



MASSACHUSETTS
Alzheimer's Disease
Research Center

KEEP IN MIND

Annual Newsletter of the Massachusetts
Alzheimer's Disease Research Center

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A Message From our Chief

Updates from Brad Hyman, MD, PhD.



Dear MADRC Community,

I want to take this opportunity to express how grateful I am for your dedication and commitment to our Center. We cannot do the work we do without your help and involvement. Despite the challenges of COVID, you have all continued to show up when needed and for that I am so very thankful.

This Spring has had its ups and downs – COVID has improved, bans have been lifted, but the situation in Ukraine has been heartbreaking and difficult to understand. For those who have been directly or indirectly affected, we stand by you and hope for peace and better times ahead.

As we welcome another year, we also welcome new staff. I am absolutely thrilled to introduce Dr. Christine Ritchie who will co-lead the Outreach, Recruitment and Engagement (ORE) core with our longstanding and dedicated ORE core leader, Dr. Dorene Rentz. Dr. Ritchie holds several leadership roles related to dementia care and engages in applied clinical research focused on caregivers and those in the community. Her passion and expertise will be an asset to our Center. To learn more about Dr. Ritchie please see page 5.

We are also lucky to welcome Dr. Kate Papp, Assistant Professor of Neurology at Harvard Medical School, as the new Massachusetts Alzheimer's Disease Research Center neuropsychologist. Dr. Papp works as a Clinical Neuropsychologist in the Department of Neurology at the Brigham and Women's Hospital and Massachusetts General hospital. Her work focuses on developing and validating digital measures of cognition that can capture subtle early changes in memory. These technology-based tools are exciting, and we hope to incorporate such tools with our research participants. To learn more about Dr. Papp and her research please refer to page 4.

Our commitment to diversity remains a top priority. I am excited to share that we now have a Spanish speaking Memory Disorders Clinic at MGH with three MADRC-affiliated neurologists (Drs. Gomez-Isla, Ramirez Gomez, and Serrano-Pozo). With the formation of this clinic, we hope the local Hispanic communities will have better access to clinical care and opportunities to engage in research. See p. 6 to read about other outreach and diversity efforts.

Thanks to our new ORE Core administrative assistant, Maria Roser Rovira Riera, we have been able to translate our educational materials into Spanish and hope to expand our bilingual resources further. We received feedback that our RoadMap series is a wonderful resource to both patients and caregivers. This series is featured on page 9. (Continued next page)

Chief

(continued from p.1)

From observational studies to clinical trials, there are many opportunities to be involved in research at MADRC. I would like to highlight the Alzheimer's Clinical & Translational Research Unit (ACTRU) which is part of the MGH Interdisciplinary Brain Center (IBC) located in Charlestown at the Navy Yard. This is a new site for some MADRC-affiliated clinical trials. To learn more about ACTRU and what it can offer to research participants please go to page 4.

On page 10 of this newsletter, you will find the link to an educational video about brain donation, and another about lumbar punctures on p.11. These topics can be scary and difficult to talk about but, I hope after watching the videos and learning more, you will understand how valuable this information is to researchers studying Alzheimer's disease and other neurodegenerative diseases.

We always love to feature our dedicated research participants. Juanita Melendez, a long-time participant of the Memory and Aging Study graciously tells us about her experience with research on page 3.

It was my honor to introduce my colleague, and dear friend, Dr. Teresa Gomez-Isla, MD, PhD as the speaker at the Raymond D. Adams Memorial Lecture on March 24, 2022 (Picture page 7). This annual conference is held to celebrate the legacy of the former Chairman of the Mass General Department of Neurology. Dr. Gomez-Isla presented her research on resilience in Alzheimer Disease.

As many of you know, in June 2021 the US Food and Drug Administration (FDA) approved aducanumab (Aduhelm), a monoclonal antibody for the treatment of Alzheimer's disease. In Fall 2021, after a close review of the data, which did not show a compelling clinical benefit, Mass General Brigham decided they would not offer aducanumab for the treatment of Alzheimer's disease. Subsequently, in April 2022, Medicare decided to not cover the cost of treatment with aducanumab outside of a clinical trial. I realize this decision may have been disappointing to some of our patients and families, but please know that you can count on us to stay informed on this topic and we will update you with any additional information as it becomes available.

Once again, thank you for being a valued member of the MADRC family. I look forward to working together, as a team, to combat these devastating diseases.

