CONDITION

Amyotrophic lateral sclerosis

Learn how amyotrophic lateral sclerosis affects movement, speech, swallowing, and breathing, and how multidisciplinary care can manage symptoms and support quality of life.

WHAT IT IS
Progressive disease damaging motor neurons

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Muscle weakness, stiffness, twitching, difficulty speaking or swallowing

WHAT CAUSES IT
Usually unknown, sometimes inherited

HOW IT IS DIAGNOSED
Clinical progression, neurological examination, electromyography

MAIN TREATMENT
Multidisciplinary supportive care and disease-modifying medicines

CAN IT BE CURED?
No, no cure currently exists

IS IT AN EMERGENCY?
Sometimes, severe or rapidly worsening breathing difficulty

LONG-TERM OUTLOOK
Progressive decline with widely varying speed

Overview

Amyotrophic lateral sclerosis, or ALS, is a progressive disease of the nervous system. It damages motor neurons, the nerve cells that control voluntary muscle movement.

Motor neurons carry signals from the brain and spinal cord to muscles throughout the body. As these cells stop working, muscles become weak, stiff, and smaller. Over time, ALS can affect walking, hand use, speech, swallowing, and breathing.

ALS is sometimes called motor neuron disease. However, "motor neuron disease" can also describe a broader group of related conditions.

ALS usually does not directly affect the senses, such as touch, hearing, or vision. Bladder

control and eye movement are often preserved until late in the disease, although each person's experience is different. Some people develop changes in thinking, behavior, or language. These changes can range from mild problems with planning to frontotemporal dementia, a disorder affecting behavior and communication.

ALS progresses over time, but the pattern and speed vary widely. There is currently no cure. Treatment can slow some aspects of disease progression, manage symptoms, preserve independence, and support comfort. Care from a coordinated ALS or motor neuron disease clinic may help people receive respiratory, nutrition, mobility, communication, and emotional support at the right time.

Symptoms

Early ALS symptoms are often subtle and may begin in one part of the body. Weakness can start in a hand, arm, foot, or leg. In other people, the first changes involve speaking or swallowing. Less often, breathing weakness is an early feature.

Possible symptoms include:

ALS can cause both upper and lower motor neuron signs. Upper motor neuron damage may cause stiffness, brisk reflexes, and slow or poorly controlled movement. Lower motor neuron damage may cause weakness, muscle wasting, cramps, and twitching.

Pain is not usually caused by the loss of motor neurons itself, but it can still occur. Muscle stiffness, cramps, limited movement, joint strain, pressure on the skin, or poor positioning may all cause discomfort.

Symptoms such as weakness, twitching, or cramps have many possible causes. Having one of these symptoms does not mean that a person has ALS.

- Weak grip, difficulty with buttons, or dropping objects
- Tripping, foot dragging, or difficulty climbing stairs
- Muscle cramps, twitching, or visible muscle loss
- Stiffness, tight muscles, or slowed movement
- Slurred, quiet, or nasal-sounding speech
- Difficulty chewing or swallowing
- Excess saliva or difficulty clearing saliva
- Uncontrolled laughing or crying that does not match the person's mood

- Shortness of breath, especially when lying flat or during activity
- Poor sleep, morning headaches, or daytime sleepiness from weak nighttime breathing

Causes and risk factors

In most people, ALS does not have one identifiable cause. Researchers believe that several processes may contribute, including abnormal protein buildup, disrupted transport within nerve cells, inflammation, and problems with how cells handle energy or repair damage.

Some cases are associated with an inherited genetic change. Genes linked to ALS include C9orf72 , SOD1 , FUS , and TARDBP , among others. The same genetic change can affect relatives differently. Some carriers may develop ALS, frontotemporal dementia, both conditions, or neither.

A family history of ALS or frontotemporal dementia raises the possibility of an inherited form. However, ALS can occur without any known family history. Genetic counseling can help people understand what testing may and may not show, how results could affect relatives, and how to handle uncertain findings.

Age is an important risk factor because ALS is more common in adulthood and becomes more likely with increasing age. It can still occur in younger adults. Some studies have found associations with military service and certain environmental or occupational exposures, but no single exposure explains most cases.

ALS is not contagious. It is not caused by something a person did or failed to do.

Diagnosis

There is no single test that confirms every case of ALS. Diagnosis is based on the pattern and progression of symptoms, a neurological examination, and tests used to look for motor neuron damage and rule out other conditions.

The evaluation usually includes a detailed history. The clinician may ask when symptoms began, which body areas were affected first, and how the symptoms have changed. Family history, medicines, previous injuries, and possible exposures may also be reviewed.

During the examination, the clinician checks muscle strength, tone, reflexes, coordination, speech, swallowing, and sensation. Evidence that weakness is spreading to different regions over time can be important.

Tests may include:

ALS can resemble cervical spine disease, neuropathy, myasthenia gravis, inflammatory muscle disease, and other treatable conditions. Referral to a neurologist with experience in motor neuron disorders can help clarify the diagnosis. A second opinion may be reasonable when findings are uncertain.

