Meet Your Primary Care Team at the ALS Multidisciplinary Clinic at Mass General

Your Physician: ____

Your Nurse Practitioner: ____

Your Nurse: ____

Our Entire Clinical Care & Research Team

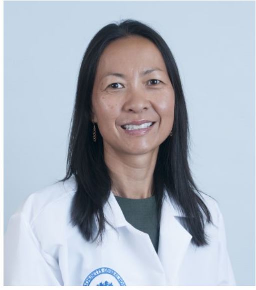
ALS Physicians

James D. Berry
MD, MPH
Chief, Division of ALS and Motor Neuron Diseases; Director, Neurological Clinical Research Institute

Sabrina Paganoni
MD, PhD
Co-Director, Neurological Clinical Research Institute

Merit Cudkowicz
MD, MSe
Chief, Neurology Department
Director, Sean M. Healey & AMG Center

Suma Babu,
MBBS, MPH
Co-Director, Neurological Clinical Research Institute



Doreen Ho, MD
ALS Clinic Director

Nazem Atassi , MD

Sheena Chew, MD

Haatem Reda, MD

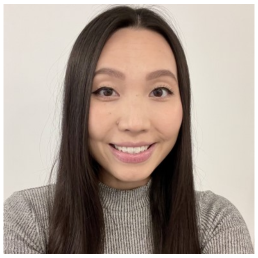
To communicate with your ALS Care Team: Patient Gateway is the best way to communicate non-urgent matters (www.patientgateway.partners.org). Our Patient Service Coordinators are also available from 8:30 am - 5:00 pm EST, Monday - Friday, to assist you please dial 617-724-3914. For emergency matters after 5:00 pm EST or on weekends, dial 617-726-2000, and ask the Page Operator to page your Physician. For medical emergencies, please call 9-1-1.

ALS Nurse Practitioners


Jennifer Scalia, NP
Associate ALS Clinic Director


Darlene Sawicki, MSN, NP-BC
David Richards Endowed

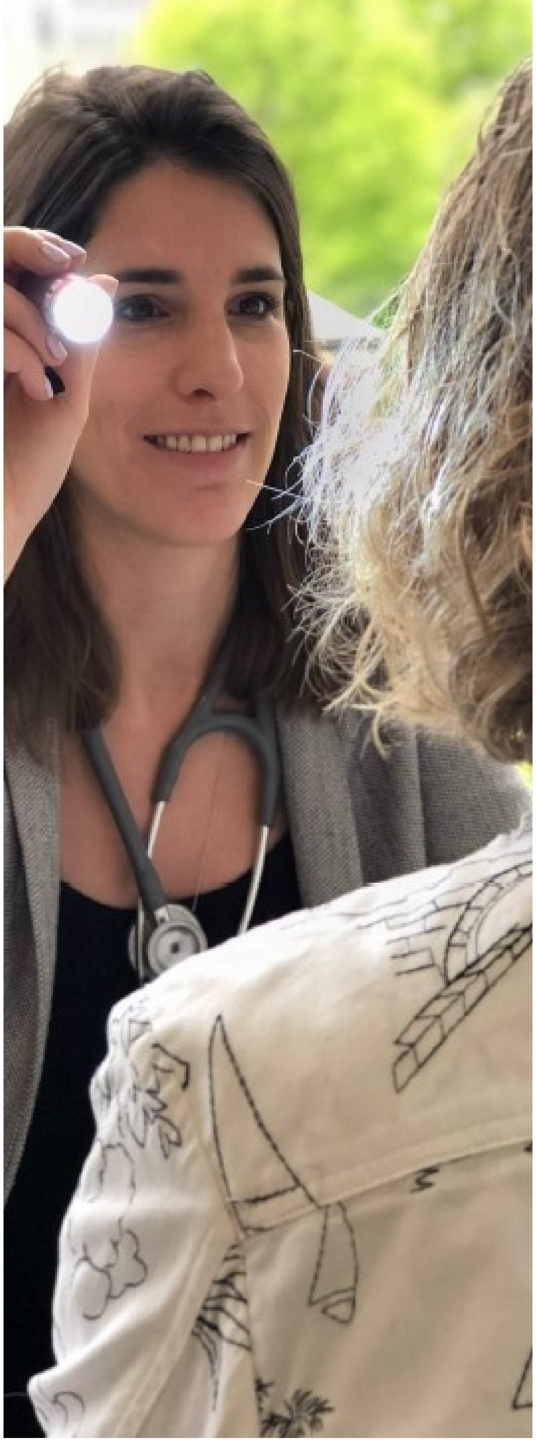

Colleen Brady, FNP


Qiaomei Liang, NP


Nicole Martinez, NP


Alexandra McCaffrey, NP


Pravin Pant, NP



Administrative Team - 617-724-3914


Daisy Feliciano
Patient Service
Coordinator II


Larissa Jackson
Administrative
Coordinator


Fianna Boyd
Patient Service
Coordinator


Richard Pingree
Patient Service
Coordinator

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ALS Registered Nurses


Judi Carey, RN
Research Access Nurse


Catherine Chin, RN
Clinical Research Nurse


Emily Ceglarski, RN
Clinical Nurse caring for Patients of Dr. Reda and Dr. Chew


Erin Clampffer, RN
Clinical Nurse Caring for Patients of Dr. Berry


Kristen Kingsley, RN
Daniella Lipper House Call Program Nurse


Devin McClain, RN
Clinical Nurse Caring for Patients of Dr. Babu and Dr. Atassi


Kiersten Pease, RN
Clinical Nurse Caring for Patients of Dr. Ho


Michelle Redenz, RN
Research ACE Nurse


Margot Rohrer, RN
Clinical Research Nurse Specializing in Expanded Access


Danica Sanders, RN
Nurse Lead, Clinical Nurse Caring for Patients of Dr. Paganoni


Aimee Roderick, RN
Clinical Nurse caring for Patients of Dr. Cudkowicz

ALS Biorepository Team


Becky Fillingham
Biorepository Manager


Ryan Pogemiller
Biorepository Technician

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Allied Health Providers & Affiliated Specialists


Amy Swartz Ellrodt
PT, DPT
Clinical Services Manager
Physical Therapist


Katherine Burke,
PT, DPT, NCS
Physical Therapist


Claire Macadam
PT, NCS
Physical Therapist


Kendall Carney, PT
Physical Therapist


Allison White, PhD
Psychologist Daniella
Lipper ALS PACT
Program


Cynthia Moore, PhD
Clinical Psychologist
Daniella Lipper ALS
PACT Program


Melanie Krause, SLP
Speech Language
Pathologist


Stacey Sullivan
MS, CCC-SLP
Speech Language
Pathologist

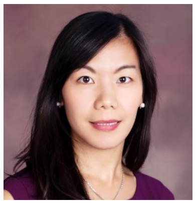

Elizabeth Christiansen
MS, CCC-SLP
Speech Language
Pathologist


Christopher Piccuito,
RRT
Respiratory Care
Coordinator


Karla Schlichtmann
RRT
Respiratory Care
Coordinator


Kate Dudley
MD, RRT
Respiratory Care


Kate T. Brizzi, MD
Neuropalliative Care
Physician


Helen Jin Yun Chen
Genetic Counselor


Diane Lucente
Genetic Counseling
Manager


Julie MacLean
OTR/L Occupational
Therapist


Erin Donovan
Occupational Therapist


Jessica Ranford
Occupational Therapist

Clinical Research Coordinators

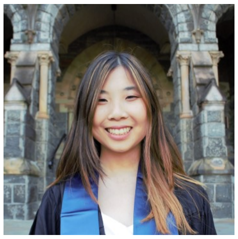

Grace Addy


Aanya Agarwal


Anika Allen


Glory Cabral


Gabriella Casagrande


Irene Chang


Shannon Chan


Emily Clark


Mackenzie DeMello


Miranda Durcan


Aisling Finnegan


Mia Fleischer


Rachel Freedman


Kayla Furney


Dario Gelevski

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Clinical Research Coordinators (continued)


Sydney Hall

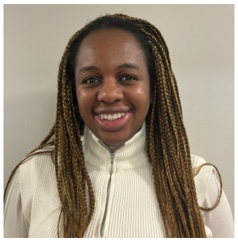

Shyanne Hill

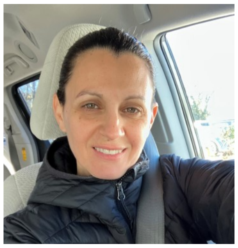

Caroline Kerr


Grace Laber


Sravan Mandepudi


Mary McCormack


Megan Okoro


Anat Weiss Sadan


Caitlin Thomas


Courtney Uek


Alison Wheeler


Jingqi Zhu

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Healey & AMG Center
Sean M. Healey & AMG Center for ALS
at Massachusetts General Hospital

Merit E. Cudkowicz, MD, MSc
Chief, Neurology Department
Director, Sean M. Healey & AMG Center for ALS
Massachusetts General Hospital
Julianne Dorn Professor of Neurology
Harvard Medical School

Welcome to the Sean M. Healey & AMG Center for ALS at Mass General. Our mission is to provide excellence in care for people with ALS while accelerating the development of effective treatments. We are at an inflection point in ALS, where there are great leaps forward in understanding the disease and many more options around treatments and clinical trials. We hope that the information the Healey faculty staff provide in-person and what is found on our website (www.massgeneral.org/als/) will increase understanding of ALS, and the research we and others are doing to understand ALS and develop better treatments.

