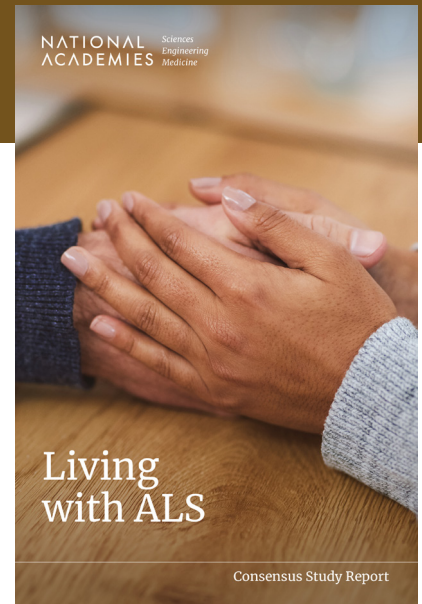


# Living with ALS

## Supporting Caregivers

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. The report also makes recommendation for improving quality of life, health, and wellbeing for caregivers.



### WHO IS A CAREGIVER?

*Caregivers* support people living with ALS in navigating the clinical care system as well as daily life. They assist with a variety of tasks, including:

- Activities of daily living, such as bathing, dressing, and using the bathroom
- Household management, including childcare and cleaning
- Developing and carrying out a care plan
- Navigating insurance
- Managing durable medical equipment

### WHAT CHALLENGES DO CAREGIVERS FACE?

- Long hours—can devote more than 100 hours per week to caregiving
- Psychological distress—burnout, depression, and anxiety
- Lack of support—no training and few available resources for navigating insurance, care plans, or durable medical equipment
- No respite care—professional, short-term care personnel could provide caregivers time away to focus on personal wellbeing and health

### HOW COULD THE REPORT'S RECOMMENDATIONS IMPACT CAREGIVERS?

If implemented, the recommendations in this report could address key issues facing caregivers by establishing:

- Insurance coverage for home health aides
- Direct financial support through tax credits, stipends, and HSA/FSA use
- Mental health resources
- Respite care
- Training for key equipment and care needs
- National advocacy priorities

Learn more and access the full report at [nationalacademies.org/Living-with-ALS](https://nationalacademies.org/Living-with-ALS).