Age Wise

The Family Caregiver's Guide to What to Expect as Your Parents Age





Chapter 7

Dealing with Dementia

Caring for a loved one with dementia can be one of the most challenging—and emotional—responsibilities a family caregiver will ever face. Dementia is not a single disease but a collection of symptoms that affect memory, reasoning, behavior, and the ability to function day-to-day. The most common type is **Alzheimer's disease**, but there are other forms—including **vascular dementia**, **Lewy body dementia**, and frontotemporal **dementia**—each with unique symptoms and challenges.

Type of Dementia	Prevalence	Main Cause	Early Hallmarks	Progression Style
Alzheimer's Disease	60-80% of all cases (most common)	Amyloid plaques & tau tangles damaging brain cells	Short-term memory loss, difficulty learning new info	Gradual decline over years
Vascular Dementia	2nd most common	Reduced blood flow (stroke or small vessel disease)	Slowed thinking, poor focus, problem-solving issues	Stepwise decline after strokes/vascular events
Lewy Body Dementia	5–10% of cases	Lewy body protein deposits disrupting brain function	Visual hallucinations, fluctuating alertness, Parkinson's-like movement problems	Fluctuating symptoms, good/bad days
Frontotemporal Dementia	Less common overall, but leading cause under 65	Degeneration of frontal & temporal lobes	Behavioral/personality changes or language difficulties	Early behavioral/language issues, memory intact initially

The magnitude of the issue is staggering. According to the National Institutes of Health, there are 7 million Americans age 65+ living with Alzheimer's or other forms of dementia. That number is projected to double to 14 million by 2060. Even more staggering is that some estimates state that by the time people reach their mid-80s, nearly 40% will show signs of Alzheimer's disease, not even counting other dementias.



The impact on Family Caregivers is equally profound as behind every diagnosis is not just one individual, but a family. In 2023 alone, 11 million Americans provided over 18 billion hours of unpaid care to loved ones with dementia, care valued at nearly \$350 billion.

"Dementia is a family disease. It affects every single member of the family."

- Dr. Miguel Rivera, Psychiatrist and Dementia Specialist

Understanding Dementia: What It Really Means

In an Age Wise conversation, Dr. Miguel Rivera, a psychiatrist who specializes in later-stage dementia, offered a simple but powerful definition; 'Dementia can be defined as an acquired and substantial decline in three main areas: cognition, activities of daily living, and behavior." [See full interview here: <u>Can Dementia Be Prevented</u>.]

Areas of Decline:

- Cognition: memory, executive function, and spatial awareness
- Activities of daily living: tasks like dressing, cooking, and managing finances
- **Behavior:** changes in mood, personality, or social interaction

These categories might sound clinical, but for caregivers they quickly become very real. Each small shift is not just a symptom—it's a reminder of how dementia reshapes daily life for everyone involved.

At **Silver Solutions**, we've seen thousands of families navigate this path. Our goal in this chapter is to provide you with a starting framework: how to recognize signs, how to respond with care, and how to set up your home and routines for success.

Recognizing the Early Signs

Early detection is critical. Dementia symptoms are often dismissed as "just aging," but timely recognition allows for earlier intervention and planning.



Common early signs include:

- Frequent memory lapses that disrupt daily life (repeating questions, forgetting appointments).
- Difficulty completing familiar tasks like cooking or balancing a checkbook.
- Struggling to follow conversations or losing track of stories.
- Misplacing items in unusual places (like car keys in the freezer).
- Personality or mood changes, such as irritability or withdrawal.
- Disorientation about time, place, or surroundings.

If you notice these patterns, encourage your loved one to get a comprehensive evaluation. Some causes of memory loss—such as thyroid disorders or vitamin deficiencies—are treatable. As Dr. Rivera cautioned, "Don't put it off. When it comes to cognitive problems, time is of the essence. The longer you wait before having that person evaluated, the less the chances are that you may be able to do something about it."

Creating a Supportive Environment

One fascinating thing is that dementias can reshape not only the mind but also how a person perceives their surroundings. A cluttered or confusing home can heighten stress and even increase the risk of accidents.

Dr. Laura Gitlin, Dean Emerita at Drexel University and author of 'Better Living with Dementia', has studied environmental strategies that make a real difference. In an Age Wise conversation, Dr. Gitlin stresses that "With disease progression, decluttering is really important. We've been in homes where people have stacks of newspapers everywhere—tripping hazards. A calmer, simpler space helps reduce confusion and stress."

Some Practical home adjustments include:

- **Declutter:** Remove excess furniture, cords, and piles of paper.
- Label and simplify: Place clear signs with words or pictures on doors and drawers.
- **Lighting:** Add nightlights and improve overall brightness. Shadows can be frightening for someone with dementia.
- **Consistency:** Keep furniture, décor, and personal items in the same place. Familiarity provides comfort.



• **Safety features:** Install locks on cabinets with hazardous items, add stove shut-off devices, and remove loose rugs to reduce falls.

These steps may seem small, but together they create an environment where your loved one feels calmer and safer.

