

Understanding Dementia

Dementia is one of the most misunderstood conditions, even by well-meaning professionals.

If you've found yourself confused by what you're seeing with your loved one, there's a reason for that. Dementia doesn't affect every brain the same way, and it doesn't progress in a predictable, straight line. What you're noticing may not match what you expected, what others describe, or what you've seen in movies.

This chapter will help you understand what dementia is and is not so you can stop questioning yourself. We'll start by going over the difference between dementia and Alzheimer's disease.

Alzheimer's Disease Versus Dementia

Sometimes dementia and Alzheimer's are talked about as if they mean the same thing. Other times, people talk as if they are completely different. All of this adds to the confusion many caregivers already feel.

Here's the simplest way to think about it: *dementia* is a general term. It describes ongoing problems with thinking, memory, and daily functioning caused by changes in the brain. It is not a specific diagnosis on its own.

Alzheimer's disease is the most common cause of dementia, but it's not the only one. Other causes include Lewy body dementia, frontotemporal dementia, and vascular dementia, among others.

In simple terms, dementia is a category, not a single diagnosis.

A helpful comparison is the word *cancer*. Cancer is a category, not a specific diagnosis. In the same way there are many types of cancer, there are many types of dementia.

When someone is told they have dementia due to Alzheimer's disease, it means that Alzheimer's is the disease causing the dementia symptoms you're seeing. But when someone is told they have dementia, it doesn't necessarily tell you which disease is causing it. Many caregivers are told their loved one "has dementia," but no one explains what kind or whether it matters.

No matter the type, all dementias affect thinking in ways that eventually interfere with a person's ability to live safely on their own day-to-day. This often shows up as difficulty managing finances, driving safely, cooking meals, keeping track of medications, or living alone.

For many families, it begins with small moments that are easy to brush off at first. A pot left on the stove. A medication taken twice. A door left unlocked. Looking back, many caregivers realize these were early signs that the brain was struggling to do things it once handled automatically.

Eventually, all forms of dementia reach a point where additional support is needed to stay safe. That support most often comes from family caregivers.

Not knowing the specific type doesn't mean you missed something or failed to advocate. It's actually extremely common not to know.

I meet new caregivers every week, and most do not know what type of dementia their loved one has. Many do not even have an

official diagnosis. Some were never directly told at all. Some discover dementia is part of the picture only after reading medical records, sometimes months or years later.

My own parents never received a formal diagnosis of a specific type of dementia.

While understanding different dementia types can be helpful, not everyone gets clear answers. Some people have more than one type at the same time, known as *mixed dementia*. In other cases, providers are unable to determine the exact cause, which is often documented as *unspecified dementia*.

Sometimes the picture becomes clearer over time as new symptoms appear. Other times, it never does. That uncertainty is far more common than most caregivers realize.

What matters most right now is not having a perfect label. What matters is understanding how dementia affects thinking and daily life so you can respond with more confidence.

Dementia Is Not a Normal Part of Aging

Age is the biggest risk factor for dementia, but dementia itself is not a normal part of aging.

Just as our chances of getting in a car accident increase the more time we spend on the road, our chances of developing dementia increase the longer we live.

Some thinking changes are normal as we get older, such as needing more time to think things through or having trouble finding the right words. These changes don't automatically make it difficult for us to take care of ourselves.

When thinking changes begin to interfere with safety, judgment, or everyday functioning, that is when it's no longer considered normal aging.

This difference matters. Many caregivers are told, or come to believe, that what they are seeing is “just age.” Understanding that dementia is not a normal part of aging helps caregivers trust their observations, seek help sooner, and advocate more confidently.

If all of this feels confusing, it's not because you're missing something. Dementia is complicated, and it doesn't always make sense.

“Is There a Point in Getting a Diagnosis?”

Many families wonder whether formal testing is worth it, especially when there is no cure. A full evaluation can be time-consuming and emotionally exhausting, and some caregivers are told there is no real point in testing.

One important reason families consider an evaluation is that some conditions can look very much like dementia but are actually treatable. I often call these *dementia look-alikes*.

For example, depression in older adults can mimic dementia. Someone may withdraw, lose motivation, struggle with concentration, or stop keeping up with daily care. Without an evaluation, these changes can be mistaken for dementia when they may improve with the right treatment.

Other issues that can look like dementia include untreated hearing loss, medication side effects, nutritional deficiencies, thyroid problems, dehydration, or sleep disorders. Identifying these doesn't rule out dementia, but it can still improve thinking and daily functioning in meaningful ways.

