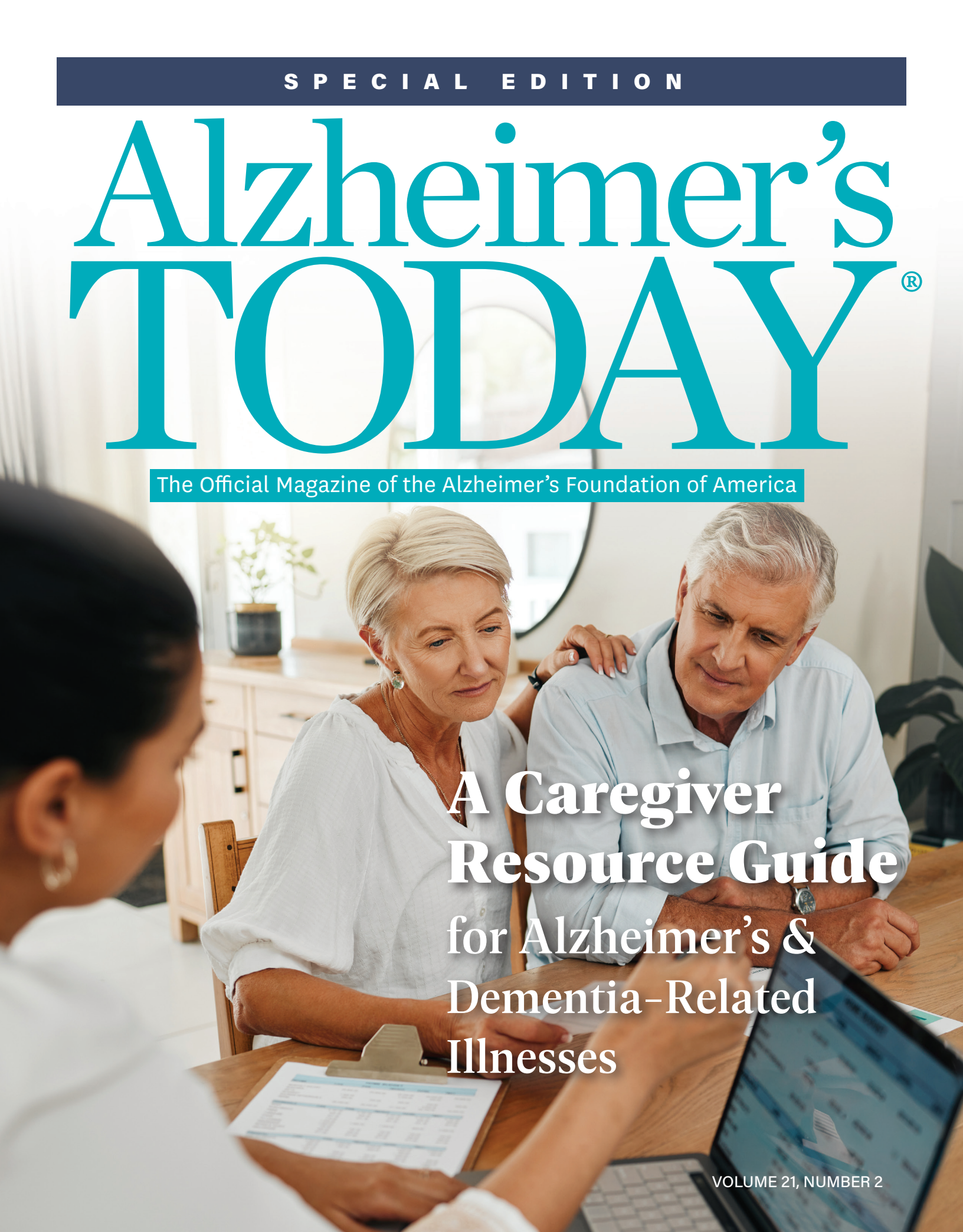
SPECIAL EDITION

Alzheimer's TODAY®

The Official Magazine of the Alzheimer's Foundation of America



A Caregiver Resource Guide for Alzheimer's & Dementia-Related Illnesses

VOLUME 21, NUMBER 2

A Message from our President & CEO

The Alzheimer's Foundation of America (AFA) created this special edition resource guide to provide you with clear, reliable information and practical support at every stage of the Alzheimer's journey. Whether you are seeking guidance following a diagnosis, caring for a loved one each day or planning for future legal and financial needs, this guide is designed to help you feel informed, prepared and empowered. We hope it serves as a trusted companion that you can return to whenever you need support.

Important topics covered in this guide include:

- Understanding Alzheimer's disease
- Steps to take after a diagnosis
- Legal planning
- Financial planning
- Safety
- Daily & long-term care
- Behavioral and emotional care
- Coping with the later stages
- Alzheimer's science and research

As you use this guide, we hope you find not only answers but also reassurance in knowing that a network of support, expertise and compassion stands beside you.

The Alzheimer's Foundation of America was founded by a caregiver who believed that no family should have to face this journey alone. Today, we remain committed to supporting individuals, families and caregivers every step of the way.

Most importantly, please remember to take care of yourself. Your health, strength and peace of mind are essential — not only for your own well-being, but also in helping you continue to provide love, support and care to those who depend on you.

With compassion and support,

Charles J. Fuschillo, Jr.
President & CEO
Alzheimer's Foundation of America

AFA is here for you.
alzfdn.org

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Go to alzfdn.org/tribute/

Publisher
Alzheimer's Foundation of America

Editor in Chief
Karen Mazzotta

Writer/Editor
Retta Blaney, M.A., M.F.A.

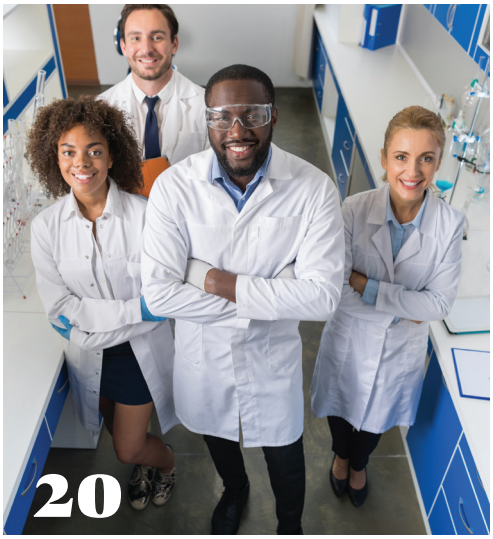
Editorial Assistant
Jada Angel

Design
The Monk Design Group

Photos
Dreamstime.com

322 Eighth Avenue, 16th Floor, New York, NY 10001
866-232-8484

Inside the AFA Resource Guide



Understanding an Alzheimer's Diagnosis

What is Alzheimer's?

Alzheimer's disease is a progressive brain disorder that impacts memory, thinking and language skills, and the ability to carry out the simplest tasks. It is the most common form of dementia. Other types include vascular dementia, Lewy body dementia and frontotemporal dementia. Dementia itself is not a disease, but a term used to describe symptoms such as loss of memory, loss of judgment and other intellectual functions. More than 7.4 million Americans live with Alzheimer's disease. This number is projected to nearly double to over 13 million by 2050.

Alzheimer's stages

The Alzheimer's Foundation of America uses the National Institute on Aging's framework, which describes Alzheimer's disease in three stages: early (mild), middle (moderate), and late (severe).

Early (mild)

In this stage, people may still be working and even driving, but may begin to have more trouble making sense of the world around them. Alzheimer's is often diagnosed in this stage. Problems can include:

- Memory loss that disrupts daily life
- Difficulty finding the right word or names
- Misplacing objects, particularly in odd places
- Forgetting something they just read
- Asking the same question repeatedly
- Trouble making plans or organizing, such as handling money or paying bills
- Confusion about time and place
- Getting lost or wandering
- Mood, personality and personal hygiene changes

Middle (moderate)

In this stage, an individual can still participate in some daily activities, with assistance, but will increasingly need more support. Symptoms may include:

- Increased confusion and memory loss
- Problems recognizing family and friends
- Problems with reading, writing and working numbers
- Repeating stories, favorite wants or motions
- Requiring assistance in choosing proper clothing
- Changes in sleep patterns, such as sleeping more during the day and being awake at night
- Withdrawal from social activities
- Restlessness, agitation, anxiety, tearfulness, especially in late afternoon or evening (sundowning)
- Hallucinations, delusions and paranoia

Late (severe)

In this stage, individuals with Alzheimer's cannot communicate and are completely dependent on others for their care. Near the end of life, the person may be in bed most or all of the time as their body shuts down. Symptoms include:

- Inability to communicate
- Weight loss with little interest in eating or drinking
- Difficulty swallowing
- Increased sleeping
- General physical decline, including dental, skin and foot problems.
- Loss of bowel and bladder control
- Seizures

Taking the First Steps Toward Support

A diagnosis of Alzheimer's or another memory-related condition can feel overwhelming. Shock, sadness or uncertainty are natural, and it's okay to take time to process the news. When you feel ready, consider sharing with people you trust. Building a small circle of support can help you feel less alone. These are the first steps on your journey.

