

Statement for the Record

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The ALS Association
For the
House Veterans Affairs Subcommittee on Disability Assistance and Memorial Affairs Hearing
Entitled
“Disability Assistance and memorial Affairs legislative Hearing on Pending Legislation”
October 24, 2023

The ALS Association would like to thank Chairperson Luttrell, Ranking Member Pappas, and the members of the Veterans Affairs Subcommittee on Disability Assistance and Memorial Affairs for the opportunity to submit this statement for the record for the hearing to review pending legislation in your subcommittee.

Amyotrophic Lateral Sclerosis (ALS) is an always fatal neurodegenerative disease in which a person's brain loses connection with the muscles. People with ALS lose their ability to walk, talk, eat and eventually breathe. There is no cure, and the average life expectancy following diagnosis is 2-5 years.

Military veterans, regardless of branch of service, regardless of the era in which they served, and regardless of whether they served during a time of peace or a time of war, are at a greater risk of dying from ALS than if they had not served in the military. For this reason, the Department of Veterans Affairs has labeled ALS as a service-connected disease and rates ALS at 100% disability upon diagnosis. This is because ALS never improves and, in all cases, leads to total body paralysis.

While high-quality, multi-disciplinary care for ALS is provided by the VA (Veterans Affairs), military veterans living with ALS require care that extends outside of the clinical setting. Veterans living with ALS rely on their spouses, children, parents, and friends to provide the round-the-clock caregiving they need. The aggressiveness of ALS leaves many veterans totally incapacitated and reliant on family caregivers. It is an incredible price that veterans living with ALS and their loved ones pay because of their service to our country.

Support for H.R. 3790 the Justice for ALS Veterans Act

The ALS Association wholeheartedly supports H.R. 3790, the *Justice for ALS Veterans Act*, to ensure families of veterans are supported after their loved one passes.

Families of veterans who die due to a service-connected disease that is totally disabling are eligible to receive boosted “Dependency and Indemnity Compensation” (DIC) payments from the VA after their loved one passes. To be eligible for this benefit, a veteran must live with a totally disabling service-connected disease for 8 years. However, with life expectancy for ALS post-diagnosis ranging from 2-5 years, most veterans who have service-connected ALS will not meet the current criterion for the additional DIC payment. This is a fixable injustice for veterans living with ALS who already have little time left with their loved ones.



OUR VISION: Create a world without ALS.

OUR MISSION: To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

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The Justice for ALS Veterans Act, sponsored by Representatives Fitzpatrick (R-PA) and Slotkin (D-MI) ensures fairness for veterans living with ALS by eliminating the 8-year survival criterion for veterans with ALS.

Families of veterans living with ALS who serve admirably as caregivers should not be penalized because of an ALS diagnosis that offers them less time with their loved ones than the current requirement stipulates. Ensuring this boosted benefit, which equates to little more than \$300 a month for a surviving family, can make a marked difference.

Additionally, H.R. 3790 requires the VA to study other totally disabling service-connected diseases where life expectancy is less than the current 8-year requirement, allowing for more families to receive the benefits they have earned.

Conclusion

H.R. 3790, the Justice for ALS Veterans Act, ensures that veterans and families who have made the ultimate sacrifice for this country receive benefits they cannot currently receive, through no fault of their own. Increased DIC payments gives peace of mind to current veterans living with ALS because they will know their families are supported after they are gone. Additionally, the increased DIC payments can help ease financial burdens for surviving family members after their loved one has passed.

The ALS Association endorses this legislation and asks the Veterans Affairs Subcommittee on Disability Assistance and Memorial Affairs to consider and swiftly pass H.R. 3790 to deliver the increased DIC benefits surviving families have earned.

Sincerely,



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