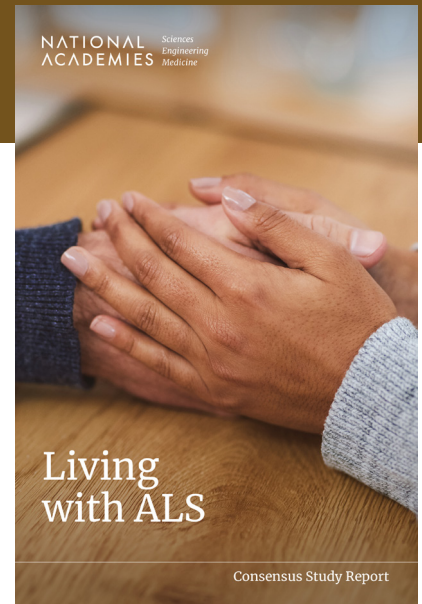


Living with ALS

Supporting At-Risk ALS Genetic Carriers

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 10 years—actions that focus on accelerating scientific progress and getting people connected to specialty care. The report also makes recommendation for improving quality of life, health, and well-being for at-risk ALS genetic carriers.



WHO IS AN AT-RISK ALS GENETIC CARRIER?

Approximately 10 to 15 percent of individuals with ALS have mutations in genes known to be associated with ALS cases; however, not every person with an ALS-associated gene will end up being diagnosed with ALS. Genetic carriers who have not yet developed ALS are a unique population of interest in many studies, especially those examining how to prevent ALS.

WHAT CHALLENGES DO AT-RISK ALS GENETIC CARRIERS FACE?

The report addresses challenges including:

- The high emotional cost of genetic testing
- Complex family relationships due to differing perspectives on genetic testing
- Navigating the medical system when many clinicians remain uneducated on how to refer confirmed at-risk individuals
- Legitimate fear that genetic status could be used to deny insurance, services, or employment

HOW COULD THE REPORT'S RECOMMENDATIONS IMPACT AT-RISK ALS GENETIC CARRIERS?

If implemented, the recommendations in this report could address key issues facing at-risk genetic carriers by establishing:

- A pathway for access to relevant resources and assistance in connecting to research studies
- Participation in a comprehensive ALS registry and larger data platform
- Increased access to genetic testing and counseling
- State-level prohibitions on genetic discrimination in life insurance, long-term care insurance, and disability insurance
- New research programs focused on unique, unmet needs

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