ALS United

Together, We End ALS®

Support the ALS Better Care Act: Protect People Living with ALS by Increasing Access to Multidisciplinary Clinic Care

Overview

ALS People living with ALS rely on coordinated care from a full team—neurologists, therapists, respiratory and speech specialists, nutrition experts, and social workers—all in one visit. This team-based model helps people live longer and maintain quality of life. But Medicare doesn't adequately cover the true cost of this care, creating real challenges for patients and families, including:

The Problem: Medicare Doesn't Cover the True Cost of ALS Specialty Care

People living with ALS need coordinated care from an entire team, including neurologists, respiratory therapists, physical and occupational therapists, speech specialists, nutrition experts, and social workers, all in the same visit. This team-based approach is one of the few evidence-based ways to help people live longer and maintain quality of life. **But Medicare does not adequately pay for the full level of care ALS requires. That gap has real consequences for patients and families, leading to:**

- Fewer opportunities to get comprehensive care. People face reduced access to the full care team, longer wait times, and fewer available appointments.
- More stress and financial responsibility placed on families. When coordinated care isn't fully supported, caregivers are left to manage complicated medical needs on their own.
- Harder access to clinical trials and new treatments. Delays in specialty evaluation can mean missed chances to enroll in research at the moment it matters most

The Solution: A Targeted, Facility-Based Payment for Integrated Services

The ALS Better Care Act is designed to protect access to multidisciplinary ALS care by ensuring Medicare supports the full range of services families depend on. While the supplemental payment goes to clinics, the impact is directly felt by people living with ALS and their caregivers.

The bill would:

- Strengthen access to coordinated, team-based care in one visit. A flat $800 supplemental Medicare payment helps clinics maintain the staffing, time, and coordination required so families can continue to see the full ALS care team together.
- Protect families from higher out-of-pocket costs. The bill includes no additional cost-sharing for beneficiaries, meaning people with ALS can receive this specialized care without added financial burden.
- Help keep specialty care available as costs rise. Annual inflation updates ensure this support keeps pace over time, so patients don't lose access to comprehensive care as healthcare expenses increase.

This is a practical, targeted fix that ensures people living with ALS, and their families supporting them, can continue to receive timely, coordinated, expert care because with ALS, every month counts.

Please co-sponsor the ALS Better Care Act (H.R. 7336, S. 3763) to help advance this targeted, bi-partisan update.

ALS United is a nationwide partnership of independent nonprofit organizations dedicated to serving the ALS community. Guided by our vision "Together, We End ALS," we unite 15 member organizations across the country to create meaningful impact through research, care, and advocacy. Our collaborative network serves more than half of the U.S. ALS population with personalized, community-driven support. **Visit alsunited.org for more information.**