



Road Map to Dementia Diagnosis Patients & Families Edition

Aging & Memory Loss Road Map Education Series

I. Dementia Diagnosis

II. Research Participation

III. Caregiving

Are You or a Loved One Experiencing Changes in Memory or 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. Following are examples of thinking and memory concerns:

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

What Are Normal, Age-Related, 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 commonly reported:

- 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 may be irritating, these memory changes should not be significant enough to affect your daily living.



Contents:

When Should I be Worried?2

Who Can Make a Diagnosis?3

What's the Process for Getting a Diagnosis?4

What Happens if I'm Diagnosed With Alzheimer's disease or a Related Dementia?5

Is Research Participation Right for me?.....5

Care at Brigham & Women's Hospital.....6

Care at Massachusetts General Hospital.....7


Patient and Caregiver Support Resources.....8

Age Related Memory Changes VS. Cause for Concern

UNDERSTANDING THE DIFFERENCE



MASSACHUSETTS
Alzheimer's Disease
Research Center

	Normal Aging	Cause for Concern
<p>Many people notice changes with their memory and thinking as they age. If these changes are causing concern, write them down and address them with your doctor.</p>  <p>www.madrc.org</p>	Forgetting, or slow to recall, names	Missing appointments
	Misplacing items	Putting items in odd places (milk in cabinet, keys in microwave)
	Forgetting where you parked	Difficulty following traffic signs
	Forgetting why you entered a room	Asking the same questions repeatedly
	Occasional difficulty finding words	Getting lost in familiar places
You are worried about your memory changes but your friends & family are not	You do not notice memory problems but friends & family are concerned	

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. Following are some other diseases that can cause dementia or dementia-like symptoms:

- Vascular dementia
- Huntington's disease
- Lewy body dementia
- Normal pressure hydrocephalus
- Parkinson's disease
- Physical injury to the head
- Frontotemporal Dementia or Pick's disease
- 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 need additional support, there are many resources available to help you through the process. (See p. 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 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 disease.
- **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 expert.

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 information 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 of your medications to share with 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 should take it
- Ensure that 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 and actions you could take in your daily life (i.e. diet, physical activity, sleep adjustments)
- Discuss how you can contact your provider if you have any questions

Talk to your doctor about scheduling periodic check-ups. Your doctor may also want to discuss opportunities to participate in research studies which focus on people with early symptoms of Alzheimer's disease (AD).



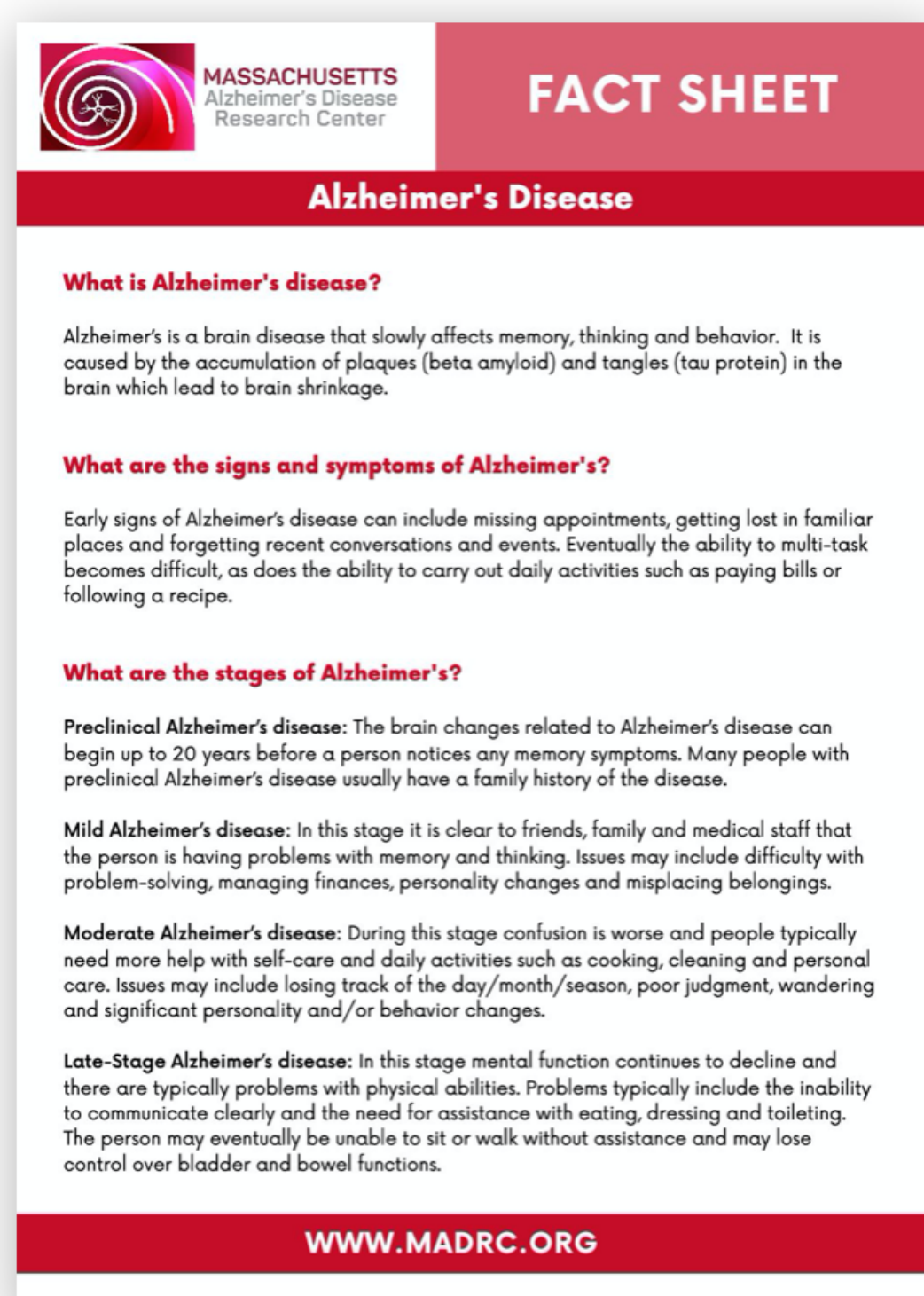
What's the Process for Getting A Diagnosis?

