

SUPPORT

THE ALS BETTER CARE ACT

(HR 5663/S.3258)



The Act will give people living with ALS desperately needed access to multidisciplinary care and clinical trials.

People living with ALS who receive multidisciplinary care live longer and have a higher quality of life.



AMYOTROPHIC LATERAL SCLEROSIS (ALS) (aka Lou Gehrig's disease) is a neurodegenerative condition affecting nerve cells that control voluntary muscular movement.

PEOPLE LIVING WITH ALS decline rapidly and require specialized care from multidisciplinary teams to address medical needs.

Medicare reimbursement does not adequately cover timely and effective care, hampering the ability of providers to research innovations to improve survival and quality of life, and reduce complications.

Adequately funded clinics could **lower preventable costs** and **long wait times**, **extend survival**, and simultaneously catalyze cutting-edge clinical research to **accelerate the path to a cure**.

CHALLENGES FACED BY ALS PROVIDERS



1

Most clinics face significant financial loss and compromise limited resources. People living with ALS may experience longer wait times; time is crucial due to the rapid nature of ALS and may also prevent people living with ALS from being evaluated for clinical trials.



2

Reimbursement is hampered by outcomes-based approaches that these interventions are not medically necessary because there is not yet a cure.



3

Multidisciplinary care is the gold standard and recognized as a Quality Care Measure defined by the Academy of Neurology. People living with ALS are seen approximately once every 2 to 3 months. These visits are shown to improve quality of life, enhance care provided at home by caregivers, and reduce preventable events (eg, falls).



4

People living with ALS require input from multiple specialties, including:

- Occupational and physical therapy
- Respiratory support, speech therapy, and communication device support
- Dietary and nutritional support
- Palliative care



5

People living with ALS may disproportionately experience poorer health outcomes due to underfunding; proper reimbursement of clinics promotes more equitable treatment and patient outcomes.

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Providing additional payment to ALS-related service providers will improve access to care for people living with ALS and could offer financial savings due to improved outcomes.

The ALS Better Care Act establishes a supplemental \$800 payment per visit to providers furnishing care to people living with ALS on Medicare beginning January 1, 2025.

This bill is endorsed by:

