garden club meeting." Again, Mrs. D nodded and repeated the words.
- Be aware of nonverbal communication. As people lose the ability to talk clearly, they may rely on other ways to communicate their thoughts and feelings. For example, their facial expressions may show sadness, anger, or frustration. Grasping at their undergarments may tell you they need to use the bathroom.

This content is provided by the NIH National Institute on Aging (NIA). NIA scientists and other experts review this content to ensure it is accurate and up to date. Content reviewed: May 17, 2017

Tips for Connecting to Loved Ones with Alzheimer's Disease

Caregivers commonly become frustrated when they aren't able to understand what their loved ones need. Or, they may have trouble getting loved ones to perform certain tasks, such as getting ready for bed or sitting down for lunch. However, it's important to remember that the individuals living with Alzheimer's disease are most likely equally upset about their inability to effectively communicate.

Provide Reassurance and Support

Acknowledge your loved one's feelings. Keep in mind that individuals with Alzheimer's disease can have issues not only with memory loss but can become confused or suspicion of others. Instead of insisting they are wrong in their feelings, try to provide reassurance and support that you understand how they feel.

Stay Positive

Be sincere, speak in a soft voice and offer compliments and encouragement as much as possible. Showing respect can help set the mood for a positive experience. Remember that negative behavioral expressions are symptoms of the disease, and instead of reacting negatively yourself, stay calm, use gentle touches and soothing words to ease the situation. Also, remember that laughter truly is the best medicine; individuals with Alzheimer's can take cues from you and often enjoy laughing and being silly along with you.

Simplify Phrases and Questions

Use short sentences and ask yes or no questions to clearly convey the messages. It's important to not overwhelm loved ones with a variety of options or answers, and you may have to repeat yourself from time to time or use visual cues to prompt a response. Be patient and slow down to your loved one's speed.

Use Nonverbal Communication Often

Offering a smile can sometimes be the most effective way to connect with your loved one. As the saying goes, actions do speak louder than words. Making eye contact, a light touch on the hand or reading body language can go a long way in relaxing your loved one and allowing you to be there in the moment with him or her.

Keep Distractions to a Minimum

When necessary, move to a quieter area. Eliminate noises and other distractions as you're trying to communicate to help reduce confusion. Make sure you have their attention, stating their name, your name, and your relationship.

Source: peabodyrc.org/blog/tips-for-connecting-to-loved-ones-with-alzheimers-disease

Music Can Be Powerful

Studies have shown music may reduce agitation and improve behavioral issues that are common in the middle-stages of the disease. Even in the late-stages of Alzheimer's, a person may be able to tap a beat or sing lyrics to a song from childhood. Music provides a way to connect, even after verbal communication has become difficult.

Caregiver Tips for picking out music for a person living with dementia:

1. Identify music that's familiar and enjoyable to the person. If possible, let the person choose the music.
2. Choose a source of music that isn't interrupted by commercials, which can cause confusion.
3. Use music to create the mood you want.
4. Encourage movement (clapping, dancing) to add to the enjoyment.
5. Avoid sensory overload; eliminate competing noises. Make sure the volume is not too loud.
6. Try music/songs from when the person was in their teens, twenties, or thirties.

Learn more at: bit.ly/MusicCareTips
alzmindfl.org
24/7 Helpline: (800) 272-3900

Five Dressing Tips

1. Be Flexible

It is critical to maintain good personal hygiene. Sometimes you may have to be flexible. Layered clothing is fine - just watch out for overheating. Offer praise, not criticism, for mismatched clothing. If your loved one insists on wearing the same outfits over and over again, buy duplicates and have similar options available.

2. Simplify Choices

Keep closets free of excess clothing. A person may panic if clothing choices become overwhelming. If appropriate, give the person an opportunity to select favorite outfits or colors, but try just offering two choices.

3. Organize the Process

Lay out clothing in the order that each item should be put on. Hand the person one item at a time while giving simple, direct instructions, such as, "Put on your shirt." rather than "Get dressed."

4. Choose Comfortable Shoes

Be sure the person has comfortable, non-slip shoes.

5. Pick Comfortable and Simple Clothing

Cardigans, shirts, and blouses that button up the front are easier work than pullover tops. Substitute Velcro® for buttons, snaps, and zippers, which may be too difficult to handle. Make sure that clothing is loose fitting, especially at the waist and hips, and select fabrics that are soft and stretchable.

Source: Alzheimer's Association

Grooming and Bathing Tips for People With Dementia

Grooming

1. Maintain Grooming Routines

If the person has always gone to the beauty shop or barber, continue this activity. If the experience becomes distressing, it may be possible to have a barber or hairstylist come to the person's home.

2. Use Favorite Toiletries

Allow the person to continue to using their favorite toothpaste, shaving cream, cologne, or makeup.

3. Perform Tasks Alongside the Person

Comb your hair and encourage the person to copy your motions.

4. Use Safer, Simpler Grooming Tools

Cardboard nail files and electric shavers can be less threatening than clippers and razors

Bathing

Bathing can be a challenge because people living with Alzheimer's may be uncomfortable receiving assistance with such an intimate activity. They may also have depth perception problems that make it scary to step into water. They may not perceive a need to bathe or may find it a cold, uncomfortable experience. Understanding these challenges can help you create a more comfortable and safe bathing experience.

Prepare the Bathroom in Advance

Setting up the bathroom before beginning makes the process smoother and reduces anxiety for everyone involved.

Gather Essential Supplies:

- Large towels for complete coverage (privacy and warmth)

- Shampoo, soap, and cleaning supplies
- Bath stool or bench
- Non-slip bath mat
- Hotel-sized plastic containers for easier handling

Create a Comfortable Environment:

- Check room temperature for comfort
- Pad shower seat and cold surfaces with towels
- Place all supplies within easy reach
- Have a washcloth ready to cover eyes during hair washing
- Monitor water temperature carefully - the person may not sense dangerous heat

Making the Bathroom Safe

Safety is paramount when bathing someone with dementia.

Essential Safety Measures:

- Install grab bars in shower and near toilet
- Use non-slip mats in tub or shower

- Keep bathroom floor dry and free of puddles
- Lower hot water heater thermostat to prevent scalding
- Provide supervision as needed, especially for unsteady individuals
- Always double-check water temperature

Help the Person Feel in Control

Maintaining dignity and choice helps reduce resistance and anxiety.

Offer Choices and Maintain Dignity:

- Ask preferences: "Would you like to bathe now or in 15 minutes?"
- Try different language: "Let's wash up" instead of "Let's take a bath"
- Give the person an active role (holding washcloth, soap, or shampoo)
- Consider same-gender assistance for comfort
- Allow person to enter shower/tub with towel on
- Use large towels to maintain privacy during undressing

Managing Resistance:

- Fill tub with only 2-3 inches of water initially
- If person becomes resistant, distract and try again later
- Have soothing music or activities ready for agitation
- Try bathing at their usual time of day (morning vs. evening)

Adapt the Bathing Process

Simple modifications can make bathing more manageable for both caregiver and care recipient.

Step-by-Step Guidance:

- Use simple phrases: "Put your feet in the tub," "Sit down," "Here's the soap"
- Demonstrate actions using the "watch-me" technique
- Guide their hand gently to show washing motions

- Use adjustable tub bench or bath chair for sitting while showering

Simplify the Process:

- Sew pockets into washcloths to hold soap
- Use all-purpose gel for both hair and body washing
- Try nylon net sponges that create suds easily
- Wash hair separately if it causes distress
- Pay special attention to genital areas and skin folds, especially with incontinence

Consider Bathing Alternatives

Flexibility with bathing standards can reduce stress while maintaining hygiene.

Alternative Approaches:

- Wash one part of the body each day of the week
- Shampoo hair on a different day than body bathing
- Give sponge baths with washcloths between full baths
- Use non-rinse soap products with warm, wet towels
- Consider professional caregiver assistance for bathing

Research shows that non-rinse products, available at pharmacies, can be equally effective for maintaining cleanliness when used regularly and thoroughly.

After-Bath Care

Proper post-bath care prevents skin problems and maintains comfort.

Essential Steps:

- Seat the person while drying and dressing
- Pat skin dry rather than rubbing
- Check for rashes, sores, or skin irritation
- Use cotton swabs to dry between toes
- Apply lotion gently to keep skin soft
- Use cornstarch or talcum powder under breasts and in skin folds

- If deodorant is refused, baking soda can be an alternative

Remember: Every Person is Different

What works for one individual may not work for another. Be patient with the trial-and-error process of finding the right approach. The goal is to maintain hygiene while preserving dignity and reducing stress for both the person with dementia and their caregiver.

Source: Alzheimer's Association. "Bathing." Help & Support: Caregiving Daily Care. Available at: ***alz.org/help-support/caregiving/daily-care/bathing***

Make Mealtimes Easier for People with Alzheimer's Disease

- Serve meals in a consistent place, way, and time.
- Offer foods the person is familiar with and likes.
- Use mealtimes to talk about things you both enjoy.
- Make the eating area quiet by turning off the TV and radio.
- Cut food into small pieces and make sure the food is soft enough to eat.
- Offer one food item at a time and don't rush the meal.

To learn about healthy eating for a person with Alzheimer's, visit nia.nih.gov/eating-alzheimers.

Source: National Institute on Aging

More Meal Tips

- **Distinguish food from the plate.** Changes in visual and spatial abilities may make it tough for someone with dementia to distinguish food from the plate or the plate from the table. It can help to use colored plates, such as red, or bowls with a contrasting color place mat. Avoid patterned dishes, tablecloths and place mats.
- **Serve finger foods.** Try bite-sized foods that are easy to pick up, such as chicken nuggets, fish sticks, tuna sandwiches, orange segments, steamed broccoli or cauliflower pieces. Or make a meal in the form of a sandwich in order to make it easier for the person to serve him or herself.

Source: Alzheimer's Association alz.org

Safety Considerations

MEDICATION SAFETY

GIVING MEDICATION TO SOMEONE WITH DEMENTIA

- Use a pill box organizer.
- Develop a routine for giving the medication.

As the disease progresses, you'll need to provide a greater level of care. Try these additional tips:

- Use simple language and clear instructions.
- If the person refuses to take the medication, stop and try again later.
- If swallowing is a problem, ask if the medication is available in another form.
- Make changes for safety.
- Have emergency numbers easily accessible.

alzheimer's association® 800.272.3900 | alz.org®

Home Safety Checklist

Individuals living with Alzheimer's disease and other dementias are at increased risk for injury or harm in certain areas of the home. As the disease progresses, they may become unaware of the dangers that exist. Consider taking the following precautions to create a safe environment, which may prevent dangerous situations from occurring and help maximize the person's independence for as long as possible.

General Home Safety Tips

☐ Store potentially hazardous items, such as medication, alcohol, matches, sharp objects or small appliances and tools, in a securely locked cabinet.

☐ Keep all cleaning products, such as liquid laundry pacs and bleach, out of sight or secured to avoid possible ingestion of harmful chemicals.

☐ Keep the number for the local poison control center handy or saved in your phone in case of emergency.

☐ Make sure carbon monoxide and smoke detectors and fire extinguishers are available and inspected regularly. Replace batteries twice a year during daylight saving time.

☐ Remove tripping hazards, such as throw rugs, extension cords and excessive clutter.

☐ Keep walkways and rooms well lit.

☐ Secure large furniture, such as book shelves, cabinets or large TVs, to prevent tipping.

☐ Ensure chairs have arm rests to provide support when going from a sitting to standing position.

☐ Apply stickers to glass doors at eye level to ensure doors are visible.

☐ Install a latch or deadbolt either above or below eye level on all doors.

☐ Remove locks on interior doors to prevent the person living with dementia from locking themself in.

☐ Consider removing firearms from the home or storing them in a locked cabinet.

Kitchen

☐ Use appliances that have an auto shut-off feature.

☐ Prevent unsafe stove usage by applying stove knob covers, removing knobs or turning off the gas when the stove is not in use.

☐ Disconnect the garbage disposal.

