

Road Map to Acute Care Management

Individuals and family members facing Alzheimer’s disease (AD) and related dementias, encounter many difficulties when navigating the healthcare system during an acute health crisis. This booklet provides information to help people communicate with medical staff and navigate the healthcare system in an acute care situation. Advance planning to manage potential emergencies is recommended and should include discussions between family members and physicians. Talk with your Doctor about having a plan in place to manage Acute Care needs.

Navigating Acute Care Emergencies

An emergency is an unplanned event that can happen at any time. Health care crisis can include: infection, flu, pneumonia, diabetic complications, stroke, dehydration, trauma and psychiatric emergencies. It’s important to understand that illness and health care management becomes more complicated to manage with age and cognitive decline. For someone living with AD and related dementias it is critical to plan for these situations.

A visit to a chaotic environment like an emergency room or urgent care facility is unsettling. Noisy medical equipment and emergency vehicles, staff in protective clothing and multiple health evaluations, can be overstimulating and scary for an individual living with dementia. A person with dementia will find it difficult to navigate and caregivers will experience increased stress.



ACUTE CARE IS A LEVEL OF HEALTHCARE IN WHICH A PATIENT IS TREATED FOR A BRIEF BUT SEVERE EPISODE OF ILLNESS, FOR CONDITIONS THAT ARE THE RESULT OF DISEASE OR TRAUMA, AND DURING RECOVERY FROM SURGERY.

ACUTE CARE IS OFTEN PERFORMED IN A HOSPITAL SETTING.

“My sister who has Alzheimer’s Disease got up and walked away in her johnny during an emergency room visit for her asthma. The nurses did not know she had dementia and they were yelling at her because she was going into another patient area. She was a nurse by training and wanted to help a person who was calling out. She was half naked and had an IV in her arm, it was scary for the patient seeking help. She became scared when staff approached her and slightly combative when redirected. The staff wasn’t aware she had dementia and I wasn’t sure what to do”

- Caregiver comment

Aging & Memory Loss
Road Map
Education Series

I. Dementia Diagnosis

II. Research Participation

III. Caregiving

IV. Prevention

V. Behavior Management

VI. Social Engagement

VII. Acute Care



For more helpful
resources, visit:



@WE_ARE_MADRC



@MASSADRC



@ADRCMASS



ADRC MASS

Avoid the Emergency Room When Possible

If a medical condition is worsening at home contact your doctor right away. Let them know your preference is to avoid emergency treatment and you would like an appointment as soon as possible to address the issues.

Planning Tips for an Emergency Room or Urgent Care Visit

Consider preparing an emergency bag with the following items:

- Completed form with medical information and medication list (see example on pages 8-10). This will make it easier for medical staff checking you in and expedite the visit.
- Medications needed for long waits or extended visits
- Phone numbers of friends or family members willing to come and relieve the caregiver so they can eat, get rest or talk with medical staff.
- Phone charger
- Have password on hand for MyChart/Patient Portal to receive live updates
- Cards/small pieces of paper listing instructions for interacting with the person living with dementia. For example: “Thanks for your patience. Please be aware that my husband has Alzheimer’s disease. Please talk with him in a calm and comforting manner. Thank you.” Do not assume that staff are aware of your family members’ dementia diagnosis.

Items to provide a distraction while you wait:

- iPad (videos to watch)
- Coloring book or notebook
- Headphones to listen to soothing music
- Squeeze ball for hands
- Photo album to look at
- Other items used at home that are portable and could be used as a distraction
- Water and snacks for long waits

How to get urgent outpatient support

The first call should always be to the primary care physician, or specialist, providing your family member with dementia care. If the doctor/specialist is not available to take your call, take time to explain the medical situation to the staff answering the phone. Let them know you need guidance, and this is an urgent situation. Tell them your preference is not to go to the emergency room if possible. Ask if they can help you avoid an emergency room visit.

The doctor is your biggest advocate in this situation, but may be unable to follow up with you in a timely manner for several reasons. Covering staff and physicians will not have the same knowledge of, and relationship with, the person living with dementia who needs assistance. It will be important for you as their advocate to provide the covering professional with as much information as you can, as quickly as you can. Providing a list of your loved one’s medical diagnosis and issues, as well as medications they take, will be extremely helpful. It may take staff time to review the patient’s information and medical record.



