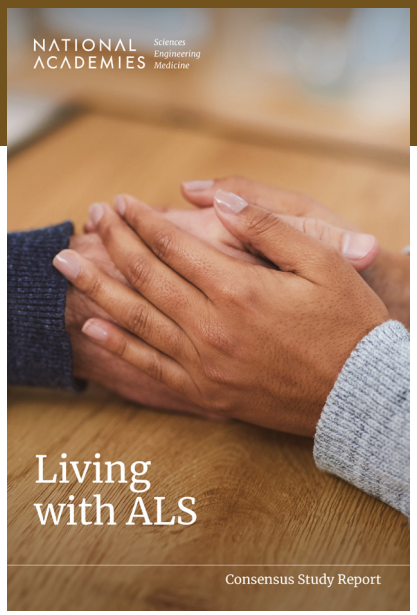
NATIONAL ACADEMIES Sciences Engineering Medicine

Living with ALS



Supporting People with ALS

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive, fatal neurological disease affecting individuals, caregivers, at-risk genetic carriers, and others. A 2024 National Academies report, *Living with ALS*, recommends key actions the public, private, and nonprofit sectors can take to make ALS a livable disease within a decade—actions that focus on accelerating scientific progress and getting people connected to specialty care.

WHEN WOULD ALS BE CONSIDERED "LIVABLE?"

"Livable" means an individual diagnosed with ALS or at genetic risk of developing ALS could survive, thrive, and live a long, meaningful life while navigating medical, psychosocial, and economic challenges of the disease. What is meaningful to a person with ALS will vary, and priorities and values may change over time. Making ALS livable has two important dimensions: (1) increasing effectiveness of treatments and ultimately finding a cure, and (2) increasing quality of life.

WHAT ARE THE MAIN CHALLENGES TO IMPROVING LIVABILITY?

Research into therapeutic and care advancements for ALS will likely take time, but accelerating these efforts is key to making ALS more livable. Additional areas for improvement include reducing diagnostic delay, increasing access to specialty care and research, removing insurance barriers, and reducing the high out-of-pocket costs faced by many people with ALS.

HOW CAN WE ADDRESS THESE ISSUES?

Living with ALS makes clear recommendations across several dimensions:

Care An integrated system of ALS care and research, modeled after similar "hub-and-spoke" systems for cancer and stroke, would fill gaps in access. While all centers would meet core care needs, "Hub" ALS centers would be expected to meet more complex care, diagnostic, imaging, and therapeutic services. Through consultations, second opinions, and telehealth, "spoke" clinics at the regional and community-based levels would be able to connect people with ALS to these services as necessary. Expanding this system with new multidisciplinary ALS clinics would increase access for more people living with ALS. Learn more in Chapter 4 of the report.

Payment Aligning Medicare and private insurance policies with the rapidly progressive nature of disease and the professionally-accepted standard of care would eliminate harmful delays in receiving treatment. Expanding Medicare eligibility for people with ALS, regardless of their employment history, age, or similar factors, would also help more people access already-existing evidence-based care. Learn more in Chapter 3 of the report.

Research The new system of care would be fully integrated with research. It would allow people with ALS to enroll in clinical trials and expanded access programs coordinated by "hub" centers to accelerate therapeutic and care advancements. Learn more in Chapters 4 and 5 of the report.

Learn more and access the full report at nationalacademies.org/Living-with-ALS.