



## *Government Assistance: Social Security, Medicare and Medicaid*

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The federal government offers financial assistance and health insurance to people with epilepsy who qualify. The two primary financial assistance programs are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). These programs are administered by the Social Security Administration (SSA). The two primary health insurance programs are Medicaid and Medicare. These programs are administered by the Centers for Medicare and Medicaid Services. States may also provide medical and financial assistance.

If you have worked in jobs covered by Social Security, you may be eligible for SSDI benefits; Medicare coverage is available 29 months after the onset date of disability, and additional benefits may be paid to your immediate family members.<sup>1</sup> Even if you have not worked outside of the home, you may be eligible for SSI benefits, if your income and resources are very limited; Medicaid eligibility begins immediately for SSI recipients. Many people receive benefits under both programs.

Benefits are also available if you are not married and your disability began prior to age 22 and continues until your parent is eligible for retirement or disability benefits, or until you are eligible for survivor's benefits. These Social Security Disability benefits are called Childhood Disability Benefits (formerly referred to as Disabled Adult Child's benefits or DAC) and can be used to support a disabled individual whose parents are no longer able to do so, even when that individual is no longer a child.

SSDI benefits are available to claimants who meet two conditions: (1) they are disabled and cannot work at any jobs, not just the jobs they held in the past; and (2) through their employment, they have

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## *Government Assistance: Social Security, Medicare and Medicaid*

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contributed enough FICA tax over the years to be covered. In general, workers who have worked at least five out of the ten years just before the disability began are covered; the rules are different for workers under age 30. Your wage history will determine your monthly benefit amount.

SSI benefits are available to disabled individuals whose income and resources are very limited. There is no work history requirement. Generally, to be eligible for SSI, an individual may have no more than \$2,000 in resources (\$3,000 for a couple) and income which is less than the SSI benefit amount. The benefit amount awarded per month for an individual and for a couple can be verified by the Social Security Administration. The benefit amounts change slightly each year. There are several items, such as a primary residence, car, and certain income that SSA will not count. Income and resources from a spouse or the parents of a minor child are deemed available to the claimant. If you are eligible for SSI, the amount of any other income you receive will reduce the amount of your SSI benefit. Claimants who are eligible for SSDI benefits but whose payment amount will be very low may also be eligible for SSI benefits.

Eligibility for disability benefits depends on the limitations you have as a result of both physical and mental impairments. Seizures, headaches, anxiety, and side effects of medication may make it impossible for you to work at a regular job. A history of seizures can preclude you from getting a driver's license, which may make getting to work impossible in some parts of the country. Coping with the effects of your condition, including limitations on working around machinery as well as the fear of when another seizure will occur, often creates a mental strain or depression which can affect your ability to function in the workplace.

SSA will evaluate your claim for disability by determining whether you have been, or expect to be, disabled for at least 12 months. First, SSA will ask whether or not you are currently working. If you are not



## *Government Assistance: Social Security, Medicare and Medicaid*

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working, and your impairment affects your ability to perform basic work related functions, SSA will then compare your condition to its criteria in the "Listings of Impairments."

A person with epilepsy who has convulsive seizures -- generalized tonic-clonic seizure (or grand mal), partial seizure with secondary generalization, or partial seizure with significant motor activity -- is considered to have a covered disability entitling them to benefits if he or she has more than one seizure per month and either experiences daytime episodes or suffers the residual effects of nocturnal seizures during the day. A person who has nonconvulsive seizures -- absence seizure (or petit mal), complex partial seizures (or psychomotor or temporal lobe), or partial seizures with functional impairment -- is considered to be covered if he or she has more than one seizure a week, and experiences "an alteration of awareness or loss of consciousness and transient postictal manifestations of unconventional behavior or significant interference with activity during the day." In addition, either type of seizures must be shown to persist for three months or longer after treatment begins and must be documented; an EEG is no longer required to document seizures.

If your condition meets any of these exact criteria, SSA will find that you are disabled. But meeting these criteria is not the only way to qualify for benefits.