An individual living with dementia may face an urgent issue due to psychiatric and behavioral symptoms they are experiencing from their brain disease. This type of urgent situation is often better managed outside of an emergency room setting. The doctor or another health care professional can help navigate and advise you on how to obtain care.

Tips for Calling the Doctor's Office

- Stay calm and speak slowly and clearly.
- State the medical situation and why it requires urgent follow-up.
- Provide as much information as possible to the staff person answering the phone.
- Explain why you feel going to an emergency room is not a good idea (remind staff of the patient's dementia diagnosis).
- Be persistent and ask to stay on the phone while they collect additional information or get a medical professional to speak with you.
- Be flexible. If staff can squeeze you in for an appointment, take it.
- If they suggest an alternative plan, be open to this suggestion.
- If the doctor is not available, a qualified colleague, such as a Nurse Practitioner or Physician's Assistant may be able to help you.

You may be sent to a professional, outside of the regular medical practice, who is expert in dealing with the condition your loved one is facing. This will require you to share all the information you have previously provided. Having planning tools, like a medical information sheet and medication list will be helpful.

Urgent Care/Emergency Room Visit: Tips to Assist the Person With Dementia

Call your doctor's office right away and ask them to call ahead to the emergency room you plan to visit. Provide the name/phone number of the hospital you will be going to so the doctor can let them know you are on your way. A family member can also call the Emergency room and ask to speak to the Triage Nurse. They can state that the doctor's office should be calling and they want to alert staff that their family member has dementia . Ask the nurse to notify staff you may be meeting on arrival. Emergency room staff will be appreciative of the heads up and will work with you.

While in the Emergency Room, consider the following to support the person with dementia:

- Stay calm and ask others to do the same. It is important to avoid raised voices or signs of panic.
- Let the person with dementia know that you are going to a place that may sound noisy or feel a little hectic, but you will be there with them.
- Encourage them to listen to music, put headphones on them.
- On arrival introduce yourself and tell the staff person checking you in that you called ahead and spoke to the Triage Nurse.
- Reassure the person with dementia they will not be alone; you and/or other family/friends will be with them
- When staff approach, greet them as if you already know them, use a calm relaxed tone of voice as you explain the situation.
- Do not assume medical providers know your medical situation, be prepared to provide additional information, and be prepared to do this more than once.

It is important to ask the Emergency Room staff to allow a family member to remain with the patient at all times. Because they have dementia, the patient will not provide an accurate history, will not remember what is discussed, and will likely be more disorientated without a familiar person.



Travelling to the Hospital

Travelling to the hospital for an emergency with a loved one living with dementia can be scary and difficult. It is not advisable for the caregiver to drive alone. Asking a family member or friend to drive you to the hospital is preferable. However, going to the emergency room by ambulance may sometimes be unavoidable. If this happens, notify the ambulance team about the dementia diagnosis when calling 911. Remind the paramedic and driver again when the ambulance arrives at the home. Provide as much information as you can, quickly.

Having written information summarizing the individual with dementia's medical history and a Medical Orders for Life Sustaining Treatment (MOLST) form, is advisable. See page 6 for additional information on a MOLST form.

Advice to Help the Person with Dementia During a Long Wait in Emergency Room

Expect to wait a minimum of four hours. The person living with dementia will need ongoing communication and reassurance in this environment.