Tell family & friends

Share the news as soon as possible. Some people want to tell everyone face-to-face. Others choose to share the news in a group email. Include the person diagnosed in the sharing process if you can. But that may not be possible, for various reasons, including denial (lack of awareness may be part of the disease). The sooner you tell others, though, the sooner you'll be able to get support. Others may already have sensed that something is wrong, so the diagnosis will create understanding. Explain briefly what Alzheimer's is and how it will progress over the years. Your person will have memory loss, difficulty following through on a task and may forget who they are over time. You always want to focus on the strengths that your loved one still has and the enjoyment you can have from spending time together.

Be proactive about encouraging others to visit. Social interaction improves the quality of life for individuals living with Alzheimer's and their care partners. Share the best time of day to see others. If you can't meet in person, encourage virtual visits on Zoom or FaceTime. To manage those who offer to help, create a care calendar for friends and family in a Google Doc.

Support interaction. Remind others of the activities your person is still able to do (have coffee, play a game, listen to music, do simple crafts, sit or walk in nature).

Assist with communication. Provide suggestions on how to greet a person with Alzheimer's, which may involve introducing yourself: "Hi Mary. I'm Jim." Ask visitors to avoid correcting the person. Instead, suggest they simply respond to ideas and feelings expressed. Remind them not to take lack of recognition or anger personally. The person living with Alzheimer's is responding to confusion in their brain.

Build a care team

A care team is a network of family members, friends and health and medical professionals who help support a person's daily needs. One of the first, and often most difficult, steps in building a care team is asking for help.

While it may feel hard to involve others or worry about being a burden, the reality is that no one can support a person living with Alzheimer's alone. Sharing responsibilities is essential to building a strong care team, one that provides the person with Alzheimer's, and their primary care partner, the understanding, assistance and support they need along the journey.

A care team is most effective when it includes three to five people and begins with one primary, trusted individual. Start by having an open conversation about specific needs, which may include grocery shopping, preparing meals together, going for walks, or simply spending time with the person living with Alzheimer's to give the main care partner time for rest and renewal. Look into an adult day program, in-home care, as well as memory cafes, social gatherings where people living with memory loss and their care partners can meet and enjoy time together.

As needs change, responsibilities within the care team may shift and evolve. Over time, the care circle will likely expand to include additional healthcare professionals and community resources as Alzheimer's progresses.

You are not alone. Caregiver support is available.

- **The Alzheimer's Foundation of America (alzfdn.org)** offers a 7-day-a-week, toll-free Helpline. You can speak with a licensed social worker via phone **(866-232-8484)**, text **(646-586-5283)** or webchat at **alzfdn.org**; text and webchat are available in 90+ languages. Connect anytime with Allison, our friendly 24/7 virtual assistant who can answer hundreds of questions.

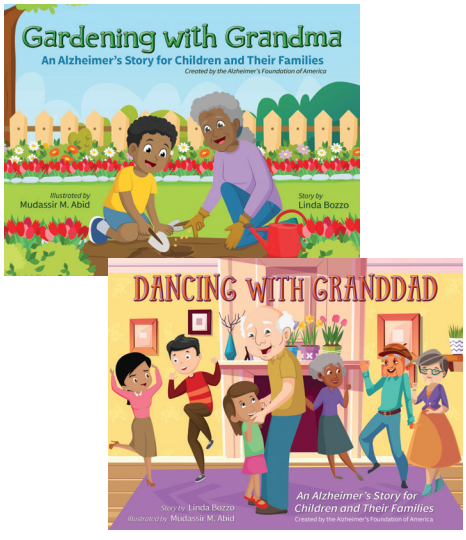
  AFA provides resources **(alzfdn.org/caregiving-resources)**, including factsheets about various topics, a monthly free Care Connection webinar series and free Educating Across America Tour conferences **(alzfdn.org/tours)**; an *Alzheimer's TODAY* quarterly magazine **(alzfdn.org/media-center/alztoday)**, memory screenings **(alzfdn.org/get-a-free-screening)** and more.

- **The Eldercare Locator (eldercare.acl.gov or 800-677-1116)** will guide you to your local Area Resource Agency on Aging, offering services, resources and information for care partners.

- **The National Institutes of Health Alzheimer's site (alzheimers.gov or 800-438-4380)** provides caregiver resources, training, advocacy and clinical trial information.

Talking with young children

AFA created *Dancing with Granddad* and *Gardening with Grandma* (for ages 5-8), in English and Spanish, to help families begin a conversation about dementia with a child. These books can be ordered through AFA's e-store at **shop.alzfdn.org** or by calling **866-232-8484**.



Legal Planning: Peace of Mind for the Road Ahead

Early planning is crucial when it involves the care of a person with Alzheimer's disease and other dementia-related illnesses. The most important reason to plan early is simple: a person must have legal capacity to sign any official document. This enables them to have input on important decisions regarding their life. When legal documents are completed later in the progression of dementia, their validity may be questioned or even challenged in court — a process that can be expensive, emotionally draining and create painful divisions within families.

Dementia progresses differently for every individual, making it difficult to predict how quickly abilities will change or what types of care will eventually be needed. What is certain, however, is that care needs increase over time and often rise beyond what families can realistically manage at home. Early planning helps ensure that the person's wishes are honored and gives caregivers the time and clarity needed to prepare for long-term care options before decisions become urgent.

Because the issues involve the care of a person as well as their property, it's important to consult an elder law attorney. They can help navigate these complex decisions and give current advice. Legislation regarding these matters changes almost yearly.

A good elder law attorney will help assess your family's medical needs and align your finances with a long-term care strategy. This planning includes preparing legal documents, such as powers of attorney, wills and trusts. An early assessment of your family's situation can make a significant difference in the ability to obtain quality care and, more importantly, in making informed choices about how and where that care is delivered.

The National Elder Law Foundation (NELF) is the only national organization accredited by the American Bar Association to certify practitioners in elder and special-needs law. NELF's Certified Elder Law Attorney (CELA) designation confirms a lawyer's exceptional expertise in this specialized field. To find recommendations, visit **www.nelf.org**.

If you cannot afford an eldercare lawyer, you can access free legal aid through **LawHelp.org**, an online directory that lists local legal aid programs in every state and U.S. territory; **Legal Services Corporation (lsc.gov)**; **USA.gov (usa.gov/legal-aid)**; the **American Bar Association** through **ABA Free Legal Answers (abafreelegalanswers.org)**, a virtual clinic where qualifying low-income individuals can post civil legal questions; and the **National Legal Aid & Defender Association (nlada.org).**

The Legal Documents That Safeguard Decision-Making

Everyone, especially when cognitive health may be a concern, should have a basic set of essential legal documents in place. Two of the most important are a **power of attorney (POA)** and a **health care proxy** (also called a **medical power of attorney**).

These documents are often more important than a **will** in the early stages because they apply while you are still living. Known as **advance directives**, they allow you to designate a trusted person to make financial or medical decisions on your behalf if you are unable to do so yourself. Having these safeguards in place protects your autonomy, reduces stress for loved ones and ensures your wishes are honored when it matters most. The **will** states how a person's property and assets should be distributed after death.

The Durable Power of Attorney (POA)

This is the most critical document for planning for incapacity. It is where we appoint a trusted person (friend, family member or lawyer) to handle our financial affairs on our behalf. Only a **durable POA** stays in effect after the principal has become mentally incapacitated. A **nondurable POA** is used in specific, short-term tasks, such as appointing an agent to close on a house for you in another state, but it ends on the completion of the task or if you become mentally or physically incapacitated. The POA does not cover medical decisions.

