



Amyotrophic lateral sclerosis (ALS)

Understanding ALS

Amyotrophic lateral sclerosis (ALS), sometimes referred to as Lou Gehrig's disease, is a progressive neuromuscular disease affecting the nerves in the brain and spinal cord that control muscle movement. Over time, people with ALS experience a weakening of their muscles, which robs them of their ability to move, speak, eat, and eventually breathe. Symptoms of ALS usually begin in late middle age, but the disease can also impact younger adults.

While the majority of ALS cases present with no family history, about 5 to 10 percent of cases are familial, suggesting a genetic factor. Military veterans and fire fighters have a significantly higher chance of getting ALS, nearly double that of the general population.¹ There is no cure for ALS; it is 100 percent fatal.



MDA's Long-Standing Commitment to the ALS Community

For nearly 75 years, the Muscular Dystrophy Association (MDA) has supported the ALS community, investing in research that matters, providing access to resources and care that strengthen, and championing public policy that brings change. Our support includes:

- **Research and Innovation:** MDA's research has contributed to a deeper understanding of ALS, paving the way for breakthroughs emerging in this new era of treatment. The power in our research approach is that we can apply learnings from one disease to enable progress in others, bringing urgently needed hope to families.
- **Access to Expert Care:** Our nationwide network of MDA Care Centers, the only coast-to-coast network of its kind, provides multidisciplinary care that is specific to the care of people living with ALS. Each center is staffed by top specialists who are not only experts in neuromuscular diseases but are also on the cutting edge of the latest treatments and research.
- **Programs that Inform and Connect:** Our programs, including the MDA Resource Center and MDA Connect, provide comprehensive support, offering guidance, resources, and a listening ear to families navigating the challenges of ALS.
- **Advocacy and Policy Influence:** Through decades of effective advocacy, MDA has been instrumental in advancing health policy and increasing funding for ALS research and care.

Learn more about the impact of ALS, and what you can do to support families living with the disease, at [MDA.org](https://www.mda.org).

1. McKay, K. A., Smith, K. A., Smertinaite, L., Fang, F., Ingre, C., & Taube, F. (2021). Military service and related risk factors for amyotrophic lateral sclerosis. *Acta neurologica Scandinavica*, 143(1), 39–50. <https://doi.org/10.1111/ane.13345>

MDA in Action: Supporting People Living with ALS



\$176M Invested in ALS Research

resulting in key research breakthroughs, the identification of genetic markers, and the development of innovative therapies for people living with ALS.

\$11M in the Last 5 Years

to accelerate development of, and access to new treatments for ALS.



47 MDA Care Centers from Coast to Coast

providing people with ALS access to top-tier medical experts, advanced treatments, and comprehensive multidisciplinary support services that have been shown to improve quality of life and increase life expectancy.¹



28 Active ALS Grants Awarded

to the world's best scientists investigating the cause of ALS and seeking potential drug therapies.



MOVIR

MDA's innovative data hub tracks patient outcomes over time, unlocking deeper understanding and more precise treatments for neuromuscular diseases.



MDA's Clinical & Scientific Conference

Bringing together the world's leading professionals in neuromuscular and genetic medicine to present their research, form new collaborations, and learn the latest developments in the field.



MedEd Program

provides information and education to clinicians and specialists to reduce delays in diagnosis and improve care for people living with ALS.

1. Hogden, A., Foley, G., Henderson, R. D., James, N., & Aoun, S. M. (2017). Amyotrophic lateral sclerosis: improving care with a multidisciplinary approach. *Journal of multidisciplinary healthcare*, 10, 205–215. <https://doi.org/10.2147/JMDH.S134992>

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