

Social Security Disability and CF: An Overview

People living with cystic fibrosis may apply for Social Security Disability Insurance or Supplemental Security Income, federal programs that serve as a source of income and health insurance coverage for people who are unable to work due to their health status.

Some people with cystic fibrosis apply for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), which are federal programs that help people who are disabled and cannot work. The Social Security Administration (SSA) oversees both programs and determines medical eligibility for the programs. These two programs are distinct. SSDI is available to people who have a sufficient work history and the financial benefit people receive is based on their lifetime earnings. SSI is for those who do not have a sufficient work history or have a low income and assets. The SSA has an application and review process that determines if an individual qualifies for SSDI or SSI. On the SSA's website you can find the disability criteria for children and adults with CF that the SSA uses to determine if you qualify.

SSA requires you to submit an application that will include medical documentation before you can receive disability benefits. It is important to connect with your care team and social worker to discuss your plans for applying. Oftentimes, applicants find it helpful to work with an experienced attorney to help guide them through their application.

In addition to monthly income, you will receive health insurance coverage as part of your disability benefits. If you are eligible for SSDI, after two years of receiving monthly checks, you will receive Medicare insurance. If you are eligible for SSI, you will receive insurance through your state Medicaid program.

After you are approved for benefits, you will receive a disability award letter, which will include, among other information, when you will have your scheduled continued disability review. SSA periodically conducts a review of your benefits to make sure you still qualify for disability benefits. For people with CF this review period is usually every seven years. SSA will ask you questions about your condition and review your medical documentation to determine if your condition has improved. If your condition has not improved, you will continue to receive benefits. Your benefits will only stop if your medical condition has improved and you are able to work regularly.

CF Foundation Advocacy for People With CF Who Are Disabled

SSDI and SSI are critical programs for people with CF, and the CF Foundation advocates to ensure these programs work appropriately for people with CF. In 2013, in an effort to ensure that the proposed SSA criteria for eligibility did not unfairly block people with CF from qualifying for disability benefits, the Foundation submitted comments to SSA and sent a letter signed by 128 care center directors to the SSA on proposed legislation that adversely affected people with CF in obtaining and maintain their benefits.

In 2016, the SSA published updated eligibility requirements for disability benefits for people with respiratory diseases, including cystic fibrosis. The eligibility criteria were expanded and updated to better reflect the needs of people living with CF, and took into consideration updated FEV₁ criteria, a wider range of CF complications and expanded eligibility for those who receive lung transplants. Additionally, the eligibility rules allow for treatments for exacerbations wherever deemed most appropriate.

In 2020, the SSA proposed new rules regarding the frequency and notice of continuing disability reviews. The CF Foundation submitted a letter to the agency outlining concerns about the new rule, as well as joined the Consortium for Citizens with Disabilities in a letter urging Congress to eliminate SSDI waiting periods for all people with disabilities. The CF Foundation continues to monitor SSA policy and weigh in on the needs of people with CF.

For More Information

The application process can often be time-consuming and confusing and working with an experienced attorney may increase the chances of your application being approved. The CF Foundation funds the CF Legal Information Hotline[®], which has staff that can answer questions about topics such as SSDI and SSI. CF Legal Hotline also runs the Social Security Project[®] (SSP), which provides free assistance to help get and keep social security benefits.

Before submitting your application or review to SSA, call CF Foundation *Compass* at **844-COMPASS** (844-266-7277) Monday through Thursday, 9 a.m. until 7 p.m. ET and Friday, 9 a.m. until 3 p.m. ET, or email compass@cff.org. One of our case managers will connect you with the CF Legal Information Hotline[®] to see if you are eligible for free assistance.

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