



Understanding Stroke:

A Guide to Your Care in the Hospital and Beyond

PARTNERS
HEALTHCARE

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Stroke is a common and often disabling disease. You are likely reading this booklet because you or someone you love has recently experienced a stroke, or is at risk for experiencing one, and you want to learn more. Knowledge and understanding are an important part of participating in your care and improving your chances of good recovery from your stroke. While there is a lot of information about stroke available online, it is often hard to tell which information is accurate and whether or not it applies to you. It can also be difficult to absorb all the information that is shared with you during your hospitalization by the doctors and your care team, and patients often leave the hospital without a trusted source of information.

With that in mind, the Partners Stroke Quality Leaders got together to create a powerful but easy to understand booklet for you to look at during your hospitalization or after you get home. We value the input and feedback from real-world patients and caregivers like you who will use this booklet, and this information was reviewed by actual patients and families. We also welcome your thoughts on how to improve it.

We hope this tool will be helpful to you and your care team as part of your journey toward stroke recovery, one that will undoubtedly be filled with success and setbacks, joy and disappointment, hope and doubt. Recovery is a process which requires both flexibility and determination, but the good news is that most people who experience a stroke also experience recovery. Some patients recover completely, others only partially, and sadly sometimes patients will not recover. Wherever your journey takes you, your care team is there to help, and we hope this booklet makes it just a little easier to understand.

Warmly,

A handwritten signature in black ink, appearing to read 'Lee H. Schwamm', followed by a long horizontal line.

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Chapter Summary

A stroke happens when:

- blood flow to the brain is interrupted (this is called an ischemic stroke)
- there is bleeding in the brain (this is called a hemorrhagic stroke)

If you experience signs of a stroke, call 911 right away. **FAST** is an acronym that helps people remember the common stroke warning signs and that stroke is a medical emergency. The signs are:

- F: Face drooping
- A: Arm weakness
- S: Speech difficulty
- T: Time to call 911

If you are admitted to the hospital for a stroke, your medical team should evaluate you, treat you based on the type of stroke you had, tell you which type of stroke you had, and what you might be able to do to lower the chances of having another one.

You may be more likely to have a stroke based on different risk factors. Some of these you can change, and some you cannot.

Risk factors you can do something about include:

- High blood pressure
- Smoking
- Obesity and physical inactivity
- High cholesterol
- Diabetes

Risk factors you cannot do something about include:

- Age
- Sex
- Race
- Family history



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If you have signs of a stroke, call 911 and go to the hospital immediately. In the emergency department, you will be seen by a team of doctors and nurses who will perform tests and recommend treatments.

During your hospital stay, you will likely be taken care of by a team of providers including:

- Doctors
- Nurses
- Therapists
- Social workers
- Case managers



These providers will talk to you about your treatment options in the hospital, medicines you should take, and your rehabilitation plan after you leave the hospital.

The next stage after the initial hospital stay focuses on maximizing your recovery and starting treatments to prevent another stroke. Depending on your level of functioning after your stroke, you may be recommended to go to an inpatient rehabilitation facility or skilled nursing facility after the need for acute hospital-based care is over. Some patients are able to go home right away and receive outpatient or home-based services. Your hospital team will help you determine the best location and identify the supports they believe would best help you recover.

As you start your recovery process, it is important to be patient, open, and ask for help from friends, family or your medical team when you need it. Recovering from stroke can be a long and difficult process. You may need to change the way you do certain things in your life. Your recovery team is there to help you.

Some patients might receive palliative care after their stroke. Palliative care is specialized medical care that focuses on helping patients cope with serious illness and live the best quality of life possible. In the past, palliative care was only offered at the very last stages of the dying process, and was often called hospice care. More recently, palliative care is offered to patients earlier in the course of serious illnesses to ease suffering and enhance quality of life. Palliative care is delivered by a team of clinicians, including palliative care physicians, nurses, social workers, chaplains, and rehabilitation therapists and can be received in the hospital, an outpatient office, or at home.

What can Palliative Care do for you?

- Help make more informed healthcare choices and decisions
- Relieve symptoms of stroke, such as pain, nausea, confusion or anxiety
- Provide emotional and spiritual support
- Help with understanding and completing advance directives or goals of care

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After a stroke, you may experience a number of physical and emotional changes. The physical changes you experience depend on which part of your brain was affected during your stroke. Stroke disability generally improves over time, though often it does not resolve completely, and members of your care team can help you manage your symptoms.