☐ Mark food with purchase date; regularly check for and throw away expired items.

☐ Discard toxic plants and decorative fruits that may be mistaken for real food.

☐ Remove vitamins, prescription drugs, sugar substitutes and seasonings from the kitchen table and counters.

Laundry Room

☐ Clean out lint screens and dryer ducts regularly to prevent fires.

☐ Consider installing safety locks on washing machines and dryers to prevent inappropriate items being put in or taken out too early.

☐ Install locks on laundry chutes to avoid temptation to climb into or drop inappropriate items down the chute.

☐ Keep all cleaning products — such as liquid laundry pacs and bleach — out of sight, secured and in the original (not decorative) storage containers to discourage someone from eating or touching harmful chemicals.

Bathroom

☐ Install grab bars for the shower, tub and toilet to provide additional support.

☐ Set the water temperature at 120 degrees Fahrenheit or less to prevent scalding.

☐ Apply textured stickers to slippery surfaces to prevent falls.

Bedroom

☐ Closely monitor the use of an electric blanket, heater or heating pad to prevent burns or other injuries.

☐ Provide seating near the bed to help with dressing.

☐ Ensure closet shelves are at an accessible height so that items are easy to reach, which may prevent the person from climbing shelves or objects falling from overhead.

Garage and Basement

☐ Limit access to large equipment, such as lawn mowers, weed trimmers or snow blowers.

☐ Keep poisonous chemicals, such as gasoline or paint thinner, out of reach.

☐ Lock and properly store ladders when not in use to prevent a tripping or climbing hazard.

☐ Remove access to car keys if the individual living with dementia is no longer driving.

☐ Install a motion sensor on the garage door.

☐ Mark stairs with bright tape and ensure railings are sturdy and secure to prevent tripping or falls.

For more information, contact the Alzheimer's Association 24/7 Helpline (800.272.3900).

Home Safety Checklist made possible through a collaboration with Procter & Gamble.

Fall Risk Assessment

Circle "Yes" or "No" for each statement below			Why it matters
Yes ☐	No ☐	I have fallen in the past year.	People who have fallen once are likely to fall again.
Yes ☐	No ☐	I use or have been advised to use a cane or walker to get around safely.	People who have been advised to use a cane or walker may already be more likely to fall.
Yes ☐	No ☐	Sometimes I feel unsteady when I am walking.	Unsteadiness or needing support while walking are signs of poor balance.
Yes ☐	No ☐	I steady myself by holding onto furniture when walking at home.	This is also a sign of poor balance.
Yes ☐	No ☐	I am worried about falling.	People who are worried about falling are more likely to fall.
Yes ☐	No ☐	I need to push with my hands to stand up from a chair.	This is a sign of weak leg muscles, a major reason for falling.
Yes ☐	No ☐	I have some trouble stepping up onto a curb.	This is also a sign of weak leg muscles.
Yes ☐	No ☐	I often have to rush to the toilet.	Rushing to the bathroom, especially at night, increases your chance of falling.
Yes ☐	No ☐	I have lost some feeling in my feet.	Numbness in your feet can cause stumbles and lead to falls.
Yes ☐	No ☐	I take medicine that sometimes makes me feel light-headed or more tired than usual.	Side effects from medicines can sometimes increase your chance of falling.
Yes ☐	No ☐	I take medicine to help me sleep or improve my mood.	These medicines can sometimes increase your chance of falling.
Yes ☐	No ☐	I often feel sad or depressed.	Symptoms of depression, such as not feeling well or feeling slowed down, are linked to falls.
Total	☐	Add up the number of points for each "yes" record the answer. If you scored 4 points or more, you may be at risk for falling. Discuss this result with your doctor.	

This checklist was developed by the Greater Los Angeles VA Geriatric Research Education Clinical Center and affiliates and is a validated fall risk self-assessment tool (Rubenstein et al. J Safety Res; 2011:42(6)493-499). Adapted with permission of the authors.

How to Assemble Your Disaster Supply Kit

You may need to survive on your own after a disaster. This means having your own food, water, and other supplies in sufficient quantity to last for at least seven days. Local officials and relief workers will be on the scene after a disaster, but they cannot reach everyone immediately. You could get help in hours, but it could take days.

Basic services such as electricity, gas, water, sewage treatment, and telephones may be cut off for days, a week, or even longer. Or you may have to evacuate at a moment's notice and take essentials with you. You probably will not have the opportunity to shop or search for the supplies you need.

A disaster supplies kit is a collection of basic items that members of a household may need in the event of a disaster.

Water

You should store at least one gallon of water per person per day. A normally active person needs at least one-half gallon of water daily just for drinking.

In determining adequate quantities, take the following into account:

- Individual needs vary, depending on age, physical condition, activity, diet, and climate.
- Children, nursing mothers, and ill people need more water.
- Very hot temperatures can double the amount of water needed.
- A medical emergency might require additional water.

To prepare the safest and most reliable emergency supply of water, it is recommended that you purchase commercially bottled water. Keep bottled water in its original container and do not open it until you need to use it. Be sure to observe the expiration or "use by" date.

If You Are Preparing Your Own Containers of Water

It is recommended that you purchase food-grade water storage containers from surplus or camping supplies stores to use for water storage. Before filling with water, thoroughly clean the containers with dishwashing soap and water, and rinse completely so there is no residual soap. Follow directions below on filling the container with water.

If you choose to use your own storage containers, choose two-liter plastic soft drink bottles – not plastic jugs or cardboard containers that have had milk or fruit juice in them. Milk protein and fruit sugars cannot be adequately removed from these containers and provide an environment for bacterial growth when water is stored in them. Cardboard containers also leak easily and are not designed for long-term storage of liquids. Also, do not use glass containers because they can break and are heavy.

If Storing Water in Plastic Soda Bottles, Follow These Steps

Thoroughly clean the bottles with dishwashing soap and water, and rinse completely so there is no residual soap. Sanitize the bottles by adding a solution of one teaspoon of non-scented liquid house-hold chlorine bleach to a quart of water. Swish the sanitizing solution in the bottle so that it touches all surfaces. After sanitizing the bottle, thoroughly rinse out the sanitizing solution with clean water.

Filling Water Containers

Fill the bottle to the top with regular tap water. If the tap water has been commercially treated from a water utility with chlorine, you do not need to add anything else to the water to keep it clean. If the water you are using comes from a well or water source that is not treated with chlorine, add two drops of non-scented liquid

Where Is Your Kit? Since you do not know where you will be when an emergency occurs, prepare supplies for home, work, and vehicles.

Home Your disaster supply kit should contain essential food, water, and supplies for at least three days. Keep this kit in a designated place and have it ready in case you have to leave your home quickly. Make sure all family members know where the kit is kept and can lift and carry the kit. Additionally, you may want to consider having supplies for sheltering up to two weeks, and plan for possible power outages at home.

Work This kit should be in one container and ready to "grab and go" in case you are evacuated from your workplace.

Make sure you have food and water in the kit. Also, be sure to have comfortable walking shoes at your workplace in case an evacuation requires walking long distances.

Car In case you are stranded, keep a kit of emergency supplies in your car.

This kit should contain maps, food, water, manual can opener, first aid kit and manual, flares, jumper cables, flashlight and extra batteries, battery-powered radio and extra batteries, fire extinguisher (5 lb., A-B-C type), blanket, rain gear, and seasonal supplies.

household chlorine bleach to the water. Tightly close the container using the original cap. Be careful not to contaminate the cap by touching the inside of it with your finger. Place a date on the outside of the container so that you know when you filled it.

Store in a cool, dark place. Replace the water every six months if not using commercially bottled water.

Food

The following are things to consider when putting together your food supplies:

- Avoid foods that will make you thirsty. Choose salt-free crackers, whole grain cereals, and canned foods with high liquid content.
- Stock canned foods, dry mixes, and other staples that do not require refrigeration, cooking, water, or special preparation. You may already have many of these on hand. (Note: Be sure to include a manual can opener.)
- Include special dietary needs.

Maintaining Your Disaster Supplies Kit

Just as important as putting your supplies together is maintaining them so they are safe to use when needed.

- Keep canned foods in a dry place where the temperature is cool.
- Store boxed food in tightly closed plastic or metal containers to protect from pests and to extend its shelf life.
- Throw out any canned item that becomes swollen, dented, or corroded.
- Use foods before they go bad, and replace them with fresh supplies.
- Place new items at the back of the storage area and older ones in the front.
- Change stored food and water supplies every six months. Be sure to write the date you store it on all containers.

- Re-think your needs every year, and update your kit as your family's needs change.
- Keep items in airtight plastic bags and put your entire disaster supplies kit in one or two easy-to-carry containers, such as an unused trashcan, camping back-pack, or duffel bag.

WANDERING

Tips to prevent wandering

Wandering can happen, even if you are the most diligent of caregivers. Use the following strategies to help lower the chances:

- Place the Alzheimer's Association 24/7 Helpline 800.272.3900 into your phone. Call anytime to gain more tips about keeping your loved one safe.
- Carry out daily activities. Having a routine can provide structure. Learn about creating a daily plan.
- Identify the most likely times of day that wandering may occur. Plan activities at that time. Activities and exercise can reduce anxiety, agitation and restlessness.
- Reassure the person if he or she feels lost, abandoned or disoriented. If the person with dementia wants to leave to "go home" or "go to work," use communication focused on exploration and validation. Refrain from correcting the person. For example, "We are staying here tonight. We are safe and I'll be with you. We can go home in the morning after a good night's rest."
- Ensure all basic needs are met. Has the person gone to the bathroom? Is he or she thirsty or hungry?
- Avoid busy places that are confusing and can cause disorientation. This could be a shopping malls, grocery stores or other busy venues.
- Place locks out of the line of sight. Install either high or low on exterior doors, and consider placing slide bolts at the top or bottom.
- Use devices that signal when a door or window is opened. This can be as simple as a bell placed above a door or as sophisticated as an electronic home alarm.
- Provide supervision. Do not leave someone with dementia unsupervised in new or changed surroundings. Never lock a person in at home or leave him or her in a car alone.
- Keep car keys out of sight. If the person is no longer driving, remove access to car keys.

Make a plan

The stress experienced by families and caregivers when a person with dementia wanders and becomes lost is significant. Have a plan in place beforehand, so you know what to do in case of an emergency:

- Keep a list of people to call on for help. Have telephone numbers easily accessible.
- Ask neighbors, friends and family to call if they see the person alone.
- Keep a recent, close-up photo and updated medical information on hand to give to police.
- Know your neighborhood. Pinpoint dangerous areas near the home, such as bodies of water, open stairwells, dense foliage, tunnels, bus stops and roads with heavy traffic.
- Keep a list of places where the person may wander. This could include past jobs, former homes, places of worship or a restaurant.
- Consider enrolling the person living with dementia in a wandering response service.
- If the person does wander, search the immediate area for no more than 15 minutes. If the person is not found within 15 minutes, call
- 911 to file a missing person’s report. Inform the authorities that the person has dementia.

WANDERING

6 in 10

people with dementia will wander.

A person with Alzheimer's may not remember his or her name or address, and can become disoriented, even in familiar places. Wandering among people with dementia is dangerous, but there are strategies and services to help prevent it.

Who is at risk of wandering?

Anyone who has memory problems and is able to walk is at risk for wandering. Even in the early stages of dementia, a person can become disoriented or confused for a period of time. It's important to plan ahead for this type of situation.

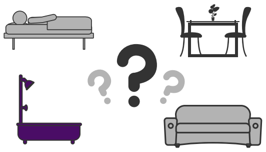
Be on the lookout for the following warning signs:

Returns from a regular walk or drive later than usual

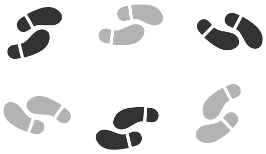
Forgets how to get to familiar places

Talks about fulfilling former obligations, such as going to work

Tries or wants to "go home," even when at home



Has difficulty locating familiar places like the bathroom, bedroom or dining room



Is restless, paces or makes repetitive movements

Asks the whereabouts of past friends and family

Acts nervous or anxious in crowded areas, such as shopping malls or restaurants

Acts as if doing a hobby or chore, but nothing gets done

ALZHEIMER'S ASSOCIATION®

800.272.3900 | alz.org®

Florida Silver Alert

The Florida Silver Alert is used to locate missing persons suffering from an irreversible deterioration of intellectual faculties. Law enforcement agencies must activate a local or regional alert as described below in an effort to locate the person prior to the issuance of a State Silver Alert.

