

Approved Drugs for ALS

There are currently two drugs that have been approved in the United States to treat people living with ALS—in addition to one that treats people who have a specific genetic mutation. These drugs can modestly slow functional decline and help people live longer, though they do not stop or reverse ALS. Researchers are optimistic that progress is accelerating, that more drugs will be approved in the near future, and that ALS will eventually become a treatable disease.

Before deciding to take any drug, discuss the potential benefits and burdens (side effects, cost, time spent, etc.) with your neurologist—ideally one who specializes in ALS and works at an ALS clinic. Your neurologist should make sure that you don't have any underlying health conditions and aren't taking any medications that would disqualify you from taking any one of these drugs.

Below are summaries of the drugs for ALS that have been approved by the U.S. Food and Drug Administration.

Rilutek® (riluzole) from Sanofi-Aventis

Initial studies showed that riluzole helped people live an average of three months more, though increased survival time may be longer. Riluzole reduces glutamate, an amino acid that is believed to damage motor neurons when its levels are high. You take either a pill, liquid, or dissolvable oral film twice a day.

Some potential side effects are mild nausea or fatigue when starting riluzole. Others notice a change in the way things taste. In rare cases, it can affect the liver, which is why doctors monitor liver function with simple blood tests.

Riluzole is inexpensive, covered by most insurances, fairly easy to get approved, and available at regular pharmacies.

Radicava® (edaravone) from Mitsubishi Tanabe Pharma

An initial clinical trial in Japan indicated that Radicava® slowed ALS functional decline by 33%, though subsequent studies have yielded mixed results. Data on its effectiveness is still being gathered.

Radicava® reduces oxidative stress, which can damage motor neurons. Radicava® was administered intravenously until Radicava ORS®, a more user-friendly oral gel, was approved in 2022. The ongoing treatment cycle involves taking this drug ten out of 14 days, followed by 14 days off. Most common side effects include bruising, problems walking, headaches, and fatigue. Serious allergic reactions are possible for people with sulfite sensitivity.

Radicava® can be expensive. How much you actually pay will depend on your insurance coverage and the final negotiated price. You will need prior authorization from insurance, which may take a few weeks, and the drug will need to be ordered through a special pharmacy.

Qalsody® (tofersen) from Biogen

Tofersen slows the rate of disease progression for the approximately 2% of ALS patients who have an SOD1 gene mutation (which can be detected through genetic testing). Tofersen blocks the production of mutated SOD1, thereby lowering the levels of this protein that is toxic to neurons and contributes to disease progression.

It is administered through a lumbar injection in the lower back. The first three doses are administered once every 14 days, followed by one maintenance dose every 28 days after that. Some side effects can be headache, injection-site pain, fatigue, joint pain, increased white blood cells, and muscle pain.

Which of these drugs should I take?

Deciding whether or not to take any of these drugs is a very individual decision. Discuss the potential benefits and burdens with your ALS neurologist, learn about each drug, and find out how much you would have to pay out of pocket. Keep in mind that different neurologists may have differing opinions about the effectiveness of each drug.

Are there any other treatments for ALS?

Yes. There are non-drug interventions, particularly non-invasive ventilation (NIV), that can help you live longer than any of the drugs listed above. Attending a multidisciplinary ALS clinic has also been proven to help people with ALS live longer and have a better quality of life.

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