



# A Road Map to Dementia Diagnosis

Information for Patients and Families

Aging & Memory Loss  
Road Map Series

I. Dementia Diagnosis

II. Research Participation

III. Caregiving

## Are you or a loved one experiencing changes in memory and thinking?

Recent studies have indicated that subtle changes in cognitive abilities can occur as early as 10-15 years before noticeable symptoms of brain disease. Thinking and memory concern examples:

- Driving and not remembering where you wanted to go and how to get there/home
- Leaving mail unopened and bills unpaid
- Forgetting appointments and important dates with loved ones

## What are normal changes in memory?

As we age, it is normal to experience some changes in memory. Most older adults experience some type of cognitive change. The following changes are the most common:

- Forgetting names more frequently
- Having trouble switching from one subject to another
- Requiring effort and time to learn new information

Normal age-related memory loss may result from your brain's decreased ability to retrieve information. It can take more time to remember or learn new things. Although it might be irritating, these memory changes should not be significant enough to affect your daily living.

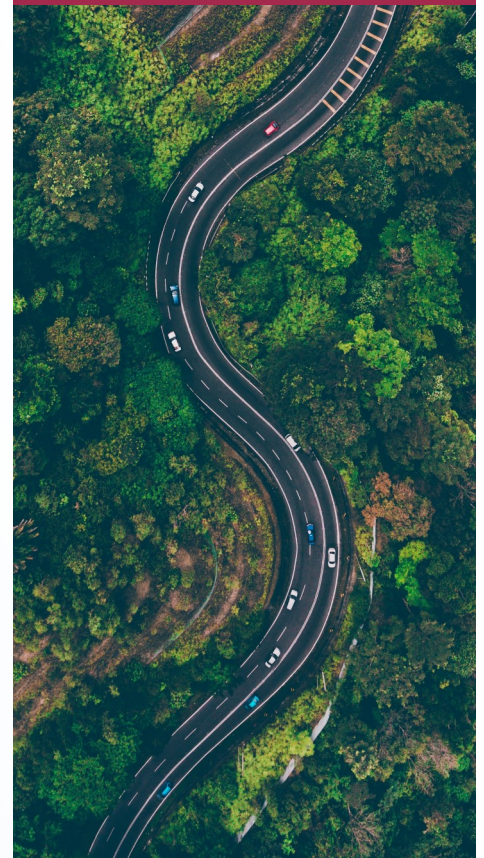


**MASSACHUSETTS**  
Alzheimer's Disease  
Research Center

**BRIGHAM HEALTH**



**BRIGHAM AND WOMEN'S**  
Center for Alzheimer Research and Treatment



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## When should I be worried?

Brain disease develops gradually; dementia begins when your thinking and memory issues interfere with your ability to complete daily tasks and activities. Dementia is an umbrella term used to describe symptoms and changes in cognitive ability, mood, behavior, and daily functioning. Alzheimer's disease (AD) is the most common cause of dementia and can occur on its own or in combination with other dementias. Below are some other diseases that can cause dementia or dementia-like symptoms:

- Vascular dementia
- Lewy body dementia
- Parkinson's disease
- Frontotemporal dementia or Pick's disease
- Huntington's disease
- Normal pressure hydrocephalus
- Physical injury to the head
- Chronic Traumatic Encephalopathy (CTE)

If you experience problems with your memory, but your symptoms are not severe enough to be classified as dementia, your doctor may diagnose you with **Mild Cognitive Impairment (MCI)**. Recent research has shown that people with MCI are more likely to later be diagnosed with dementia, but having MCI does not always mean that you will go on to develop dementia. MCI symptoms may not always interfere with your daily activities and it is less threatening than AD. Symptoms of MCI can include:

- Short-term memory complications
- Word finding difficulties
- Mood changes (i.e. depression, anxiety, apathy, and irritability)
- Impaired high level daily functioning (i.e. managing finances)

## What steps should I take?

Feeling that you may have a problem with your memory or thinking can be worrisome but there are many ways to seek help. *If you have concerns, talk to your primary care physician first.* Your primary care physician may be able to give you a diagnosis if there is a problem. However, they may also refer you to another doctor that specializes in memory and cognition. There are several different types of specialists that can address your symptoms, develop a treatment plan, and refer you to a research program.