- Electromyography: A thin needle records electrical activity in selected muscles. This can show loss of nerve supply and ongoing muscle changes.
- Nerve conduction studies: Small electrical signals test how well peripheral nerves carry messages.
- MRI: Imaging of the brain, neck, or spine may identify conditions such as spinal cord compression, stroke, or a tumor.
- Blood and urine tests: These can look for thyroid disease, vitamin deficiencies, infections, immune disorders, muscle disease, or other explanations.
- Breathing tests: Measures such as forced vital capacity help assess respiratory muscle strength.
- Swallowing or speech assessment: A speech-language pathologist may evaluate safe swallowing and communication.
- Genetic testing: Testing may be offered after counseling, particularly when there is a family history, an early age at onset, or a treatment linked to a specific gene.

Treatment and management

ALS care is tailored to the person's symptoms, goals, genetic findings, and stage of illness. A multidisciplinary team may include neurologists, respiratory clinicians, nurses, physical and occupational therapists, speech-language pathologists, dietitians, social workers, mental health professionals, genetic counselors, and palliative care specialists.

Disease-modifying medicines may be discussed. Riluzole can modestly slow disease progression or extend survival for some people. Edaravone may slow decline in physical function in selected patients. Tofersen targets production of the abnormal SOD1 protein and is approved for ALS associated with a confirmed SOD1 gene mutation. Each medicine has potential side effects, monitoring needs, and practical considerations. A specialist can explain the expected benefit and uncertainty for an individual situation.

Breathing support is a central part of care. Noninvasive ventilation uses a mask connected to a machine to support breathing, often during sleep at first. It may improve sleep, daytime energy, comfort, and survival. Cough-assist devices, suction, and techniques for clearing mucus may

be useful when the cough becomes weak. Some people later consider ventilation through a tracheostomy, an opening made in the windpipe. This decision requires detailed discussion about goals, caregiving needs, and long-term support.

Swallowing problems can lead to fatigue during meals, weight loss, dehydration, or food entering the airway. A speech-language pathologist and dietitian can recommend changes to food texture, meal timing, posture, and calorie intake. A feeding tube placed into the stomach may provide nutrition, fluids, and medicines when swallowing is no longer safe or adequate. It does not necessarily prevent all aspiration because saliva or stomach contents can still enter the airway.

Communication support should begin before speech becomes very difficult. Options include speech strategies, writing boards, text-to-speech devices, eye-gaze systems, and voice or message banking. Early planning gives the person time to learn and personalize these tools.

Physical and occupational therapy can help maintain safe movement and independence. Gentle range-of-motion activity may reduce stiffness and protect joints. Braces, canes, walkers, wheelchairs, transfer equipment, and home modifications can reduce falls and caregiver strain. Exhausting exercise is generally avoided, but comfortable activity may be encouraged based on professional guidance.

Other treatments can address cramps, muscle stiffness, pain, saliva, constipation, sleep problems, anxiety, depression, and uncontrolled laughing or crying. Medicines and supportive approaches depend on the symptom and the person's overall health.

Palliative care can be added at any stage. It focuses on symptom relief, communication, emotional support, and treatment choices. It can be provided alongside disease-directed treatment. Hospice care may become appropriate when the focus shifts mainly to comfort near the end of life.

Complications

Weak swallowing can cause poor nutrition, dehydration, choking, or aspiration. Aspiration means food, liquid, saliva, or stomach contents enter the airway. This can contribute to pneumonia.

Weak respiratory muscles may cause shallow breathing and difficulty clearing mucus. Breathing problems often develop gradually and may be more noticeable during sleep or when lying flat.

Reduced mobility can lead to falls, joint stiffness, skin pressure injuries, swelling, and blood clots. Communication loss can make it harder to report symptoms or participate in decisions

unless assistive tools are prepared early.

Cognitive or behavioral changes may affect judgment, planning, safety, and family relationships. Caregiver exhaustion is also an important concern. Respite services, home health support, counseling, and community resources can help.

Follow up

Regular follow-up allows the care team to track strength, breathing, swallowing, nutrition, communication, mobility, mood, and caregiver needs. Visits may become more frequent as needs change. Breathing tests and weight checks can identify problems before they become severe.

Contact the ALS team promptly about increasing difficulty swallowing, repeated choking, unplanned weight loss, new morning headaches, breathlessness when lying down, a weaker cough, fever, or trouble clearing mucus. These changes may need timely assessment but are not always emergencies.

Seek emergency care for severe or rapidly worsening breathing difficulty, blue or gray lips, inability to wake normally, new severe confusion, or choking with an airway that cannot be cleared. Sudden weakness, chest pain, or other abrupt symptoms also require urgent assessment because they may have a cause other than ALS.

Advance care planning is part of routine care, not a sign that treatment is stopping. It allows the person to record preferences about ventilation, feeding support, emergency care, and who should make decisions if communication becomes impossible.

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