Even if you do not have the exact test results required, SSA will continue to evaluate your claim by considering your vocational factors (age, educational background, and work history) along with your physical and mental residual functional capacities to decide whether you are disabled or whether there are jobs that you can do. Keep in mind that you can base your disability claim on a combination of several impairments that may not be disabling when considered separately, but when evaluated together show that you cannot work. SSA will rely both on tests and on observations from your doctor. Your doctor will be asked to submit



## *Government Assistance: Social Security, Medicare and Medicaid*

at least one detailed description of a typical seizure, and must indicate whether this description is based on his or her own observations or from another witness. If your doctor has not seen you experience a seizure, be sure to have a family member or friend provide a detailed description.

It is important that you continue to receive medical treatment because SSA will rely on the results of medical tests to determine whether you can be found disabled. According to SSA's Social Security Ruling 87-5, "An ongoing relationship with a treatment source is necessary. 'Treatment source' for purposes of application of this provision is a licensed physician, irrespective of specialty. To achieve good control of epilepsy, there must be close rapport between doctor and patient so that the doctor can 'tailor' anticonvulsant drugs to the patient's needs. There must be a constant treating source to whom the patient turns for advice and treatment, especially when seizure control wavers. It is not necessary that the claimant see the same physician on each visit, e.g.; regular visits to an outpatient clinic would be considered an 'ongoing relationship.'"

Compliance with medication is crucial, as an individual can only be found to be disabled "if the impairment persists despite the fact the individual is following prescribed anti-epileptic treatment." If you are not able to comply with your prescribed treatment, be sure to discuss alternatives with your doctor, and be sure that your doctor is able to explain to SSA why compliance is not possible. SSA will consider your serum drug levels, and will ask your doctor why your blood drug levels may be low. If there is no explanation, such as an individual idiosyncrasy in absorption or metabolism of the medication, SSA will presume that you are not complying with your prescribed treatment and will deny benefits for that reason. In addition, you may be able to show that other impairments, such as anxiety, headaches or cognitive problems caused by the side effects of medication can prevent you from working, even if your seizures are controlled by medication. SSA



## *Government Assistance: Social Security, Medicare and Medicaid*

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recognizes that the side effects of medication may cause additional impairments and will consider these additional impairments as part of the disability claim as well.

You can get the application forms from SSA by calling 1-800-772-1213. You can apply for SSDI and SSI benefits online at [www.socialsecurity.gov](http://www.socialsecurity.gov) or at any Social Security office. The office closest to you can be located on Social Security's webpage by scrolling down to the bottom and clicking on "Use your zip code to find our office." It is important to complete the form with as much information as possible. Give the full names and addresses of your doctors, and the dates of any hospitalizations and surgeries. Make a list of the medications you are taking, or other treatments you use and their side effects, and any medications and treatments you have tried but which no longer work for you. Include a description from your doctor or another person about your seizures. Describe your daily activities, including how long you can stand or walk, how often you must rest, and how your seizures affect your daily activities. It is often helpful to keep a log or diary to help you recall. Tell your doctors that you are applying for disability benefits, and ask for their help when SSA contacts them for more information on your medical condition.

If your application is initially denied there are several steps in the appeal process. Only about 30 percent of disability applications (for all types of disabilities) will be approved at the first step of the process. Many claimants who receive denials file appeals. Over half of the claimants who request a hearing before an administrative law judge will receive favorable decisions awarding benefits. For those who are turned down again, the next steps of the appeals process are the SSA Appeals Council, and, if necessary, federal court. If you live in Massachusetts, Connecticut, Rhode Island, New Hampshire, or Maine, the appeals process will be slightly different, but the information you must show to prove your disability is the same. The amount of time and effort it takes to pursue an appeal is definitely daunting. Perseverance and persistence are crucially



## *Government Assistance: Social Security, Medicare and Medicaid*

important. It is not uncommon for a claimant to wait 6 - 12 months for a decision on an application for disability benefits. Claims which must be appealed administratively (to an administrative law judge and the Appeals Council) or to federal court will take much longer. To give you some perspective on the program, consider that almost three million applications for disability benefits were filed in 2005. When a case is finally approved, benefits will be paid to cover the months you were waiting for a decision.

