



Together
to End Stroke™

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Caregiver Guide to Stroke

Practical tips and resources for new caregivers

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Introduction

Stroke recovery can be a difficult and confusing process for the survivor and the caregiver. This guide is meant to help you, the caregiver, better navigate the recovery process and the financial and social implications of a stroke.

We've provided you with tips on how to communicate with the healthcare team and manage the effects of a stroke, as well as information on legal resources, financial support, and health coverage.

To learn more about stroke, visit [StrokeAssociation.org](https://strokeassociation.org). For caregiving or general stroke inquiries, please contact togethertoendstroke@heart.org.



Part 1: Emotional Support

Shock, helplessness and worry are common emotions for stroke survivors and their loved ones. Immediately after a stroke, it's not unusual to feel overwhelmed, fearful and uncertain about your new role as a caregiver. These emotions may be a result of your loved one's severely limited physical functioning and personality changes. You may also fear that he/she will have another stroke and that it's your duty to help prevent it. Your relationship with your loved one has also been altered. In addition to your previous responsibilities, you may have to take on more household chores and other tasks that your loved one handled.

To help you adjust to your new responsibilities, this section will help you find the emotional care and support you need from your community, family and friends.

Get Informational Support

By increasing your knowledge about what a stroke is and what to expect, you can feel more in control and less overwhelmed.

- **Ask questions.** What type of stroke did your loved one have? What side of the brain was affected? What caused the stroke? How can another stroke be prevented?
- **Learn about stroke.** To start, visit [StrokeAssociation.org](https://www.strokeassociation.org). Download and look through our free [Life After Stroke Information Sheets](#) to learn more about specific questions you have right now. It is important to learn the signs and symptoms of a stroke in case another one occurs. To learn the signs of stroke, go to [StrokeAssociation.org/warningsigns](https://www.strokeassociation.org/warningsigns).
- **Learn about the effects of stroke.** Go to [Part 3](#) to find out more about stroke and what to ask the healthcare team.



*"Take time to take care of yourself.
If you don't, you will not be of
service to the survivor."*

Janet Scott,
Caregiver for over 15 years

- **Seek additional information on caring for a stroke survivor.** Call 1-888-4-STROKE (1-888-478-7653) to request the *Resources for Stroke Family Caregivers Packet*.
- **Talk with someone who understands.** If you are seeking additional support or just need to talk to someone about your questions or concerns, call the Stroke Family Warmline at 1-888-4-STROKE. The Warmline is staffed by specially trained representatives who have had personal experiences with stroke.

Find Support From Others

- **Reach out to family and friends.** Talk to your family and friends about what you are experiencing. Visits, phone calls, e-mails or some shared time at a movie or restaurant can go a long way to help you feel supported, rejuvenated and refreshed.
- **Build a network with other stroke survivors and caregivers.**
 - *Stroke Connection magazine* provides information and inspiration to stroke survivors and caregivers. The print and online magazine includes conditions that may lead to stroke, such as high blood pressure, as well as the physical, communicative and behavioral conditions stroke may cause. It also offers tips for daily living and helpful information for family caregivers.
 - Join the [Support Network](#). Recovering from a stroke, or caring for someone who is, can be an emotional experience. Being there for each other is why we've launched a virtual support community for stroke and heart disease survivors and their families.
 - The online [Support Network](#) also houses all the tools and resources needed to start an in-person support group, including train-the-trainer materials for group leaders, checklists for building groups and even sample agendas for meetings. We invite you to join us! Find encouragement and inspiration, or offer your own words of wisdom. Go to strokeassociation.org/supportnetwork.
- **Consider seeking professional help.** Mental health professionals and pastoral counselors can listen to your questions and concerns while teaching you coping skills to help you understand and better address your emotions.

Get Logistical/Active Support

Providing care for a stroke survivor can be rewarding. But it can be stressful and frustrating when you're suddenly thrust into the role of caregiver. Even under the best

circumstances, caregiving is a tough job. In fact, it is among life's most challenging roles. There's often little rest and little time to prepare.