Health Care Proxy

Medical decisions are covered in a **health care proxy**. This document appoints a trusted person to make medical decisions for you when you can no longer make them for yourself. This could be about surgery, medications, life-sustaining treatments or anything health-related.

Living Will

A **living will** is a document detailing specific preferences for end-of-life medical care and treatments (e.g., life support such as feeding tubes, ventilators or resuscitation; organ and **brain donation***). Due to the progressive nature of dementia, early planning is crucial. This will reduce the burden on family members who might otherwise struggle to make these decisions in line with your wishes.

***A single donated brain** can support hundreds of research studies that will contribute to helping advance scientific understanding of Alzheimer's and other dementia-related illnesses. It can also confirm a diagnosis. Among the many places to donate are **Alzheimer's Disease Research Centers**, congressionally designated centers of excellence that support the nation's increased effort to address Alzheimer's. You can find centers in your state, and information about donation, at **Alzheimers.gov/taking-action/national-research-centers**.

A Will

A **will** spells out what you want to do with your money, property and other assets after death, and appoints an executor to manage your estate. You can give assets outright or put them in a trust for a particular person.

Guardianship & Conservatorship

Guardianships (or conservatorships) are court-appointed arrangements for people who can no longer manage their own finances or medical decisions due to incapacity, such as Alzheimer's. They're necessary when someone hasn't completed planning documents — like a durable power of attorney or health care proxy — that would otherwise authorize someone they trust to act for them.

A guardianship can be initiated by a family member, friend, hospital or nursing home. After a hearing, a judge decides whether the person is incapacitated and then appoints a guardian, who may or may not be someone the person knows, to make decisions on their behalf. Guardianships aren't inherently negative. They are critical safety nets when no planning has been done. But they often lack the most important perspective: the wishes of the person whose life will be affected.

Managing Changes in Behavior

Neuropsychiatric symptoms (NPS)

Just as people living with Alzheimer's and other dementias may develop impairments that affect memory, communication and reasoning, they often experience changes in mood and personality that can lead to troubling or disruptive behaviors. Research shows that nearly all individuals with dementia will eventually develop these changes. Known as neuropsychiatric symptoms (NPS), they are the non-cognitive, behavioral manifestations of dementia. Importantly, these symptoms can appear even before a formal diagnosis of a neurocognitive disorder — and may be among the earliest signs.

Common NPS symptoms

- apathy
- depression
- irritability
- agitation and aggression
- psychosis: delusions, perceptual errors and hallucinations
- motor activity and wandering
- sleeping and eating disorders

Treatment options

The first step in accessing appropriate care is to consult a qualified dementia healthcare provider for a comprehensive evaluation. This may include a geriatrician, neurologist or geriatric psychiatrist.

For mild cases, non-pharma approaches should be tried first: music therapy, aromatherapy, exercise or physical therapy, pet/animal therapy and, for some, psychotherapy. If these fail or if symptoms are persistent or severe, medications may be necessary.

All medications carry risks that need to be discussed and weighed against possible benefits. Dementia-focused providers, especially geriatric psychiatrists, may recommend medications from the antidepressant class (selective serotonin reuptake inhibitors, SSRIs) or from the atypical antipsychotic class. Though often effective, use of antipsychotics is generally a last resort and should be approached with caution, as these have been associated with an increased risk of death. Use of sedative hypnotics should generally be avoided as they often worsen confusion and cause falls.

Clinical trials

Experimental non-antipsychotic medication clinical trials are ongoing. Information about where these are offered and how to begin the process of enrollment can be found at **alzfdn.org/clinical-research-trials.**

Care partners need care

Although these behaviors, collectively referred to as NPS, contribute directly to caregiver stress and burnout, they can often be successfully addressed by working with professionals using a variety of intervention approaches. Seek support, guidance and resources by contacting the **AFA Helpline**, staffed by licensed social workers trained in dementia care, available 7 days a week by phone **(866-232-8484),** text **(646-586-5283)** or webchat at **alzfdn.org.**

Caring At Home

Alzheimer's disease and other memory loss conditions often gradually affect everyday activities, making once simple routines more challenging and increasing the need for support and patience from care partners.

Dressing

In the early stages, a person may benefit from simple reminders, such as where they left their shoes. As the condition progresses, they may need more supervision and hands-on assistance. A supportive, person-centered approach can help preserve independence and dignity while reducing stress.

Helpful tips

- **Allow extra time.** Dressing can become confusing or overwhelming. If needed, hand your loved one each item of clothing one at a time, in the order it should be put on.
- **Offer simple choices.** For example, say "Would you like the blue sweater or the green one?" Whenever possible, choose favorites in preferred colors, fabrics and styles.
- **Pay attention to behavior.** Changes in behavior may be a form of communication. If your loved one resists certain clothing or removes it at inappropriate times, it may signal discomfort, such as pain, overheating, rash or infection.
- **Choose comfortable clothing.** Select soft, non-restrictive garments. Tagless clothing and flat seams can help reduce irritation and pressure points. Check regularly for signs of discomfort.
- **Prioritize ease and function.** Clothing that is easy to put on and remove can make dressing less stressful. Adaptive designs, such as back openings or simplified fastenings, can help.
- **Use reassuring body language.** Stand beside — not directly in front of — the person to help them feel supported, not confronted. Gentle touch, eye contact and a calm presence can provide reassurance and build trust.

Bathing

Personal hygiene, once a familiar routine, can become confusing, disorienting and even distressing. Tasks such as washing hands, brushing teeth, shaving and nail care may become difficult. Bathing, in particular, is highly personal, and your loved one may feel embarrassed, frustrated by a loss of independence or believe they have already bathed. They may not recognize the need for help.

Start by encouraging your loved one to do as much as they can, offering gentle support only when needed so they still feel in control. Focus on one area of the body at a time, use a calm and reassuring tone and involve them throughout the process whenever possible.

Helpful tips

- Establish a consistent routine that reflects their past preferences (time of day, frequency).
- Ensure the bathroom is safe, with grab bars and a shower chair.
- Provide as much privacy as possible.
- Encourage choice, such as selecting towels or clothing.
- Make sure the room is warm before undressing.
- Prepare ahead of time. Have soap, towels and supplies within reach.
- Use soft, gentle products to avoid skin irritation.
- Always test the water temperature.
- Keep showers brief. Wash the most important areas first.
- Limit bathing to a manageable frequency (e.g., about three times per week).
- Consider alternatives such as a bath with assistance or sponge bathing.
- Demonstrate or guide the steps if needed.
- Involve a trusted family member, especially if your loved one prefers help from someone of the same gender.
- Create a calming environment with soothing music or pleasant scents.
- Offer a favorite snack or activity (e.g., TV) afterward.

Eating & Drinking

As dementia progresses, eating and drinking can become more challenging, making proper nutrition a concern. A thoughtful approach can help support nutrition while preserving dignity and comfort.

Helpful tips

- **Keep a consistent routine.** Sequencing the steps involved in eating may become difficult and interest in food may decline. Eating at the same time and place each day can provide structure, comfort and a sense of security. If your loved one lives alone, use reminders to prompt meals.
- **Make mealtime appealing.** Turn food preparation into a social activity. Invite your loved one to help with simple tasks, such as setting the table or folding napkins. Familiar foods and their aromas can stimulate appetite and evoke positive memories.
- **Include favorite foods.** If your loved one becomes focused on a particular meal, that's okay. It's often more important that they eat something rather than nothing at all. Still, aim for balance and nutrition when possible.
- **Keep it simple.** Make meals easy to manage by offering one item or course at a time. A crowded plate can feel overwhelming.
- **Use appropriate utensils.** A spoon may be easier to use than a fork. Consider adaptive utensils, such as weighted cutlery, to help with grip and reduce tremors. Pre-cut foods and finger foods can also make eating easier.
- **Watch for swallowing problems.** Trouble speaking may signal difficulty swallowing. Offer food slowly, making sure each bite is swallowed before the next. Keep a drink nearby. Consult a healthcare professional about the right food textures when needed.
- **Make meals social.** Sit and eat together when possible. Mealtime can be an opportunity for connection, conversation and gentle support.

Incontinence

Dementia often leads to bladder and bowel changes that can be distressing for both the person and the caregiver. These challenges are caused by changes in the brain that affect the ability to recognize the need to use the bathroom or control these functions.

