



**Together** to End Stroke™

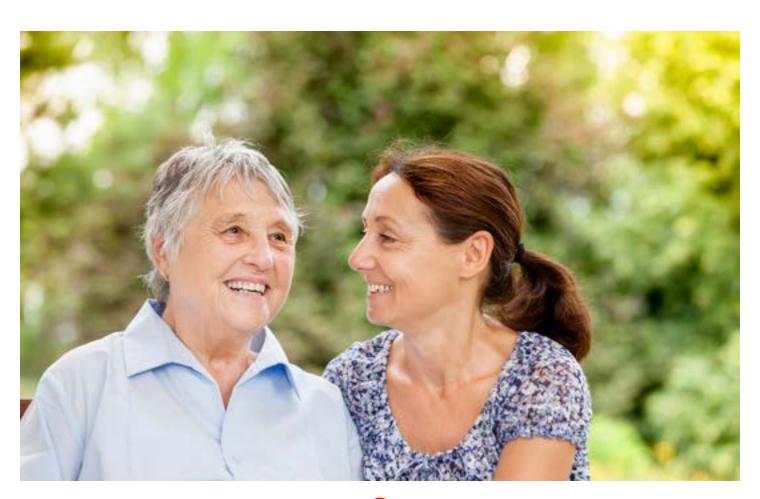
# AFTER STROKE GUIDE

The American Stroke Association's Finances After Stroke Guide provides information and resources that can help you immediately after a stroke.

You probably already know that the financial impact of stroke can be overwhelming and unpredictable. The lifetime cost of ischemic stroke has been estimated at \$140,048¹. This includes inpatient care, rehabilitation and follow-up care necessary for lasting deficits. Because the financial impact of stroke can be significant, this guide is meant to help you get started.

This Finances After Stroke Guide highlights four core areas that may assist you during your stroke recovery:

- Social Security Administration Benefits
  - » Social Security Disability Insurance
  - » Supplemental Security Income
  - » Ticket to Work Program and Other Assistance Programs
- Patient Advocate Foundation: Get Help Navigating the Healthcare Maze
- Managing the Cost of Prescription Drugs
- Getting the Most Therapy Coverage



## Getting Started: About the Social Security Administration Benefits

The Social Security Administration (SSA) pays diability benefits to people with disabilities through two programs: (i) the Social Security Disability Insurance (SSDI) program and (ii) the Supplemental Security Income (SSI) program.

To qualify as "disabled" under these programs, you must be unable to work because of a medical condition that is expected to last at least 12 months (one year) or result in death. Partial disability or short-term disability do not qualify. However, most stroke survivors will meet this strict definition of disability and thus be eligible for benefits.

You may be eligible to receive benefits under both the SSDI and SSI programs.

Website: Information, applications and other publications are

#### **Social Security Administration Resources**

- available online at www.socialsecurity.gov.

  Phone: Contact SSA toll-free at 1-800-772-1213 between 7 a.m. and
- 7 p.m., Monday through Friday. Generally, you'll have a shorter wait time if you call during the week after Tuesday. SSA also provides information by automated phone service 24 hours a day.
- » Visit a local SSA Office: Find your local SSA office by going to the Office Locator at www.socialsecurity.gov/locator and entering your ZIP code.
- Mailing address:
   Social Security Administration
   Office of Public Inquiries
   6401 Security Blvd.
   Baltimore, MD 21235-6401



## Social Security Administration Benefits

#### **Social Security Disability Insurance**

Social Security Disability Insurance (SSDI) provides disability benefits to you and certain members of your family if you have a disability and are "insured" by workers contributions to the Social Security trust fund based on your earnings. In general, to be eligible for SSDI benefits, you must meet two different earnings tests:

- » A "recent work" test based on your age at the time you became disabled; and
- » A "duration of work" test to show that you worked long enough under Social Security.



#### Finance Tip:

Apply for SSDI benefits as soon as possible after your stroke because it may take as long as three to five months for SSA to process your application.



disability

Apply for SSDI benefits as soon as possible after your stroke because it may take as long as three to five months for SSA to process your application. You must be disabled for at least five full months before your payments can begin.

SSA will review your application to make sure that you meet some basic requirements. If you meet these requirements, SSA will forward your case to your state Disability Determination Services office, comprised of doctors and disability specialists. The state agency will review the facts of your case and make the final disability decision. They may ask your doctors for information about your condition, including information about your ability to do work-related activities, such as walking, sitting, lifting, carrying and remembering instructions. They may also require you to take a physical examination. SSA will pay for the exam and for some of the related travel costs.

If it is determined that you are eligible for SSDI, you will receive a notice explaining how much your monthly SSDI payments will be and when your payments will start. Payments usually start in your sixth month of disability. SSDI payments are based on your average lifetime earnings; each January, your benefits will increase automatically if the cost of living has gone up.