Criteria

The person must be 60 years and older; or, the person must be 18-59 and law enforcement has determined the missing person lacks the capacity to consent and that the use of dynamic message signs may be the only possible way to rescue the missing person.

The person must have an irreversible deterioration of intellectual faculties (e.g. Alzheimer's disease or dementia) that has been verified by law enforcement.

State Silver Alert Criteria

In addition to the above criteria, the person must be traveling by motor vehicle with an identified license plate number or other vehicle information.

Local/Regional Activation Steps

According to the Florida Silver Alert Plan, activation of a state or regional Silver Alert consists of the following steps, although each agency may have their own policy or requirements for activation of a local Silver Alert:

Local law enforcement must conduct a preliminary investigation in which the agency has concluded that the disappearance poses a credible threat to the person's welfare and safety.

Local law enforcement must enter the missing person into the Florida Crime Information Center (FCIC) and issue a statewide BOLO (Be on the Lookout).

Local law enforcement must contact media outlets in the area and/or surrounding jurisdictions.

If a law enforcement agency has activated a local/regional Silver Alert and believes that activation of highway dynamic message signs may assist in the recovery of the missing person, the agency may request activation of a State Silver Alert.

State Activation Steps

Local law enforcement must have activated a local Silver Alert by, at a minimum, completing the steps outlined previously. Then:

The local law enforcement agency will activate a local or regional Silver Alert.

The local law enforcement agency will call the FDLE Missing Endangered Persons Information Clearinghouse (MEPIC) at 1-888-356-4774.

The Florida Department of Law Enforcement (FDLE) will work in conjunction with the local law enforcement agency of jurisdiction to determine the areas for activation and prepare information for public distribution.

The FDLE will ensure that the information is broadcast via dynamic highway message signs when applicable and via email/text through sign-up by public citizens and other resources.

Resources

- Florida Department of Elder Affairs (850) 414-2000
- Media Alert (813) 282-8612
- A Child is Missing, Inc. 1-888-875-2246
- Florida Department of Highway Safety Motor Vehicles Medical Reporting Form flhsmv.gov/ddl/faqmed.html

Find a Ride Florida

Families, caregivers, and friends play a large role in an older adult’s safety and mobility. Resources to help prepare families and caregivers to discuss safe driving concerns, including the process to reduce or stop driving, can be found at Find a Ride Florida's website and also in the Safe Mobility for Life Coalition’s Tips for Talking with Aging Drivers about Safe Driving Concerns brochure. To view or request a free copy of the brochure visit the Resource Center.

To request a ride, visit: findarideflorida.com

Mission Statement

To provide older Floridians access to local medical and non-medical transportation options to help them remain active and independent within their communities.

Dementia and Driving

Because driving requires the ability to react quickly to a variety of circumstances, a person living with Alzheimer's will, at some point, be unable to drive. Driving is very personal and often tied with a sense of independence. With a diagnosis, it is important to start having conversations and then monitor for signs that it is time to stop driving. Planning ahead can help ease the transition. Learn more at alz.org/driving

HAVING THE CONVERSATION

- Be empathetic
- Acknowledge a person's feelings
- Preserve the person's independence
- Ensure the person's safety and the safety of others

PLAN AHEAD

- Remember that each situation is unique
- Involve family, health care professionals, trusted friends or an elder attorney
- Confront resistance
- When the person is still in the early stage of Alzheimer's, ask them to sign a driving contract that gives you their permission to help them stop driving when the time comes. For an example, visit bit.ly/Driving_Contract

TRANSPORTATION OPTIONS

- Arrange family or friends to drive
- Arrange a taxi or other driving service
- Use special services for older adults. Visit the Community Resource Finder to learn more, alz.org/crf
- Reduce need by having prescriptions and groceries delivered

SIGNS OF UNSAFE DRIVING

- Forgetting how to locate familiar places
- Failing to observe traffic signs
- Making slow or poor decisions in traffic
- Driving at an inappropriate speed
- Hitting curbs
- Using poor lane control
- Confusing the brake and gas pedals
- Getting scrapes or dents on the car
- Having trouble parking
- Becoming angry or confused while driving
- Returning from a routine drive later than usual
- Forgetting the destination you are driving to during the trip

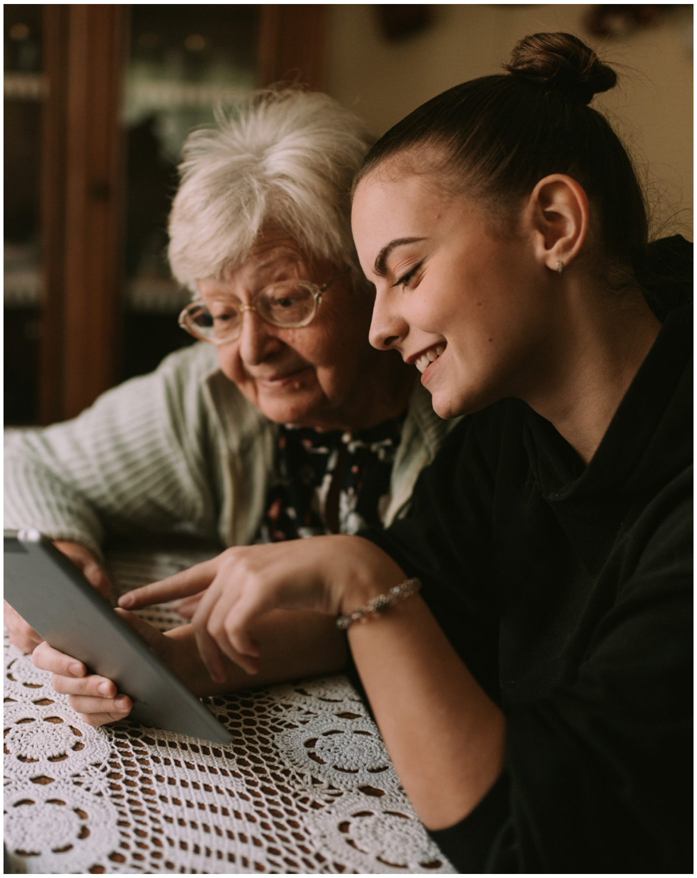
As the danger with driving increases, you may need to prevent them from being able to use the car. Please call our 24/7 Helpline (800.272.3900). We will assist you in creating a personalized plan.

Caregiving Emotions

10 Ways to Manage Stress and Be a Healthy Caregiver

Caregiving can be overwhelming, but it is important to make your health a priority. Taking care of yourself can help you be a better caregiver.

1. **Find time for yourself.** Consider respite care so you can spend time doing something you enjoy.
2. **Know what resources are available.** Adult day programs, in-home assistance, and meal delivery are some of the services that can help.
3. **Become an educated caregiver.** As the disease progresses, it may become necessary to adopt new caregiving skills and strategies.
4. **Get help and find support.** Seek comfort and guidance through local support groups, the Alzheimer's Association's free 24/7 Helpline and ALZConnected® online social networking community.
5. **Make legal and financial plans.** Putting plans in place after an Alzheimer's diagnosis is important. This step allows the person with the disease to participate in decision-making and offers guidance to caregivers.
6. **Manage your level of stress.** Try to find relaxation techniques that work for you, If stress becomes overwhelming, seek professional help.
7. **Take care of yourself.** Try to eat well, exercise, and get plenty of rest.
8. **Know you're doing your best.** Remember that the care you provide makes a difference and that you are doing the best you can.
9. **Accept changes as they occur.** The needs of people with Alzheimer's change over time. For care beyond what you can provide, utilize community resources.



10. **Visit your doctor regularly.** Take time to get checkups. Pay attention to exhaustion, sleeplessness, or changes in appetite or behavior. Ignoring symptoms can cause your health to decline.

Further Resources:

- Free 24/7 Helpline: (800) 272-3900
- Alzheimer's and Dementia Caregiver Center: alz.org/care

Source: Alzheimer's Association

> *More cheerful, eye contact, more touching, letting go of things that didn't matter.*
>
> *-Ms. L*

Caregiver Stress

Caregivers devote a significant amount of time and energy to the person with dementia. Too often, caregivers do not recognize their own needs, delay tending to them, or do not know where to turn for help.

10 Common Signs of Caregiver Stress

1. **Denial** about the disease and its effect on the person who has been diagnosed.
"I know Mom is going to get better."

2. **Anger** at the person living with dementia or frustration that the individual can't do the things that things that once came naturally. "He knows how to get dressed. He's just being stubborn."

3. **Social withdrawl** from friends and activities.
"I don't care about visiting neighbors anymore."

4. **Anxiety** about the future.
"What happens when he needs more care than I can provide?"

5. **Depression** that affects your ability to cope.
"I just don't care anymore."

6. **Exhaustion** that interferes with daily tasks.
"I'm too tired for this."

7. **Sleeplessness** caused by worrying.
"What if she wanders out of the house?"

8. **Irritability** that triggers negative responses.
"Leave me alone!"

9. **Lack of concentration** that disrupts familiar tasks.
"I was so busy, I forgot my appointment."

10. **Health problems** that begin take a mental and physical toll.
"I can't remember the last time I felt good."

Grief and Loss

It is common for caregivers to have feelings of loss and grief as their life is changed by Alzheimer's. You are entitled to these emotions and may start to experience them as soon as you learn of the diagnosis. Share your feelings and seek support as you go through this process.

Some common experiences in the grieving process include:

Denial

- Hoping that the person is not ill
- Expecting the person to get better
- Convincing yourself that the person has not changed
- Attempting to normalize problematic behaviors

Anger

- Being frustrated with the person
- Resenting the demands of caregiving
- Resenting family members who cannot or will not help provide care
- Feeling abandoned

Guilt

- Having unrealistic expectations with thoughts like: “I should have done …” “I must do everything for him or her” or “I must visit him or her every day”
- Feeling bad because you are still able to enjoy life
- Feeling that you have failed if, for example, you cannot care for the person at home
- Having negative thoughts about the person or wishing that he or she would go away or die
- Regretting things about your relationship before the diagnosis

Sadness

- Feeling overwhelmed by loss
- Crying frequently
- Withdrawing from social activities or needing to connect more frequently with others
- Withholding your emotions or displaying them more openly than usual

Acceptance

- Learning to live in the moment
- Finding personal meaning in caring for someone who is terminally ill
- Understanding how the grieving process affects your life
- Appreciating the personal growth that comes from surviving loss
- Finding your sense of humor
- Asking for and accepting help from others

Ways to Cope

Face your feelings. Think about all of your feelings — positive and negative. Let yourself be as sad as you want, and accept feelings of guilt because they are normal. Work through your anger and frustration. These are healthy emotions. Know that it is common to feel conflicting emotions. It is okay to feel love and anger at the same time.

Prepare to experience feelings of loss more than once. As dementia progresses, it is common to go through feelings of grief and loss again. Accept and acknowledge your feelings. They are a normal part of the grieving process.

Claim the grieving process as your own. No two people experience grief the same way. Grief hits different people at different times; some people need more time to grieve than others. Your experience will depend on the severity and duration of the person's illness, on your own history of loss and on the nature of your relationship with the person who has Alzheimer's.

Everyone grieves differently and at their own pace. If your grief is so intense that your well-being is at risk, ask for help from your doctor or a professional counselor.

Talk with someone. Talk with someone you trust about your grief, guilt and anger. If you decide to meet with a therapist who specializes in grief counseling, interview several so you can choose one you are comfortable with.

Combat feelings of isolation and loneliness. Caregivers often give up enjoyable activities and companionship. Make a lunch or movie date with friends. Taking a break may help you relieve stress and grief, and strengthen your support network. Stay involved in activities that you enjoy.

