

H.R.542 & S.141: Elizabeth Dole Home Care

A bill to improve the quality and access to home health care.

Summary

Veterans are up to ten times more likely to be diagnosed with ALS than civilians. While we don't know why, there is enough evidence to prove that there is a link between military service and being diagnosed with ALS. In fact, the US government has designated ALS as a 100% military service-connected disease.

Veterans living with ALS will progressively need more and more assistance for this fatal disease. To get the caregiving they need, the VA's current policy forces Veterans into moving into nursing homes and other long-term care facilities. This separates Veterans from their families and loved ones and often leads to a lower quality of life & increased stress on the Veteran and their family and network of support.

To better address the medical needs of Veterans the Elizabeth Dole Home Care ACT would improve VA support systems and increase access to home and community based care services. Increased access to receiving caregiving at home would allow Veterans and their families and loved ones to stay together and be more involved in the Veterans' healthcare. It would also provide them with systems of support to ensure the Veteran can age at home, have a better quality of life and help provide support for their caregivers.

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, use their legs, to speak, to eat and ultimately ALS 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 quit their jobs. In addition, ALS is an extraordinarily expensive disease. These two factors negatively impact the financial stability of military families. Currently, the law provides surviving spouses the DIC kicker only when the veteran lives with a disability for eight years. Most people living with ALS live only 2-5 years after their diagnosis. The current policy does not assure eligibility for spouses of veterans with ALS.

While the cause of ALS is unknown, we know 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 returned veterans – this is more than 3.7 times the prevalence of ALS in the U.S. population over a similar time period. Shockingly, the prevalence is even higher for some Air Force personnel (pilots, aircraft crew, missile operators and combat operation staff). This is why the Department of Veterans Affairs rightly recognizes ALS as a presumptive service-connected disease

Bill Components

- Increases the expenditure cap for noninstitutional care alternative programs from 65 percent to 100 percent of nursing home care costs;
- Expands access to home and community-based alternative care programs to veterans at all VA medical facilities, as well as to veterans living in U.S. territories and Native veterans enrolled in IHS or tribal health programs;
- Requires the creation of a centralized website to disseminate information and resources related to home and community-based programs and help veterans and caregivers determine their eligibility;
- Requires VA to review staffing and resource needs, accessibility, and other aspects of the Office of Geriatrics and Extended Care and Caregiver Support Program Office to make certain they are appropriately serving veterans and caregivers;
- Creates a pilot program to provide home health aide services for veterans that reside in communities with a shortage of home health aides; and
- Requires VA to establish a warm handoff process for veterans and caregivers who are discharged from or ineligible for the Program of Comprehensive Assistance for Family Caregivers.

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 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 with ALS usually have no more than 2-5 years to live following diagnosis.

CONTACT TO SUPPORT

Rep. Julia Brownley (D-CA-26)
Sen. Jerry Moran (R-KS)
Sen. Jon Tester (D-MT)

Rep. Jack Bergman (R-MI-01)
Sen. Maggie Hassan (D-NH)