Certain members of your family, such as your spouse or minor children, may also qualify for benefits based on your work.

Generally, your SSDI benefits will continue as long as your medical condition has not improved and you cannot work, although benefits will not necessarily continue indefinitely. SSA will review your case periodically to make sure you are still disabled. How often your medical condition is reviewed depends on how severe it is and the likelihood it will improve. Your notice of eligibility for benefits will tell you when you can expect your first review.

After you start receiving SSDI benefits, you may want to try working again. There are special rules called "work incentives" that can help you keep your cash benefits and Medicare while you test your ability to work. You are eligible for a trial work period while you are still disabled and can continue to receive benefits for up to nine months.

Your monthly SSDI benefit payments may be reduced if you also receive other government benefits such as Workers' Compensation or disability benefits from certain federal, state or local government programs.

After you receive SSDI for 24 months (two years), you are eligible for Medicare .

You may apply for SSDI benefits either by:

- Applying online at www.socialsecurity.gov or
- 2 Calling SSA toll-free, 1-800-772-1213, and making an appointment to file a disability claim at your local SSA office.

When you schedule an appointment, SSA will send you a Disability Starter Kit to help you prepare for your disability claims interview (available online at www.socialsecurity.gov/disability). SSA may be able to process your application faster if you provide the following information with your application:



Your birth certificate;

Names, addresses and phone numbers of the doctors, caseworkers, hospitals and clinics that took care of you, and dates of your visits;

Names and dosage of all the medicine you take;

Medical records from your doctors, therapists, hospitals, clinics and caseworkers that you already have in your possession;

Laboratory and test results;

A summary of where you worked and the kind of work you did; and

A copy of your most recent W-2 Form (Wage and Tax Statement) or, if you are self-employed, your federal tax return for the past year.

Even if you cannot get all of this information together right away, apply for benefits anyway. You can compile the information during the application process.

If you disagree with any decision that is made, you have the right to appeal the decision within 60 days. You may choose to have an attorney or anyone else represent you in the appeal.

#### **Supplemental Security Income**

The Supplemental Security Income (SSI) program makes monthly payments to people with limited income and resources who are 65 or older, blind, or disabled.

Unlike SSDI, which is based on your earnings, the basic SSI amount is the same nationwide. Whether you can get SSI depends on your income (wages, Social Security benefits and pensions, food, shelter, etc.) and resources (real estate, bank accounts, cash, stocks, bonds, etc.). This depends partly on where you live. In addition, many states will add money to this basic benefit. Payments begin immediately upon approval for SSI benefits.

If you are eligible for SSI, you are also eligible for Medicaid, which helps you pay doctor and hospital bills. Your state or local welfare office or Medicaid agency will decide if you qualify. Medicaid benefits vary from state to state.



#### Finance Tip:

If you are eligible for SSI, you are also eligible for Medicaid, which helps you pay doctor and hospital bills. Your state or local welfare office or Medicaid agency will decide if you qualify. Medicaid benefits vary from state to state.

If you work, there are special rules to help you. You may be able to keep getting SSI payments while you work. As you earn more money, your SSI payments may be reduced or stopped, but you may be able to keep your Medicaid coverage. You also may be able to set aside some money for a work goal or to go to school. In this case, the money you set aside will not reduce the amount of your SSI. You may also get free special services to help you returning to work, including counseling, job training and help in finding work.

To apply for SSI, you can complete a large part of your application online at www.socialsecurity.gov. To schedule an appointment with a local SSA office, call toll-free at 1-800-772-1213.

Some of the information you will need to provide when applying for SSI includes:

- Your Social Security card or a record of your Social Security number;
- Your birth certificate or other proof of your age;
- Information about the home where you live, such as your mortgage or your lease and the landlord's name;
- Payroll slips, bank books, insurance policies, and other information about your income and the things you own;
- The names, addresses and telephone numbers of doctors, hospitals and clinics that you have been to;
- Proof of U.S. citizenship or eligible noncitizen status; and
- Your checkbook or other papers that show your bank, credit union or savings and loan account number.

#### **Ticket to Work Program and Other Assistance Programs**

Both SSDI and SSI beneficiaries are eligible to participate in the Ticket to Work program. SSA will send you a Ticket, which you can use to obtain training and other services to help you return to work at no cost to you.

In addition to these federal programs, check with your state and local governments for other assistance programs. In some states, stroke families may qualify for tax exemptions for personal property and real estate. A hospital social worker or your state's social services office is a good place to start your search for such programs.

# Patient Advocate Foundation: Get Help Navigating the Healthcare Maze

Navigating the healthcare system can be overwhelming, especially for stroke families, who often have ongoing needs. The Patient Advocate Foundation (PAF), which provides services for patients in all 50 states, can:

- » Negotiate with hospitals for the uninsured.
- » Intervene with insurance companies for the insured.
- » Work with rehabilitation organizations to get stroke survivors more services.
- » Make co-payments for those who can't.
- » Negotiate with banks to help you pay your mortgage.

