

Living with ALS

Role of the U.S. Congress

Congress requested that the National Academies of Sciences, Engineering, and Medicine convene a committee of experts to recommend actions public, private, and nonprofit sectors should undertake to make amyotrophic lateral sclerosis (ALS) a livable disease within 10 years. This included considering pathways for developing more effective and meaningful treatments as well as a cure; identifying the type and range of care and services people with ALS and their families need; and ensuring equitable access to comprehensive care to improve quality of life.

The committee recognizes that Congress passed the Accelerating Access to Critical Therapies for ALS Act (ACT for ALS) in 2021, which created initiatives to support expanded access to investigational therapies and accelerated development of therapeutic interventions for ALS. ACT for ALS public-private partnerships hold enormous promise, and the committee believes realizing the full potential of current ACT for ALS initiatives is critical to achieving the goal of making ALS a livable disease in 10 years. The committee's report describes how an integrated and adequately funded ALS care and research system will be the foundation for introducing the new therapies these ACT for ALS initiatives are working to accelerate. Implementing the recommendations in this report would make ALS a more livable disease and will require strong federal support from all parts of government, including Congress.

Recommendations to Congress focus on (1) giving the Centers for Medicare & Medicaid Services (CMS) authority to allow people with ALS to receive needed services in the clinic and at home; (2) expanding the status of ALS as a qualifying condition for Medicare coverage; (3) reimbursing multidisciplinary ALS care to be commensurate with the services provided; (4) providing tax credits and other types of financial relief for caregivers; and (5) creating a network for ALS clinical care, research, and education at the U.S. Department of Veterans Affairs (VA).

RECOMMENDATIONS

The committee found that some services people with ALS need are not yet covered by Medicare because CMS lacks the authority to pay for concomitant services at home and as an outpatient. **Congress should grant CMS the authority to provide concomitant services at home and as an outpatient for progressive, neurodegenerative diseases such as ALS (see Recommendation 3-1 in the report).**

The committee found that even though Congress has recognized the exceptional nature of ALS and made important changes to eligibility requirements for federal programs to make it easier for people with ALS, not everyone with ALS is eligible for disability benefits and Medicare access. **Congress should take action to enable all persons with ALS to access and make full**

use of ALS care. Congress should act quickly to enable all persons with ALS to access timely, specialty ALS care by expanding the status of ALS as a qualifying condition for Medicare coverage, such that persons with ALS are eligible for Medicare coverage regardless of age, employment history, or other criteria influencing Medicare or Social Security Disability Insurance eligibility (see Recommendation 3-2 in the report).

Multidisciplinary care provides coordinated, team-based management across multiple specialties. Office visits can be lengthy and often involve several health professionals; however, such care is reimbursed at the same rate as a single specialist's 30- to 60-minute office visit. The committee found that multidisciplinary ALS clinics are strained, and many rely heavily on philanthropy or institutional resources, thus hindering clinics' ability to hire, retain, and expand staff. The committee concluded that the current funding structure for ALS clinics is unsustainable and exacerbates variations in resources across health care systems in the United States. **Congress should require reimbursement of multidisciplinary ALS care under a bundled payment method commensurate with the services provided (see Recommendation 3-2 in the report).**

The committee found that the fear of financial catastrophe can have a negative impact on quality of life for a person with ALS and their caregiver. The total cost of ALS care is higher than it is for other neurological diseases. Home modification needs and technologies and devices that make the disease more livable are often paid out of pocket. Significant financial burdens occur, even with health insurance. VA provides substantial

supports to caregivers for veterans with ALS, and the committee believes similar supports and financial resources should be available to all caregivers. **Congress should provide financial support for caregivers by amending the tax code to provide a tax credit that could be used by caregivers for individuals living with ALS, as well as all progressive neurodegenerative diseases, to alleviate the financial burden of providing unpaid care. Congress should also provide other types of financial relief for caregivers, including allowing them to apply health savings account or flexible saving account funds to caring for a parent or parent-in-law (see Recommendation 3-4 in the report).**

VA is known for strong, comprehensive rehabilitative programs for veterans with complex disabilities, many of which were established through congressionally directed funding. The VA ALS system of care is interdisciplinary, proactive, and patient-centered. Literature indicates an increased risk of ALS in persons with military service, but there has been no specific work within VA to further understand and propose means to mitigate this. Veterans receiving ALS care within VA clinics have limited access to clinical research. VA's ALS care system does not ensure equitable access across the country or address the projected shortage in the ALS health care and clinical research workforce. **Congress should allocate specific funding to create a VA network for ALS clinical care, research, education, and innovation to align with the new system of ALS care and research outlined in this report (see Recommendation 4-4 in the report).**

To access the full report and supporting materials, visit <https://nationalacademies.org/Living-with-ALS>.