Medicare is a health insurance program for people aged 65 and older, and for people under age 65 who are disabled and have received, or were eligible to receive SSDI or Railroad Disability benefits for two consecutive years. This program covers hospital-related expenses, such as inpatient care, at no cost to the beneficiary. As of January 1, 2006, Medicare also provides prescription drug coverage benefits (see [www.epilepsy.com](http://www.epilepsy.com) for more information on this issue). Additional insurance coverage for medical services such as doctor's visits is also available for a premium. For those who have limited income and assets, the state may pay your premium.

Medicaid is a benefit program that provides healthcare services to people with low incomes. Depending on the state, Medicaid is either free or requires a co-pay of \$1.00 to \$5.00 for services. It is available for many recipients of SSI and SSDI, and others who may not qualify for SSI, but whose medical expenses exceed a certain level, as established by each state. In many, but not all, states, SSI recipients automatically qualify for Medicaid. Each state also offers a children's health insurance program that provides health insurance to children (SCHIP), and in some states, pregnant women, at little or no cost depending upon the income level of the household in which the child lives. To learn more about the children's health insurance program in your state, call 1-877-543-7669, or visit the Social Security Administration's Kids webpage: <http://www.socialsecurity.gov/people/kids/>.



## *Government Assistance: Social Security, Medicare and Medicaid*

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Before January 1, 2006, Medicaid paid for the prescription coverage of eligible beneficiaries. Today, Medicaid beneficiaries will have their prescriptions filled under the Medicare Part D Prescription Drug Benefit. These individuals are classified as “dual eligibles” (eligible under both Medicaid and Medicare).

Generally, recipients of financial assistance and health benefits can continue to receive benefits for a limited time even after they return to work. Many SSDI recipients can receive their full benefits for as long as one year while they “test” their ability to be gainfully employed. SSI recipients may continue to receive benefits as long as their monthly income does not exceed the minimum income allowed. In determining how much assistance a person will receive under SSDI or SSI, the SSA excludes from your gross income work-related expenses related to your impairment such as work-related equipment and assistants. Recipients of SSDI and SSI who return to work also may be eligible for free rehabilitation services, job training and educational programs. SSDI recipients can continue to receive Medicare benefits for up to 93 months after returning to work, while those SSI and SSDI recipients who are eligible for Medicaid can continue to receive benefits as long as their monthly income falls below the maximum allowed to be eligible for SSI and the recipient needs Medicaid in order to work.

To apply for SSDI or SSI, visit your local Social Security office or call the SSA at 1-800-772-1213 to make an appointment. While recipients of SSDI and SSI may automatically be enrolled in Medicare or Medicaid, you should contact your local Department of Health or the Social Security agency to learn whether you need to apply.

An individual who feels he or she has been unfairly denied benefits may appeal this decision and subsequent denials as well. While not true in all cases, many persons are more successful on appeal than during the initial application stage. If you plan to appeal, we suggest that you consult a local attorney.



## *Government Assistance: Social Security, Medicare and Medicaid*

For more information about SSDI or SSI, call the SSA at 1-800-772-1213 or see the SSA's website (<http://www.ssa.gov>). For more information about Medicaid and Medicare, see the Centers for Medicare and Medicaid Services' website (<http://www.cms.hhs.gov>).

For information on obtaining a referral to an attorney in your area that may be able to provide specific advice or representation concerning an appeal of a denial of Social Security benefits, please visit the website for the Jeanne A. Carpenter Epilepsy Legal Defense Fund, at <https://www.epilepsy.com/get-help/legal-issues>, or call our Epilepsy and Seizures Helpline toll free at 1-800-EFA-1000 (1-800-332-1000).

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