Getting a diagnosis can sometimes require you to see multiple specialists and have several diagnostic tests and medical evaluations. This process can take time; do not be discouraged. If you or a loved one needs additional support, there are several resources available to help you through the process. (See page 8 for resources).



## Who can make a diagnosis?

Several different healthcare providers can diagnose and treat dementia. Your primary care physician may make a diagnosis, or they may refer you to one of the following specialists:

- **Geriatrician.** A primary care physician (MD) who specializes in conditions unique to older adults.
- **Geriatric Psychiatrist.** A doctor (MD) who specializes in psychology among older adults. They help detect mood and behavior symptoms associated with dementia such as depression or anxiety.
- **Neurologist.** A specialist (MD) in diseases of the brain and nervous system. A behavioral or cognitive neurologist further specializes in the diagnosis and treatment of conditions like Alzheimer's.
- **Neuropsychologist.** A psychologist (PhD or PsyD) with specialized training in how to assess the structure and function of the brain with standardized tests. Typically, a referral from your doctor is needed to meet with this type of specialist.

## How do I prepare for my appointments?

- Prepare in advance - write down a list of your concerns and symptoms before your visit and know what you want to get out of the visit
- Consider bringing someone you trust to your appointment to take notes and listen
- Bring a list of all your medications for your doctor
- Discuss any new diagnosis and what you can expect
- If you are prescribed a new medication, make sure you know the name and why you are starting to take it
- Ensure you know why a test or procedure is recommended, what happens during the procedure, and what the results could mean
- Ask your doctor about prevention you could implement in your daily life (i.e. diet, activity, & sleep adjustments)
- Know how you can contact your provider if you have questions

Talk to your physician about scheduling periodic check-ups. In addition, there are several new research studies enrolling people with early symptoms of Alzheimer's disease that your doctor may discuss with you.







## What causes Alzheimer's disease?

Alzheimer's disease is the most common form of dementia. Doctors do not yet know what causes the AD. Current research suggests that the following factors may contribute to the development of AD:

- Age
- Family history
- Certain genes
- Abnormal protein deposits in the brain
- Environmental factors
- Immune system deficiencies



## How do I get a diagnosis?

A medical workup is necessary to evaluate how well your brain is functioning. A medical work up may begin with a visit to your primary care provider and will often include a referral to a memory specialist. Memory evaluations used to determine a diagnosis may include:

- Review of personal & family *medical history*
- General *physical exam*
- *Neurological exam* including tests of reflexes, coordination, eye movement, speech, sensation, muscle strength and tone, walking, and balance
- *Brain scan* (CT, MRI, or PET): MRI (magnetic resonance imaging) and CT (computed tomography) scans provide images of the structure of the brain tissue showing its shape and volume. The PET (positron emission tomography) scan uses a contrast to either provide a functional image of the cell activity in the brain or an image of the pathological changes seen in Alzheimer's disease such as amyloid plaques (a protein that is deposited in the brains of patients with Alzheimer's disease).
- *Neuropsychological exam*: Neuropsychological tests evaluate cognitive ability; they consist of interviews, pencil and paper testing, and sometimes computerized tests. These tests can sometimes be frustrating, but they help specialists better understand how your brain is functioning.
- *Questionnaires* about your mood, behavior, and daily functioning. These are usually asked of both the patient and somebody who knows them well, like a family member.

It may take several appointments with different types of healthcare providers to get a diagnosis. All medical practices, academic centers, or primary care practices function in different ways. Alzheimer's disease and other related dementias do not always present the same way in everyone; they are often difficult to diagnose and may require additional evaluations. Make sure to talk to your doctor about the steps involved in your diagnosis and ask your doctor to write down this information for you.