We want to provide critical and up-to-date information that will enable you to maintain control over the issues that might affect your life and to have a greater understanding of approaches to ALS's medical management and options for new treatments. Our ALS Multidisciplinary Team partners with researchers all over the world to accelerate discoveries for our patients. Our clinic is supported by the Muscular Dystrophy Association and through the generous support of individual contributions to our Mass General ALS Fund, which focuses on patient care improvements and acceleration of research to cure ALS. Our research efforts are funded by several foundations, the federal government and through the generous support of individuals.

We hope your experience in our clinic is a positive one and provides you with the information you need to make good decisions about ALS. We welcome your feedback and ideas for how we can keep improving how we care for you. It is our pleasure to serve you.

Merit Cudkowicz, MD, MSc

Healey & AMG Center
Sean M. Healey & AMG Center for ALS
at Massachusetts General Hospital

James D. Berry, MD, MPH
Chief, Division of ALS &
Motor Neuron Diseases
Massachusetts General Hospital

I'd like to welcome you to our ALS Multidisciplinary Clinic in the Healey Center for ALS at Mass General. We are all truly glad you've chosen to visit and look forward to doing everything we can to help you. Whether you are coming for an initial evaluation, or a second opinion, or to learn about our research opportunities, know that two principles drive everything we do in clinic — we care deeply and we aim to provide hope.

From diagnosis, to symptom management, to exploring research opportunities, we are deeply committed to providing you with the best possible care.

With multidisciplinary care, people with ALS live better and longer. We have assembled a team of experts with a broad array of skills to provide comprehensive care in a single stop –speech, physical and respiratory therapists, genetic counselors, nurses and nurse practitioners, to our neuropalliative care specialist, ALS physicians, affiliated pulmonologists, and our comprehensive research team. We have developed innovative programs to support ALS care, as well. ALS Parenting at a challenging time (ALS PACT), Virtual Visits, and the ALS House Call Program are all aimed at broadening our support for people with ALS and caregivers even more.

Our ALS Clinic Team is thoroughly integrated with our ALS Research Team at the Sean M. Healey & AMG Center for ALS at Mass General Hospital. We view research as a key part of clinical care for those who are interested, and our goal is to provide opportunities to participate in research to all people with ALS. With all this going on, you should not be surprised to hear that your visit to our clinic could take some time. Plan to spend several hours with us.

We are constantly innovating to provide care for people with ALS the way they need it, not just the way insurance reimburses it. We hope you are as excited to visit our clinic as we are to see you!

Sincerely,

James D. Berry, MD, MPH

Connecting to Research

Resources

ALS Research at MGH Healey Center

Review our trials for opportunities to participate in investigational medication trials and observational studies at the Healey Center at Mass General.

→ https://www.massgeneral.org/neurology/als/research/als-clinical-trials

ALS Research Paper Review (RPR)

ALS RPR hosts seminars where patients interview researchers about their work with the intent of providing a deeper understanding of the scientific principles and research processes that go into finding a treatment for an extremely complex disease.

→ https://rarediseases.org/rare-diseases/amyotrophic-lateral-sclerosis/#:~:text=ALS%20is%20a%20rare%20disorder,new%20cases%20diagnosed%20each%20year

ALS Therapy Development Institute (TDI)

TDI's Lab focuses on drug discovery, research, and therapeutic development for ALS. Its website hosts information about research ril, news, & webinars.

→ https://www.als.net/als-research/

ALS Untangled

Read scientific reviews about alternative and off-label treatments (AOTs) for management of ALS to help make better informed decisions about them. This website is managed by Dr. Richard Bedlack, ALS Neurologist at Duke University.

→ https://www.alsuntangled.com/completed-reviews/

ClinicalTrials.gov

Access a database of privately and publicly funded clinical studies conducted around the world. Information is provided and updated by the sponsor or principal investigator of the clinical study and the website I maintained by the U.S. National Library of Medicine (NLM) at National Institutes of Health (NIH).

→ https://clinicaltrials.gov/

I Am ALS's ALS Signal: Clinical Research Dashboard

This dashboard is a tool designed for and by patients and caregivers to provide an overview of treatments and supplements that are being tested for use in ALS from around the world. This website also hosts a list of common research terms.

→ https://iamals.org/get-help/als-signal-clinical-research-dashboard/

National ALS Registry

Participate in surveys to help provide a picture of who gets ALS ad risk factors for the disease. Researchers can use the Registry data to look for disease pattern changes over time and help identify any common risk factors among individuals with ALS.

→ https://www.cdc.gov/als/

Northeast ALS Consortium (NEALS)

This organization provides a comprehensive clinical trial database of federally and privately funded trials focusing on ALS and Motor Neuron Diseases (MNDs). The website hosts an array of educational and research webinars.

→ https://www.neals.org/

Podcats

Resources

ALS Pathways Podcast Series

This podcast covers a range of topics relating to ALS. There are episodes on caregiving, symptom management, and the basics of ALS including the history and science of the disease as well as various tests that monitor progression.

→ https://www.alspathways.com/als-resources/

ALS Therapy Development Institute's Endpoints Podcast

This series has a research section as well as an ALS Stories section in which individuals with ALS share their story. The research podcast focuses on the current ALS research by breaking down different therapies and trials while the ALS Stories podcast focuses on individuals and their journeys.

→ https://www.als.net/endpoints/

Connecting ALS Podcast

This all encompassing podcast covers everything from advocacy and research to mobility and home modifications. The 20 minute episodes include weekly guests that may be researchers, volunteers, and people with ALS.

→ https://connectingals.org/podcasts/

I'm Dying to Tell You Podcast

This podcast is narrated by Lorri Hugs, who was diagnosed with ALS in 2004. She shares a variety of stories about what gives her hope, inspiration, and strength to focus on the positives and live life to the fullest.

→ https://imdyingtotellyoupodcast.com/

National Organization for Rare Disorders Podcast

Raring: The Voice of Rare Disease podcast has created a forum for medical professions, patients, and their families to discuss rare disorders. This podcast focuses on creating a community for those with a rare disorder to learn and share their story.

→ https://rarediseases.org/nordpod/

Nothing Left Unsaid Podcast

This podcast is hosted by Tim and Troy Green. Each week, Tim and Troy sit down with guests that range from celebrities, athletes, academics, doctors, authors, and more. As Tim battles his ALS diagnosis, nothing is out of bounds and there is nothing left unsaid.

→ http://www.youtube.com/@TimGreen-NothingLeftUnsaid

Connecting to Community

Resources

ALS Association (ALSA)

ALSA is an organization that serves, advocates for, and empowers people living with ALS to live their lives to the fullest, and works to discover treatments and a cure for ALS.

→ https://www.als.org/

ALS Charitable Foundation

Dedicated to providing patient services in support of people living with Amyotrophic Lateral Sclerosis (ALS) in the New England area and raising funds for research efforts to find better treatment options and a cure.

→ https://alsfamily.org/

ALS Information at the National Institute of Health (NIH)

Comprehensive overview of ALS provided by MedlinePlus, a service of the U.S. National Library of Medicine.

→ https://medlineplus.gov/amyotrophiclateralsclerosis.html

ALS ONE

ALS ONE is an organization dedicated to improving the care of people living with ALS, and expediting treatments that lead to a cure for ALS through collaboration.

→ https://alsone.org/

ALS Ride for Life

ALS ride for Life is a charity that supports research and offers grants for ALS patients who do not have healthcare coverage for respite care. This organization gives the family caregiver an opportunity to take a break and offers grant for legal services related to ALS.

→ https://alsrideforlife.org/about-rfl/our-story/

ALS Therapy Development Institute (TDI)

Provides resources designed to get you answers quickly keep you up-to-date, and connect you with others in the ALS community through forums, virtual town hall meetings, and podcasts.

→ https://www.als.net/resources/

Compassionate Care ALS (CCALS)

CCALS provides resources including equipment, educational opportunities, Medicare/Medicaid assistance, communications assistance, guidance and awareness with regards to living with ALS, caregiving, and exploring end-of-life when invited.

→ https://ccals.org/

Everything ALS

A non-profit organization that offers people with ALS a platform for direct engagement with other patients, caregivers, researchers, and drug companies. Everything ALS hosts bi-monthly community meetings designed to provide support and information to patients & caregivers.