The PAF website is full of downloadable information on many subjects pertinent to stroke families. They have an online chat where you can ask questions and get answers the same day. There are also videos on YouTube. And it's all FREE.

Patient Advocate Foundation patientadvocate.org 1-800-532-5274 help@patientadvocate.org





# Managing the Cost of Prescription Drugs

Most stroke survivors leave the hospital with several prescriptions. Cost of these can be a significant blow to any budget. Below are some resources that may help. Typically, these types of programs require:

- » Doctor's consent
- » Proof of your financial status
- » Proof that you are uninsured or have no drug benefit coverage.

# Find out if you're eligible for a Pharmacy Assistance Program (PAP)

Most pharmaceutical companies offer prescription assistance programs for patients. The programs provide free or low-cost drugs to uninsured people who can't afford their medication. Most brand name drugs are included in the programs.

- The Partnership for Prescription Assistance (PPA) is a clearinghouse for more than 475 public and private assistance programs, including nearly 200 offered by pharmaceutical companies. The programs help qualifying patients without prescription drug coverage get the medicines they need. The PPA website is a portal through which you can enroll in programs that allow you to get your medications free or nearly free. For more information, call 1-888-477-2669 or visit pparx.org.
- » The RX Assist website (http://rxassist.org) has a directory of assistance programs. You can also get a drug discount card that provides 10 40 percent savings for many generic and brand name medications. They also list programs that help with medication co-pays and those that provide free and low-cost healthcare and information for Medicare Part D beneficiaries.
- » The Needy Meds website (http://www.needymeds.org) has a searchable list of diagnosis-based assistance programs with a description and contact information. They also have a list of statesponsored programs and offer a prescription drug discount card and generic drugs. Their Helpline is 1-800-503-6897.

#### **Other Ways to Cut Costs**

- Talk to your doctor. Before switching to generic drugs or less expensive brand name prescription drugs, discuss your concerns about costs with your doctor. Your doctor may be able to give you free samples of medications until you can enroll in an assistance program.
- » Compare costs at your local pharmacies. Many pharmacies list their prices for commonly prescribed drugs online, or you can call local pharmacies to request prices for your medications.





#### **Medicare Part D**

Medicare prescription drug coverage, commonly called Part D, covers brand name and generic prescription drugs at participating pharmacies in your area. Everyone enrolled in Medicare is eligible, regardless of income, health status or current prescription expenses.

Extra Help: This program helps eligible Medicare recipients pay for some or most of their prescription drugs. The level of assistance depend on your situation; for instance, if you're enrolled in Medicare or Medicaid or receive SSI, the program offers a discount card.

You can't use a discount card and Part D coverage at the same time. If you're enrolled in Part D, it's better to use your discount card only during your plan's deductible and coverage gap periods ("doughnut hole"). Your co-pays count toward Part D's out-of-pocket limit (\$4,550 in 2014). But any drugs received through Patient Assistance Programs don't count toward your out-of-pocket costs. For more information, go to http://www.medicare.gov/part-d.

#### **Safety Net Providers**

Pharmacies in some government-funded hospitals and community health clinics provide medication at low cost and charge you based on your income. Some of these pharmacies waive co-pays for Part D drugs if you ask for assistance.

#### **State Pharmaceutical Assistance Programs**

Some states have PAPs to help pay for prescriptions. Many of these programs coordinate with Medicare Part D regarding co-pays and out-of-pocket costs. To see a list of programs in your state, go to Medicare. gov and type "State Pharmaceutical Assistance Programs" in the search window.





### Getting the Most Therapy Coverage

Finance Tip:

Ask your therapist for a home plan. A home therapy plan often helps maximize your results and therapy. Stroke survivors can almost always benefit from more therapy (physical, speech, occupational), but most insurers limit the amount of therapy coverage. Getting more therapy is not as simple as asking nicely. You must understand your insurance benefits and discuss them knowledgeably with your insurer, their Utilization Review Nurse (URN) and your rehab provider.

#### **Maximizing Your Rehab and Recovery**

Since rehabilitation coverage is limited, make sure you maximize your therapy while you have good insurance coverage. Here are some considerations to maximize your therapy:

- Work hard to continue to achieve the best outcomes. If you're making progress in therapy, you may be able to continue if you get authorization from your insurance provider. Authorization is only granted when consistent progress has been achieved and documented by your rehab provider. Discuss your progress with your therapy team and follow your treatment plan. Compliance can affect your progress. Always ask for copies of therapy exercises or the therapy report that goes to the insurer.
- » Ask your therapist for a home plan. A home therapy plan often helps maximize your results and therapy.
- » If you can afford it, consider out-of-pocket rehabilitation to continue your therapy. Some insurance companies have a set dollar amount for rehabilitation therapy. If you're in therapy and you want to continue past your policy's cutoff, talk to your therapist and doctor and expect out-of pocket costs.
- Be proactive if you're not meeting your goals. If you believe your rehab is inadequate, talk to your doctor about transferring to a new provider. Don't waste your rehab benefits if your rehabilitation is not meeting your goals. Continuing in rehab without making progress is the quickest way to lose services.

