



## **A Professional's Guide to Assisting Persons with ALS and Their Families with Obtaining Government Benefits What Benefits are Available to the Disabled through Social Security?**

### **Social Security Disability Insurance (SSDI)**

Social Security Disability Insurance (SSDI) provides monthly cash benefits and Medicare entitlement to those blind or disabled individuals who have paid sufficient FICA and Medicare taxes on their earnings to meet certain insured status requirements. Spouses and children of SSDI recipients may also be eligible for cash benefits.

According to the Social Security Act, the definition of disability is the “inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months.”

### **Supplemental Security Income (SSI)**

Supplemental Security Income (SSI) provides cash to meet basic needs for food, clothing and shelter to those age 65 and over, blind, or disabled who have little or no income. Individuals and their children may be eligible for SSI even if they have never worked or have an insufficient insured status for SSDI.

SSI is a Federal income supplement program funded by general tax revenues, *not* Social Security taxes. Each individual who applies for SSDI is also screened for SSI benefits. SSI payments may be available during the usual 5-month waiting period before SSDI cash benefits begin. Those eligible for SSI may also be automatically eligible for Medicaid benefits.

*Note:* SSA can make a determination of “**presumptive disability**” for SSI benefits. This provision allows SSA to pay up to 6 months of SSI payments before they make their disability determination, based on the finding that there is a high probability that the applicant is disabled. Therefore, persons with ALS, especially those with significant bulbar signs or gross disturbance of gait, should inquire about this provision at the time of application. (SSA does not provide for presumptive payments to individuals applying for SSDI benefits.)

### **Medicaid**

Medicaid provides health insurance for *low-income and needy parties*. It covers children, the aged, blind and/or disabled individuals. Medicaid is jointly funded by the Federal and State governments.

Certain states may have different Medicaid programs available for those who are not as financially needy, such as programs designed for catastrophic or high monthly out of pocket costs. A person who has *any* financial hardship should contact their State's Medicaid program for information. For contact information for a specific state, you can go [www.aphsa.org/links/statecontacts.asp](http://www.aphsa.org/links/statecontacts.asp).

### **Medicare Waiver**

Due to the tireless lobbying efforts of The ALS Association, other groups, and individuals with ALS and their families, Congress passed landmark legislation in July, 2001 benefiting the ALS Community. The





usual 24-month waiting period for Medicare was eliminated for SSDI recipients disabled by ALS. Medicare entitlement now begins the first month the recipient receives cash benefits (approximately 5 months after an individual is deemed disabled!)

## Medicare Benefits

### What is Medicare?

Medicare is a federal health insurance program administered by the Centers for Medicare and Medicaid Services (CMS.) Medicare is available to the following groups of individuals:

- Persons age 65 and older and their spouses
- Persons eligible for SSDI (and some disabled civil service workers *not* eligible for SSDI due to not having paid FICA taxes.) *Incidentally, individuals with end stage renal disease may also be eligible for Medicare.*

### *Medicare has two parts:*

#### **Part A (Hospital Insurance)**

*Helps pay for:* Care in hospitals as an inpatient, skilled nursing facilities, hospice care and some home health care. *This coverage is free to SSDI recipients.*

#### **Part B (Medical Insurance)**

*Helps pay for:* Doctors' services, outpatient hospital care, and some other medical services that Part A does not cover, such as physical and occupational therapy, and some home health care. Part B helps pay for these services and supplies when they are medically necessary. There is a monthly premium for this coverage. If an individual is also a Medicaid recipient, their monthly premium for Medicare may be paid by their Medicaid benefits.

*Due to the fact that Medicare coverage is subject to change, please refer to the official Medicare website for the most up-to date information at <http://www.medicare.gov/Coverage/Home.asp>, or call 1-800-MEDICARE.*

### **Should a Person Apply for Social Security Disability Insurance/Supplemental Security Income Benefits?**

Anyone under age 65, who feels unable to work due to disability, should investigate possible SSDI and SSI entitlement benefits. *Individuals under 65 receiving regular Social Security Retirement benefits may be entitled to higher monthly benefits and Medicare under SSDI if they subsequently become disabled.*

For financial planning purposes, it is important to remember that ***there is a 5-month waiting period for cash benefits to begin under SSDI.*** Therefore, it is possible that an individual who stops working may be without any income for approximately 5 months. The waiting period begins the first full month following the month that Social Security determines an individual is not engaging in substantial gainful activity. When an individual applies for SSDI, they are automatically screened for Supplemental Security Benefits (SSI), which *can* assist during the waiting period for SSDI.

