



# Understanding Stroke: A Guide to Your Care in the Hospital and Beyond



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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'. The signature is fluid and cursive, with a long horizontal line extending to the right.

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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



### What is a Stroke?

There are two different types of stroke, based on what has happened to the blood vessels in the brain. An **ischemic stroke** is caused when blood flow cannot get to the brain because an artery is blocked. This is the most common type of stroke, and is the cause in about 85% of all strokes. A **hemorrhagic stroke** is caused when a blood vessel bursts and there is bleeding into the brain. They are less common but more dangerous, and tend to cause more severe strokes. Many times doctors will refer to ischemic strokes simply as a “stroke”, so be sure to ask which type of stroke you had since the treatments can be very different.

The blood vessels that carry blood to the brain are called arteries. Arteries carry oxygen and nutrients to the brain which the brain requires for its energy supply. If a stroke occurs and blood flow cannot reach the area of the brain that controls a particular body function (such as arm movement), then that part of the body will not work as it should.

When the blood flow is interrupted, brain cells begin to die within minutes. If blood supply is restored quickly, many brain cells can survive and resume normal function. Even if brain cells do die from the stroke, other parts of your brain may begin to adapt to help you recover some of the lost functions.

#### Ischemic Strokes

There are 2 main causes of ischemic strokes.

- **Embolism:** Embolic strokes happen when a blood clot forms in another part of the body’s circulation system, like the heart or a larger upstream branch, and then travels downstream up into the brain until it gets stuck in a brain artery. This causes the blood flow in that artery to stop, just as stepping on the hose that supplies a lawn sprinkler will stop water from flowing to nourish that segment of the lawn.
- **Thrombosis:** Thrombotic strokes are caused when a brain artery is diseased due to plaque build-up or other injury, and a blood clot forms in that artery at the site of disease which blocks blood flow.

#### Hemorrhagic Strokes

There are 2 subtypes of hemorrhagic strokes.

- **Intracerebral Hemorrhage:** Intracerebral hemorrhage is caused when a blood vessel located within the substance of brain tissue bursts and leaks blood into the brain tissue. This blood quickly starts to solidify into a clotted mass called a hematoma, and puts abnormal pressure on the adjacent brain tissue. Those cells in that part of the brain stop functioning or die, and that part of the brain stops doing its job effectively.
- **Subarachnoid Hemorrhage:** Brain arteries travel through fluid filled cavities called the subarachnoid space on their way into the substance of the brain. When the blood vessel ruptures in this subarachnoid space, it is called a subarachnoid hemorrhage. They are usually caused when an abnormally formed blood vessel in the brain ruptures, and the most common type of abnormality is a balloon shaped defect in the wall of the artery called a cerebral aneurysm. Aneurysms can run in families, so it is important to tell your doctor if someone in your immediate family was diagnosed with a cerebral aneurysm.

### Transient Ischemic Attacks

A transient ischemic attack (TIA) occurs when blood flow to a part of the brain is only temporarily interrupted and no brain cells die. Unlike a stroke, symptoms are brief and fully resolve. TIA symptoms are the same as ischemic stroke symptoms, but they disappear quickly and do not cause permanent brain damage. If a stroke is like a blackout when all the lights and appliances abruptly shut off, a TIA is like a power surge when the lights flicker but come back on quickly. TIAs are sometimes called mini-strokes or warning strokes because the risk of a stroke increases significantly after a TIA, and is especially high in the first 2-4 weeks. If symptoms are brief but there is still evidence on brain scans of permanent brain injury, then this would be described as an ischemic stroke even though the symptoms resolved fully on their own. Either way, it is important to call 911 if you are having stroke symptoms, even if they resolve on their own, so that you can be evaluated by a stroke expert or neurologist.

### Stroke Signs and Symptoms

#### FAST

FAST is an acronym that helps people remember the common stroke warning signs. These are:

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

#### SUDDENS

FAST does not include all of the stroke warning signs and focuses mostly on the symptoms of ischemic stroke, but it is very easy to remember and has been a popular method of educating the public about stroke. But there are some other symptoms you may wish to learn about. Some of these are just more descriptive versions of FAST elements. Call 911 right away if you experience any of these symptoms.

**Sudden NUMBNESS or WEAKNESS of face, arm, or leg, especially if only on one side of the body**

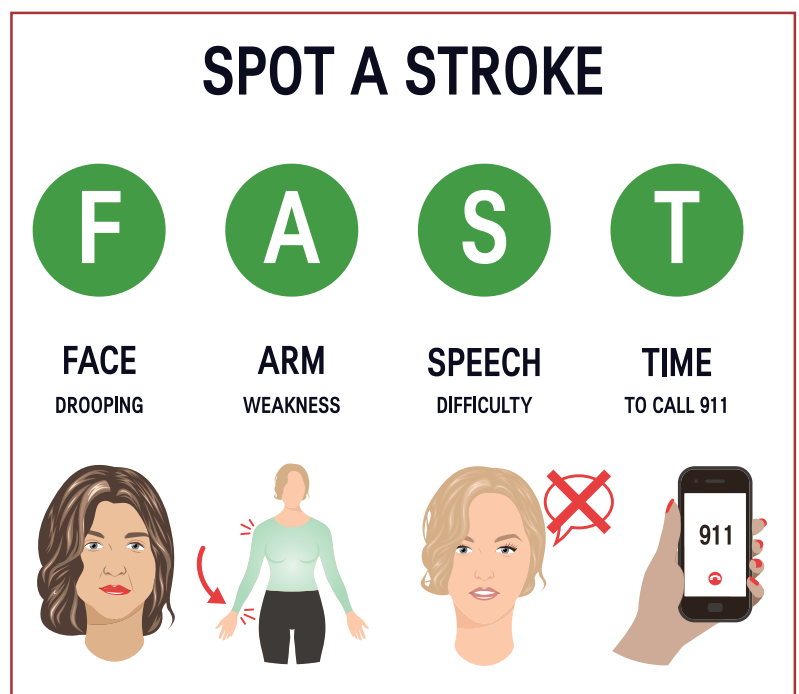
**Sudden CONFUSION, trouble speaking or understanding speech**

**Sudden TROUBLE SEEING in one or both eyes**

**Sudden TROUBLE WALKING, dizziness, loss of balance or coordination**

**Sudden SEVERE HEADACHE with no known cause**

It is important to call 911 as soon as stroke symptoms are noticed. This increases the chances of receiving treatments that can restore blood flow, relieve increased pressure on the brain, or prevent further injury.





## Stroke Risk Factors

There are a number of factors that increase your risk of having a stroke. Some of these risk factors you can do something about with medications or lifestyle changes. Other factors you cannot do something about, but it may still be helpful to understand more about them. We talk more about risk factors and what you can do to prevent future strokes in Chapter 6 of this booklet.

### Common Risk Factors You Cannot Do Something About



**Age:** Arteries become more rigid or diseased with age.

**Sex:** Women have more strokes than men, due in part to pregnancy-related conditions (e.g., pregnancy itself, preeclampsia, gestational diabetes), oral contraceptive use, and post-menopausal hormone therapy.

**Race and Ethnicity:** African-Americans and Hispanics are at an increased risk for stroke compared to Caucasians.

**Family History:** Your risk of stroke is increased if someone in your family had a stroke or a heart attack at an early age.

**Transient Ischemic Attacks or a Previous Stroke:** Your risk of stroke is increased if you have already had a stroke or TIA.

### Common Risk Factors or Conditions You Can Do Something About

(for more information, see Chapter 6)

- High blood pressure (hypertension)
- High cholesterol (hyperlipidemia)
- High blood sugar (diabetes)
- Physical inactivity and obesity
- Unhealthy diet
- Smoking tobacco
- Excessive alcohol use
- Estrogen-containing hormone use
- Atrial fibrillation
- Atherosclerosis
- Carotid artery narrowing
- Structural heart defects
- Cerebral aneurysms and arteriovenous malformations (AVM)
- Obstructive sleep apnea
- Blood clotting disorders





## Chapter Summary

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

### Treatment for Stroke in the Hospital

It is important to call for help and get to a hospital as soon as possible if you have symptoms of a stroke. This chapter talks about what you can expect during your hospital stay and immediately afterwards.

#### The Emergency Department (ED)

When you arrive at the ED, you will be met by a number of highly trained and specialized staff members including doctors, nurses, and others who care for patients with stroke and other emergency conditions. If you are admitted to a teaching or academic hospital, one where junior doctors are trained by more senior experienced doctors, you will most likely be cared for under the supervision of a neurologist who specializes in the diagnosis and management of stroke. Some hospitals have put in place the systems and services to be certified as a Stroke Center. There are many different levels of Stroke Centers, and they depend on how sophisticated and extensive the services are that they offer. Comprehensive Stroke Centers can perform emergency surgery or procedures to treat patients with major ischemic strokes or hemorrhagic strokes, and are often the destination of choice for ambulances transporting patients with a suspected major stroke. The emergency department team will perform a physical exam and obtain your vital signs. They will do blood tests and imaging tests to take pictures of your brain.



#### Your Hospital Stay

During your hospital stay, doctors and nurses will talk to you about your treatment options, your goals for care, medications, and rehabilitation. Below are some of the common tests and procedures that might be performed while you are in the hospital.

**Tissue plasminogen activator (tPA):** This is a clot-dissolving medication that can be given through an IV to dissolve a blood clot that is blocking blood flow to the brain. It must be given within the first few hours from the onset of a stroke, so your doctors will quickly determine if tPA is the right medication for you. This is why doctors may ask you or your family several times about exactly when the symptoms started and when was the last time someone saw you to be without the stroke symptoms.

**A Computerized tomography (CT) scan:** This is a quick scan of your head that takes pictures of your brain. The machine looks like a big donut and uses a small amount of radiation to make the pictures. It is very good at determining if you have had a hemorrhagic stroke, but it cannot always show if there has been an ischemic stroke. Almost all emergency departments have a CT scanner, and almost all patients with a suspected stroke will get a scan.





