

What doctors want patients to know about ALS

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Lou Gehrig—the New York Yankees’ first baseman known as the “Iron Horse”—was one of the greatest players in baseball history. But his career was tragically cut short when he was diagnosed with amyotrophic lateral sclerosis (ALS), a progressive neurodegenerative disease that slowly robs people of their ability to move, speak and eventually breathe.

In Gehrig’s case, the disease ended his record-setting consecutive games played streak at 2,130 in 1939. He died two years later, though his endurance record remained unbroken for 56 years. While it became known as Lou Gehrig’s disease, he was not the first person to have ALS. The disease was officially identified by French neurologist Jean-Martin Charcot in 1869. Recent advances in understanding ALS and potential therapies offer hope for those living with the disease and their families.

There are close to 35,000 people with ALS in the U.S. with about 5,000 new diagnoses of this disease each year. Most people who develop ALS are between 55 and 75 years old and live between two to five years after symptoms develop, according to the Centers for Disease Control and Prevention. But the disease also can afflict people in their 20s and 30s, or even younger.

In younger people, ALS is 20% more common in men than women. But with increasing age, the incidence of ALS tends to be more equal between men and women. Familial ALS is also found equally among men and women. Meanwhile, about 90% of ALS cases occur without any known family history or genetic cause. The remaining 5–10% of ALS cases are inherited through a mutated gene with a known connection to the disease, [says the ALS Association](#). For unknown reasons, military veterans are more likely to be diagnosed with the disease than the general public.

The AMA's What Doctors Want Patients to Know™ series gives physicians a platform to share what they want patients to understand about today's health care headlines.

For this installment, two physicians took time to discuss what patients need to know about ALS. These AMA members are:

- [Ryan Hakimi, DO, MS](#), a neurointensivist in Greenville, South Carolina, and a delegate in the [AMA House of Delegates](#) for the American Society of Neuroimaging.
- Amir H. Sabouri, MD, PhD, a neurologist and a neuromuscular subspecialist and medical director of The Permanente Medical Group Multidisciplinary ALS Clinic in Walnut Creek, California.

[The Permanente Medical Group](#) is part of the [AMA Health System Member Program](#), which provides enterprise solutions to equip leadership, physicians and care teams with resources to help drive the future of medicine.

ALS is weakness, but not pain

"The key is that ALS gradually starts with weakness in some skeletal muscles. It can be in the hand, leg, tongue or affect breathing," Dr. Sabouri said. "We classify ALS into two main categories. One we call limb-onset ALS, which means arm and leg. Or there is bulbar-onset ALS, which means it starts from the tongue or affects breathing. So, it's either weakness or difficulty with speech and swallowing or breathing."

"ALS typically presents with painless, gradually progressive asymmetric motor weakness. So, if somebody comes and tells me they have pain and weakness," then there is no worry about ALS because pain doesn't fit with this disease, he said. "Or if somebody comes and tells me that they have weakness, and also numbness on the same location, I'm happy because ALS doesn't cause numbness."

"But if someone comes and tells me they have weakness in their hand that's been gradually going on for some time and there is no pain or numbness, I get worried. That could be ALS," Dr. Sabouri said.

Symptoms of ALS vary from person to person

It is important to note that ALS symptoms are very individualized. Some people with ALS may experience difficulty holding a pen or lifting a cup while others might first experience changes in their voice or speech. Symptoms can also begin in the hands or arms, legs or feet, or muscles that control speech or swallowing, according to the ALS Association.

An early sign of ALS is painless, gradual muscle weakness. Other early symptoms of ALS may include:

- Tripping or difficulty walking.
- Dropping objects.
- Fatigue in the arms or legs.
- Slurred or slowed speech.
- Muscle cramps or twitching.
- Episodes of uncontrollable laughing or crying.

While not everyone experiences the same symptoms or order of progression, what all people with ALS share is progressive muscle weakness and paralysis over time.

ALS worsens over a person's lifespan

"It's a neurologic disease that's progressive, meaning that it continues to get worse over the course of the person's lifespan," Dr. Hakimi said. ALS "has some early symptoms of asymmetric weakness in the limbs, meaning one side is much greater than the other or one side only—most commonly in the upper extremities, particularly hand weakness.

