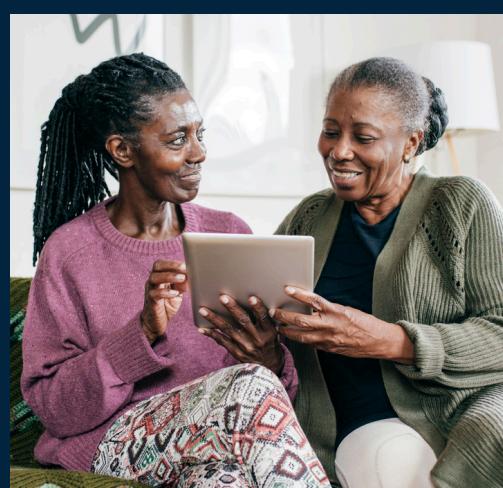
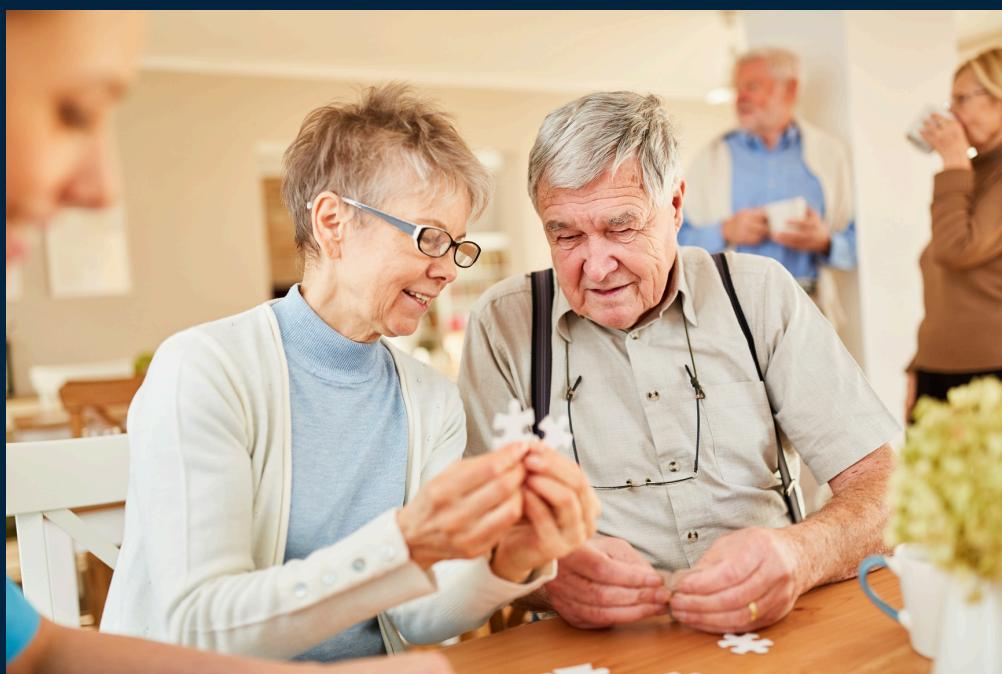


# Caregiver's Guide:

## Alzheimer's and Dementia Care





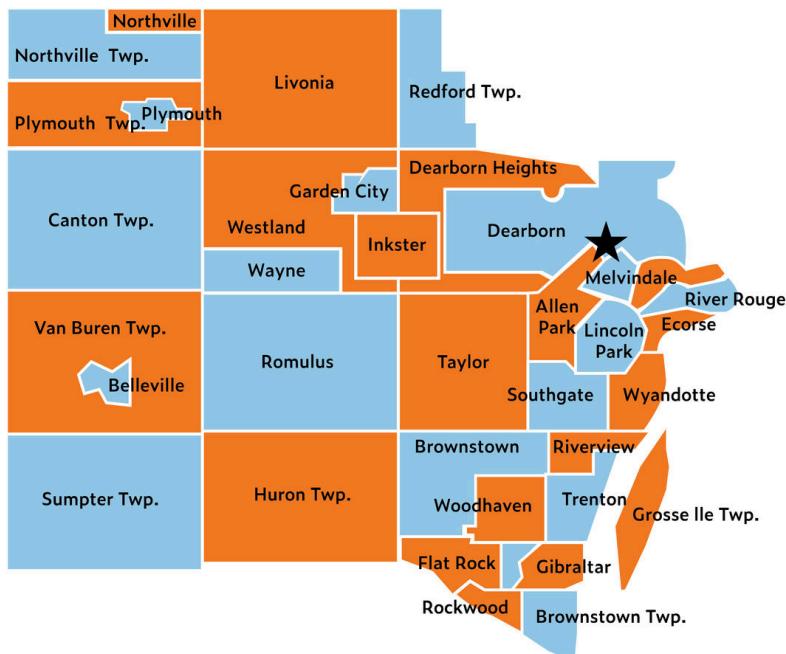
**The Senior Alliance is dedicated to enhancing and preserving the independence of older adults and individuals with disabilities, as well as providing support to caregivers.**

The Senior Alliance is a 501(c)(3) nonprofit agency designated as the Area Agency on Aging for the 34 communities of western Wayne County and Downriver. Our mission is assisting people to thrive as they live, grow, and age.