-Brad

Research Volunteers Spotlight

The Importance of Research Participation

Why is your participation in research so important? Through research, scientists can analyze data and observations which play a key role in:

- Discovering new treatments and making sure those treatments work on all of us
- Making sure existing treatments are being used in the best possible way
- Teaching us more about what factors cause diseases
- Highlighting possible avenues towards prevention
- Identifying ways to support people living with dementia and their caregivers in the here and now
- Making sure your voice is heard

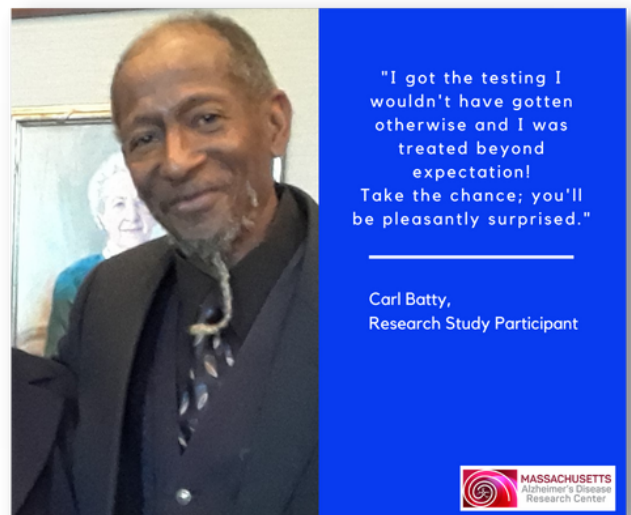
Researchers rely on the support of volunteer participants to advance their studies.

Participating in research is a very personal decision. Individuals who choose to participate are offering their time and bodies in the hopes that their efforts will contribute to a discovery that can improve the quality of life for those living with dementia or prevent dementia altogether.

Participating in research may feel intimidating at times, but for many it also provides a sense of purpose, accomplishment, and pride. Our Center is especially committed to having research volunteers who are diverse

in race, gender, ethnicity, age and identity. This diversity is critical to make sure treatments work for everyone. Don't just take our word for it, read over the quotes, throughout this newsletter, from some of our current research study participants!

MADRC has research opportunities available for all people, whether you are cognitively healthy, have a diagnosis of Alzheimer's or related dementia, or are just concerned about your memory and thinking. To learn about opportunities for research participation, visit: www.madrc.org/how-to-participate-as-a-research-subject/ or call (617) 278-0600.



Research Participant Perspective

The following interview was conducted by MGH Clinical Research Coordinator, Roberto Obregon Garcia. He spoke with 76-year-old, Orocovis, Puerto Rico native, Juanita Melendez, who participates remotely in the MGH Study of Memory and Aging.

Why did you decide to participate in this research study?

I am interested in continuing to participate in Alzheimer's research to see if they find a cure or remedy for the disease.

What does it mean to you? To your family?

For me, it is important to participate because it means helping the community and the people who might develop Alzheimer's, especially my children.

Can you describe your experience as a research participant?

It has been a positive experience.

Have you found language to be a barrier?

No.

What would you say to others considering taking part in this study?

I would tell other people who are considering participating in this study to consider it. It is a decision that helps the Hispanic community. We can help others understand the disease of Alzheimer's and how it impacts the Hispanic community.

For more information about the Memory and Aging Study, contact Roberto Obregon Garcia: robregongarcia@mgh.harvard.edu



Juanita Melendez and her husband

MEMORY & AGING STUDY

Do you have trouble with your memory?

Are you caring for a loved one who has trouble with their memory?

Do you have a normal memory but want to help support research?

We're looking for adults 65 and older to join our study to understand how memory loss develops in the human brain. Once a year you will be examined by a doctor and have memory testing. Participants will be compensated \$40/visit.

For more information call Judy Johanson at (617) 726-5571 or email: jjohanson1@mgh.harvard.edu

MASSACHUSETTS GENERAL HOSPITAL

MASSACHUSETTS Alzheimer's Disease Research Center

Prevention Studies Highlight

There are currently two prevention studies underway within MADRC:

The Ornish Study

The Ornish study aims to see if lifestyle changes may slow the progression of Alzheimer's disease. Participants in this study will make changes to their diet, and participate in daily exercise, stress management, and group support.

Currently, all FDA approved treatments of Alzheimer's are medications. This study is examining if it is possible to slow down, lessen, or reverse the symptoms of Alzheimer's disease through a lifestyle intervention.

To learn more about the Ornish study: Email: jwood20@mgh.harvard.edu or call (617) 643-4802

The AHEAD Study

The AHEAD Study is testing whether an investigational treatment can lower people's risk of memory loss due to Alzheimer's disease. This study seeks cognitively normal (no memory loss) adults, ages 55-80, who may be at increased risk of memory loss associated with Alzheimer's disease. This is the first Alzheimer's disease prevention trial to enroll people as young as 55.

To learn more: www.studymemory.org or call 857-307-0345

NMN Study Overview

A new clinical trial aims to determine if an oral dietary supplement, NMN, can benefit people living with Alzheimer's disease. NMN is a naturally occurring nutrient that is found in all living things and in various food products. In the USA, NMN is available to purchase without a prescription as a nutritional supplement, but it is not an FDA approved drug.