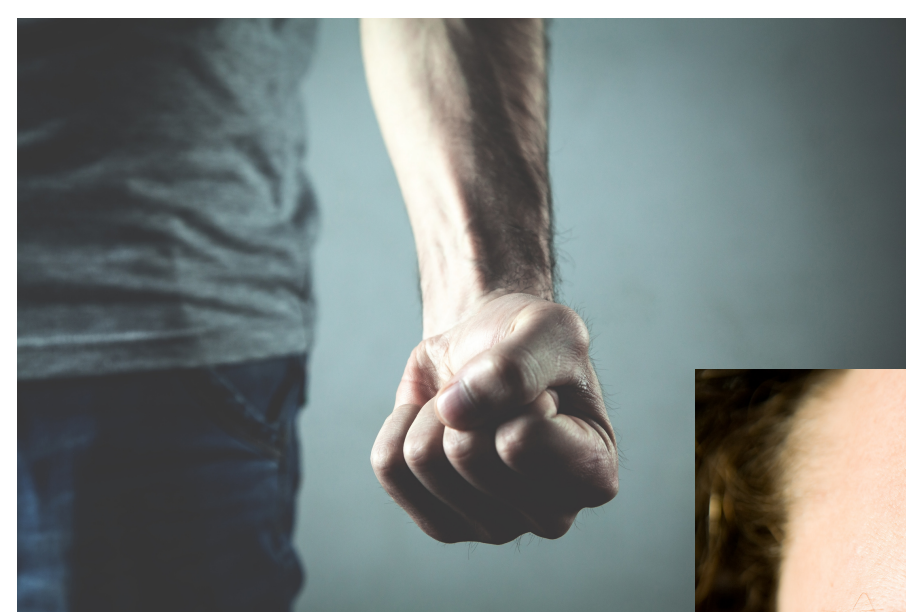
- Find a comfortable spot (chair, couch, stretcher) and tell staff where you will be waiting
- Ask where restrooms are and if there is one close by to use that may be less busy
- Provide verbal reminders of why you're making this medical visit and reassure the patient that the health care team (strangers) are there to help.
- After initial evaluation ask healthcare staff if it would be possible to wait in a quiet area, other than the general waiting area, such as an open evaluation bay.
- Close curtain, dim lights and use distraction methods while waiting.
- Do not leave the person with dementia alone. Ask a nurse or assistant to sit with them if the caregiver needs to go to the bathroom or the cafeteria.
- Advise staff that decreasing stimulation will help keep patient with dementia calm
- Provide ongoing comfort in both verbal and nonverbal ways: warm blanket, pillow, smile, touching their hand or shoulder, make eye contact, continuously explain that things will be ok this is a temporary situation.

"Someone in my support group recommended I always have paperwork on me with my husband's medical information, medications, his doctors name and email addresses, insurance information. This was the best information I ever received. My husband fell from a stool with a bottle in his hand and needed stitches. When I showed up with the paper in the emergency room the person at the front desk copied it right away. I showed it to several people after that. It said he had dementia in red on the front page. I could see the staff understood and really helped both of us stay calm as blood was spurting out of his hand. It allowed me to focus on my husband more and less on information others needed from me."

- Caregiver comment

Be on the lookout for symptoms of pain that the person may be unable to express (i.e., furrowed brow, clenched teeth or fists, kicking).

Assume the person has pain if the condition or procedure is normally associated with pain. Ask for pain evaluation and treatment every 4 hours - especially if the person has labored breathing, loud moaning, crying or grimacing, or if you are unable to console or distract him or her.



Hospital Visit Tips for Dementia Caregivers

Source: nia.nih.gov/health/going-hospital-tips-dementia-caregivers

- Try to limit questions asked of the person with dementia as they may not be able to answer correctly.
- Talk with the doctor outside the patient's room when possible.
- Help staff understand the person's functioning and behavior while at home.
- Ask family members and friends, or hire a caregiver, to stay with the person with dementia as much as possible. A friendly face will help the person with dementia stay calm.
- Let the medical staff know if the person with dementia suddenly seems to act or behave different or if medical issues worsen. Medical issues such as fever, infection, (example- recent UTI, pneumonia, etc), medication side effects, and dehydration can cause delirium, a state of extreme confusion and disorientation.
- Ask a friend or family member to be an advocate for you and to make calls and/or emails to keep others informed about the patient's progress.
- Help staff fill out menu requests and be sure to open food containers and ensure the person with dementia is eating.
- Provide reminders to drink fluids. Offer fluids regularly and have person with dementia make frequent trips to the bathroom.
- Assume the person with dementia will have trouble finding the bathroom and/or using a call button, bed adjustment buttons, and the phone. Tie a small stuffed animal, ribbon, etc. on the call light so it can be easily picked up.
- Since an unfamiliar place, medicines, invasive tests, and surgery will make a person with dementia more confused, they will likely need more assistance with personal care.
- The caregiver must take care of themselves. Get help from other family members.

If anxiety or agitation occurs, try the following:

- Put personal clothes away and out of sight; they may remind the person of getting dressed and going home.
- Post reminders or cues, like a sign labeling the bathroom door
- Minimize background noise to prevent overstimulation (turn off the TV, telephone ringer, and intercom).
- Offer reassurance, a comforting touch, make eye contact and repeat answers to questions when needed.
- Distract the person with offers of snacks and beverages.
- Listen to soothing music or try comforting rituals, such as reading, praying, singing, or reminiscing.
- Slow down; try not to rush the person.