Another reason families pursue evaluation is for understanding and peace of mind. While no one wants to hear that someone they love has dementia, many caregivers describe a sense of relief knowing there is an explanation for what they've been seeing. A diagnosis

can help families stop questioning themselves and begin planning for the future with clearer expectations.

In some cases, early assessment may also open the door to treatment options or support services that require documentation.

Whether or not to pursue testing is a personal decision. What matters most is understanding why evaluation can be helpful, so you can decide what feels right for you and your family.

“It Can’t Be Dementia; Her Memory Is Fine”

When most people think about dementia, they think about memory loss. That makes sense, because memory problems are the main symptom in Alzheimer’s disease.

But memory loss is not always required.

Some dementias affect behavior, personality, judgment, language, or problem-solving first. Memory may appear okay, especially early on.

Thinking abilities include more than memory. They include attention, judgment, language, social awareness, and coordination. A significant decline in even one of these areas can interfere with safety and independence.

This is why dementia can look very different from person to person.

Dementia doesn’t have a single look or pattern.

Comparing your experience to someone else’s often creates unnecessary fear. Hearing another caregiver’s story does not mean that is what is coming next for your loved one.

In early stages, many people with dementia remain active in their communities. They may still drive, live alone, work, volunteer, or manage daily responsibilities.

This can make caregiving especially isolating. Others may only see brief snapshots where your loved one seems fine, while you live

the full picture day after day. When others don't see what you see, caregivers can be left feeling like they are exaggerating or overreacting, even when they are not.

Over time, abilities change. Risks increase. More supervision becomes necessary.

It is not the diagnosis that takes away freedoms. It is how the disease affects current abilities.

“They Did Just Fine Yesterday”

One of the most confusing parts of dementia is that ability is not lost all at once.

In early stages especially, dementia affects consistency before it affects ability.

A person may manage a task one day and struggle with the same task the next. They may seem clear in the morning and confused later that same afternoon.

This inconsistency causes many caregivers to second-guess what they're seeing. Are they pretending? Is this really dementia?

Dementia does not progress in a straight line. Skills can come and go, even as overall decline continues. A good day does not mean the dementia is gone. A difficult day does not mean everything has suddenly changed.

Both can exist at the same time.

It's easy to overlook symptoms early on. Many people are already in the moderate stages of dementia by the time they have their first formal evaluation, often because changes happened slowly and gradually.

This is not something to be upset with yourself about.

Just as it's hard to notice our own aging when we look in the mirror every day, it's hard to see slow changes in someone we love and see regularly.

A friend of mine has a mother who was diagnosed with early-onset Alzheimer's disease, meaning symptoms began before age 65. Her parents were physically strong and active, and they trained together for a half marathon in Arizona.

On the day of the race, her dad finished first and waited at the finish line. As time passed and she never arrived, panic set in. Based on her training, she should have finished long ago.

Eventually, they found her. She was safe, but she had become lost on the trails.

That day, the family realized that ability did not equal safety.

This back-and-forth is often harder to adjust to than steady decline. It keeps many caregivers in a constant state of emotional tension and self-doubt.

Key Takeaways

- Dementia is a category, not a single diagnosis. Alzheimer's disease is one cause, but there are many others.
- Not knowing the exact type does not mean you missed something or failed to advocate. Unfortunately, uncertainty is common.
- Dementia is not a normal part of aging. When thinking changes begin to interfere with safety and daily life, that is different from typical age-related changes.
- Memory loss is not always the first or main symptom. Changes in judgment, behavior, language, or personality can appear first.

- Dementia does not progress in a straight line. Good days and difficult days can exist at the same time.
- Ability does not always equal safety. A person may still be capable of doing something and no longer be safe doing it.
- Confusion about what you are seeing is not a sign that you are doing something wrong. Dementia itself is complex and inconsistent.

Looking Ahead

Dementia is complex, unpredictable, and deeply misunderstood.

If you've felt confused about dementia, testing, or the symptoms you're seeing, that's a natural response to something that can change over time and look very different from one person to another.

You don't need perfect answers or timelines to keep moving forward.

As dementia changes the brain, it changes how your loved one understands what's happening, communicates, and responds. What you see on the outside often shows up as behaviors.

In Chapter 2, you'll learn why those behaviors happen and how understanding what drives them can reduce stress, burnout, and difficult decisions about safety and care.