The NMN study will compare the study supplement, NMN, to a placebo to find out if the supplement enters the brain and how it is metabolized by the body.

To learn more about the NMN study, Email: ilevesque@bwh.harvard.edu or call (617) 278-0381.

"There are many research studies requiring different levels of commitments and risks. They all need diverse participants. One can start with one that feels right and matches their interests and comfort level."

Dennis Chan,
Research Study Participant

MASSACHUSETTS Alzheimer's Disease Research Center

At Home Cognitive Screening

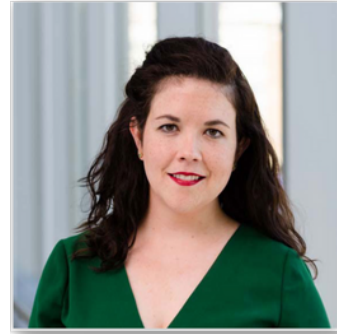
A Self-guided, web-based, cognitive assessment tool may be an early detector of Alzheimer's disease.

Neuropsychologist, Kathryn Papp, PhD. and colleagues, recently published a paper on the Boston Remote Assessment for Neurocognitive Health (BRANCH) system. The report states that there were 234 clinically normal participants, ranging in age from 50 to 89 years old who used mostly smartphones to complete the assessment at home. Additionally, some in the cohort also received in-person cognitive testing and some also received neuroimaging.

The BRANCH Study team found that the monthly, self-monitored test was easy to complete and that when compared with in-person cognitive testing, lower BRANCH scores were associated with greater amyloid and tau pathology on PET imaging. By allowing for remote, unsupervised, and more frequent assessments, this technology has the potential to detect cognitive changes earlier than less frequent, traditional, in-person testing.

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To learn more about the BRANCH study: habs.mgh.harvard.edu/affiliated-studies/branch/



Kathryn Papp, PhD

"Superagers" Study

Typically as people age, the communication between different areas in their brains slow down, which can lead to memory issues. However, a recent study on a rare group of "Superagers" shows that they can learn and recall new information as well as a person in their mid-twenties.

These superagers are part of an ongoing longitudinal study of aging led by Dr. Brad Dickerson, Director of the MGH Frontotemporal Disorders Unit. They were first identified in 2016 due to outstanding performance on memory testing.

In 2021, the superagers had their brains imaged through functional magnetic resonance imaging (fMRI) while undergoing a challenging memory test. A separate group of young adults took the same test while their brains were imaged in the same manner. An fMRI shows activity in different areas of the brain while completing tasks.

The fMRI study found that the memory performance of the superagers was indistinguishable from those who are 25 years old. Results showed that compared with their peers, superagers have a thicker cortex in the brain. This was evident not just in brain areas traditionally associated with memory, but also in areas that relate to attention or executive function.

Researchers plan to study these individuals further to determine if interventions to specific brain areas can help improve memory in older adults.

To learn more, visit: ftdboston.org/research/

ACTRU Adds Data Visualization Room

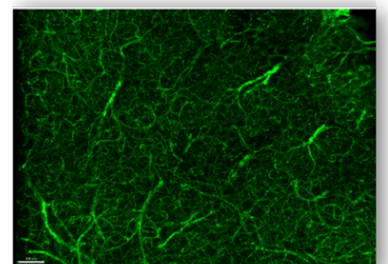
Dr. Steven Arnold, MD is the director of the Alzheimer's Clinical & Translational Research Unit (ACTRU) and works with a team of brilliant minds to design patient-oriented experimental and clinical trials for aging and dementia. These studies include advanced digital health assessments, neuroimaging, and ultra-sensitive molecular biomarker detection technologies in blood, cerebrospinal fluid, and brain tissue. ACTRU is a new state of the art facility for some MADRC-affiliated clinical trials.

The ACTRU space was recently renovated and has exciting cutting-edge technology, including a data visualization room. Here, researchers can convert 2D images into a virtual reality. Dr. Ted Zwang, PhD describes how he has been using this technology in his work.

"This image is of blood vessels in a brain with Alzheimer's disease. It exemplifies how difficult it can be to track two dimensional structures on a screen. Try to pick a starting point and track where a blood vessel goes across the image. It's challenging!"

Now we can use the data visualization room to load this data into a virtual reality, which will allow us to see the data in 3D, as if we are in the brain. In virtual reality, we can "walk" along the blood vessels to see where they lead like we are walking along a brightly lit path. The technology helps us understand how these complicated structures within the brain change alongside nearby pathology."

To learn more about ACTRU: www.actru.org/clinicalresearch.