Some physical changes you might experience are:

- Muscle weakness or incoordination
- Loss of sensation or painful sensation
- Loss of vision
- Reduced ability to walk independently
- Fatigue
- Difficulty swallowing

These symptoms may make it hard to do everyday tasks like dressing, washing up, going to the bathroom, eating, or sleeping. Physical, occupational, and speech-language therapists will work with you to come up with exercises to help improve your symptoms and keep you safe. These might include stretching, exercises, modifying how you do certain tasks, allowing time for a nap during the day, and turning your head to see more of your surroundings if you experience some vision loss.

Trouble with swallowing is called dysphagia. Swallowing can be difficult or dangerous if you are having trouble sitting upright or staying awake, or controlling the act of swallowing. This can make it more likely that food or drink will go down 'the wrong way' and cause coughing, choking or even pneumonia. A speech language therapist might recommend exercises or certain foods and drinks to avoid if you have dysphagia.

Communication and cognitive changes can also occur after a stroke. These include:

- Difficulty understanding what others are saying
- Using numbers or telling time
- Speaking too loudly or softly or thinking of the words you want to say
- Paying attention
- Reading or spelling words
- Slurring your speech
- Difficulty remembering things or learning new things

Writing down important information, watching body language, using simpler words, and removing distractions may help you deal with these changes.

Stress, depression, and anxiety are common after a stroke. You may feel sad, scared, worried, or helpless. Ask for help from your care team if you are experiencing these feelings. They can refer you to a psychologist or mental health provider. It might also help to meditate, spend time with your family and friends, exercise regularly, or attend a stroke support group.

You may experience changes in your relationships with your family, friends, and acquaintances. You may find that your social circle becomes smaller, but also stronger. Maintaining these relationships is important to stroke recovery.



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Many patients are able to return to their home or to the home of a close friend or relative after being hospitalized for a stroke. Discussions and planning for your return home often begin early in your recovery process.

The timing of when you are able to go home will depend on your ability to:

- Move safely around your home and community
- Dress, bathe and feed yourself
- Communicate your needs to others
- Take prescribed medications and get to follow up appointments with your doctors

You may need home health services or changes made to your home to make it safer. You may also need help from others, like family or friends or other community resources. Your team may suggest modifications to your home such as hand holds or grab bars in your bathroom near the shower and toilet, removing rugs or carpets, arranging your home so you can live on just one floor, or making sure you have a walker or wheelchair, if needed.

After your stroke, your doctor may prescribe new medications for you to take. It is important to follow all the instructions from your doctor, and make sure that you and your family understand:

- The name of the medication
- What the medication is for
- How often you should take it and for how long
- The dose
- Potential side effects
- What to do with other medications you were taking before the stroke
- What to do if you miss a dose

If you have any questions about your medications, if you've accidentally taken too much medication, or if you think you may be having a side effect of one of your medications, call your doctor or pharmacist right away.

A follow up visit with a neurologist will usually occur around 3 months after your stroke, to assess your progress and review the details of your hospitalization and any issues that may have come up since then. When it is time for your visit, it is helpful to arrive early, bring a list of your current medications, and bring any questions.



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After your stroke, it may be possible to return to your job, or go back after some changes are made to your work environment, schedule, or job responsibilities. You may also have the option to return to your job after you have had more time to recover from your stroke. Your care team and employer can help you explore these options.

Some things to keep in mind as you return to work:

- Know and understand your own needs, and remember that recovery is ongoing
- Start out slow and gradually increase activity
- Remember that communication is key

Some people are not able to return to their previous jobs. If this may be the case for you, make sure to consult with an employment lawyer or specialist to fully understand the implications of your choices about returning to work before you take any action. Depending on your age and other eligibility requirements, you might qualify for:

- A retirement or disability pension
- Federal programs, such as Social Security Disability Insurance or Supplemental Security Income

You might also consider volunteering or training for a new job that better suits your abilities.

Whether or not you decide to return to work, you should explore transportation options in your community. Many stroke survivors will be able to drive again. Since your vision, cognitive processing or strength may be affected by your stroke, it is important to do the following:

- Talk to your doctor, therapists and family about returning to driving
- Take a self-assessment screen to better understand your individual changes and how they might affect driving
- Contact your Registry of Motor Vehicles to learn more about the laws regarding driving after stroke

Your doctor or occupational therapist may recommend getting an evaluation by a driver rehabilitation specialist. You may need retraining in driving skills or modifications to your vehicle to ensure safety.

If you are unable to drive, you can:

- Ride with family or friends
- Take a taxi, ride sharing service (e.g., Uber, Lyft) or local shuttle bus
- Use public transportation such as buses, trains and subways
- Talk with your social worker about other resources available in your community, and how you can apply for assistance.



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As you start on your journey of recovery, it is very important to understand the risk factors for stroke. There are some risk factors that you can do something about, and we discuss these more below. Visit the American Heart Association's "Life Simple Seven" website to see more information and tips on how to get healthier.