A medical workup is necessary to evaluate how well your brain is functioning. This process may begin with a visit to your primary care doctor and often includes a referral to a memory specialist. Memory evaluations used to determine a diagnosis may include the following:

- A review of personal and family medical history
- A general physical exam
- A neurological exam, including tests of reflexes, coordination, eye movement, speech, sensation, muscle strength and tone, walking and balance
- A brain scan (CT, MRI or PET)
 - CT - Computed tomography and MRI - Magnetic resonance imaging: These scans provide images of the structure of the brain tissue and show its shape and volume
 - PET - Positron emission tomography - This 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).
- A Neuropsychological exam: These tests evaluate cognitive ability. They consist of interviews, paper and pencil testing and sometimes computerized tests. These tests can be frustrating, but they help specialists better understand how your brain is functioning.
- Questionnaires: Questions about your mood, behavior and daily functioning are typically asked of both the patient and someone who knows them very well, such as a family member.

Getting a diagnosis may require several appointments with different types of healthcare providers. All medical organizations, academic centers and 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. Be sure to talk to your doctor about the steps involved in your diagnosis and ask them to write it down for you.

Visit www.MADRC.org to learn more about additional types of dementia



MASSACHUSETTS Alzheimer's Disease Research Center

FACT SHEET

Alzheimer's Disease

What is Alzheimer's disease?

Alzheimer's is a brain disease that slowly affects memory, thinking and behavior. It is caused by the accumulation of plaques (beta amyloid) and tangles (tau protein) in the brain which lead to brain shrinkage.

What are the signs and symptoms of Alzheimer's?

Early signs of Alzheimer's disease can include missing appointments, getting lost in familiar places and forgetting recent conversations and events. Eventually the ability to multi-task becomes difficult, as does the ability to carry out daily activities such as paying bills or following a recipe.

What are the stages of Alzheimer's?