ORE Core Welcomes Co-Director

Late last year Dr. Christine Ritchie, joined Dr. Dorene Rentz as Co-Director of the MADRC Outreach, Recruitment & Engagement (ORE) Core. Dr. Ritchie is the Kenneth L. Minaker Chair in Geriatrics and Director of Research for the Division of Palliative Care and Geriatric Medicine at the Massachusetts General Hospital. She leads the MGH Dementia Care Collaborative effort and works closely with Dr. Gomez-Isla our Clinical Core leader and associate director of the Center.

Dr. Rentz states, "I am delighted that Dr. Christine Ritchie has joined me as Co-Director. She brings a wealth of experience in the area of dementia care and adds a dimension to our ORE team that has been missing. Her presence will allow us to combine all the resources available across the dementia spectrum under Mass General Brigham. Welcome Christine!"

Dr. Ritchie's research interests focus on improving quality of life for those living with dementia and those caring for them. Much of her work builds on what persons living with dementia along with

their caregivers state - that they need to lead better lives, including developing supportive care interventions for caregivers and structured clinical care programs designed to support persons with dementia and their caregivers.

Dr. Ritchie had the honor of caring for her father in her home when he had Lewy Body Dementia. She is passionate about listening to and learning from diverse communities about dementia care needs and giving everyone the chance to have their voices heard through research participation.



Dr. Christine Ritchie

Support Teams Collaborate

As former First Lady, Rosalynn Carter once said, "There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers."

Across our research centers at Mass General Brigham, we know caregiving is a critically important, and often difficult, role. We strive to provide as much support as possible to the care partners for people living with dementia.

To ensure that caregiver needs are being met, we recently launched a collaboration between the MADRC Outreach, Recruitment & Engagement (ORE) team, the MGH Dementia Care Collaborative (DCC), and the BWH Resilience Through Neurological and Emotional Wellness Program. The goal is to cross promote each groups' unique programs so caregivers are aware of all available resources and support options.

The DCC is part of the MGH Division of Palliative Care & Geriatric Medicine. The DCC provides opportunities for caregivers which offer a source of connection with others, to address the common experience of isolation and loneliness, including:

Caregiver Support Groups

These groups provide an opportunity for people to discuss their caregiving experiences, share resources and feelings. Participation is not limited to caregivers for people who are patients at MGH.

Conversations With Caregivers

This is a monthly forum featuring a speaker who is an expert in a particular field. Some of the topics covered recently include art therapy, practical tools for caregiving, and defining palliative care and hospice.

For a complete list of all DCC programs, visit: dementiacarecollaborative.org

The BWH Resilience Through Neurological and Emotional Wellness Program (RENEW) offerings include cognitive skills training, support groups, caregiver training, and general wellness/lifestyle programs:

Caregiver Dementia Skills & Wellness Group

During this six-week program caregivers will learn strategies for communication and engagement with their person living with dementia. Additionally, registrants will learn mindfulness and compassion exercises to assist with their own mental health. In addition to sessions for caregivers, the RENEW program provides supportive trainings for people with memory loss as well as a Lifestyle and Healthy-Living Skills Group.

To learn more about RENEW program offerings: brainhealth.bwh.harvard.edu/renew-flyers/

The MADRC ORE team provides support for caregivers via the Aging & Memory Loss Road Map Education Series. The series includes presentations and guidebooks on issues related to caregiving and provides practical tips and advice. The guidebooks can be accessed (in English and Spanish) at: www.madrc.org/community/



Extending MADRC's Outreach

Community Connections

The ongoing COVID-19 pandemic made it necessary to alter the ways we partnered with community-based organizations. As always, our center remains dedicated to ensuring that all members of the community have access to information about dementia-related research and resources. Thus, we continuously adapt and interact with community organizations both virtually and, where appropriate, in person.

We value our collaborations with community groups such as The Harvard Family Van, Union Capitol Boston and the Dimock Center. These partnerships enable us to seek critically important input from community members and gain insight on their thoughts about participation in Alzheimer's and related dementia research.

The Harvard Family Van travels throughout Boston to bring curbside screenings, health coaching and social services directly to the people who have the greatest need. The van staff foster trust with area residents and remove barriers to care, thus reducing health disparities. The program provides an alternative to costly emergency room visits by providing preventive services.

MADRC has collaborated with the Harvard Family Van to bring information about Alzheimer's disease and related dementia research to the community.



Union Capitol Boston (UCB) is a nonprofit organization that invests in civic engagement by partnering with health centers and community groups to build relationships, provide information and resources and rewarding members for community involvement. Together MADRC and UCB have provided virtual programming on multiple topics over the last year to residents of under-resourced Boston neighborhoods.

Located in Roxbury, the Dimock Center provides access to high-quality, low-cost health care and human services that might not otherwise be available to the local community. The center administers health services, behavioral health services and child and family services. MADRC staff have networked with the Dimock Center to bring education about the importance of Alzheimer's and related dementia research to the community.