→ https://www.everythingals.org/

HARK ALS

HARK ALS is a non-profit that runs a wheelchair accessible van donation program and assists with travel expenses for people with ALS to attend important family events.

→ https://hark-als.org/

Additional Community Resources

HealthWell Foundation

HealthWell assists with insurance premium costs and co-pays of drug prescriptions. This program s for individuals who have health insurance that covers part of the cost of treatments.

→ https://www.healthwellfoundation.org/fund/amyotrophic-lateral-sclerosis/

Her ALS Story

Her ALS Story provides a community for members that offers instant connection and support. They use their stories to raise awareness and advocate to deliver better therapies to ALS patients faster, partnering with ALS nonprofits including Project ALS, I AM ALS and ALS TDI to support research and legislative initiatives

→ https://heralsstory.org/

I Am ALS

An organization dedicated to educating and advocating for ALS and connecting people impacted by ALS to an array of community resources. I Am ALS is a platform for patients living with ALS to take lead in the fight against ALS and search for a cure.

→ https://iamals.org/

Mary Beth Benison Foundation

The Mary Beth Benison Foundation is a non-profit that offers financial aid to people with ALS and their families to obtain medical equipment and transportation. The foundation helps organize and fun family vacations for families facing medical challenges.

→ http://www.mbbloves.com/

Muscular Dystrophy Association (MDA)

MDA supports the largest network of clinical care centers including MGH's ALS Multidisciplinary clinic and information specialists and educational resources are available to offer guidance and support, The website contains information on advocacy clinical trials, support groups, and research news.

→ https://www.mda.org/disease/amyotrophic-lateral-sclerosis

My ALS Decision Tool

Les Turner Foundation is the Midwest's leading ALS organization dedicated to providing comprehensive care and support to families impacted by ALS. Use their decision tool to learn about some common ALS treatments and procedures, answer a few questions to help you think about what is most important to you, and get ready to talk with your ALS care team about your options.

→ https://lesturnerals.org/my-als-decision-tool/

PatientsLikeMe

PatientsLikeMe's mission is to improve the lives of patients through new knowledge derived from shared real-world experiences and outcomes. While patents share their health experiences to help others, the data they share brings real patient perspectives to the healthcare industry and drive necessary change.

→ https://www.patientslikeme.com/

Peter Frates Foundation

This foundation is a non-profit with the mission to assist progressed ALS patients and their families with the costs of home health care.

→ https://petefrates.com/contact/

Additional Community
Resources

Project Main Street

Project Main Street is a non-profit organization that aims to support and care for ALS patients until there is a cure. Project Main Street offers grants for eye-gaze equipment, renovations to make homes ADA accessible, home care, and life expenses.

→ https://projectmainst.org/

Your ALS Guide

An online guide to help those recently diagnosed with ALS walk through the most important things to know about your diagnosis to planning ahead.

→ https://www.youralsguide.com/newly-diagnosed.html

Roon

Roon, the place online for people navigating complex health conditions with a current focus on helping people with ALS. Get answers to an array of questions about clinical care and research from ALS experts and people with lived experience.

—> https://www.roon.com/

Grants Resources

ALS Association — Massachusetts Chapter

This grant program assists individuals with ALS or PLS with expenses incurred that are not traditionally covered by insurance such as private insurance, Medicare, Medicaid (Mass Health), and other assistance programs. It will cover respite, travel costs related to ALS clinics or research, generators, durable medical equipment repairs, and personal emergency response systems, and other ALS related expenses.

→ https://www.als.org/massachusetts/local-care-services/grants-assistance

ALS Foundation For Life

The ALS Association Massachusetts Chapter maintains the ALS Foundation for Life's webpage as a service to those who have contributed to the foundation. The Massachusetts Chapter shall continue to maintain this page to honor the legacy the Foundation's two decades working to support persons with ALS and their families.

→ https://www.als.org/massachusetts/local-care-services/grants-assistance

The Assistance Fund - Amyotrophic Lateral Sclerosis (ALS) Financial Assistance Program

This programs provides financial assistance to patients who have been diagnosed with ALS for the following out-of-pocket costs: prescription drug assistance (copays, deductibles, and coinsurance) on FDA-approved treatment, health insurance premiums, therapy administration costs, and treatment-related ground travel costs.

→ https://enroll.tafcares.org/TAF_ProgramInformation?Id=S5PkZIFzlN%2FVosCPzFQfxfm5qD9fGk4wAflQWeYvQdUVs5TKzuvaLMFCsIE%2Bq%2BKg

HARK - Financial Assistance Program

HARK provides assistance to alleviate the financial burdens faced by families battling ALS.

→ https://hark-als.org/

HealthWell Foundation - Amyotrophic Lateral Sclerosis Fund

Provides financial assistance for insurance co-payments and premium for the prescription drugs and biologics used in the treatment amyotrophic lateral sclerosis.

→ https://www.healthwellfoundation.org/fund/amyotrophic-lateral-sclerosis/

Project Main Street

Helping those who are experiencing financial challenges as a direct result of ALS.

→ https://projectmainst.org/

Team Gleason

Helps financially with respite care, communication devices and adventure travel.

→ https://teamgleason.org/

Mary Beth Benison Foundation

Provides funds to patients with ALS and their families, as well as medical equipment, transportation, and personal requests.

→ http://www.mbbloves.com/contact/
→ mbbfoundation@gmail.com (774) 275-0240

Susie Foundation

The TSF Flex Grant program helps to alleviate the non-medical support needs of ALS patients and their families.

→ www.thesusiefoundation.org
→ Ryan.Matthews@TheSusieFoundation.org (203) 490-6694

Racing for ALS

Racing for ALS hosts high performance driving events to build ALS awareness and to battle ALS head on with supports focused on pharma research, no placebo clinical trials and individual ALS patients in need.

→ www.racingforals.com/patient-assistant-van-fund

Benefits

Resources

U.S. Department of Veterans Affairs (VA)

The U.S. Department of Veterans Affairs (VA) has recognized ALS as a service-connected disease, which means that the VA provides financial and medical support to veterans with at least 90 continuous days of active duty. If you qualify for these benefits, they can provide significant assistance in obtaining medical care, assistive devices and financial support. The Paralyzed Veterans of America (PVA) can guide you through the process of connecting with the VA.

→ https://www.pvanewengland.org/contact/

Social Security Disability (SSDI) and Medicare

Social Security Disability Insurance (SSDI) is a program that provides monthly income for people who become unable to work due to a disability. The amount you receive each month depends on how much you earned and paid into Social Security over the years.

Medicare is a national health insurance program for seniors and some disabled people. It covers the bulk of medical and equipment expenses for most people living with ALS.

SSDI and Medicare are two separate programs, but you apply for them together.

Most people living with ALS qualify for Medicare and Social Security Disability Insurance—regardless of age. Medicare can cover the bulk of your healthcare costs and SSDI provides a monthly income.

→ https://www.youralsguide.com/ssdi--medicare.html

FMLA (Family Medical Leave Act)

The Family and Medical Leave Act (FMLA) provides certain employees with up to 12 weeks of unpaid, job-protected leave per year. It also requires that their group health benefits be maintained during the leave.

→ https://www.dol.gov/general/topic/benefits-leave/fmla

PFML (Paid Family Medical Leave)

Learn more about Massachusetts's Paid Family and Medical Leave (PFML), including how to apply, “leave” benefits, and approval timelines. Your employer may have responsibilities under both PFML and FMLA law, refer to your state government’s webpage for information. To check on other states’ PFML laws, refer to your state government’s webpage for more information.

→ https://www.mass.gov/info-details/paid-family-and-medical-leave-pfml-overview-and-benefits

Disabled Parking Permit

If you would benefit from having a disabled parking permit, let us know if we can assist you with the application. Or for more information, please visit the website below.

→ https://www.mass.gov/how-to/apply-for-a-disability-placard-or-license-plate

Mass Health (Medicaid)

Mass Health (Medicaid) is the state healthcare program that provides benefits based on state residency status and financial eligibility.

→ https://www.mass.gov/how-to/apply-for-masshealth-the-health-safety-net-or-the-childrens-medical-security-plan

Connecting to Family

Resources

5 Ways to Help Kids Cope with a Parent's ALS – ALS News Today

Kristin Neva, a mother of two whose husband Todd was diagnosed with ALS, provides a couple of points for parents to keep in mind while dealing with talking to their children, taking care of themselves, and caring for another family member.

→ https://alsnewstoday.com/columns/help-kids-cope-death/

Talking with Children – ALS Worldwide

Sarah Byer conveys the importance of open and age-appropriate communication with children about ALS to help drive successful conversations. It also provides some books at the end of the article for children that have a parent of family member with ALS.