If you've just become a caregiver, keep this in mind: To be successful, you must take care of your needs as well as those of the survivor.

- **Define exactly what you need.** Don't hesitate to ask for help with grocery shopping, meals, doctor's visits, yard work, etc.
 - Write down the things that are most difficult for you to get accomplished and look for the right person for the job. Then ask that person to help you with a specific task.
- **Consider seeking professional healthcare services.** If you are unable to care for him/her or would like help, visit [AARP's Care Provider Locator](#). If you're considering long term care, read [this helpful article](#) on various options and use [AARP's Long-Term Care Calculator](#) to estimate costs.
- **Seek respite care.**
 - For resources in your area, visit eldercare.gov or call 1-800-677-1116. Or use the National Respite Care Locator at archrespice.org.

Take Time for Yourself

- Eat a balanced nutritious diet. Learn about how you can maintain [good eating habits](#) and can help prevent stroke and heart disease.
- Get regular physical activity.
- Find time to do at least one hobby once a week.
- Spend time with your family and friends.
- Start a [journal](#). Journaling can help you relieve stress, organize your thoughts and spend time by yourself.

More Resources

- [Rx for Caregivers](#)
- [How Not to be Overwhelmed by the Overwhelming](#)
- [Tips from a Caregiving Pro](#)
- [Caregiver Rights](#)
- [Caregiver Classes](#)
- [Top 10 Tips to Refresh Yourself](#)
- [Family Caregiver Alliance](#)
- [Veterans Affairs Website for Caregivers](#)

Part 2: Medical Management

Communicating with the healthcare team can help you understand what happened during your loved one's stroke, what to expect during the recovery process and how to help him/her recover. As a result, you can feel less stressed and overwhelmed.

Provide the Healthcare Team With a Thorough Medical History

Information to share with your healthcare team may include:

- Past illnesses and/or diseases
- Medications
- Family history
- Previous surgeries
- Allergies

Ask Questions

- What type of stroke did he/she have? (large vessel, small vessel, ischemic hemorrhagic, etc.)
- What side of the brain did the stroke occur?
- What caused the stroke?
- What risk factors may have contributed to having the stroke? (high blood pressure, cigarette smoking, atrial fibrillation, etc.)
- How can another stroke be prevented?
- What is the likelihood of having another stroke?
- What are the potential **long-term effects**?
- What rehabilitation services are available?



"You have to be your healthcare advocate. Translation: Be pushy. When the stroke happened, I didn't know what to ask the doctors, and I accepted most of what they said. Eventually, I learned to speak up. As the weeks went by, I became John's voice. I asked questions and if I wasn't satisfied with the answers I'd probe until I was."

Mailyn Manno,
Caregiver

- What rehabilitation services will my loved one need?
- What are your nutrition recommendations?
- How do I prepare my home for my loved one's return?
- What medications does my loved one need and how do I administer them?
 - Maintain a [medicine chart](#) to help manage your loved one's prescriptions.

Rehabilitation

Rehabilitation is a critical part of recovery for many stroke survivors. The greatest percentage of survivors' recovery is usually within the first year after their stroke. However, recovery may continue for years — particularly if they continually work on the areas they want to improve. But the pace of recovery after the first year will likely slow down considerably.

Rehabilitation may help improve stroke survivors' independence in many areas, including self-care, mobility, communication, cognitive and social skills. Under the doctor's direction, rehabilitation specialists provide a treatment program specifically suited to the stroke survivor's needs.

Caregivers play an essential role in stroke survivors' rehabilitation as key members of the treatment team. Caregivers should ask the healthcare team about rehabilitation services as soon as possible to ensure that their loved one is on the road to recovery immediately. Thereafter, they can talk to the doctors about how they can help with rehabilitation at home and appropriately assist with their loved one's individualized recovery plan.

