

INCLUDING THE

Multidisciplinary Team Approach in Your Care



ALS
ASSOCIATION

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**INCLUDING THE
MULTIDISCIPLINARY
TEAM APPROACH IN
YOUR CARE PLAN**



A note to the reader: The ALS Association has developed the Living with ALS resource guides for informational and educational purposes only. The information contained in these guides is not intended to replace personalized medical assessment and management of ALS. Your doctor and other qualified health care providers must be consulted before beginning any treatment.

Including the Multidisciplinary Team Approach in Your Care Plan

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TABLE OF CONTENTS

SOMETHING HAS CHANGED	3
WHAT IS ALS?	3
WHO DEVELOPS ALS?	3
DIAGNOSING ALS	4
THE ALS ASSOCIATION CLINICAL PROGRAMS – MULTIDISCIPLINARY TEAM APPROACH	5
THE ALS ASSOCIATION CERTIFIED TREATMENT CENTERS OF EXCELLENCE	5
THE ALS ASSOCIATION RECOGNIZED TREATMENT CENTERS	5
WHAT YOU CAN EXPECT DURING A TYPICAL CLINIC VISIT	6
OPPORTUNITIES FOR RESEARCH AND CLINICAL TRIAL PARTICIPATION	8
ADDITIONAL OPTIONS FOR YOUR CARE	9
IN THEIR OWN WORDS: PATIENT THOUGHTS ON THE VALUE OF ATTENDING A MULTIDISCIPLINARY CLINIC	13
THOUGHTS FROM MEDICAL DIRECTORS: COORDINATED CARE – THE VALUE OF INCORPORATING MULTIDISCIPLINARY CARE IN YOUR CARE PLAN	14
CORE MULTIDISCIPLINARY TEAM MEMBERS	16
THE ALS ASSOCIATION	20
ACKNOWLEDGEMENTS	20

“There is a difference between curing and healing.

Unfortunately, at this time, there isn't a cure for ALS. We do, however, believe we can heal the patient. This can be done by addressing the fact that ALS is not just a physical disease, but an emotional, spiritual, and psychological disease as well. The multiple aspects of ALS are best addressed in the setting of a multidisciplinary clinic that acknowledges the unique challenges that ALS patients and their families face. ALS doesn't just affect one person, but the entire family. Studies show that care in an ALS clinic improves quality of life as well as longevity. The clinic provides a medical home away from home where patients are treated like family. Although there are no right or wrong choices regarding patients' wishes in ALS care, an experienced team can help guide patients and families through their journey by providing deep knowledge of the disease process and aiding with difficult decisions. After all, the key to patient care is to care about the patient, and love is a form of medicine. We take this concept to heart and have a poster in our clinic which reads, “A Physician once said the best medicine for humans is love, someone asked what if it doesn't work, the physician smiled and said, ‘Increase the dose.’”

Scott D. Miller, MD, The ALS Association Recognized Treatment Center
at Kaiser Permanente South Bay Medical Center

SOMETHING HAS CHANGED

An engineer in his fifties is playing a game of volleyball with his friends. Suddenly he trips and falls without good reason. A lifelong athlete, he later notices he's having trouble standing on just one leg when he's getting dressed.

A business woman who conducts numerous presentations notices she is slurring her words. This observation is confirmed by her colleagues.

A geologist who travels a lot on business starts to realize his neck feels unusually tired and heavy after a long flight. His arm and hand continue to get weaker on one side over the months that follow.

Soon there's a visit with a primary care physician, then a neurologist, then some tests, and perhaps more specialist consultations.

And then, the physician tells the person:

"I have your diagnosis. You have amyotrophic lateral sclerosis, ALS, also known as Lou Gehrig's Disease. It is a progressive, degenerative, neurological disease resulting in weakness of voluntary muscles. The cause is unknown. There is much research being done, but at this point, we cannot reverse the progress of the disease. But we will be with you, supporting, helping, and guiding you, every step of the journey."

WHAT IS ALS?

ALS, or amyotrophic lateral sclerosis, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. A-myo-trophic comes from the Greek language. "A" means no. "Myo" refers to muscle, and "Trophic" means nourishment — "No muscle nourishment." When a muscle has no nourishment, it "atrophies" or wastes away. "Lateral" identifies the areas in a person's spinal cord where portions of the nerve cells that signal and control the muscles are located. As this area degenerates, it leads to scarring or hardening ("sclerosis") in the region.

Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to their demise. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, people may lose their ability to speak, eat, move, and breathe. Examples of voluntary movements are verbal communication, swallowing, picking up things, reaching for a smart phone, walking, or stepping off a curb. These actions are controlled by the muscles in the arms, legs, and face.

WHO DEVELOPS ALS?

ALS occurs throughout the world with no racial, ethnic, gender, or socioeconomic boundaries and can affect anyone. Most people who develop ALS are between the ages of 40 and 70, with an average age of 55 at the time of diagnosis. However, ALS does occur in persons in their teens through 90s. Sporadic ALS, which has no known cause, is most

common and occurs in 90-95 percent of cases. In the remaining cases (approximately 5-10 percent), there are two or more people in a family affected. This is referred to as familial ALS (fALS).

Half of all people affected with ALS live at least three or more years after diagnosis. While the average survival time is three years, about 20 percent of people with ALS live five years, 10 percent will survive 10 years and 5 percent will live 20 years or more. There is some evidence that people with ALS are living longer, at least partially due to clinical symptom management interventions and pharmaceutical treatments.

There are several research studies — past and present — investigating possible risk factors that may be associated with ALS. More work is needed to conclusively determine what genetic and/or environmental factors contribute to developing ALS. It is known, however, that military veterans, particularly those deployed during the Gulf War, are approximately twice as likely to develop ALS in their lifetime as someone who never served in the military.

DIAGNOSING ALS

ALS is considered a clinical diagnosis, meaning there is no specific test to determine the diagnosis. A clinician, usually a neurologist, will take a detailed history from a person and ask about what challenges they are dealing with and what was the first thing they noticed “was different.” A thorough neurological examination is performed, followed by a series of tests to rule out other conditions. Due to the complex and serious nature of the diagnosis, a second opinion with a neuromuscular/ALS specialist is usually recommended.

Feelings of shock, fear, and confusion about what to do next are common reactions to receiving the diagnosis. It can be overwhelming to receive the news, as people are unsure about what the future holds. People often wonder what steps they can take to be proactive in managing life with ALS and how to maximize their quality of daily living.

“This disease can start in many different ways: weakness, cramps, stiffness, and changes in speech, just to mention some common ones. The problems can be noted almost anywhere in the body. This leads to ALS being a disease that can be very difficult to diagnose early on. The varied rate at which the disease worsens means that treatments also have to be individualized. Focusing on preserving functions is often helpful for maintaining as positive an outlook as circumstances can allow. We have patients who live 10 or even 20 years or more with the disease and we certainly do what we can to increase the number of patients with long survival.

ALS poses many challenges, some of which can be avoided, and many of which can be mitigated. Addressing the challenges in a timely manner avoids unnecessary delays and additional problems. Different challenges present themselves at different times during the disease and it is worthwhile to try to stay a step ahead. We try to prevent our patients being overwhelmed and aim at delivering the right information at the right time — some patients want to know everything up front, others prefer to get the information when it is clinically useful. Our goal is to let our patients make the choices that keep them doing what they want for as long as possible, and we are getting more and more tools to do so.”

– Björn E. Oskarsson, MD, The ALS Association Certified Treatment Center of Excellence
at Mayo Clinic

THE ALS ASSOCIATION CLINICAL PROGRAMS — MULTIDISCIPLINARY TEAM APPROACH

The ALS Association collaborates with many experienced ALS clinicians across the United States to help ensure people living with ALS have access to specialized care. The ALS Association's Certified Treatment Centers of Excellence and Recognized Treatment Centers provide compassionate care in a supportive, family-oriented atmosphere. Centers that achieve either of these designations meet program requirements and follow recommended best practices as outlined in the American Academy of Neurology Practice Parameter and collaborate with their local Association Chapter to offer care and support to people living with ALS and their families.



People with ALS can maintain independence longer and enjoy improved quality of life when provided with options for symptom management, assistive technology, adaptive equipment, education, care services, and emotional support.

“ALS multidisciplinary care has been shown to result in higher quality of life than the more fragmented, traditional patient care. The integrated care at ALS centers is a model for the multidisciplinary approach, and studies have supported the value that patients perceive in such care.”

