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 recommendations 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.