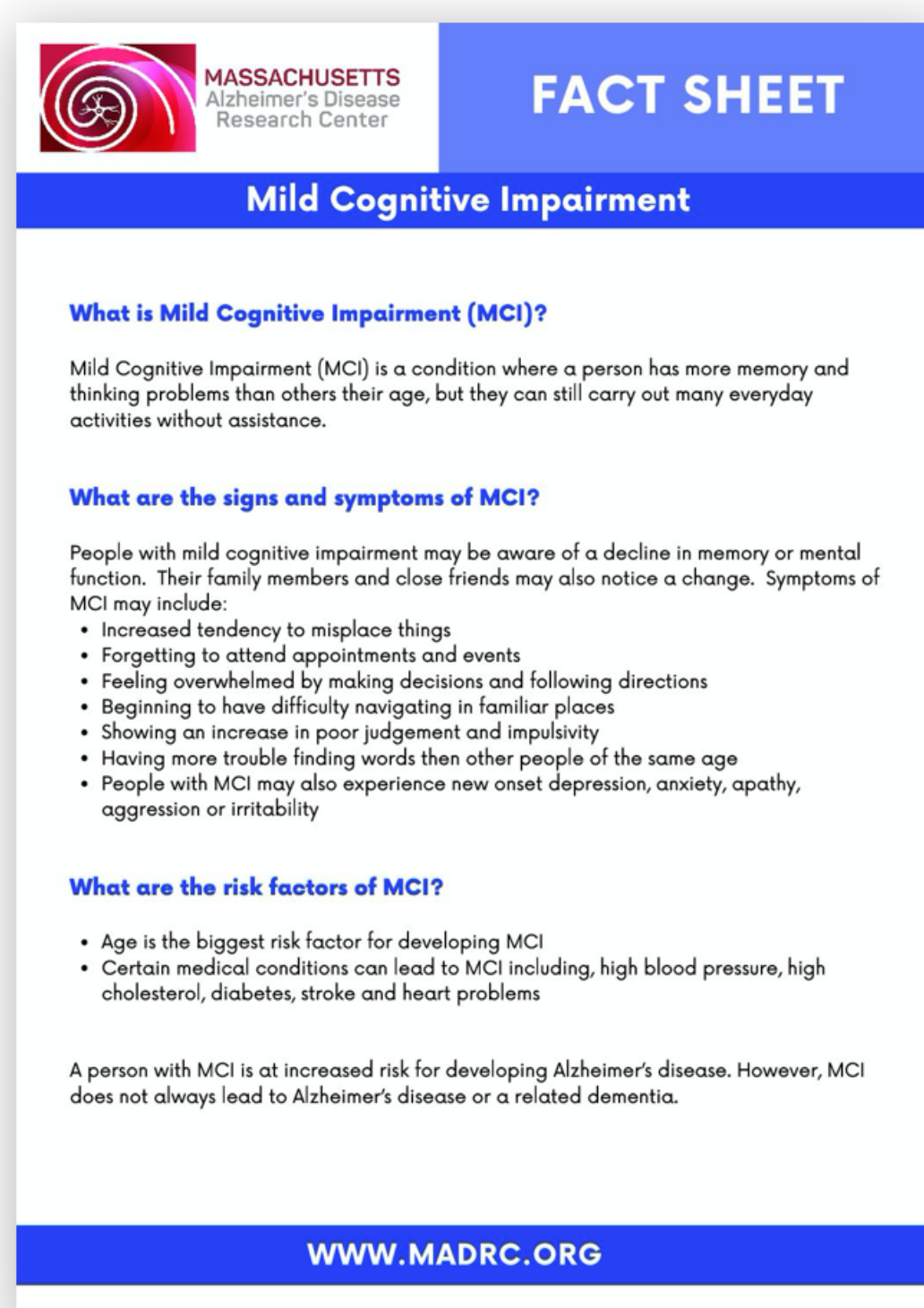
Preclinical Alzheimer's disease: The brain changes related to Alzheimer's disease can begin up to 20 years before a person notices any memory symptoms. Many people with preclinical Alzheimer's disease usually have a family history of the disease.

Mild Alzheimer's disease: In this stage it is clear to friends, family and medical staff that the person is having problems with memory and thinking. Issues may include difficulty with problem-solving, managing finances, personality changes and misplacing belongings.

Moderate Alzheimer's disease: During this stage confusion is worse and people typically need more help with self-care and daily activities such as cooking, cleaning and personal care. Issues may include losing track of the day/month/season, poor judgment, wandering and significant personality and/or behavior changes.

Late-Stage Alzheimer's disease: In this stage mental function continues to decline and there are typically problems with physical abilities. Problems typically include the inability to communicate clearly and the need for assistance with eating, dressing and toileting. The person may eventually be unable to sit or walk without assistance and may lose control over bladder and bowel functions.

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MASSACHUSETTS Alzheimer's Disease Research Center

FACT SHEET

Mild Cognitive Impairment

What is Mild Cognitive Impairment (MCI)?

Mild Cognitive Impairment (MCI) is a condition where a person has more memory and thinking problems than others their age, but they can still carry out many everyday activities without assistance.

What are the signs and symptoms of MCI?