Join a support group. When you talk with other caregivers, share your emotions. Cry and laugh together. Do not limit conversations to caregiving tips.

Know that some people may not understand your grief. Most people think grief happens when someone dies. They may not know that it is possible to grieve deeply for someone who has a progressive cognitive illness.

Accept yourself. Think about what you expect from yourself. Is it realistic? Learn to accept the things that are beyond your control. Make responsible decisions about the things you can control.

Take care of yourself. The best thing you can do for the person you are caring for is to stay healthy. This includes taking care of your physical, mental and emotional well-being. Create balance in your life. Do things that bring joy and comfort, and give yourself time to rest. Ask for help when you need it, and accept the help that is offered.

Source: Alzheimer's Association alz.org

Future Planning

Getting your Affairs in Order

Advance Care Planning

Making health care decisions for yourself or someone who is no longer able to do so can be overwhelming. That's why it's important to get a clear idea about preferences and arrangements while you can still make decisions and participate in legal and financial planning together.

Use this checklist to ensure health care and financial arrangements are in place before serious illness or a health care crisis.

- Start discussions early with your loved one while everyone can still help make decisions.
- Create documents that communicate health care, financial management, and end-of-life wishes for yourself and the people you care for, with legal advice needed.
- Review plans regularly and update documents as circumstances change.
- Put important papers in one place. Make sure a trusted family member or friend knows the location and any instructions.
- Make copies of health care directives to be placed in all medical files, including information on every doctor seen.
- Give permission in advance for a doctor or lawyer to talk directly with a caregiver as needed.
- Reduce anxiety about funeral and burial arrangements by planning ahead.

Visit nia.nih.gov/caregiving/advance-care-planning

Source: National Institute on Aging

Documents to Prepare for the Future

No one ever plans to be sick or disabled. Yet, planning for the future can make all the difference in an emergency and at the end-of-life. Being prepared and having important documents in a single place can give you peace of mind, help ensure your wishes are honored, and ease the burden on your loved ones.

Checklist for Getting Your Affairs in Order

This list provides common steps to consider when getting your affairs in order.

1. Plan for Your Estate and Finances

Depending on your situation, you may choose to prepare different types of legal documents to outline how your estate and finances will be handled in the future. Common documents include a will, durable power of attorney for finances, and a living trust.

- **A will** specifies how your estate — your property, money, and other assets — will be distributed and managed when you die. A will can also address care for children under age 18, adult dependents, and pets, as well as gifts and end-of-life arrangements, such as a funeral or memorial service and burial or cremation. If you do not have a will, your estate will be distributed according to the laws in your state.
- **A durable power of attorney** for finances names someone who will make financial decisions for you when you are unable to.
- **A living trust** names and instructs a person, called the trustee, to hold and distribute property and funds on your behalf when you are no longer able to manage your affairs.

2. Plan for Your Future Health Care

Many people choose to prepare advance directives, which are legal documents that

provide instructions for medical care and only go into effect if you cannot communicate your own wishes due to disease or severe injury. The most common advance directives include a living will and a durable power of attorney for health care.

- **A living will** tells doctors how you want to be treated if you cannot make your own decisions about emergency treatment. You can say which common medical treatments or care you would want, which ones you would want to avoid, and under which conditions each of your choices applies. Learn how to prepare a living will.
- **A durable power of attorney** for health care names your health care proxy, a person who can make health care decisions for you if you are unable to communicate these yourself. Your proxy — also known as a representative, surrogate, or agent — should be familiar with your values and wishes. A proxy can be chosen in addition to or instead of a living will. Having a health

care proxy helps you plan for situations that cannot be foreseen, such as a serious auto accident or stroke. Learn how to choose a health care proxy.

These documents are part of advance care planning, which involves preparing for future decisions about your medical care and discussing your wishes with your loved ones.

3. Put Your Important Papers and Copies of Legal Documents in One Place

You can set up a file, put everything in a desk or dresser drawer, or list the information and location of papers in a notebook. For added security, you might consider getting a fireproof and waterproof safe to store your documents. If your papers are in a bank safe deposit box, keep copies in a file at home. View a list of important papers.

4. Tell Someone You Know and Trust or a Lawyer Where to Find Your Important Papers

You don't need to discuss your personal affairs, but someone you trust should know where to find your papers in case of an emergency. If you don't have a relative or friend you trust, ask a lawyer to help.

5. Talk to your loved ones and a doctor about advance care planning.

A doctor can help you understand future health decisions you may face and plan the kinds of care or treatment you may want. Discussing advance care planning with your doctor is free through Medicare during your annual wellness visit. Private health insurance may also cover these discussions. Share your decisions with your loved ones to help avoid any surprises or misunderstandings about your wishes.

6. Give permission in advance for a doctor or lawyer to talk with your caregiver as needed.

If you need help managing your care, you can give your caregiver permission to talk with your doctors, your lawyer, your insurance provider, a credit card company, or your bank. You may need to sign and return a form. Giving permission for your doctor or lawyer to talk with your caregiver is different from naming a health care proxy. A health care proxy can only make decisions if you are unable to communicate them yourself.

7. Review your plans regularly.

It's important to review your plans at least once each year and when any major life event occurs, like a divorce, move, or major change in your health.

Which documents do you need to have in place?

When you're getting your affairs in order, it's important to prepare and organize important records and files all in one place. Typically, you will want to include personal, financial, and health information. Remember, this is a starting place. You may have other information to add. For example, if you have a pet, you will want to include the name and address of your veterinarian.

Personal Information

- Full legal name
- Social Security number
- Legal residence
- Date and place of birth
- Names and addresses of spouse and children
- Location of birth and death certificates and certificates of marriage, divorce, citizenship, and adoption
- Employers and dates of employment
- Education and military records

- Names and phone numbers of religious contacts
- Memberships in groups and awards received
- Names and phone numbers of close friends, relatives, doctors, lawyers, and financial advisors

Financial Information

- Sources of income and assets (pension from your employer, IRAs, 401(k)s, interest, etc.)
- Social Security information
- Insurance information (life, long-term care, home, car) with policy numbers and agents' names and phone numbers
- Names of your banks and account numbers (checking, savings, credit union)
- Investment income (stocks, bonds, property) and stockbrokers' names and phone numbers
- Copy of most recent income tax return
- Location of most up-to-date will with an original signature
- Liabilities, including property tax — what is owed, to whom, and when payments are due
- Mortgages and debts — how and when they are paid
- Location of original deed of trust for home
- Car title and registration
- Credit and debit card names and numbers
- Location of safe deposit box and key

Health Information

- Current prescriptions (be sure to update this regularly)
- Living will
- Durable power of attorney for health care
- Copies of any medical orders or forms you have (for example, a do-not-resuscitate order)
- Health insurance information with policy and phone numbers

Who can help with getting your affairs in order?

You may want to talk with a lawyer about setting up a general power of attorney, durable power of attorney, joint account, or trust. Be sure to ask about the lawyer's fees before you make an appointment.

You do not have to involve a lawyer in creating your advance directives for health care. Most states provide the forms for free, and you can complete them yourself. Learn more about completing an advance directive.

You should be able to find a directory of local lawyers on the internet or contact your local library, your local bar association for lawyers, or the Eldercare Locator. Your local bar association can also help you find what free legal aid options your state has to offer. An informed family member may be able to help you manage some of these issues.

What other decisions can you prepare for in advance?

Getting your affairs in order can also mean making decisions about organ donation and funeral arrangements, or what you want to happen to your body after you die. Deciding and sharing your decisions can help your loved ones during a stressful time and best ensure your wishes are understood and respected.

Organ and Brain Donation

When someone dies, their healthy organs and tissues may be donated to help someone else. You can register to be an organ donor when you renew your driver's license or state ID at your local department of motor vehicles. You can also register online. Some people also choose to donate their brain to advance scientific research. It may be possible to donate organs for transplant as well as the brain for scientific research. Learn more about organ donation and brain donation.

Funeral Arrangements

You can decide ahead of time what kind of funeral or memorial service you would like and where it will be held. You can also decide whether you would like to be buried or cremated and whether you want your body's ashes kept by loved ones or scattered in a favorite place. Be sure and specify certain religious, spiritual, or cultural traditions that you would like to have during your visitation, funeral, or memorial service. You can make arrangements directly with a funeral home or crematory. Read these tips on planning a funeral. If you choose not to be embalmed or cremated, most states allow families to take care of transportation, preparation of the body, and other needed arrangements. Learn more about the burial options available in your state. Put your preferences in writing and give copies to your loved ones and, if you have one, your lawyer.

For more information about getting your affairs in order:

- American Bar Association
  (800) 285-2221
  americanbar.org
- CaringInfo
  National Hospice and Palliative Care Organization
  (800) 658-8898
  caringinfo@nhpco.org
  caringinfo.org
- The Conversation Project
  (866) 787-0831
  theconversationproject.org
- Eldercare Locator
  (800) 677-1116
  eldercarelocator@n4a.org
  eldercare.acl.gov
- National Academy of Elder Law Attorneys
  (703) 942-5711
  naela@naela.org
  naela.org
- National Elder Law Foundation
  (520)881-1076
  info@nelf.org
  nelf.org
- PREPARE for Your Care
  info@prepareforyourcare.org
  prepareforyourcare.org

This content is provided by the NIH National Institute on Aging (NIA). NIA scientists and other experts review this content to ensure it is accurate and up to date. Content reviewed: February 01, 2023

End-of-Life Planning Checklist

QUESTIONS	RESOURCES	YES	NO
Have wishes or desires for end-of-life care been discussed?	- **Aging with Dignity Five Wishes** Provides resources for end-of-life planning agingwithdignity.org - **The Conversation Project** Offers a guide for how to talk about the end of life. theconversationproject.org		
Is a power of attorney in place for financial needs?	- **Alzheimer's Association®** Provides information on costs to expect and tips for financial planning. alz.org/care/alzheimers-dementia-common-costs.asp		
Is a power of attorney in place for health care decisions?	- **National Association for Elder Law Attorneys** Offers a directory of elder law attorneys. naela.org		
Is palliative or hospice care appropriate for the patient?	- **National Hospice and Palliative Care Organization** Provides information about hospice and palliative care and local hospice and palliative care organizations. nhpco.org/find-hospice		

What Are Palliative Care and Hospice Care?

Many Americans die in facilities such as hospitals or nursing homes receiving care that is not consistent with their wishes. It's important for older adults to plan ahead and let their caregivers, doctors, or family members know your end-of-life preferences in advance. For example, if an older person wants to die at home, receiving end-of-life care for pain and other symptoms, and makes this known to health care providers and family, it is less likely he or she will die in a hospital receiving unwanted treatments.

If the person is no longer able to make health care decisions for themselves, a caregiver or family member may have to make those decisions. Caregivers have several factors to consider when choosing end-of-life care, including the older person's desire to pursue life-extending treatments, how long he or she has left to live, and the preferred setting for care.

Palliative Care

Palliative care is specialized medical care for people living with a serious illness, such as cancer or heart failure. Patients in palliative care may receive medical care for their symptoms, or palliative care, along with treatment intended to cure their serious illness. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family.

Who Can Benefit From Palliative Care?

Palliative care is a resource for anyone living with a serious illness, such as heart failure, chronic obstructive pulmonary disease, cancer, dementia, Parkinson's disease, and many others. Palliative care can be helpful at any stage of illness and is best provided soon after a person is diagnosed.

In addition to improving quality of life and helping with symptoms, palliative care can help patients understand their choices for medical treatment. The organized services available through palliative care may be helpful to any older person having a lot of general discomfort and disability very late in life.

Who Makes up the Palliative Care Team?

A palliative care team is made up of multiple different professionals that work with the patient, family, and the patient's other doctors to provide medical, social, emotional, and practical support. The team is comprised of palliative care specialist doctors and nurses, and includes others such as social workers, nutritionists, and chaplains. A person's team may vary based on their needs and level of care. To begin palliative care, a person's health care provider may refer him or her to a palliative care specialist. If he or she doesn't suggest it, the person can ask a health care provider for a referral.