Some individuals experience functional incontinence, meaning they recognize the urge but cannot reach the bathroom in time. This may be due to memory loss (forgetting where the toilet is), confusion (mistaking other spaces for a toilet), mobility issues, difficulty communicating needs or trouble removing clothing quickly.

Helpful tips

- **Help them remember.** Establish a regular bathroom schedule to ensure that the bladder is emptied frequently. If you're going out in public, plan time for bathroom stops.
- **Use easy-to-remove clothing.** Elastic waistbands rather than buttons and zippers and adaptive pants with alternating waist and leg openings make frequent restroom visits easier.
- **Keep pathways clear.** Make sure the door to the bathroom is open and the light is on.
- **Limit fluids in the evening.** This makes overnight accidents less likely. Try putting a portable commode near your person's bed.
- **Use protective undergarments and bed pads.** They can help manage accidents and protect skin.

- **Approach the situation with patience and understanding.** Reassurance, gentle reminders and a calm tone can help the person feel more comfortable.

Keeping Your Person Safe

Creating a dementia-friendly home

Almost every part of a home can impact the quality of life and safety of someone living with a memory loss condition. People with Alzheimer's have increased fall risk due to balance issues, impaired depth perception, inability to recognize danger and medication side effects. Even seemingly cosmetic choices like color schemes, furniture patterns and dishware make a difference, but most residences are not built with these needs in mind. AFA created The Apartment, a model, full-scale dementia-friendly studio residence built as a teaching tool to help families learn how to make a home safer and more comfortable. Located in AFA's New York City headquarters, it can be visited virtually any time at **alzfdn.org/theapartment**. Along with the video tour, a 20-page companion guide, available in electronic and print formats, takes individuals through each room.

Watch for wandering

Wandering is one of the most common behaviors among people living with Alzheimer's. It often stems from an unmet need or desire for purpose and sometimes is a form of communication. Individuals may leave their homes because they believe they need to go to work, even if they are retired. Others are looking for something or someone.

What you can do

- Pay attention to your person's patterns — frequency, duration, time of day — and prepare activities (socialization or recreational) that can be used to redirect their attention. Ensure basic needs (hunger, thirst, restroom) are met.
- Know the individual's past and present favorite spots in the neighborhood. If they wander from home, this will help in your search.
- Know the individual's phone carrier and number to track them by phone.
- Install a motion paging system by their bedside or door. When a motion is detected, a silent wireless signal is sent to the care partner.
- Install video doorbells to alert a care partner when someone is approaching or leaving the home.
- Use medical identification bracelets, necklaces and tracking devices for monitoring. Check whether your municipality has a **Project Lifesaver program (projectlifesaver.org, or call 877-580-LIFE).** Project Lifesaver uses locating devices to aid in the search and rescue of individuals.
- Familiarize yourself with your state's public alert (Silver Alert) service, a notification system that broadcasts information about missing persons to solicit aid in locating them.
- Understand how to contact your police department and call 911 in an emergency.

Driving

Conversations about giving up driving usually happen in the first to middle stages of dementia, when the person may not fully understand what's happening. That is why it's important to have these conversations well before driving stops.

Warning signs that it may be time to stop driving include getting lost while driving alone, fender benders and traffic violations. Earlier signals may include reduced confidence or deferring driving to a partner. Note that tasks like making left turns — which require higher executive function — can be especially telling. Care partners can ask themselves, "Would I let my children ride with this loved one?"

Nathaniel Chin, M.D., a member of the AFA medical advisory board, recommends involving a healthcare provider in the conversation, if needed. While physicians can't assess driving ability directly, they can refer patients to occupational therapists who can and make recommendations about safety. Families should plan for alternatives, such as car services or rides from family, friends or neighbors. If all else fails, you could tell a person the car is under repair and have it removed from the home. Safety first.

TIP: Be Prepared for Any Hospital Emergency

Prepare "go bags" with ID, medications, comfort items, tips for health care providers and doctors' contact information. The experience could be challenging for the person and the staff caring for them.

Comfort & Connection with Activities

Enhancing the day-to-day experience of those with memory loss is at the heart of care. These trusted activities for all stages of progression will encourage engagement and a sense of belonging.

Music

Music can be a powerful way to connect with someone experiencing memory loss. It often sparks meaningful memories and emotions, especially when the songs are familiar or spiritual.

- Add music throughout the day. Play favorite songs during daily routines: on the way to appointments, at mealtimes or during moments of anxiety. Creating different playlists can be helpful, such as one for calming agitation and another for lifting mood.
- Encourage gentle movement. Invite light dancing or swaying to the music. Mirroring their movements can foster connection and create a comforting sense of togetherness.
- Engage with rhythm. Clap, tap on a table or use simple items like pots, pans or wooden spoons to follow the beat. If they have a musical background, offering familiar instruments can deepen the experience and enjoyment.

Early- to middle-stage

- Offer comfort through nurturing. Pets, especially dogs and cats, can provide comfort at every stage. If real pets aren't possible, consider stuffed animals. For parents, baby dolls can be especially meaningful, as the instinct to nurture often remains and can evoke memories of caring for others.
- Incorporate familiar tasks. Activities tied to past roles can offer comfort and purpose. An accountant may enjoy writing checks; a former building superintendent might appreciate fixing a loose screw. Simple household tasks, such as folding towels, matching socks, sweeping, drying dishes or sorting coins, can also be engaging.
- Take mindful walks. Visit a favorite location and turn it into a gentle scavenger hunt by looking for simple items, such as a dog, a flower, or a stop sign.
- Reconnect through photos. Spend time exploring photo albums together to spark recognition and conversation.
- Encourage light movement. Toss a balloon back and forth for a simple, enjoyable activity.
- Engage with nature. Spend time in a garden or with indoor plants. Plant seeds and watch them grow or create small bouquets from flowers or greenery.
- Play simple brain games. Activities such as Sudoku, Hangman or word association (e.g., naming items that begin with a certain letter) can provide gentle mental stimulation.
- Create a reminiscence box. Fill it with photos, keepsakes and favorite items to encourage memories and conversation.
- Provide soothing tactile activities. Fidget blankets made from quilts, towels or aprons with ribbons, buttons and zippers can safely help occupy restless hands.
- Introduce guided relaxation. Gentle meditation can promote calm and add structure to the day.
- Try shared storytelling. When younger generations are present, create a story together. This removes pressure and may bring back meaningful memories.
- Explore creative expression. Set aside time for drawing, coloring, painting or collage-making. Offer simple guidance, create alongside them and celebrate their efforts.

Late stages

- Be present. Sit together, listen to music, and, if welcomed, hold their hand to provide comfort and reassurance.
- Foster familiarity through sound. Read aloud or play recordings of favorite songs, stories, poems or familiar voices.
- Provide comforting touch. Holding a soft object, such as a blanket, can provide soothing tactile stimulation and a sense of security.

When Extra Help is Needed at Home

When caring for a person with Alzheimer's or another form of dementia, there often comes a time when in-home support is essential for safety, well-being and your own balance as a caregiver. While family and friends may help, you may choose to hire professionals such as personal care or home health aides or companions. If your person is resistant, start with short-term help and present aides as companions for enjoyable activities or small chores, helping preserve a sense of independence. A written recommendation from a trusted professional, such as a physician, can also ease the transition.

Finding Care

Local referrals from friends and family, social workers and doctors' offices are all ways to begin your search for home aides. Some reliable, national-level resources:

- **The Eldercare Locator (eldercare.acl.gov):** Search by ZIP code or call the national helpline at **800-677-1116.**
- **Community Resource Finder (communityresourcefinder.org)**
- **Medicare (medicare.gov/care-compare)** will provide short-term, part-time care for a limited number of hours and days based on its assessment of your situation and specific eligibility requirements. When appropriate, Medicare provides visiting nurses and physical, occupational and speech therapy.
- **Medicaid (medicaid.gov)** can provide support for those who qualify based on income, assets, and level of need, often through Home and Community Based Services (HCBS) programs.

Q. Can family caregivers get paid to take care of a family member?

A. Medicaid (**medicaid.gov**) is the primary way family caregivers can get paid. Many states offer self-directed programs that allow the care recipient to choose their caregiver, including adult children, relatives and sometimes spouses. If the care recipient is a veteran, the VA Caregiver Support Program (855-260-3274) may provide a stipend and training. In some states, paid family leave may be available from an employer as short-term wage replacement while employees take time off. Other options include long-term care insurance or personal agreements between family members.