– Zachary Simmons, MD, The ALS Association Certified Treatment Center of Excellence at Penn State Hershey Medical Center

THE ALS ASSOCIATION CERTIFIED TREATMENT CENTERS OF EXCELLENCE

The ALS Association's nation-wide network of Certified Treatment Centers of ExcellenceSM provides evidence-based, multidisciplinary ALS care and services in a supportive atmosphere with an emphasis on hope and quality of life. To become certified as a center of excellence, an ALS clinic must meet clinical care and treatment standards, participate in ALS-related research, and successfully complete a comprehensive site review.



THE ALS ASSOCIATION RECOGNIZED TREATMENT CENTERS

The ALS Association Recognized Treatment Centers have the same high-quality approach to multidisciplinary care as The ALS Association Certified Treatment Centers of Excellence and provide services through a multidisciplinary care team. These centers, however, do not directly participate in ALS research.





“The ALS Association Certified Treatment Centers of Excellence offer a unique service to patients diagnosed with ALS. At each appointment, patients and their families see a group of specialists with great ALS experience in a few hours, avoiding up to eight separate appointments. This is the best in a “one stop shopping” experience. Each clinician is experienced in seeing ALS patients and can approach the many problems from different points of view. And most importantly, these clinics offer collaborative care — so a patient can get the benefit of many clinicians working together. Each clinic includes a session where the clinicians sit down and report on their findings and discuss best options and care together. A report is then provided to the patient. Finally, another benefit of going to an ALS Association Center of Excellence is the availability of clinical research. The vast majority of clinical research done for ALS patients in the USA occurs through these clinics.”

– Louis Libby, MD, The ALS Association Certified Treatment Center of Excellence
at Providence ALS Center

WHAT YOU CAN EXPECT DURING A TYPICAL CLINIC VISIT

The ALS Association’s Centers have full multidisciplinary teams of ALS specialists at the clinic who will work collaboratively with you and your family. Descriptions of the team members can be found near the end of this booklet.

The ALS Association Centers are designed to give you and your family a regular, thorough, and interdisciplinary evaluation; answers to your questions; and potential solutions to your problems. Typically, a clinic visit involves a full morning or afternoon and occurs every three months.



Prior to an appointment, you may be asked to give an update on your status over the phone to the clinic coordinator and/or you may be asked to have blood drawn or complete a pulmonary function test.

Team members, patients, and their families often develop relationships over time, and it shows in the conversations that are typical when you return for one of your visits. Team members may ask how last month's trip to see relatives went, whether a staff member brought a picture of their new baby, or whether the family is still planning the cross-country trip in the motor home. One patient shared that it feels like each visit to a Center is a "homecoming."

All members of the multidisciplinary team are available to see you for evaluation and discussion. For example, a dietitian may talk about nutrition and hydration needs, compare your weight to the last visit, and discuss any issues that have come up in the meantime. The nurse/coordinator may gather general information about how you are feeling and answer questions. The nurse may also help coordinate care and facilitate any special consultations or follow-up care.



From the respiratory therapist, you may hear the results of your pulmonary function test and may discuss options for improving breathing both during the day and at night. With the physician, your overall condition is assessed and discussed. Options for participation in clinical trials may be discussed, or outpatient tests may be recommended.

The speech therapist may evaluate changes in swallowing and talk about options for communication devices that you and your family might want to consider in the future. The physical therapist could help you learn how to use a cane properly for support, or may evaluate the need for a wheelchair. An occupational therapist may suggest new silverware or a specially-designed plate to make eating much easier.

The ALS Association chapter liaison may provide educational materials, talk about the monthly support group, or offer available loaner equipment that another team member may have recommended to you. The social worker may help in handling an insurance reimbursement problem or suggest a counselor for a teenage daughter who is having difficulty dealing with your diagnosis.

“Working closely with our clinic partners is essential to achieving the continuity of care that is so necessary for people living with ALS. Our Chapter Care Managers provide key insights related to each family’s journey. As members of the multidisciplinary team, we are able to contribute to the robust treatment that each person with ALS receives at our partner clinics.”

– Fred Fisher, MSW, LCSW, The ALS Association Golden West Chapter

The ALS Association Chapter liaison is a key member of the multidisciplinary team. “We have worked for years with the Care Services Manager for The ALS Association Kentucky Chapter, to provide a continuum of care to our patients and their families from the clinic to home setting. Consistent communication and support between our organizations has enabled a truly holistic approach to patient care.”

