THE CAREGIVER'S GUIDE TO COGNITIVE IMPAIRMENT

Dementia, Alzheimer's and Beyond

acofp | AMERICAN COLLEGE OF OSTEOPATHIC FAMILY PHYSICIANS

About This Guide

Caring for someone with a cognitive condition is demanding work and most caregivers enter it without a roadmap. A diagnosis of dementia like Alzheimer's or a related condition raises immediate questions about what to expect, how to communicate with physicians, how to plan, and how to sustain the effort over time.

This guide addresses those questions directly.

Cognitive conditions affect more than memory. Depending on the diagnosis and its progression, they can alter personality, behavior, language, judgment and physical function. The earlier caregivers understand what they are managing, the better positioned they are to make informed decisions about care, legal and financial planning, and their own wellbeing.

The pages that follow draw on physician expertise and caregiver experience. They cover the full spectrum of cognitive decline, what to expect at each stage, how to navigate the medical system and find support.

WHAT YOUR PHYSICIAN WANTS YOU TO KNOW

By Lynn M. Wilson, DO, FACOFP, FAAFP, AGSF, DipABLM

An early diagnosis opens doors that a late one cannot — the opportunity to explore lifestyle interventions, discuss emerging treatment options, and ensure patients can still speak for themselves about the care they want.

Over the years caring for older adults and their families, one thing has become increasingly clear to me: when it comes to cognitive health, we're still starting the conversation too late. By the time many patients come to see me — or even acknowledge changes themselves — they've often already lost the ability to meaningfully participate in decisions about their own care. I understand the hesitation. A possible cognitive impairment diagnosis is scary. But what I want patients and caregivers to know is this: acting early preserves something we can't give back later, a patient's voice in their own future.

Dementia isn't a single disease. It's a broad term that describes changes in memory, thinking and social function, and includes conditions like Alzheimer's disease, vascular dementia, Lewy body dementia and frontotemporal dementia. Before settling on that diagnosis, I always emphasize the importance of a thorough evaluation. Some conditions that look like dementia can be partially reversible — things like thyroid dysfunction, vitamin B12 deficiency, or underlying kidney, liver or blood sugar issues. It's also critical to distinguish dementia from delirium. Dementia develops gradually over time; delirium is sudden and often signals an acute medical issue. A rapid change in someone who was previously stable should always be treated as an emergency.

Ideally, we would begin cognitive screening before symptoms ever appear. Establishing a baseline early makes it much easier to detect meaningful changes down the line. Regardless of where someone is in that process, there are steps we can all take today. The same habits that support cardiovascular health — a Mediterranean-style diet, regular physical activity and good sleep — also benefit brain health. Staying mentally engaged with activities like puzzles and maintaining strong social connections adds another layer of protection. The evidence is there and none of these interventions require a diagnosis to begin.

I've sat with too many families who wish they had come in sooner. This isn't about creating fear — it's about creating opportunity. Acting early gives people the chance to have a say in what lies ahead, for themselves and for the people who love them.

A ROADMAP OF WHAT TO EXPECT

This guide uses the Global Deterioration Scale, also known as the Reisberg Scale, the most widely used clinical framework for assessing cognitive decline. However, no two people experience cognitive decline the same way, not everyone will move through all seven stages, and not every form of dementia follows the same pattern.

STAGE 1:
No Cognitive Impairment

- **What it looks like:** There is no memory loss or cognitive decline; brain function is normal.
- **What caregivers might consider:** The habits built now directly affect cognitive health later — and this applies to all adults. Eat a Mediterranean-style diet, get 150 minutes of moderate exercise per week, ensure good quality sleep, participate in mentally stimulating activities and maintain social connections. These all have documented protective effects and are recommended for everyone, not just for people in the early stages of dementia or those with a family history of the condition.

STAGE 2:
Very Mild Cognitive Decline

- **What it looks like:** The person might experience occasional forgetfulness, such as misplacing objects and struggling to recall a name, that is not yet noticeable to family members or physicians and is often attributed to normal aging.
- **What caregivers might consider:** There may not be a formal caregiver yet but if you have noticed something, trust that instinct. This is a reasonable time to encourage a baseline cognitive screening with a primary care physician to establish a reference point.

A ROADMAP OF WHAT TO EXPECT (CONT.)

STAGE 3:
Mild Cognitive Decline

- **What it looks like:** The individual shows increased forgetfulness, difficulty concentrating, trouble finding words, getting lost more easily and declining work performance. Those close to them will notice and a physician may detect early signs.
- **What caregivers might consider:** Begin the diagnosis conversation and stress the need for an evaluation. Accompany your loved one to appointments when possible. Connect with a caregiver support group and identify local resources now, before you are in crisis. This is also a good time to establish your own relationship with a physician — and a mental health professional — if you do not have one.