In-home aides can provide:

Personal care
Household support
Companionship
Monitoring
Errands
Respite for caregivers

Get help with care planning

A geriatric care manager (also called an aging life care professional) is a trained expert who helps older adults and their families navigate care decisions, coordinate services and plan for changing needs over time. They are often social workers or licensed nurses who serve as private advocates, helping families navigate the increasingly complex responsibilities of caring for a loved one with dementia — and they can be particularly helpful to caregivers who live out of town. Cost is paid privately. Families are encouraged to verify credentials when seeking a qualified care manager.

Find local help through the **Aging Life Care Association (aginglifecare.org, 520-881-8008)**, where you can search by ZIP code, city or state. Geriatricians, neurologists, memory care programs, and hospital social workers may also be good sources for referrals.

As Needs Increase: Considering Long-Term Care

There may come a time when your loved one needs more support than can be comfortably provided at home. Although exploring long-term residential care can seem overwhelming, it can also lead to a safe, supportive environment with meaningful daily activities. Visiting assisted living communities, nursing homes and memory care units can help you find the right fit.

When long-term care may be needed

- **Safety at home is compromised (walking difficulties, wandering, forgetting to turn off stove)**
- **Medical or cognitive needs outgrow home support**
- **Daily-living activities require continuous help (bathing, eating, dressing, toileting)**
- **Caregiver stress becomes unsustainable**
- **A physician advises a higher level of care for safety**

Facility Tours: Questions to ask

- What services are included in the base monthly rate? What additional services are available if needs increase?
- Does the facility have a secure, specialized section for Alzheimer's or persons living with dementia?
- What is the staff-to-resident ratio, including at night? What training do care providers have?
- How often is an RN on site? What is the policy on the use of medications?
- Observe the facility for cleanliness, maintenance and dining quality. Request to see the most recent state inspection survey and plan of correction.
- What does the daily routine look like? Request to see menus and activity calendars.
- Can you visit multiple times, without scheduling ahead, to see how things run at different times?
- For privately funded facilities, ask what happens if your funds run out. Will the facility accept Medicaid or would a move be required?*

*Planning ahead is important if funds are limited and a move is needed, since many well-regarded facilities that accept Medicaid have waiting lists.

How to search for a long-term care facility

- **Medicare's Care Compare tool** (Medicare.gov/care-compare)
- **The Eldercare Locator** (eldercare.acl.gov)
- Your local **Area Agency on Aging**
- State or county **Department of Health** websites (e.g., Health.NY.gov, CalLongTermCareCompare.org, FloridaHealthFinder.gov)
- **U.S. News and World Report** rankings (health.usnews.com/best-nursing-homes)

You have an ombudsman

Each state runs a long-term care ombudsman program funded through the Older Americans Act. Long-term care ombudsmen are free, government-mandated advocates who protect the health, safety, welfare and rights of residents in nursing homes, assisted living facilities and residential care communities. They investigate complaints, mediate disputes between residents and staff and ensure resident rights are not violated. They work for the resident, not the facility.

To learn more, visit **The National Consumer Voice for Quality Long-Term Care (theconsumervoice.org/get-help)**. To find your local ombudsman, select your state from the **State List**.

Coping with the Last Stage – Grief, Palliative Care, Hospice Support

Alzheimer's and other forms of dementia do not follow a predictable path, making the end-of-life experience different for everyone. People can live with these conditions for years. Loved ones may push aside the reality of impending death. But grief may inevitably seep in. This is called anticipatory grief and is not uncommon.

Anticipatory grief is the emotional pain, anxiety and mourning experienced before an impending loss. It involves grieving future losses, witnessing the decline and, for loved ones, preparing for life after the loss. While it brings sadness and fear, it can also allow for closure, resolving regrets and expressing love.

How to cope

- **Acknowledge the feelings:** Accept that feeling sad or even angry while a person is still alive is normal, not disloyal.
- **Spend quality time:** Use the time to share memories, resolve conflicts and say goodbye.
- **Prepare practically:** Discuss end-of-life wishes and organize affairs.
- **Seek support:** Connect with counselors, support groups or trusted friends.
- **Practice self-care:** Engage in physical activity, journaling and breathing exercises to lower stress.

It is important to understand that anticipatory grief does not mean you will not feel grief again after the death; rather, it is a process of preparing for that moment.

Help for the final stages

As a serious illness progresses, care often shifts toward comfort, dignity and quality of life. Understanding the support available, including palliative care and hospice, can help families make informed, compassionate decisions during a difficult time.

Palliative care and hospice both improve quality of life for serious illnesses by managing pain and symptoms. The core difference is:

- **Timing:** Palliative care is available at diagnosis or any time during a serious illness; hospice is for the final months of life.
- **Curative treatment:** Palliative patients can continue treatments aimed at curing their illness; hospice patients generally forgo curative, aggressive treatment.
- **Location:** Palliative care is often in hospitals or clinics; hospice is commonly provided at home, nursing homes or specialized facilities.
- **Goal:** Both focus on comfort, but palliative care helps manage symptoms during active treatment, while hospice focuses specifically on comfort and quality of life at the end of life.

Similarities:

- Both provide comprehensive care, including physical, emotional and spiritual support.
- Both utilize interdisciplinary teams (doctors, nurses, social workers, chaplains).
- Both forms of care are designed to support not only the patient but also their family members.

Planning for the Financial Side of Care

It's important to understand that standard health insurance does not cover long-term disabilities, such as Alzheimer's disease. Many seniors are surprised to learn that once a person needs ongoing custodial care — assistance with daily activities like bathing, dressing, eating and supervision for safety — these services are considered non-medical. As a result, individuals and families must arrange and pay for long-term care themselves. Whether this care is provided at home, in an assisted living facility or in a nursing home, it is expensive. Families pay for these costs with personal funds, long-term care insurance (if they have a policy) or state programs (e.g., Medicaid) for those who qualify. Often, it's a combination of a few resources.

Medicare vs. Medicaid

Medicare and Medicaid are both government health insurance programs, but they serve different populations and cover different types of care.

Medicare	Medicaid
Who it's for	
▪ People age 65+ ▪ Younger people with certain disabilities or serious medical condition	▪ People with limited income and assets ▪ Includes many older adults and individuals needing long term care
Eligibility	
▪ Based on age or disability, not income ▪ Coverage is time limited for post hospital care	▪ Based on income, assets and level of care needed ▪ Rules and benefits vary by state
What it covers	
▪ Hospital care and doctor visits ▪ Limited skilled nursing facility care (short term only) ▪ Prescription drugs (Part D) ▪ Preventive and outpatient services	▪ Long-term nursing home care ▪ In-home and community-based services ▪ Personal care and supervision ▪ Medical care, prescriptions and therapies
What it does not cover	
▪ Long-term custodial care (help with bathing, dressing, supervision) ▪ Extended nursing home stays ▪ Most in-home personal care	▪ Room and meals in assisted living facilities or at home. (i.e., Medicaid helps pay for care, not the place you live, outside of nursing homes) ▪ A private room in a nursing home, unless it is medically necessary.
How they work together	
▪ Many people qualify for both programs ("dual eligibles") ▪ Medicare pays for medical care ▪ Medicaid pays for long-term care and services that Medicare does not cover, but only if you have limited assets.	

LEARN MORE

Consult with an **elder law attorney** or visit **Medicare (medicare.gov)**, **Medicaid (medicaid.gov)** and the **National Council on Aging (ncoa.org).**

Note: If someone other than the policyholder will need to access an account, the policyholder must sign a special form designating that person as their representative.

This is another reason why early planning is so important. It is best to establish a representative while the person with dementia still has the legal capacity to make that designation.

Ways to Manage Care Costs

Medicare GUIDE Program: Free Dementia Services

The Guiding an Improved Dementia Experience (GUIDE) program is a new Medicare initiative that provides free dementia care navigation and support services for eligible patients and their caregivers. This nationwide pilot began in July 2024 and will run for eight years, but it is not available in all locations.

