# Justice for ALS Veterans Act of 2025

## Summary

Current VA policy unintentionally excludes the spouses of Veterans living with ALS, despite the fact they cared for a Veteran who had a service-connected disability that was rated totally disabling. Their exclusion is because people typically only live for 2-5 years following their ALS diagnosis. The current policy states that the Veteran must have lived for 8 years with the disease in order for spouses to receive the additional DIC compensation. This leaves many surviving spouses who lost their loved one to a rapidly progressing neurodegenerative disease ineligible for the DIC kicker—the same spouses who may have left their jobs to take care of a loved one as they progressively lost muscle control, became paralyzed, and relied heavily on their caregiver to stay alive.

## Rationale

ALS is a military service-connected progressive nervous system disease that affects nerve cells in the brain and spinal cord, causing loss of muscle control. People living with ALS lose their ability to use their arms and legs, to speak, to eat and ALS ultimately will rob them of their ability to breathe. This loss of mobility and function means Veterans with ALS often rely upon their spouses for care. To serve as caregivers, many spouses must leave their jobs, leading to loss of wages. In addition, ALS is an extraordinarily expensive disease. According to a 2024 study, the annual cost for people with ALS increases significantly with disease progression from $31,411 in early-stage disease, to $51,481 in midstage disease, and $121,903 in late-stage disease. These two factors negatively impact the financial stability of military families.

Veterans are twice as likely to be diagnosed with ALS than civilians. A recent study revealed that among deployed-post-9/11 Veterans, the prevalence of ALS is 19.7 per 100,000 over 14 years. The prevalence of ALS in the U.S. is almost four times lower, at 5.2 per 100,000. More disturbingly, the prevalence is significantly higher for some Air Force personnel (pilots, aircraft crew, missile operators, and combat operation staff).

## Components

### + EXTENDS INCREASED DEPENDENCY AND INDEMNITY COMPENSATION

Paid to surviving spouses of Veterans who die from ALS, regardless of how long the Veterans lived with ALS.

## Contact to Support

Rep. Chris Pappas (D-NJ)
Rep.Brian K. Fitzpatrick (R-PA)

Sen. Chris Coons (D-Del.)
Sen. Lisa Murkowski (R-Alaska)

## About ALS

ALS is a disease that attacks cells in the body that control movement. It makes the brain stop talking to the muscles, causing increased paralysis over time. Ultimately, people living with ALS become prisoners within their own bodies: unable to eat, talk, breathe or move on their own. Their mind, however, often remains sharp so they are aware of what's happening to them. ALS will affect 1 in 300 people in our lifetimes, and people usually have no more than 2-5 years to live following diagnosis. Veterans are two-times more likely to be diagnosed with ALS than civilians.

## About I AM ALS

I AM ALS is leading the most impactful ALS advocacy movement of the 21st century. We've built this movement by working with the ALS community to harness their collective power to find treatments and a cure for this disease.

Our superpower is our people—those living with, impacted by, and highly motivated to end ALS. They're fueled by a track record of legislative successes and tangible impact:

- More federal funding for ALS research than ever, secured by the I AM ALS patient-led community
- More access to treatments and patient-vetted information, giving patients living with ALS hope for more years and a higher quality of life
- More ways to transform pain into action by facilitating advocacy opportunities, meaning the potential for real legislative impact and empowerment

I AM ALS