

Caring For A Loved One With Dementia

a practical
guide
for family
caregivers
3

How to Get a Diagnosis *and what to do next?*



Introduction

At every stage of life, it is wise to pay attention to how your brain and memory are functioning.

This is especially true at age 55 and older. Taking steps early can help prevent diseases, delay progression, and lead to treatment and interventions that can extend quality of life.

While normal aging includes experiences like slower recall, more difficulty remembering names, and taking longer to learn new things, these are, in fact, normal experiences. Cognitive disorders, or memory disorders, are conditions that cause individuals to have difficulty thinking clearly. They can impair perception, memory, communication, reasoning, judgment, or socially appropriate behavior. Some people may also have changes in mood. Not all memory loss means Alzheimer's disease. Memory loss can also be the product of other medical and psychiatric conditions, including depression.

No matter the cause, memory loss is NEVER normal at any age, and you should always seek medical attention for someone experiencing changes in memory, and begin treatment as soon as possible as most disorders are treatable when detected early.



Alzheimer's disease has a gradual onset, and it can be easy to miss early signs, or write them off as “getting old”. This can result in waiting too long to get treatment, so it is important to know the signs.

Get an annual memory assessment¹ after 55 years old.
Ask your doctor for more information.

Know the Signs



- 1 MEMORY LOSS INTERFERING WITH DAILY LIFE**
Forgetting recently learned information, important dates or events, or need memory aids.
- 2 CONCENTRATION DIFFICULTIES**
Experiencing a change in one's ability to plan, solving problems, or focus on familiar tasks.
- 3 CHALLENGES IN COMPLETING TASKS**
Having difficulty in completing daily tasks, such as keeping track of the monthly bills, or following a recipe.
- 4 DISORIENTATION**
Becoming disoriented in familiar places and experiencing confusion with time.
- 5 VISUAL AND SPATIAL CHALLENGES**
Experiencing visual and spatial difficulties, including trouble judging distances, reading, or determining colors and contrasts, which may make driving more challenging.



- 6 MOOD AND PERSONALITY CHANGE**
Becoming depressed, fearful, suspicious, anxious, upset, or confused. Becoming distressed at work, with friends, or in places where they are not in their comfort zone.
- 7 DIFFICULTY SPEAKING AND WRITING**
Having trouble finding the right words, following or joining a conversation, repeating oneself, or forgetting in the middle of a sentence.
- 8 MISPLACING THINGS AND LOSING THE ABILITY TO RETRACE STEPS**
Placing things in unusual places. Losing something and lacking the ability to retrace their steps to find it. Accusing others of stealing or become distrustful.
- 9 DECREASED JUDGMENT AND DECISION MAKING**
Using poor judgement when dealing with money (i.e., giving large amounts to telemarketers). Starting to pay less attention to personal hygiene and grooming.
- 10 WITHDRAWAL FROM WORK OR SOCIAL ACTIVITIES**
Having trouble keeping up with a favorite sport or hobby, and starting to remove themselves from social activities.

Despite the frightening experience of seeking or getting a diagnosis of Alzheimer's disease or another dementia, there are treatments and interventions available that can help slow the progression, decrease symptoms, and improve function over a number of years.

Being proactive is the best action you can take to manage any memory loss condition with the best possible long term outcomes.

Here are steps to advocate for yourself or a loved one with possible memory loss:

1. Get a memory assessment.

The first step to self-care for memory is a yearly memory assessment. Think of it as your annual physical, but for your brain. An in-person memory assessment can help normalize changes, detect early symptoms of a memory problem, and provide education to reduce your risk. Alzheimer's disease has a gradual onset. It can be easy to miss early signs, or write them off as “getting old”. The assessment takes about an hour, may be covered by insurance, and will help you stay on top of these changes.

When a memory assessment is not available in your area, you can request a cognitive assessment from your primary care physician every year.

In the event that a memory disorder is suspected, detected, or simply evident to yourself or your loved ones, it is important to take swift and direct action for treatment.

What is the next step?

2. See a Neurologist.

Many times a memory disorder is diagnosed by a primary care physician. While this may be a good first step, it is not your final destination.

A neurologist is a doctor that specializes in the nervous system, and specifically treating the brain and spinal cord. Some neurologists will further specialize in neurodegenerative disorders, such as Alzheimer's disease, Parkinson's disease, or Multiple Sclerosis. In the same way that you would see an oncologist to treat cancer, you should see a neurologist for a brain or memory disorder. Often times, the neurologist will have access to treatments, medications, and therapies that may not be well-known in general medicine. They may also order additional tests, scans, and imaging that will help establish an accurate diagnosis and provide options for treatment.

Your neurologist is the best person to provide all options for treatment and inform you about your choices. You may be told that you don't need to see a neurologist, or that nothing more can be done. Ask. Insist. Persist. You deserve the best and most comprehensive care, and can decide for yourself after exploring this resource.



