

ORGANIZATION NEWS

Information/Education Page

A Guide to Understanding the Benefits of a Multidisciplinary Team Approach to Amyotrophic Lateral Sclerosis (ALS) Treatment

Have you or a loved one recently been diagnosed with amyotrophic lateral sclerosis?

Amyotrophic lateral sclerosis (ALS) is a complex disease that affects the nerve cells in your brain and spinal cord, which affects many parts of the body. The brain loses the ability to control muscles throughout the body, including the ability to speak, eat, move arms and legs, and eventually breathe. Because ALS affects the brain, some people also begin to have difficulties with their thinking and mood. The symptoms of ALS can affect everyone differently; and as a result, most people with ALS need treatment from many different types of medical care providers. Patients often find the numerous appointments and recommendations from different specialty providers to be difficult and overwhelming to manage. Many hospitals and treatment clinics offer a multidisciplinary team approach to treat ALS, with the goal to improve the quality and access to care for the person with ALS and the caregiver.

What is a multidisciplinary treatment team?

A multidisciplinary treatment team is a group of medical and mental health care providers who work together to treat a patient. For ALS treatment, this multidisciplinary team may include a neurologist, physiatrist, physical therapist, occupational therapist, respiratory therapist, dietician, neuropsychologist, speech language therapist, nurse, and social worker. Depending on a patient's health needs, the team may also provide home health care providers, a medical equipment specialist, and an assistive technology specialist. The multidisciplinary team evaluates the patient's health status to develop a personalized plan to meet the patient's and caregiver's needs. Usually, the team meets before the arrival of a patient, and sometimes after, to determine the most appropriate treatment plan according to the patient's needs and lifestyle.

Why it is important to seek a multidisciplinary team approach to my ALS treatment?

In a multidisciplinary clinic, patients with ALS receive care and recommendations from a team of providers specializing in ALS.

By having access to a multidisciplinary ALS clinic, the patient might feel relieved from the possible stress that is caused by trying to schedule and attend many appointments with numerous health care providers.

Higher levels of anxiety and depression can be related to poorer quality of life due to health issues. Multidisciplinary care team approaches have been shown to improve quality of life, mental health, social functioning, and survival in patients with ALS.¹⁻⁴ It is important for patients and caregivers to learn about the psychological support that they can obtain throughout the course of treatment.⁵ Overall, the goal is to keep the person with ALS healthy, safe, and independent for as long as possible, which is better accomplished through multidisciplinary team treatment.

Who is the ALS care team?

Neurologist

- Neurologists are medical doctors who specialize in the brain and nervous system. They will oversee and manage your treatment plans.
- Expect your neurologist to develop and update your plan of care. They will start you on medications approved for ALS (eg, riluzole) as well as treat your ALS-related symptoms, such as increased salivation, emotional lability, cramps, and stiffness.

Physiatrist

- Also known as a rehabilitation physician, a physiatrist is a medical doctor who primarily focuses on maintaining patient safety and maximizing physical capabilities with activities of daily living.
- They will evaluate and prescribe you various equipment and adaptive devices, including manual and power wheelchairs, braces, shower seats, etc. based on your discussion of limitations and needs.

Physical and occupational therapist

- Physical and occupational therapists seek to maximize independence, mobility, and activities of daily living.
- They maximize independence through the use of education, adaptive devices, specialized exercises, and equipment prescription.

- Ask your physical therapist for equipment needs related to walking, balance, and moving around in your home and community.
- Ask your occupational therapist for help with improving activities of daily living such as eating, bathing, toileting, and dressing.

Pulmonologist/respiratory therapist

- A pulmonologist is an internal medicine doctor who, with the assistance of a respiratory therapist, helps you understand how the disease may affect your breathing. They will help you maintain respiratory independence for as long as possible.
- Contact these providers with changes in breathing, such as shortness of breath during regular movement, bathing, eating, talking, or lying down.

Gastroenterologist/dietician/nutritionist

- A gastroenterologist is a doctor who specializes in gastrointestinal issues.
- Dieticians and nutritionists are experts in food and nutrition. They will provide diet guidance on the appropriate amount of calories, vitamins, fats, and protein you should intake on a daily basis.
- Weight management is an important aspect of ALS care, as it has been shown to be related to rate of progression of the disease.
- They will discuss the types and consistency of food for ease of swallowing and the need for feeding tube placement, which is a surgical procedure performed by the gastroenterologist.
- Ask these providers for help developing an appropriate diet plan. Also seek help from these providers if you notice difficulties in chewing, swallowing, or drinking, or if you notice weight loss.

Neuropsychologist

- A neuropsychologist is a doctoral-level clinical psychologist who will monitor your cognitive, emotional, and behavioral functioning. They care for your mental health, as well as assess for possible dementia.
- They will provide supportive therapy for you and your caregivers, if warranted, and provide recommendations for further treatment of emotional issues related to ALS, such as uncontrolled crying or laughter.
- Discuss any changes in mood or thinking skills that you or your caregivers may observe with the neuropsychologist.

Speech therapist/speech language pathologist

- The speech therapist serves the role of evaluating and monitoring swallowing and speech production.
- They employ assistive swallowing strategies, work with the dietician to adjust diet consistency, and utilize compensatory speech strategies and devices to assist in communication. They will also discuss feeding tube placement with patients.
- Consult this provider for help if you notice any change in your speech, such as rate, volume, or clarity. Also discuss with them any augmentative/alternative communication methods available and the pros and cons for feeding tube placement.

Table 1 ALS resources

Organization	Web Address
ALS Association	www.alsa.org
ALS Therapy Development Institute	www.als.net
National Institute of Neurological Disorders and Stroke—National Institutes of Health	https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Amyotrophic-Lateral-Sclerosis-ALS-Fact-Sheet
Project ALS	www.projectals.org
Muscular Dystrophy Association	www.mda.org

Nurse

- Nurses serve as the liaison between patients and the treatment team.
- They assist in carrying out the treatment plan established by the physician, as well as aiding in the overall health of you and your caregivers by providing integrative care and treatment planning.
- Contact the nurse with health issues or concerns regarding medication use or side effects.

Social worker

- Social workers provide education and counseling on financial issues, disability insurance and services, transportation, employment, and homecare, as well as provide information on community resources and programs available for you and your caregiver.
- Ask this provider for help with living wills, durable powers of attorney, medical insurance, hospice need, or planning for end-of-life concerns.

Resources

There are many hospitals, Veterans Affairs medical centers, and health care facilities across the United States that offer a multidisciplinary team approach to ALS treatment. While some clinics operate full-time, other specialty clinics operate on a schedule (eg, monthly). The ALS Association and the Muscular Dystrophy Association partner with health care facilities across the nation to provide specialty certified centers and care clinics for persons affected by ALS. At their websites below, patients and caregivers can search by state to find a specialty clinic in their area. Additionally, many of these websites can connect individuals with equipment loan banks in their area; these banks (or closets) primarily lend used and donated medical equipment to patients for no or little charge. [Table 1](#) presents some available resources for patients with ALS.

Authorship

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