"So, somebody might notice that they have a hard time gripping things or they might be dropping things. They may notice having difficulty with something like using their keys," he added. "However, it could involve the shoulders and therefore affect the person's posture and range of motion."

"In the lower extremities, it very commonly leads to weakness of one of the ankles leading to what's called a foot drop where the ability of the individual to raise their foot as they walk

is impaired so their toe catches and therefore can lead to falls,” Dr. Hakimi said. “Then, lastly, the least common initial presentation is what we call bulbar symptoms that are related to the head and neck. Those can be things like somebody having slurred speech or difficulty swallowing, but are much less common.”

As ALS progresses, the disease “often can lead to some slowness because part of the brain—the frontal lobe—which is involved with executive function, for example writing checks or remembering to pay your bills or those types of things that require a lot of thought,” he said. “Then a little bit later you get rigidity called spasticity where a joint is difficult to move, so it becomes tighter and that can lead to falls because somebody’s balance is affected.”

Then “as it progresses further, you start seeing muscle atrophy or shrinkage of the muscles. And so, you might notice that somebody has very asymmetric arms or legs,” Dr. Hakimi said.

ALS diagnosis can be delayed

“Unfortunately, it takes about a year on average to make the diagnosis because you have to keep in mind that those initial symptoms are extremely common neurologic symptoms for a variety of different diseases,” Dr. Hakimi said. “For example, hand weakness is most commonly due to carpal tunnel syndrome. So, when somebody presents with hand weakness, that’s sort of the first thought.”

With ALS, “it’s the evolution in the person’s symptoms because the symptoms spread from one location to an adjacent location,” he said. “And then once you start getting involvement of the forearm or at the elbow or even the shoulder, then you know that that’s not carpal tunnel syndrome.”

Furthermore, “the weakness of the person’s foot on one side is a very common presentation for somebody who has a pinched nerve in their low back,” Dr. Hakimi said. “We all develop arthritis as time goes on and there’s a reasonable chance that we can develop that kind of symptom. And when somebody has those symptoms, that’s the first thing people think about as opposed to ALS. Therefore, that leads to difficulty in making

that diagnosis.”

ALS is fatal

“Unfortunately, ALS is a fatal disease and recognizing that endpoint is always going to be the same, which is death. That’s not a very good outlook,” Dr. Hakimi said. “Some of the medicines that are out there can slow the progression of the disease by about three to six months.”

Those few months can mean a lot, he noted. “That might be very valuable for a given person. For example, if their child is going to graduate from high school or they’re going to be a grandparent.”

There’s a test for familial ALS

“Overall, familial ALS is relatively uncommon. It’s about 5–10% of all ALS,” Dr. Hakimi said. “However, in patients who have a positive family history—if there’s a family member who has that—then those are the individuals who we would potentially offer genetic testing to.”

That’s “because the majority of times it’s what we call autosomal dominant, meaning that if I have it then my children are going to have it. If my children have it, then they’re going to pass that on,” he explained. “It’s important to keep in mind that ALS is part of a collection of neurodegenerative disorders such as [Alzheimer’s disease](#) and [Parkinson’s disease](#).”

“So sometimes if you have a number of family members who have these degenerative conditions, that might be a clue that you should be thinking about testing somebody,” Dr. Hakimi added.

Time is the best diagnostic tool for ALS

“We don’t order genetic testing for every ALS patient as part of the initial workup,” Dr. Sabouri said. “However, this approach may change in light of the recent Food and Drug Administration approval of the ALS medication called Tofersen, which is specifically

indicated for a small minority of familial ALS patients with a particular mutation known as SOD-1.”

“Sometimes time is the best diagnostic tool for ALS, since there is no specific test to confirm the diagnosis,” he said. “Some families come in and want to know immediately whether it is ALS or not, but it’s about ruling out other conditions first and the time to determine gradually progressive disease course.”

“We typically avoid mentioning ‘ALS’ or ‘Lou Gehrig’s disease’ to patients or families until we achieve a reasonable certainty, ruling out other potential diagnoses,” Dr. Sabouri said, emphasizing that “the concept of time is the best diagnostic tool for ALS.”