People with mild cognitive impairment may be aware of a decline in memory or mental function. Their family members and close friends may also notice a change. Symptoms of MCI may include:

- Increased tendency to misplace things
- Forgetting to attend appointments and events
- Feeling overwhelmed by making decisions and following directions
- Beginning to have difficulty navigating in familiar places
- Showing an increase in poor judgement and impulsivity
- Having more trouble finding words than other people of the same age
- People with MCI may also experience new onset depression, anxiety, apathy, aggression or irritability

What are the risk factors of MCI?

- Age is the biggest risk factor for developing MCI
- Certain medical conditions can lead to MCI including, high blood pressure, high cholesterol, diabetes, stroke and heart problems

A person with MCI is at increased risk for developing Alzheimer's disease. However, MCI does not always lead to Alzheimer's disease or a related dementia.

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Subjective Cognitive Decline (SCD) is when a person self-reports worsening memory problems, but still functions normally in their everyday activities. There are many reasons why a person may start to notice changes in their memory, which can include normal aging, changes in mood, or reduced sleep. For a very small subset of cases, SCD may be an early sign of changes due to Alzheimer's disease.

www.MADRC.org



What Happens if I am Diagnosed With Alzheimer's Disease or a Related Dementia?

The most common form of dementia is Alzheimer's disease (AD). It is characterized by a decline in brain function over time. This decline is usually a slow and progressive process. Memory loss in AD 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 AD occurs differently in everyone diagnosed with it. Be sure to communicate with your healthcare provider if you experience anything out of the ordinary. In the early stages of AD, 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 Participation 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 studies 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 to receive access to a possible new treatment.

The Massachusetts Alzheimer's Disease Research Center (MADRC) at Massachusetts General Hospital and the Center for Alzheimer's Research and Treatment (CART) at Brigham and Women's Hospital offer a variety of study types, ranging from observational studies to clinical trials.

If you are interested in participating in research, at either of these centers, please call (617) 278-0383.



A lack of volunteers to participate in research studies is the biggest obstacle for potential treatments in Alzheimer's disease. Researchers cannot do it on their own. Every clinical trial needs volunteers. Study participants become part of the research team, receive updated health information and are typically reimbursed for travel expenses.



Follow MADRC for more helpful tips and information!



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Care at Brigham and Women's Hospital

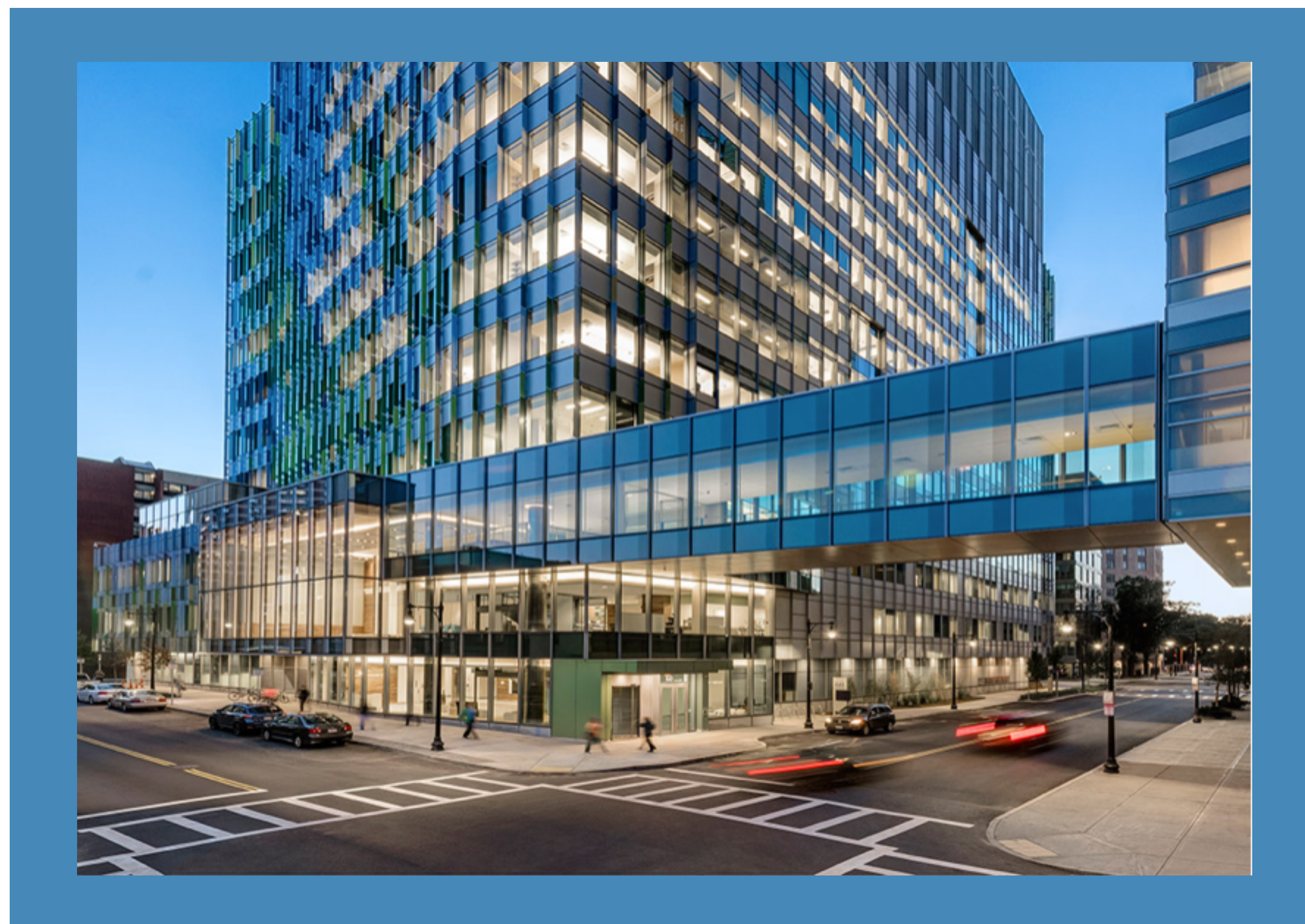
At Brigham and Women's Hospital, the Clinical Care Program of the Alzheimer's Disease Center (ADC) is part of the Center for Brain Mind/Medicine and the Division of Cognitive and Behavioral Neurology. It provides comprehensive evaluation and treatment for this complex disease. The care provided spans 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 service for patients with the following neurologic conditions:

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

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



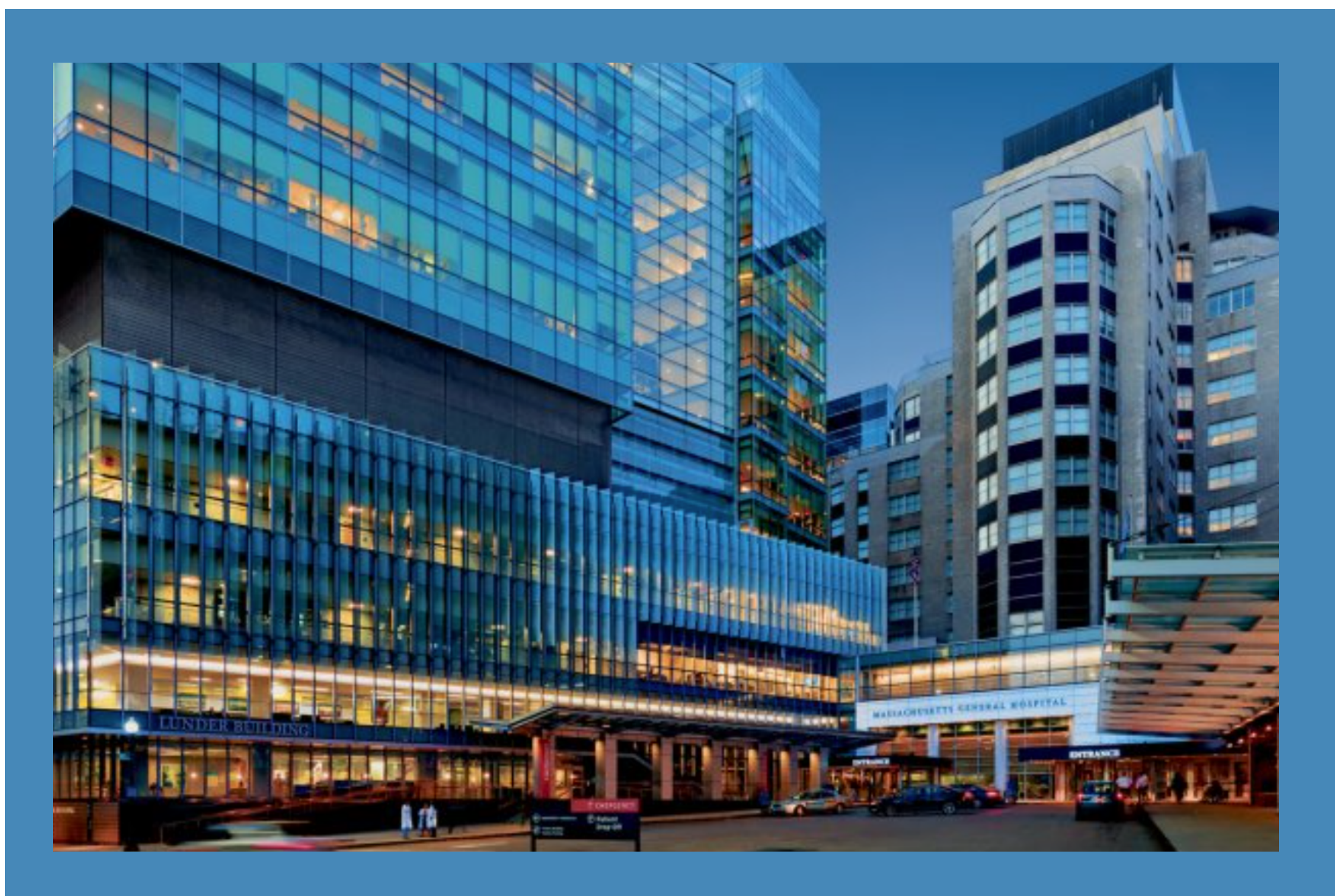
Center for Brain/Mind Medicine
Brigham & Women's Hospital
(617) 732-8060