Interacting With Hospital Staff

Remember that not every medical professional understands the same basic facts about Alzheimer's disease, and related dementias. You may need to help hospital staff by suggesting the best approach to interacting with the patient with dementia and identify what causes them distress.

- Remember to provide a personal information on likes, dislikes, triggers, and comfort measures to staff
- Offer to help with bathing, eating, or using the bathroom.
- Provide reminders about hearing difficulties and/or other communication problems and offer ideas to enhance communication when possible.
- Make staff aware of wandering and other behavioral issues and concerns to ensure safety.
- Advocate and ask for additional information on hospital procedures/tests and confirm they are necessary.
- Request information on eligibility for home health services. Prepare for an increased level of caregiving when you leave the hospital.

For more information on dementia and hospitalization, see the University of California, San Francisco, Memory and Aging Center's Tips for Hospitalization:

memory.ucsf.edu/treatments-stays/surgery-hospitalization/tips-hospitalization

The Massachusetts Alzheimer's and Dementia Act was signed into law in August 2018. This law requires hospitals, licensed by Department of Public Health, to develop an operational plan for the recognition of dementia and/or delirium by 10/1/22. The Governor has convened committees to make recommendations for improved care for individuals diagnosed with dementia. One committee is looking to improve education for professionals on care needs facing dementia patients in the emergency room setting. Professional training and education for hospital staff on interventions for individuals living with the early stages of dementia has been recommended.

As a caregiver you are faced with helping hospital staff understand the needs of a patient living with dementia. Dementia symptoms may not be easily recognized by healthcare staff. Additionally, dementia patients sometimes face difficulty communicating about symptoms or changes in their condition. You will need to advocate for them in an acute care emergency.

Improving understanding of the complexities associated with emergency room care in this patient population is important. Challenges may lead to unnecessary hospitalization.

Post Hospitalization Planning

Communication with your Doctor:

There are several reasons to follow-up with your Doctor after a visit to an urgent care or emergency room setting. It is important for your doctor to understand the outcome of this visit and assess if additional support/treatment is needed. If hospitalization has occurred there is a risk of re-hospitalization should any outstanding medical conditions not be properly managed at discharge. Ensuring that a patient with dementia is on the correct medications, and plan of treatment, post-discharge is critical to providing ongoing care and support at home. Caregivers should follow-up with their treating physician to determine if follow-up is needed.

Help at home:

If you need help at home it is important to have this discussion prior to leaving the hospital setting. You can discuss this need with your doctor, nursing staff and social workers, so they can help identify resources. Coordination at the time of discharge is necessary. Communication about issues you face at home is critical to ensure proper follow-up.

Advance Care Planning

Having an Advance Care Plan ensures that an individual living with dementia will receive treatment and care according to their preferences, even when they can no longer express themselves. People living with dementia benefit when their wishes are granted and they have a greater influence on their own end-of-life-care decisions. The primary care doctor, dementia care physician, social workers and other health care staff can assist caregivers, individual diagnosed with dementia, and their family members with these discussions.

A form called Medical Orders for Life Sustaining Treatment (MOLST) should be completed and readily available to give health care providers in an emergency. This form can be found here:

<https://bit.ly/MOLSTform>

Have a copy of this form included with all medical information. Present the form to health care providers when seeking treatment for a loved one with dementia in an emergency. Keep this form on a home refrigerator for easy access by medical personnel in case they come to the house in an emergency.

The Importance of Research Participation

Research participation is critical to finding a cure for Alzheimer's disease and related dementias. 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) has a variety of study types, ranging from observational studies to clinical trials. To learn more, visit: madrc.org/join-a-study/ or call (617) 525-3666

References and Resources

Moore, J., & Sullivan, M. (2017). Enhancing the ADMIT Me Tool for Care Transitions for Individuals With Alzheimer's Disease. *Journal of Gerontological Nursing*, 43(5), 32-38.

www.alz.org

www.madrc.org

www.honoringchoicesmass.com

NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center
800-438-4380 (toll-free), adear@nia.nih.gov, www.nia.nih.gov/alzheimers

The NIA ADEAR Center offers information and publications about Alzheimer's and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

www.Alzheimers.gov

Information and resources on Alzheimer's and related dementias from across the federal government.