Eligibility

- A dementia diagnosis
- Enrolled in Medicare Parts A and B
- Cannot reside in a long-term nursing home
- Cannot be enrolled in Medicare hospice or PACE
- Must live in a ZIP code within service area

Services provided

- 24-hour phone access to care navigators to help coordinate service needs
- Up to $2,500 annually in respite care to allow caregivers time to manage other responsibilities
- Education about the disease

Visit the **Centers for Medicare & Medicaid Services (cms.gov/priorities/innovation/innovation-models/guide)**

Program of All-Inclusive Care for the Elderly (PACE)

PACE is a combined Medicare and Medicaid program that provides comprehensive care and services to individuals who might otherwise need nursing home care, available in select states and communities.

How it works

- Provides medical care, social services and long-term care support
- Designed to help individuals continue living at home

Coverage options

- Available in select states and communities
- Services are coordinated through a local PACE organization
- Eligibility is based on age, health needs and ability to live safely in the community

Contact **Medicare at 800-663-4227** or visit the **PACE page** on **medicare.gov**

State Health Insurance Assistance Program (SHIP)

SHIP is a national program available in every state that provides free, one-on-one counseling and assistance with health insurance questions.

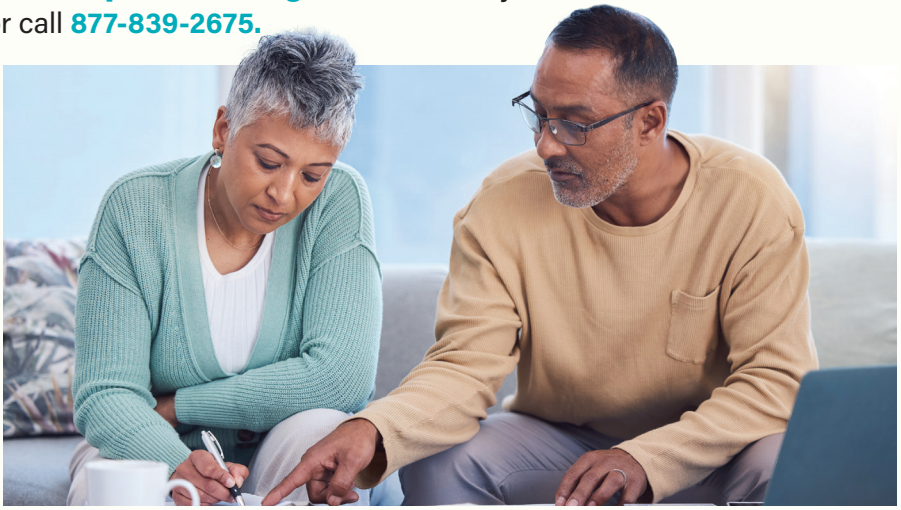
How it works

- Offers personalized guidance on Medicare, Medicaid and Medigap coverage

Services include

- Assistance with eligibility and enrollment
- Support with claims, billing issues and appeals
- Guidance tailored to your family's specific needs

Visit Shiptacenter.org/SHIPs to find your local SHIP office or call **877-839-2675.**



Ways to Manage Care Costs

Department of Veterans Affairs (VA)

The U.S. Department of Veterans Affairs (VA) offers healthcare and long-term care services to eligible veterans.

How it works

- Provides coverage for care in a facility or at home
- Services may include nursing home care, assisted living and in-home support
- Eligibility is based on military service, health needs and other factors

Services include

- Long-term care in VA facilities or approved community settings
- Home- and community-based services
- Care coordination through VA medical centers

Contact **VA Health Care Benefits, 877-222-8387 (va.gov/health)**

National Council on Aging (NCOA)

The NCOA offers a free service called Benefits CheckUp to help older adults find federal and state programs that may assist with everyday expenses.

How it works

- Complete a brief questionnaire about the person who needs care
- Receive a personalized list of benefit programs to explore
- Programs may help with prescription drugs, heating bills, housing, meals and legal services

Go to **NCOA's benefitscheckup.org.** For additional federal, state and local benefits, go to **benefits.gov** or call **800-FED-INFO (800-333-4636).**

Social Security Administration

The Social Security Administration offers financial assistance through two programs: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

How it works

- **Social Security Disability Insurance (SSDI):** For individuals under 65 who meet the SSA's definition of disability, have worked in a Social Security-covered job and have a medical condition expected to last at least a year or result in death
- **Supplemental Security Income (SSI):** Provides monthly payments to adults 65 and older (or younger adults with disabilities) who meet income and resource limits

Key features

- SSDI applications can take 3–5 months
- "Compassionate allowances" expedite benefits for serious conditions, including early-onset Alzheimer's and other dementias
- SSI and SSDI help cover living and medical expenses for those with disabilities

Contact the **Social Security Administration (ssa.gov), 800-772-1213 (TTY: 800-325-0778)**

Life Insurance

Some life insurance policies can help pay for long-term care, offering financial flexibility when care needs arise.

Contact your **life insurance professional** or the **National Association of Insurance Commissioners (NAIC)** at **(content.naic.org)**

Ways to Manage Care Costs

Long-Term Care Insurance

Long-term care insurance helps cover the cost of services and support for individuals who need assistance with daily activities or ongoing care.

What it covers

- Help with activities of daily living (such as bathing, dressing and eating)
- In-home care services, assisted living facilities, nursing home care and palliative and hospice care

Contact the **National Association of Insurance Commissioners (content.naic.org)**, the **National Council on Aging (ncoa.org)** or the **National Institute on Aging (nia.nih.gov)**

Trusts

Trusts are legal tools that allow you to set aside and manage assets for future needs, including long-term care.

How they work

- You transfer assets (such as savings or a home) into a trust
- A trustee manages those assets according to your instructions
- Funds can be used to help pay for care or preserved for loved ones
- Some trusts may help you qualify for programs like Medicaid

Things to consider

- 5-year Medicaid look-back period on asset transfers

Contact your **elder law attorney** or **financial advisor**

Reverse Mortgages

A reverse mortgage is a special type of home loan that allows homeowners to turn part of their home's equity into cash — without having to sell their home.

How it works

- No monthly payments are required
- Loan is repaid when the homeowner sells the home, moves out or passes away
- Funds received are generally tax-free
- Money can be used for any purpose, including long-term care expenses

Other options

- Home equity loan
- Refinancing your current mortgage to lower monthly payments

Visit the **Consumer Financial Protection Bureau (consumerfinance.gov), 855-411-2372** or the **National Reverse Mortgage Lender's Association (nrmlaonline.org)**

Annuities

An annuity is a contract with an insurance company that converts your savings into a steady income, helping cover living and long-term care expenses.

Contact your **financial advisor** or the **U.S. Securities and Exchange Commission (investor.gov/introduction-investing/investing-basics/investment-products/annuities)**

Source: NIA.NIH.Gov

You may want to seek the counsel of an **elder law attorney**, **financial planner or investment advisor**. Learn more **at U.S. Securities and Exchange Commission (investor.gov), the National Association of Personal Finance Advisors (napfa.org)** or **FPA Planner Search (plannersearch.org).**

Advances in Science: A New Era of Hope

For many years, Alzheimer's disease has been one of the most challenging conditions to treat. Families have often faced a difficult reality: available medications could ease symptoms, but they could not slow the disease itself. Today, that reality is beginning to change. A growing wave of research is transforming how scientists understand Alzheimer's, and how it may one day be treated or prevented. While there is still no cure, recent advances are bringing new hope to individuals living with the disease and those who care for them.

Slowing progression

One of the most important breakthroughs is the development of disease-modifying treatments. Anti-amyloid therapies (e.g., lecanemab, donanemab) remove toxic plaques and can slow cognitive decline in early stages. Next generation versions aim to improve safety, convenience (e.g., injections or pills instead of infusions) and effectiveness. While these therapies are not cures, they mark a major shift: Alzheimer's may no longer be untreatable at its core.

Growing focus on prevention

Researchers now believe Alzheimer's may begin years or even decades before symptoms develop. Many studies are focusing on early intervention and prevention. Research continues to reinforce the role of healthy lifestyle choices, such as staying physically active, following a balanced Mediterranean-based diet and managing chronic conditions, such as diabetes and high blood pressure, in reducing risk or delaying onset.

A broader understanding

Alzheimer's is now viewed as a complex condition involving multiple changes in the brain — not just a single cause. In addition to amyloid, researchers are studying tau protein tangles, closely tied to memory loss; inflammation in the brain, which may accelerate damage; and breakdowns in communication between brain cells. This broader perspective is leading to new treatment approaches that target several factors at once, offering the potential for more effective care over time.