High Blood Pressure (Hypertension): Blood pressure, or hypertension, is the amount of pressure or force that is pushing against your blood vessels. There is no permanent cure for hypertension, but medication and lifestyle changes can help control high blood pressure and reduce the risk of another stroke. Blood pressure is written in the form of two numbers, with the systolic number on top and diastolic on the bottom. A normal blood pressure is less than 120/80 mmHg.

Some tips to manage your blood pressure are:

- Eat healthy meals and avoid salty foods (sodium)
- Keep your weight or body mass index (BMI) in a healthy range
- Take your medications as prescribed
- Increase your physical activity
- Try to reduce stress
- Quit smoking



High Cholesterol (Hyperlipidemia): Cholesterol is an essential substance that is produced by the body and is also ingested from food. It is important to know your "numbers" and make sure they fit within the normal ranges. LDL is considered "bad" cholesterol because it can lead to fatty build up in your arteries, putting you at a higher risk for stroke. HDL is considered "good" cholesterol because it can help transport bad cholesterol away from your arteries and to the liver where it can be processed and removed from your body.

Some tips to maintain a healthy level of cholesterol are:

- Have your cholesterol checked annually and speak to your doctor about your numbers, your goal level and treatment options
- Talk to a nutritionist or dietitian about a heart healthy diet
- Maintain a healthy weight and get the recommended amount of weekly exercise
- Take your medications as prescribed

High Blood Sugar (Diabetes): Diabetes is a disorder that makes it difficult for the body to process and store sugar for energy, leading to high sugar levels in the bloodstream. Insulin is a hormone in your body that helps transport sugar. Your body may be unable to produce enough insulin (Type 1 diabetes) or the insulin that is produced may not be effective enough (Type 2 diabetes).

Some tips for managing diabetes are:

- Eat healthy meals low in saturated and trans fats, and salt and try to avoid added sugars
- Keep your weight or body mass index (BMI) in a healthy range
- Take your medications and/or insulin as prescribed
- Increase your physical activity

Physical Inactivity: Exercise is recommended for 30 minutes or more at least 5 days a week, or preferably 7 days per week, for a minimum of 150 minutes per week to lower your risk of heart attack or stroke. There are many types of activities that will increase your heart rate and keep you healthy. These can include walking with a friend or dog, playing a sport, yoga, jogging, walking upstairs, or doing yard work. Try to find something that you like to do, and do it with a friend or family member.

Getting the recommended amount of weekly exercise:

- Reduces body weight
- Reduces blood pressure
- Reduces LDL or bad cholesterol
- Increases HDL or good cholesterol
- Increases insulin's ability to transport sugar in the bloodstream
- Improves muscular function, strength, and the body's ability to take in and use oxygen
- Improves your cognitive function and reduces the risk of dementia

Unhealthy Diet and Obesity: In order to lose weight, it is important not only to get the recommended amount of daily exercise but to also follow a healthy diet.

Some tips for eating healthy and losing weight are:

- Read food labels to understand which foods contain added sugars, salt, saturated, and trans fats
- Watch your calories and try to consume fewer than you burn during physical activity
- Try to substitute soda and sugary juices with low calorie options such as water, seltzer waters, and caffeine free teas
- Drink enough water to keep yourself hydrated throughout the day
- Eat smaller portions



- Try to cook at home, preparing healthier meals for yourself and your family
- Speak to a dietician or nutritionist about a weight loss plan that is right for you
- Join a local weight loss program

Smoking: Smoking causes atherosclerosis, or plaque build-up on arterial walls, which can make blood clots more likely to form. It also raises blood pressure, decreases HDL or good cholesterol, and increases LDL or bad cholesterol.

Some tips for quitting are:

- Discuss treatment options with your doctor, including medications, nicotine supplements, and addiction therapy
- Explore resources and programs available to help you
- If your partner or someone at home smokes, talk to them about quitting together



Stress: Stress may also increase your risk of high blood pressure, poor blood sugar control, and over-eating and excess weight gain, all of which in turn can further increase your stroke risk.

Some tips for managing stress are:

- Taking slow, deep breaths
- Taking time to think of a relaxing or soothing place and focusing on this image
- Practicing meditation on your own, or with the help of a guided video or recording
- Praying alone or with a group, according to your own religious, spiritual and sacred beliefs
- Practicing yoga or tai chi



Excess Alcohol Use: If you drink alcohol, it is recommended that you do so in moderation. According to the American Heart Association, this means on average less than two drinks per day for men and one drink per day for women. Drinking more than the recommended amount of alcohol can contribute to high blood pressure, high cholesterol, obesity, stroke, dementia, breast cancer, suicide, and accidents.

