

Road Map to Caregiving Patient & Family Edition



Caregivers: Who are they?

Caregivers are the people who provide assistance with everyday activities for someone they care about who has been diagnosed with Alzheimer’s disease or a related dementia. Primary caregivers are often a family member or close friend who are sometimes unpaid and not professionally trained to manage many of the issues they face.

Caregiving is mentally and physically difficult. Having access to tools and resources to support someone living with dementia is critical to maintaining health and well-being. Caregiving often requires the help of your doctor and other healthcare providers.

Why do Caregivers Need Support?

Caregivers are often on duty 24 hours a day and research shows that they are at increased risk of facing loneliness, depression, and other medical issues. Caregivers need resources to support both themselves and those for whom they are caring. Though a caregiver may feel they can handle everything on their own, it's important to connect with other people and find resources to prevent burnout and/or health problems.

This booklet contains information to help you on the caregiving journey. If you are feeling overwhelmed, begin by talking with your own doctor. Most hospitals and health care centers have social workers on staff who can provide support.

Social workers are healthcare professionals specifically licensed and trained to assist patients and families in navigating healthcare systems. Here are some things social workers can do for you:

- Provide emotional support and counseling
- Facilitate communication and coordination within care teams
- Navigate advanced directives and complex insurance coverage
- Assist in identifying and applying for community resource programs



MASSACHUSETTS
Alzheimer's Disease
Research Center



Mass General Brigham

Aging & Memory Loss Road Map Education Series

I. Dementia Diagnosis

II. Research Participation

III. Caregiving

IV. Prevention

V. Behavior Management



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Concern and Diagnosis

The caregiving journey can often begin before the person with memory concerns receives a diagnosis. Individuals with Alzheimer's disease (AD) may start to have changes in their brain 15-20 years before significant symptoms of the disease become apparent.

When symptoms first appear they will be subtle, occur sporadically, and may not seem too concerning. At some point you may feel like something is wrong. Do not over think it. Share your concerns with the family member or friend and discuss scheduling an appointment with his or her primary care physician.

Other people such as a colleague, may also notice changes happening with your friend or family member. You may want to ask if anything at work has changed or become more challenging. AD and related dementias are diseases of the brain. As with any other disease the first place to begin is by recognizing the symptoms and getting a diagnosis.

Once you and the person you are supporting have discussed concerns, schedule an appointment with a primary care physician. Write down a list of all issues and plan to attend the medical visit with your loved one so you can be supportive and help communicate information.

The Importance of a Diagnosis

Getting a diagnosis for AD or a related dementia allows the person you are supporting, their doctor, their family and their friends to better understand the dementia symptoms they are experiencing. There are several things your doctor can recommend, including medications to help individuals experiencing symptoms of AD and related dementias.

Additionally, there are research opportunities available that may provide access to a new experimental medication that could possibly delay disease progression. It is important to understand what is going on with your loved one/friend's brain so you can take charge of care planning and put supports in place to allow for control over future decisions. The sooner a diagnosis is made, the more time you will have to chart the road ahead.



Mapping the Road Ahead

The Importance of Early Planning

Once your family member or friend receives a diagnosis, and understands the course of the illness, it allows them to initiate control of their life planning. For example, establish advanced directives, selecting an executor to oversee finances, determine durable power of attorney, and create a health care proxy to oversee care wishes. These steps help the individual to have control when they lose the ability to remember what they wanted and assures their friends/loved ones that their wishes are being carried out.

Building a Support Network and Care Team

The care team for your family member or friend diagnosed with AD or a related dementia will be the people you will rely on for connection and support. Care teams can include; family, friends, neighbors, clergy, doctors, social workers, nurses, dementia care specialists and other healthcare providers who can provide support and direction.

Families and all the people you love often want to help and provide support but do not know what to do or how to do it. It is critical to identify opportunities for support and understand what resources are available to you. AD and related dementias are diseases that affect the entire family.

It is important to be aware of what to expect when someone has AD or a related dementia. Symptoms of the disease affect every individual very differently. It will be difficult to anticipate what will happen daily and how the person with dementia will respond. Talking to other caregivers and people living with the disease will provide a perspective that is critical, but your circumstances may be different. Remember to talk to the doctor about your situation.

Here are some examples of available support networks:

- **Healthcare Providers:** your primary care physician, neurologist, psychiatrist, geriatrician, nurse practitioner, or social worker
- **Nonprofit Organizations:** Alzheimer's Association, Alzheimer's Foundation, The Association for Frontotemporal Degeneration, Lewy Body Dementia Association, etc.
- **Social Engagement Programs:** senior centers, memory cafes, support groups
- **Training Opportunities:** savvy caregiver training and other formal caregiving training is available
- **Educational Forums:** on a variety of topics (research, care and decreasing social isolation)
- **Religious Organizations:** some people seek support from clergy in their religious community



 MASSACHUSETTS Alzheimer's Disease Research Center

 GLOBAL ALZHEIMER'S PLATFORM FOUNDATION

**AGING & MEMORY LOSS
ROAD MAP EDUCATION SERIES**

- Road Map to Dementia Diagnosis
- Road Map to Research Participation
- Road Map to Caregiving
- Road Map to Prevention
- Road Map to Behavioral Management

Learn more: www.madrc.org/community/

The Road Map Education Series is a great resource for people navigating the journey through memory loss, Alzheimer's disease or a related dementia.