Where Is Palliative Care Provided?

Palliative care can be provided in hospitals, nursing homes, outpatient palliative care clinics and certain other specialized clinics, or at home. Medicare, Medicaid, and insurance policies may cover palliative care. Veterans may be eligible for palliative care through the Department of Veterans Affairs. Private health insurance might pay for some services. Health insurance providers can answer questions about what they will cover.

In palliative care, a person does not have to give up treatment that might cure a serious illness. Palliative care can be provided along with curative treatment and may begin at the time of diagnosis. Over time, if the doctor or the palliative care team believes ongoing treatment is no longer helping, there are two possibilities. Palliative care could transition to hospice care if the doctor believes the person is likely to die within six months (see What does the hospice six-month requirement mean?). Or, the palliative care team could continue to help with increasing emphasis on comfort care.

Hospice Care

Increasingly, people are choosing hospice care at the end of life. Hospice care focuses on the care, comfort, and quality of life of a person with a serious illness who is approaching the end of life.

At some point, it may not be possible to cure a serious illness, or a patient may choose not to undergo certain treatments. Hospice is designed for this situation. The patient beginning hospice care understands that his or her illness is not responding to medical attempts to cure it or to slow the disease's progress.

Like palliative care, hospice provides comprehensive comfort care as well as support for the family, but, in hospice, attempts to cure the person's illness are stopped. Hospice is provided for a person with a terminal illness whose doctor believes he or she has six months or less to live if the illness runs its natural course.

It's important for a patient to discuss hospice care options with their doctor. Sometimes, people don't begin hospice care soon enough to take full advantage of the help it offers. Perhaps they wait too long to begin hospice and they are too close to death. Or, some people are not eligible for hospice care soon enough to receive its full benefit. Starting hospice early may be able to provide months of meaningful care and quality time with loved ones.

Where is hospice care provided and who provides it?

Hospice is an approach to care, so it is not tied to a specific place. It can be offered in two types of settings — at home or in a facility such as a nursing home, hospital, or even in a separate hospice center.

Hospice care brings together a team of people with special skills — among them nurses, doctors, social workers, spiritual advisors, and trained volunteers. Everyone works together

with the person who is dying, the caregiver, and/or the family to provide the medical, emotional, and spiritual support needed.

A member of the hospice team visits regularly, and someone is usually always available by phone — 24 hours a day, seven days a week. Hospice may be covered by Medicare and other insurance companies. Check to see if insurance will cover the person's particular situation.

It is important to remember that stopping treatment aimed at curing an illness does not mean discontinuing all treatment. A good example is an older person with cancer. If the doctor determines that the cancer is not responding to chemotherapy and the patient chooses to enter into hospice care, then the chemotherapy will stop. Other medical care may continue as long as it is helpful. For example, if the person has high blood pressure, he or she will still get medicine for that.

Although hospice provides a lot of support, the day-to-day care of a person dying at home is provided by family and friends. The hospice team coaches family members on how to care for the dying person and even provides respite care when caregivers need a break. Respite care can be for as short as a few hours or for as long as several weeks.

What are the benefits of hospice care?

Families of people who received care through a hospice program are more satisfied with end-of-life care than those who did not have hospice services. Also, hospice recipients are more likely to have their pain controlled and less likely to undergo tests or be given medicines they don't need, compared with people who don't use hospice care.

Source: nia.nih.gov/health/hospice-and-palliative-care/what-are-palliative-care-and-hospice-care

Choosing a Residential Care Setting

Choosing a residential care setting may seem like an overwhelming task, but asking the right questions and knowing what to look for in a long-term care setting can make it more manageable. Because residential care is available in a variety of settings, it's important to understand the needs of the person with dementia so you can choose the best care.

Questions to Ask

When choosing a care community, there are a number of factors to consider, including the staff, the environment, the programs and the type of treatment provided. Consider asking the following:

Family Involvement

- Are families encouraged to participate in care planning?
- How are families informed of changes in resident's condition and care needs?
- Are families encouraged to communicate with staff?

Residents

- Is personal care (e.g., bathing, grooming, toileting) done with respect and dignity?
- Is there flexibility in personal care times based on an individual's schedule?
- Are residents comfortable, relaxed and involved in activities?
- Are residents well-groomed, clean and dressed appropriately?
- What is the rate of falls?
- Are residents with psychiatric illness as their primary diagnosis on the same unit as residents with dementia?

Staffing

- Is medical care provided? How often are physicians and nurses or nurse practitioners on premises?
- Is there a registered nurse on site at all times?
- Is personal care and assistance provided?
- Is care personalized to meet specific needs, abilities and interests?
- Are staff trained in dementia care?
- How long is the training and what topics are covered?
- On average, how long have workers been on staff?
- How does staff handle challenging behaviors?
- What is the ratio of residents to staff?

Environment

- Is the facility free of unpleasant odors?
- Do indoor spaces allow freedom of movement and promote independence?
- Are indoor and outdoor areas safe and secure? Are they monitored?
- Is the facility easy to navigate?
- Is there a designated family visiting area or a private place to have visitors?
- Are resident rooms clean and spacious?
- Are residents allowed to bring familiar items (e.g., photos, bedding, a chair)?

Meals

- Are there regular meal and snack times?
- Is food appetizing? (Ask to see the weekly menu and come for a meal.)
- Is there flexibility in meal times based on the individual's personal schedule?
- Is the dining environment pleasant and comfortable?
- Are family and friends able to join mealtime?
- Is there a plan for monitoring adequate nutrition (food and fluid)?
- Is staff able to accommodate special dietary needs (e.g., low sodium, diabetic)?
- Do staff provide appropriate assistance based on person's abilities (e.g., encouragement during meals or assisted feeding if needed)?
- Are there any environmental distractions during mealtime (e.g., noisy TV)?

Programs and Services

- Are appropriate services and programming available based on specific care needs? (e.g., small groups, quiet rooms, dementia specific)
- Do planned activities take place? (Ask to see an activity schedule; was the activity on time?
- Are activities available on weekends or evenings?
- Are activities designed to meet specific needs, interests and abilities?
- Is transportation available for medical appointments and shopping?
- Are care planning sessions held regularly? Are times flexible/convenient?
- Which therapies (e.g., physical, occupational, speech, recreational) are offered?
- Is there a dementia-specific (special care) unit?
- Are religious services and celebrations available to residents?

Policies and Procedures

- Can family and friends participate in care?
- Do visiting hours work for your family?
- Has the discharge policy been discussed? What situations/conditions lead to a discharge (such as change in behavior or financial circumstances)?
- Is continuing care available as a resident's needs change?
- Is there an "aging in place" policy where residents remain in the community — even the same room — throughout the course of the disease?
- Does the community provide an escort to the emergency room if a visit is required?
- Does the community provide end-of-life care? Is hospice care available if needed?

For more information, visit alz.org/residentialfacilities.
Visit the Alzheimer's Association & AARP Community Resource Finder (alz.org/CRF) to access a database of dementia and aging-related resources in your area, including residential care facilities.

TRANSAMERICA®

Financial Planning in the Shadow of Dementia

CAREGIVER'S CHECKLIST

When dealing with dementia, it's critical to take immediate action before your loved one loses "legal capacity"—the ability to appreciate the nature and consequences of one's actions.

Unless your loved one appoints a durable power of attorney before losing legal capacity, courts might get involved. This process can be time-consuming, and a judge might appoint an undesired conservator or guardian to make decisions.

Here are five steps you and your financial professional can take to help alleviate some of your family's financial worries when creating a plan for a loved one living with Alzheimer's disease or another form of dementia.

1

UPDATE THE ESTATE PLAN

Ensure you and the financial professional have a complete view of your loved one's assets, how they are managed, and their estimated value.

This includes:

○ Real estate
○ Investments and brokerage accounts
○ Retirement plans
○ Household items

You may also want to:

○ Review how property is titled (with an attorney), and ask whether wills, trusts, and beneficiary designations should be updated

2

IDENTIFY ALL INCOME SOURCES

Review your loved one's income sources, insurance policies, and bank accounts. It is critical to know all account logins and passwords and the location of all important documents.

INCOME

○ Employment income
○ Pensions
○ Veteran's benefits
○ Annuities
○ Social Security
○ Social Security Disability Income
○ Supplemental Security Income
○ Retirement accounts (IRA, 401(k))
○ Reverse mortgage
○ Other income (e.g., rental property)

INSURANCE

○ Health insurance (does it cover dementia care?)
○ Life insurance
○ Long-term care insurance
○ Medicare
○ Medigap

BANK ACCOUNTS

○ Checking
○ Savings
○ Certificates of deposit

IMPORTANT DOCUMENTS

○ Titles & deeds
○ Beneficiary designations
○ Trust documents
○ Power of attorney (finances)
○ Power of attorney (health care)
○ Standard will
○ Living will/medical directives
○ Birth certificate
○ Passport
○ State ID/driver's license
○ Social Security card
○ Marriage license
○ Vehicle registration

NAADCCL0715

3 LEARN YOUR LOVED ONE'S FUTURE INTENTIONS

It is imperative to understand your loved one's wishes and how to ensure they are fulfilled.

- ○ Ask who your loved one wants as an advocate to make decisions when he or she is no longer able
- ○ Ask where the person wants to live as the disease progresses (assisted living, nursing home, etc.)

Consider working with an elder law attorney to:

- ○ Create a power of attorney for finances
- ○ Create a power of attorney for health care
- ○ Create an advance directive regarding health care and end-of-life decisions

4 ENSURE FINANCIAL OBLIGATIONS ARE BEING MET

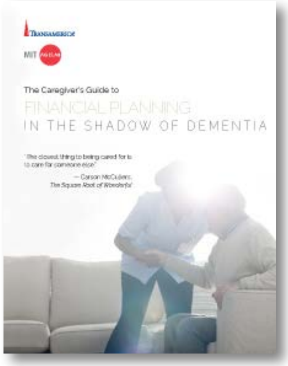
Work with your loved one's financial professional to ensure finances are properly managed and all bills are being paid on time.

- ○ If you are appointed as the advocate or durable power of attorney, ensure that your loved one authorizes you to speak with the financial professional.
- ○ If you are not appointed as durable power of attorney, or do not wish to handle that responsibility, ensure a trusted person who understands what it means to be a fiduciary serves in this role. A fiduciary is legally bound to place the interests of the person in need ahead of his or her own
- ○ Consider working with a daily money-management service
- ○ Consider looking into the Social Security Representative Payment Program

5 DISCUSS CARE MANAGEMENT

Work with a financial professional to discuss how to finance care. This includes conversations about:

- ○ Whether home modifications are necessary for a loved one determined to stay in his or her residence as long as possible
- ○ Working with a geriatric care manager
- ○ Meals on Wheels and other community services


The Caregiver's Guide to
FINANCIAL PLANNING
IN THE SHADOW OF DEMENTIA

Transamerica's *Caregiver's Guide to Financial Planning in the Shadow of Dementia*, written in collaboration with researchers at the Massachusetts Institute of Technology (MIT) AgeLab, provides more detail about creating a comprehensive financial plan for a loved one living with Alzheimer's disease and other forms of dementia. In addition, you can learn 10 symptoms of caregiver stress and advice to help you manage your own well-being.

To get a copy, contact your financial professional or visit yourta.com/guide.

Resources

Florida Alzheimer's Center of Excellence

Services and Activities

Through FACE, Care Navigators in communities across Florida support caregivers and people with dementia with care planning, education access to resources, and ongoing support. The Care Navigators live and work in the communities they serve to ensure the care plans they help families develop include the best resources in the area.

As FACE continues to develop, the program will offer recognition to direct care settings that demonstrate excellence in staff training and support. The third layer of FACE outlines parameters to acknowledge industry leaders in Alzheimer's disease and related dementias clinical care and research. The model follows a similar framework developed by the Department of Health's Cancer Centers of Excellence by creating benchmarks and best-practice standards. The recognition as a FACE Partner will allow families to seek the best professionals in the field and raise the bar of care standards.

