

WEST VIRGINIA LEGISLATURE

2026 REGULAR SESSION

ENGROSSED

Committee Substitute

for

House Bill 5327

By Delegates Young and Worrell

[Originating in the Committee on Health and Human

Resources; Reported on February 26, 2026]

A BILL to amend the Code of West Virginia, 1931, as amended, by adding a new article, designated §16-14-1 and §16-14-2, relating to the creation of amyotrophic lateral sclerosis program, providing legislative findings; requiring Department of Human Services to perform program functions.

Be it enacted by the Legislature of West Virginia:

ARTICLE 14. WEST VIRGINIA ALS CARE SERVICES.

§16-14-1. Legislative findings.

(a) (1) The Legislature finds that individuals living with Amyotrophic Lateral Sclerosis (ALS) face significant financial and medical burdens, requiring targeted state support to improve their quality of life and to help them remain in their homes under family-based care.

(2) ALS clinics reduce the cost of care for Medicaid and other insurers by consolidating multidisciplinary services into a single location, thereby minimizing the need for repeated specialist visits and emergency room visits. By providing comprehensive, coordinated care, these clinics improve patient outcomes, reduce hospital admissions, and decrease reliance on costly long-term care facilities. Additionally, ALS clinics facilitate access to clinical trials and advanced treatment options, potentially slowing disease progression and reducing overall healthcare expenditures.

(3) As the disease progresses, the needs of individuals living with ALS increase, making it critical to keep patients in their homes with family-based care. Home-based care improves patient outcomes, enhances emotional well-being, and reduces overall healthcare costs by preventing unnecessary hospitalizations and delaying or eliminating the need for long-term institutional care. By supporting in-home caregiving solutions, the state can ensure that individuals with ALS receive compassionate, cost-effective care in a familiar environment.

§16-14-2. Establishment of ALS Care Services Program.

(a) The Department of Human Services shall administer the West Virginia ALS Care Services Program.

3 (b) The program shall provide for the following initiatives:

4 (1) Care Services Coordination and Support – Ensures that West Virginians living with ALS
5 and their caregivers receive disease education, specialized support navigating complex systems,
6 individualized resource linkage, and ongoing compassionate assistance. This initiative improves
7 well-being and safety while reducing the emotional and financial burdens of ALS and enhancing
8 overall quality of life.

9 (2) Assistive Technology, Medical Equipment, and Ramp Reutilization Loan Programs –
10 Provides access to expensive but essential equipment for individuals with ALS and their
11 caregivers. These loan programs significantly enhance safety, independence, and the ability to
12 remain in their home and community. By reducing the costs of care on state and federal programs
13 and promoting the reuse of ramping materials and equipment, this initiative also has a positive
14 environmental impact.

15 (3) Multidisciplinary ALS Clinics – Facilitates access to specialized multidisciplinary care
16 that adheres to the highest clinical care and treatment standards. Research has demonstrated that
17 multidisciplinary ALS clinic care extends life expectancy and improves quality of life. These clinics
18 provide comprehensive family support, reduce the burden of care by addressing multiple needs in
19 a single visit, and help lower healthcare costs for both individuals with ALS and state and federal
20 programs.