

Dementia: *First Steps after Diagnosis*

What you need to know today

“You have dementia.” People react to these words in different ways. It’s natural to feel sad and grieve for a while. Take your time to understand your emotions and what your diagnosis means for you and your family.

What you may be feeling

- **Denial.** When first diagnosed, many people think, “Not me — the test results must be wrong” or “I can ignore this.” At first, denial may actually help keep you from getting overwhelmed. It lets the truth sink in little by little as you’re ready.
- **Fear or anxiety.** It is scary to learn that you have dementia. What will the future hold? Learning more will help calm your fears.
- **Anger.** Newly diagnosed patients often think, “Why me?” It’s normal to be angry. Dementia is not something you wanted or planned for.
- **Sadness.** People often go through a period of sadness after a diagnosis of dementia. For most people, this feeling stems from a sense of loss. You, too, may need to grieve the loss of your “old” (pre-diagnosis) self-image or lifestyle.

For most people, these feelings ease with time. You may have just gotten a diagnosis, but the changes that cause dementia have been active in your brain for years. Dementia is a slow process, and the changes ahead will also probably come on slowly.

Now that you have a diagnosis, you can plan for your future and focus on what matters most.



Tips for today

Use these tips to help cope with your feelings:

- **Give yourself time to adjust in your own way.** Some people need to talk. Some want to start reading the medical research. And others just want to be left alone for a while. Pay attention to your feelings, and take care of yourself in the way that’s best for you.
- **Talk about your feelings.** You may feel more at peace by talking to someone you trust about what you’re going through. Ask your healthcare provider to refer you to see a counselor or connect you with local support groups.
- **Learn to relax.** Find ways to relax your mind and body. Some people find exercise and hobbies relaxing. Others prefer meditation, prayer, or yoga. Simple deep breathing can also help you relax.
- **Most of all, try not to get too discouraged.** With time — and a little help from others — you can move through your grief and better cope with the changes ahead.

When you feel ready for more information, the rest of this fact sheet can answer some of your questions and give you links for more detail.

What is dementia?

Dementia is a condition that causes ongoing problems with thinking, remembering, and behavior. It happens most often in people older than 65. While everyone forgets things or behaves differently on occasion, people with dementia experience these changes more often. And, the changes get worse over time.

For example, people with dementia may:

- Ask the same question or repeat the same story over and over
- Get lost in familiar places
- Struggle to follow simple or familiar directions (like how to work the microwave)
- Get confused about time, people, and places
- Neglect personal safety, nutrition, and bathing

Those who may have some trouble remembering but can still do normal daily activities on their own have **mild cognitive impairment (MCI)**. Sometimes a person's MCI gets worse and becomes dementia. Sometimes, it gets better or doesn't change at all.

In early dementia, you won't feel sick. Most people who are diagnosed with dementia feel healthy for a very long time (years).

What causes dementia?

There are different types of dementia, all resulting from brain cells that stop functioning:

- Most people with dementia have **Alzheimer's** [ahltz-HAHY-merz] **disease**, which causes changes in the brain slowly, usually over 4 or more years.
- The next most common kind of dementia is **vascular dementia**, which happens when the brain doesn't get enough blood due to a stroke or when blood flow is blocked by a blood clot.
- Less-common forms of dementia include:
 - **Dementia associated with Parkinson's disease**—caused by a decline in nerve cells as Parkinson's disease progresses
 - **Frontotemporal** [fruhnt-oh-TEM-per-uh] **dementia**—caused by a decline in the “lobes” of the brain that control personality, behavior, and language
 - **Dementia with Lewy bodies**—caused by protein deposits that develop in nerve cells in the brain

The difference between Alzheimer's disease and vascular dementia

Alzheimer's Disease	Vascular Dementia
Happens when damage to nerve cells spreads throughout the brain	Happens when a stroke or changes in the brain's blood supply lead to the death of some brain tissue
Symptoms begin slowly and get worse over time	Symptoms usually begin suddenly and vary depending on the part of the brain affected and how severe the stroke or blood clot
Forgetfulness over time develops into problems with thinking, judgment, recognizing familiar people, and performing daily activities	Problems with memory, language, reasoning, and coordination may happen along with mood and personality changes

How is dementia diagnosed?