FACE began in 2022 to support caregivers and people with Alzheimer's and related dementias in the community using evidence-based and no-wrong-door strategies. The creation of FACE marked the final pillar of Governor DeSantis' five-point dementia action plan that he announced at the start of his first term in 2019 as part of the state's deep commitment to leading the nation in research, care, and support for individuals with Alzheimer's disease and related dementias (ADRD).

FACE achieves a holistic care model for clients and caregivers to address two primary goals: to allow Floridians living with ADRD to age in place and to empower family caregivers with increased capacity. FACE provides the resources to create a family-centered support system throughout the continuum of care by building on Florida's current infrastructure of ADRD resources, initiatives, and funding by connecting the state's Memory Disorder Clinics, Dementia Care and Cure Initiative Task Forces, the Alzheimer's Disease Advisory Committee, and the Department of Elder Affairs' Care Navigators.

How Can FACE Help?

Care Navigators within FACE offer ongoing support, guidance, and assistance to connect families with helpful resources to get the best outcomes possible.

Each of Florida's 11 Area Agencies on Aging can refer families to the program. The program is available at no cost to Florida seniors and their families. A formal diagnosis of Alzheimer's or dementia is not required.

To receive support from a Care Navigator, call the Elder Helpline at 1-800-963-5337 (1-800-96 ELDER) or your local Memory Disorder Clinic.

Elder Helpline

Information regarding elder services and activities is available through the Elder Helpline Information and Assistance service within each Florida County.

All Elder Helplines can be accessed through the Florida Telecommunication Relay System (1-800-955-8771 for TDD or 1-800-955-8770 for Voice) which allows telephone calls to be placed between TDD users and non-users with the help of specially trained operators translating the calls.

A listing of local Elder Helpine numbers can be found on page 73.

Information is one of the keys to help promote the well-being and independence of Florida's seniors, their families, and caregivers. Through the network of Elder Helpline Information and Referral (I&R) services, individuals are informed about long-term care options, resources, and opportunities available within their community.

As a gateway to the aging service system, I&R service provides a single contact point within each of its planning and service areas via the statewide toll-free Elder Helpline number 1-800-963-5337 (1-800-96 ELDER).

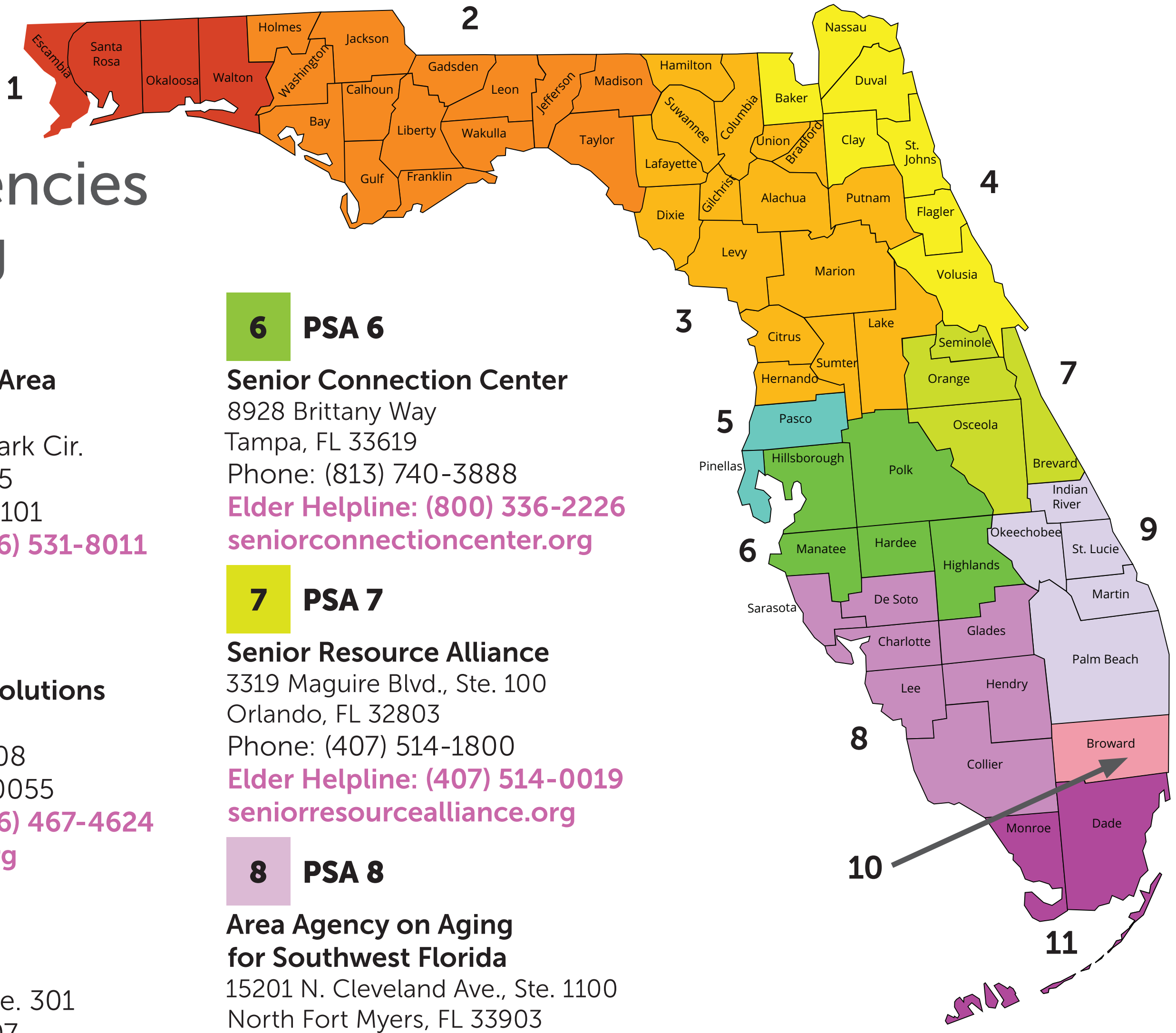
I&R is a foundational support service to caregivers, who are among the most frequent seekers of the service. The request for caregiver support is one of the top 10 services requested at the Helpline. Many elders prefer to remain in their own home and communities. Families who are willing to support the client's choice may contact the Helpline to learn about options to help maintain the client at home when possible. Services may include respite to allow the caregiver to take a much needed break, caregiver training, support groups and counseling.

Consumers contacting the Helpline about becoming a paid caregiver, can receive information about the Home Care for the Elderly (HCE) and Statewide Medicaid Managed Care Long-term Care Program (SMMC LTC). The client's care plan must include the Participant Direction Option to receive the caregiver benefit in the SMMC LTC Program.

The Helpline is also an access point to the Aging and Disability Resource Centers (ADRCs). The ADRCs, working in coordination with the Department's Comprehensive Assessment and Review of Long-Term Care Services (CARES) and the Department of Children and Families, function as a single, coordinated system for information and access to services for individuals seeking long-term care services.

For information about any of the Department's programs, to request help accessing services, seeking information about community resources or volunteer opportunities, call the toll-free Elder Helpline at 1-800-963-5337, Monday through Friday, 8:00 a.m. to 5:00 p.m. I&R services can also be accessed through the Florida Relay Service for the hearing impaired by dialing 711.

The national Eldercare Locator Service can assist with information and assistance with referrals outside of Florida. Call the Eldercare Locator at 1-800-677-1116.



Area Agencies on Aging

1 PSA 1

Northwest Florida Area Agency on Aging
5090 Commerce Park Cir.
Pensacola, FL 32505
Phone: (850) 494-7101
Elder Helpline: (866) 531-8011
nwflaaa.org

2 PSA 2

Advantage Aging Solutions
414 Mahan Dr.
Tallahassee, FL 32308
Phone: (850) 488-0055
Elder Helpline: (866) 467-4624
advantageaging.org

3 PSA 3

Elder Options
100 S.W. 75th St., Ste. 301
Gainesville, FL 32607
Phone: (352) 378-6649
Elder Helpline: (800) 262-2243
agingresources.org

4 PSA 4

ElderSource
10688 Old St. Augustine Rd.
Jacksonville, FL 32257
Phone: (904) 391-6600
Elder Helpline: (888) 242-4464
myeldersource.org

5 PSA 5

Area Agency on Aging of Pasco-Pinellas
9549 Koger Blvd.
Gadsden Bldg., Ste. 100
St. Petersburg, FL 33702
Phone: (727) 570-9696
Elder Helpline: (727) 217-8111
agingcarefl.org

6 PSA 6

Senior Connection Center
8928 Brittany Way
Tampa, FL 33619
Phone: (813) 740-3888
Elder Helpline: (800) 336-2226
seniorconnectioncenter.org

7 PSA 7

Senior Resource Alliance
3319 Maguire Blvd., Ste. 100
Orlando, FL 32803
Phone: (407) 514-1800
Elder Helpline: (407) 514-0019
seniorresourcealliance.org

8 PSA 8

Area Agency on Aging for Southwest Florida
15201 N. Cleveland Ave., Ste. 1100
North Fort Myers, FL 33903
Phone: (239) 652-6900
Elder Helpline: (866) 413-5337
aaaswfl.org

9 PSA 9

Area Agency on Aging of Palm Beach/Treasure Coast, Inc.
4400 N. Congress Ave.
West Palm Beach, FL 33407 Phone:
(561) 684-5885
Elder Helpline: (866) 684-5885
aaapbtc.org

10 PSA 10

Area Agency on Aging of Broward County
5300 Hiatus Rd.
Sunrise, FL 33351
(954) 745-9567
Phone: (954) 745-9567
Elder Helpline: (954) 745-9779
adrcbroward.org

11 PSA 11

Alliance for Aging
760 NW 107th Ave., Ste. 214
Miami, FL 33172
Phone: (305) 670-6500
Elder Helpline: (305) 670-4357
allianceforaging.org

County coloring represents area served by the corresponding Area Agency on Aging.

PSA - Planning and Service Area

Facing Alzheimer's or other dementia and need help?

Alzheimer's Association
24/7 Helpline

800.272.3900

Call the Alzheimer's Association for:

- Information on Alzheimer's and other dementia.
- Challenges in caregiving.
- Treatment options.
- Safety issues.
- Solutions to difficult symptoms.
- Legal and financial planning.
- Referrals to local programs, support groups and services.

Call the Elder Helpline for:

- Referrals to local programs and services.
- Financial assistance.
- Transportation assistance.
- In-home services.
- Legal assistance.
- Ramp construction & other home modifications/repairs.
- Medicare & long-term health.
- Insurance assistance.
- Prescription drug assistance.

Florida Dept. of Elder Affairs
Elder Helpline
Monday to Friday
8 a.m. to 5 p.m. ET

800.963.5337

Scan for more from the Alzheimer's Association

ALZHEIMER'S ASSOCIATION®

Memory Disorder Clinics

The Florida Legislature has authorized 17 Memory Disorder Clinics to provide comprehensive diagnostic and referral services for individuals with Alzheimer's disease and related dementias (ADRD). All clinics receive state funding and are also tasked with conducting service-related research, developing caregiver training materials, and offering educational opportunities.

Memory Disorder Clinics are required to:

- Provide diagnostic services to individuals suspected of having ADRD. This includes accepting referrals from all ADI respite and service providers and conducting evaluations for referred individuals, as well as the general public, within the clinic's designated service area.

- Deliver at least four hours of in-service training annually to ADI-funded respite care providers in their service area. Clinics must also develop and distribute training models to service providers and the Florida Department of Elder Affairs. A designated staff member at each clinic will serve as a training liaison for service providers.

- Create training materials and educational opportunities for both family and professional caregivers. This includes offering specialized training to caregivers, caregiver groups, and relevant organizations in the service area.

- Conduct applied service-related research, which may include studies on therapeutic interventions, caregiver support, and services for persons living with ADRD.

- Collaborate with respite and service providers by establishing at least one annual contact with each provider. These meetings aim to plan, develop, and conduct service-related research projects.