– Johanna Harris, MSN, RN, NP-C, The ALS Association Recognized Treatment Center at University of Louisville Physicians Neurology

The staff may gather for a team meeting to review challenges and solutions to help ensure every possible approach has been considered for each individual patient. The team then communicates its recommendations to you with a reminder to call anytime questions arise.



OPPORTUNITIES FOR RESEARCH AND CLINICAL TRIAL PARTICIPATION

Clinical research encompasses an array of opportunities to identify possible causes and contributing factors, evaluate the various presentations and progression of disease, and discover potential new medications and interventions for symptom management and disease modification. It also affords the opportunity to better understand the impact on quality of life for people living with ALS and their caregivers.

Certified Treatment Centers of Excellence are involved in one or more categories of ALS-specific research. These may include basic science (laboratory), biomarkers, clinical studies, clinical trials, genetics research, and quality of life studies. For many people living with ALS, research means hope for the future.

“For patients, it is gratifying to be doing something to combat the disease and, for physicians and staff, research is essential to slowing the progression of ALS and finding new approaches to treatment.”

– Rup Tandan, MD, The ALS Association Certified Treatment Center of Excellence
at the Vermont ALS Clinical and Research Center



ADDITIONAL OPTIONS FOR YOUR CARE

Your care needs will change throughout your journey with ALS. These may be a result of changes in your physical wellbeing, a change in your residence, additional care requirements, or any other factors that impact your quality of life. Your care team may recommend that you receive additional care and/or support from other providers. Some of those are listed below.

Affiliated Clinics and Collaborations

The ALS Association Chapter network collaborates with ALS clinics across the country that provide treatment and care based on a multidisciplinary model, but may not include all the multidisciplinary team members. These clinics may also work with other organizations, including private foundations, and may be a part of a large university or community medical system or the Veterans Administration. In addition to providing care and support for people living with ALS, some affiliated clinics may offer opportunities for people living with ALS to participate in research.

It is important to note that other models of care delivery are necessary to meet the needs of people living with ALS in a variety of residential settings and along the continuum of the disease's progression. Many of these providers work closely with The ALS Association chapters to help reach people living with ALS, regardless of where they live. Chapter care services professionals may provide educational and other support to these practitioners and their patients in their local community. The following are examples of models of care that supplement the Centers of Excellence and Recognized Treatment Centers.



Clinics and Large Group and Solo Practices

Neurologists diagnose and care for people with neurological illnesses, and some complete additional training and focus their practice on caring for people with neuromuscular diseases. Physiatrists or primary care physicians may also work closely with people living with ALS. Not everyone lives near a Certified Treatment Center of Excellence, Recognized Treatment Center or an Affiliated Clinic. However, they may receive high-quality care from clinics, private practice physicians, or group practices. These providers may also be affiliated with and/or supported by private foundations, a university medical system, or another non-profit organization. One goal of The ALS Association chapters is to work closely with these providers in their local communities to ensure that people living with ALS receive the health care and support services they need and deserve.

Veterans Administration (VA) Centers/Clinics

The Veterans Administration officially recognizes ALS as a presumptive 100 percent service-connected disease, which increases access to care, services, and support for those veterans living with ALS. The VA has a network of facilities throughout the nation and some provide specialized services for those with neuromuscular diseases such as ALS. These programs are eligible to apply for the more formal ALS Association Center designations.

“The VA has prioritized establishing compassionate multidisciplinary teams with expertise in ALS care for every geographic area. I feel honored to be able to serve in a health care delivery system that has put veterans and their caregivers at the center of our efforts. In addition to covering all available treatments, the VA recognizes the importance of quality of life. By offering home modification grants and by helping to provide wheelchair accessible vehicles, we enable our patients to stay in their homes with their families while also staying connected to their communities. Durable medical equipment, augmentative communication devices, home care services, and caregiver respite are additional resources that support our patients.”

– Ezgi Tiriyaki, MD, Minneapolis VA Health Care System

Telehealth/Telemedicine

Traveling to attend a multidisciplinary team visit often presents significant and unique challenges for ALS patients and their caregivers. This is especially true as the disease progresses, mobility declines, and fatigue ensues. Identifying options that allow for a strong continuum of care, and are cost-effective, can support quality patient outcomes.

Advances in technologies and their application in providing remote care without direct provider-to-patient contact has allowed many providers the opportunity to expand access to services. Telehealth, as defined by the Center for Connected Health Policy, encompasses a broad variety of technologies and tactics to deliver virtual medical, health, and education services. Telehealth is not a specific service, but a collection of means to enhance care and education delivery.