Detecting Alzheimer's earlier

Another major advance on the horizon is the ability to detect Alzheimer's much earlier, before symptoms

appear. New blood tests can identify biological signs of the disease now, helping doctors diagnose Alzheimer's more quickly and accurately. In the future, tests may also predict who is most at risk and how the disease might progress. Researchers now know that several genes are linked to Alzheimer's disease. Some increase the likelihood of the disease; others cause it (these are rare). But there are still others that appear to be protective.

Personalized approaches

The future of Alzheimer's care may be increasingly personalized. Scientists are studying how genetics and individual health factors influence the disease, with the goal of tailoring treatments to each person. Researchers are also exploring entirely new approaches, from metabolic therapies (e.g., improving brain energy production) to treatments that affect how genes function, reflecting a deeper understanding of how Alzheimer's develops.

A future filled with possibility

Today, hundreds of clinical trials are testing a wide range of new therapies, signaling unprecedented momentum in the field. While a cure remains the ultimate goal, progress is happening, and it is meaningful. To learn more, go to **alzfdn.org/clinical-research-trials**. For families, these advances point toward a future where Alzheimer's can be detected earlier, treated more effectively, and, one day, possibly prevented.

The Blood Tests

New FDA-approved blood tests for Alzheimer's are a game-changer for diagnosis. Less expensive and far less invasive than previous methods, these tests can detect early signs of amyloid plaques and tau tangles in the blood, biological markers that are strongly associated with Alzheimer's in the brain. An easier diagnosis can lead to earlier treatment and better care planning for everyone.

However, these blood tests are not stand-alone diagnostic tools. They are intended to be used alongside a person's medical history, cognitive assessments and other clinical evaluations, and are most appropriate for individuals who are already showing symptoms of cognitive decline.

Will insurance cover?

Private insurance and Medicare coverage for the new blood tests are evolving, with some FDA-approved tests, such as Fujirebio pTau-217 or Roche/Eli Lilly Elecsys pTau-181, seeing partial coverage while others are considered experimental, often costing hundreds of dollars out-of-pocket ($300-$1,200, depending on the test and the technology). It's best to confirm with 1-800-MEDICARE or your insurance provider if a specific test is covered.

"The field of blood tests for Alzheimer's is evolving rapidly," Jeremy Koppel, M.D., says. "Individuals who are experiencing a memory condition should contact their medical provider, the one who is managing their cognitive condition, whether that is your primary care physician, neurologist, geriatric psychiatrist or geriatric medicine specialist."

The proposed ASAP Act (Alzheimer's Screening and Prevention Act) aims to increase Medicare coverage for these blood tests. Alzheimer's is a growing public health crisis, with the disease currently impacting over 7.4 million Americans.

Jeremy Koppel, M.D., is co-director of the Litwin-Zucker Center for the Study of Alzheimer's Disease, Feinstein Institutes of Medical Research.

FDA-Approved Medications

Several prescription drugs are approved by the U.S. Food and Drug Administration (FDA) to help manage symptoms of Alzheimer's or slow its progression. Most work best in the early- to mid-stage, which is why the Alzheimer's Foundation of America recommends regular memory screenings to identify problems early. While treatments can help, there is currently no cure. When considering treatment, it's important to talk with a healthcare professional about what may be most appropriate.

Slowing progression

Lecanemab (Leqembi®) and **donanemab (Kisunla®)** are anti-amyloid intravenous (IV) infusion therapies for early Alzheimer's. These drugs can change the course of the disease in its early stage, giving people more time to remain independent. They reduce beta-amyloid plaques in the brain (one of the two key pathological features of Alzheimer's). While they do not reverse or stop the underlying disease process, clinical trials have shown that they are associated with a modest slowing of decline in cognitive and functional outcomes in some individuals. Each works differently and targets amyloid at different stages. Individuals receiving these medications require ongoing monitoring for potential side effects, including brain swelling or bleeding.

Reducing cognitive symptoms

For mild to moderate Alzheimer's

Cholinesterase inhibitors (donepezil/Aricept®, galantamine/Razadyne®, benzgalantamine/Zunveyl®, and rivastigmine/Exelon®) prevent the breakdown of acetylcholine, a chemical messenger important for memory and thinking. As Alzheimer's progresses, the brain produces less of this. These inhibitors may help stabilize or modestly improve cognitive and behavioral symptoms for a period of time.

For moderate to severe Alzheimer's

A glutamate regulator (memantine/Namenda®) is used to treat moderate to severe Alzheimer's by blocking the toxic effects associated with excess glutamate, a chemical messenger. It may help people maintain daily functions for a longer period (e.g., use the bathroom independently). Memantine may be prescribed alone or in combination with donepezil.

Other approved treatments for later stages include **donepezil**, the **rivastigmine patch**, and the combin-ation **memantine/donepezil (Namzaric®)**.

Managing behavioral symptoms

Behavioral symptoms such as agitation, anxiety, sleep problems and wandering are common. Experts recommend trying non-drug strategies first (routine, environmental adjustments, reassurance) and using medications only when symptoms are severe or distressing.

For insomnia

Suvorexant (Belsomra®) has been approved to address insomnia, tested in people with dementia, and shown in clinical trials to be effective for people living with mild to moderate Alzheimer's. Possible side effects include impaired alertness, worsening of depression and sleep-walking.

For agitation

Dextromethorphan-bupropion (Auvelity®) has been approved for the treatment of agitation associated with dementia due to Alzheimer's. It is a new first-in-class treatment for agitation, and a significant milestone since it is not classified as an anti-psychotic treatment (these have been shown to have more serious side effects).

Brexpiprazole (Rexulti®) has been approved for the treatment of agitation associated with dementia due to Alzheimer's. In addition to common side effects such as weight gain, sleepiness and restlessness, it is important to recognize the risk of extrapyramidal symptoms and other motor side effects, including parkinsonism, stiffness, tremor and akathisia. As with all antipsychotic medications, there is also an increased risk of death in older adults with dementia-related psychosis. Many atypical antipsychotic medications are used "off label" to treat dementia-related behaviors, but Rexulti® is the only one currently FDA approved for agitation in Alzheimer's.

Note: Rexulti® is not approved for the treatment of people with dementia-related psychosis without agitation.

Side effects and safety All medications can cause side effects. Doctors typically start with a low dose and increase gradually. Patients should be monitored closely, and any unusual symptoms should be reported promptly. Seek out the manufacturer's websites for more detailed information.

Healthy Habits Reduce Dementia Risk

Many people regularly practice good habits to protect their physical health but don't give much thought to developing practices that promote brain health. There is more evidence than ever that dementia can be delayed or prevented by modifying lifestyle habits. Allison B. Reiss, M.D., an associate professor of medicine at NYU Grossman Long Island School of Medicine and an AFA medical advisory board member, is passionate about raising awareness of how people can prevent cognitive decline.

Diet

The Mediterranean diet has long been recognized as increasing life expectancy. It also keeps our brains strong. Focus on eating plant-based foods (vegetables, fruits and olive oil), and lean meats such as chicken and fish. The most emphasis is placed on dark, green, leafy vegetables; berries; whole grains; and healthy, unsaturated fats (such as salmon, avocados, olive and nuts). It also consists of a low intake of sugary foods and beverages, fried foods and red meat. Reiss also recommends low or no alcohol consumption and avoidance of tobacco and illicit drugs.

People whose Vitamin D levels are low are more likely to develop some form of dementia. Although sunlight is the most common source of Vitamin D, many people avoid sun exposure. Vitamin D can be found in fatty fishes (e.g., salmon, trout, mackerel), mushrooms, eggs and fortified milk, orange juice and cereals.

Exercise

A healthy diet needs to be supplemented with exercise, which is good for the brain and heart, Reiss says. "Try to do a mix of aerobic exercise, resistance training and stretching, balance and range-of-motion activities. Physical activity keeps the heart and vascular system in good shape, enabling them to supply blood and nutrients to the brain. Exercise also lifts mood and relieves anxiety; stress and depression can negatively affect mental function."

Sleep

"During sleep, there is consolidation of learning and memory and strengthening of synaptic connections," Reiss says. "Many physiological processes occur that are vital to maintaining brain health, restoring balance to the nervous system and ridding the brain of waste products. Get a consistent sleep of at least seven to nine hours. Poor sleep quality can bring on or exacerbate depression, which is associated with poor cognitive function."