Our Caregiver Guide provides resources and information to help new and experienced caregivers better care for themselves and their loved ones.

Contact The Senior Alliance for additional information on local caregiver resources and services, or visit our virtual caregiver hub at [caregivinghaven.org](http://caregivinghaven.org).

Our Service Area



## Contact Us

[www.thesenioralliance.org](http://www.thesenioralliance.org) | [www.caregivinghaven.org](http://www.caregivinghaven.org)

734-722-2830

[info@thesenioralliance.org](mailto:info@thesenioralliance.org)

3200 Greenfield Rd, Suite 100, Dearborn, MI 48120

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# Introduction

“

*It is a strange, sad irony that so often, in the territory of a disease that **robs** an individual of memory, **caregivers are often forgotten.***

- Karen Wilder

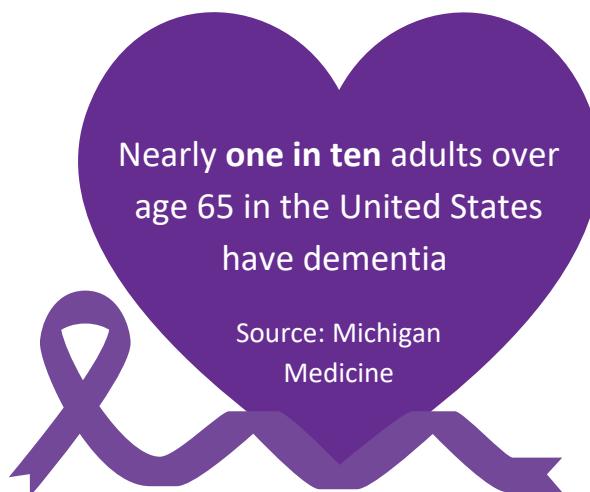
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When a loved one is **diagnosed with dementia**, it can **feel overwhelming**. With so **many types** of dementia and **unanswered questions** about the disease, it's hard to know **what to expect or how to prepare**. This guide is here to support you. While it doesn't have all the answers, it offers tips and strategies that have helped other caregivers navigate this journey and care for their loved ones with **confidence and compassion**.

## What is Dementia?

"Dementia" refers to a group of symptoms that impact **memory**, **thinking**, and **social abilities**, making daily life more difficult. It is not a single disease but an **umbrella term** that includes several conditions.



Dementia is NOT a normal part of aging:

It is more common in older adults, but not something that happens to everyone as they age.

Symptoms can vary:

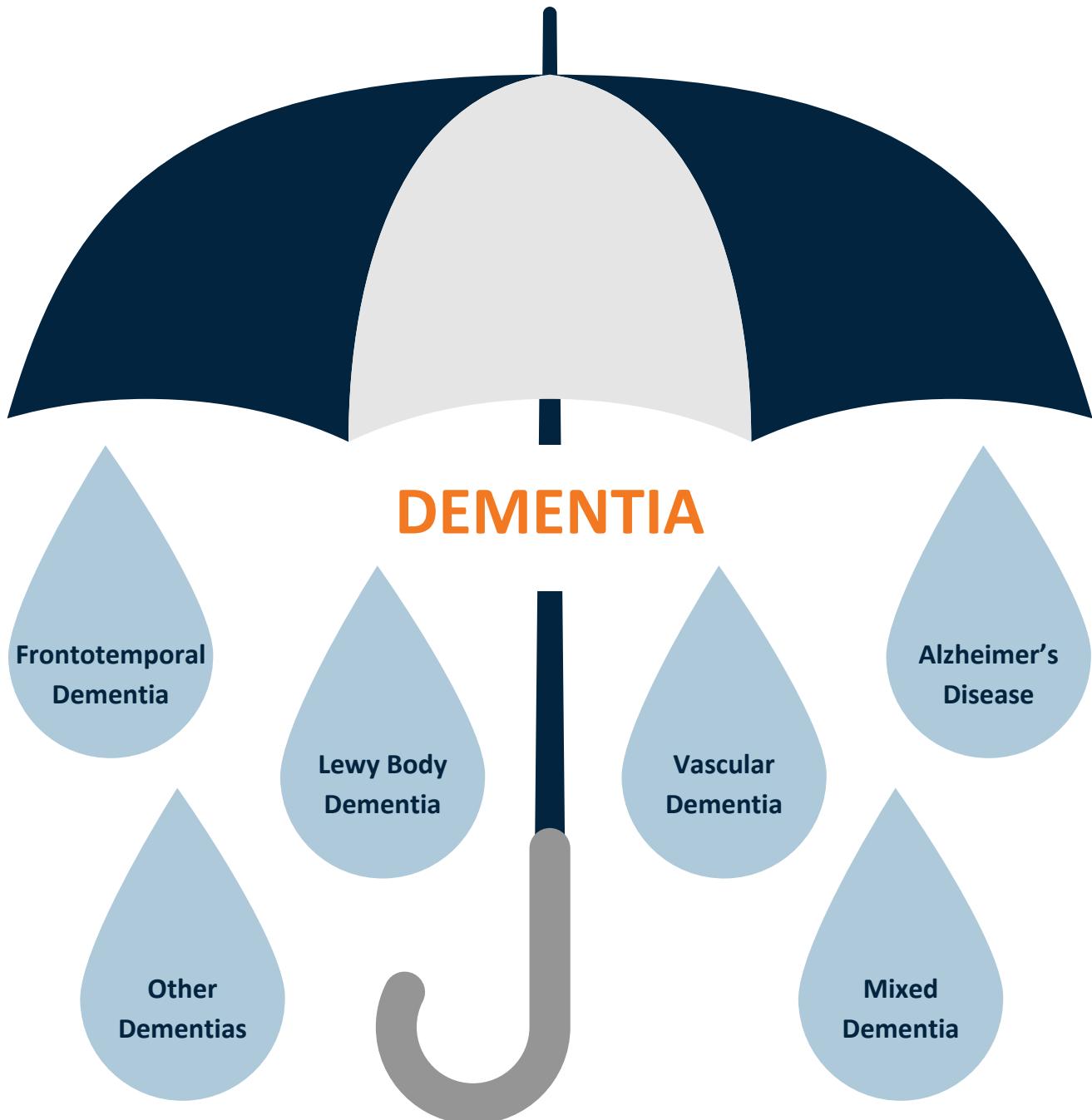
The symptoms of dementia can vary from person to person, depending on the type of dementia and the areas of the brain affected.

Early detection is important:

Noticing early signs of dementia and getting medical advice can make it easier to manage symptoms and plan ahead.

## The Dementia Umbrella

The **dementia umbrella** covers a range of conditions, including Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia, Frontotemporal Dementia, mixed dementia, and others. Each condition under this umbrella has **unique causes and characteristics**, impacting people in different ways (National Institute on Aging).



## Types of Dementia

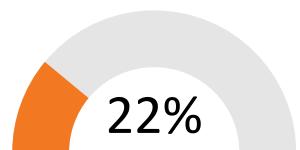
Alzheimer's Disease	Vascular Dementia	Frontotemporal Dementia	Mixed Dementia
Brain Changes			
Causes a buildup of <b>plaques and tangles</b> in the brain, which damage nerve cells and lead to <b>brain shrinkage</b> .	Caused by <b>reduced blood flow</b> to the brain, often due to strokes or small blood vessel damage.	Affects the <b>front and side parts of the brain</b> , which control behavior, emotions, and language.	A <b>combination of two or more types</b> of dementia, like Alzheimer's and vascular dementia.
Effects			
<b>Memory</b> loss, confusion, trouble with <b>thinking</b> and daily tasks, and changes in <b>mood</b> or <b>personality</b> .	Problems with <b>thinking, planning, or decision-making</b> , along with physical symptoms like <b>weakness</b> or trouble <b>walking</b> .	Changes in <b>personality or behavior</b> , difficulty <b>speaking</b> , and sometimes trouble with <b>movement</b> .	Symptoms depend on the specific types involved but may include <b>memory loss, confusion, and difficulty with daily tasks</b> .
Typical Age			
Most common in people <b>over 65</b> , but early-onset Alzheimer's can occur in people as young as <b>40-50</b> .	More common <b>after age 65</b> but can happen earlier in people with heart disease or stroke history.	Often starts earlier, between <b>ages 40 and 65</b> .	Common in people <b>over 75</b> .

