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MADISON NEUROLOGY LLC

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Neurology Care 7 days a Week. Because Your Brain Matters.

Amyotrophic Lateral Sclerosis (ALS / Lou Gehrig's Disease)

Patient education guide · Neurodegenerative & Memory · Madison Neurology LLC

What is it?

ALS is a progressive disease of the motor neurons — the nerve cells that control voluntary muscles. As these neurons die, muscles weaken and waste, affecting walking, speaking, swallowing, and eventually breathing. Sensation, bladder control, and (usually) intellect are preserved.

How does it happen?

About 90% of cases are sporadic with no known cause; roughly 10% are familial (genes include C9orf72, SOD1, FUS). The disease involves a mix of genetic susceptibility and environmental factors, with abnormal protein handling in motor neurons playing a central role.

Common symptoms

- Progressive weakness, often starting in a hand, foot, or the speech/swallowing muscles
- Muscle twitching (fasciculations) and cramps
- Stiff, tight muscles (spasticity)
- Slurred speech and difficulty swallowing
- Breathing weakness in later stages; thinking/behavior changes in some patients

How is it diagnosed?

Diagnosis is made by a neurologist using examination, electromyography (EMG), and tests that exclude mimics (MRI, blood tests, sometimes lumbar puncture). Genetic testing is offered to all patients because results can guide treatment and family decisions.

How is it treated?

Riluzole and edaravone modestly slow progression; tofersen treats the SOD1 genetic form. Care at a multidisciplinary ALS clinic — respiratory therapy, nutrition (including feeding tube timing), speech and communication devices, physical therapy — measurably extends survival and quality of life. Noninvasive ventilation supports breathing, and many clinical trials are available.

What does the future hold?

Average survival is 3-5 years from symptom onset, but about 10% live more than 10 years, and the course varies widely. Modern respiratory and nutritional support meaningfully extends life and comfort. Early planning and connection to ALS organizations help families at every step.

Questions patients commonly ask

Q: Is ALS hereditary?

A: Only about 10% of cases are familial; genetic testing is offered to everyone with ALS, and counseling helps interpret results for the family.

Q: Will I lose my ability to think?

A: Most people keep clear thinking; about a third develop some cognitive or behavior changes, and a smaller number develop frontotemporal dementia.

Q: Why is a multidisciplinary clinic recommended?

A: Studies show coordinated care — breathing, nutrition, mobility, communication — helps people with ALS live longer and better.

National support groups & resources

- **ALS Association** — als.org — 1-800-782-4747
- **Muscular Dystrophy Association** — mda.org
- **National Organization for Rare Disorders** — rarediseases.org — 1-800-999-6673

(Organization contact details were current at the time of compilation; please verify online.)

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