Home Health Care

Home health care plays an important role in the health care system. People with injury, illness, or disability are now able to receive care at home that was once only provided in hospitals. The most commonly provided home health care services for people with ALS are nursing and assistive/custodial care (personal care based on a person's eligibility); however, other services such as therapy and hospice are available as well.

Nursing care services are provided by registered nurses and licensed practical nurses who specialize in home health care. They are often highly experienced and knowledgeable professionals who can help a person with their care needs, ranging from management of ALS symptoms to tracheostomy and ventilator care.

Assistive/custodial (personal) care is non-medical assistance with activities of daily living when the disease has made it difficult to manage everyday tasks on one's own. This type of care can be provided by home health aides, certified nursing assistants, homemakers, and companions. Many people with ALS benefit from assistive care throughout their diagnosis as their disease progresses. The breadth of services depends on a state's scope of services.

Therapeutic care includes physical therapy, occupational therapy, speech language pathology, and respiratory therapy, all of which can help a person manage their condition safely at home, increasing independence and comfort.

Palliative Care

The goal of palliative care is to improve the quality of life for a person living with ALS and their family throughout the disease. A person can receive palliative care at any stage of ALS and in conjunction with curative treatment. Care may be provided in a physician's office, hospital outpatient setting, at home/residence, or via telehealth/telemedicine by a variety of appropriate health care professionals. Palliative care may address issues such as weight loss, pressure sores and other skin breakdowns, nutrition and dehydration, bowel impactions, urinary difficulties, changes in one's ability to move/transfer, psychosocial factors, and spiritual needs.

Hospice

Hospice can provide a loving, respectful, and peaceful end to an otherwise difficult experience with ALS. Hospice is generally recommended when the treating physician or primary care provider believes the person with ALS has six months or less to live, and is interested in this type of care. Services include medical care and symptom and pain management as well as emotional and spiritual support to both the patient and their loved ones. A hospice care team usually includes nurses, physicians, therapists, social workers, and home health aides who specialize in comfort and end-of-life care.

Many people think accepting hospice care is "giving up," but in fact, hospice care does not hasten death. It simply seeks to improve quality of life during the end-of-life period. Although it can be tempting to put off hospice until a person "really needs it," a person with ALS can derive the most benefit from hospice when services are started sooner, rather than later. Timely admission into a hospice program allows the hospice team to fully evaluate a person's and family's needs and develop an appropriate care plan. In addition, the regular visits from the hospice nurse and other team members help the hospice team to anticipate needs and intervene before a crisis situation develops. It is important to understand that a person has the option to discontinue hospice services at any time.



In Their Own Words: Patient Thoughts on the Value of Attending a Multidisciplinary Clinic

“My husband and I began making quarterly visits to an ALS clinic shortly after he was diagnosed with ALS. We could not have gotten through this traumatic time in our lives without the encouraging support from the dedicated team there. Their tests, evaluations, and support have been invaluable in guiding us through this devastating illness.”

– Valerie Torretti, wife of Gary Torretti, person who is living with ALS
(Greater Philadelphia Chapter)

“Coming to an ALS Association Certified Treatment Center of Excellence every three months allows us the opportunity of learning about the progression of our disease, whether the progression has not occurred, or whether it is getting worse. We would not know this if we didn’t go to a Certified Treatment Center of Excellence. At Certified Treatment Centers of Excellence, we have the opportunity of seeing a multidisciplinary team of experts who let us know what to do to keep our physical and emotional condition at its very best. Without their expertise, we would not fully understand where we stand in our disease progression. It provides us with a sense of reassurance.”

– Cary Marsh (Greater New York Chapter)

“We learned a lot of various aspects of dealing with ALS when we attended the Treatment Center of Excellence, ranging from nutrition to speech therapy. Every time we go back, armed with questions as our situation evolves, we learn more helpful approaches to dealing with the disease.”

– Judith Massey (Northern Ohio Chapter)

“I have received excellent care from the VA ALS Clinic. The clinic combines all disciplines all at once to see us in the same day, rather than multiple appointments on multiple days. Some of those disciplines we see are respiratory, physical therapy, occupational therapy, therapists, and several others. It makes for a long day, but only one day.”