Care at Massachusetts General Hospital

The Memory Disorders unit at Massachusetts General Hospital (MGH) 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 Division, the Frontotemporal Disorders Unit, the Normal Pressure Hydrocephalus Clinic and the Lewy Body Dementia Unit. Additionally, the Multicultural Assessment and Research Center (MARC) at MGH offers culturally and linguistically appropriate neuropsychological services to diverse adult patients with brain disorders.

Additional Information About MGH Programs

- The **Frontotemporal Disorders Unit** specializes in comprehensive diagnosis and treatment for Frontotemporal focal dementia syndromes and disorders. They aim to develop better knowledge about diagnosis of, and treatment for, all forms of Frontotemporal focal dementia and related focal dementia syndromes.
Email: MGHTFDUNIT@partners.org Telephone: (617) 726-8689
- The **Lewy Body Dementia Unit** coordinates clinical care and research for patients with Lewy body Dementia. It is a Lewy Body Dementia Association Research Center of Excellence.
Email: mquan4@mgh.harvard.edu Telephone: (617) 726-1728
- The **Psychology Assessment Center** provides neuropsychological and psychological assessment for individuals, including Spanish speakers.
Telephone: (617) 726-3647
- The **Multicultural Assessment and Research Center** is dedicated to best practices in multicultural neuropsychology. The bilingual staff focuses on providing culturally and linguistically proficient neuropsychological services to diverse adult patients with a variety of disorders that impact cognitive functioning.
Email: MARC@mgh.harvard.edu Telephone: (617) 643-5883



Memory Disorders Division
Massachusetts General Hospital
(617) 726-1728

Patient and Caregiver Support Resources

- **Alzheimer's Association:** Information on advocacy, research, support programs and education
24/7 Helpline 1-800-272-3900, www.alz.org/MANH
- **Alzheimer's Foundation of America:** Educational resources and direct services for patients and caregivers.
National Helpline 1-800-232-8484 www.alzfdn.org
- **Association for Frontotemporal Degeneration (ATFD):** www.theaftd.org, 1-866-507-7222
- **Lewy Body Dementia Association (LBDA)** www.lbda.org, Caregiver link: 1-800-539-9767
- **MADRC Aging & Memory Loss Road Map Education Series** www.madrc.org/community
- **National Institute on Aging: Alzheimer's Disease Education & Referral Center (ADEAR):** Dementia related information and resources on diagnosis, treatment, care and research.
Helpline 1-800-438-4380, www.nia.nih.gov/health/alzheimers

National Clinical Trial Information

Participation in research, by you or a loved one, will help significantly in the search to find a cure for Alzheimer's disease (AD) and related dementias. The first person to be cured of AD will be a clinical trial participant!

- NIH Clinical Trial Finder: www.nia.nih.gov/alzheimers/clinical-trials
- Alzheimer's Association TrialMatch: www.trialmatch.alz.org



Brigham & Women's Hospital Center for Alzheimer Research & Treatment

(617) 732-8085
CART@partners.org



Massachusetts General Hospital Massachusetts Alzheimer's Disease Research Center

(617) 278-0600

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