In addition to the collaborations mentioned above, MADRC connects with community members through focus groups and customized educational events. In February, we partnered with Afrobeat Fit to host "Get Moving With Your Brain" in celebration of Black History Month. This event featured a presentation about brain health and the importance of exercise, as well as an interactive Afro line dance session.

Our annual Memory Sunday program provides another important opportunity for the MADRC team to connect with community members. Read more about this collaborative event for faith communities on this page.

Reaching Faith Families Through Memory Sunday

In June we will hold our 5th Annual Memory Sunday New England (MSNE) event. Memory Sunday is a faith-based collaboration made up of leaders at the community, city and state levels. Held the 2nd Sunday each June, the goal of this event is to raise awareness about memory loss, Alzheimer's disease and related dementias, in the African American/Black community. Studies have shown that in the United States Black Americans are roughly 1.5 to 2 times as likely than whites to develop Alzheimer's and related dementias. Memory Sunday provides an opportunity for leaders of Black churches to incorporate education about the prevalence of Alzheimer's disease into religious services and related programs. This includes discussion about ways to reduce the risk of developing Alzheimer's disease, support available for caregivers of those with the disease, and raising awareness about the importance of research.

The MSNE Committee creates educational program content for faith communities to share with their congregations. This includes materials for both in-person and/or virtual presentations, so organizations can choose whichever format works best for them.

Memory Sunday began with one church in 2018 and has expanded to numerous faith communities over the years. For more information about Memory Sunday, visit: madrc.org/memory-Sunday



"I like to participate in Memory Sunday because it has become an integral part of ministry at the Berea SDA Church over the past several years. Beyond the annual June programming, the partnership with Memory Sunday New England has opened the door for our members to gain a better understanding of the development and progression of Alzheimer's and dementia. Another aspect of the partnership is the understanding of available resources to support families who are providing care for loved ones. Beyond just the informational elements, the shared experiences of our members have been invaluable resources. They provide support to members who did not recognize that their journey was shared by others within the congregation. I look forward to continuing our partnership for many more years to come."

Omar Jarvis, Pastor
Berea Seventh Day Adventist, Boston

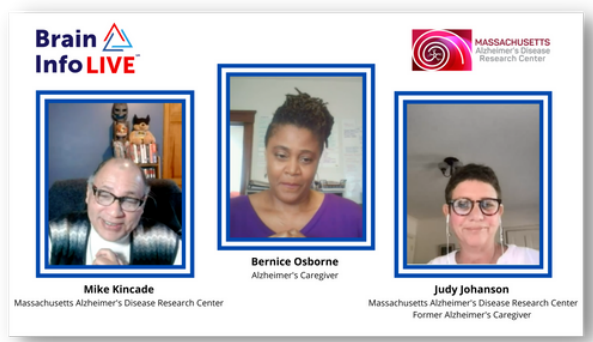


Brain Info Live Partnership

Last summer MADRC launched an exciting partnership with the Bright Focus Foundation. A main component of the foundation's outreach is Brain Info Live – a new, live-streaming community education series that provides entertaining and interactive brain health information.

The goal of this virtual community outreach series is to develop a sustained educational campaign that addresses equity, diversity, and health disparities in the Alzheimer's disease and related dementia space. Brain Info Live (Boston edition), is hosted monthly by Mike Kincade, MADRC's Outreach Coordinator. Each session includes culturally-tailored information from a local expert on a particular brain health topic. The sessions also include movie/TV clips and a lively seated chair exercise program with fitness guru, John Lewis!

To view recent episodes, visit:
www.brightfocus.org/braininfolive



Spanish Presentations Launched

MADRC recently kicked off its first community presentation in Spanish with Dr. Juan Carlos Urizar! Dr. Urizar, Medical Director, Brigham and Women's Hospital, Geriatric Psychiatry Division, presented Road Map to Behavioral Management.

This Road Map session focusses on the many complicated behaviors and symptoms of Alzheimer's disease and related dementias. The presentation offers advice on identifying what triggers these behaviors and how to best manage them.

Keep your eye on our events page for future Spanish presentations! www.madrc.org/events/



Se Habla Español

All of the research centers under the MADRC umbrella work to foster a diverse & inclusive environment. To that end, expanding the resources available for Spanish speakers was a major focus in the last year.

The MADRC Outreach Recruitment and Engagement (ORE) team recently welcomed Spain native, Roser Rivera to its team. Roser got right to work spearheading the Spanish translation of our resources for patients and families. This includes translation of our Aging & Memory Loss – Road Map Education Series guidebooks as well as our numerous fact sheets and infographics centered on Alzheimer's disease and related dementias.

The ORE team also added Dr. Liliana Ramirez Gomez as a new team member. Dr. Ramirez Gomez specializes in Cognitive and Behavioral Neurology, including evaluating and treating patients with Alzheimer's Disease and other related dementias.

