



American Stroke Association®  
A division of the American Heart Association.

Together to End Stroke®



# Caregiver Guide to Stroke

Practical Tips and Resources for New Caregivers

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# Introduction

Stroke recovery can be difficult and confusing for survivors and caregivers. This guide is meant to help you, the caregiver, better navigate the recovery process and the financial and social fallout of a stroke. We have provided tips on how to communicate with the health care team and manage stroke's effects, as well as information on legal resources, financial support, and health coverage.



To learn more about stroke, visit [Stroke.org](https://www.stroke.org)

# Emotional Support

Shock, helplessness, and worry are common among stroke survivors and their loved ones. Right after a stroke, it's not unusual to feel overwhelmed, uncertain and even fearful about your new role as a caregiver — perhaps because of severe physical limitations or personality changes in your loved one. You might also worry about another stroke and that it's your duty to help prevent it.

Your relationship with your loved one has also been altered. Besides 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 guide you in finding 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 does that affect my loved one's abilities? How can another stroke be prevented?
- Do your research. Stroke can be beatable and rehabilitation is key to achieving victories along the way to recovery. During this journey, you will have to make a lot of decisions and serve as an advocate for your loved one. Visit [Stroke.org/Recovery](https://www.stroke.org/Recovery).
- Visit the [Life After Stroke](https://www.stroke.org/LifeAfterStroke) section of [Stroke.org](https://www.stroke.org) to read or download our complementary resources for answers to your questions. It's important to learn the signs and symptoms of a stroke in case another one occurs (see [Stroke.org/WarningSigns](https://www.stroke.org/WarningSigns)).
- Learn the [effects of stroke](https://www.stroke.org/effects-of-stroke). Every stroke is unique and understanding the effects of your loved one's stroke, will help to ask the right questions of their health care team.
- Seek more information on caring for a stroke survivor. Call the Stroke Family Warmline to talk with our trained specialists who can provide helpful information, connect you to local services or just be a listening ear. You can also request a packet of information be mailed to you based on your specific needs. 1-888-4-STROKE (1-888-478-7653) or [Stroke.org/SpeakWithUs](https://www.stroke.org/SpeakWithUs).

## Find Support from Others

- Reach out to family and friends. Tell them what you are experiencing. Visits, phone calls, e-mails or some other shared time can go a long way to help you feel supported and rejuvenated.
- Build a network with other stroke survivors and caregivers.
  - Monthly [Stroke Connection e-news](https://www.strokeconnection.org) provides information and inspiration to stroke survivors and caregivers. In it, you'll find information and updates on 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 caregivers. Sign up at [StrokeConnection.org](https://www.strokeconnection.org).
  - Join the [Support Network](https://www.stroke.org/support-network). Recovering from a stroke, or caring for someone who is, can be emotional. Being there for each other is why we've launched a virtual support community for stroke and heart disease survivors and their families.

- Join a support group. Use our [Stroke Support Group Finder](#) tool to find a list of groups near you, you can even filter by audience at [Stroke.org/SupportGroup](https://www.stroke.org/supportgroup).
- Help organize a stroke support group or strengthen an existing one in your community. Visit [Stroke.org](https://www.stroke.org) and learn more about starting a support group.
- Consider seeking professional help. Mental health professionals and pastoral counselors can listen to your questions and concerns while teaching you coping skills.

## 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 caregiver role.

Caregiving is a tough job. In fact, it's 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 succeed, you must take care of your needs as well as the survivor's.

