Welcome
To the Healey Center for ALS at Mass General
An MDA Care Center of Excellence
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
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 neuropsychiatric 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
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How do YOU become a New Patient?

Step 1: Patient Registration

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

Provide your MRN (Medical Record Number) and 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

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 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

**Plan for Visit**

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.

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

**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.

**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:
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

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

Parking

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).

Cafeterias & Cafés

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

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

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

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

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

Pharmacy

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

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

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
Welcome to the ALS Multidisciplinary Clinic in the Healey Center for ALS at Mass General

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

William David
MD, PhD

Suma Babu
MBBS, MPH

Doreen Ho
MD

Nazem Atassi
MD, MMSc

Haatem Reda
MD

Mark Garret
MD

Sheena Chew
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.
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How Members of Our Team Help to Take Care of You

- **Physicians** lead your evaluation and management plan. Your ALS Physician can be reached for non-emergencies by sending a message through Patient Gateway or calling clinic (8:30am-5pm) at 617-724-3914. Please ask the operator to be connected with your physician or physician’s primary nurse to ask any questions related to your care or to help with medication refill questions. For an emergency, please call the Page Operator at 617-726-2000 and ask to “please have your physician paged.” For extreme emergencies, please call 911 for immediate medical care.

- **Patient Service Coordinator (PSC)**: Serves as the team lead and point person for day-to-day clinic operations. The PSC provides comprehensive administrative support to the ALS providers functioning as the primary interface between the patient and physicians. The PSC assists in scheduling procedures, diagnostic testing, coordinating referrals, procedures and managed care related issues. The PSC can also help obtain insurance approval for Radicava and coordinate administration of Radicava with local infusion companies. Main Contact Number: 617-724-3914

- **Nurse Practitioner**: Works in collaboration with our physicians to manage your care. Our NPs conduct clinic visits, see patients for individual health concerns and urgent matters that develop in between regular clinic visits.

- **Clinical Nurse**: Works closely with physicians to assist with providing care to patients, both in clinic and between visits. The nurse is the primary member of your care team for health concerns and medication questions and refills, and is available Monday-Friday, 8:30 am - 5 pm ET. (Please contact your nurse via patient gateway or by phone).

- **Research Access Nurse**: Meets with patients to talk about current and upcoming research trials and then works with you to determine what trials may be right for you to consider participating in. Main Contact Number: 617-724-8995

- **Physical Therapist**: Evaluates mobility and overall function for patients and makes suggestions to improve mobility and safety, optimize function, and enhance participation in daily activities, including recreational activities, for as long as possible. Assists with family training for functional mobility or recommendations to referrals to other specialists, such as an occupational therapist or orthotist.

- **Speech Language Pathologist**: Evaluates speech and swallowing issues caused by ALS and recommends techniques for maximizing communication and swallowing safety and efficiency.

- **Occupational Therapist**: Helps the patient maintain the highest level of independence in activities of daily living along with work, community, and leisure tasks.

- **Respiratory Therapist**: Assists in evaluating breathing concerns, educating patients about supportive respiratory equipment and making appropriate recommendations.

- **Orthotist**: Specialist in bracing, works with patients and MD/PT to create custom braces and supports, including ankle, neck, and shoulder braces. Talk to your physical therapist if you need a recommendation for a local orthotist.

- **Genetic Counselor**: Provides clinical care to patients and families with neurodegenerative conditions, including diagnostic testing for patients with symptoms and pre-symptomatic testing for individuals with a 50% chance of inheriting a genetic condition. Also provides genetic counseling and testing to ALS patients and their families who are participating in research.

- **Neuropalliative Care Provider**: Brings an approach to care that is appropriate at any stage of illness and focuses on helping patients live well. The goal is to improve quality of life for both patients and their families. The palliative care provider works together with the multidisciplinary team to manage physical and emotional symptoms, while also helping patients navigate treatment choices.

- **Clinical Research Coordinator**: Brings patients to clinic rooms for visits and assists patients with tasks requested by your physician including completing various questionnaires and performing vital capacities.

- **ALS Parenting at a Challenging Time (PACT) Program**: A psychologist or psychiatrist provides parent guidance to individuals diagnosed with ALS who have children (infants through young adults). The team is available to meet parents during clinic visits, or work with them through phone or virtual appointments. Main Contact Number: 617-724-3914

- **ALS House Call Team**: Supplements care provided at the ALS Multidisciplinary Clinic. The House Call team delivers timely, responsive and personal targeted care for patients living with ALS. Face to face visits provide an opportunity to assess for disease progression, optimize symptom management, assess the home environment for safety and DME needs and to provide support.
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. How long can I expect to be in Clinic?
A. Call 617-724-3914 and speak with one of our ALS Patient Service Coordinators who will assist you 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 is the traffic to and from Mass General Hospital?
A. Peak traffic times are unpredictable in and around Boston. To lessen your stress, allow for extra travel time to arrive 15 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

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. The location of your visit is listed on your appointment letter. If you are unsure of location, please call one of our Patient Service Coordinators at 617-724-3914

Please visit our main campus interactive map to find the building where your appointment is located: https://www.massgeneral.org/visit/maps-and-directions/

Traffic, Parking, & Clinic Location

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Please visit our main campus interactive map to find the building where your appointment is located: https://www.massgeneral.org/visit/maps-and-directions/

Q. Could I bring snacks or beverages to my visit?
A. Yes, you can bring your own bag of snacks. However, Mass General has tasty assortment of food stations and Cafes in the hospital. If you or your accompanying care giver want to step away from clinic to purchase food or a drink, there are several cafeterias and coffee shops located throughout the hospital. 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 be able to 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.
Communicating with the Team

Q. How can I communicate with 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 and ALS Care Team for non-urgent matters. Please allow up to 24 hours for a response back from your Provider. 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 pm EST, dial 617-724-3914 to speak to a Patient Service Coordinator. Our Coordinators can help you in touch with a member of your Care Team to better assist you. Also, for any urgent concerns throughout the week you can also dial 617-726-2000 and ask the Page Operator to page your Physician.

For urgent concerns or questions after normal business hours (8:30-5 EST) or on the weekends, dial 617-726-2000 to speak to an MGH Page Operator and ask to have your Physician paged.

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.
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 principle 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/
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/amyotrophiclateral sclerosis.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/

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


### I Am ALS
An organization dedicated to reshaping the public understanding of ALS and connecting patients, family, and friends to community resources whose mission is to educate and motivate all about ALS. 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/](https://iamals.org/)

### 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](https://www.mda.org/disease/amyotrophic-lateral-sclerosis)

### PatientsLikeMe
PatientsLikeMe’s mission is to improve the lives of patients through new knowledge derived from shared real-world experiences and outcomes. While patients 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/](https://www.patientslikeme.com/)

### Peter Frates Foundation
The Peter Frates 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/](https://petefrates.com/contact/)

### 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/](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](https://www.youralsguide.com/newly-diagnosed.html)
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.

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.

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 in mind when telling others about a diagnosis.

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.

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.

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.

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.

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.

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.
**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/](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.


**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.


**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/](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/](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/](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.


**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/](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.

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/

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/
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’s 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.
To make a donation:

Visit → giving.massgeneral.org/donate/healey-center/

Checks may be made out and mailed to:
Massachusetts General Hospital Healey Center
Mass General Development Office
Attn: Healey Center/Department of Neurology
125 Nashua Street, Suite 540
Boston, MA 02114

Or scan here!

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And the many generous Donors like YOU!

We are humbled by your support