



The ALS Disability Insurance Access Act of 2019 (S. 578)

December 7, 2020

On December 2, 2020, the Senate [passed](#) the ALS Disability Insurance Access Act of 2019 (S. 578), which would amend the Social Security Act to eliminate the five-month waiting period for Social Security Disability Insurance (SSDI) benefits for disabled workers with amyotrophic lateral sclerosis (ALS). This Insight discusses the waiting period for SSDI and congressional action on S. 578.

SSDI

[SSDI](#) provides benefits to non-elderly disabled workers and their eligible dependents. To qualify, individuals must have worked for a sufficient period in Social Security–covered employment and be unable to perform substantial work due to any medically determinable physical or mental impairment that is expected to last for at least 12 months or result in death. Disabled workers are automatically entitled to Medicare after 24 months of entitlement to SSDI. In [October 2020](#), SSDI provided benefits to 8.2 million disabled workers and 1.5 million dependents.

Five-Month Waiting Period

Disabled workers must satisfy a [five-month waiting period](#) before they become entitled to cash benefits. The waiting period ends five full consecutive calendar months after a claimant’s disability onset date, which is the first day a claimant meets (1) the definition of *disability* under Title II of the Social Security Act and (2) all other entitlement requirements. For example, if a claimant’s onset date were April 11, the waiting period would begin on May 1 and would end on September 30. Under current law, there are no impairment-related exceptions to the five-month waiting period for disabled workers with certain medical conditions, even those considered terminal.

Rationale for the Waiting Period

Since SSDI was enacted in 1956, disabled workers have been required to serve a non-compensatory waiting period. [Originally](#), lawmakers required disabled workers to serve a six-month waiting period, which was the standard used by most private insurance companies. Lawmakers later reduced the

requirement to five months in 1972 to address concerns that the waiting period caused financial hardship for some low-wage workers.

Lawmakers required a waiting period primarily for three reasons. First, it was viewed as an administratively simple method for screening temporary impairments from long-term ones. Second, the forgoing of earnings and lack of benefits during the waiting period was viewed as reducing the attractiveness of SSDI, such that some marginally disabled workers who could otherwise work would be discouraged from applying for benefits. Third, it reduces cost to the program by (1) preventing the payment of benefits to claimants who medically improve or die during the waiting period and (2) reducing the number of months for which benefits are payable over the beneficiary's lifetime.

ALS and the SSDI Application Process

ALS, also known as Lou Gehrig's disease, is a progressive neuromuscular disease that attacks the nerve cells (neurons) in the brain and spinal cord responsible for controlling voluntary muscles. In 2015, about 16,600 people in the United States had ALS, and approximately 5,000-6,000 new cases occur each year. In December 2015, there were 5,666 disabled-worker beneficiaries with ALS in current-payment status. There is no known cure for ALS, and most patients with the disease die within two to five years of diagnosis.

Under its **Compassionate Allowances (CAL)** initiative, the Social Security Administration (SSA) expedites claims involving certain impairments that invariably meet SSDI's disability standard, including ALS. The average processing time for CAL claims is **39 days**, compared with **110-120 days** for all initial disability claims. However, this fast-track process has no effect on the five-month waiting period. Thus, upon receiving an award notice from SSA, most disabled workers with ALS must continue to wait the remainder of the five-month period before becoming entitled to SSDI.

SSDI beneficiaries with ALS are **exempt** from the 24-month waiting period for Medicare. Disabled workers with ALS are automatically entitled to Medicare beginning with the month in which they become entitled to SSDI (i.e., the month following the end of the five-month waiting period).

ALS Disability Insurance Access Act of 2019 (S. 578)

S. 578 would amend Title II of the Social Security Act to specify that an individual who meets the requirements for disabled-worker benefits and who is medically determined to have ALS shall be entitled to such benefits beginning with the first month during all of which the individual is under a disability. In effect, the bill would **eliminate** the five-month waiting period for disabled workers with ALS. The bill's provisions would be effective for applications filed after the date of enactment.

In 2018, SSA **estimated** that if the bill's provisions were effective beginning in 2019, SSDI benefit outlays would have increased by \$200.3 million through 2027. This estimate does not include additional costs stemming from the acceleration of Medicare entitlement for disabled workers with ALS.

Congressional Action on S. 578

Senator Sheldon Whitehouse introduced S. 578 on February 27, 2019. Representative Seth Moulton introduced a companion bill, H.R. 1407, on the same day.

On December 2, 2020, the Senate proceeded with consideration of S. 578. Senator Mitch McConnell **offered** an amendment on behalf of Senator Charles Grassley to increase the Social Security overpayment collection threshold from \$10 to 10% of benefits, which was a **proposal** in the FY2021 President's budget. Senator Grassley **noted** that the amendment was designed to offset the bill's cost as well as future costs

from similar waivers that lawmakers might later provide for other impairments. The amendment was defeated by a vote of 48-49. The Senate then passed S. 578 by a vote of 96-1.

Senator Tom Cotton [stated](#) that the bill would ensure that ALS patients “don’t have to worry about benefits and can focus instead on the things that really matter during what could be their final months on Earth.” Senator Whitehouse [noted](#) it “made no sense” to require ALS patients to wait five months for SSDI, a period during which “support makes the most difference in terms of the quality of life that remains.”

One Senator voted against the bill. In justifying his vote, Senator Mike Lee [stated](#) he supported eliminating the waiting period for ALS patients, but he believed the bill’s provisions should have been extended to individuals with other incurable and fatal diseases, some of which have lower average life expectancies than ALS.

The House is [scheduled to vote](#) on the bill on December 8, 2020.

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