– Excerpt from Troy Musser’s Rockwell Speech (Iowa Chapter)

“The positive, caring, informative staff; they ALL were exceptional. We learned so much. We left feeling hopeful rather than helpless.”

– Anonymous (Mid-America Chapter)

Thoughts from Medical Directors: Coordinated Care — the Value of Incorporating Multidisciplinary Care in Your Care Plan

You and your loved ones will face a variety of challenges along the journey. These physical, emotional, social, spiritual, and financial challenges can often become overwhelming. As the disease progresses and new symptoms and difficulties arise, the number of people involved in your care increases as well. Clear communication among the care team and coordination of care and services becomes vital. The multidisciplinary team can help facilitate shared decision-making and the continuum of care along the journey.

“ALS doesn’t just impact motor neurons — it is a life-altering diagnosis that impacts individuals, families, and communities. For that reason, the far-reaching effects of ALS cannot be managed by a single provider, but rather requires a cohesive team of health care providers surrounding the patient and family. An ideal ALS clinic team must work something like a successful aerospace engineering team. You need specialists who have expertise in their particular field, enough understanding about their colleague’s jobs, and the ability to work together under tight time constraints. If you just have one specialist, for example a very skilled electrician, you might have beautiful blinking lights, but you’ll never fly.”

– Ileana Howard, MD, The ALS Association Certified Treatment Center of Excellence
at the VA Puget Sound Health Care System

“ALS patients and their families try to seek out the best care possible. For most, the concept of a multidisciplinary approach is a novel experience. Thus, it is important to carefully explain to them how this model of care will benefit them. Multidisciplinary clinic care in ALS has been proven beneficial in research studies. Our clinic philosophy is to ensure that patients and their families have all information necessary to make decisions regarding care that will optimize their quality of life. This approach also allows the clinic team to offer the best in proactive management in anticipating patient needs before they become urgent problems.”

– Paul E. Barkhaus, MD, The ALS Association Certified Treatment Center of Excellence
at The Medical College of Wisconsin

“Shared decision-making is a care model in which patient values and goals are recognized as central but potentially fluid. Doctors’ years of training and experience are utilized to facilitate interpretation of data, empowering patients to make more informed decisions. Through such teamwork, health outcomes and satisfaction can be optimized.”

– Richard S. Bedlack, MD, PhD, The Certified Treatment Center of Excellence at Duke ALS Center

“The Centers are the most comprehensive way for us to manage patients. People who come to the Centers live longer and receive a personal and hopeful approach to their care, which is a hugely important aspect of what we do.”

– Todd Levine, MD, The ALS Association Certified Treatment Center of Excellence
at Phoenix Neurological Associates

“People with ALS travel to The ALS Association Certified Centers because of the expertise of the physicians, nurses, and allied therapists who optimize and coordinate medical care as well as help people with ALS and their caregivers to navigate some of the social and legal issues that arise during their care. The care provided is holistic but also solidly rooted in science and sharing of best practices. People living with ALS are also motivated to attend certified clinics to participate in the active local and national research programs offered at all of The ALS Association Certified Treatment Centers of Excellence.”

– James Caress, MD, The ALS Association Certified Treatment Center of Excellence
at Wake Forest Baptist Health

“ALS is a complex and challenging disease and we have been fortunate to develop those relationships necessary to have a meaningful impact. Optimal management of this disease is way beyond the skill and time availability for even the best neurologists. Thus, the value of a multidisciplinary program that can give each patient and their family a full team of talented professionals to screen and manage the myriad effects of ALS. This team involves our clinical staff, residents, and students along with our partners from The ALS Association, who participate in every clinic and are involved with every meaningful decision about the management of our patients. Huge and vital contributions in social service, counseling, and the identification and coordination of resources come from our patient care specialists from The ALS Association. Our educational programming for patients and families is dependent on The ALS Association. The Association serves as a repository of information, listening, and caring for our families and represents an integral part of our center and its missions. Beyond providing talented people, funding, and programs, I have an existential view that The ALS Association serves as a connection to truth and defines ‘state of the art’ for patient care. The Association is a voice of reason, making sense of new treatment strategies and fueling better research (and allowing me to give the patients more than just my opinion). I feel like The ALS Association provides a framework and an infrastructure for dealing with this disease. And, at the same time, serves as a nest of listening, understanding, and compassion in which our patients can land and rest along the course of their journey. We need a strong team with a deep bench and together with The ALS Association our program at IU has both.