**Magnetic resonance imaging (MRI):** This is another tool for taking a picture of the brain. The MRI is a long tube or tunnel that you are placed inside, and it uses magnetic fields to make pictures. Patients who have devices that can be damaged or influenced by magnetic fields such as pacemakers and defibrillators may not be able to receive an MRI. You will be screened before you have an MRI to make sure it is safe for you. Many hospitals have access to an MRI in or near the ED, but not all stroke patients will get an MRI in the urgent phase of their stroke care.

**Carotid Doppler ultrasound:** This test uses ultrasound waves to look at the carotid arteries in the neck that travel up to the head to supply blood to your brain. It is a quick and noninvasive exam that provides information about possible areas of artery narrowing or blockage.

**CT or MR angiography:** These tests use either a CT or MRI machine to take pictures of the blood as it moves through the blood vessels in your head and neck. It can show where there are blockages, and determine if you might be eligible for the use of clot dissolving medications or clot-extracting devices. It often involves the injection of a contrast material which is a liquid that makes the flowing blood easier to visualize. You may be asked about prior allergies to contrast injections.

**Endovascular therapy:** This is a procedure for certain patients with blockages of the very large blood vessels in the brain. The blood clots that cause this type of blockage often do not respond to IV injections of tPA alone, and require a catheter to be placed directly into the clot to extract it out of the blocked artery. This procedure is sometimes called mechanical or endovascular thrombectomy, because it removes the thrombus (blood clot) that is blocking the artery. To reach the clot, a specialist will perform a catheter angiogram. This is done by numbing the skin over the upper leg area and placing a needle directly into the major artery in the leg to advance a catheter up into the brain under continuous x-ray guidance.

**Aneurysm clipping or coiling:** These procedures are performed for patients who had a subarachnoid hemorrhage caused by a ruptured aneurysm. Some patients require surgery performed by a neurosurgeon who will remove part of the skull and place a special metal clip onto the artery to seal it safely shut, while other patients will have the aneurysm treated using a catheter advanced into the damaged area to seal off the leaking segment.



### Treatment Locations after your Hospital Stay

Your team of doctors, nurses, therapists, social workers and case managers will work to identify the most appropriate care location and services for you after you leave the hospital. The primary goals of the “acute” hospitalization are to investigate what caused your stroke, start preventive treatments, and to make sure that you are medically healthy enough to start rehabilitation. The

goal of rehabilitation after stroke is to maximize your function, minimize your disability, and facilitate your return home in the safest way possible, whenever possible.

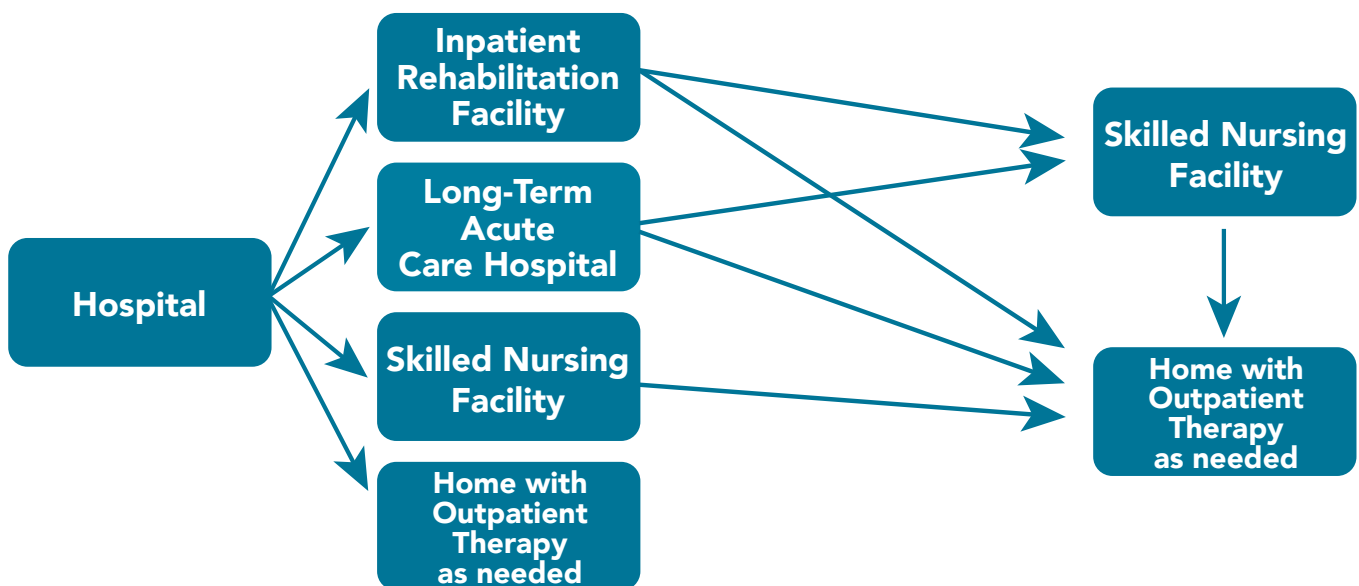
In some cases, you may be able to go directly home after the hospital. Case managers can work with you to make sure that the services you may need at home (such as visiting nurses and therapists) are identified for you, and that you get access to all the benefits to which you are entitled to pay for these services.

In other cases, because you will need time to regain strength and functioning after your stroke, you will be recommended to first go to a rehabilitation hospital or nursing facility. Each of these places have their own teams of doctors,

nurses, therapists, and case managers who will continue your care. The decision of what type of facility to go to next will involve an assessment of your level of function, your support network, your home environment and what type of health insurance benefits you have available to help you pay for the various treatments.

Below is a list of possible types of locations where you might go after the hospital. Your case manager will provide you with a detailed explanation of what each of these are and a comprehensive list of facilities.

- **Inpatient Rehabilitation Facilities** are dedicated hospitals or units that provide intensive rehabilitation services. They have many more therapists but fewer doctors than acute care hospitals, and to be referred here patients must be capable of engaging in many hours of therapy each day. Sometimes the nearest inpatient rehabilitation facility may be many hours from your home.
- **Long-Term Acute Care Hospitals** are facilities that specialize in the treatment of patients with medical conditions that require care on an ongoing basis but no longer require the level of care provided in an acute hospital.
- **Skilled Nursing Facilities** provide specialized medical care from registered nurses and rehabilitation



from therapists. Patients who have minimal medical needs or who are unable to engage in many hours of rehabilitation per day often are referred to these facilities.

Services at your home may be a possibility if you are safe to return to a home environment. Hospital case managers can help arrange services to help your rehabilitation and recovery at home.

## Rehabilitation

Rehabilitation is the process of helping you achieve the highest level of recovery of function, independence, and quality of life possible after your stroke. A coordinated team effort is paramount in helping you achieve your goals. Rehabilitation after a stroke will vary in intensity based on your needs, and can be provided in many different types of facilities. When someone on your care team says that you will be discharged to another facility for rehabilitation, or that you are “going to rehab”, you should ask what type of facility so you can participate meaningfully in the decision and not be confused.



### Members of your Care Team

**Neurologists** understand and treat disorders of the nervous system, including strokes. Your team at the hospital will often be led by a neurologist, and you will usually have one or more follow-up visits with a neurologist to discuss your stroke care and recovery. If you had another serious medical condition that brought you to the hospital, such as a heart attack or need for surgery, your team might be led by another type of doctor with a neurologist acting as a consultant.

**Physiatrists** specialize in rehabilitation medicine and the process of rehabilitation. Physiatrists manage your medical care during your stay at rehabilitation hospitals.

**Internists** will diagnose and treat many medical complications that may result from your stroke. For example, your primary care doctor is an internist. At rehabilitation centers, internists may help to manage medical issues that come up. After your discharge, it is important that you visit your primary care doctor to help ensure a smooth transition of your treatment plan.



**Nurses** provide care for you in different settings from the hospital to rehabilitation centers to nursing homes. Sometimes nurses will visit you at home to provide care. Your nurse will usually spend more time with you at the bedside than any other professional, and they usually serve as an excellent source of support, advocacy, education and comfort.

**Physical Therapists** assess the physical limitations that have resulted from your stroke and provide treatments that reduce pain, restore function, promote mobility, and reduce disability. You may be prescribed physical therapy after you are discharged.

**Occupational Therapists** evaluate functional limitations that have resulted from your stroke and provide treatments that help you achieve the things that you want and need to do in your everyday life. You may be prescribed occupational therapy after you are discharged.

**Speech-language Pathologists** assess, diagnose, and treat impairments in swallowing, communication (speaking, understanding, reading and writing), and cognition (thinking, remembering, planning) that result from your stroke. You may be prescribed speech or cognitive therapy after you are discharged.



**Pharmacists** help to manage and provide medications for you, and help make sure that the medicines you receive are compatible with each other and are within the expected dose range. Medication errors are common in hospitals, and though most are minor discrepancies in the time of administration or dosing, some can be serious. Make sure the doctors have a clear list of the medicines you have been prescribed at home and be honest about the ones that you don't actually take regularly or as prescribed.

**Social Workers** help to enhance your social functioning and overall well-being by helping you to re-integrate into your social networks and communities after your stroke.

**Case Managers** will help you to assess, evaluate, plan, and facilitate options, facilities, and services to meet your health and rehabilitation needs after your stroke.

### Keys for Rehabilitation Success

**Be Patient but Determined:** Recovery after stroke is a process that can take months to years. Be patient in the process of healing, but always strive to improve.

**Be Open:** Your brain and body are undergoing a substantial number of changes as you heal from your stroke. Be open to change the ways that you do things in your life and accomplish your goals.

**Ask for Help:** Recovering from stroke is a challenging process. Ask for help when and where and from whomever you need it. Your team is dedicated to your success.



### Palliative Care

For patients with severe strokes, who are elderly, or who have complex medical issues, palliative care can help. Palliative care is specialized medical care that focuses on helping patients with serious illness live the best quality of life possible. 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 healthcare choices and decisions
- Relieve symptoms of stroke, such as pain, nausea, or anxiety
- Provide emotional and spiritual support
- Help with understanding and completing advance directives
- Support caregivers

#### What is the difference between Palliative Care and Hospice?

Palliative care and hospice are not the same. Palliative care can be delivered at any time during the course of an illness and focuses on enhancing quality of life. Palliative care can work alongside medical treatments and help you and your family live well.