## Types of Dementia

Lewy Body Dementia	Parkinson's Dementia	Creutzfeldt-Jakob Disease	Huntington's Disease
Brain Changes			
Caused by protein deposits ( <b>Lewy bodies</b> ) disrupting brain function, with <b>cognitive symptoms first</b> .	Caused by protein deposits ( <b>Lewy bodies</b> ) disrupting brain function, with <b>movement symptoms first</b> .	Caused by abnormal proteins ( <b>prions</b> ) that damage brain cells quickly.	Caused by a <b>genetic mutation</b> that damages brain cells over time.
Effects			
<b>Hallucinations, sleep issues, and thinking or attention problems.</b> Movement symptoms after 1+ years.	<b>Muscle stiffness, tremors, slow movement, and shuffling walk.</b> Cognitive symptoms after 1+ years.	Rapid <b>memory loss, confusion, severe mental decline</b> , and physical symptoms like <b>muscle twitching</b> .	Difficulty with <b>thinking, memory, and decision-making</b> , along with <b>involuntary movements and mood changes</b> .
Typical Age			
Usually begins <b>after age 50</b> .	Usually develops several years <b>after a Parkinson's Disease diagnosis</b> , often <b>after age 60</b> .	Can occur at <b>any age</b> but is more common in older adults, typically between <b>50 and 75</b> .	Symptoms usually begin between ages <b>30 and 50</b> .

## Dementia Caregiver Profile

**Nearly 1 in 5 American Adults (53 million) are family or informal caregivers...**



**of them, 11.5 million (22%) care for someone with Alzheimer's disease and related dementias.**



**67% of dementia caregivers are female**



**Average caregiving duration is 4+ years**

**50**



**Average family caregiver age**

**31 hours per week spent on caregiving tasks**



**41% of dementia caregivers have a household income of \$50k or less.**



**25% of dementia caregivers are “sandwich generation” caregivers**



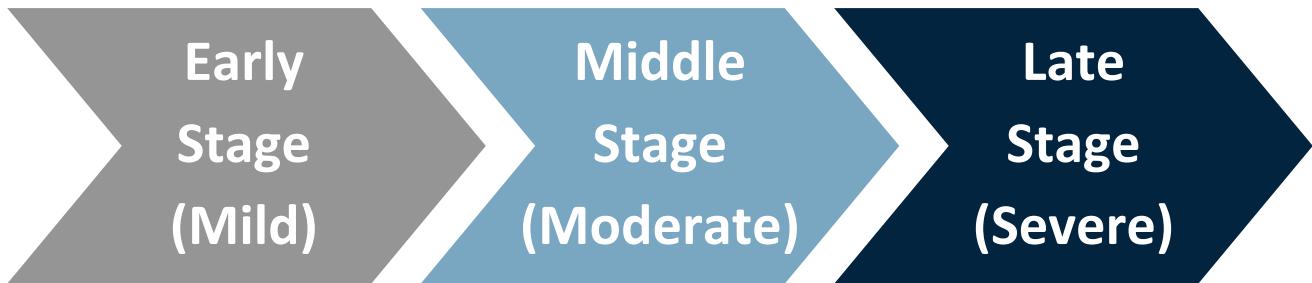
**59% of dementia caregivers experience “high emotional stress”**

**Nearly half of all older adult caregivers (48%) care for someone with dementia**

# Stages of Dementia

Dementia is **progressive**, meaning **symptoms get worse** and start to interfere with daily life. Over time, your loved one will need more help with **activities of daily living**, such as cooking, dressing, or managing personal care. How quickly dementia progresses can vary, depending on factors like **age**, **overall health**, and the **type of dementia**.

Some experts say dementia progresses through **seven stages**, ranging from **no cognitive decline to severe cognitive decline**. However, symptoms can **change or fluctuate** day to day, making it difficult to pinpoint an exact stage. For simplicity, it can be helpful to think of dementia in **three broad stages**: **early**, **middle**, and **late**.



You cannot control how dementia progresses, and it can be painful to see your loved one move from one stage to the next. However, **understanding these stages** can help you prepare and provide the support they need as their condition changes.

“  
*Let go of what was,  
to appreciate what  
is possible.*  
- Teepa Snow



## Early Stage

In the **early stage of dementia**, changes are **mild but noticeable**. Your loved may still live independently, but need help staying organized and remembering details. It's a good time to plan for the future, focus on their strengths, and keep them active and involved. **Common changes and challenges include:**

-  Changes in **personality, behavior, or mood**, including apathy, irritability, and losing interest in previously enjoyed activities
-  **Forgetting appointments, conversations, or recent events** (e.g., not remembering a lunch date or repeating themselves several times)
-  **Losing track of time or misplacing things** (e.g., forgetting what day it is or asking about the same event multiple times)
-  Feeling anxious or **hesitant to socialize** with others because they're afraid of forgetting names or details
-  Trouble **following plans, managing finances, or completing complex tasks** (e.g., trouble balancing a checkbook, paying bills, or following a recipe)
-  **Vision or perception difficulties**, (e.g., trouble judging distances or missing steps on the stairs)



*The early stage  
of dementia lasts  
around 2 years  
on average*

Alzheimer's Society

## Middle Stage

The **middle stage of dementia** brings more noticeable changes, and your loved one will need **more support in day-to-day**. Caregivers take on a **larger role**, keeping things running smoothly. **Common changes and challenges include:**