Rehabilitation services may include:

- Rehabilitation nursing
- Physical therapy
- Occupational therapy
- Speech, language, and/or hearing therapy
- Recreational therapy

- Nutritional care
- Rehabilitation counseling
- Social work
- Psychiatric or psychological treatment
- Chaplaincy
- Patient/family education
- Support groups
- Vocational evaluation
- Driver's training
- Programs to improve physical and emotional stamina to return to work

Create an Emergency Kit

In the event of an emergency, be prepared to provide the healthcare professionals with necessary information and documents. Store them in a safe location, such as a nightstand, and tell your family members and/or friends where they are located. Download a [complete list of emergency documents](#) at caregiverstress.com.

- List of key contacts (physicians, family members, etc.)
- List of medications, including doses and frequencies
- Copy of your loved one's health insurance card

More Resources

- [More Tips for Communicating with Healthcare Professionals](#)
- [Medication Information](#)
- [The Caregiver's Advocacy Armor](#)
- [Assessing a Rehab Facility Checklist](#)

Part 3: Effects of a Stroke

Stroke recovery varies from person to person and is nearly impossible to predict. But understanding what happens during the recovery process can help you be prepared. The effects of a stroke and how long they may last depend on several factors, including the location and size of the brain injury, the quality and quantity of medical care received, the strength of one's support circle and and his/her will to get better.

There are some effects of a stroke that are common regardless of which side of the brain the injury occurs, such as:

Emotional and Behavioral Conditions

- Depression
- Anxiety
- Memory Loss
- Pseudobulbar Affect (PBA) (crying or laughing at unexpected, sometimes inappropriate times)
- Dementia

Physical Effects

- Fatigue
- Dysphagia (swallowing problems)
- Shoulder Pain (on the affected/recovering side of the body)
- Central Pain Syndrome (unexplainable pain, temperature sensitivity, sensitivity to light and touch)
- Vision Problems
- Balance Issues
- Claw Toe and Hammertoe
- Foot Drop
- Seizures
- Spasticity (tightening of the muscles in the affected limb)



Some common effects of a stroke are most often associated with an injury to either the left or right hemisphere of the brain.

Left Brain Effects

Injury on the left side of the brain may cause:

- Paralysis on the right side of the body
- Aphasia is language impairment that inhibits your ability to use or comprehend words
 - [Learn About the Types of Aphasia](#)
 - [How Technology Helps People with Aphasia](#)
 - [How to Help Others Get Comfortable with Your Loved One's Aphasia](#)
- Apraxia of speech (verbal apraxia) is difficulty initiating and executing voluntary movement patterns necessary to produce speech when there is no paralysis or weakness of speech muscles
 - [Learn More About Apraxia of Speech](#)
 - [Aphasia vs. Apraxia](#)
- Slow, cautious behaviors

Right Brain Effects

Damage on the right side may cause:

- Paralysis on the left side of the body
- [Left-side neglect](#)
- Quick, impulsive behavioral style

Brain Stem Effects

When stroke occurs in the [brain stem](#), depending on the severity of the injury, it can affect both sides of the body and may leave someone in a “locked-in” state. When a locked-in state occurs, the patient is generally unable to speak or achieve any movement below the neck.

Additionally, brain stem stroke may cause ataxia, which is the body's inability to coordinate how muscles move together. Ataxia may affect the movement of arms, legs and chest muscles and may be associated with tremors.

More Resources

- To find an ASHA-certified speech-language pathologist in your area, visit the American Speech-Language Hearing Association at www.asha.org.
- Go to the [Tips for Daily Living Library](#) to get video tips and advice from stroke survivors.

Part 4: Legal, Financial and Health Coverage 101

As a new caregiver, getting a grasp of legal, financial and health issues can be overwhelming. This section will provide a quick overview to get you started.

First Things First: Determine What Documents Your Loved One Needs

Documenting the healthcare desires of your loved one can help ensure they receive medical treatment if you can't communicate their wishes.