Hospice is a specialized service for patients who are near the end of life. Hospice prioritizes relieving your symptoms and ensuring comfort. Hospice can be delivered in a variety of settings, including the home environment, nursing homes, or hospice-dedicated facilities. If you are interested in hospice, the case manager can work with you and your family to determine what facility will work best.



## Chapter Summary

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

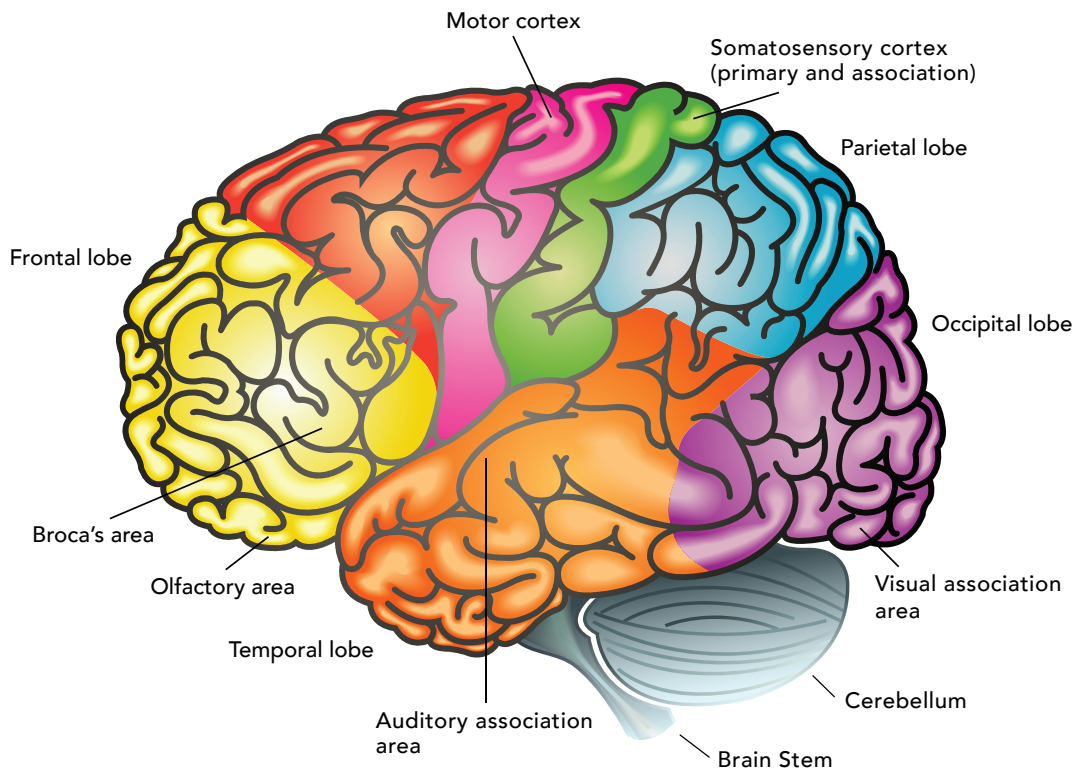
Writing down important information, watching body language, using simpler words, and removing distractions may help you deal with these changes.

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.

## Common Symptoms After Strokes Affecting Various Brain Locations

- Frontal lobe (left)** Difficulty looking to the right; right face, arm, leg weakness; difficulty producing speech; urinary retention; impulsivity; reduced ability to multi-task; lack of will or emotion
- Frontal lobe (right)** Difficulty looking to the left; left face, arm, leg weakness; urinary retention; impulsivity; reduced ability to multi-task; lack of will or emotion
- Temporal lobe (left)** Difficulty understanding words; speaking in a manner that is confusing or hard to understand; difficulty seeing the right side of the world
- Temporal lobe (right)** Difficulty seeing the left side of the world



- Parietal lobe (left)** Difficulty feeling or interpreting sensation on the right side of the body; impaired arithmetic skills
- Parietal lobe (right)** Difficulty feeling or interpreting sensation on the left side of the body; seeming unaware of objects or weakness on the left side; apathy
- Basal ganglia** Weakness of the opposite face, arm, and leg often to an equal degree
- Thalamus** Decreased sensation on the opposite face, arm, and leg; post-stroke pain
- Brainstem** Room-spinning sensation; double vision; difficulty swallowing; difficulty staying awake; weakness on one or both sides; slurred speech; difficulty with breathing and heart function; laughing or crying for no reason
- Cerebellum** Reduced accuracy of movements; imbalance or unsteadiness with falls; tremor; nausea
- Occipital** Inability to see objects on the side opposite the stroke

# Physical Changes After Stroke

## Muscle Weakness

The ability to move muscles of the face, arm, leg or trunk may be impaired after a stroke, varying from a mild weakness to complete inability to move. Arm weakness, especially in the arm that is dominant, may impair many activities of daily living such as eating and dressing. Occupational therapy can help you regain the ability to perform these activities.

Trunk and leg weakness may lead to difficulty maintaining balance while sitting or standing and limit the leg's ability to hold weight. This can impact the ability to walk and even stand or drive a car safely. Physical therapy is very helpful in diagnosing balance or gait disturbances and providing treatment. If appropriate, your doctor may prescribe fluoxetine, an antidepressant that has been shown in some studies to improve motor recovery.

Sometimes a stroke increases muscle tone which is the degree of muscle contraction at rest. This may cause the muscles to stiffen and make joints less mobile. Positioning devices and stretching exercises may help maintain joint flexibility to counteract the effects of increased muscle tone. You may also experience shoulder pain on the weaker or affected side of the body due to paralysis of muscles, including the rotator cuff. It is important to properly support and align the shoulder using special slings, pillows or other devices recommended by your occupational or physical therapist. Sometimes medicines or botox injections are prescribed to help reduce muscle tone or spasticity.

## Sensation

Some people experience changes to the sensory system after stroke. This may manifest as numbness, tingling, hypersensitivity and difficulty recognizing where your body part is in space. Changes in sensation can put your body at risk for injury.

Some exercises to help with sensation include:

- Touching different textured objects and trying to differentiate between them
- Hiding objects in a bowl of rice or dry beans and trying to find objects without looking
- Closing your eyes and having someone move your affected limb. See if you can tell what position it is in.
- Closing your eyes and having someone place objects into your hand. Try to determine what they are without looking.

Safety tips to compensate for sensory loss:

- Test water temperature with your unaffected arm or leg prior to bathing or washing
- Use unaffected hand to handle sharp objects
- Use specially modified utensils with large grips to avoid dropping items
- Use vision to observe where your limbs are in space



### Pain

Many stroke survivors will experience pain after stroke, especially if a limb is immobilized due to the stroke. Pain may be more localized to an affected arm or leg or can be considered central. Central pain is related to damage to neurological pathways where the messages to the brain are misinterpreted. It is important to tell your medical team if you are experiencing pain. Your doctors will work with you to prescribe medications and/or activity to manage both types of pain.

### Fatigue

Fatigue is common after stroke and can affect your ability to do everyday tasks. This can be frustrating because fatigue does not always resolve after taking a break or resting.

#### Tips for managing fatigue:

- Talk to your friends, family and employer about what you are experiencing
- Give yourself plenty of time to rest, including naps or scheduled rest periods during the day
- Be kind to yourself. Do not push yourself beyond your limits, especially if you are having a challenging day
- Give yourself plenty of time. It may take you longer to get ready to go places.
- Build up stamina and strength slowly and steadily. Maintain some level of regular exercise and gradually increase it. Your therapist can help you understand your new limits
- Eat a healthy diet. Include plenty of fruits, vegetables and whole grains. Consult your healthcare professional if you have questions about what diet is best for you
- Listen to your body. You are the expert on how you feel.



Sleep-related breathing disorders including obstructive sleep apnea are a common cause of unexplained fatigue, and occur frequently after stroke. They are experienced by many different patients, not just by those with the stereotypical body type (e.g., those who are overweight or have short thick necks or big tongues). Sleep apnea may limit stroke recovery or increase the risk of another stroke. Tell your doctor if you sleep poorly, awaken feeling unrefreshed even after a long night of sleep, or if your partner tells you that you snore loudly or choke or gasp for air during the night. Screening for sleep apnea should be considered if you have these symptoms.

### Vision

Some people experience visual changes after stroke. You may experience partial or total loss of vision in one or both eyes. Loss of peripheral vision can increase your risk of tripping or bumping into things. This is especially true when vision loss is compounded by visual inattention or neglect, a neurological condition



that impacts your ability to pay attention to one side of your body or the environment. Vision changes often make it unsafe to drive a vehicle, so it is very important to have these assessed and to review them with your doctor. Many patients may need to undergo a driving test or simulation before returning to driving to ensure they can safely operate a vehicle. It can take many months for visual function to return after stroke.

Eye muscle weakness can result in double vision, where objects are duplicated horizontally, vertically or at an angle. If you experience any of these visual changes, you may be seen by a neuro-ophthalmologist, a medical doctor who specializes in visual disturbances of the nervous system, who will determine a treatment plan. Sometimes eyeglasses with special lenses will be prescribed to help reduce double vision or other visual impairments.

