

Senators Coons, Murkowski introduce legislation to improve access to multidisciplinary care for ALS

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WASHINGTON – U.S. Senators Chris Coons (D-Del.), Co-Chair of the Senate ALS Caucus, and Lisa Murkowski (R-Alaska) introduced legislation this week to improve access to quality, interdisciplinary care for people living with amyotrophic lateral sclerosis (ALS). The ALS Better Care Act would establish a supplemental, facility-based payment in Medicare for ALS-related services and directs the Government Accountability Office (GAO) to study ALS-related care and develop a baseline for those payments.

ALS is a debilitating and fatal disease that affects 1 in 300 people – approximately 30,000 Americans. Specialized, multidisciplinary ALS care that addresses the complex needs that come with an ALS diagnosis – including occupational, respiratory, and physical therapists; mental health providers; neurologists; social workers; and nurses – has been shown to extend survival and improve patients' quality of life. Extending Medicare coverage for the critical healthcare services provided at multidisciplinary clinics will help improve access to coordinated and high-quality care.

"Improving access to multidisciplinary treatments for a disease that has caused so much anguish for countless Americans and their families is a priority for me as Co-Chair of the Senate ALS Caucus," **said Senator Coons**. "My hope is that by supporting quality, collaborative care that ALS patients need, we improve the quality of life for patients and their families."

"ALS is a ruthless disease that impacts individuals as well as their families, friends, and communities. By improving access to comprehensive care for people living with ALS, we can make a difference in the fight," **said Senator Murkowski**. "My friend and colleague Senator Chris Coons and I have worked together on several successful ALS efforts, and I'm proud to join him in leading the ALS Better Care Act. This bill will invest in research, improve the quality of care, and combat ALS while also improving the lives of those living with the disease."

"It is important that we ensure access to multidisciplinary clinics because they can be a valuable component of quality health care for individuals living with ALS," **said Andrea Goodman, CEO of I AM ALS**. "Unfortunately, too many people living with ALS lack access; some live hundreds of miles away from the nearest clinic. Our hope is that with stronger reimbursement through the ALS Better Care Act, we can strengthen and encourage the expansion of more clinics, thereby improving equitable access to quality care. We truly appreciate the consistent and valiant leadership of Senators Coons and Murkowski on behalf of the ALS community."

"The ALS Better Care Act meets an urgent need for ALS care teams and people living with this devastating disease," **said Laura Freveletti, CEO of the Les Turner ALS Foundation**. "ALS is a complex and demanding disease, but evidence has shown that multidisciplinary ALS care makes it possible for people with ALS to live longer and more fulfilling lives. This critical legislation will support doctors and clinics that provide innovative, high-quality ALS care, and it will help bring that care to people and families who desperately need it."

"Multidisciplinary care is one of the few evidence-based practices that extends and improves the lives of people living with ALS," **said Calaneet Balas, CEO of the ALS Association**. "More Americans living with ALS should be able to access this highest standard of care through our certified network of multidisciplinary ALS clinics across the country. We thank Senators Coons and Murkowski for their leadership on the ALS Better Care Act to address the care needs of people living with ALS, their loved ones, and their healthcare team."

The ALS Better Care Act would:

- Ensure multidisciplinary clinics can continue to provide the quality and collaborative care ALS patients need;
- Create a supplemental, facility-based payment to qualified facilities, while requiring those skilled facilities to provide care following a multidisciplinary standard established by the Secretary of Health and Human Services;
- Provide a starting quarterly \$800 payment per patient to reimburse qualified ALS providers or clinics, starting January 1, 2025; and
- Direct the GAO to conduct a study on ALS-related services ordinarily provided and the cost of those services. As a result, the GAO will be able to finetune the appropriate supplemental payment amount beginning in coverage year 2026.

The bill is supported by I AM ALS, the ALS Association, the ALS Hope Foundation, the Les Turner ALS Foundation, the American Academy of Neurology, and the Muscular Dystrophy Association.

This bipartisan bill is led in the House of Representatives by Congresswoman Jan Schakowsky (D-Ill.) and Congressman Brian Fitzpatrick (R-Pa.).

The full bill text is available [here](#).

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