

A Road Map to Caregiving



When someone you care about is dealing with Alzheimer’s disease (AD) or a related dementia: Information on building a care team, accessing resources and getting the information and help you need to provide support and maintain health and well-being for both the individual who is newly diagnosed and their caregiver.

Caregivers: Who are they?

Primary caregivers are often a family member or close friend who are sometimes unpaid and untrained to manage many of the issues they face when someone they care about is diagnosed with Alzheimer’s disease or a related dementia. It is important for caregivers to know they do not have to go it alone. Caregiving is mentally and physically taxing, so having access to the tools and support they may need while supporting someone through the journey of living with dementia is critical to maintaining health and well-being. This often requires the help of your doctor and other healthcare providers.

Why do caregivers need support?

Research shows that caregivers are at increased risk of facing loneliness, depression, and other medical issues. Caregivers are often on duty 24 hours a day and must get the help they need to support themselves and the person they are caring for. Several tools and resources are needed to support you on your journey. Building a support network to support someone living with dementia is crucial for successful caregiving. At first you may feel like you can handle things on your own but allowing others to support you will prevent primary caregiver burnout, depression, and health problems.

The following pages contain the information and resources to get you started on the caregiving journey. There are several different types of resources. Always begin by talking with your doctor and letting him or her know if you are feeling overwhelmed and need additional information and support. Most hospitals and health care centers have a social worker on their team. Social workers can support you on your journey and help you along the way.



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Concern and Diagnosis

The caregiving journey can often begin before the person with memory concerns receives a diagnosis. Individuals with 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. Ask your family member or friend about your concerns and discuss scheduling an appointment with his or her primary care physician.

Someone else, like a colleague, may also notice changes happening in 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 and like any other disease the first place to begin is by recognizing the symptoms and getting help to make 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 concerns and request to go along to the medical visit so you can be of support and help communicate information.

Why should we seek a diagnosis?

Getting a diagnosis for AD or related dementia allows you, your doctor, your family, and friends to better understand why you are experiencing dementia symptoms. While there are no medications to treat the underlying causes of AD or related dementias, there are medications to help with symptoms. Also, there are research opportunities available that may provide you access to a new experimental medication that could possibly delay disease progression. It is important to understand what is going on with your brain so you can take charge of your care planning and put systems in place to allow you to have control over future decisions. The sooner a diagnosis is determined, the more time you will have to map the road ahead in collaboration with the person with dementia or AD.



Mapping the Road Ahead

Why is early planning important?

When you have a brain disease diagnosis and understand the course of illness, it allows you to initiate planning for control of your life. For example, advanced directives, selecting an executor to oversee your finances, durable power of attorney, and a health care proxy to oversee your care wishes. It helps to have control when you lose the ability to remember what you wanted. You are able to put a plan in place that assures others around you they are carrying out your wishes.

Why build a support network and care team? Who will be willing to help me?

Your care team will be the people you and your family member or friend diagnosed with AD or a related dementia will rely on for support and connection. Care teams are made up of 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. Everyone around the person dealing with a diagnosis will need access to information and resources.

It is important to understand 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 help provide support and a perspective that is critical, but your situation may be different. Remember to talk to your doctor about your situation. There are all kinds of support networks available. Here are some examples:

- **Healthcare Providers:** your primary care physician, neurologist, psychiatrist, geriatrician, nurse practitioner, social worker, or local clergy
- **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)



See resource page at the back of this booklet for where to access this information.

Care management discussion:

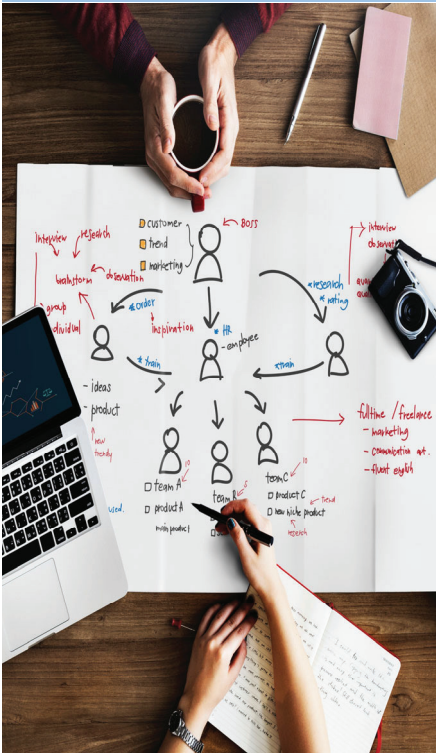
Things may not change for the person with a diagnosis for some time, but as the caregiver you need to have the discussions about care management before changes begin to take place. Even if these discussions are uncomfortable, they are critical for successful care management in the future. If you are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

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

Need help from a social worker? Ask a doctor on your care team for a referral.



Caregiver Takes the Wheel

Eventually, the time will come when the family caregiver must take charge. The person you are caring for now needs 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 at this moment? How does that align with their wishes?
- Do I need someone to help me like a geriatric care manager? (someone paid to help me 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? Where can I find more?
- 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 to access the extensive set of resources available to you online and within the greater Boston community.

Things to have on hand:

Be prepared for things that may come up and have resources available that you can easily access.

- 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 support you.
- An emergency contact back-up to the designated caregiver.