"I was surprised to learn how patients respond to music, pet and other sensory therapies. They can trigger emotional memory and recognition even if patients with significant cognitive decline, and reduce agitations, anxiety and depression."
– Lyndsey A., caregiver

STAGE 4:
Moderate Cognitive Decline

- **What it looks like:** The person has difficulty managing finances and complex tasks, forgets recent events and begins to withdraw socially. While many patients are still in denial, physicians, family members and friends can now clearly detect cognitive decline.
- **What caregivers might consider:** If a formal diagnosis has not been made, pursue one. This is the window for patient-directed planning and an opportunity to act while your loved one can still participate in decisions about their own care. This includes establishing a durable power of attorney, updating a will and advance directives, gathering insurance and financial documents, consulting an elder law attorney, mapping out a financial plan for care, and determining risk interventions around driving, medication and falls.

  Caregivers expecting to take a primary role should explore FMLA eligibility and state and local financial assistance programs. Your local Area Agency on Aging is a good starting point. The emotional weight of this stage is also significant. Connecting with a therapist or caregiver support group takes on increasing importance to your own wellbeing.

A ROADMAP OF WHAT TO EXPECT (CONT.)

STAGE 5:
Moderately Severe Cognitive Decline

- **What it looks like:** By this point, the loved one has significant memory gaps, confusion about time and date and difficulty managing daily activities. They need assistance with medications and clothing selection, though family members are generally still recognized.
- **What caregivers might consider:** Hands-on caregiving begins here. Consistent routines help reduce confusion and if you have not sought outside support, research now — adult day programs, in-home respite care, and caregiver support groups are all worth exploring. Monitor your own stress closely. Persistent exhaustion, irritability and neglecting your own health are signs the current care structure needs to change and that you may need to bring in additional help for yourself and your loved one.

STAGE 6:
Severe Cognitive Decline

- **What it looks like:** The individual cannot manage activities of daily living without assistance. May forget names of close family members, experience incontinence, have difficulty speaking, and exhibit personality changes, delusions, or anxiety.
- **What caregivers might consider:** Around-the-clock supervision is required. For many families, that level of care at home is no longer feasible and this is when memory care — a residential setting with staff trained specifically in dementia — becomes a necessary consideration. Research and visit facilities before a crisis forces the decision.

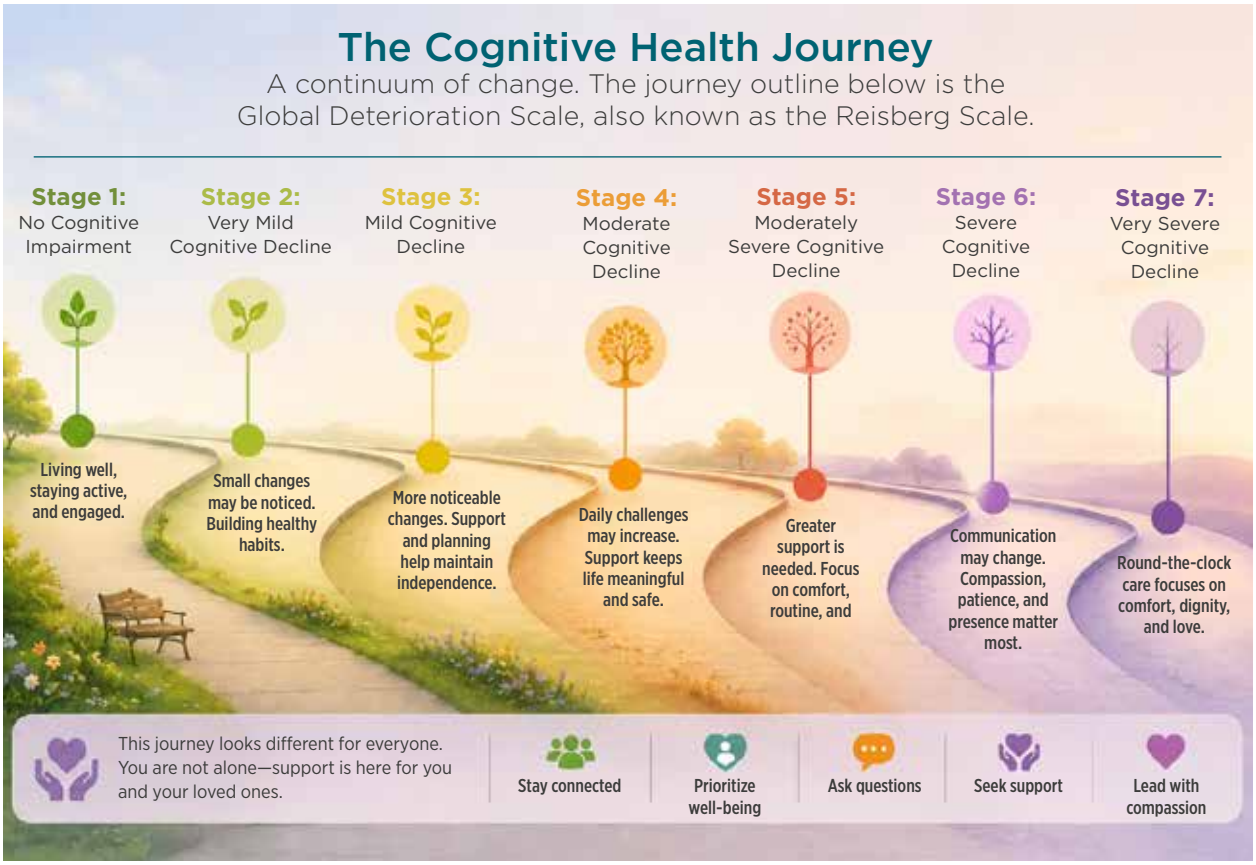
  It's not uncommon to experience family dynamics in this stage where expectations differ on home versus facility care. However, caregiver burnout is most acute at this stage. If you are the primary caregiver, be honest with yourself and your family about what you can and cannot sustain.