Our Spanish speaking staff across MADRC teams was further expanded over the last several months to include the following:

- Dr. Sergio Ramirez-Salazar – BWH Center for Alzheimer Research & Treatment.
- Dr. Ricardo Salazar – BWH Center for Alzheimer Research & Treatment.
- Roberto Obregon Garcia –MGH Clinical Research Coordinator
- Andrea Roman – MGH Research Assistant
- Daniel Soberanes – BWH Research Assistant
- Caitlyn Christiano – MGH Memory & Aging Cohort Study

To further enhance communication with Spanish speakers, our website (WWW.MADRC.ORG) can now be viewed in Spanish.

Gomez-Isla Receives Award



Dr. Bradley Hyman, MD, PhD presents a plaque to Dr. Teresa Gomez-Isla, MD, PhD honoring her as the 2022 Raymond D. Adams Memorial Lecture speaker. This annual event celebrates the legacy of the former Chairman of the Neurology Department at the Massachusetts General Hospital (1951-1978). Dr. Gomez-Isla presented her research on brain resiliency in Alzheimer's disease.

Boost Your Brain!

Research suggests that boosting your brain health can reduce your risk of developing Alzheimer's disease. The team at MADRC encourages you to make your brain a priority this year!

Diet, Sleep, Exercise, Social and Mental Activity are all very important parts of a brain healthy lifestyle. Read on to learn why.

DIET: Eat healthy! Research shows that a Mediterranean-style diet, rich in fish, whole grains, green leafy vegetables, olives, and nuts helps maintain brain health and may reduce the risk of Alzheimer's disease.

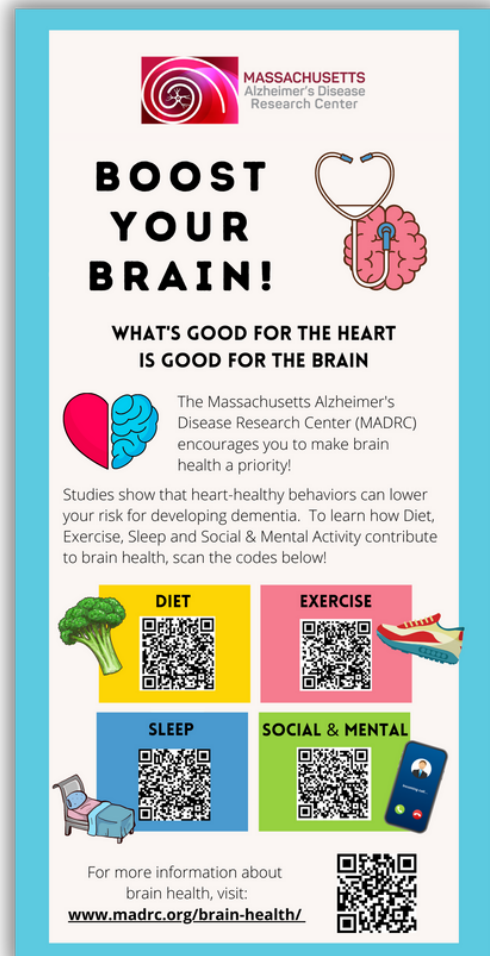
EXERCISE: Get moving! Aerobic exercise (cardio) raises your heart rate and increases blood flow to the brain.

SLEEP: Prioritize sleep! Studies show the changes that occur in our brains while we sleep affect our cognitive fitness and capacity for new learning.

SOCIAL & MENTAL ACTIVITY: Stay socially connected! Having strong social ties and challenging your mental skills can lower your risk of dementia.