Mass General Brigham Resources



- Massachusetts Alzheimer's Disease Research Center: www.madrc.org
- MGH Memory Disorders Division: www.massgeneral.org/neurology/treatments-and-services/memory-disorders-division
- MGH Multicultural Assessment and Research Center: www.massgeneral.org/psychiatry/treatments-and-services/multicultural-assessment-and-research-center
- BWH Center for Alzheimer Research & Treatment: www.bwhcart.org
- BWH Center for Brain/Mind Medicine: www.madrc.org/bwh-center-for-brain-mind-medicine/
- BWH Rapid Diagnostic Clinic: www.madrc.org/bwh-center-for-brain-mind-medicine//wp-content/uploads/2016/09/RDC-Clinician-Info.pdf
- McLean Memory Diagnostic & Assessment Clinic: www.mcleanhospital.org/older-adult

TABLE B

EMERGENCY INFORMATION

ADMIT ME

Alzheimer's, Dementia, and Memory Impaired Transitions

Name: _____ Nickname: _____
Address: _____
Date of Birth: ____/____/____ Sex: M F Blood Type: _____
Height _____ Weight _____

CODE STATUS: () Full () DNR () CMO () Other _____

****Attach: Medical Orders for Life Sustaining Treatment (MOLST)**

HEALTH PROVIDER SIGNATURE: _____ **DATE:** _____

ALLERGIES/reactions (medication, food, etc.):

Hospital of Choice: _____

Power of Attorney or Healthcare Proxy? ((if YES, attach and fill in below)

Name of Healthcare Proxy: _____

Home Phone #: _____ Cell Phone #: _____

Alternate Name: _____ Phone #: _____

EMERGENCY CONTACTS (1st responders, use these contacts)

Name: _____ Home/Cell Phone #: _____

Relation: _____ Work Phone #: _____

Name: _____ Home/Cell Phone #: _____

Relation: _____ Work Phone #: _____

Primary Provider: _____ **Specialty Provider:** _____

Phone #: _____ Phone #: _____

Address/Practice: _____ Address/Practice: _____

Home Care Provider: _____ Phone #: _____

MEDICAL INSURANCE

Med Ins Company: _____

Policy #: _____

Other Med Ins Company: _____

Policy #: _____

ATTACH RECENT PHOTO.

POST ON REFRIGERATOR.

MEDICAL DATA

Last Updated: ____/____/____

Surgeries & Dates: _____

MEDICAL CONDITIONS (check all that apply)

<input type="checkbox"/>	Alzheimer's Disease	<input type="checkbox"/>	Dementia	<input type="checkbox"/>	Implanted Devices/Stents
<input type="checkbox"/>	Anemia	<input type="checkbox"/>	Diabetes	<input type="checkbox"/>	Leukemia/Lymphoma
<input type="checkbox"/>	Angina/M.I.	<input type="checkbox"/>	Dialysis: Mon Tue Wed Th Fri Sat	<input type="checkbox"/>	Memory Impaired
<input type="checkbox"/>	Asthma	<input type="checkbox"/>	Eye Disease: Glaucoma/Macula	<input type="checkbox"/>	Pacemaker
<input type="checkbox"/>	Bleeding Disorder	<input type="checkbox"/>	Fistula	<input type="checkbox"/>	Restricted Extremity: L R
<input type="checkbox"/>	Cardiac Dysrhythmia	<input type="checkbox"/>	G.I Bleed	<input type="checkbox"/>	Renal Failure
<input type="checkbox"/>	Clotting Disorder	<input type="checkbox"/>	Heart Failure	<input type="checkbox"/>	Seizure Disorder
<input type="checkbox"/>	COPD	<input type="checkbox"/>	Heart Valve Prosthesis	<input type="checkbox"/>	Stroke
<input type="checkbox"/>	Coronary Bypass Graft	<input type="checkbox"/>	Hypertension	<input type="checkbox"/>	Transplant

Other Medical Conditions: _____

Medications (Use pencil to make changes)

Name of Medication	Amount	Time of Day

Name and phone # of Pharmacy: _____

Baseline Mental Status: _____

COMMUNICATION (check all areas that apply)

() Primary language: _____ () Non-Verbal () Uses Sign Language
() Blind () Deaf () Hearing Impaired () Vision Impaired Other: _____

ASSISTIVE DEVICES (check all areas that apply)

() Hearing aids () Dentures () Glasses () Walker () Cane () Wheelchair
() Other: _____

PERSONAL CARE (check the areas where help is needed)

() Dressing and Undressing () Bathing or Showering () Grooming () Eating
() Walking () Transferring (e.g.; bed to chair, etc.) () Toileting () Taking
Medications