3. Know the Diagnosis

There are more than 60 types of dementia.² The most common of these is Alzheimer's disease, which accounts for about 70% of all cases. Vascular dementia, Lewy Body dementia, and Frontotemporal dementia are also common types. Although all types of dementia result in memory impairments, each type may have different symptoms, course of illness, behaviors associated with it, and treatment options.

Getting the right diagnosis can help you as a caregiver anticipate the behaviors and changes that may occur, and choose appropriate treatment options. Further, it will help you educate family and friends, and perhaps find a support group tailored to that type of illness. The type of dementia can also help your family understand any hereditary or genetic risks that may be associated with the disease. While Familial Alzheimer's disease (FAD) is very rare, accounting for less than 3% of all cases, some types are more likely to have a stronger genetic component. Knowing and understanding you and your family's medical history increases your ability to manage it and make decisions.



4. Learn about the Diagnosis

Some diagnoses can be made with certainty, others may be the “most likely” diagnosis. Either way, a great way to advocate for and inform yourself is to learn about the diagnosis. This will give you resources, coping skills, and the ability to make informed decisions.

Lewy Body Dementia

Patients tend to have hallucinations, delusions, body stiffness and rigidity.

Frontotemporal Dementia

Individuals can be very impulsive, and exhibit behaviors they would not normally have done, such as stealing or singing loudly in restaurants.

Different types of dementias may present with very different symptoms and behaviors. Two people who diagnosed with dementia may behave very differently.

Some may decline fast, others may stay the same for a long time. Behaviors may come and go, and techniques for calming, redirecting, or supporting the patient may work one day and not the next.

Each person's course of illness is directly affected by lifestyle, genetics, environment and other medical conditions. Getting a good idea of what to expect and what the diagnosis means will help you plan for what is next.

5. Explore Treatment Options

It is a common belief that there are no treatments for Alzheimer's disease or other dementias, thankfully, this is not true. Research, clinical trials, and advances in medicine and healthcare have discovered interventions and options to manage dementia as a treatable health condition. This is not a curable condition, and the damage cannot be reversed or stopped, but the progression of the disease may be slowed by some interventions.

Here are some interventions supported by research and shown to help brain function:

• **Socialization.** First and foremost, socialization is shown to profoundly help us maintain brain function. While it may be tempting to retreat to home and not share the diagnosis with friends or family, continuing to socialize and interact is one of the most helpful steps in treating dementia.



• **Exercise.** Exercise has an immediate benefit for every part of the body. Not only will it keep you moving fluidly and help manage cardiovascular conditions, it also helps reduce the risk of vascular dementia.

• **Diet.** A healthy diet at any age can have its benefits. In the MIND Diet Study, 82 year old patients who adhered most closely to the MIND Diet were found to have an improvement in cognitive skills the equivalent of being 7.5 years younger!

Research: MIND Diet³

- Study population: 960 participants / 81.4 average years
- Participants who adhered most closely to the MIND diet had statistically significant slower rates in cognitive decline.
- The difference in rates was the equivalent of being 7.5 years younger.



• **New Learning.** Learning a new activity or skill can help keep your brain strong and healthy. When we learn new things, our brain forms new connections. The elasticity of those connections is improved, improving our ability to access and recall information for a longer period of time. Engaging in challenging brain exercises, such as puzzles, games, and memory tasks can also support brain health.

• **Reduce Stress.** When we are under significant stress, our cognitive performance is reduced. Think about it: do you drive as well in a severe thunderstorm as on a sunny day? Of course not, and the change in performance is mostly due to stress. The same is true for our memory skills. We will remember better, and think more clearly with less stress.



The MIND Diet suggests that a person should eat:

More:

- Green leafy vegetables
- Berries
- Unsalted nuts
- Olive oil
- Whole grains
- Fish and poultry (not fried)
- Beans

Less:

- Butter, margarine
- Cheese
- Red meat
- Fast fried foods
- Pastries and sweets

• **Treat Depression.** Depression is a well-known risk factor for speeding up the progression of dementia. Treating it helps reduce that risk. Depression can be treated through therapy, anti-depressants, or a combination of both, which tends to be the most effective treatment.

• **Medications.** Work with your neurologist to explore the medication options available for the diagnosis. A combination of medications has been shown to have the best outcomes for slowing progression of dementia.



While medications may have side effects, they are a critical piece of treatment. In some cases, they may extend the quality of life and continued independence for a patient for 10 years. The earlier a patient can start on medications, the better the long term prognosis.

6. Educate Family & Friends

Sharing the diagnosis with others can be frightening. Some people worry that others will judge them, blame them, or that they will embarrass their loved one by telling others. No one chooses to develop dementia, any more than one would choose to have a heart attack or stroke.

Dementia is a very stigmatized diagnosis, although no one brings this upon themselves or is at fault for having Alzheimer's disease.

Some people may continue to live independently with Alzheimer's disease for many years, others will need assistance sooner.