→ https://alsworldwide.org/about-us/

Telling Children about ALS – ALS Connect

This blog post from ALS Association emphasizes not shielding children from the diagnosis and being open and honest to alleviate fears and establish trust and comfort, and also discusses things to keep when mind when telling others about a diagnosis.

→ https://als.org/sites/default/files/2021-03/Families%20and%20ALS%20Guide-%20Manual.pdf

Supporting Kids and Teens through ALS – I Am ALS

I Am ALS provides a list of many tips for parents dealing with ALS while taking care of children. They also provide a list to resources for children, teens, and adults.

→ https://iamals.org/get-help/supporting-kids-and-teens-through-als/

Families and ALS – ALS Association

This guide from the ALS Association dives into talking with children, caregiving for children, impacts at school, and loss, while providing sources and types of resources. It is filled with information, which may be overwhelming, but chapters and headings make it easy to pick and choose what's looked at.

→ https://www.als.org/navigating-als/resources/Families-and-ALS-Resource-Guide

Talking to Your Kids about ALS – MDA

Aimee Chamerik, who lives with her husband and three kids while being diagnosed with ALS, reiterates a lot of the talking and parenting points from other resources, but provides a perspective of someone directly affected who knows what it's like to deal with it day to day.

→ https://www.mda.org/alsn/article/talking-your-kids-about-als

Discussing ALS with Children – ALS Association

Another ALS Association resource provides a couple of communication points for parents to keep in mind while telling their children, as well as talks through helpful practices while living with the progressive disease and caring for children.

→ https://secure2.convio.net/alsa/site/SPageNavigator/discussing_als_with_children.html;jsessionid=00000000.app277b?NONCE_TOKEN=80E2147E25AD56BD7E9B94ECC5F524A3

Parenting through Terminal Illness – NYT

Kelsie Snow, a mother of two whose husband is diagnosed with ALS, and psychotherapist Andrea Warnick discuss honest communication with children, and how adult reactions towards things that arise with ALS shape some of children's feelings.

→ https://www.nytimes.com/2021/08/04/parenting/terminal-illness-sick.html

Supporting Children When Someone Has a Terminal Illness – Marie Curie

This guide is the similar to the one compiled by the ALS Association, but it is more general in terms of conversations about disease. They have a lot of good similar information, though the resources they provide outside of the guide are only relevant to patients in the UK.

→ https://www.mariecurie.org.uk/globalassets/media/documents/how-we-can-help/booklets-pdfs-only/supporting-children-young-people-when-someone-has-a-terminal-illness.pdf

Caregiver
Resources

ALS Pathways—Caregiver Support

ALS Pathways provides support and resources to ALS caregivers as well as information aimed to assist in understanding and monitoring the disease.

→ https://www.alspathways.com/caregiver-support/

ALS Care Connection

ALS Care Connection lets caregivers start a care team to post request for support, give updates, and streamline communication to keep their community in the loop.

→ https://www.als.org/navigating-als/for-caregivers/als-association-care-connection

ALS Caregiving Toolkit

From I Am ALS, their caregiving toolkit provides first steps for coping with a diagnosis and communicating with providers. They include resources for navigating work and financial decisions/changes and finding in-home support.

→ https://www.iamals.org/get-help/caregivers-start-here/

Family Caregiver Alliance

The FCA compiles resources for caregivers of adults with physical and cognitive impairment including support groups, financial planning, research updates, and navigating familial relationships. Their CareNav tool connects caregivers to local resources and a resource specialist that can help with unique needs.

→ https://www.caregiver.org/

SimpliHere

SimpliHere is an application that helps people with ALS and their caregivers communicate, manage daily activities, and stay connected. The app features a voice assistant that helps to communicate basic needs, contact providers, find equipment and get ALS news.

→ https://www.simplihere.com/

The Susie Foundation

The mission of the Susie Foundation is to provide assistance to young caregivers and families struggling with the family challenges of living alongside ALS. They provide financial assistance and host events to connect families.

→ https://www.thesusiefoundation.org/

MDA Guide for Caregivers

This comprehensive guide delves into the many aspects of caring for an individual with a neuromuscular disease and discusses topics from daily care and ventilation to quality of life.

→ https://www.made.org/sites/default/files/2024/01/MDA_Caregivers_Guide.pdf

Caring for Persons with ALS

This document was created by the Les Turner ALS Foundation and discusses home health and activities of daily living. It also includes helpful questions to ask when hiring a caregiver for persons with ALS.

→ https://lesturnerals.org/section-5/

Taking Care of YOU: Self-Care for Family Caregivers

This resource created by the Family Caregiver Alliance discusses the importance of caregivers not only caring for their loved one, but also for themselves. The importance of self-care and well-being are emphasized in this article, as well as techniques and skills to help reduce stress

→ https://www.caregiver.org/resource/taking-care-you-self-care-family-caregivers/

Health & Wellness
Resources

Medical Psychology Group

ALS Pathways provides support and resources to ALS caregivers as well as information aimed to assist in understanding and monitoring the disease.

→ https://www.mpc.care/

Center for Healthy Aging

ALS Care Connection lets caregivers start a care team to post request for support, give updates, and streamline communication to keep their community in the loop.

→ https://beverlyhospital.org/services/senior-health/center-for-healthy-aging

The Daniella Lipper ALS Parenting At a Challenging Time (PACT) Program

The Daniella Lipper ALS PACT Program provides parent guidance to support parents in addressing the illness-related challenges faced by their children and adolescents.

→ https://www.massgeneral.org/neurology/als/services/als-parenting-pact

MGH Dental Group

This dental group has offices in Boston and Danvers and may offer home visits for patients not on ventilators. This is also the Mobile Dental Hygiene group if patient is on MassHealth.

—> https://www.mobiledentalhygiene.com/

How do YOU become a New Patient?

Step 1

Patient Registration

Step 1: If this is the first time you are seeing a physician at Mass General Hospital or within the Partners HealthCare Network, please call Mass General Registration at **1-866-211-6588** to obtain an MRN (Medical Record Number).

If you **live internationally** and are interested in coming to our Multidisciplinary Clinic, dial **617-726-2787** or visit: www.massgeneral.org/international/

Step 2

Scheduling Appointment

Step 2: Please call our ALS Multidisciplinary Clinic at **617-724-3914**

Provide your MRN (Medical Record Number)

You will be given helpful information about becoming a patient in our clinic

Within a few business days, one of our Patient Service Coordinators will contact you about scheduling a New Patient appointment.

The fax number to send your Medical Records to our clinic is **617-724-7290.**

Step 3

Follow-up Communication

Step 3: You will receive a Reminder Letter of your appointment in the mail or via email with helpful information for the day of your visit.

For future communications with your ALS team you have the option of setting up a **Patient Gateway** account once you have your MRN by visiting: www.patientgateway.partners.org

*If patients do not wish to have this, they can call **800-745-9683** and ask to have it disabled on their account.*

If you have urgent or immediate needs, it is best to reach out to your team by calling the clinic at **617-724-3914**

Preparing for your first visit

Q+A

Write down your Questions

On the day of your appointment, please **bring a list of all your medical & general questions** so that we can be address all your concerns.

To assist you, our team has compiled a Q+A list of the most frequently asked questions. Please look in your Welcome Folder or visit our website at:

Plan for Visit

Plan for Visit

Our multidisciplinary team combines **multiple specialists' appointments in one clinic visit.** We want you to know that your time with un in clinic may be **several hours, especially if it's your first visit.**

We hope this information helps you with planning your day to allow for enough time to spend with us in clinic.

Arrive Early

Arrive Early

Peak traffic times are unpredictable in and around Boston.

To lessen your stress, allow for extra travel time in order to arrive **15 minutes before your appointment**, find parking and then make your way to our clinic.

Clinic Q+A

About Appointments & Scheduling

Q. HOW LONG CAN I EXPECT TO BE IN CLINIC?
A. Our multidisciplinary team combines multiple specialists' appointments in one clinic visit. We want you to know that your time with us in clinic may be several hours, especially if it's your first visit.

Q. CAN I REQUEST TO BE SEEN BY A CERTAIN PROVIDER?
A. We understand that a certain provider in our clinic may have been recommended to you. We will try our best to schedule you with that ALS provider. We do aim to have you seen in our clinic as quickly as possible and this may mean that you are seen by a different provider in order to expedite your care. We are a close-knit care team that collaborates in order to provide you with our best care.