## What happens if I am diagnosed with Alzheimer's disease or a related dementia?

The most common form of dementia is Alzheimer's disease; it is characterized by a decline in brain function over time. This decline is usually a slow and progressive process. Memory loss in Alzheimer's disease is caused by one's diminished ability to consistently store new information.

Sudden changes in a person with dementia should always be evaluated by a healthcare provider. These changes may be caused by other health issues, such as:

- Side effects of medication
- Dehydration
- Thyroid imbalance
- Poor nutrition
- Infection
- Fatigue

The progression of Alzheimer's disease occurs differently in everyone with AD. Make sure to communicate with your healthcare provider if you experience anything out of the ordinary. In the early stages of Alzheimer's disease, some common mood and behavior symptoms are:

- Depression
- Anxiety
- Irritability

Behavioral symptoms that may occur during later stage Alzheimer's disease are:

- Aggression and anger
- Emotional distress
- Anxiety and agitation
- Sleep issues

## Is research right for me?

Research participation is critical to finding a cure. Whether or not you have been diagnosed with Alzheimer's disease or a related dementia, you may be able to participate in research. People participate in research for a variety of reasons. Healthy volunteers and people living with the disease say they participate in clinical trials to help others, contribute to moving the science forward, or receive access to a possible new treatment.

The Massachusetts Alzheimer's Disease Research Center (MADRC) at Massachusetts General Hospital (MGH) and the Center for Alzheimer Research and Treatment (CART) at Brigham and Women's Hospital (BWH) offer a variety of different types of studies ranging from observational studies to clinical trials. If you are interested in research participation at either of these centers, you may call **(617) 278 - 0383**.

**Are you or someone you love experiencing changes in your memory and thinking?** *Recent studies have indicated that subtle changes in cognitive abilities can occur as early as 10-15 years before noticeable symptoms of brain disease.*

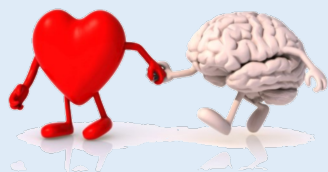




## What can I do to maintain my brain health?

Certain lifestyle choices can help to optimize brain function and may help prevent or delay the onset of Alzheimer's disease:

1. Exercise regularly
2. Stimulate your brain
3. Manage stress
4. Get a good night's rest
5. Socialize
6. Eat light and healthy



## Care at Brigham and Women's Hospital

At Brigham and Women's Hospital, the Clinical Care Program of the Alzheimer's Disease Center (ADC), which is part of the Center for Brain/Mind Medicine and the Division of Cognitive and Behavioral Neurology at the new Hale Building for Transformative Medicine, provides comprehensive evaluation and treatment for this complex disease. The care provided spans all aspects of a patient's life. The multidisciplinary team of specialists in behavioral neurology, neuropsychiatry, geriatric psychiatry, neuropsychology, and social work address the cognitive, emotional, and behavioral components of Alzheimer's disease during each stage of the illness.

The Division of Cognitive and Behavioral Neurology provides comprehensive diagnostic and evaluative services for patients with the following neurologic conditions:

- Alzheimer's disease
- Non-Alzheimer dementias
- Mild Cognitive Impairment
- Frontotemporal Degeneration
- Autism and Asperger Syndromes
- Learning disabilities
- ADHD

The Division of Cognitive and Behavioral Neurology also treats patients experiencing cognitive and neuropsychiatric difficulties that are secondary to the following conditions:

- Parkinson's disease
- Traumatic brain injury
- Brain tumors and other central nervous system cancers
- Cerebrovascular disease
- Seizures and epilepsy

*Center for Brain/Mind Medicine,  
Brigham and Women's Hospital*

**Phone:** (617) 732-8060

**Fax:** (617) 738-9122

**Can dementia be cured?** *We have not yet found a cure for most types of dementia, although there is ongoing research surrounding drugs, vaccines and other treatments.*





## Care at Massachusetts General Hospital

The Memory Disorders Unit at Massachusetts General Hospital provides comprehensive diagnostic and treatment services for people with Alzheimer's disease and other types of dementia, such as Frontotemporal Degeneration or Lewy Body Dementia. These services are provided at specialized outpatient clinics, including the Memory Disorders Unit, the Frontotemporal Disorders Unit, the Normal Pressure Hydrocephalus clinic, and the Lewy Body Dementia Unit. There is also a Memory Disorders Unit clinic with Spanish speakers to provide comprehensive care to the Latino community.