– Robert Pascuzzi, MD, The ALS Association Certified Treatment Center of Excellence
at Indiana University School of Medicine



CORE MULTIDISCIPLINARY TEAM MEMBERS INCLUDE:

ALS/Neuromuscular Neurologist (MD, DO)

The physician who provides an expert evaluation of an individual's neurologic function, makes a diagnosis, and monitors the long-term course of the disease; also, the team leader who develops a plan of overall care management.

Clinical Coordinator

A member of the multidisciplinary team who generally serves as the primary point person for the ALS clinic. The coordinator may also serve in another role on the team (e.g., nurse, PT) and triages questions to the appropriate professionals, organizes the clinic schedule, facilitates flow of the clinic day, and coordinates follow-up appointments and orders to support continuity of care for people living with ALS.

Mental Health Professional

A licensed professional who has received specialized education in psychology, psychiatry, and/or counseling. Because living with ALS does impact a person's mental well-being, including potential thinking and behavior changes, having a mental health professional available during the visit or as a consult is very important for understanding these changes and developing a care plan.

Nurse (LPN, RN, NP)

A nursing professional may coordinate visits to the Center, arrange for appropriate specialty consultation, help run clinical research studies, and act as a resource person when patients have questions about their disease or care plan.

Occupational Therapist (OT)

A licensed professional who evaluates difficulties conducting daily activities (e.g., dressing, self-feeding, bed mobility, and toileting); also assists individuals in adapting to upper limb weakness and maintaining as much independent function as possible.

Physical Therapist (PT)

A licensed professional who evaluates an individual's muscle strength, walking ability, balance, and endurance; and recommends appropriate exercise programs, mobility aids, and orthotic devices to maximize safety, function, and independence.

Pulmonologist (MD, DO)

A physician who evaluates and monitors respiratory function, treats pulmonary infections and breathing difficulties, and advises people living with ALS regarding major decisions about long-term respiratory and nutritional support. The pulmonologist may be at the ALS clinic or may serve on a consultation basis if a respiratory therapist is part of the clinic team.

Registered Dietitian (RD)

A trained professional who evaluates an individual's weight and nutritional status and eating and swallowing difficulties. The dietitian provides recommendations for fluid and caloric intake, dietary modifications, and nutritional supplements as appropriate.

Respiratory Therapist (RT)

A licensed professional who evaluates an individual's breathing by measuring the strength of respiratory muscles, educates patients and families regarding the effect of ALS on the respiratory system, and recommends options for airway clearance, non-invasive and invasive ventilation. However, in some clinics, a pulmonologist may work collaboratively with the respiratory therapist during ALS clinic or may manage all aspects of respiratory care, including testing, education, and treatment.

Speech-Language Pathologist (SLP)

A licensed professional who assesses an individual's speech and swallowing problems and provides strategies to overcome these problems; recommends supplemental or alternative methods of communication, ranging from rapid access to hi-tech as appropriate.

Social Worker (SW, LCSW)

A licensed professional who helps individuals and their families utilize appropriate community resources for their health care needs; discusses health care benefits and concerns related to work and financial matters; and may also provide psychosocial support. In some clinics, a licensed clinical social worker may also serve in the role of mental health professional at the ALS clinic and will work with the neurologist to address psychological needs of the person with ALS and their family. Some situations may require

a referral to a psychotherapist, psychologist, or psychiatrist for more intense therapy or follow-up.

The ALS Association Chapter Liaison

The local chapter liaison, typically the Care Services Coordinator or Director, helps people living with ALS and their families cope with the day-to-day challenges of living with ALS by providing information, resources, and referrals to specialty and community organizations. This individual is a key member of the multidisciplinary team and a direct conduit to ALS Association chapter programs and services.

“As the ALS Association MN/ND/SD Chapter representative for the ALS Center of Excellence at Hennepin County Medical Center in Minneapolis, MN, my role is to make sure that people with ALS and their families are aware of our Chapter’s programs and services. It is an honor and a privilege to work alongside this dedicated team of professionals as we collaborate to provide support and resources to enhance the quality of life for people with ALS. To ensure that needs are addressed between clinic visits, individuals are encouraged to contact the Clinic or the Chapter if questions or concerns arise so they can be dealt with in a timely manner.”