Social life & learning

Reiss encourages people to interact in their community and participate in group activities.

"Learning and challenging the brain to do new things builds up nerve pathways and helps to cushion you from loss of brain function by bolstering cognitive reserve. The mental stimulation that comes with learning helps to give the brain resilience and keep it sharp."

Head injuries

One often-overlooked risk factor for cognitive decline is head injury. If you sustain a concussion, follow your healthcare provider's guidance closely and take precautions to prevent another. Wear helmets and protective headgear when appropriate, buckle seatbelts and take steps to reduce fall risk.

Get a free memory screening.

Memory screenings are an important part of a wellness routine — even when the person is not experiencing cognitive concerns.

Memory screenings can catch changes early, opening the door to timely care and treatment.

It's easy. Schedule a free, 15-minute virtual screening at **alzfdn.org/get-a-free-screening** or call **866-232-8484**.

AFA-Funded Research

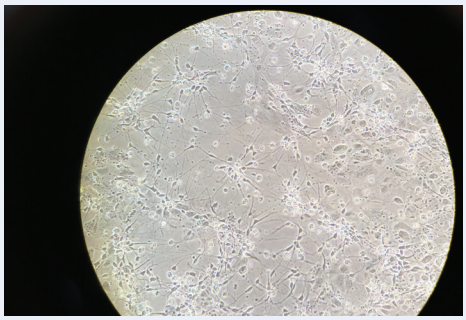
Research is the foundation for progress — driving better prevention, earlier diagnosis, more effective treatments and, ultimately, a cure for Alzheimer's disease. As part of AFA's mission, research remains a priority, with more than $5.2 million invested through 2025. Recent projects follow.

A Path to New Treatment, Causes, Biomarkers

Scientists at the NYU Grossman Long Island School of Medicine (NYULISOM) Biomedical Research Institute are studying brain neuronal activity through blood samples, an approach previously only possible after death. This allows scientists to study potential Alzheimer's treatments, underlying causes and biomarkers using the blood samples of people living with the disease and as well as those free of it. Individualized blood samples will enable researchers to obtain a personalized profile of each person's amyloid processing machinery, potentially making it possible, over time, not only to predict Alzheimer's risk but also to guide precision medicine-based treatment regimens.

The researchers are focusing on exosomes, small particles shed from every cell in the human body that serve as intercellular communicators. Their specific interest is in neuron-derived exosomes, which carry genetic material and proteins that reflect what is happening inside brain cells. Researchers are investigating differences in this information between healthy individuals and those with Alzheimer's. Since these reflect differences in actual brain neurons, they plan to use the data gained to reprogram Alzheimer's neurons to behave more like those in healthy people.

The NYULISOM team is also modeling Alzheimer's in cell culture using human neurons and microglia to test drugs and treatments before they enter clinical trials. Because animal models often fail to accurately predict human responses, this approach could save substantial time and resources by filtering out ineffective candidates earlier.

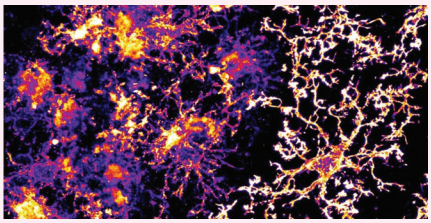


Brain neurons derived from stem cells showing Alzheimer's disease.
Credit: NYU Winthrop Research Institute

This work builds upon years of research led by Dr. Allison Reiss, head of the Inflammation Laboratory.

"There is an urgent need for transparency and solid science in Alzheimer's research. We hope that our work inspires the screening of Alzheimer's disease drug candidates in human cell models before committing significant effort and resources to clinical development," Reiss said. "People living with this disease — and their families — deserve treatments built on strong, reproducible evidence.

Allison B. Reiss, M.D., is a member of AFA's Medical, Scientific and Memory Screening Advisory Board.



Credit: One Mind

One Mind Accelerator, Brain Immunity

AFA supported the One Mind Accelerator, which backs visionary founders of early-stage startups with catalytic tools — network, education, and capital — to rapidly build robust, scalable and ethical companies that take innovation to market faster and with greater impact for people facing serious mental illness.

One Mind projected the program will enable 15,000 to 45,000 people to receive cutting-edge treatments and services in the next several years. The organization is one of the leading brain health nonprofits in the United States, working to improve the lives of people affected by brain illnesses and injuries through global, collaborative action.

AFA has also supported a One Mind study with The Broad Institute of Harvard and MIT to examine the role of the brain's immune cells in the onset and progression of Alzheimer's. This could lead to new biological insights and inform the identification of biomarkers for early detection, progression monitoring and therapy evaluation.

Investment in Hope

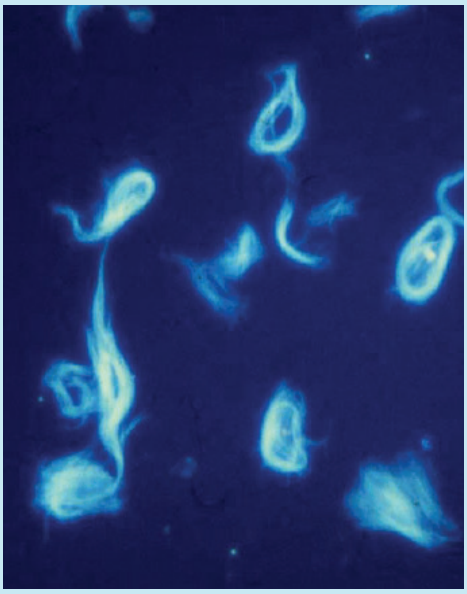
Treating Hallucinations and Aggressive Behavior

Among the most difficult and heartbreaking situations families face when caring for a person with Alzheimer's is dealing with the agitation, paranoia, hallucinations and aggression that occur in half the individuals. These are among the most troubling behaviors associated with Alzheimer's and are often one of the reasons families move their loved one into a residential healthcare setting.

Researchers at the Litwin-Zucker Center for the Study of Alzheimer's Disease at the Feinstein Institutes for Medical Research in New York want to change that. They are exploring the underlying causes of the more disturbing behaviors associated with Alzheimer's to find ways to treat them.

Geriatric psychiatrist Jeremy Koppel, M.D., has identified a series of changes, including the accumulation of tau in the brain's frontal cortex, perhaps driven by excess dopamine concentrations, as a potential cause of psychosis. The abnormal accumulation of the protein tau is one of the hallmarks of Alzheimer's.

AFA has funded a multi-year study to test a variety of new drugs, including tau antibodies, as potentially targeted treatments without the dangerous side effects. It is hoped that the study's findings will lead to the emergence of compounds for testing in clinical trials.



Tangles in the brain's frontal lobe
Credit: The Feinstein Institutes for Medical Research

Jeremy Koppel, M.D., is a member of AFA's Medical, Scientific and Memory Screening Advisory Board.

Minority Outreach, Arts + Health Laboratory

AFA has for many years supported Emory University's Goizueta Brain Health Institute (Emory Goizueta BHI) in its efforts to increase outreach to minority communities that have been underserved in education, screening and treatment for Alzheimer's.

AFA recently extended its support to the Institute to advance ground-breaking research exploring how artistic engagement may promote brain health and emotional well-being.

This latest research grant funds a new community-based participatory research collaboration in Atlanta, Arts + Health Laboratory: Georgia's NeuroArts Coalition, a partnership involving Emory, the Atlanta Symphony Orchestra (ASO) and Performance Hypothesis. The coalition aims to investigate how the arts improve both brain and overall health and use scientific findings to expand access to arts-based programs statewide. The team will evaluate the program's impact on joy, respite, connection and changes in behavior and mood, with the long-term goal of replicating the model in communities nationwide.

Photo credit: Atlantic Symphony Orchestra/Rand Lines

According to Emory Goizueta BHI, there have been remarkable advancements in music therapy for individuals with brain disorders such as Alzheimer's, Parkinson's and stroke, and that research has shown that attending concerts and other arts events can improve memory and semantic fluency.

Monica Parker, M.D., who is heading the research team, is also director of outreach, recruitment and engagement (ORE) for Emory's Goizueta Alzheimer's Disease Research Center. She is the chairwoman of AFA's Medical, Scientific, and Memory Screening Advisory Board.

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