Q. How do I schedule an appointment?
A. Call **617-724-3914** and you will be helped with scheduling a clinic visit. If you reside outside the United States, to request an appointment with the MGH-ALS Multidisciplinary Clinic, call the Mass General International Office at **1-617-726-2787** or visit our website for international patients: https://www.massgeneral.org/international/

Q. WHAT DO I NEED TO BRING TO MY CLINIC VISIT?
A. If this is your first visit to the MGH-ALS clinic, please bring your insurance card, photo identification, current medication and supplement list, medical records, imaging on disk, and, your co-payment. Your clinic visit can make for a long day for you. Please bring your necessary respiratory equipment and/or nourishment. To update your insurance and contact information prior to your appointment, please call Patient Registration at **1-866-211-6588.**

Q. CAN I BRING SNACKS OR BEVERAGES TO MY VISIT?
A. Yes, you can! Also for your convenience, Mass General has a several cafes and cafeterias throughout the hospital for you or your accompanying care giver to step away from clinic to get food or a drink. Please visit our cafeteria webpage: https://www.massgeneral.org/services/visitor-cafeterias

Q. WHAT DO I DO IF I AM GOING TO BE LATE FOR MY CLINIC APPOINTMENT OR NEED TO CANCEL IT?
A. For those unforeseen circumstances that may require you to be late for your appointment, call us at **617-724-3914** and provide us with your estimated time of arrival. If you have to cancel your clinic appointment, please call us 24 hours in advance, so we may offer that visit to another patient.

Q. ARE INTERPRETER SERVICES AVAILABLE?
A. Yes, let one of our ALS Patient Service Coordinators know that you will need an interpreter at the time you schedule your appointment.

Traffic, Parking, & Clinic Locations

Q. HOW IS THE TRAFFIC TO AND FROM MASS GENERAL HOSPITAL, BOSTON?
A. Peak traffic times are unpredictable in and around Boston. To lessen your stress, allow for extra travel time to arrive 15-20 minutes before your appointment. We do understand sometimes being late for an appointment cannot be helped, please call us at **617-724-3914** and provide us with your estimated time of arrival. For driving directions to Mass General Hospital, walking instructions and public transportation options, please visit: https://www.massgeneral.org/visit/maps-and-directions/locations-and-parking-guide

Q. WHERE DO I PARK FOR MY APPOINTMENT?
A. Valet parking is available at the entrance for the Wang Ambulatory Carey Center. Visit the webpage for main campus locations, nearby parking garages, and reduced visitor parking rates at MGH parking garages. Please visit: https://www.massgeneral.org/visit/parking-and-shuttles/parking or view page 4 of this handout.

Q. WHERE ARE THE MULTIDISCIPLINARY CLINIC VISITS LOCATED?
A. Most clinic visits are located in the Wang Ambulatory Care Center on the 8th Floor Neurology Suite. On rare occasion, your clinic visit may be on the 6th floor of 165 Cambridge Street (a few minutes up the street from the Wang Building, and). The location of your visit is listed on your appointment letter. If you are unsure of the location, please call one of our Patient Service Coordinators at **617-724-3914**

Q. WHERE IS THE MULTIDISCIPLINARY CLINIC IN WALTHAM?
A. Our Waltham clinic is located in the Mass General Brigham Healthcare Center, 52 2nd Ave, 4th Floor of the blue building, Waltham, 02451. The location of your visit is also on your appointment letter.

Q. WHERE DO I PARK FOR MY CLINIC VISIT IN WALTHAM?
A. The Mass General Brigham Healthcare Center in Waltham offers free parking. The patient parking garage can be located by turning onto 2nd Ave into garage for Mass General Waltham located across the street from Costco. We do understand sometimes being late for an appointment cannot be helped, if this happens, please call **617-724-3914** to give us your estimated time of arrival.

Q. DO YOU NEED HELP LOCATING THE BUILDING OF YOUR CLINIC APPOINTMENT IS TAKING PLACE?
A. Pictures of outside views of each building are below, view the map found on Page 4, or, visit the interactive map for our Boston campus only to identify the building for your appointment: https://www.massgeneral.org/visit/maps-and-directions/


Wang Building, Boston


165 Cambridge St, Boston


Mass General, Waltham

Communicating with the Team

Q. HOW CAN I CONTACT MY ALS PHYSICIAN AND OTHER MEMBERS OF MY CARE TEAM?

A. For emergencies, dial **911** or go to your local Hospital for immediate medical care.
Patient Gateway (patientgateway.partners.org/login/) is a convenient and secure way to communicate with your Physician, Nurse Practitioner, and, ALS Care Team for non-urgent matters. Please allow up to 3 business days for a response to your gateway message. We make every effort to respond as soon as possible.

By logging into your account, you can send a descriptive message to most members of your Care Team, request prescription refills, or to review visit notes, lab results and medication refills.
For urgent concerns or questions during weekdays, from 8:30-5:00pm EST, call **617-724-3914** to talk to a Patient Service Coordinator. Our coordinators can connect you with a member of your care team to assist you. Also, for any urgent concerns throughout the week, you can call **617-726-2000** and ask the Page Operator to page your physician.

Hotels

Q. ARE THERE HOTEL ACCOMMODATIONS NEARBY?

A. If you are traveling a considerable distance to get to Mass General Hospital and want to stay overnight at a local hotel, please visit our Visiting Boston webpage for information on nearby hotel accommodations. https://www.massgeneral.org/assets/mgh/pdf/social-service/accommodations-list.pdf

Insurance & International Patients

Q. DO I NEED A REFERRAL?

A. If you reside in the U.S., check with your insurance company about your coverage requirements. If you need a referral, we can guide you through the process to obtain a referral. Generally, the MGH Multidisciplinary ALS Care Clinic doesn't require a Doctor's referral. However, obtaining one can help the ALS Team better determine your specific care needs. If you reside outside the U.S., contact our International Office at **1-617-726-2787** or visit our website for international patients: https://www.massgeneral.org/international/ for further assistance.

Important Numbers

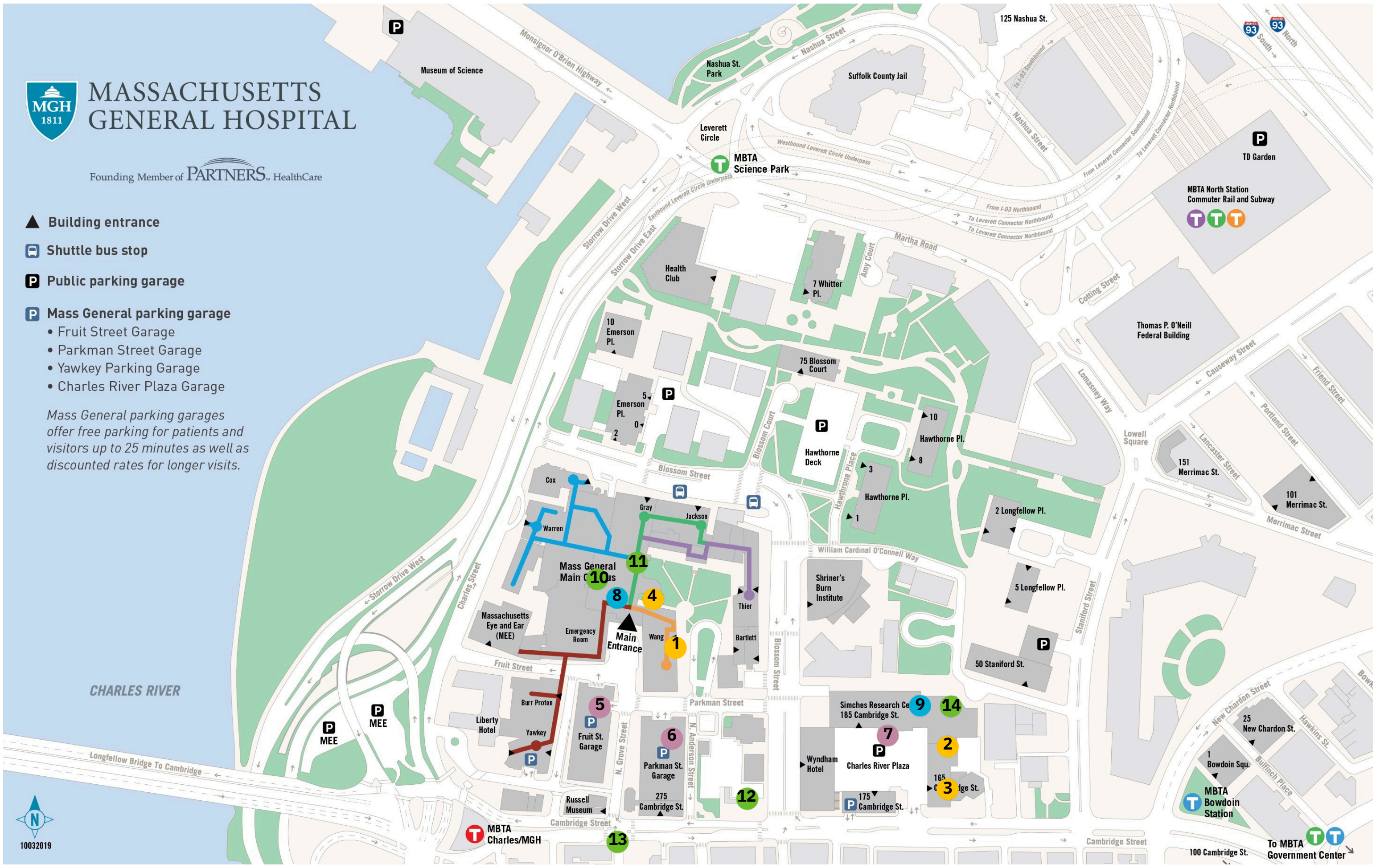
Call 911 if there is a medical emergency.

