

From Symptoms to Diagnosis

ALS (also referred to as Lou Gehrig's disease or MND) is a neurodegenerative disease that weakens muscles throughout the body. Early signs of ALS are different for everyone and can begin in different parts of the body. Regardless of how or where ALS first appears, the common symptom is the gradual, painless weakening of muscles.

Early ALS symptoms may be subtle enough that they are initially overlooked or attributed to something else, but as symptoms progress, they begin to affect day-to-day activities enough that they become difficult to ignore.

Roughly two thirds of ALS cases begin in one of the limbs—often in a hand or a foot. ALS usually progresses throughout one limb before spreading to another. Early signs of limb onset may include muscle weakness without pain, muscle stiffness, difficulty walking (including tripping and catching your foot on the ground), difficulty with tasks that involve fine motor skills like buttoning a shirt, involuntary jerking of a limb, muscle cramping, and muscle twitching.

In about one third of all cases, ALS begins by affecting muscles around the lower face that control speaking and swallowing. Early signs of bulbar onset ALS may include slurred speech, difficulty swallowing, choking on liquids, hoarseness, drooling, and episodes of uncontrollable laughing or crying.

ALS can begin by affecting respiratory muscles first, though this is rare. The primary symptom of respiratory onset is shortness of breath.

The ALS Diagnosis Process

ALS can be a difficult disease to diagnose. There is no one definitive test for ALS, which means your neurologist may need to run a series of tests to rule out other diseases and conditions before arriving at a definitive diagnosis.

The diagnosis process is different for everyone. Some people get diagnosed early by the first neurologist they see. Others end up seeing multiple doctors, or getting diagnosed with something else first, before receiving an accurate ALS diagnosis a year or more after their first symptoms arise.

It is important to be proactive and get an accurate diagnosis as soon as possible because early support and intervention can help you live longer and have a better quality of life.

In order to confirm or rule out an ALS diagnosis, neurologists need to gather information from a variety of sources. During your exam, the neurologist will review your medical history, ask about the progression of your symptoms, and test your reflexes, muscle strength, and other responses. Common tests include an EMG, nerve conduction study, MRI of the brain and spinal cord, and blood and urine tests.

Though relatively rare, people can get misdiagnosed with ALS when, in fact, the symptoms are being caused by a different disease or condition. More common, however, is that people who do have ALS are first misdiagnosed with something else, which can result in unnecessary surgeries and delay.

What if I'm worried I might have ALS?

If you are worried you might be showing early signs of ALS, you can start by seeing your primary doctor or scheduling an appointment with a local neurologist. If ALS seems like a possibility, make an appointment with a neurologist who specializes in ALS.

Ask your general neurologist or ALS United NC for ALS neurologist recommendations. Find out if you need a referral in order to schedule an appointment.

If you do receive an initial diagnosis of ALS, it is reasonable to seek a second opinion. Though relatively rare, people can get misdiagnosed, especially by neurologists who have little experience with ALS and may not be aware of some of the other diseases or conditions that can mimic ALS.

Get Local Support



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