There are several low-tech interventions that can help improve symptoms of visual changes, such as patching

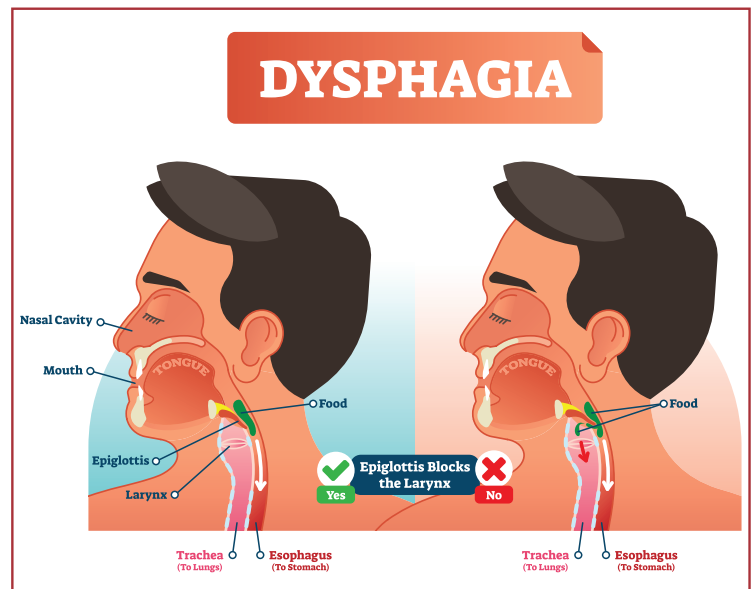
### Tips to reduce impact of visual impairments:

- Compensate for vision loss by scanning with the eyes to bring the unseen area into view
- Use frequent head turning to maximize field of vision in the environment
- Reduce clutter in the environment, especially objects low to the ground that can be tripped over
- Use bright tape to signify the start/end of the page of a book or magazine
- When reading, use a ruler to help avoid skipping lines when moving gaze back to the left margin of the page and minimize visual stimuli
- Increase illumination and contrast where possible

one eye to decrease double vision, visual scanning strategies to compensate for peripheral vision loss, and eye exercises to improve muscle strength and help the eyes move together.

## Swallowing (Dysphagia)

Swallowing problems, also known as dysphagia, can be quite common immediately after a stroke. This occurs because of damage to areas of the brain that control muscle movements, sensation, and awareness and coordination of the face, mouth, tongue and throat. Dysphagia following a stroke may be temporary, though some changes to swallowing may be more long lasting.





Swallowing may be unsafe following a stroke if you have difficulty staying awake, sitting upright, or feeding yourself. In addition, a strong cough, well-coordinated sequence of swallowing and stable breathing are important for safe eating and drinking.

When dysphagia occurs, it can lead to food or liquid going down “the wrong way” and entering the lungs. This is called aspiration and can lead to coughing or choking, or even pneumonia or other respiratory complications. Dysphagia also makes it hard to eat enough food to maintain your weight or drink enough to remain hydrated.

Aspiration is not always obvious and does not always lead to coughing/choking, especially when the stroke also causes sensory changes. This is called “silent aspiration” and may require special attention to be properly identified as a swallowing problem.

### Common Signs and Symptoms of Dysphagia

- Coughing or frequent throat clearing immediately during or after eating or drinking
- Wet, congested voice or shortness of breath immediately during or after eating or drinking
- Food or liquid remaining in the mouth after swallowing
- Food or liquid spilling from the mouth while eating or drinking
- Increased time or effort to get through a meal
- Feeling that food is sticking in your throat or chest region
- Frequent pneumonias or chest infections
- Unintended weight loss due to reduced intake

### Swallowing Evaluation and Treatment

The speech-language pathologist (SLP) is the team member who specializes in the diagnosis and management of swallowing disorders. Swallowing treatment aims to maximize safe and efficient nutrition and reduce aspiration and dehydration risk. In partnership with you and your family, treatment goals and decisions will balance your quality of life with health and safety risks. These may include identifying specific swallowing exercises, strategies, changes in head positioning and postures, and altering diet and liquid textures that make it easier for you to swallow.

The SLP will review your medical history and any history of swallowing problems, assess the strength and movement of the muscles of your face, mouth, and throat, and observe how you eat and drink. A further video xray test or endoscopy is often recommended to further examine your swallowing function and help determine best ways to help you safely eat and drink. Because proper nutrition is essential for recovery and maintenance of health, your doctors may recommend that a feeding tube be placed through the nose for temporary nutritional support and medication delivery, or through the wall of the stomach for longer term support if swallowing is not likely to recover for several months.



### Safe Swallowing Tips

Although targeted recommendations can only be made following a complete swallow evaluation, some general safety tips you might find helpful are:

- Sit up straight in your bed or in a chair when eating and drinking
- Take small bites of food and sips of drink and eat slowly
- Concentrate on eating and drinking and avoid distractions such as phone, talking, watching as on the television or being in large groups
- Check that food does not get trapped between the cheek and gums on the weaker side of the mouth. Brush your teeth and clean out your mouth after eating

### Communication (Aphasia)

Communication changes can occur when a stroke damages areas of the brain linked to talking, understanding, reading, and writing. This is called aphasia. The symptoms of a stroke may also include changes in cognition, which is the way we think, pay attention, remember, plan and organize. Losing the ability to communicate your thoughts, feelings, and ideas can be very challenging and isolating for you, your friends and loved ones.



Some difficulties for people with aphasia include:

- Thinking of the words you want to say or saying the wrong word
- Speaking nonsense words or mixing made-up words and real words together into sentences that do not make sense
- Having trouble understanding what others are saying, particularly when people are speaking rapidly, softly, over the telephone or in noisy or distracting environments
- Reading words, directions, books, and computer screens
- Spelling or putting words together to write sentences
- Using numbers, doing math, telling time, or counting money

When individuals have trouble clearly pronouncing or articulating words because of muscle weakness or dyscoordination, but understanding of speech is preserved, this is called dysarthria. In this condition, simple words or phrases can feel like hard to say tongue-twisters. Some difficulties for people with dysarthria include:

- Clearly articulating words or longer sentences
- Slurring your speech
- Controlling the volume of your voice (too loud or too soft)

### Cognition

Stroke may also affect “cognitive skills”, or thinking skills depending on where in the brain the damage occurred. Some difficulties for people with cognitive dysfunction include:

- Learning new things
- Remembering things you’ve been told, or people or events from your life
- Paying attention or not putting together complete thoughts
- Organizing your daily schedule, problem solving, multitasking; and accurately judging unsafe situations

#### Tips for Supporting Communication & Cognition

- Reduce background noise and distractions when speaking in a conversation
- Keep eye contact and watch body language and gestures
- Keep the words you use simple
- Use shorter sentences and repeat key words that you want to understand
- Slow down and over-emphasize pronunciation
- Ask “yes” and “no” questions that may be easier than questions needing a lengthy response
- Write down important pieces of information
- Use a calendar, daily planner, or your smart phone to set reminders
- Break-up instructions into smaller pieces
- Let people know you’ve had a stroke and ask them to speak more slowly and clearly



#### Seizures

Seizures are uncommon immediately following a stroke but occur in up to 20% of stroke survivors who had a stroke that involved the surface or cortex of the brain. Medications can help reduce the frequency and severity of seizures. Just as with loss of vision following stroke, many states restrict driving for individuals who have had a recent seizure or unexplained episode of loss of consciousness. Always check with your doctor if you are unsure about the safety of driving.

### Emotional Changes After a Stroke

Stress, depression, and anxiety are very common after stroke, and may interfere with recovery. Some examples of signs and symptoms that may occur include physiological (increased heart rate, difficulty breathing), cognitive (hopelessness, helplessness, worry, negative thoughts, loss of pleasure), emotional (sadness, fear, anger, guilt) and behavioral (isolation, unhealthy habits, sleep difficulties, challenges with following medical recommendations).

Post-traumatic stress also occurs in some patients who have had a stroke. Signs and symptoms include flashbacks and nightmares, intense fears and panic, fear of a recurrent stroke, difficulties thinking about the stroke experience, and hopelessness and helplessness.

Talk with members of your care team if you are feeling any of these symptoms during your time in the hospital, and tell your providers if you have struggled with mental health issues in the past since this may increase the benefit of an early intervention to support you. Early and effective treatments exist and can prevent chronic emotional symptoms that can impact your recovery.



### The following experiences are also common after stroke:

- Rapid changes in emotions, including being quicker to laugh or cry than before
- Frustration, anger, sadness, irritability, lack of motivation
- Sense of loss
- Intense panic
- Fear of recurrence
- Changes in eating and sleep
- Changes in mood, such as increased depression, anxiety, and/or anger
- Changes in thinking, such as problems with memory, attention, problem-solving, or judgment, which can affect your ability to drive, work, and make decisions
- Changes in behavior, such as odd language or actions

During your hospital stay, talk with your care team about any symptoms you may be experiencing, and ask for help. For the most part these symptoms improve as your physical recovery progresses. However, getting appropriate help in the hospital can make you feel more comfortable and speed your recovery.

After you are discharged, contact your primary care provider if you are concerned about depression, post-traumatic stress or any of the above experiences. Be sure to ask for help if you need it, since most symptoms can be treated. Treatment can include psychotherapy, medication, or both. Talk to your doctor if you need additional help managing your emotions. It may be helpful to talk to a psychologist or mental health specialist.

### Suggestions for coping with emotional challenges after stroke:

- Find other people who understand what you are going through, such as a stroke support group
- Get regular physical exercise
- Rest when you feel fatigued



- Schedule and do things you enjoy – at least one thing every day
- Celebrate the small steps and gains you make in your recovery
- Spend time with friends and family and others in the community
- Try to be patient but determined about the pace of your recovery—it is slow for many stroke survivors and can continue for months to years
- Take deep, slow breaths to calm your body.
- Try to meditate—use smartphone or computer apps available for free like Headspace or Calm
- Don't compare yourself with others or with who you were before the stroke
- Remember that setbacks, mistakes, and frustration are normal
- Try not to label your feelings as “good” or “bad”
- Talk positively to yourself and with compassion
- Work with your caregiver and family to communicate clearly, kindly, and simply about what help you need or how to work better together
- Think of things that fill you with a sense of gratitude



### Social Changes After Stroke

You may notice changes in your social relationships after stroke. Your social network, meaning the group of friends and family who surround you, may become smaller and more tightly-knit. For many people, this is a natural response to an illness event, and may lead to stronger relationships with the people who matter most to you.

Sometimes, however, these social network changes are not good for stroke recovery. Relationships with friends or acquaintances are lost, and there can be increased tension among family members. Friends, coworkers, and less familiar acquaintances can be surprisingly important to stroke recovery. They allow stroke survivors to engage in new conversations about fresh topics. These conversations allow you to practice language skills, cognitive reasoning, and social rituals. Patients who maintain ties with such friends and acquaintances often report better recovery outcomes after stroke. What we know for sure is that a stimulating social environment helps with recovery, so whatever path you take make sure it includes meaningful social connections and new experiences to keep your mind nimble and exercised.