Memory Disorder Clinic services are available to individuals diagnosed with, or suspected of having, memory loss that includes cognitive changes interfering with Activities of Daily Living (ADLs).

A map and contact information for all Memory Disorder Clinics can be found on page 76 and 77 of this publication.

Research: The Alzheimer's Disease Initiative Brain Bank

The Alzheimer's Disease Initiative Brain Bank is a statewide network focused on service, education, and research. Its primary mission is to help find a cure for Alzheimer's disease by collecting and studying the brains of individuals who were clinically diagnosed with dementia.

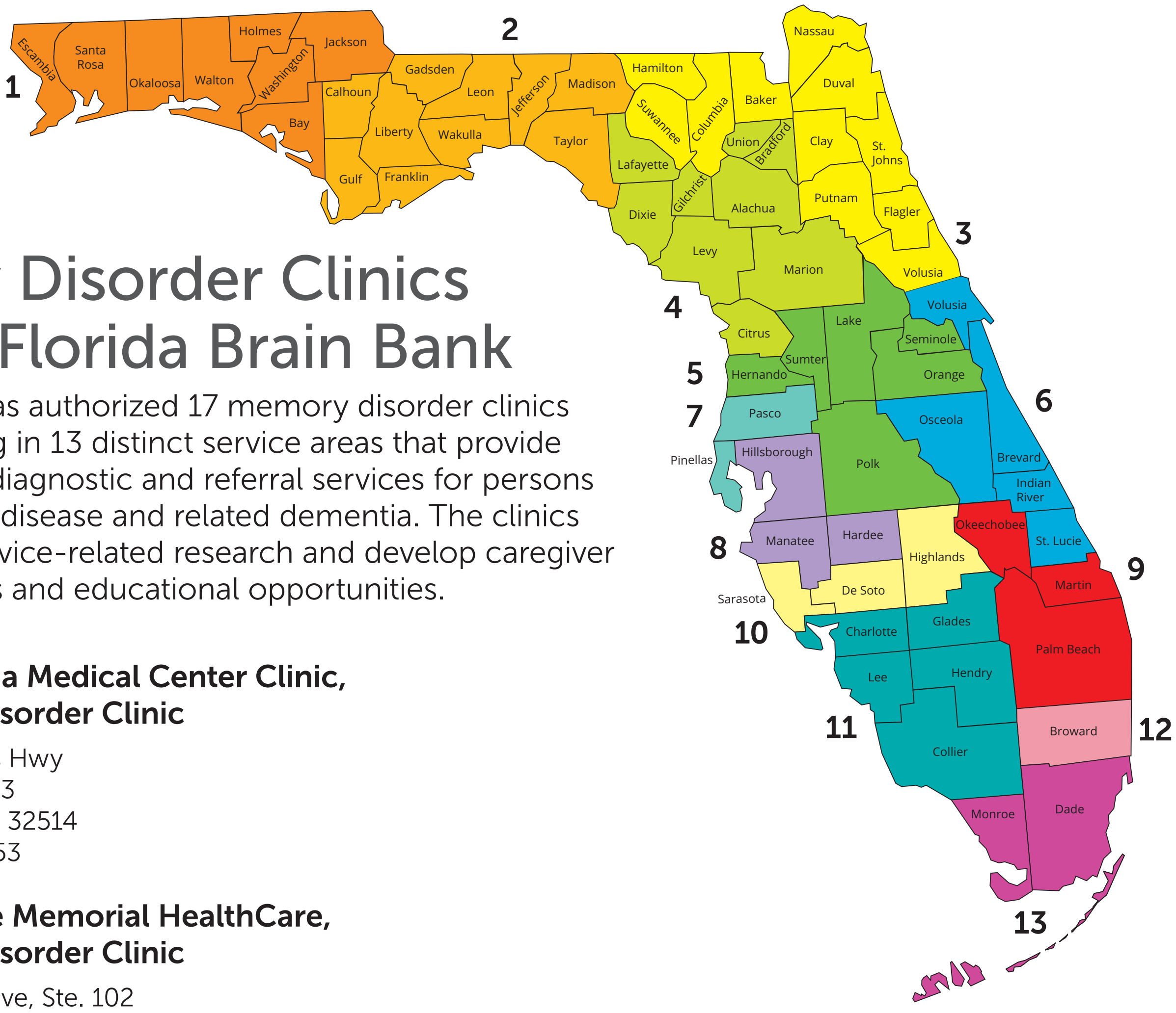
The Brain Bank is operated under an annual contract between the State of Florida and Mount Sinai Medical Center, which oversees the central repository. Regional coordinators in Orlando and Miami assist with participant recruitment and serve as liaisons between the Brain Bank and participants' families.

Participants are also recruited through Alzheimer's respite care providers and Memory Disorder Clinics across the state.

Families who participate in the Brain Bank program receive two primary benefits:

1. Diagnostic confirmation of Alzheimer's disease, provided in clear, understandable language.

2. Opportunities to engage in research activities, both within Florida and through national collaborations.



Memory Disorder Clinics and the Florida Brain Bank

The legislature has authorized 17 memory disorder clinics (MDCs) operating in 13 distinct service areas that provide comprehensive diagnostic and referral services for persons with Alzheimer's disease and related dementia. The clinics also conduct service-related research and develop caregiver training materials and educational opportunities.

1

West Florida Medical Center Clinic, Memory Disorder Clinic

8333 N. Davis Hwy
Bldg. 1, Floor 3
Pensacola, FL 32514
(850) 474-8353

2

Tallahassee Memorial HealthCare, Memory Disorder Clinic

2473 Care Drive, Ste. 102
Tallahassee, FL 32308
(850) 431-5001

3

Mayo Clinic, Memory Disorder Clinic

4500 San Pablo Rd.
Jacksonville, FL 32224
(904) 953-7103

4

University of Florida, Memory Disorder Clinic

3009 SW Williston Rd.
Gainesville, FL 32608
(352) 294-5400

5

Orlando Health Neuroscience Institute's Center for Aging and Memory Disorder Clinic

76 W. Underwood St. 2nd Floor
Orlando, FL 32806
(321) 841-2800

5

AdventHealth Memory Disorder Clinic

265 E. Rollins Street, 6th Floor
Orlando, FL 32803
(407) 392-9237

6

Health First Memory Disorder Clinic

3661 S. Babcock St.
Melbourne, FL 32901
(321) 434-7612

7

Madonna Ptak Center for Alzheimer's Research and Memory Disorders Clinic

430 Morton Plant St., Ste. 401
Clearwater, FL 33756
(727) 298-6025

8

University of South Florida Memory Disorder Clinic

3515 E. Fletcher Ave.
Tampa, FL 33613
(813) 974-3100

9

St. Mary's Medical Center Memory Disorder Clinic at Palm Beach Neuroscience Institute

901 Village Blvd., Ste. 702
West Palm Beach, FL 33409
(561) 990-2135
8756 Boynton Beach Blvd., Ste. 2500
Boynton Beach, FL 33472
(561) 990-2135

9

Florida Atlantic University Louis and Anne Green Memory and Wellness Center

777 Glades Rd., Bldg. AZ-79
Boca Raton, FL 33431
(561) 297-0502

10

Sarasota Memorial Hospital Memory Disorder Clinic

1515 S. Osprey Ave., Ste. A-1
Sarasota, FL 34239
(941) 917-7197

11

Lee Physicians Group Memory Care Clinic

12600 Creekside Lane, Ste. 7
Fort Myers, FL 33919
(239) 343-9220

12

Broward Health Memory Disorder Center

201 E. Sample Rd.
Deerfield Beach, FL 33064
(954) 786-7392

13

Mt. Sinai Medical Center Wien Center for Alzheimer's Disease and Memory Disorders

4302 Alton Rd., Ste. 650
Miami Beach, FL 33140
(305) 674-2543 ext. 55725

13

University of Miami Center for Cognitive Neuroscience and Aging

1695 N.W. 9th Ave., Ste. 3202
Miami, FL 33136
(305) 355-9065

13

Frank C. & Lynn Scaduto MIND Institute at Miami Jewish Health

5200 NE 2nd Avenue
Miami, FL 33137
(305) 514-8652

Brain Bank Locations

5

State of Florida Brain Bank- Satellite Office Orlando Alzheimer's and Dementia Resource Center

1410 Gene Street
Winter Park, FL 32789
(407) 436-7750

13

State of Florida Brain Bank Wien Center for Alzheimer's Disease and Memory Disorders

4302 Alton Road, Suite 650
Miami Beach, FL 33140
(305) 674-2121

NOTE: County coloring represents area served by the corresponding Memory Disorder Clinic.

Caregiver Support Programs

According to the Administration for Community Living, families are the primary source of support for older adults and people with disabilities in the U.S.

While family caregivers can be a son or daughter caring for a parent, caregivers may also be a spouse or other adult family member or friend. Caregivers over the age of 50 may become vulnerable to a decline in their own health. Programs like the National Family Caregiver Support Program (NFCSP) and the Home Care for the Elderly (HCE) Program can help reduce stress from the daily task of caregiving, caregiver depression and allow them to provide care to the client longer and avoid the need for institutional care.

The NFCSP provides support for family caregivers or older individuals who are aged 60 and older, and grandparents aged 55 or older, or older adults who are relative caregivers of children not older than 18 years old or individuals with a disability. Services may include:

- Information to caregivers about available services;
- Help in gaining access to services;
- Individual counseling, support groups, and caregiver training;
- Respite care; and
- Supplemental services.

The HCE Program supports care for Floridians age 60 and older in family-type living arrangements within private homes as an alternative to nursing homes or other institutional care settings. A basic subsidy is provided for support and maintenance of the elder. A special subsidy may also be provided for services and/or supplies. Assistance in arranging specialized services is also available as needed.

Caregivers and individuals seeking information and assistance in accessing caregiver support services are encouraged to call the Elder Helpline at 1-800-963-5337 or contact the local Aging and Disability Resource Center elderaffairs.org/resource-directory/aging-and-disability-resource-centers-adrcs.

Long-Term Care Ombudsman Program

The Ombudsman program advocates for residents of nursing homes, board and care homes, assisted living facilities, and other similar adult care facilities. State Ombudsmen and their designated representatives work to resolve problems individual residents face and effect change at the local, state, and national levels to improve quality of care.
In addition to identifying, investigating, and resolving complaints, Ombudsman program responsibilities include:

- Educating residents, their family and facility staff about residents' rights, good care practices, and similar long-term services and supports resources;
- Ensuring residents have regular and timely access to ombudsman services;
- Providing technical support for the development of resident and family councils;
- Providing information to the public regarding long-term care facilities and services, residents' rights, and legislative and policy issues;
- Advocating for changes to improve residents' quality of life and care;
- Representing resident interests before governmental agencies; and
- Seeking legal, administrative and other remedies to protect residents.

Long-Term Care
Ombudsman Program FLORIDA

Program Highlights

- Since 2013, the Florida LTCOP has saved the state an estimated $8.5 million
- LTCOP has over 200 certified volunteer Ombusdsman
- # of Assessments 3,084
- # of Visits 1,585
- # of Complaints 4,119
- # of Facilities 3,978

**State FY 2021/2022*

SHINE, MIPPA, and the Senior Medicare Patrol

Through a statewide network, the Serving Health Insurance Needs of Elders (SHINE) Program provides Medicare-related counseling assistance for Florida's Medicare beneficiaries, their families, and caregivers. SHINE is part of the national State Health Insurance Assistance Program (SHIP).

Services and Activities

Trained volunteers of the state's 11 AAAs provide free and unbiased information, counseling, and assistance related to Medicare, Medicaid, long-term care insurance, prescription assistance, supplement insurance, preventive benefits, fraud prevention, cost-saving programs, and beneficiary rights. Services are provided in-person at counseling sites, via telephone and email, and through web-based video conferencing programs.

In addition to counseling, SHINE volunteers provide community education and outreach through presentations on Medicare and health insurance issues and by disseminating information focused on health promotion, consumer protection, and beneficiary rights at health and senior fairs throughout the state.