Call 617-724-3914 if you are...

- Late for your appointment
- Unsure of the location
- Questions during the weekdays
- Looking for a patient service coordinator

Other questions?
Page Operator: **617-726-2000**
International office: **1-617-726-2787**
Patient Registration/Insurance Information: **1-866-211-6588**

Mass General Brigham Map



Our Locations

① **Wang Ambulatory Care Center**
15 Parkman St, Boston MA 02114
- ALS Clinic Visits (Mon & Tues)...........8th floor
- Labs for Blood Draws........................2nd floor
- EKGs...2nd floor
- Occupational Therapy & Orthotics.....1st floor

② **Sean Healey Center**
165 Cambridge St, Boston MA 02114
- Research & ALS Clinical Visits...........6th floor

③ **Neuromuscular Clinic Institute**
165 Cambridge St Boston MA 02114
- EMG Infusion Suite............................8th floor
- ALS Botox Injections.........................8th floor

④ **Ellison Building**
55 Fruit St Boston MA 02114
- Outpatient Surgeries, Room 210......2nd floor

More Information

Lost & Found
- Contact the MGH Police & Security department center at 617-726-2121

Wi-Fi
- For free Wi-fi please join the PHSPIAGUEST network

Parking

For detailed direction to the hospital, please visit our website: https://www.massgeneral.org/cancer-center/about/visitor-information/directions

⑤ **Fruit Street Garage**
Preferred parking lot for Family/Friends visiting the emergency room or inpatient units

⑥ **Parkman Street Garage**
Preferred parking lot for patients visiting Wang Ambulatory Care Center or main campus (Valet Parking available upon request).

⑦ **Charles River Plaza Garage**
Preferred parking lot for patients visiting the Sean Healey Center (underground parking is available at 207 Cambridge Street).

Pharmacy

⑧ **Mass General Outpatient Pharmacy**
55 Fruit St Boston MA 02114.................Lobby
Phone #: 617-724-2100
Mon-Fri, 9am-5:30pm

⑨ **CVS Charles River Plaza**
191 Cambridge St Boston MA 02114
Phone #: 617-367-0441
Mon-Fri, 9am-8pm
Sat, 10am-5pm

Cafeterias & Cafés

⑩ **Tea Leaves & Coffee Beans**
15 Parkman St Boston MA 02114..............Lobby
- Mon-Fri, 7:30am-3pm

⑪ **Eat Street Café**
55 Fruit St Boston MA 02114................Basement
- Mon-Fri, 7am-8pm

⑫ **Flour Bakery + Café**
209 Cambridge St, Boston MA 02114
- Mon-Fri, 6:30am-7:00pm

⑬ **Blank Street Coffee**
282 Cambridge St, Boston MA 02114
- Mon-Fri, 6:30am-4pm

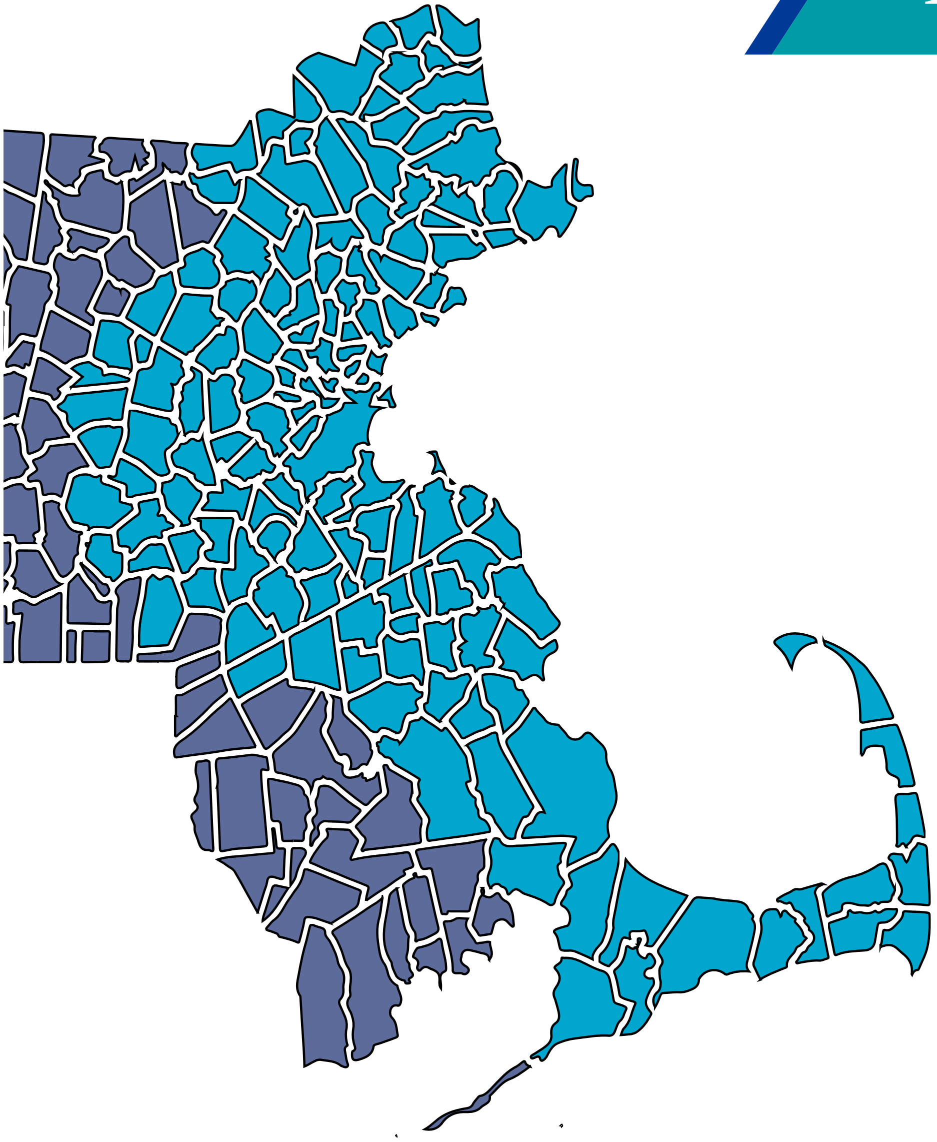
⑭ **Whole Foods Market**
181 Cambridge St, Boston MA 02114
- Open Daily, 7am-9pm

Healey & AMG Center
Sean M. Healey & AMG Center for ALS
at Massachusetts General Hospital

CCALS
COMPASSIONATE CARE ALS
LEADING A NEW VISION IN ALS CARE SINCE 1998

The Daniella Lipper ALS House Call Program

The Daniella Lipper ALS House Call Program is a collaborative effort between the ALS Multidisciplinary Clinic at Massachusetts General Hospital and Compassionate Care ALS (CCALS). Members from our team visit patients and caregivers in the comfort of their homes with the goal of improving patient care while reducing the burden of accessibility. We coordinate care and design home visit schedules to integrate with the care provided at the ALS Multidisciplinary Clinic at Mass General.



🟦 **Primary Territory**

Meet Our Team

From MGH

Carl Lewenhaupt, CNP

Kristen Kingsley MSN, RN

From CCALS

Kristine Copley
Communication Coordinator

Erin Lajeunesse, MSW, LICSW
Senior Family Care Liaison

Ron Hoffman
Founder of CCALS

Eileen Garry
Senior Family Care Liaison

Updated February 2024

Patient Testimonials

"The house call was amazing. It was so great to have them come to us to see what we are dealing with at home…The team was positive, helpful and knowledgeable."

"I feel like the providers have a much better understanding of me as an individual, my house, and caregiver's situation, and what needs may arise in the future"

"Thank you very much for the home visit. It was invaluable, and I greatly appreciate your generosity and kindness."

Frequently Asked Questions

How often are home visits scheduled?
The team can be flexible and schedule to see you in your home every three months and on an as-needed basis. House Call visits are offered between the hours of 9:00am to 3:00pm. If you prefer a different time, please let us know and we will do our best to accommodate your request.

If I am already seen by CCALS or a visiting nurse, am I eligible for the program?
Yes, our program is designed for patients to receive additional clinical support. CCALS and/or your visiting nurse will continue to make their regularly scheduled visits.