- Build a support system. Define exactly what you need, ask for help and delegate responsibilities such as grocery shopping, meals, doctor visits, yard work, etc.
  - Write down the things that are most difficult for you to accomplish and look for the right person for the job. Then ask that person to help you with the specific task.
- Prioritize your time. You may have other roles and responsibilities outside of being a caregiver such as being a parent, employee, or community leader. It's important to continue to find balance for yourself and your family.
- Consider seeking professional health care services. If you can't care for the stroke survivor or would like help, visit [AARP's Care Provider Locator](#). If you're considering long-term care, use AARP's [Long-Term Care Calculator](#) to estimate costs.
- Seek respite care.
  - For resources in your area, visit [eldercare.acl.gov](https://www.eldercare.acl.gov) or call 1-800-677-1116. Or use the National Respite Care Locator at [archrespite.org](https://www.archrespite.org).

## Take Time for Yourself

- Eat a balanced diet. Learn how you can maintain [good eating habits](#) and help prevent stroke and heart disease.
- Get regular physical activity.
- Find time to enjoy 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

- [7 Practical Tips for Self-care](#)
- [Top 10 Caregiver Tips For Staying Healthy and Active](#)
- [Family Caregiver Alliance](#)
- [National Alliance for Caregiving](#)

# Medical Management

Communicating with the health care team can help you understand what happened during your loved one's stroke, what to expect during the recovery process and how to support recovery. This can help you feel less stressed and overwhelmed.

## Provide the Health Care Team with a Thorough Medical History

You'll probably need to share information such as:

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

## Ask Questions

- What type of stroke did they have? (large vessel, small vessel, ischemic, hemorrhagic, etc.)
- On what side of the brain did the stroke occur?
- What are the potential long-term effects?
- What rehabilitation services will my loved one need, and how do we access them?
- What caused the stroke?
- What risk factors may have contributed to the stroke? (high blood pressure, cigarette smoking, atrial fibrillation, etc.)
- What is the likelihood of having another stroke?
- How can another stroke be prevented?
- What medications does my loved one need, what do they treat and how do I administer them?
  - Maintain a medicine chart to help manage your loved one's prescriptions, for example, high blood pressure
  - Be sure to mention any over-the-counter medications as they can interfere with the action of prescribed drugs
- What are your nutrition recommendations?
- How do I prepare my home for my loved one's return?



## Rehabilitation

Rehabilitation is critical to many stroke survivors' recovery. The greatest percentage of recovery usually occurs in the first year after a stroke, although it might continue for years — particularly if survivors keep working on the areas they want to improve. But the pace of recovery after the first year is likely to slow considerably.

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

Caregivers play an essential role in stroke survivors' rehabilitation. Caregivers should ask the health care team about rehabilitation services right away to ensure your loved one is on the road to recovery as soon as possible. Then you can talk to the health care and rehabilitation team about how you can help with rehabilitation at home and otherwise assist with your loved one's individualized recovery plan.

### Rehabilitation services may include:

- Rehabilitation nursing
- Physical therapy
- Occupational therapy
- Speech, language, cognitive and/or hearing therapy
- Recreational therapy
- Nutritional care
- Rehabilitation counseling
- Social work
- Psychiatric or psychological treatment (for example, for post stroke depression)
- Chaplaincy
- Patient/family education
- Support groups
- Vocational evaluation
- Driver's training
- Programs to improve physical and emotional stamina to return to work

Rehabilitation is an important step during a stroke survivor's road to recovery. Review our post stroke exercise videos with your health care team to help restore strength and control. Learn more at [Stroke.org/PostStrokeExercise](https://www.stroke.org/poststrokeexercise).

## Create an Emergency Kit

In the event of an emergency, be prepared to provide health care 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](https://www.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(s)
- A copy of the medical advance directive

## More Resources

- [Communicating With Health Care Professionals](#)
- [Rehab Expectations](#)
- [Stroke Treatment](#)

# Effects of a Stroke

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

Some stroke effects are common regardless of which side of the brain the injury occurs. They include:

## Emotional and Behavioral Conditions

- Depression
- Anxiety
- Memory loss
- Pseudobulbar affect (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 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, a language impairment that inhibits the ability to use or comprehend words
  - [Learn About the Types of Aphasia](#)
  - [How Technology Helps People With Aphasia](#)
- Apraxia of speech (verbal apraxia), or difficulty initiating and executing voluntary movement patterns needed to produce speech when there is no paralysis or weakness of speech muscles
  - [Aphasia vs. Apraxia](#)
- Slow, cautious behaviors

### Right Brain Effects

Injury on the right side of the brain 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 — generally unable to speak or achieve any movement below the neck.