Daily Routines and Meaningful Activities

Structure can be grounding for someone with dementia. Daily routines give rhythm and predictability, helping reduce anxiety.

Care strategies that make a difference:

- **Simplify choices.** Too many options can overwhelm. Offer two clothing choices instead of five.
- **Break tasks into steps.** For example, "Pick up your toothbrush. Now let's add toothpaste."
- **Use nonverbal cues.** Smiles, gentle touches, and pointing often communicate better than words.
- Maintain meaningful activities. Music, art, gardening, or light chores can provide purpose and joy.
- **Be flexible.** Agitation and resistance are common—if one approach isn't working, pause and try again later.

Caring for the Caregiver

The role of a dementia caregiver is relentless. The emotional and physical toll is real, and ignoring your own needs is dangerous. It's been noted that a caregiver is depressed or distressed about their life as they care for their loved one, they have a **67% higher mortality rate** than people their age who are not caregiving." Dr. Gitlin echoes this with her advice to families, "I tell families: don't cancel your own doctor's appointments. Keep exercising, eat well, stay socially connected. You're in this for the long haul, and you must take care of yourself."



Ways to protect your own well-being:

- **Respite care:** Adult day programs, in-home aides, or short stays in residential communities can give you a break.
- **Support groups:** Sharing your story with others who understand reduces isolation and guilt. (See sidebar on support groups below.)
- **Build a team:** Involve siblings, friends, or faith communities. Caregiving is not meant to be a solo act.
- **Set realistic expectations:** You cannot control the progression of dementia. Focus on what you can influence, safety, comfort, and small joys.

Why Support Groups Matter Insights from a Certified Alzheimer' Educator

For more than a decade, Tino Negri, a Certified Alzheimer's Educator and co-owner of <u>ComForCare South Florida</u>, has led dementia caregiver support groups. His perspective is clear:

"My job is not to change their loved ones with dementia. My job is to change caregivers".

Tino started with a single group 13 years ago. Today, he and his team run 15 support groups across South Florida, plus a virtual Zoom group twice a month that draws 20–40 participants from around the country. Families from as far away as California and Canada log in. Why do caregivers keep showing up? Tino hears the same message again and again, "Number one, I hear people finally feel like they're not alone anymore. When they come into a group and see others going through this, you can see the weight lift off their chest."

Support groups also provide practical tools. In Tino's sessions, caregivers learn strategies like the CART approach (Don't Correct, Argue, Reason, or Test) and practice new ways of responding.

Perhaps most importantly, groups help families process grief. Tino says, "People are grieving three times. They grieve the person they knew, they grieve for what's coming, and then they grieve again after their loved one passes. Talking about that in a group makes them realize they're not crazy—it's part of the journey."



Takeaway: Whether in-person or online, support groups can be a lifeline. They provide education, coping strategies, and—most critically—the reminder that you are not alone.

Can Dementia Be Prevented—or Slowed?

While there is currently no cure, research suggests that lifestyle choices can lower the risk or slow progression. Both Dr. Rivera and Dr. Gitlin highlighted the role of **inflammation**, **cardiovascular health**, **and social connection**. Dr. Rivera explained, "What's good for the heart is good for the brain. If you address inflammation, through diet, activity, and stress management, you're also addressing the risk for dementia."

Dr. Gitlin pointed to an influential 2020 report in The Lancet that identified **12 modifiable risk factors** that could reduce dementia cases worldwide by up to **40%**. These include:

- Staying physically active.
- Quitting smoking.
- Controlling blood pressure and diabetes.
- Reducing social isolation.
- Maintaining healthy hearing, vision, and sleep.

She emphasized the hopeful message: "It's never too early—and never too late—to prevent dementia."

The Road Ahead

The journey through dementia is long, unpredictable, and deeply personal. It is not a sprint but a marathon, marked by small victories and difficult losses.

For caregivers, it often means redefining what love looks like shifting from correcting to comforting, from insisting on facts to honoring feelings, from doing it all alone to building a team.

At <u>Silver Solutions</u>, we've seen thousands of families take this journey. We know it is exhausting, heartbreaking, and, at times, overwhelming. But we also know it can be filled with moments of connection, laughter, and grace.



Key Takeaways

- **Recognize early signs.** Forgetfulness that disrupts daily life, confusion, or personality changes should prompt a medical evaluation.
- Adapt the environment. Declutter, label, improve lighting, and keep things consistent. Safety and simplicity reduce stress.
- Communicate with compassion. Use nonverbal cues, avoid correcting or arguing, and focus on feelings rather than facts.
- **Establish routines.** Consistent daily rhythms and meaningful activities can provide comfort and purpose.
- Care for yourself. Seek respite, join support groups, maintain your own health and connections.
- **Plan ahead.** Know when memory care may be the safest option, and research communities carefully.
- **Prevention is possible.** Lifestyle factors—exercise, diet, social engagement, and managing health conditions—may reduce risk or slow progression.
- You are not alone. Support groups, professionals, and community resources can make the journey lighter.