-  Struggling with tasks that involve **multiple steps** (e.g., preparing a meal, managing medications, or using appliances)
-  **Forgetting** familiar people, places, or events (e.g., not recognizing a close friend or forgetting the layout of their home)
-  Trouble **finding** words, **following** conversations, or **communicating** clearly (e.g., using vague language like “that thing” or repeating questions)
-  Changes in mood or behavior, such as **restlessness**, **frustration**, or **wandering** (e.g., pacing the house or becoming upset without a clear reason)
-  Needing **help with daily tasks** (e.g., needing reminders or hands-on help to dress, bathe, or eat)
-  Becoming **confused** or **disoriented** in new or old environments (e.g., getting lost even in the home or neighborhood they know well)
-  Hearing or seeing things that are not there (**hallucinations**), or believing things that are not true (**delusions**)



*The middle stage  
of dementia lasts  
around 2-4 years  
on average*

Alzheimer's Society

## Late Stage

In the **late stage of dementia**, your loved one will need **full-time care and support**. They will become more dependent on others and less aware of their surroundings. As a caregiver, you can provide **comfort and reassurance** to help them feel safe. **Common changes and challenges include:**



**Limited ability to communicate with or recognize** loved ones (e.g., responding only to facial expressions or tone of voice)



**Loss of physical abilities**, including walking, sitting up, or swallowing (e.g., needing assistance to move or eat pureed food)



**Increased infections or health complications** (e.g., frequent illnesses, bedsores, blood clots)



**Sleeping more** and being **less aware of their surroundings** (e.g., spending much of the day in bed)



**Depend on caregivers for personal care tasks** (e.g., needing help with eating, toileting, and hygiene)



Easily **distressed or agitated**, often for reasons that are hard to understand, like delusions or hallucinations.



*The late stage of dementia lasts around 1-2 years on average*

Alzheimer's Society

# Diagnosis

## Importance of Early Diagnosis

**Fear, shame, or uncertainty** can make caregivers hesitant to seek a dementia diagnosis for their loved one, but getting an **early diagnosis has benefits** and is often the best choice.

An early diagnosis can make treatments work better. There is no cure for dementia, but some **medications can help with symptoms** like memory loss and confusion. A formal diagnosis may also allow your loved one to **join clinical trials**, which could help them and support future research.

An early dementia diagnosis gives your family time to **prepare and plan**. Your loved one can share their wishes and make important decisions, such as **setting up a will, power of attorney, or guardianship**. They may also have time to complete **personal goals**, like taking a trip, finishing a project, or reconnecting with loved ones.

An early diagnosis gives caregivers **time to learn** about dementia, understand what to expect, and **find support** services that can help. This can improve the care and support your loved one receives.

An early diagnosis can also **help financially**. Studies show that diagnosing “**mild cognitive impairment**” early can help families **save in care costs** (Alzheimer’s Association, n.d.). It gives families time to **plan finances** and **access resources** to reduce the burden.

An early diagnosis empowers your loved one to **challenge the stigma** of dementia. They can **advocate for themselves, share** their experiences, and **connect** with others in similar situations. This helps them and promotes **understanding and acceptance** of the condition.

Even with all the benefits, pursuing a formal diagnosis can still feel scary. Remember, **not all memory problems are caused by dementia**. The symptoms you’ve noticed might be related to something else, which is why seeking help is so important. If it is dementia, it’s better to be prepared for what’s ahead than caught off guard.



## The Diagnostic Process

Receiving a dementia diagnosis can be a complex process because **no single test can determine whether a person has dementia**. Instead, doctors use a **combination of approaches** to assess whether symptoms point to dementia and, if so, to identify the type (Mayo Clinic, n.d.).

If you think your loved one might have dementia, reach out to their **primary care doctor**. They know the most about your loved one, and can help guide the process. Discuss changes you've noticed in your loved one's **memory, thinking, behavior, or daily activities**. It's also important to **review current medications, family history, or other factors** that could explain these changes. If the doctor shares your concerns, they will likely suggest cognitive testing as the next step.

Cognitive tests assess memory, problem-solving skills, attention, language, and other cognitive abilities. Commonly used tools include the **Mini-Mental State Examination (MMSE)** and the **Montreal Cognitive Assessment (MoCA)**. These assessments are quick and non-invasive, making them less stressful for you and your loved one.



The doctor may recommend **laboratory tests**, such as a **blood panel**, to rule out other potential symptom causes, like infections, thyroid issues, or vitamin deficiencies. An **MRI or CT scan** may be ordered to look for brain abnormalities, such as strokes, tumors, or changes in brain structure, to explain the symptoms.

After reviewing all the information, doctors will try to determine the cause of the symptoms, which may **result in a diagnosis** like Alzheimer's, Vascular Dementia, or Lewy Body Dementia. If they're unsure, they may **monitor symptoms over time and update the diagnosis** as needed.