- **Advance Directive** (living will) — Patient's clear statement of his or her wishes with respect to his or her healthcare. This helps avoid disputes about treatment options and gives direction to healthcare providers. To access state-specific advance directive instructions and forms, visit the [U.S. Living Will Registry](#) website.
- **Last Will and Testament** — Specifies who will receive your assets when you die. This also accomplishes other objectives, including naming guardians for minor children.
- **Durable Power of Attorney** — Appoints another person to make legal and financial decisions if you are no longer able to do so.
- **HIPAA Representative Form** — The Health Insurance Portability and Accountability Act Form outlines who can access your confidential medical information.

Financial Assistance

Stroke rehabilitation and recovery can be costly, even when you have good health coverage. But compounded with loss of work, it can be a drain on your family's finances. Here are some resources to explore that may help ease the strain:

- Talk to the Experts
 - Social workers can help you navigate private and government disability and insurance programs. Social workers are available at most hospitals and rehab facilities and can be located at [eldercare.gov](#) or by calling 1-800-677-1116.
 - Certified financial planners and attorneys specializing in elder care and disability can also be a helpful resource.



- **Employment Services for People with Disabilities** — Information about the Social Security Administration's employment support programs.
- **AARP Tax-Aide** — Provides security, protection and empowerment for low-income older persons in need.
- **AARP Money Management Program** — Daily money management service to help low-income, older or disabled people who have financial difficulty.
- **American Association of Daily Money Managers** — Daily money managers (DMMs) assist with personal monetary affairs, from organizing and keeping track of financial and medical insurance papers, to assisting with maintaining bank accounts.
- **Foundation for Health Coverage Education** — Simplified public and private health insurance eligibility information and 24/7 multi-language help line. Uninsured patients can learn their health coverage options through multiple channels.
- **Veterans Health Administration** — Veterans older than 65 may qualify for a tax-free benefit called Aid & Attendance Special Pension, which can help pay for in-home care, a nursing home or assisted living.
- **Social Security Disability Insurance (SSDI)** — Talk to a social worker about applying for SSDI as soon as possible. Stroke survivors often don't get approved the first time they apply, and if they do, it's a long process.
- **Supplemental Security Income** — Federal income program to help people with disabilities who have little or no income.
- **NeedyMeds.org** — Database of patient assistance programs offered by pharmaceutical companies to offset some of the cost of necessary prescriptions.
- **Rx Assist** — Lists public and private resources available, though limited, that may help patients afford the medicines they need.
- **Medicare** — Information about the Medicare prescription drug plan.

Health Insurance

- **Understand Your Current Health Insurance**
 - Call the health insurance company. Determine what services will and will not be covered and what rehab services are available.
 - If the health insurance company will not pay for your loved one's care, you can file an appeal. [Learn more](#) about filing an appeal.
- **Obtaining Health Insurance**
 - The new **Health Insurance Marketplace** opened nationwide on Oct. 1, 2013, providing millions of uninsured Americans with access to affordable coverage options. [Learn more](#) about the reform and how to apply.
 - **Pre-Existing Condition Care Plans** are insurance programs for those who have been without health insurance coverage for 6 months or more due to a pre-existing condition. To find out how to apply, go to "Find Your State" at pcip.gov.
 - ◇ In January 2014, companies can no longer deny coverage due to pre-existing conditions as a result of the **Affordable Care Act**.
 - Gaining health insurance coverage can be a challenging process. Consult the **Patient Advocate Foundation** (PAF) for free direct advocacy services, including help with obtaining health insurance and solving medical debt issues.
- **Learn More About Your Medicare Benefits** — The Foundation of Health in Aging created a [downloadable tip sheet](#) to help guide you through the Medicare system.

Prescription Drug Costs

Prescription drug costs can add up quickly and take a significant financial toll on your family. Consult the following resources to help reduce your medical expenses:

- **Together Rx Access®** — Free prescription savings program that helps eligible uninsured Americans save on medicines. Cardholders bring their Together Rx Access® Card and prescription to their pharmacist, and the savings are calculated at the pharmacy.

More Resources

- [Learn More About Health Insurance](#)
- [Health Insurance FAQs](#)

*The **Patient Advocate Foundation (PAF)** provides free, direct advocacy services, including helping obtain health insurance, solving medical debt issues and working to keep survivors in rehab.*