1 drink equals:

- 12 oz of beer
- 4 oz of wine
- 1.5 oz of 80-proof liquor or 1.0 oz of 100-proof liquor

Hormone Use: Some studies have shown that estrogen alone or with progesterone increases a woman's risk of stroke. These types of hormones are found in birth control (contraceptives) and hormone replacement therapy frequently prescribed during or after menopause. Discuss the use of birth control or hormone replacement therapy carefully with your neurologist and/or Ob-Gyn specialist.

Atrial Fibrillation: Atrial fibrillation (Afib) is an abnormal heart rhythm which can cause blood to collect within one of the chambers of the heart. This collection of blood can form a blood clot that may travel to the brain and cause an ischemic stroke. Those with Afib are most often treated with anticoagulation medications that help prevent blood clots from forming.

Symptoms of Afib may include:

- Heart palpitations, rapid or irregular heart beat
- Shortness of breath, especially with activity
- Fatigue or mild confusion
- Anxiety
- Feeling faint or dizzy
- Chest pain or pressure – this is a medical emergency

Atherosclerosis: Atherosclerosis is the hardening of your arteries due to the build-up of plaques made of cholesterol. Arteries are blood vessels that carry oxygen-rich blood from your heart to other parts of your body. Over time, this plaque can harden and narrow your arteries, which limits the flow of blood. Sometimes the plaque can dislodge or rupture and cause an ischemic stroke.

Carotid artery narrowing: When plaque builds up in the large arteries in the neck, it usually does not cause symptoms until it gets to greater than 50% narrowing. The risk of a stroke increases as the narrowing worsens.

Structural heart defects: Most structural heart defects are serious conditions, and are a major cause of stroke in young children and newborns. They are often repaired with surgery or procedures in the first few years of life.

Cerebral Aneurysms and Arteriovenous malformations (AVM): Normally blood flows from arteries into brain tissue and then drains back into veins to return to the heart. Rarely there are abnormally formed blood vessels where the arteries drain directly into the veins, and these are called arteriovenous malformations (AVMs). AVMs can cause swelling and bleeding in the brain, and are often treated with surgery, endovascular procedures or radiation. When a brain artery has an abnormal outpouching or balloon-shaped defect in its wall, it is called a cerebral aneurysm. These can rupture and are a major cause of brain hemorrhage. Unless they are very small when discovered, most aneurysms are treated with surgery or an endovascular procedure.

Obstructive Sleep apnea: Obstructive sleep apnea is a disorder of breathing that occurs during sleep. Breathing is often interrupted, and loud snoring or gasping can often be heard. When sleep apnea is severe and goes untreated, it can cause changes in heart function that can increase risk of ischemic stroke.

Blood clotting disorders: The process by which our flowing blood forms clots is vital to our survival, otherwise we would never stop bleeding after any nick, cut or bruise. Some people will have an increased tendency to form blood clots. Your doctors may do extensive blood tests to determine if you may be at risk for a blood clotting disorder. Treatment varies by condition, and anticoagulant medications are often prescribed to prevent ischemic stroke in patient with clotting disorders.

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If you are caring for someone who has had a stroke, remember that it is also important to make time to care for yourself. Many caregivers take responsibility for coordinating appointments, advocating for their loved one, taking on more household responsibilities, monitoring medications, providing emotional support and encouragement, and delivering physical care. These activities can be stressful, so it is important for you to also make time to focus on your own health and wellbeing.

It can be helpful to learn about stroke and the recovery process, and also make sure that you get the support you need. Take the time to attend your loved one's doctor's appointments if you can. Don't be afraid to take notes, ask questions, and find out more about how exactly your loved one's stroke might have affected them.

Reach out to family and friends for help. Often, in situations where your family is affected by a serious diagnosis, family and friends are always willing to lend a hand – they just need to know how! As a caregiver, visiting with friends and family, phone conversations, or even e-mails can go a long way. Don't be shy about giving people specific tasks such as cooking, cleaning, or shopping to help you manage.

You can also seek out additional resources such as online support networks, local stroke support groups, and mental health professionals such as therapists, social workers, and pastoral counselors who can listen to your questions and concerns, provide coping skills, and help you to better understand and address some of your emotions. If you find yourself feeling depressed or overwhelmed by the situation, contact your doctor to discuss treatment options. Depression and anxiety are common in caregiving. Know that you are not alone and help is available.

Continue to make time for yourself and the activities you enjoy. Find a relaxing activity for yourself, such as taking a walk, reading, meditation, yoga or Pilates, taking a bath, or listening to music. Make sure to take care of your physical health by eating healthy and enjoying regular exercise for at least 30 minutes most days of the week.



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