Brain stem stroke may also cause **ataxia**, which is the body’s inability to coordinate how muscles move together. **Ataxia** can 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 [asha.org](http://asha.org).
- Go to the [Tips for Daily Living Library](#) to get video tips and advice from stroke survivors.

# Legal, Financial and Health Coverage 101

As a new caregiver, getting a grasp on legal, financial and health issues can be overwhelming. This section will get you started.

## First Things First: Determine the Documents Your Loved One Needs

Gather key legal and health documents your loved one has created or might need to create or update. These include:

- Advance directive (living will) — A patient's clear statement of wishes about his or her health care. This helps avoid disputes about treatment options and gives direction to health care providers. To access state-specific advance directive instructions and forms visit the [U.S. Advance Care Plan Registry](#).
- Last will and testament — Specifies who will receive a person's assets upon death. This also accomplishes other objectives, including naming guardians for minor children.
- Power of attorney — Appoints another person to make legal and financial decisions.
- HIPAA representative form — The Health Insurance Portability and Accountability Act form outlines who can access a person's confidential medical information.



## Financial Assistance

Stroke rehabilitation and recovery can be costly, even when a patient has good health coverage. But compounded with loss of work, these can drain family finances. Explore these resources 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 through [eldercare.acl.gov](https://www.eldercare.acl.gov) or by calling 1-800-677-1116.
  - Certified financial planners and attorneys specializing in elder care and disability can also be helpful.
- **AARP Money Management Program** — Daily money management service to help low-income, older or disabled individuals who have financial difficulties.
- **AARP Tax-Aide** — Aims to help provide assistance in completing tax forms for individuals age 50 and older.
- **American Association of Daily Money Managers** — Daily money managers help with personal monetary affairs, such as organizing and keeping track of financial and medical insurance papers and maintaining bank accounts.
- **Social Security Disability Insurance (SSDI)** — Talk to a social worker about applying for SSDI as soon as possible if you're not already on Social Security. 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.
- **The Patient Advocate Foundation** provides free, direct advocacy services, including helping obtain health insurance, solving medical debt issues and working to keep survivors in rehab.
- **Veterans Health Administration** — Veterans 65 and older 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.

## Prescription Drug Costs

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

- **GoodRx** — Assists individuals by providing help to find better information and prices every month on prescriptions.
- **FamilyWize** — This discount card partnership helps improve the health and well-being by making prescription medications more affordable.
- **Medicare Drug Coverage** — Information about the Medicare prescription drug plan.
- **NeedyMeds.org** — Database of patient assistance programs offered by pharmaceutical companies to offset some of the cost of prescriptions.
- **Rx Assist** — Lists public and private resources available, though limited, that may help patients afford the medications they need.

## Health Insurance

- Understand your current health insurance
  - Call the health insurance company. Determine what services will and will not be covered and what rehabilitation services are available.
  - If the health insurance company will not pay for your loved one's care, you can file an appeal or consider coordinating two plans i.e., Medicare plus Medigap insurance or plus other private insurance.
- Consider obtaining health insurance if needed
  - The [Health Insurance Marketplace](#), launched in 2014 as part of the Affordable Care Act, provides access to health insurance options with a standardized set of benefits.
  - Gaining health insurance coverage can be challenging. Consult the [Patient Advocate Foundation](#) for free direct advocacy services, including help with obtaining health insurance and solving medical debt issues.
- [Medicare](#): Learn more about your Medicare benefits and enrollment process system.

## More Resources

- [Health Insurance FAQs](#)