Care Management Discussion

Things may not change right away for the person with a diagnosis, and as the caregiver you need to have the discussions about care management before changes begin to take place. Even if these discussions are uncomfortable, they are critical for successful care management in the future. If you are having trouble initiating these conversations, talk with your doctor. It is important to learn how to communicate effectively. The more clearly you can express your concerns, the better doctors will be able to help both the patient and caregiver. For more guidance on talking with your doctor: <http://bit.ly/2QvNKbZ>

When the Caregiver Takes the Wheel

Eventually, the time will come when the caregiver must take charge. The person you are caring for will need consistent supervision and care. As you determine the caregiving strategies that work best for you, caregivers will need to consider the following questions:

- What does the person I am caring for need the most in this moment? How does that align with their wishes?
- Do I need someone like a geriatric care manager to help me? (people paid to help with care planning)
- Should I take a training program that prepares caregivers to manage issues that will arise?
- How will I continue to provide care and support?
- What resources are available to me?
- How do I not become overwhelmed when the burden of AD support gets more difficult?
- Who will I call first, second, and third if I am having problems?
- This booklet does not contain all the answers to these questions. However, it will provide information on the extensive resources available to you online and within the greater Boston community.

Finding the Right Resources

There is no “one size fits all” response to caring for someone with AD. Each journey is different. Determine which resources work best for you. Resources can be accessed via internet, by phone, in person, in group settings and more. Try different options and determine which resources help you the most.

Caregiver Checklist

- ☒ Current medication list
- ☒ Care team contact list with phone numbers (MD, social worker, trusted friend etc.)
- ☒ A photo of the person diagnosed and the local police station phone number. (If the person you are caring for with AD or another dementia becomes lost or wanders, the local police are trained to assist)
- ☒ An emergency contact/backup for the designated caregiver

Learning Opportunities

Many people have walked this caregiving path before you. There are many educational programs available that cover best practices and tips on topics including:

- Communication
- Distraction techniques
- Behavior management
- Recognizing anxiety and depression
- Importance of social engagement
- Interacting with family members and talking to children

Making Hard Decisions

As you navigate the more challenging symptoms of dementia, remember - you are not alone. Talk to your doctor. There are resources available to support you with issues such as:

- Driving evaluation programs - When is driving no longer safe?
- Daily caregiver support - Seeking supplemental help from others to assist with activities of daily living.
- Wandering and/or getting lost - Do you need tools to help ensure safety like a medical alert or GPS bracelet?



Late Stage in the Disease

During the advanced late stage, the person with dementia may not recognize close family members and will eventually be unable to move without assistance. At this point, they will depend on others for all care needs. Individuals with AD and related dementias can sometimes require professional caregiving 24 hours a day. Some people attend day programs and have professional caregivers come to the home to assist the family caregiver. Sometimes care is provided in a skilled dementia care facility. This late stage support requires planning and evaluation. There are several websites in the reference section of this booklet that provide additional information on the following:

- Home companion services
- Home care support services
- Assisted Living facilities
- Dementia Care facilities
- Day Care programs

At this stage, your focus as a caregiver will be to keep the person with AD or related dementia comfortable and executing the wishes they stated at the beginning of care planning. You may need to stop providing medical treatments to keep the patient as comfortable as possible. Making big decisions like this will be difficult. That is why it is so important to make comprehensive plans with them early, upon diagnosis, while they can express their future wishes.

Caring for the Caregiver

You must take care of yourself to provide care for someone else. Ask family members or trusted friends to help, or use an adult daycare service, so you can do something you enjoy. Remember, it is better for you and the individual you are caring for if you take a break when needed. Start by asking people for help in specific ways like providing a meal, doing an activity, or taking the person you are caring for on a walk so you can have some time to rest.



The Value of Support Groups

Joining a support group is a great opportunity to meet new people who share similar experiences in caregiving. Alzheimer’s and dementia support groups are facilitated by seasoned social workers.

There are over 50 support groups for patients and caregivers in Massachusetts. To join one, call the Alzheimer’s Association MA/NH chapter at (617) 868- 6718 or the Alzheimer’s Family Support Center of Cape Cod at (508) 896-5170.

Bereavement

Dealing with the changes that occur in someone you care for as they decline is the *longest loss* for caregivers. You may need support to come to terms with loss long before you lose someone to AD or a related dementia. It is important to talk with your doctor about the emotions you are experiencing and seek assistance from a support group or a professional if needed. Helpful resources are listed below.