BEHAVIORS (check all that exist)

<input type="checkbox"/>	Biting	<input type="checkbox"/>	Inappropriate sexual behavior	<input type="checkbox"/>	Swearing
<input type="checkbox"/>	Calling out for loved one	<input type="checkbox"/>	Multiple phone calls	<input type="checkbox"/>	Spitting
<input type="checkbox"/>	Complaining	<input type="checkbox"/>	Pacing up and down	<input type="checkbox"/>	Suspicion
<input type="checkbox"/>	Following/Shadowing	<input type="checkbox"/>	Repetitive questions	<input type="checkbox"/>	Sleeplessness
<input type="checkbox"/>	Hallucinations	<input type="checkbox"/>	Repetitive phrases	<input type="checkbox"/>	Sundowning
<input type="checkbox"/>	Hiding and losing things	<input type="checkbox"/>	Repetitive actions/movements	<input type="checkbox"/>	Trying to leave building
<input type="checkbox"/>	Hitting	<input type="checkbox"/>	Scratching	<input type="checkbox"/>	Undressing in public
<input type="checkbox"/>	Hoarding	<input type="checkbox"/>	Shouting or screaming	<input type="checkbox"/>	Wandering
<input type="checkbox"/>	Intentional falling	<input type="checkbox"/>		<input type="checkbox"/>	

TRIGGERS TO BEHAVIORS: _____

CALMING TECHNIQUES (check all that apply)

() Music – () Swing () Big Band () Rock n’ Roll () Classical () Other: _____
() Singing () Stuffed animals () Baby doll () Reminiscing () Exercise () Holding
hands
() Arts & Crafts () Housework (e.g. folding laundry) () Other _____

Favorite Conversations Enjoyed: _____

Activities/Interests/Hobbies: _____

Nutritional Preferences/Considerations/Difficulty Swallowing: _____

Completed by: _____ Relationship: _____ Date: _____

ADMIT ME was designed by Elms College School of Nursing students and faculty in 2015. Delina DeVillier, Erica Dybas, Meghan Sullivan and Dr. Janet Moore were the original creators. Copyright pending. Address correspondence to:
moorejane@elms.edu.



MASSACHUSETTS
Alzheimer's Disease
Research Center



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
- Road Map to Social Engagement
- Road Map to Acute Care Management

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

www.madrc.org/community/

STAY CONNECTED WITH MADRC!



@MassADRC



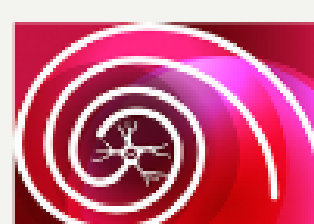
@We_Are_MADRC



@ADRCMass



ADRCMASS



MASSACHUSETTS
Alzheimer's Disease
Research Center



Additional Caregiver Resources

Special thanks to the caregivers who shared their experiences in this booklet. For more caregiver resources, see Road Map to Caregiving: madrc.org/community/

MGH Dementia Care Collaborative
dementiacarecollaborative.org

- Caregiver Support Groups
- Conversations With Caregivers Program
- Health & Resiliency Program

Contact: dementiacaregiversupport@mgh.harvard.edu

BWH Resilience Through Neurological and Emotional Wellness (RENEW) - brainhealth.bwh.harvard.edu

- Executive Function Skills Group
- Memory Skills Group
- Caregiver Skills and Wellness Group
- “My Healthy Brain” Group

Contact: BrainHealthGroups@bwh.harvard.edu

MGH Frontotemporal Dementia (FTD) FTD Unit Support
ftdboston.org/support/

- AFTD-Affiliated Caregiver Support Group
- FTD Educational videos

Contact: mghftdunit@mgh.harvard.edu

Road Map to Acute Care Management Curriculum Committee:

- Dorene Rentz, PsyD
Gad Marshall, MD
Lenore Jackson-Pope BSN, MSM, CCRP
Christine Brown
Judy Johanson
Janet Moore, PhD, RN
Linda Pellegirini NP
Alison Pietras PA
Catherine Riberio PA
Eileen Obrien-Meade RN, CEN
Kei Ouchi MD



MASSACHUSETTS
Alzheimer's Disease
Research Center

 **Brigham and Women's Hospital**
Founding Member, Mass General Brigham



MASSACHUSETTS
GENERAL HOSPITAL