## Normal Aging or Dementia

**Normal changes** in memory and behavior can sometimes be **mistaken for signs of dementia**. This chart can help differentiate between **normal aging and potential dementia symptoms**, but remember to always consult a doctor if you have concerns.

Symptom	Normal Aging	Dementia Symptom
<b>Memory Loss</b>	Occasionally forgetting names, personal history, or appointments but remembering them later	Frequently forgetting recent events or conversations and not remembering them later
<b>Finding the Right Words</b>	Sometimes having trouble finding the right word	Struggling to find words, substituting for unusual words, or using inappropriate words
<b>Problem Solving</b>	Making occasional errors while managing finances or solving puzzles	Inability to manage finances, or having trouble following instructions, either written or verbal
<b>Getting Lost</b>	Getting lost or taking a wrong turn, but finding your way back without help	Not remembering how you got lost, or how to get back home.
<b>Mood and Behavior</b>	Sometimes being in a bad mood, or having a bad day	Frequent mood swings, confusion, suspiciousness, or fearfulness
<b>Social Withdrawal</b>	Not wanting to go out sometimes	Withdrawning from clubs, groups, or activities they enjoy

# **Challenging Behaviors**

Along with memory loss and cognitive changes, most people with dementia will experience behavioral symptoms as the disease progresses. How often and how severe these behaviors occur varies. Medical conditions, the environment, and some medications can make them worse (Alzheimer's Association, 2021).

## **Sleep Disturbances**

Difficulty falling asleep, staying asleep, or changes in sleep patterns, leading to restlessness at night and drowsiness during the day.

## **Anger & Agitation**

Physical or verbal aggression, emotional distress, restlessness, pacing, repetitive actions, or excessive yelling.

## **Delusions**

A strong belief in something that isn't true, resulting in confusion, misunderstandings, and fear.

## **Hallucinations**

Perception of things that aren't real, such as seeing, hearing, or feeling objects or people that are not there.

## **Wandering**

Walking around without a clear direction or purpose, leading to getting lost or confused.

## Potential Causes

Cognitive decline makes it **harder to understand the world**, which can cause distress or challenging behaviors. If your loved one has a **sudden change** in behavior, it might be due to an **underlying issue** they can't communicate (Alzheimer's Association, 2021).

### Discomfort or Pain

**Unmet physical needs**, such as hunger, thirst, or the need to use the bathroom, along with pain or discomfort from conditions like arthritis or infections, can lead to **frustration, restlessness, or aggression**, especially when the person cannot communicate their discomfort.

### Medication

Medications for dementia or other conditions can **cause side effects** such as **agitation, drowsiness, or dizziness**. **Combining medications or incorrect dosages** may increase confusion, worsen memory issues, or trigger behavior changes.

### Environment

**Changes in the environment**, like too much noise, busy activity, or unfamiliar places can make a person feel confused, anxious, or unsafe. This might lead to behaviors like wandering or becoming agitated.

### Unmet Social Needs

**Lack of social interaction** or meaningful activities can cause **boredom** and feelings of **purposelessness**. This may lead to behaviors like **agitation, restlessness, repetitive actions, or wandering** as the person seeks stimulation or connection.

### Communication Challenges

**Difficulty expressing needs** or understanding others can lead to **frustration and confusion**. This may result in behaviors like **yelling, refusing help, or resisting instructions** as the person struggles to communicate.



## Managing Challenging Behaviors

### Sleep Disturbances

**Sleep disturbances, restlessness, or confusion** in the **late afternoon and night** (sometimes called “**sundowning**”) are common in dementia. To manage, **stick to a routine** for meals, activities, and bedtime. Encourage your loved one to **stay active during the day** and spend time in natural light, which can help them sleep better at night.

In the evening, **avoid some foods and drinks** like caffeinated sodas and teas, alcohol, sugary snacks, heavy meals, or spicy items. Activities such as watching **intense TV shows**, having **serious discussions**, or **exercising** should also be avoided.

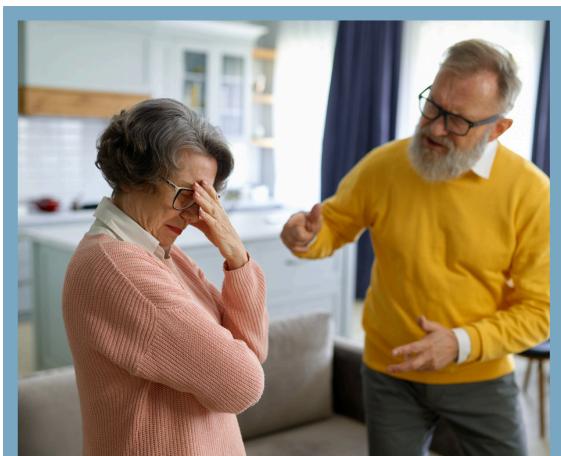
Encourage relaxation with **calming activities** like reading or listening to soft music. Make sure their bedroom is **quiet, comfortable**, and **dark**, but use a nightlight to prevent confusion or injury if they wake during the night. If they become agitated, **remain calm** and gently guide them back to bed. Consult their doctor if challenges continue or get worse. **Treatment options** might include new medications, adjusting current ones, or changing medication schedule.