Will I still see my ALS provider in clinic?
Yes, you will continue to see your provider and care team every 3-4 months, in-person, via phone, or virtual visit. The House Call Program is part of our multidisciplinary approach to providing at home visits in collaboration with your care team.

How do I pay for the House Call Program?
You may be responsible for a typical co-payment following your visit.

Who will be coming to my house?
Carl Lewenhaupt, MGH Nurse Practitioner, or Kristen Kingsley, MGH Registered Nurse, will visit you at home. A colleague from CCALS will often participate in your visits.

To learn more
scan the QR code or follow the link:

massgeneral.org/neurology/als/services/house-call-program

Get Connected with CCALS

Email and Website:
info@ccals.orgccals.org

Phone:
(508) 444-6775

Updated February 2024

Healey & AMG Center
Sean M. Healey & AMG Center for ALS
at Massachusetts General Hospital

Mass General Brigham

The Daniella Lipper ALS PACT Program

Parenting At a Challenging Time

Updated February 2024

The Daniella Lipper ALS PACT Program offers parenting consults to adults cared for in the MGH multi-disciplinary ALS clinic and their co-parents, at no charge.

Our team offers guidance about helping children cope with ALS in a parent or grandparent, recognizing that you are the expert on your own children.

Common consult topics include:

- communication with children about ALS symptoms and interventions
- how children may adjust to changes
- supporting children's resilience, given their unique strengths and needs
- when to consider additional resources for a child

To schedule a consult, please contact us at **mghALSpact@mgh.harvard.edu**

For more information, http://www.massgeneral.org/als-pact

The Daniella Lipper ALS PACT Program has been made possible thanks to philanthropic support from the **EGL Charitable Foundation.**
To make a donation please visit: https://giving.massgeneral.org/donate/als-pact-program
or ask us about how you can help. **Thank you!**

Suggestions for supporting children affected by an adult’s ALS

Start by acknowledging your medical condition. Call your condition by its name, ALS, or describe it— a problem with motor neurons. For younger children, share that it is not contagious to reduce concern about others “catching” ALS.

The worst way for a child to learn about difficult news is to overhear it. News learned by accident is often confusing and inaccurate. Let children know they can trust you by telling them directly what is happening and what to expect. Welcome all of your child’s questions. Try to be available when and where your child is more likely to talk with you, for example, in the car, while you cook, or at bedtime.

Figure out the “real” question your child wants to ask. Ask children to tell you what they are wondering about, and why. This may help you and your child uncover underlying worries. Many times, there is a specific concern that can be more easily answered than the first question. Not all questions need answers right away. It’ s all right to say, “That’s a good question. I’ll need to think about it or talk it over with my (doctor, nurse, family member) and get back to you.”

Don’t let your child worry alone. Encourage children to share their worries with you. Sometimes people say unhelpful things with kind intentions, so ask children what others say about ALS in general, and about you. Let children know that ALS is different for everyone, so someone else’ s experience won’ t be exactly like yours.

Respect a child’s wish to not talk. All children need basic information about your illness, especially details that directly affect them. But it’ s okay if they don’t want to have long discussions about it. Check in to find out if they are hearing too much, too little or the right amount about your illness and medical care.

Try to maintain your child’s usual schedule. Regular routines provide a sense of normalcy. It may help to assign tasks, post schedules, make lists or use calendars to help children and caregivers know what each day holds.

Keep the channels of communication open with other caregivers, such as teachers and grandparents, and let children know you’ve done so. Notify these people of changes in your condition or medical care so they can better support your children. Decide with children - even college students - whom they will talk to if they are having a hard day at school.

Protect family time. Maintain regular times when your children have your full attention, without phone calls or visitors. Ask to hear details about their days. Some families choose a “captain of kindnesses” who can organize other family and friends to find ways to be most helpful.

Visit Our Website to Learn More

https://bit.ly/3SEmJCj

Learn together about ALS. Teens and even younger children often use the internet to learn about new things. Remind them that you and your medical team have the best information, and talk together about anything they read. Help them understand that online statistics describe groups of people, and your experience may be different.

Take good care of yourself. This may include spending time with friends and family, doing favorite activities, or finding quiet time. It also includes seeking the information you need to feel confident about your medical care and getting support to address your emotional needs. Consider connecting with the larger ALS community, through family or fundraising events sponsored by advocacy groups.

Massachusetts General Hospital
Founding Member, Mass General Brigham

Healey & AMG Center
Sean M. Healey & AMG Center for ALS
at Massachusetts General Hospital

Health Care Proxy (HCP) Form

What is an HCP Form?

A health care proxy (HCP) form is a legal document that allows you to designate a trusted family member or friend as your "proxy" or "Health Care Agent (HCA)". This person will communicate your preferences and decisions around your health care on your behalf, in the event that you are unable to make or communicate your medical decisions. It is important to have ongoing conversations with your proxy to ensure a clear understanding of your health care preferences.

Why is it important to fill out an HCP?

A HCP form conveys your wishes for your health care and treatment preferences in the event you are unable to communicate. At Mass General Hospital, we ask all of our patients to complete a form for us to put in your electronic medical record so that anyone caring for you can have access to this information.

Who should complete an HCP Form?

Any adult, 18 years or older, who is medically competent (able to make their own health care decisions) should complete an HCP form. When you fill out your HCP form, two adult witnesses must be present to sign it too. It is optional for your designated proxy to be present and sign the form and it is not necessary for an attorney or notary to review this form. It is in your best interest for your proxy and loved ones to know your wishes about your health in the event you are unable to communicate.

Where do I find an HCP Form for my state?

Whether or not you live in Massachusetts, you can use the MA HCP form if you receive your health care in Massachusetts. Below is a list of some ways to obtain a HCP Form for your state of residence:

- "Google”: Health Care Proxy form [insert name of state].
- Ask your primary care provider to send you one.
- Contact your local Area Agency on Aging. You can find your area agency phone number by visiting the Eldercare Locator or by calling 800-677-1116.
- Download your state's form online from one of these national organizations: AARP, American Bar Association, or National Hospice and Palliative Care Organization.
- If you are a veteran, contact your local Veteran's Affairs (VA) office. The VA offers an advance directive specifically for veterans.

Where should I file a completed HCP Form?

We recommend you keep a copy at home and a copy with your proxy, and send your clinical team(s) a copy to be uploaded into your medical record. If you are a patient at MGH, you can scan or take a picture of it and upload through the Patient Gateway portal.

MASSACHUSETTS HEALTH CARE PROXY

Information, Instructions, and Form

What does the Health Care Proxy Law allow?

The **Health Care Proxy** is a simple legal document that allows you to name someone you know and trust to make health care decisions for you if, for any reason and at any time, you become unable to make or communicate those decisions. It is an important document, however, because it concerns not only the choices you make about your health care, but also the relationships you have with your physician, family, and others who may be involved with your care. Read this and follow the instructions to ensure that your wishes are honored.

Under the Health Care Proxy Law (Massachusetts General Laws, Chapter 201D), any competent adult 18 years of age or over may use this form to appoint a Health Care Agent. You (known as the "Principal") can appoint any adult EXCEPT the administrator, operator, or employee of a health care facility such as a hospital or nursing home where you are a patient or resident UNLESS that person is also related to you by blood, marriage, or adoption. Whether or not you live in Massachusetts, you can use this form if you receive your health care in Massachusetts.

What can my Agent do?

Your Agent will make decisions about your health care *only* when you are, for some reason, unable to do that yourself. This means that your Agent can act for you if you are temporarily unconscious, in a coma, or have some other condition in which you cannot make or communicate health care decisions. Your Agent cannot act for you until your doctor determines, in writing, that you lack the ability to make health care decisions. Your doctor will tell you of this if there is any sign that you would understand it.

Acting with your authority, your Agent can make any health care decision that you could, if you were able. If you give your Agent full authority to act for you, he or she can consent to or refuse any medical treatment, including treatment that could keep you alive.

Your Agent will make decisions for you only after talking with your doctor or health care provider, and after fully considering all the options regarding diagnosis, prognosis, and treatment of your illness or condition. Your Agent has the legal right to get any information, including confidential medical information, necessary to make informed decisions for you.

Your Agent will make health care decisions for you according to your wishes or according to his/her assessment of your wishes, including your religious or moral beliefs. You may wish to talk first with your doctor, religious advisor, or other people before giving instructions to your Agent. It is very important that you talk with your Agent so that he or she knows what is important to you. If your Agent does not know what your wishes would be in a particular situation, your Agent will decide based on what he or she thinks would be in your best interests. After your doctor has determined that you lack the ability to make health care decisions, if you still object to any decision made by your Agent, your own decisions will be honored unless a Court determines that you lack capacity to make health care decisions.

Your Agent's decisions will have the same authority as yours would, if you were able, and will be honored over those of any other person, except for any limitation you yourself made, or except for a Court Order specifically overriding the Proxy.