There is currently no definitive blood test or imaging study (like an MRI or CT scan) that tells your doctor that you have dementia. Instead, your doctor and other specialists will gather information from several sources before diagnosing dementia including:

- Performing a screening memory test (called a “Mini-Cog”) and a follow-up test (called “MoCA”)
- Asking you and your family or friends about life at home — are there things that you could once do easily but now struggle with
- Ordering some lab tests or reviewing recent ones you've had
- Suggesting getting an MRI or CT scan of your brain
- Referring you to a specialist, like a **neurologist** [noo-ROL-uh-jist] or **neuropsychologist** [noo r-oh-sahy-KOL-uh-jist], for more detailed memory testing

Who can help?

You may have a variety of healthcare providers on **your team** to support you and teach you ways to live with new challenges. Your team may include doctors, nurses, neuropsychologists, neurologists, counselors, speech language pathologists, registered dietitian nutritionists (RDNs), care managers, health advocates, and others in your community.

Keep in mind that **YOU** are the most important person on your care team. Regularly talk to your team about your needs and concerns.

Follow your treatment plan, and involve **your care partner** — a spouse, adult child, close friend, or neighbor.

How is dementia treated?

While some medicines can help with some symptoms, there currently is no cure for dementia. However, there are a number of things that you and your doctor can start doing right now to help slow down the process and live the healthiest, happiest life possible:

- **Manage medical conditions that can make memory worse.** Certain health conditions also cause problems with thinking and remembering. These include:
 - Untreated thyroid disease
 - Vitamin B12 deficiency
 - Depression
 - Infections
 - Delirium
 - Heart failure
 - Diabetes
 - Obstructive sleep apnea
 - High cholesterol
 - High blood pressure
 - Kidney failure
 - Drug and alcohol use
- **Go to all of your appointments.** The only way your doctor can monitor how you are doing and support your needs as they develop is by you keeping your regular follow-up appointments.
- **Focus on taking care of yourself.** Develop a self-care plan for managing your medicines, diet, exercise, safety, and planning for the future. With your care manager, use Intermountain’s fact sheet: **[Dementia: Personal Action Plan](#)** to help you get started.
- **Ask for support.** Talk with your family and friends about your diagnosis. Tell them what you want for your care and living situation in the years to come. Join a local support group, and use the many online resources available at **[alz.org](#)**, such as:
 - **Patients Newly Diagnosed:** **[alz.org/i-have-alz/just-diagnosed.asp](#)**
 - **Taking Care of Yourself:** **[alz.org/i-have-alz/taking-care-of-yourself.asp](#)**
 - **Tips for Daily Life:** **[alz.org/i-have-alz/tips-for-daily-life.asp](#)**

For caregivers, family, and friends

Learning that your loved one has dementia can be upsetting. It is a serious problem, but changes will happen slowly over time, giving you and your loved one time to plan for the future and enjoy the present.

Here are a few things to keep in mind:

- **Your loved one needs time to adjust.**
Give your loved one some time and space to process the diagnosis in the first days after the diagnosis. Be supportive: Listen without making judgments or offering advice.
- **You'll need to change and learn, too.**
Dementia will affect your family life, at first in small ways, and then in larger ways. You can make this process easier if you take time to learn more about dementia and how to support necessary lifestyle changes.
- **You will also need support.** Just because you're not the one with dementia doesn't mean you have it easy. You will likely feel denial, fear, anxiety, anger, and sadness — just like your loved one. This is normal. Talk with people outside your family about these feelings.
Be sure to take time for yourself, eat right, and get enough exercise. Reach out for support. Making contact with your local Alzheimer's Association is a great place to start.



Helpful Links for Caregivers

- **Taking Action Workbook:**
[alz.org/i-have-alz/downloads/lwaspwd_taking_action_workbook.pdf](https://www.alz.org/i-have-alz/downloads/lwaspwd_taking_action_workbook.pdf)
- **Healthy Caregiving:**
[alz.org/care/alzheimers-dementia-healthy-caregiver.asp](https://www.alz.org/care/alzheimers-dementia-healthy-caregiver.asp)
- **Tips for Communicating:**
[alz.org/care/dementia-communication-tips.asp](https://www.alz.org/care/dementia-communication-tips.asp)
- **Caregiving for Early-Stage Dementia:**
[alz.org/care/alzheimers-early-mild-stage-caregiving.asp](https://www.alz.org/care/alzheimers-early-mild-stage-caregiving.asp)



Questions for my doctor

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