### Anger & Agitation

**Speak gently, avoid arguments**, and use **soothing body language**, such as slow and relaxed movements, a soft facial expression, and gentle eye contact. **Check for triggers** like hunger, discomfort, or changes in routine, and address them.

Redirect their focus to **calming activities**, like listening to music, folding laundry, or taking a walk. If you feel overwhelmed, or like you can't control your reactions, **take a short break**. Remember, their behavior is part of the disease, not a reflection of their feelings toward you, so try to be patient.



## Managing Challenging Behaviors

### Delusions and Hallucinations

When your loved one has delusions or hallucinations, it's important to stay calm and avoid arguing, as trying to convince them they're wrong can **make things worse**. Instead, focus on **validating their emotions and providing reassurance**. For example, if they believe someone stole something (**delusion**), you might say, "Let's look for it together," or gently redirect their attention without directly challenging the belief. If they see or hear something that isn't there (**hallucination**), offer comfort by saying something like, "I'm here with you, and you're safe." The goal is to comfort them without making them feel embarrassed or upset.

**Distractions** can be very helpful. **Redirect their attention** to something else, like a favorite activity or item. A consistent routine and quiet environment can **reduce delusions**, and keeping spaces well-lit and free of shadows can **minimize hallucinations**. If these behaviors happen often and cause distress, talk to their doctor for advice or treatment options. Remember, delusions and hallucinations are part of the disease, and **responding with patience and kindness** can make these moments easier for both of you.

### Wandering

Wandering is common in dementia, but there are ways to **manage it safely and respectfully**. Pay attention to **when and why** wandering happens - it may be triggered by certain times of day, boredom, or anxiety. A consistent routine and activity **schedule** can reduce restlessness and keep them occupied.

Make sure your loved one has identification, like an **ID bracelet**, in case they wander. If wandering happens often, you might need to add **locks, alarms, or cameras** to keep them safe and let you know if they leave. These steps can feel hard to take, but they are sometimes needed for protection. Talk to their doctor for more ideas on keeping them safe while **supporting their independence**.



# Dementia Friendly Communication

As the disease progresses, you'll need to **change how you talk and interact** with your loved one. This can be challenging, especially if you're used to communicating a certain way. But adapting doesn't mean losing your connection - it's about finding **new ways to meet your loved one where they are.**

## Slow Down & Simplify

When talking to someone with dementia, **slow down** and **speak clearly**. They may have a hard time understanding if you rush your words. **Enunciate** your words and use simple, **straightforward language**.

When giving instructions, **don't overwhelm them with too much information**. Instead of saying, "Mom, get your shoes on, grab your coat, glasses, umbrella, and insurance cards, we need to leave in five minutes," **break it down into individual steps**, saying, "Hey Mom, could you please grab your umbrella? I don't want to get wet on the way to your doctor's appointment." Move on to the next step once the first task is completed.



## Be Patient & Show Concern

When your loved one resists something, try to **be patient**. For example, if your dad doesn't want to eat dinner, **avoid pressuring** him. Try a gentle approach, saying, "I want to make sure you stay healthy. Is there something you'd like to eat?" This shows your care and concern, and makes them feel independent.

## Encourage Autonomy

Whenever possible, allow your loved one to **maintain their independence**. It can be frustrating for them if you take over tasks they are attempting to do themselves. Instead of stepping in with, "Let me do that for you," **let them try**, and if they struggle, **offer help** by saying, "Can I help you with that?" This approach respects their dignity.

## Avoid Memory Tests

**Never ask your loved one if they remember something.** Instead of saying, “Don’t you remember, we went to the doctor’s office this morning,” rephrase it as, “We went to the doctor’s office this morning - you did great, and the doctor said you’re healthy.” This **avoids putting them on the spot** and reduces the likelihood of frustration or embarrassment.