To maintain social ties after stroke, it's important to do the following:

- Keep in touch with friends, coworkers, and acquaintances over any mode of communication that is comfortable such as in-person, online, by telephone, email, or texting
- Let friends and family know that you want them in your life after stroke

- Meet new friends at events that you are comfortable attending such as community events, dances, religious or cultural events
- Remember that you are not alone. Many other people are struggling with major emotional, physical or mental health challenges and you may find you have much in common

### Intimacy After Stroke

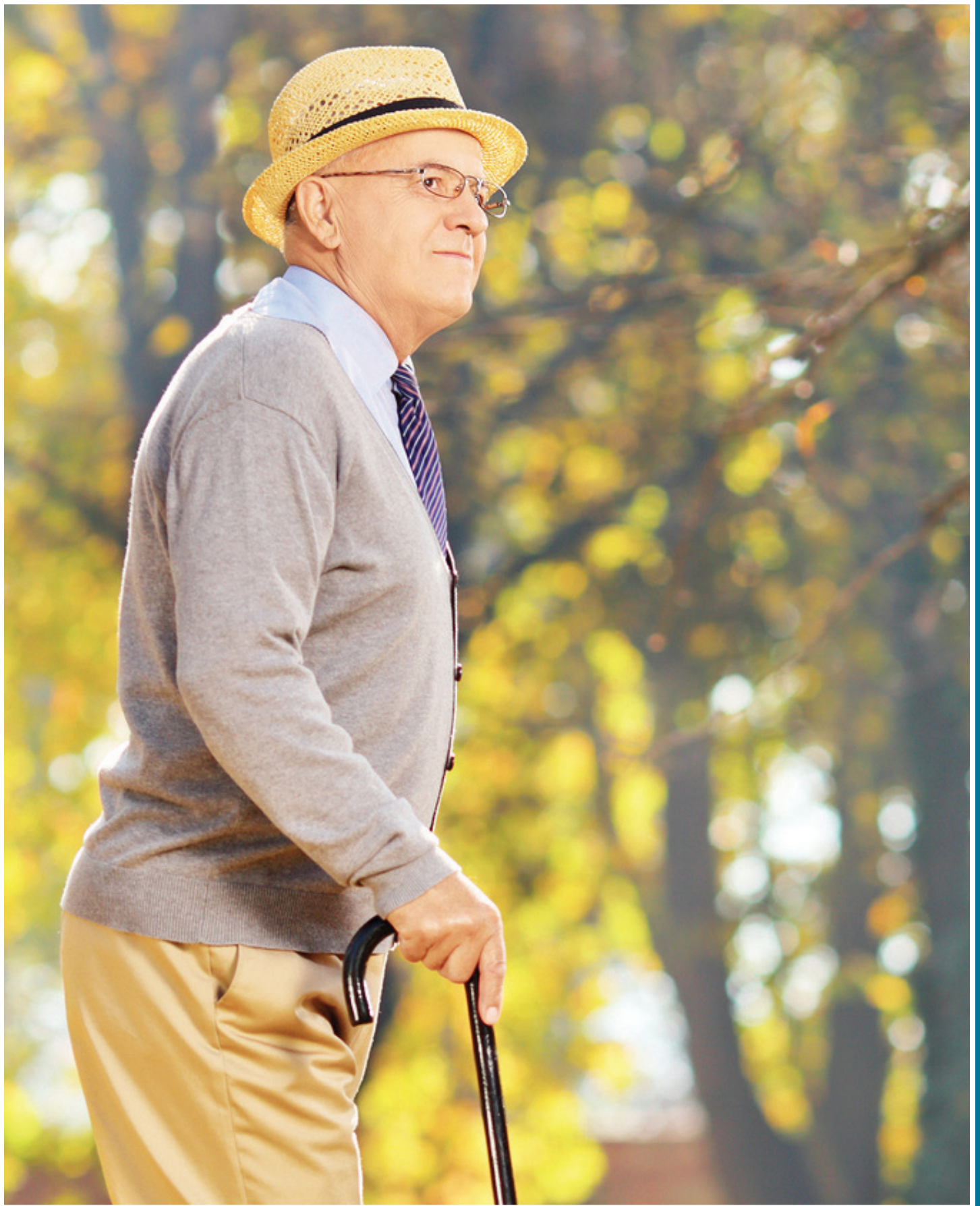
Stroke survivors often have questions about how to physically and emotionally connect with a partner after a stroke and if there are risks of returning to having sex after stroke. For most people, sexual activity does not increase the risk of having another stroke. However, it is important to talk with your doctor about when you may be medically ready to engage in sexual activity.

Stroke survivors may also notice changes in their level of sexual desire or arousal. Changes to sex drive or arousal are often a combination of both physical and emotional factors. They may be temporary and take time to process emotionally, or could be related to medications or the brain region damaged by the stroke. Some medications may have side effects such as reduced sexual drive, difficulty with achieving an erection or difficulty climaxing. Ask your doctor about how your medications may be affecting your sexual desire or arousal, and seek additional referral to a specialist if the recommendations of your doctor do not solve the problem.

Although it may take time to resume having intercourse or other sexual activity with your partner, there are alternative ways to express intimacy, such as holding hands, kissing, or cuddling. Explore what forms of affection work for you and your partner and find ways to incorporate them into your time together.

Communication in your relationship may also feel different. It can be useful to talk about your experience with your partner to help identify ways to support each other throughout the recovery process. Communication can be verbal or nonverbal (touch, gestures, written) and can bring about a new sense of shared understanding about what you are both going through.





## Chapter Summary

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.



### Home Modification and Daily Activities

Home modifications are changes made to adapt your living space, so you can live at your home or that of a loved one as safely and independently as possible. Home modifications may include simple steps or may be more involved depending on your needs.

Your rehabilitation team will assess whether you need any medical equipment at your home such as a wheelchair, walking device, hospital bed, or transfer devices. Your occupational therapist will assess what adaptive equipment you might need to perform daily activities safely and teach you strategies for adapting everyday tasks. This may include a chair for the shower, a commode or raised toilet seat, adaptive utensils for eating and cooking, and one-handed techniques for getting dressed. Certain features and their locations on clothing can make them very difficult to put on and take off after a stroke, such as laces, zippers, clasps and buttons. Your therapists or online stroke support websites may have suggestions for modifications such as elastic shoelaces, elastic waistbands, or bras without fasteners, to make you more independent in dressing and undressing.

Not all modifications are covered by insurance, but there may be other sources of funding available. Start by asking members of your healthcare team in the hospital or rehabilitation setting, community agencies, contractors and medical supply businesses, or places of worship.



#### Home modification tips for safety as needed:

- Remove things you can trip over (such as throw rugs, papers, shoes) from places you walk
- Remove doors, door sills or thresholds, and molding to widen doorways enough for wheelchair and walker access if needed
- Have handrails and lights in all staircases
- Keep items you use often in cabinets you can reach easily without using a step stool
- Install grab bars in the bathroom near the shower and toilet
- Use a bedside commode or raised toilet seat to help make toileting easier if needed
- Use a long-handled sponge or a bath mitt to make showering while sitting easier
- Rearrange furniture and rooms for one-level living as able



- Build or rent a wheelchair ramp where there are four stairs or fewer

### Understanding Your Medications

Before you leave the hospital, your doctor will likely prescribe new medications for you to take. It is important that you take your medications exactly as prescribed. Be sure that you and your family understand the following about each new medication prescribed:

- What is the name of the medication?
- What is the medication for?
- What dose should I take?
- How often do I take it?
- For how long will I need to take the medication?
- What are the possible side effects?
- What do I do with other medications I was taking before the stroke?



- What should I do if I miss a dose?

Note that many medications have two names, a generic name and a “brand” name. For example, atorvastatin is also called “Lipitor”. Generic versions in the US must be approved by the FDA before they can be sold, and to gain this approval they must show they are the exact same active ingredients and have the same effects. Don’t pay extra for brand name versions if generic versions are available.

Don’t stop or change the amount or frequency of any medication that you take without talking to your doctor. Abruptly stopping or taking too much of certain medications can be very dangerous.

Be aware that many over the counter medicines or supplements have aspirin or other active ingredients in them already, and can interact poorly with your prescribed medications, so always check the label before taking a new medicine. 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.

Commonly prescribed medications after stroke include those that work to prevent blood clots, or lower blood cholesterol, blood sugar or blood pressure. They are listed in the following table by their generic name with the common brand names in parentheses.

The process by which our blood forms clots is vital to our survival, otherwise we would never stop bleeding after any nick, cut or bruise. Medicines that inhibit the tendency of blood to clot are called antithrombotics and they mostly fall in two major categories: antiplatelet medicines and anticoagulants.

Unlike thrombolytic drugs like tPA that dissolve already formed blood clots, antithrombotics help prevent new clots from forming in inappropriate locations. There is always a balance that must be struck between preventing undesirable clotting versus encouraging too much bleeding. Most patients will be prescribed an antiplatelet drug after stroke to help prevent another stroke, and the most commonly used are aspirin and

<b>Examples of medications often prescribed for stroke prevention</b>		
<b>Medications that inhibit blood clots</b>	<b>Medications that lower cholesterol</b>	<b>Medications that reduce high blood pressure</b>
<b>antiplatelet medications</b>	Atorvastatin (Lipitor)	Lisinopril (Prinivil, Zestril)
Aspirin	Rosuvastatin (Crestor)	Losartan (Cozaar)
Clopidogrel (Plavix)	Simvastatin (Zocor)	Hydrochlorothiazide (Microzide)
Ticlopidine (Ticlid)	Lovastatin (Mevacor)	Chlorthalidone (Thalitone)
Dipyridamole/Aspirin (Aggrenox)	Pravastatin (Pravachol)	Labetalol (Normodyne, Trandate)
<b>anticoagulant medications</b>	Ezetimibe (Zetia)	Carvedilol (Coreg)
Warfarin (Coumadin, Jantoven)	Niacin	Atenolol (Tenormin)
Apixaban (Eliquis)	Fenofibrate (Tricor, Triglide)	Metoprolol (Toprol)
Rivaroxaban (Xarelto)	Gemfibrozil (Lopid)	Amlodipine (Norvasc)
Dabigatran (Pradaxa)	Cholestyramine	Hydralazine (Apresoline)
Edoxaban (Savaysa)		Prazosin (Minipress)
Enoxaparin (Lovenox)		

clopidogrel. These are given either alone, or may be given in combination for a period of time before one of them is stopped.