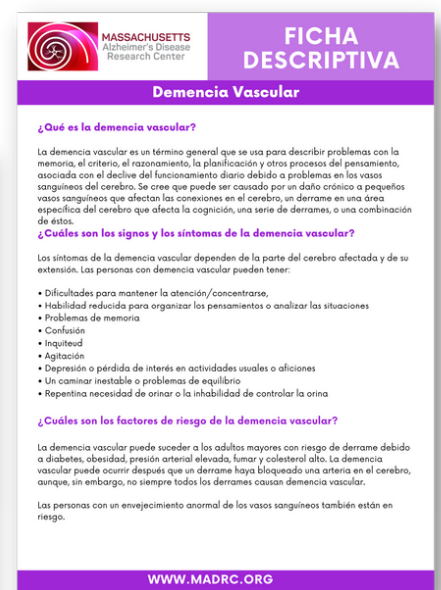
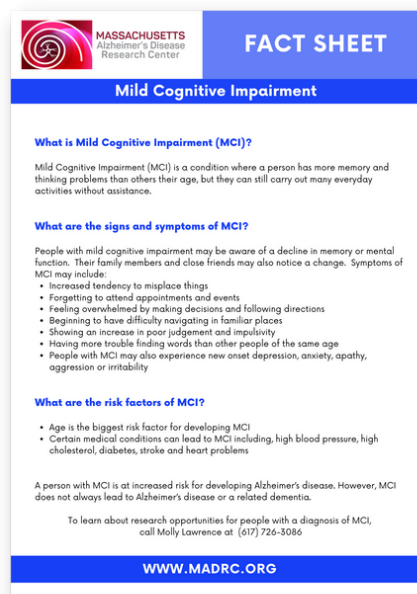
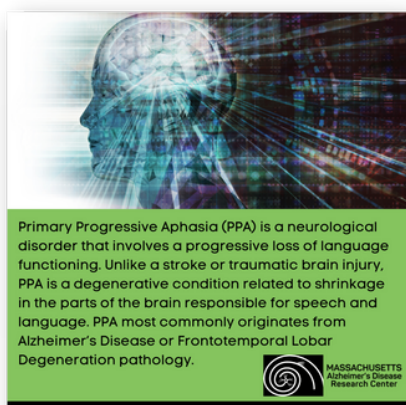
Scan the QR codes on the Boost Your Brain graphic elsewhere on this page to see our healthy brain campaign tips! Remember, you are never too young or too old to adapt these brain healthy lifestyle suggestions.

For more information on boosting your brain:
madrc.org/brain-health/



Get the Facts!

Understanding the many different causes of dementia and their symptoms can be confusing. The MADRC team has created a series of fact sheets and informational graphics on the various types of dementia diagnosis to help clarify this for patients and families. This information can be found in both English and Spanish on the website here: madrc.org/news-events/get-the-facts/



Education Series Expansion

Our Aging & Memory Loss: Road Map Education Series continues to expand. These community education programs are a great resource for people navigating the journey through memory loss, Alzheimer's disease, or a related dementia.

Sessions cover topics including when to be concerned about memory and thinking changes; how to discuss concerns with your primary care doctor; how to access research opportunities; strategies to help prevent brain disease; advice for caregivers; tools for managing dementia-related behaviors, and more!

The Road Map series includes:

- 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

These presentations can be done in person or virtually for both community and professional groups. To request a Road Map presentation, visit: <https://bit.ly/MADRCSpeakRequest> to complete a request form.


Companion guidebooks for each Road Map presentation are available in both English and Spanish on our website at: www.madrc.org/community/



Did You Know?


Age Related Memory Changes vs. Cause for Concern

UNDERSTANDING THE DIFFERENCE



MASSACHUSETTS
Alzheimer's Disease
Research Center

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.



WWW.MADRC.ORG

NORMAL AGING	CAUSE FOR CONCERN
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

Brain Donation: How Does It Work?

Did you know that one donated brain can provide tissue for hundreds of research studies? Thus, providing the gift of hope for future generations at risk!

Brain donation, at the time of death, is the most generous gift a patient and their family can give to research. Being able to examine brain tissue from a post-mortem donor helps scientists discover new ways to treat and cure Alzheimer's disease and related dementias.

Most diseases that affect the brain can only be diagnosed with certainty by the examination of brain tissue after death. Many families want to know for sure what condition affected their relative. This is especially important when more than one person in the family has suffered from the disease.

The Massachusetts Alzheimer's Disease Research Center (MADRC) has a brain donation program at Massachusetts General Hospital (MGH) for people enrolled in our research studies and other patients in the Mass General Brigham system.

Healthy donors - without memory or other cognitive problems - are also welcomed to donate their brains. Information from these donors helps identify what changes in the brain are related to normal aging, versus what is associated with Alzheimer's disease or other dementias.

If you have ever thought about brain donation and wondered how it all works, visit: madrc.org/brain-autopsy-and-donation-information/ to review an informative video presentation with Dr. Matthew P. Frosch, Director, Neuropathology Service, Massachusetts General Hospital.



To learn more about brain donation watch:
[Understanding Brain Donation: An Irreplaceable Gift for Dementia Research](#)



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 **Mass General Brigham**



Who Can Donate Their Brain?

The Massachusetts Alzheimer's Disease Research Center (MADRC) has a brain donation program at Massachusetts General Hospital (MGH) for people enrolled in our research studies and other patients in the Mass General Brigham system.

Healthy donors - without memory or other cognitive problems - are also welcome to donate their brains. Information from these donors helps identify what changes in the brain are related to normal aging, versus what is associated with Alzheimer's disease or other dementias.

Is There a Cost for the Brain Autopsy Procedure?

Generally, not as long as the donor has been a patient or research participant at Mass General Brigham. However, if the individual is not a participant in our clinical trials or other specific research studies, the family may need to pay for transportation of the body, and for brain removal and transportation if the autopsy is performed elsewhere.