The Memory Disorders Unit is on the eighth floor of the Wang Ambulatory Care Center of the hospital. Patient appointments are held on Monday and Tuesday afternoons.

**Memory Disorders Unit**  
**Massachusetts General Hospital**

**Phone: (617) 726-1728**

**Fax: (617) 726-4104**

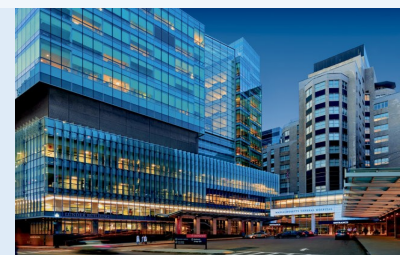
Additional programs at Massachusetts General Hospital:

- The **Frontotemporal Disorders Unit** at Massachusetts General Hospital specializes in comprehensive diagnosis and treatment for Frontotemporal focal dementia syndromes and disorders. Their aim is to develop better knowledge about, diagnosis of, and treatment for all forms of Frontotemporal focal dementia and related focal dementia syndromes. Email [MGHFTDUnit@partners.org](mailto:MGHFTDUnit@partners.org) or call **617-726-5571**.
- The **Lewy Body Dementia Unit** at Massachusetts General Hospital coordinates clinical care and research for patients with Lewy Body Dementia. It is a Lewy Body Dementia Association Research Center of Excellence. To contact the MGH Lewy Body Dementia Unit please call **617-726-5532**.
- The **Psychology Assessment Center** at Massachusetts General Hospital provides neuropsychological and psychological assessment for individuals, including Spanish speakers. Contact the Psychology Assessment Center for further information at **617-726-3647**.
- The **Multicultural Alzheimer Prevention Program** is an initiative to advance culturally informed understandings of Alzheimer's disease and prevent cognitive decline. The Multicultural Alzheimer Prevention Program encompasses programs such as MUNODS, a multicultural neuropsychology program that provides culturally and linguistically appropriate care to Latino adults and Spanish speakers, as well as the Boston Latino Aging Study which focuses on understanding aging in Latinos. To find out more, please visit the new website at [mapp.mgh.harvard.edu](http://mapp.mgh.harvard.edu).

For additional information on how to talk with your doctor...

Go to the following link on your web browser: [bit.ly/2Hdmplu](http://bit.ly/2Hdmplu)

OR scan the QR code on the right with your smartphone camera.





## Resources for Patient and Caregiver Support

**Alzheimer’s Association:** The premier source of information for advocacy, research, support programs, and education.

- 24/7 Helpline: 1-800-272-3900
- MA/NH Chapter contact: 617-868-6718

**Alzheimer’s Foundation of America:** Direct services and educational resources to patients and caregivers.

- National Toll-Free Helpline: 1-866-232-8484

**Association for Frontotemporal Degeneration (ATFD):** www.theaftd.org; Helpline 1-866-507-7222

**Lewy Body Dementia Association (LBDA):** www.lbda.org; LBD Caregiver Link 1-800-539-9767

**National Institute on Aging: Alzheimer’s Disease Education and Referral Center (ADEAR)**

- The latest dementia related news and publications on diagnosis, treatment, care, and research.
- www.nia.nih.gov/health/alzheimers
- Toll-Free Helpline: 1-800-438-4380

## National Clinical Trial Information

You or your loved one’s participation in research studies will significantly help in the search for a cure for Alzheimer’s disease and related dementias. The first person to be cured of Alzheimer’s will be a clinical trial participant!

**NIH Clinical Trial Finder:** www.nia.nih.gov/alzheimers/clinical-trials

**Alzheimer’s Association Trial Match:** www.trialmatch.alz.org

### Brigham and Women’s Hospital



### Massachusetts General Hospital



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