Antiplatelet medicines: Aspirin is the most commonly prescribed antiplatelet medicine, and it comes in two doses (75 and 325 mg) without a prescription, so be sure to get the correct dose. These drugs work by preventing clots from getting started on damaged blood vessels, often where there is a cholesterol plaque. Another common medicine in this group is called Plavix (or clopidogrel) and these are often prescribed for patients who have heart disease.

Anticoagulants are more potent medicines that prevent clots from forming in blood vessels all over the body, and increase the risk of bleeding more than antiplatelet medicines. They are prescribed less often and only in conditions where the risk of clots forming is significantly elevated, which occurs in diseases such as a heart rhythm disturbance called atrial fibrillation, in heart failure when the heart’s pumping function is very reduced, in the presence of some artificial heart valves, and in uncommon disorders of the clotting system.

Cholesterol reducing medicines help prevent cholesterol plaque from building up in our arteries, a process known as atherosclerosis. They have become a very important therapy in stroke prevention in recent decades. They work by removing cholesterol from the bloodstream so it has less chance to damage the arteries. This process also causes heart disease and heart attacks, and the statin class of cholesterol medicines are widely used to prevent heart disease as well. Most people with elevated cholesterol have a genetic mutation that makes their body produce too much cholesterol, so dietary changes are often not sufficient to achieve the necessary reductions in cholesterol.

## Chapter 4 – Transitioning Back Home

Insulin and other medicines help reduce blood sugar to prevent damage to arteries that is caused by excess sugar attaching itself to chemicals and proteins in the blood and to the vessel wall itself. Lastly, many different types of medicine are available to reduce blood pressure. They work by slowing down the heart rate, increasing the amount of urine produced, or relaxing the artery wall.

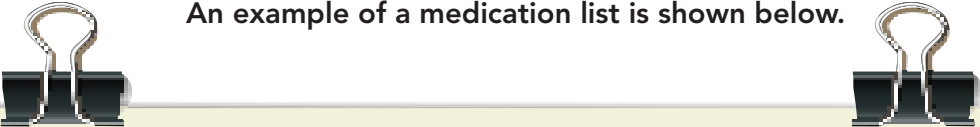
### Side Effects

Many medications prescribed after stroke can cause unwanted and unexpected symptoms, called side effects. Common side effects of stroke medications may include bleeding, easy bruising, muscle aches, and lightheadedness, especially upon standing. If you believe you are experiencing these or any other side effects of your medication, call your doctor right away. Do not abruptly stop any medications or change the dose you are taking without talking to your doctor.

### Managing Medications

Many patients find it helpful to keep a card or sheet with a list of all their medications, doses, and frequencies in an easy-to-find place, like in their wallet or on the fridge.

An example of a medication list is shown below.



Patient Name: Steven Survivor		Date Last Updated: January 24, 2019						
Medication Name on Bottle:	Purpose:	Dose:	When To Take:					Special Instructions:
			Morning	Breakfast	Lunch	Dinner	Bedtime	
Aspirin	Prevent clotting	81 mg		X				
Plavix	Prevent clotting	75 mg		X				Stop Feb 1st
Atorvastatin	Lower Cholesterol	80 mg					X	
Lisinopril	Lower Blood pressure	40 mg		X				
Labetalol	Lower Blood pressure	400 mg		X	X			
Metformin	Lower Blood sugar	850 mg		X	X			
Levothyroxine	Raise Thyroid	75 mcg	X					
Iron	Treat Anemia	200 mg	X					Take with juice

The following tips can help you remember to take your medications:

- Whenever possible, take your medications at the same time every day, for example, when you brush your teeth, with meals, or at bedtime
- Use a pillbox with separate compartments for each day of the week and each time of day. Fill the pillbox or ask a family member to help you fill the pillbox at the beginning of each week
- Set an alarm on a wristwatch, or use a smart phone app with reminder alarms
- Ask your family and friends to help remind you to take your medications

### Paying for Medications

After you leave the hospital, health insurance will usually cover most of the cost of your medications, though you often need to pay part of the cost as a “co-pay”. If you think you may have difficulty paying for your medications consistently, let your doctors know so they can prescribe more affordable medications and identify resources that may be available to assist you:

- Your social worker can help connect you to programs to assist with the cost of certain medications
- Your doctor may be able to work with your insurance company to secure coverage of important medications
- Your pharmacist may be able to identify lower cost generic versions of medications, when available
- Your health insurance company may be able to direct you to lower cost alternatives for filling your prescriptions, such as a mail order pharmacy service or Veterans Affairs Medical Center if you qualify

Be sure to let your care team know before you leave the hospital about any concerns you have regarding the cost of medications. Avoid trying to buy cheaper medications online from overseas as there is no quality control and these pills are often not what they claim to be.





### Follow-Up Appointments

Care for your stroke does not stop after you leave the hospital or complete your stay at a rehabilitation facility. You will have the option of having a range of care providers following you on a regular basis. The type and frequency of outpatient care will be personalized depending on your needs. At a minimum, you should have a follow-up with a neurologist as well as your primary care doctor.

A follow up visit with a neurologist will usually occur at around 3 months after your stroke. The neurologist will review the details of your hospitalization, assess your progress in recovery, and address any issues that may have come up since discharge. If any questions arise prior to your scheduled follow-up visit, please call your primary care doctor or the number provided on your discharge paperwork.

At the visit, you may be asked to complete some paperwork in the waiting room. To prepare for your visit, it is recommended that you:

- Arrive early
- Bring a list of all current medications
- Bring any questions that you have

You may choose to schedule a follow-up with a neurologist closer to your home, rather than with the neurologist affiliated with the hospital where you were treated. Please ask for copies of the paperwork and test results from your hospitalization so that you can bring this to your neurologist's office. This will be the best way to ensure that your doctor gets all the information that they need.



## Chapter Summary

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.



### Returning to Work

Going back to work after your stroke depends on the demands of your job, the effects of your stroke, your age, and good planning and communication.

After your stroke, you may:

- Return to previous employment without difficulty
- Return with some changes to your work environment, job demands, or behaviors
- Be unable to return to your previous job because your skills or abilities have changed
- Decide to retire



There are services available to assist you with returning to work. Employers have a responsibility to make reasonable accommodations in the workplace for employees who become disabled. It is important to work with your doctor and members of your rehabilitation team to determine if you can go back to your old job and what kind of accommodations, if any, you will need. Accommodations might include making some physical changes to your work environment or modifying your work schedule.

You may be close to or over retirement age and decide you do not want to return to work. You may be eligible for a retirement pension, employment insurance or a disability pension. You can talk with your social worker and/or human resource department to help you find out what benefits you are eligible for.

### What Are My Legal Rights After My Stroke?

The American with Disabilities Act (ADA) was signed into law in 1990 to prevent discrimination based on a person's disability and to promote greater accessibility in various settings. The ADA:

- Requires employers to provide reasonable accommodations to employees with disabilities.
- Requires that public services be available to people with disabilities and public transportation be accessible to people with disabilities.
- Prohibits retaliation, coercion, or retaliating against people with disabilities for people attempting to assert their rights under the ADA.

Please contact an attorney or specialist if you have legal questions about your rights or disability.



### If You are Unable to Return to Work Right Away

You or your family may have questions about employment and disability benefits after a stroke. The first place to start is calling your employer to discuss your benefit options. The amount of medical information you provide to them is up to you. However, it is generally helpful to inform your employer that you are currently unable to work and are interested in learning about what benefits you may qualify for. Your manager or the human resources department should then discuss your benefit options with you. Below are some basic guidelines for disability benefits.



#### Benefits from Your Employer

The Family and Medical Leave Act (FMLA) may be used for your own medical needs or to care for a family member (spouse, daughter, son or parent). Eligibility for this program depends on several factors, including the size of your employer and how long you have been at your job. Eligible employees are entitled to 12 unpaid work weeks over the course of a one year period. During this time, your job is protected and your health insurance coverage continues under the same terms and conditions you had prior to your leave. If you are eligible, your employer will give you FMLA paperwork which you will then need to complete with your care team.

Some employers provide short-term disability benefits in which they will pay you a percentage of your income during your absence from work. Similarly, you may be eligible for long-term disability benefits from your employer during an extended leave of absence.

#### Tips for a Successful Return to Work

- Do not rush through the recovery process
- Do not let external stressors outweigh readiness when deciding to return to work
- Know and understand your own limitations
- Start out slow and gradually increase activity
- Communication is key
- You are your own best advocate

### If You Are Not Sure You Can Return to Work

If you are unable to return to your previous job or type of work, you may want to consider a job that better suits your current abilities. There are resources available to help you determine what kind of work you might be suited for and vocational rehabilitation programs that may help you get training in a new type of job. 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.

You may want to consider pursuing new activities or do volunteer work that can provide social interaction and personal satisfaction. These activities may be a stepping stone to returning to work later. You may also be eligible for federal disability benefits after your stroke, including Social Security Disability Insurance and Supplemental Security Income.

### Driving

Regaining independence after stroke includes being able to get around in your community. Many stroke survivors will be able to drive again. Driving utilizes many of the skills that can be affected by stroke, such as vision and arm weakness, so it is important that you take the necessary steps to determine driving abilities prior to returning to the road.

- 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 the 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. This will include a vision exam as well as an assessment of your physical, visual and cognitive abilities to determine if you can move and react in ways to keep you safe on the road.

For some, an on-the-road driving assessment may be performed to look more closely at your skills. You may need retraining in driving skills or modifications to your vehicle to ensure safety. Driving rehabilitation assessment and services may be covered by insurance, but often these services are paid for by the individual or their family. Consult your insurance company for more information on your specific policy.

### If you are unable to drive

There are other ways to maintain independence and access to your community even if you are not able to return to driving after a stroke.