How Do I Become A Brain Donor?

- Have a discussion with your family and your doctor about your intent to donate your brain.
- Request and review an authorization form (this is provisional authorization as legal consent is given by next of kin at the time of death).
- Upon completion of authorization form you will be provided a brain donor card to have handy when the need arises.
- At the time of death, your health care proxy or next of kin should call 617-726-1728. If after hours, press "0" (urgent matter/brain donation). A person from the urgent answering service will come on the line to assist you.

What Will Happen to my Brain During the Autopsy?

The first step of the autopsy is to make a simple incision on the scalp. Then using surgical procedures, the skull is opened and the brain is removed. After the brain is removed, the skull is closed and the incision is stitched as in a surgical operation. The body is then released to the funeral director, or to the designated person, according to family wishes. An open casket service or other traditional arrangement will still be appropriate after the brain autopsy. The exact funeral arrangements remain the responsibility of the donor's family or estate.

What Happens After the Brain is Donated?

The Brain Tissue Center will acknowledge the receipt of the donation to the family. The Center will then review the donor's medical history and prepare a detailed neuropathological report including laboratory test results. This report will be sent to the family, and our staff are also available to answer any questions the family might have about the report.



"There are a couple of reasons why the brain donation was important to my family. Besides the fact that we were contributing to the research into the causes and manifestations of Alzheimer's and other dementias, it was also important to learn the state of Dennis' brain at his death. The fact that he had some signs of vascular dementia was somewhat of a comfort to my son, given that he worries about the genetic aspect of Alzheimer's and that vascular dementia can be caused by many other non-heritable factors."
- Donor family member

To learn more about the brain donation program:

📞 (617) 726-5571

✉ jjohanson1@mgh.harvard.edu

Taking the Mystery out of PET's & LP's

When discussing research studies, two types of testing are often mentioned: a PET scan and a Lumbar Puncture. But what are these tests exactly and what happens when you have them?



A Positron Emission Tomography (PET) scan is often used by doctors when diagnosing and treating brain diseases like Alzheimer's disease and other related dementias. This imaging test helps doctors see what is

happening in a person's brain, including the presence of amyloid plaques and tau tangles which are indicators of Alzheimer's disease. Previously, these could only be found on autopsy after a person had died.

The PET technology uses a radioactive tracer which lights up the area of the brain where amyloid and tau (often referred to as plaques and tangles) are located.

The tracer is given in an intravenous solution in the arm at the time of the imaging test. The tracer will collect in the areas of a person's body that have higher levels of metabolic or biochemical activity, which often pinpoints the location of disease. This technology is also used in the detection and treatment of several diseases like cancer and heart disease.

A Lumbar Puncture (LP), also called a spinal tap, is conducted to help diagnose or treat various conditions. For example, women may have an LP procedure during childbirth, and cancer patients may receive LPs during treatment.

Alzheimer's disease is characterized by abnormal clumps of proteins called amyloid and tau in the brain. The amount of these proteins is reflected in the levels of cerebrospinal fluid. An LP can indicate the presence of these and whether the brain is affected by Alzheimer's disease.

For this procedure, the healthcare provider inserts a hollow needle into the space surrounding the spinal column (subarachnoid space) in the lower back to withdraw some cerebrospinal fluid (CSF) or inject medicine. Headache is the most common side effect of this procedure; however, it does not occur for everyone who has this test.

To learn more about a Lumbar Puncture test, check out this video: <https://bit.ly/LumbarPunctureVideo>



"Ask questions, and then ask more questions. Get involved -- it is easy to participate. And, here's a bonus; as a study participant, you will be treated with respect, admiration and excellent ancillary clinical care!"

Carolyn Ingles,
Research Study Participant



"The certainty that I have elevated amyloid plaque is better than wondering about it. And knowing that experts are watching my brain condition through MRI's and cognitive testing assures me that I won't wake up one morning and find that I'm in an unexpected crisis."

Joe Costello,
Research Study Participant



"Having met many others through the study, both at the Brigham and a couple who are in other states, has been enjoyable as well as getting to know the doctors and staff at CART."

Helene Decoste,
Research Study Participant



Support Our Center

At the Massachusetts Alzheimer's Disease Research Center our expert staff from both Mass General Hospital and Brigham and Women's Hospital work closely together to lead cutting-edge research. Our goal is to find effective treatments and eventually a cure for Alzheimer's disease and related dementias.

If you would like to make a donation to support our work, please make checks payable to the Massachusetts Alzheimer's Disease Research Center and mail to:

Massachusetts ADRC
114 16th Street #2011
Mass General Hospital
Charlestown, MA 02129



Follow Us!

Stay connected with MADRC throughout the year for updates on research news, helpful resources, upcoming community events and brain-healthy lifestyle tips!