#### A Change in Your Condition

If you're not in therapy, but have noticed a change — positive or negative — in mobility or speech, talk to your doctor about getting more therapy. Your doctor must validate changes in your condition and prescribe additional rehab — *if it's medically necessary*. Medical necessity must meet one of these standards:

- 1 The service is expected to prevent the onset of an illness, condition or disability.
- 2 The service is expected to reduce the physical, mental or developmental effects of an illness, condition or disability.
- The service will help the person achieve or maintain maximum functional capacity in performing daily activities.



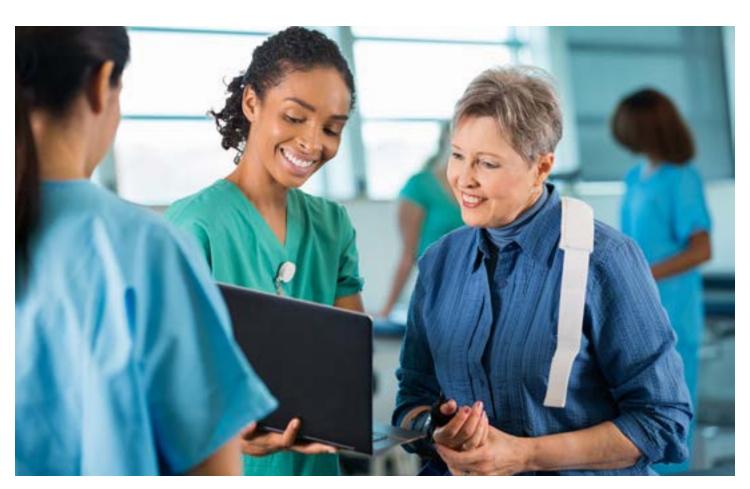
Once rehab is authorized, you may participate until maximum medical improvement has been achieved. Services stop when progress stops. Again, make sure your provider is documenting your progress and ask for a copy.

Whenever you or your caregiver see a change in your functional ability, get re-evaluated by your rehab doctor or therapist. Functional abilities include self-care skills such as feeding, dressing and grooming as well as transfers, walking and wheelchair skills. If your caregiver is having more difficulty helping you, that may meet the standard for more therapy.

#### **Work with Your Insurer's Review Nurse**

Create an ally in your Utilization Review Nurse, who works for your insurance company to control overuse of services, reduce costs and manage care. The URN reviews bills and records and discusses your case with your provider. That's why documentation is so important.

Insurers follow protocols to determine overuse of care and may refuse to reimburse for services that don't meet those standards. Your URN will know and understand those protocols. He or she may determine other areas of your policy that can cover services once the rehab portion is used up. Insurers make exceptions under specific circumstances. URNs know the rules. They can guide you in getting the right documentation.



#### **Need More Help?**









We hope this guide helps you maximize your recovery and navigate the complex healthcare environment.

For more information on stroke and recovery, visit StrokeAssociation.org.

Other helpful organizations for financial questions:

#### **Employment Services for People with Disability**

Receive accurate information about the SSA's employment support programs and where you can get the services you need to make a successful entry into the workforce. You will find the best information at the Ticket to Work website. (http://www.ssa.gov/work)

#### **AARP Tax-Aide**

AARP Tax-Aide is administered through the AARP Foundation in cooperation with the IRS. The AARP Foundation is AARP's affiliated charity. Foundation programs provide security, protection and empowerment for low-income older persons in need. (http://www.aarp.org/money/taxes/aarp\_taxaide)

#### **AARP Money Management Program**

This program offers daily money management service to help low-income older or disabled people who have difficulty budgeting, paying routine bills and keeping track of financial matters. (http://www.aarp.org/aarp-foundation/our-work/income/money-management.html)

#### **Foundation for Health Coverage Education**

The Foundation for Health Coverage Education offers simplified public and private health insurance eligibility information through its website and 24/7 multi-language help line. Uninsured patients can learn their health coverage options through multiple channels. (https://coverageforall.org)



**Together** to End Stroke™

For more information on stroke, visit <u>StrokeAssociation.org</u> or call 1-800-4-STROKE



1. Sources: Data retrieved from http://circ.ahajournals.org/content/129/3/e28.full.pdf+html