Educating your family and friends about a diagnosis is the first step to de-stigmatizing, teaching others, and gathering resources for support.

As a caregiver, you may have friends or family that would like to offer support, but don't know how to help. They may be fearful about what to expect or simply do not understand the disease. In order to best gather support for your journey, share with others what you have learned about the disease and the course of the illness. Let them know what to expect, and how they can help. When others offer support, take it. You will need a break to care for yourself, and your loved one will benefit from interacting with others.



7. Plan Ahead

Denial is a defense mechanism that might serve its purpose for a short time, but begins to work against you if not addressed and replaced with higher-order coping mechanisms. Failing to plan ahead is a form of denial, and you can avoid unpleasant repercussions by taking a few steps to put things in order.

You may consider assembling a team of professionals to help you navigate the process. This team may include a geriatric case manager, neurologist, primary care physician, geropsychiatrist or neuropsychologist, elder law attorney, home care company, caregiver resource center, and pastor, priest, clergy, spiritual or other support. Refer to the e-book *Assembling a Team for the Journey* for more details.

Planning ahead may include interviewing a home care company, touring an assisted living facility and becoming familiar with those who provide services **long before you need them**. Having a contingency plan will help reduce stress. Utilizing professionals who treat, support, and understand dementia can help make your journey more effective, pleasant, organized, and ensure that you are taking all the steps necessary for the best outcomes and quality of life for both of you.

8. Ongoing Monitoring

Alzheimer's disease and other dementias are ever-changing constellations of new and old symptoms and behaviors, and requires an ability to adapt on an on-going basis. As a caregiver, you will want to continue to keep an eye on the changes, especially the following:

1. Driving.⁴ Assess if your loved one is still safe to drive. If you are concerned, report it to their neurologist or primary care doctor, who will do an assessment. In some cases, patients can take a driving test and retain their license. If they are not safe to drive, the physician will take appropriate steps to keep your loved one and others safe on the road.

2. Activities of Daily Living. Is your loved one able to manage their medications by themselves, or do they need assistance? Are they able to self-initiate personal hygiene, self-care, and regulate food and sleep? If not, you may need to provide assistance yourself or utilize a professional caregiver.

3. Living Alone or Being Alone. One of the best ways to assess if someone is safe to live alone or be alone is through assessing their emergency response. You may ask someone how they would respond in case of a fire, then assess:

- Can the patient recite the emergency number? (911)
- Can the patient dial the emergency number? (911)
- Can the patient recite his/her home address?
- Is posting the emergency number and home address near the phone needed as a temporary solution?

If someone is not able to recall “911” or responds in another way, such as “I’d call my daughter”, they are probably not safe to be home alone and should have 24/7 supervision.

Failing to provide this supervision could put you as a caregiver, at risk for liability, if your loved one or someone else is hurt.

Summary of Key Points

<u>DO</u>	<u>DON'T</u>
(1) Get a memory assessment every year.	Isolate, watch TV and sleep excessively during the day.
(2) Be active and proactive in getting assessments and a diagnosis.	Assume memory loss is just part of getting older.
(3) Explore treatment and begin medication if appropriate.	Try to get a different diagnosis. Deny that anything is wrong.
(4) Advocate for your medical care and see a neurologist. Learn about the diagnosis.	Assume there is nothing that can be done.
(5) Monitor changes and adjust and adapt as needed.	Hide from others for fear of judgement or embarrassment.
(6) Share with friend and family and accept support	

References and Resources

¹Memory Assessment

Check with your doctor if they provide memory assessments at their office.

²Types of Dementia

www.alz.org/dementia/types-of-dementia

³MIND Diet Study

"MIND diet associated with reduced incidence of Alzheimer's disease." *Alzheimers Dement.* 2015 Sep;11(9):1007-14. doi: 10.1016/j.jalz.2014.11.009. Epub 2015 Feb 11.

Authors: Morris MC, Tangney CC, Wang Y, Sacks FM, Bennett DA, Aggarwal NT.

⁴Driving Assessment Resources

- Your local hospital may offer driving tests to determine if your loved one is safe to drive.
- You may also contact your local chapter of the Alzheimer's Association for a referral to a Driver Rehabilitation Specialist. Call at 800-272-3900 for more information.

The series of Caregiver Books "Caring For A Loved One With Dementia - A practical guide for family caregivers" was developed by *Alzheimer's Family Center* in Huntington Beach, California thanks to the generous support of the Arthur N. Rupe Foundation.

Contributors to the series are:

Cheryl Alvarez, PsyD; Corinne Enos, LCSW; Jovanni Juarez, CNA; Tanya Kim, LVN; Judy Osuna; Marie Oyegun, MA; Tracy Pham, RN; Traci Roundy, RN; Roxanne Segroves, RN; Gloria Wear, LVN; Patrick Wallis, MSG.

www.AFSCenter.org