Determine what resources work for you:

There is no one-size-fits-all response to caring for someone with AD. Each journey is different, so you will need to determine which resources work best for you. Resources can be internet based, by telephone, in person, in group settings and much more. Try a little bit of everything so you can find which resources help you the most.

Education available:

Luckily, plenty of people have walked this path before you. Learning about these topics and techniques will help you provide support as a caregiver (examples below).

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



Making hard decisions:

There are resources available to support you as you navigate dealing with the more challenging symptoms of dementia. You are not alone. Talk to your doctor.

- Driving evaluation programs- When is driving no longer safe?
- Caregiver daily support- Seeking supplemental support from others to support activities of daily living.
- Getting lost or wandering- Do you need support tools to help ensure safety like a medical alert or GPS bracelet or other things to ensure safety?

Late Stage:

During advanced late stage, the person with dementia will often not recognize close family members and will eventually be unable to move around without assistance. At this point they will be depending 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 support the family caregiver. Sometimes care is provided in a skilled dementia care facility. This later stage support requires planning and evaluation. There are several web sites in the reference section of this booklet that will provide you 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 transitioning to keeping the person with AD or related dementia comfortable and executing the wishes they stated at the beginning of care planning. It may be the case that you will 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 on upon diagnosis, while they can express their future wishes.

Caring for the Caregiver

You must take care of yourself in order to provide care for someone else. You can ask family members or trusted friends to help out, do something you enjoy, or use an adult day care service. If you have trouble asking for support, remember it is better for you and the individual you are caring for that you take a break when you need it. 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 may have some time to rest.





Why join a support group?

Joining a support group is a fantastic opportunity to meet new people who share similar experiences in coping with the disease. Alzheimer's and dementia support groups are facilitated by seasoned social workers.

There are more than 50 different support groups for patients and caregivers in Massachusetts alone. If you would like 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 to someone you care for as they decline is the *longest loss* for caregivers. You may need support to cope 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 dealing with and seek support from a support group or see a professional if needed.

This program and booklet are not designed to answer all your questions or address all the issues a caregiver faces while caring for someone with AD or a related dementia. It is designed to be a support tool to direct caregivers to resources and educate patients and families on the importance of caregiver planning and support. If you need additional support please see local contacts in the resource section on page 7.

We are Here to Help

Services at Massachusetts General Hospital:

Dementia Care Collaborative

Founded in 2018, the Dementia Care Collaborative (DCC) serves as a resource for patients, families and staff at Massachusetts General Hospital. The DCC's innovative programs help to provide patients with dementia with coordinated, effective care when they are at MGH for inpatient hospitalizations, during emergency department visits, and in specialty clinics and primary care.

Programs provided for everyone: Monthly *Conversations with Caregivers* seminar series and *Caregiver Support Groups*.

To receive announcements and to register for our monthly programs, and for information about our existing clinical services, please email: dementiacaregiversupport@mgh.harvard.edu or call (617) 724-0406.

Services at Brigham and Women's Hospital:

Center for Brain/Mind Medicine

Brigham and Women's Hospital (BWH) Center for Brain/Mind Medicine (CBMM) has social workers who see patients receiving care at CBMM. If you are a patient, your neurologist can make a referral to social work. In addition to one to one meetings with a social worker, there is also a new program called the *Caregiver Dementia Skills and Wellness group*, a time limited group to learn more about dementia related behavior and how to cope. If you are interested, please speak with your neurologist about referring you to the group.

Additional Alzheimer’s and Dementia Caregiving Resources

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 national Helpline: 1-800-272-3900

Alzheimer’s Family Support Group of Cape Cod

Support groups, counseling and assistance, & educational programs available on and off Cape Cod

www.alzheimerscapecod.org; Phone: (508) 896-5170

Dementia Friends Massachusetts

Initiative to help community members understand what dementia is an how it affects people so we can make a difference in lives of people touched by dementia. www.dementiafriendsma.org

Family Caregiver Support Program

Phone: 1(844) 422-6277; Ask for a Caregiver Specialist

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

Massachusetts Age Friendly and Dementia Friendly Massachusetts

Local town and city services developed to improve the lives of individuals as we age

www.mass.gov/dementia-friendly-massachusetts

Massachusetts Memory Cafés

Welcoming place for people with forgetfulness or other changes in their thinking and for their family and friends. Memory cafés meet at a variety of places including coffeehouses, museums, or community organizations. To find a memory café near you visit this website:

www.memorycafedirectory.com/memory-cafes-in-massachusetts/

Massachusetts Office of Elder Affairs

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



National Resources

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, visit 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

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.
Toll-free contact: 1-800-438-4380, visit www.nia.nih.gov/health/alzheimers

U.S. Department of Veteran Affairs: Dementia Caregiver Support

Caring for a Veteran? resources on dementia care through the VA and information on new research on Veterans with dementia. visit www.caregiver.va.gov

Clinical Trial Information

You or a dementia patient’s participation in research studies will significantly help in the search for more effective treatments for Alzheimer’s Disease and related dementias. If you live in Massachusetts and are interested in participating in a clinical trial call one of our research clinics (see box to the right). For national clinical trial information please visit www.clinicaltrials.gov.

MADRC Research Clinics

BWH Center for Alzheimer Research & Treatment	(617) 732-8085
Frontotemporal Disorders Unit	(617) 726-1728
Lewy Body Dementia Movement Disorder Unit	(617) 726-5532
Alzheimer’s Clinical & Translational Unit (ACTRU)	(617) 643-2351

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