A ROADMAP OF WHAT TO EXPECT (CONT.)

STAGE 7:
Very Severe Cognitive Decline

- **What it looks like:** At this late stage, the loved one might have lost the ability to speak, walk and perform any activities of daily living. It also becomes difficult for the patient to swallow or get enough nutrition. Full-time care is required and many patients become bedridden.

- **What caregivers might consider:** The focus shifts to comfort and dignity and the grieving process often begins, even if death is not immediate. Hospice social workers and bereavement counselors are there to provide support to families, not just patients.



This information is for general awareness and not a substitue for professional medical advice. Please consult a healthcare professional for personalized guidance.

AI was used to help create and refine this graphic.

KNOW THE TERMS

The following terms come up regularly in medical appointments, care facilities and support groups. Having a working understanding of them helps caregivers ask better questions and make more informed decisions.

Types of Dementia

Alzheimer's disease
The most common form of dementia, caused by abnormal protein deposits that damage and kill brain cells over time.

Frontotemporal dementia (FTD)
A form of dementia affecting personality, behavior and language, often before memory is notably impaired.

Lewy body dementia
A form of dementia caused by abnormal protein deposits in the brain; often includes hallucinations and movement symptoms similar to Parkinson's disease.

Mixed dementia
The presence of more than one type of dementia simultaneously, most commonly Alzheimer's and vascular dementia.

Vascular dementia
Cognitive decline caused by reduced blood flow to the brain, often following a stroke.

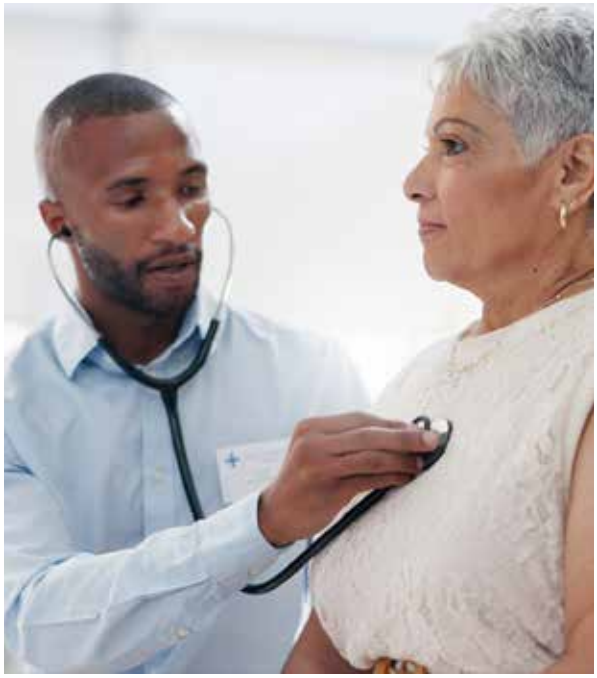
Related Conditions

Delirium
A sudden, severe change in cognition that develops within hours or days; a medical emergency distinct from dementia.

Mild cognitive impairment (MCI)
A noticeable but modest decline in cognitive function that does not yet significantly interfere with daily life; not all MCI progresses to dementia.