– Lisa Kronk, RN, The ALS Association MN/ND/SD Chapter

Some ALS centers may have additional members of their care team. Other medical, allied health, and community professionals may be active participants in providing care and support. These additional team members may not be present on ALS clinic day but available by consultation or referral at the institution or in the community. These specialists may include:

Assistive Technology Professional (ATP)

A certified professional who assesses the needs of people living with disabilities and assists in the selection of appropriate assistive devices and equipment to aid in activities of daily living, such as communication, environmental controls, and mobility. The ATP also provides training in the use of selected devices and equipment.

Chaplain

A member of the clergy who counsels individuals and families regarding spiritual and emotional difficulties, and may provide information about living wills and end-of-life issues.

Clinical Research Coordinator

A professional with specialized training in the management of clinical trials and research studies. This individual works closely with the principal investigator (often the neurologist/clinic medical director) to present information about clinical research opportunities; discuss eligibility criteria, potential risks, and benefits of participation; and manages study operations.

Hospice Liaison

A professional with knowledge and expertise in the areas of hospice and palliative care. This individual has knowledge about Medicare, Medicaid, and private insurance hospice benefits and eligibility for services. This individual works with the community to educate about the roles of the hospice team members and scope of services offered in the home or inpatient setting.

Neurogenetics Counselor

A professional with specific skills and expertise regarding hereditary neurological conditions. Their specialized education encompasses neurology, counseling, and medical genetics. The counselor provides guidance and education to people living with the disease about the potential risk for their family, and whether genetic testing is right for them.

Palliative Care Specialist

A health care provider, typically a physician or nurse, with specialty training in symptom management and the care of people living with serious illnesses. This professional focuses on quality of life and typically works with other team members to provide additional support to patients and families.

“Palliative care specialists add an additional layer of expertise to the ALS care team, working collaboratively with the chapter and clinic staff to ensure that symptoms are being managed and care planning needs are being addressed. Often, they are able to see the patient in their home, and can provide needed support and follow-up in between clinic visits.”

– Leslie Ryan, MSPT, The ALS Association, Rocky Mountain Chapter

“Palliative Care teams should be integrated into the care of ALS patients, and can assist with assuring that patients and families are prepared for what to expect, have completed advance care planning, as well as provide psychosocial support, and expert symptom management.”

– Amelia Cullinan, MD, Dartmouth-Hitchcock Medical Center

Physiatrist (MD, DO)

A physician who specializes in physical and rehabilitation medicine and has expertise in the treatment of various diseases and conditions, including those affecting the brain and spinal cord. Treatment is focused on optimizing function and the well-being of the individual.

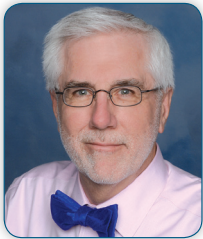
THE ALS ASSOCIATION

Established in 1985, The ALS Association is the only national non-profit organization fighting Lou Gehrig's Disease on every front. As the preeminent ALS organization, The ALS Association leads the way in research, care services, public education, and public policy — giving help and hope to those facing the disease. The ALS Association's nationwide network of chapters provides comprehensive care services and support to the ALS community. The mission of The ALS Association is to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

The Association's chapter network provides much-needed care services and support to people living with ALS and their families. To connect with your local ALS Association chapter, visit www.alsa.org/community/chapters.

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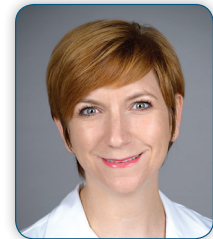
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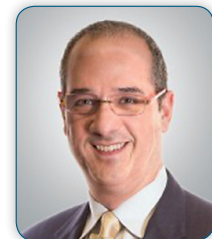
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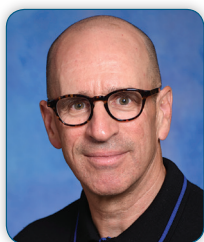
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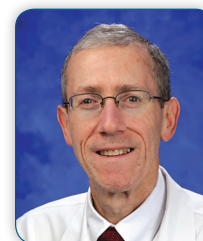
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The ALS Association Greater Ohio Chapter

**The ALS Association Greater Philadelphia
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The ALS Association Iowa Chapter

The ALS Association Mid-America Chapter

University of Kansas Health System

The ALS Association Texas Chapter

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About The ALS Association

The ALS Association is the only national nonprofit organization fighting Lou Gehrig's Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

For more information about
The ALS Association, visit our
website at www.alsa.org.