

Living with ALS

Role of the Centers for Medicare & Medicaid Services

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.

In its report, the committee makes specific recommendations to the Centers for Medicare & Medicaid Services (CMS) in order to (1) facilitate expedited access to and coverage of essential ALS medical and support services; (2) enable access to respiratory devices and needed services; (3) address the needs of unpaid caregivers; and (4) build and sustain an inclusive and integrated ALS multidisciplinary care and research system.

RECOMMENDATIONS

The committee found that people with ALS can face challenges acquiring medically indicated equipment, technology, and therapeutics in addition to navigating an often convoluted system for obtaining prior authorizations. Challenges also exist around accessing high-quality, affordable home health services for

complex, evolving needs. As such, **the committee recommends CMS and private insurers should act quickly to enable expedited access to essential ALS medical and support services, including:**

- **Providing coverage for home-based and outpatient physical and other support services for persons with ALS as necessary, of the type and duration needed by persons with ALS, even if services are occurring concomitantly.**
- **Requiring expedited (within 72 hours) responses to prior authorization requests for all therapies, durable medical equipment, assistive technologies, and services for persons with ALS.**
- **Not denying services for persons with ALS based on failure to show functional improvement, given the progressive nature of the illness.**
- **Establishing a call center for persons living with ALS, and possibly other rare diseases, and their caregivers to report challenges in receiving care and services.**
- **Working with ALS organizations and persons living with ALS and their families to develop a “Know Your Rights” document that describes Medicare, Medicaid, and private insurance requirements and**

empowers individuals living with ALS to combat misinformation and improper denial of services (see Recommendation 3-1 in the report).

The committee also found that despite strong evidence that proactive respiratory management prolongs survival and improves quality of life, barriers remain to delivering optimal clinical respiratory care. As such, **the committee recommends CMS and private insurers should immediately align coverage of respiratory devices and services for persons with ALS with the current standard of care. CMS and private insurers should also develop reimbursement models that allow respiratory professionals to provide high-quality, longitudinal respiratory care in the home of a person with ALS (see Recommendation 3-5 in the report).**

The fear of financial catastrophe can have a negative impact on quality of life for a person with ALS and their caregivers. 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. The U.S. Department of Veterans Affairs (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. As such, **the committee recommends CMS and others should address the needs of unpaid caregivers, including respite care, reimbursement for caregiving, and mental and other health support services. CMS should ensure**

legally covered services for home health aides are accessible. CMS should also expand tests of payment and service delivery models, such as the Guiding an Improved Dementia Experience model for people with dementia and their caregivers, to include ALS, or create new programs specifically designed to support persons with ALS and their unpaid caregivers (see Recommendation 3-4 in the report).

There is notable variation in the quality and consistency of care across ALS clinics. A reimagined, inclusive, and integrated ALS care and research system, building on what already exists, is needed to ensure care quality, provide additional infrastructure to collect population health data, and coordinate care for individuals with ALS across care settings. As such, **the committee recommends that CMS partner with the National Institutes of Health (NIH), current ALS multidisciplinary care clinic leaders (e.g., VA, ALS Association, Muscular Dystrophy Association), and community-based providers to build a care and research system comprised of Community-Based ALS Centers, Regional ALS Centers, and Comprehensive ALS Care and Research Centers. CMS should also work with NIH and private insurers to ensure that reimbursement is aligned with the goals of the new care and research system (see Recommendations 4-1 and 4-3 in the report).**

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