SHINE also operates two other programs. The MIPPA (Medicare Improvements for Patients & Providers Act) Program is able to help eligible clients enroll. Benefits are available for qualified Medicare Beneficiaries to help them save money on their copays, premiums, and deductibles.

The statewide Senior Medicare Patrol (SMP) Program. The SMP Program empowers seniors to prevent Medicare fraud. Through the SHINE/SMP Program, volunteers educate beneficiaries to protect, detect, and report potential errors, fraud, and abuse with their Medicare coverage.

Eligibility

All Medicare beneficiaries, their representatives, family members, and caregivers are eligible to receive free, unbiased services and information from SHINE.

Contact Us

If you would like to make an appointment with a SHINE counselor or find out more information about volunteering, you may call the Elder Helpline toll-free at 1-800-96-ELDER (1-800-963-5337). You may also visit our website at floridashine.org and click "Join OurTeam."

SHINE
SHIP | SMP FLORIDA

SHIP
State Health Insurance Assistance Program

SMP
Senior Medicare Patrol

Online Resources

National Organizations

AARP

https://www.aarp.org/caregiving/

Alzheimer's Disease Supportive Services Program (ADSSP)

acl.gov/programs/support-people-alzheimers-disease/support-people-dementia-including-alzheimers-disease

Alzheimer's Foundation of America

alzfdn.org

John A. Hartford Foundation

johnahartford.org

National Alliance for Caregiving

caregiving.org

National Academy of Elder Law Attorneys

naela.org

National Alzheimer's Disease Education and Referral Center (NIH ADEAR)

nia.nih.gov/health/about-adear-center

National Alzheimer's and Dementia Resource Center (NADRC)

nadrc.acl.gov

National Alzheimer's Project Act

aspe.hhs.gov/daltcp/napa

National Council of Aging

ncoa.org

National Family Caregiver Support Program

ncoa.org/caregivers

National Institute on Aging

nia.nih.gov/health/caregiving

Alzheimer's Association

To find a chapter in your community:
alz.org/local_resources/find-your-local-chapter

National Institutes of Health

nih.gov

National Resource Center on LGBT+ Aging

lgbtagingcenter.org

SAGE Advocacy & Services for LGBT+ Elders

sageusa.org

US Federal & International Organizations

Administration for Community Living (ACL)

acl.gov

ACL Brain Health Resources

acl.gov/brain-health

Alzheimer's Society

alzheimers.org.uk

**Centers for Disease Control
Healthy Brain Road Map**

cdc.gov/aging/healthybrain/roadmap.htm

Dementia Alliance International (DAI)

dementiaallianceinternational.org

US Department of Health and Human Services

hhs.gov

US Department of Veterans Affairs

va.gov

Veterans Administration (VA)

va.gov/GERIATRICS

World Dementia Council

worlddementiacouncil.org

World Health Organization (WHO)

who.int/news-room/fact-sheets/detail/dementia

State of Florida Alzheimer's Organizations

211 Florida

unitedwayncfl.org/211

Alzheimer's Association

Alz.org

Alzheimer's Family Organization

alzheimersfamily.org

Alzheimer & Parkinson Association

alzpark.org

Disaster Preparedness

floridadisaster.org

Find a Ride Florida

findarideflorida.org

Florida Department of Elder Affairs

elderaffairs.org

- **Alzheimer's Disease Initiative (ADI)**
  elderaffairs.org/programs-services/bureau-of-elder-rights/alzheimers-disease-initiative
- **Caregiver Assistance Programs**
  elderaffairs.org/programs-services/caregiving/community-care-for-the-elderly-cce-program
- **Dementia Care and Cure Initiative (DCCI) Task Forces**
  elderaffairs.org/programs-services/bureau-of-elder-rights/dementia-care-cure-initiative
- **Elder Law**
  law.elderaffairs.org
- **Long-Term Care Ombudsman Program**
  ombudsman.elderaffairs.org
- **Memory Disorder Clinic**
  elderaffairs.org/wp-content/uploads/MDC-Map_WEB.pdf
- **Office of Public and Professional Guardians**
  elderaffairs.org/programs-services/office-of-public-professional-guardians-oppg
- **SHINE**
  floridashine.org

Florida Abuse Hotline

myflfamilies.com/service-programs/abuse-hotline

Florida Adult Protective Services (APS)

www.myflfamilies.com/service-programs/adult-protective-services

Florida Council on Aging

fcoa.org/index.php

Florida County Health Departments

floridahealth.gov/all-county-locations.html

Florida Department of Veterans' Affairs

floridavets.org/locations/#svnh

Florida Silver Alert

www.fdle.state.fl.us/Amber-Plan/Silver-Alert

Florida Special Needs Registry
snr.flhealthresponse.com

Florida Associations

Florida Adult Day Services Association
fadsafl.org

Florida Assisted Living Association
fala.org

Florida Health Care Association
fhca.org

Home Care Association of Florida
homecarefla.org

Florida Hospice and Palliative Care Association
floridahospices.org

Florida Senior Living Association
floridaseniorliving.org

Aging Life Care Association
aginglifecare.org/ALCA/Regional_Chapters/Florida_Chapter/Florida_Chapter_Home_Page.aspx

Leading Age Florida
leadingageflorida.org

Alzheimer's and Related Dementias Organizations

Association for Frontotemporal Degeneration
theaftd.org

Huntington's Disease Society of America
hdsa.org

Lewy Body Dementia Association
lbda.org

Parkinson's Foundation
parkinson.org

CurePSP PSP
CurePSP.org
Email: info@curepsp.org

Note: CurePSP covers PSP (Progressive Supranuclear Palsy), CBD (Corticobasal Degeneration), and MSA (Multiple System Atrophy).

Florida Department of Elder Affairs Partner Organizations

Aging and Disability Resource Centers (ADRCs)
elderaffairs.org/resource-directory/aging-and-disability-resource-centers-adrcs

AARP
aarp.org

- **Age-Friendly States and Communities**
  aarp.org/livable-communities/network-age-friendly-communities
- **Dementia**
  aarp.org/health/dementia

Dementia Friendly America
dfamerica.org

Florida Department of Health
floridahealth.gov

- **Florida Department of Health SHIP**
  floridahealth.gov/about/state-and-community-health-assessment/ship-process/FINAL_SHIP.pdf
- **Florida Health Finder**
  floridahealthfinder.gov/index.html

Florida Safe Mobility for Life Coalition

safemobilityfl.com/FamiliesandCaregiverResources.htm

USAging

usaging.org

Organizations for Persons Living with Dementia

Dementia Action Alliance (DAA)

daanow.org

Dementia Mentors

dementiamentors.org

I'm Still Here Foundation

imstillhere.org

Living Well with Dementia, University of Waterloo

uwaterloo.ca/partnerships-in-dementia-care

Memory Café Directory

memorycafedirectory.com

Caregiving Resources

ALZConnected

alzconnected.org

A Place for Mom

aplaceformom.com/assisted-living/florida

BrightFocus® Foundation

brightfocus.org/alzheimers

Care Patrol

carepatrol.com

Community Resource Finder

communityresourcefinder.org

Easterseals, Inc. Caregiver Support Groups

easterseals.com/explore-resources/for-caregivers/

Eldercare Locator

eldercare.acl.gov/Public/Index.aspx

Family Caregiver Alliance

caregiver.org

Health In Aging

healthinaging.org

Help for Alzheimer's Families

helpforalzheimersfamilies.com

Information & Support for In-Home Dementia Caregivers developed by the Veterans Health Administration (VHA) Office of Rural Health

https://www.ruralhealth.va.gov/vets/resources.asp#support

Long-Term Care

acl.gov/ltc

National Long-Term Care Ombudsman Resource Center

ltcombudsman.org

Talking with Your Doctor Toolkit

nia.nih.gov/health/publication/talking-your-doctor-presentation-toolkit

Project Lifesaver

projectlifesaver.org

Rosalynn Carter Institute for Caregivers

rosalynncarter.org

Scent Evidence K9

scentevidencek9.com

Senior Living

seniorliving.org

Veterans Affairs Caregiver Support

caregiver.va.gov

Research Organizations

1Florida Alzheimer's Disease Research Center

1floridaadrc.org

Alzheimer's Prevention Registry

endalznow.org

Brain Health Registry

brainhealthregistry.org

ClinicalTrials.gov

clinicaltrials.gov

DS-Connect®

dsconnect.nih.gov

Florida Brain Bank

msmc.com/neurosciences/wien-center-florida-brain-bank

Join Dementia Research (UK)

joindementiaresearch.nihr.ac.uk

Mayo Clinic Alzheimer's Disease Research Center

mayo.edu/research/centers-programs/alzheimers-disease-research-center

National Alzheimer's Coordinating Center

nia.nih.gov/research/dn/national-alzheimers-coordinating-center-nacc

Recruiting Older Adults into Research (ROAR)

nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit

TrialMatch

alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp

The Michael J. Fox Foundation for Parkinson's Research

michaeljfox.org

Caregiver Training

ACTS 2 Project African American Alzheimer's Caregiver Training and Support (ACTS) 2 Project

Acts2project.org/index.html

Alzheimer's Association

alz.org/help-support/caregiving

Alzheimer's Community Care

alzcare.org

Alzheimer's Foundation of America

alzfdn.org/caregiving-resources/webinars-support-groups

Alzheimer's Project

alzheimersproject.org

Best Practice Caregiving

bpc.caregiver.org/#home

BrightFocus® Foundation

brightfocus.org/alzheimers/caregiving

Center for Applied Research in Dementia

cen4ard.com

REACH: Resources & Education for Aging, Community, and Health

reach.med.fsu.edu

Books for Kids and Teens

Alzheimer's changes the lives of everyone it touches. You are not alone. Does someone in your family have Alzheimer's disease? Check out the books on this list that talk about what it's like and learn more about the disease.

Books for Kids

The Secret Life of Lincoln Jones
Author: Wendelin Van Draanen
Publisher: Knopf Books for Young Readers, 2016

Weeds in Nana's Garden
Author: Kathryn Harrison
Flipturn Publishing, 2016

Still My Grandpa
Author: Véronique Van den Abeele
Illustrator: Claude K. Dubois
Publisher: Eerdmans Books for Young Readers, 2007

Graduation of Jake Moon
Author: Barbara Park
Publisher: Aladdin, 2002

Memory Box
Author: Mary Bahr
Illustrator: David Cunningham
Publisher: Albert Whitman Concepts, 1992

Wordsworth Dances the Waltz
Author: Frances H. Kakugawa
Illustrator: Melissa DeSica
Publisher: Watermark Publishing, 2007

Why Did Grandma Put Her Underwear in the Refrigerator?
Authors: Max Wallack, Carolyn Given
Publisher: CreateSpace, 2013

Books for Teens

Curveball: The Year I Lost My Grip
Author: Jordan Sonnenblick
Publisher: Scholastic Paperbacks, 2014

The Dementia Diaries: A Novel in Cartoons
Author: Matthew Snyman and Social Innovation Lab, Kent
Publisher: Jessica Kingsley, 2016

The Human Brain: Inside Your Body's Control Room
Author: Kathleen Simpson
Publisher: National Geographic, 2009

Neurocomic
Author: Hana Ros
Illustrator: Matteo Farinella
Publisher: Nobrow Press, 2014

Pop
Author: Gordon Korman
Publisher: Blazer and Bray, 2011

Trudy
Author: Jessica Lee Anderson
Publisher: Milkweed Publishing, 2005

When the Brain Dies First
Authors: Margaret Hyde, John Setaro
Publisher: Franklin Watt, 2000

Source: Alzheimer's Association alz.org

Get Involved

We ask that you help us by sharing this critical information with your partners, clients, and members. If you have any questions, please let us know. Do you have a resource that we haven't listed? Do you believe your agency should be included? Do you have any testimonies that we could include? We are welcoming any and all suggestions on how this toolkit can continue to evolve. Please email your suggestions to us at alz@elderaffairs.org.

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Tallahassee, Florida 32399-7000

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