



May 4, 2025

The Honorable Senator Patricia Jehlen, Chair
The Honorable Representative Thomas Stanley, Chair
Joint Committee on Elder Affairs

Re: Support for H.762 An Act Relative to Home Care

Dear Chair Jehlen, Chair Stanley and Members of the Joint Committee on Elder Affairs,

I am writing on behalf of The ALS Association and the 431 patients and their families we serve in the Commonwealth, in support of H.762, which would expand the Massachusetts Home Care Program to include people living with ALS.

Amyotrophic lateral sclerosis (ALS) or “Lous Gehrig’s” is a fatal progressive neurodegenerative disease that slowly robs a person’s ability to walk, talk, eat, and eventually breathe, usually within 2-5 years of diagnosis. It is a devastating condition that can strike anyone at anytime and currently has no known cures. The cost of care for someone living with ALS is astronomical, with annual out-of-pocket expenses reaching as much as \$250,000 per year.

One issue that our families face that contributes to this crushing financial burden is access to affordable home care services. Due to the complex nature of ALS, home care services can be very expensive, and difficult to access depending on insurance, location, and specific needs of the person. Often, family members become primary caregivers, including spouses, adult children, and parents. In a survey conducted by the ALS Association, 68% of caregivers said they spent more than 30 hours per week providing care for their loved one, and almost half of caregivers felt unprepared for changes in responsibilities as ALS progresses. More than half of respondents cited worries about the future and lack of time to relax or engage in self-care, which can lead to depression, marital and familial strain, and caregiver burnout.

Access to home care alleviates the need for children to perform caregiving tasks, allows spouses to continue working and avoid losing two incomes, and prevent caregiver burnout and injury, which can lead to a dependency on neighbors, friends, and older family members. Additionally, home care allows people living with AL to remain in their homes longer and ensures that care is being safely performed by trained professionals.

Massachusetts currently has a home care program designed for people enrolled in Medicaid who are over 60 or have Alzheimer’s Disease. These services are offered through the State to qualifying individuals and are income-based. While most people living with ALS use Medicare as their primary insurance, many qualify through Medicaid due to the financial burden of the disease. ALS can strike anyone at any time, and many people are diagnosed under the age of 60.

The MA home care program has a carve out for people with Alzheimer’s Disease but currently leaves out people living with ALS who are under 60. The ALS Association currently serves 113 people living with ALS who are under 60. Of those, 40% are currently enrolled in Medicaid. This makes up approximately 13% of the total number of patients we serve who are without access to affordable home care services. **This legislation would allow anyone living with ALS, regardless of age, who are otherwise eligible for this program to access these services.** Making this small change to an already existing program would help meet the needs of the most vulnerable people living with ALS in the commonwealth.

By enacting this legislation, Massachusetts will demonstrate a commitment to serving the most vulnerable people living with ALS and their families in the Commonwealth. For all these reasons, we urge the committee to support H.762 and hope to see a favorable report.

Sincerely,
Danielle Spadafora
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The ALS Association
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