## Other Considerations



The ALS Association, 27001 Agoura Road, Suite 150, Calabasas Hills, CA 91301-5104,  
Phone: (800) 782-4747 / [alsinfo@alsa-national.org](mailto:alsinfo@alsa-national.org) / [www.alsa.org](http://www.alsa.org)



There are usually a number of additional **Social Security-related questions** that people with chronic illnesses face, such as questions about the Consolidated Omnibus Budget Reconciliation Act (COBRA) benefits, the Health Insurance Portability and Accountability Act (HIPAA), and state high risk insurance pools. Fortunately, The Advocating for Chronic Conditions, Entitlements and Social Services (A.C.C.E.S.S.) Program provides free Social Security representation to the ALS community, as well as helpful planning and referral services. Feel free to contact them at 888-700-7010.

It is very important that individuals examine **how their newly elected Medicare benefits will affect their current insurance plan**. Your State Health Insurance Counseling Program (SHIP) has expert volunteers who can assist individuals free of charge. To locate your area SHIP agency, call 1-800- 677-1116 (Eldercare Locator) or go to [www.medicare.gov/Contacts/Related/Ships.asp](http://www.medicare.gov/Contacts/Related/Ships.asp).

### **How Does Someone Apply for Social Security Disability Programs?**

- Individuals can apply for Social Security benefits by telephone or in person. To apply via telephone, one can call toll free at 1-800-772-1213, Monday-Friday, 7am-7pm Eastern Time. To apply in person, an individual may go to their local Social Security Administration (SSA) office to schedule an appointment. To obtain information regarding the SSA office nearest you, go to the Social Security's website at [www.ssa.gov](http://www.ssa.gov). *For assistance with making an application to Social Security, an individual may also contact the A.C.C.E.S.S. program at 1-888-700-7010.*
- The representative will ask for the applicant's social security number, name and address. Additional information the applicant will eventually need to provide to SSA includes, but is not limited to:
  - Birth certificate
  - Names and addresses of hospitals & physicians
  - Medications
  - Marriage information
  - Dependent children's names, addresses and social security numbers
  - Employers over the last 15 years
  - Income

**Note:** SSA has an expedited procedure for processing terminal illness cases to ensure that a favorable decision can be made expeditiously. The code word for this type of case is "TERI" case. A person with ALS (particularly if advanced symptoms are present) may want to advise SSA, at the time of application, that TERI case procedures are appropriate.

Once SSA collects the information, the decision about disability will be made by a designated state agency called a Disability Determination Service (DDS.) The applicant may receive correspondence from both SSA and the DDS. The formal decision will be provided to the applicant by mail. Initial claims decisions typically take 3 to 4 months. However, shorter or longer processing times are possible. ***One of the best things applicants can do to shorten processing time is to supply full medical records at the time of filing, or alerting treating physicians to reply expeditiously to any requests for medical records from the DDS.***

### **What If An Applicant Is Denied Social Security Benefits?**



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Individuals might be denied SSDI benefits for a number of reasons including:

- Not enough time worked and paid into Social Security
- Not a U.S. citizen
- Not considered disabled
- Failure to cooperate with SSA

A person who is denied benefits from Social Security has appeal rights with strict time limitations.

**Please consider referring to the A.C.C.E.S.S. program at 888-700-7010 for free representation or advice.**

You may also contact The ALS Association's Advocacy Department for potential congressional support at 877-444-ALSA (2572), or [steve@alsa-national.org](mailto:steve@alsa-national.org).

**Additional Resources:**

Social Security Administration:	1-800-772-1213; <a href="http://www.ssa.gov">www.ssa.gov</a>
Medicare Information Line:	1-800-MEDICARE (1-800-633-4227); <a href="http://www.medicare.gov">www.medicare.gov</a>
Medicare Rights Center:	1-800-333-4114; <a href="http://www.medicarerights.org">www.medicarerights.org</a>
Center for Medicare Advocacy:	1-800-846-7444; <a href="http://www.patientadvocacy.org">www.patientadvocacy.org</a>

Please feel free to contact The ALS Association's Patient Services Department with questions on our toll-free Patient Hotline at 800/782-4747, or 818/880-9007. You may also email us at [alsainfo@national.org](mailto:alsainfo@national.org).



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