Helpful Resources Mass General Brigham

Services at Massachusetts General Hospital

Dementia Care Collaborative

The Dementia Care Collaborative (DCC) serves as a resource for patients, families and staff at Massachusetts General Hospital (MGH). The DCC's innovative programs provide patients who have dementia with coordinated, effective care while they are at MGH for inpatient hospitalizations, emergency department visits, and appointments in specialty clinics and primary care.

Programs include: a monthly Conversations with Caregivers seminar series Caregiver Support Groups and Health and Resiliency programs.

For information about clinical services, programs and resources, email: dementiacaregiversupport@mgh.harvard.edu, call (617) 724-0406 or visit: dementiacarecollaborative.org

Services at Brigham & Women's Hospital

Center for Brain/Mind Medicine

Brigham & Women's Hospital (BWH) Center for Brain/Mind Medicine (CBMM) has social workers for patients receiving care at CBMM. Patients at CBMM can ask their neurologist to make a referral to the social work department. In addition, the Caregiver Dementia Skills and Wellness group, is a time limited group to teach people about dementia related behavior and how to cope. If you are interested, speak with your neurologist about a referral to the group.

For more information about CBMM, visit: brighamandwomens.org/neurology/cognitive-and-behavioral-neurology/center-for-brain-mind-medicine

Additional Resources for Alzheimer's & Related Dementia Caregiving

Local Resources

Alzheimer's Association, Massachusetts/New Hampshire Chapter

The premier source of information for advocacy, research, support programs, and education. MA/NH Chapter contact: (617) 868-6718; www.alz.org/MANH, 24-hour Helpline: 800-272-3900

Alzheimer's Family Support Group of Cape Cod

Support groups, counseling, assistance, & educational programs available on and off Cape Cod www.alzheimerscapecod.org; Phone: (508) 896-5170

Dementia Friends Massachusetts

Initiative to educate community on what dementia is and how it affects people, in order to make a difference in lives of people touched by dementia. www.dementiafriendsma.org

Local Resources (Continued)

Dementia Friendly Massachusetts

Local services developed to improve the lives of individuals as we age:

<https://www.mass.gov/alzheimers-disease-and-related-dementias>

Family Caregiver Support Program

Phone: Caregiver Specialists - 1(844) 422-6277; <https://www.mass.gov/family-caregiver-support-program>

Hebrew Senior Life—Center for Memory Health

Education and interventions for caregivers and families: www.hebrewseniorlife.org/cmh Phone: (617) 363-8000

Honoring Choices

www.honoringchoicesmass.com/

Massachusetts Alzheimer's Disease Research Center

Resources on diagnosis, prevention, how to get involved with research and more. Aging & Memory Loss Road Map

Education Series: www.madrc.org/community/ Call: (617) 278-0600 to speak with an Outreach team member.

Massachusetts Memory Cafés

Social gatherings for people with memory issues or other changes in their thinking and for their family/friends

www.jfcsboston.org/Our-Services/Older-Adults/Alzheimers-Related-Disorders-Family-Support/Directory-of-Memory-Cafés-in-Greater-Boston

Massachusetts Office of Elder Affairs

Comprehensive listing of state resources: www.mass.gov/orgs/executive-office-of-elder-affairs

National Resources

AARP

Caregiving resources: www.aarp.org/caregiving/answers/info-2017/caregiver-workshops-and-training/

Alzheimer's Foundation of America

National toll-free helpline (866-232-8484) staffed by licensed social workers, educational materials, and free quarterly magazine for caregivers www.alzfdn.org

The Association for Frontotemporal Degeneration

Research, awareness, support, education, and advocacy for people affected by Frontotemporal Degeneration and their caregivers. Helpline: 1-866-507-7222, www.theaftd.org

Lewy Body Dementia Association

Outreach, education, and research information for those affected by Lewy body dementias

Lewy Body Dementia Caregiver Number: 888-204-3054, www.lbda.org

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; 800-438-4380; www.nia.nih.gov/health/alzheimers

U.S. Department of Veteran Affairs (VA): Dementia Caregiver Support

Resources on care for veterans with dementia. www.caregiver.va.gov

Clinical Trial Information

Participation in research studies, by either the person with dementia and/or their caregiver, will significantly help scientists find more effective treatments for Alzheimer's disease and related dementias. Numerous research opportunities are available through the Massachusetts Alzheimer's Disease Research Center sites (see below).

For national clinical trial information: www.clinicaltrials.gov



Brigham & Women's Hospital
Center for Alzheimer Research & Treatment
(617) 732-8085
CART@partners.org

Massachusetts General Hospital
Frontotemporal Disorders Unit
(617) 726-8689
MGHTFDUNIT@partners.org



Massachusetts General Hospital
Alzheimer's Clinical & Translational Research Unit
KCROPP1@mgh.harvard.edu

Massachusetts General Hospital
Lewy Body Dementia Unit
(617) 726-1728
mquan4@mgh.harvard.edu



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Massachusetts Alzheimer's Disease Research Center
<https://www.madrc.org/join-a-study/>
To speak with someone about research studies: (617) 278-0600

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