Sundowning
Increased confusion, agitation or behavioral changes occurring in the late afternoon or evening, common in middle and later stages.

Younger-onset dementia
A diagnosis of dementia in someone under age 65.



KNOW THE TERMS (CONT.)

Diagnosis and Testing

Cognitive assessment
A structured evaluation of memory, language, problem-solving and other cognitive functions.

MMSE (Mini-Mental State Examination)
A standard clinical test used to screen for and measure the severity of cognitive impairment.

MoCA (Montreal Cognitive Assessment)
A brief screening tool used to detect mild cognitive impairment and early dementia.

MRI / PET scan
Imaging tools used to examine brain structure and activity; often part of a dementia workup.

Neuropsychological testing
A comprehensive evaluation performed by a specialist to assess specific cognitive domains and help distinguish between conditions.

SLUMS
A tool to screen individuals for mild cognitive impairment and dementia, consisting of 11 questions that test attention, memory, calculation, spatial ability and executive function.

Medications

Cholinesterase inhibitors
A class of medications used to manage symptoms of Alzheimer's and some other dementias; they do not stop progression.

Memantine
A medication used to manage moderate to severe Alzheimer's symptoms, sometimes prescribed alongside cholinesterase inhibitors.

Legal and Financial Planning

Advance directive
A legal document recording a person's wishes about medical treatment if they become unable to communicate them.

Durable power of attorney
Legal authorization for a designated person to make decisions on someone else's behalf, including if they become incapacitated.

Health care proxy
A person legally designated to make medical decisions on behalf of someone who cannot make them independently.

Care Terms

Activities of daily living (ADLs)
Basic self-care tasks including bathing, dressing, eating, mobility and toileting; used clinically to measure functional decline.

Hospice
Care focused on comfort and quality of life for patients with a terminal prognosis, rather than curative treatment.

Palliative care
Specialized medical care focused on relief from symptoms and stress of illness; can be provided alongside curative treatment at any stage.

KNOW THE TERMS (CONT.)

Respite care
Temporary relief care for primary caregivers, provided at home or in a facility.

Care Settings

Adult day program
A community-based program offering structured activities and supervision during daytime hours; provides caregivers with scheduled respite.

Assisted living
A residential option combining independent living with available personal and medical care support.

Memory care
A specialized residential setting with staff trained specifically in dementia care.

Skilled nursing facility
A licensed facility providing 24-hour medical care; appropriate when medical needs exceed what memory care can provide.

Medical Specialists

Family medicine physician
A primary care doctor who treats patients across all ages and is often the first to identify and monitor cognitive concerns.

Geriatric psychiatrist
A psychiatrist specializing in mental health conditions in older adults, including behavioral symptoms of dementia.

Geriatrician
A physician specializing in the care of older adults.

Neurologist
A physician specializing in disorders of the brain and nervous system.

Neuropsychologist
A specialist who evaluates cognitive function through detailed testing.

Nearly 12 million Americans provide unpaid care for people with Alzheimer's or other dementias, according to the Alzheimer's Association.

RESOURCES

The following organizations offer reliable information, practical tools and direct support for caregivers and families navigating cognitive care.

Alzheimer's Association—
alz.org | 800-272-3900
The most comprehensive national resource for dementia caregivers. Offers a 24/7 helpline, local chapter support, care planning tools and a clinical trials finder.

ALZConnected—alzconnected.org
An online community for people living with dementia and their caregivers, moderated by the Alzheimer's Association.

Alzheimer's Foundation of America—
alzfdn.org | 866-232-8484
Provides free memory screenings, caregiver support groups and social work consultations by phone.

Family Caregiver Alliance—
caregiver.org | 800-445-8106
Research-backed fact sheets and guidance on care transitions, respite care and caregiver health.

Legal and Financial Planning

Eldercare Locator—
eldercare.acl.gov | 800-677-1116
A public service of the U.S. Administration on Aging connecting caregivers with local services including legal assistance, transportation and in-home care.

National Academy of Elder Law Attorneys—naela.org
A directory for finding attorneys who specialize in power of attorney, Medicaid planning and guardianship.

Benefits.gov—benefits.gov
A federal resource for identifying government benefits including Medicare, Medicaid and caregiver assistance programs.

For FMLA eligibility and workplace leave information, visit the Department of Labor website or talk to your employer's HR department.

Mental Health and Caregiver Support

NAMI
(National Alliance on Mental Illness)—
nami.org | 800-950-6264
Mental health support for caregivers experiencing depression, anxiety or burnout, with a helpline, support groups and local chapter resources.

988 Suicide and Crisis Lifeline—
call or text 988
Available 24/7 for anyone in mental health crisis, including caregivers.

https://acofp.org/cognitive-care