How do I fill out the form?

1 At the top of the form, print your full name and address. Print the name, address, and phone number of the person you choose as your Health Care Agent. (**Optional:** If you think your Agent might not be available at any future time, you may name a second person as an Alternate Agent. Your Alternate Agent will be called if your Agent is unwilling or unable to serve.)

2 Setting limits on your Agent's authority might make it difficult for your Agent to act for you in an unexpected situation. If you want your Agent to have full authority to act for you, leave the limitations space blank. However, if you want to limit the kinds of decisions you would want your Agent or Alternate Agent to make for you, include them in the blank.

3 **BEFORE** you sign, be sure you have two adults present who will be witnesses and watch you sign the document. The only people who cannot serve as witnesses are your Agent and Alternate Agent. Then sign and date the document yourself. (Or, if you are physically unable, have someone other than either witness sign your name at your direction. The person who signs your name for you should put his/her own name and address in the spaces provided.)

4 Have your witnesses fill in the date, sign their names and print their names and addresses.

5 **OPTIONAL:** On the back of the form are statements to be signed by your Agent and any Alternate Agent. This is not required by law, but is recommended to ensure that you have talked with the person or persons who may have to make important decisions about your care and that each of them realizes the importance of the task they may have to do.

Who should have the original and copies?

After you have filled in the form, remove this information page and make at least four photocopies of the form. Keep the original yourself where it can be found easily (*not* in your safe deposit box). Give copies to your doctor and/or health plan to put into your medical record. Give copies to your Agent and any Alternate Agent. You can give additional copies to family members, your clergy and/or lawyer, and other people who may be involved in your health care decisionmaking.

How can I revoke or cancel the document?

Your Health Care Proxy is revoked when any of the following four things happens:

1. You sign another Health Care Proxy later on.
2. You legally separate from or divorce your spouse who is named in the Proxy as your Agent.
3. You notify your Agent, your doctor, or other health care provider, orally or in writing, that you want to revoke your Health Care Proxy.
4. You do anything else that clearly shows you want to revoke the Proxy, for example, tearing up or destroying the Proxy, crossing it out, telling other people, etc.

AFTER FILLING IN THE FORM, REMOVE THIS INSTRUCTION PAGE. BE SURE TO TALK WITH YOUR AGENT.

YOUR BIRTH DATE (m/d/y)
_____/_____/_____

MASSACHUSETTS HEALTH CARE PROXY

1 I, ____, residing at
(Principal: PRINT your name)

____
(Street) (City/town) (State/ZIP)

appoint as my **Health Care Agent**: ________________________________
(Name of person you choose as Agent)

of____
(Street) (City/town) (State/ZIP)

Agent's tel (h) ____________________ (w) ____________________ E-mail ____________________

OPTIONAL: If my agent is unwilling or unable to serve, then I appoint as my **Alternate Agent**:

____
(Name of person you choose as Alternate Agent)

of____
(Street) (City/town) (State/ZIP) (Phone)

2 My Agent shall have the authority to make all health care decisions for me, including decisions about life-sustaining treatment, subject to any limitations I state below, if I am unable to make health care decisions myself. My Agent's authority becomes effective if my attending physician determines in writing that I lack the capacity to make or to communicate health care decisions. My Agent is then to have the same authority to make health care decisions as I would if I had the capacity to make them **EXCEPT** (here list the limitations, *if any*, you wish to place on your Agent's authority):

I direct my Agent to make health care decisions based on my Agent's assessment of my personal wishes. If my personal wishes are unknown, my Agent is to make health care decisions based on my Agent's assessment of my best interests. Photocopies of this Health Care Proxy shall have the same force and effect as the original and may be given to other health care providers.

3 **Signed**:____________________________________ **Date:** ___/___/___ (mo/day/yr)

Complete only if Principal is physically unable to sign: I have signed the Principal's name above at his/her direction in the presence of the Principal and two witnesses.

______________________________ ______________________________
(Name) (Street)

____
(City/town) (State/ZIP)

4 **WITNESS STATEMENT:** We, the undersigned, each witnessed the signing of this Health Care Proxy by the Principal or at the direction of the Principal and state that the Principal appears to be at least 18 years of age, of sound mind and under no constraint or undue influence. Neither of us is named as the Health Care Agent or Alternate Agent in this document.
In our presence, on this day ____/____/____ (mo / day / yr).

Witness #1 __________________________ Witness #2 __________________________
(Signature) (Signature)

Name (print) __________________________ Name (print) __________________________

Address __________________________ Address __________________________

______________________________ ______________________________

5 Statements of Health Care Agent and Alternate Agent (OPTIONAL)

Health Care Agent: I have been named by the Principal as the Principal's **Health Care Agent** by this Health Care Proxy. I have read this document carefully, and have personally discussed with the Principal his/her health care wishes at a time of possible incapacity. I know the Principal and accept this appointment freely. I am not an operator, administrator or employee of a hospital, clinic, nursing home, rest home, Soldiers Home or other health facility where the Principal is presently a patient or resident or has applied for admission. But if I am a person so described, I am also related to the Principal by blood, marriage, or adoption. If called upon and to the best of my ability, I will try to carry out the Principal's wishes.

(Signature of **Health Care Agent**)____

Alternate Agent: I have been named by the Principal as the Principal's **Alternate Agent** by this Health Care Proxy. I have read this document carefully, and have personally discussed with the Principal his/her health care wishes at a time of possible incapacity. I know the Principal and accept this appointment freely. I am not an operator, administrator or employee of a hospital, clinic, nursing home, rest home, Soldiers Home or other health facility where the Principal is presently a patient or resident or has applied for admission. But if I am a person so described, I am also related to the Principal by blood, marriage, or adoption. If called upon and to the best of my ability, I will try to carry out the Principal's wishes.

(Signature of **Alternate Agent**)____

* * * * *

Health Care Proxy developed by Massachusetts Health Decisions in association with the following member organizations of the Massachusetts Health Care Proxy Task Force:

Boston University Schools of Medicine and Public Health:
  Law, Medicine, and Ethics Program
Deaconess ElderCare Program
Hospice Federation of Massachusetts
Massachusetts Bar Association
Massachusetts Department of Public Health
Massachusetts Executive Office of Elder Affairs
Massachusetts Federation of Nursing Homes
Massachusetts Health Decisions
Massachusetts Hospital Association
Massachusetts Medical Society
Massachusetts Nurses Association
Medical Center of Central Massachusetts
Suffolk University Law School:
  Elder Law Clinic
University of Massachusetts at Boston:
  The Gerontology Institute
Visiting Nurse Associations of Massachusetts

Additional information and resources for individuals, organizations and professionals available at **https://masshealthdecisions.org**. Or email: **proxy@masshealthdecisions.org**

Massachusetts Health Decisions

1/2018

“Our greatest privilege is caring for you and your loved ones!”

Supporting ALS Research & Care

“There’s never a better time than now, for action in our quest to cure ALS.” – At the Sean M. Healey & AMG Center for ALS at Mass General, we are deeply grateful for the outpouring of financial support from MDA ALS Care Center, ALS One and the generosity of individuals like you.

Your generous gifts, coupled with patient participation in clinical trials, place our research center at the forefront of innovative ALS research. With your support, it is possible to push progress, move innovation forward quicker, and challenge our determined experts to cure ALS. We are at an exciting and critical time in our ALS research, with a pipeline of promising therapies to bring forward to clinical trials for people with ALS. Utilizing new tools and technologies available to scientists, we are accelerating the discovery of therapies into action for people with ALS.

Your contributions span beyond helping to fund research by also supporting our multidisciplinary clinic and allowing us to provide comprehensive care for our patients through the expertise of physical and speech therapists, occupational therapists, respiratory therapists, a genetic counselor, nurse and nurse practitioners, to our palliative care doctor, several ALS neurologists, a physical medicine, rehab physician, affiliated psychiatrist, pulmonologists, psychologists, and our research team too.

In addition, we are able to offer ALS House Calls, tailoring physical and medical support to meet needs of our patients at home; TeleHealth, providing coordinated patient care in a way that is most convenient and best suited to the patient’ needs through virtual technology; and ALS PACT, (Parenting at a Challenging Time), which offers guidance for parents addressing the disease related challenges faced by their children.

Now more than ever, we depend increasingly on philanthropic partnerships with our sponsors, patients, families, friends and people like you to ensure we can continue to train the leaders in neurology to explore new pathways and discover effective approaches to treating, reversing and ultimately preventing ALS. We sincerely thank you for believing in us and inspiring every member of our team to work tirelessly to break down barriers, accelerate research, and bring light to hope to many patients previously without access to new, innovative, and personalized therapeutics. ***(Please read the next page for a list of the many ways to support ALS research.)***

Your support is what makes our rapid progress possible.

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