ALS management is multidisciplinary

“There’s no cure for ALS, but several treatments can control symptoms, prevent complications, and ease living with the disease,” Dr. Sabouri said, emphasizing that “ALS management requires a multidisciplinary approach with interventions tailored to disease progression.”

“Speech therapy is initiated at—or often before—the onset of speech issues. Physical therapy is needed when mobility problems, particularly leg weakness, emerge. Occupational therapy helps maintain independence, especially when hand function declines,” he explained. “Additionally, social workers provide emotional and psychological support, and assistance with social and financial matters as needed by patients or their families.”

“There is a very well-structured system in the U.S. and many parts of the world known as multidisciplinary ALS clinics, effectively a ‘one-stop-shop,’” Dr. Sabouri said. “You go there, you see all relevant specialists in one place avoiding the need to spend your valuable time visiting them at different sites on different days.”

For example, Kaiser Permanente has several ALS clinics across the health system, Dr. Sabouri said, noting “if you go to the [ALS Association](#) or the [Muscular Dystrophy Association](#) website, there is useful information and locations for clinics, including our

center inside Kaiser in Northern California.”

Make appropriate lifestyle changes with ALS

While there is no cure for ALS, “the main management is lifestyle modification, so things like exercise,” Dr. Hakimi said. “If you know that you’re going to develop some element of weakness, maximizing your capability to have strength, coordination, muscle control and things like that with exercise before the disease has progressed very far is very good.”

“The other lifestyle modifications include just making sure your home is safe, using assistive devices like a cane or walker,” he said. “In some cases, once it involves your respiratory situation, using things like a BiPAP, which are like the CPAP machine—similar concept, but the machine helps you breathe so that you don’t develop oxygen problems.”

“And there’s a number of other things, of course, that need to be considered. One is nutrition. For some of these patients, as the disease progresses, they will develop swallowing difficulty,” Dr. Hakimi said. “Therefore, one would consider putting a feeding tube in that individual to make sure that they get enough nutrition because if your muscles are already shrinking and becoming weak, not getting enough nutrition is surely going to affect that as well.”

“There are medicines also to treat muscle spasms, weakness, depression and things like that. And of course, there’s sort of the bigger picture kinds of things which are family planning type of things or getting your affairs in order because unfortunately it is a fatal condition,” he said.

Stick with a neurologist for ALS

“Consult with your neurologist or multidisciplinary clinic team before making any significant health-related decisions.” Dr. Sabouri said. “Be vigilant about businesses that may unfortunately exploit the vulnerability of those affected and steer clear of ‘hope shops’ or ‘miracle stores’ that offer expensive, yet unapproved treatments that may look scientific.”

“It breaks my heart whenever I reflect on the journey of an ALS patient who was devastated by the absence of a cure and had a hard time accepting the harsh reality,” he said. “Tragically, she fell into the trap of those who peddle false hope. In her case, she placed all her trust, along with her entire fortune, into a ‘cleansing diet’—an unproven and potentially harmful pseudo-treatment.

“Ultimately, she succumbed to the disease earlier than expected,” Dr. Sabouri said. That is why “it’s important to stick with a neurologist who you trust and follow the clinic for all-in-one care.”

Family support is essential with ALS

“It’s obviously extremely emotionally taxing recognizing that somebody is going to get worse as time goes on regardless of what you do for them,” Dr. Hakimi said. “What you’re impacting as a family member is that trajectory of how quickly they’re worsening and also giving them emotional support. So, making sure that you keep a positive outlook for them and do whatever you can.”

Additionally, “patients often get to the point that they need to be fed even though they’re adults. So, as a family member, ensuring that you sit with that person and very slowly feed them ... is important,” Dr. Hakimi said.

Families “can help by being present to listen to their loved one with ALS, to support them physically and emotionally,” Dr. Sabouri said. “As ALS doctors, we gain valuable insights into the dynamics of the patient’s family and the best thing to do is reach out to the neurologist and multidisciplinary team members and share the struggle either physically, emotionally or financially. Everything. Any challenge—not only about the patient, but also the family.”