- Ride with family and friends
- Take a rideshare, taxi 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





## Chapter Summary

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 mid 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.

### Non-Modifiable Stroke Risk Factors

Age  
Sex  
Race and Ethnicity  
Family History  
Transient Ischemic Attacks or a Previous Stroke



### Modifiable Stroke Risk Factors

High Blood Pressure (Hypertension)  
High Cholesterol (Hyperlipidemia)  
High Blood Sugar (Diabetes)  
Physical Inactivity  
Unhealthy Diet and Obesity  
Smoking  
Excess Alcohol Use  
Estrogen-Containing Hormone Use  
Atrial Fibrillation  
Atherosclerosis  
Carotid Artery Narrowing  
Structural Heart Defects  
Cerebral Aneurysms and  
Arteriovenous Malformations (AVM)  
Obstructive Sleep Apnea  
Blood Clotting Disorders

## Risk Factors You Can Do Something About

### High Blood Pressure (Hypertension)

Blood pressure is the amount of pressure or force that is pushing against your blood vessels. High blood pressure damages the blood vessels by damaging the inner lining, increasing the risk for buildup of atherosclerotic plaque or stiffening of the arteries. There is no permanent cure for hypertension, but medication and lifestyle changes can help control the high blood pressure and reduce the risk of stroke.

Blood pressure is written in the form of two numbers. The top number is the systolic blood pressure, or pressure when your heart is beating. The bottom number is the diastolic blood pressure, or the pressure when your heart is relaxing. A normal blood pressure is less than 120/80 mmHg, but some patients with long-standing high blood pressure develop side effects at this level of control and so may need a slightly higher level.

When it comes to blood pressure, your doctor might have a specific target range that is right for you. They may recommend lifestyle modifications, medications, or other treatments to help keep your blood pressure within range. Having a consistently elevated blood pressure can increase your risk of atherosclerotic heart disease and both ischemic and hemorrhagic stroke.

Although your doctor checks your blood pressure each time you see them, this is only a one-time reading. This number may not be representative of your average blood pressure, or your blood pressure in other settings, such as when you are at home. It is important to come up with a plan with your doctor for monitoring and managing your blood pressure, and that often includes purchasing an inexpensive automated machine to check your pressures regularly at home.



### Tips to manage your blood pressure:

- Eat healthy meals: low in saturated and trans fats, low in salt (sodium), and with no added sugars
- Keep your weight or body mass index (BMI) in a healthy range. If you do not know what your BMI (a measure of height and weight) is or what range is right for you; you can ask your doctor.
- Take your medications as prescribed. If you are not taking them as prescribed due to side effects or cost, make sure to inform your doctor.
- Increase your physical activity. The American Heart Association recommends at least 40 minutes of moderate physical activity at least 3 to 4 times per week.
- Try to reduce stress through activities such as meditation or exercise.
- If you are a smoker, come up with a plan to quit. Smoking can increase blood pressure and can cause atherosclerotic narrowing and damage to your blood vessels.
- If you experience anxiety or depression, ask your doctor to refer you to a trained provider.



### 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. Most people with elevated cholesterol require medications to reduce their cholesterol, and the class of statin medications has been a powerful treatment to reduce risk of stroke and heart attacks in patients who have had a stroke.

**LDL:** this is considered “bad” cholesterol because it can lead to fatty build up in your arteries, putting you at a higher risk for stroke or heart disease including heart attacks. For patients with stroke and atherosclerosis, the recommended treatment is to lower the LDL cholesterol using the strongest doses of the statin medications that can be tolerated. For patients who cannot tolerate statins due to serious liver or muscle side effects, or simply don’t get their LDL low enough, there are now new treatment options with an injectable cholesterol reducer called PSK-9 inhibitors that have shown powerful results in preventing heart disease.

**HDL:** this 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. The recommended HDL cholesterol should be at least 40 mg/dL. You can increase your HDL by consuming foods rich in omega-3 fatty acids like fish and nuts.

Total cholesterol is the measure of cholesterol in your bloodstream. The recommended fasting total cholesterol level is less than 200 mg/dL.

### Tips to maintain a healthy level of cholesterol:

- Have your cholesterol checked annually and speak to your doctor about your numbers, your goals and treatment options.

- Talk to a nutritionist or dietitian about a heart healthy diet, limiting saturated fats and cholesterol.
- Maintain a healthy weight and get the recommended amount of weekly exercise.
- Take your medications as prescribed. If you are not taking them as prescribed due to side effects or cost, make sure to inform your doctor.



### 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 that is secreted by an organ in your body called the pancreas, and it 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 in controlling your blood culture (Type 2 diabetes).

The prevalence of diabetes is increasing, even in younger populations. This is due to a higher number of people who are overweight, don't eat a healthy diet, and don't get the recommended amount of exercise. Also, due to genetics, there is a higher rate of diabetes in those who are of Hispanic or Latino, African American, Native American, and Asian descent.

Blood glucose or sugar is easily measured by a simple lab test. Hemoglobin A1c (HbA1c) is a blood test that looks at how your blood sugars have been on average over the past few months. This test might be used for patients with prediabetes (A1c 5.7 - 6.4) and diabetes (A1c  $\geq$  6.5).

Some common symptoms of diabetes include excess hunger and thirst, urinating frequently throughout the day, dry mouth and itchy skin, slow-healing cuts or sores, or numbness or tingling in your feet. If you have any of these symptoms, it is important to talk to your doctor. Doctors also typically test your HbA1c level during physical exams.

Diabetes can cause excess glucose in the bloodstream which over time can lead to increased fatty deposits or clots inside blood vessels. These fatty deposits or clots can block the blood supply to the brain, preventing oxygen from reaching brain tissue causing a stroke.

### **Tips for managing diabetes:**

- Talk to your doctor or endocrinologist (diabetes specialist) about how to manage your diabetes.
- Eat healthy meals low in saturated and trans fats, also low in salt (sodium), and avoid added sugars (carbohydrates).
- Keep your weight or body mass index (BMI) in a healthy range. If you don't know what your BMI (a measure of height and weight) is or what range is right for you; you can ask your doctor.
- Take your medications and/or insulin as prescribed. If you are not taking them as prescribed due to side effects or cost, make sure to inform your doctor.
- Increase your physical activity. The American Heart Association recommends at least 30 minutes of moderate physical activity at least 5 times per week for a total of >150 minutes per week.

### Physical Inactivity (Time spent being sedentary)

Exercise is recommended for 30 to 40 minutes at least 4 days a week, or preferably 7 days per week, to lower your risk of heart attack or stroke. If you find 30 to 40 minutes too difficult starting out, break it up into 10 or 20 minute sessions throughout the day. If you find yourself sitting for too long, set an alarm on your phone to take a 1 minute walk around the house or workplace every hour.

Exercise does not have to be vigorous, but it should be enough to elevate your heart rate above resting levels and make you a bit short of breath while still allowing you to talk through the exercise. 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

If you have had a stroke or heart disease, are over 45 years of age, and have 2 or more risk factors for cardiovascular disease (immediate family member with heart disease, cigarette smoker, hypertension, elevated cholesterol levels, diabetes, obesity, or sedentary lifestyle), it is recommended that you speak to your doctor before starting an exercise regimen.

### Unhealthy Diet and Obesity

There are many reasons to maintain a healthy weight. Here are a few:

- Your body can more efficiently circulate blood throughout the body
- You are less likely to develop diabetes, heart disease, certain types of cancers, and breathing problems including sleep apnea
- You will have more energy and an increased self esteem

In order to lose weight, it is important to not only get the recommended amount of daily exercise but to also follow a healthy diet. The best studied and healthiest type of foods are found in a Mediterranean style of eating.



### Tips for Eating Healthy and Losing Weight:

- Read food labels to understand which foods contain added sugars, salt, hydrogenated oils, saturated, and trans fats
- Watch your calories and try to consume fewer than you burn during physical activity
- Try to eliminate soda and sugary juices by drinking more low calorie options such as water with your favorite fruit, seltzer waters, and caffeine free teas
- Drink enough water to keep yourself hydrated throughout the day. For most individuals 2 to 3 liters of total water (including what you consume in food) is recommended. Check with your doctor if you have a fluid or water restriction.
- Eat smaller portions
- Eat a variety of food groups and avoid limiting an entire food group – it's all about moderation
- 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 which can keep you accountable and on track to reach your goals
- Discuss making lifestyle changes with your partner and family. Having support and eating similar meals can help make healthy eating stick.



#### The good (what to include in your diet)

Fruits and vegetables

Whole grains

Beans and legumes

Nuts and seeds

Fish (those rich in omega-3 fatty acids)

Lean meats such as skinless chicken

Low fat dairy products

Healthier fats such as olive oil and avocado

#### The bad (what to limit in your diet)

Added sugar, including sugary juices and soda

Excess sodium (salt)

Saturated fats such as butter, lard, fatty beef, pork, lamb, cheese, whole or 2% dairy products, chicken skin

Trans fat – hydrogenated oils, fried food, and pastries including doughnuts, cookies, muffins, pies, and cakes



### Smoking

Smoking is a significant risk factor that can double the risk of stroke. Smoking causes atherosclerosis or plaque build-up on arterial walls which make blood clots more likely to form. It also raises blood pressure, decreases HDL or good cholesterol, and increases LDL or bad cholesterol. You should also discuss the safety of smoking marijuana with your doctor, especially if you have 1 or more other risk factors for stroke or heart disease.

Cannabis or marijuana has been shown to have an effect on the cardiovascular system including elevated heart rate and high blood pressure. In some individuals, it has been also shown to cause vasospasm – which is a temporary narrowing of the blood vessels making it difficult for blood and oxygen to get to brain tissues.

Why should you quit smoking? You will get immediate cardiovascular benefits!