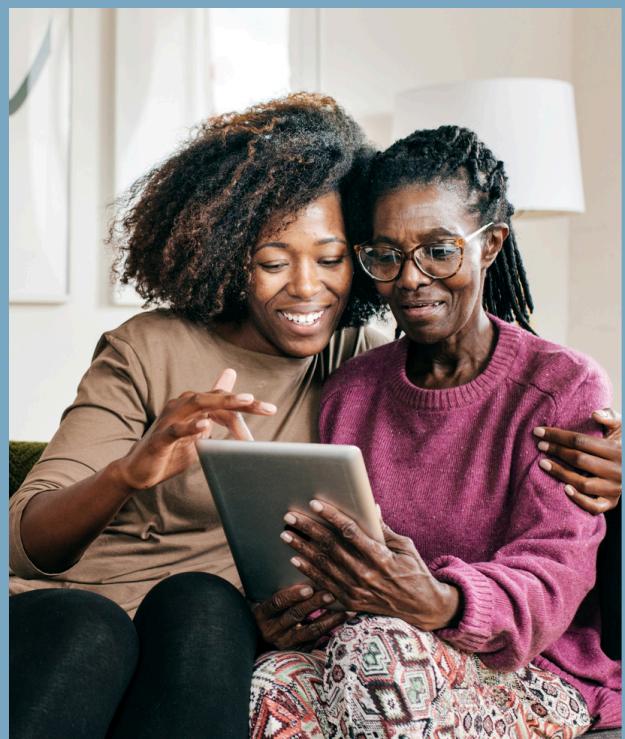
## Live in Their World

**Meet your loved one where they are.** If they talk about something from the past or want to visit a friend who has passed away, **avoid correcting them directly.** Instead, gently **redirect the conversation** using details from their memory.

For example, you could say, “Isn’t Joe a teacher? We wouldn’t want to bother him while he’s in class. Let’s try reaching out later.” Telling them outright that someone has passed can cause unnecessary distress, as that person still feels very real to them. While it might feel uncomfortable, **guiding them within their reality** can be a kinder approach.

*If we want a different outcome, we need to change how we are approaching the entire situation.*

- Teepa Snow



# Dementia Friendly Activities

Consider your loved one's **current stage of dementia** when planning activities. What might be enjoyable and engaging for someone in one stage may not be suitable for someone in another stage.

## Early-Stage Activities

In the **early stage** of dementia, your loved one still has independence and stronger cognitive abilities. This is a great time to **learn a simple new skill**, as they may still enjoy growing and trying new things.

## Middle-Stage Activities

In the **middle stage** of dementia, your loved one may struggle with tasks that involve multiple steps. **Simplify activities** by breaking them into **one step at a time**. **Crafts or other creative projects** can be enjoyable and manageable during this stage.

## Late-Stage Activities

In the **late stage** of dementia, your loved one may find it difficult to communicate or recognize people and familiar things. **Simple sensory activities** can be comforting and engaging during this time.



## Creative Activities

### Painting & Coloring

Get a large roll of paper, like butcher paper, along with colored paints, pencils, and markers. The big paper gives your loved one plenty of **space to create without feeling limited**, and the bright colors help them express themselves freely.

### Crafts

Pick simple crafts that let your loved one **explore different textures**. They could try playing with soft moldable clay, stringing colorful beads, arranging flowers, or even sorting fabrics like felt or silk. These activities are fun, soothing, and stimulating.

### Collage

Find pictures from magazines or print family photos of things your loved one likes, like food, clothes, or places. Let them **arrange the pictures** to make simple scrapbook pages.

### Fulfilling Activities

#### Folding Laundry

Folding laundry can give your loved one a **sense of purpose**. Start with simple items like towels or socks. Don't worry if they fold something "wrong" - you can fix it later.

#### Untie Knots

Tie loose, simple knots in a thick rope and **ask your loved one to help untie them**. This activity provides mental and physical stimulation, is relatively easy and frustration-free.

#### Puzzles

Choose puzzles with **large pieces, bright colors, or simple pictures and shapes**. Work on the puzzle together for a fun and engaging activity that stimulates the mind.



## Sensory Activities

### Exercise

Take your loved one for a **walk in the yard or at the park**. Talk about what you **see, hear, smell**, and **feel** along the way. Try simple exercises like chair yoga or stretching to help them relax and sleep better.

### Touch & Feel Boxes

Fill a box with items that have **different textures**, like soft fabrics, sponges, smooth stones, cotton balls, or even sand. Let your loved one **explore the items with their hands**, enjoying the different sensations while staying calm and engaged.

### Aromatherapy

Make **smell jars** filled with items like cinnamon sticks, coffee beans, orange peels, or herbs. Let your loved one explore each jar and **describe the scents** they notice.



## Reminiscing Activities

### TV, Movies, and Music

**Entertain and stimulate memories** by watching and listening to classic films, shows, and music together. Ask what they **think, feel, or remember** while doing this activity

### Board Games

Play a board game your loved one used to enjoy. Don't worry about following the rules - **let them play in their own way**. Encourage them to **take the lead or "teach"** you to play.



### Photo Albums & Storytelling

Look through photo albums or watch home videos together. Let your loved one share memories **as they remember them**, even if some details aren't accurate. Only offer corrections if they ask for them.

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