In 20 minutes: Your heart rate and blood pressure decrease

In 48 hours: Your ability to smell and taste improves

In 1 to 9 months: Coughing and shortness of breath decrease and your lungs are more effective

In 5 years: Your stroke risk reduces dramatically and is similar to a non-smoker after 5 to 15 years of quitting

In 10 years: Lung cancer death rate is about half of someone that continues to smoke and the risk of cancer in the mouth, throat, esophagus, bladder, cervix, and pancreases decreases

In 15 years: the risk of heart disease is the same as a non-smoker

### Tips for Quitting:

- Discuss treatment options with your doctor, including medications, nicotine supplements, and addiction therapy
- Explore resources and programs available to help you
- If your partner smokes, talk to them about quitting together. This will drastically increase your chances of quitting and remaining abstained from tobacco exposure.
- Plan to quit more than once, since many smokers must try several times before they finally succeed

### Excess Alcohol Use

If you drink alcohol, it is recommended that you do so in moderation. According to the American Heart Association (AHA), this means on average less than two drinks per day for men and one drink per day for women. People pour drinks of different sizes, and different beverages have varying amounts of alcohol.



In general, 1 drink equals:

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

Drinking more than the recommended amount of daily alcohol can predispose you to high blood pressure, high cholesterol, obesity, stroke, dementia, breast cancer, suicide, and accidents.

Excessive drinking can cause stroke, cardiac arrhythmias (abnormal heart rhythm), or cardiomyopathy (disease of the heart muscle). Those with prolonged exposure to alcohol are at a higher risk of developing brain atrophy (shrinkage), premature dementia, and peripheral nerve damage in the form of neuropathy.

There are some studies that suggest benefits of moderate alcohol consumption as above such as increased HDL cholesterol and anti-clotting properties. However, the AHA does not recommend that non-drinkers start drinking for these reasons. You should speak to your doctor about the benefits and risks of drinking alcohol in moderation.



### Estrogen-Containing 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. Standard dose hormone therapy can increase a woman's risk by up to one-third compared to women who do not use hormone therapy. This risk is greater for women older than 60 years of age, especially for women who smoke or have certain types of migraine headaches.

Discuss the use of birth control or hormone replacement therapy carefully with your neurologist and/or Ob-Gyn specialist. If you are currently on hormone therapy, make sure to discuss with your doctor before abruptly discontinuing the medication. There may be other options available such as a hormone patch that do not pose the same risk as other estrogen containing medications or therapies

### Atrial Fibrillation

Atrial fibrillation (Afib) is an abnormal heart rhythm where the upper two chambers of the heart beat rapidly and irregularly (sometimes up to 300-400 times per minute), 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.

Afib can place you at a significantly higher risk of having a stroke compared to those without Afib. It is important to know that proper management of Afib by a doctor such as a cardiologist can prevent you from having a stroke. Those with Afib are most often treated with an anticoagulant medication (often called a “blood-thinner” even though it doesn’t actually make your blood thinner) to help prevent blood clots from forming. There are other ways to manage Afib-related complications such as with heart rate controlling medications or cardioversion (a procedure to convert your heart rhythm from Afib back to a regular rhythm) but this is not always successful.

If you have Afib and are not on a blood-thinner, it is important to discuss this with your doctor. Some people have reasons why blood thinners are not prescribed, usually due to an increased risk of bleeding. If you are prescribed blood thinners, it is very important to not miss any doses and take them exactly as prescribed. If you don’t take enough medication, your risk of stroke will increase, and if you take too much medication you increase your risk of bleeding.

### Symptoms of Afib include:

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

Some people do not have any Afib symptoms. If this is the case, your doctor may be able to pick up Afib on an EKG during your general physical exam if you are in Afib at the time. However, since most patients go in and out of Afib it can be difficult to capture it on a periodic EKG test.

If your doctor has a high suspicion for Afib, he or she will recommend that you wear a long-term heart rhythm monitor for up to 30 days or have an implantable heart rhythm recording device implanted underneath the skin of your chest which can monitor for longer periods.

Some patients with Afib cannot tolerate blood thinner medications. For these patients, newer procedures to reshape the left atrium of the heart may offer some protection against stroke. Ask your doctor if you might benefit from this alternative treatment strategy.

### Atherosclerosis

Atherosclerosis is defined as the hardening of your arterial blood vessels due to the build-up of plaque in your arteries. Arteries are blood vessels that carry oxygen-rich blood to your heart and other parts of your body. Atherosclerotic plaque is made up of cholesterol, calcium, and other undissolved substances found in the blood. Over time, this plaque can harden and narrow your arteries thus limiting the flow of oxygen-rich blood to various parts of your body, particularly your heart and brain. Furthermore, build-up of cholesterol and calcium rich plaque in your neck arteries can cause progressive narrowing of these arteries and limit blood supply to your brain. Sometimes a small piece of that plaque can dislodge and travel to an artery in

your brain causing it to block. This can lead to an embolic ischemic stroke. Atherosclerosis can begin in early adulthood and increases as you age.

### 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. If you experience a stroke due to a carotid artery narrowing and it is at least 50% blocked, your doctors will likely recommend surgery or stenting to re-open the artery and reduce your risk of a subsequent stroke. If you have never had any stroke symptoms and the carotid narrowing was only detected on screening tests, your doctor may recommend intense medication treatment rather than surgery to prevent a stroke.

### Structural Heart Defects

Most structural heart defects are serious conditions, and are a major cause of stroke in young children and neonates. They are often repaired with surgery or procedures in the first few years of life. However, one particular structural heart condition is normal in human fetuses before birth, but if it persists after birth it can increase risk of stroke. All human fetuses have a patent foramen ovale, which is a connection between the two upper chambers (right and left atrium) of the heart when the fetus is still in the mother's womb. This is how blood containing oxygen and nutrients travels from the mother's placenta via the umbilical cord to the baby. In most people, this connection closes permanently at birth, and all blood returning to the heart from the body via the veins to be filtered by the lungs which can remove carbon dioxide and small particles. In some people, this connection remains open, on rare occasions for blood clots or other material to travel across the wall that separates these two chambers, bypassing the lung and going directly up to the brain where they can cause an ischemic stroke.

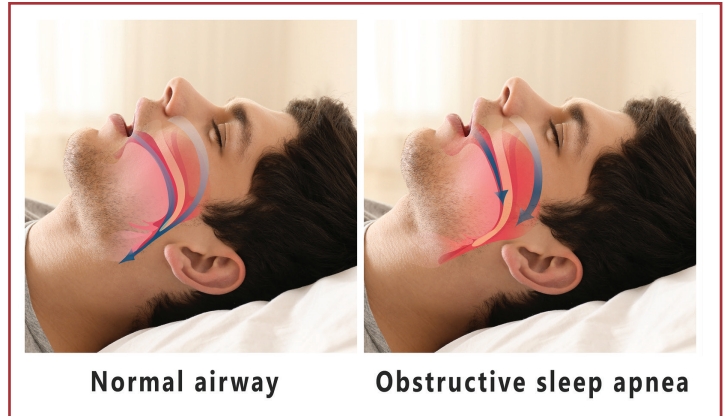
### Cerebral Aneurysms and Arteriovenous Malformations (AVM)

Normally blood flows from arteries into brain tissue via tiny blood vessels called capillaries 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 endovascular procedure.



### Obstructive Sleep Apnea

Obstructive sleep apnea is a disorder of breathing that occurs during sleep. It occurs when the smooth flow of air is intermittently blocked by the collapsing of the muscles of the throat or other structures in the mouth. 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. Treatments for obstructive sleep apnea are available and include the use of devices to keep the airway open either through applying air pressure through a mask or inserting a mouthpiece to adjust the jaw.



### Blood Clotting Disorders

The process by which our 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 ("hypercoagulable" or "prothrombotic" disorders). Many of these conditions are due to genetic mutations that are inherited, but some can also arise spontaneously either due to the production of antibodies or for unclear reasons. Some of these genetic conditions are common, such as sickle cell anemia, but most are quite rare. Your doctors will do extensive blood tests to determine if you may be at risk for one of these blood clotting disorders. Treatment varies by condition, and anticoagulant medications are often prescribed to prevent ischemic stroke.



## Chapter Summary

If you are caring for someone who has had a stroke, remember that it is also important to make time to care for yourself. It can be helpful to learn about stroke and the recovery process, and also make sure that you get the support you need. Do not hesitate to reach out to family and friends for support, or seek out specific support groups online or in your area. Continue to make time for yourself and the activities you enjoy.

## Tips for Caregivers

If you are caring for someone who has had a stroke, remember that it is also important to make time to care for yourself. It can be helpful to learn about stroke and the recovery process, and also make sure that you get the support you need. Do not hesitate to reach out to family and friends for support, or seek out specific support groups online or in your area. Continue to make time for yourself and the activities you enjoy.

Having a stroke can be a scary, confusing, and difficult time for not only the person who suffered the stroke but also for their closest friends, family, and caregivers. There are cognitive, emotional, physical, social, and financial changes in one's life that occur after a stroke. Often, the caregiver is responsible for coordinating appointments, advocating for their loved one, taking on more household responsibilities, monitoring medications, providing emotional support and encouragement, and delivering physical care. The responsibilities of caregiving can be stressful, and it is important for the caregiver to also maintain their own good health. However, it can also be a rewarding process as you help your loved one recover.



## Know the Facts

Information is power! The more you as a caregiver can learn about stroke and recovery, the more empowered you will feel about understanding all the changes that can happen following a stroke. 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.

There are many different types of strokes that involve different areas of the brain. Understanding where a stroke occurred can help you understand some of your loved one's symptoms or changes in their emotional or physical health. Chapter 3 of this booklet discusses many of these changes in more detail. They include depression, anxiety, swallowing difficulties, and communication difficulties.

### Get Support

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 afraid to ask for help. Many people will offer to help, but don't know what you need. Don't be shy about giving people specific tasks such as cooking, cleaning, and 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.

### Take Care of Yourself

Stroke caregivers are happier when they can enjoy their own hobbies and interests. 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.



Share your feelings with others. Confide in a close friend or family member or look for caregiver support groups in your area to meet others and share your experience, joys, and frustrations. Try to avoid negative thoughts. 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.

It is important to understand and appreciate the benefits of caregiving and helping your loved one through this difficult time. Caregiving can offer many positive experiences for the caregiver and their relationship with the stroke survivor. Work with your loved one who survived a stroke and your family to communicate clearly, kindly, and simply about what help is needed and how to work better together.

# Acknowledgements

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