My Stroke Resource Guide

PennState Health

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My Stroke Worksheet

I was admitted on: _____

I was discharged on: _____

The type of stroke I had was: _____

My stroke symptoms were: _____

My stroke was:

☐ On the **right** side of my brain

☐ On the **left** side of my brain

☐ Due to a blocked blood vessel (ischemic)

☐ Due to a damaged blood vessel bleeding into brain tissue (intracerebral hemorrhage)

☐ Due to a damaged blood vessel bleeding into the area between the brain and its lining (subarachnoid hemorrhage)

The cause of my stroke was:

_____

_____

_____

We aren't 100% sure what caused this, but it could have been because:

_____

_____

_____

The treatment I received was:

☐ Tenecteplase (Clot dissolving medication)

☐ Thrombectomy (Clot removal surgery)

☐ Surgery: _____

_____

_____

☐ Medical management

My Stroke Worksheet

My personal risk factors:

☐ High blood pressure	☐ High cholesterol
☐ Atrial fibrillation (aFib - irregular heartbeat)	☐ Coronary artery disease
☐ Diabetes	☐ Excess weight and inactivity
☐ Smoking	☐ Alcohol abuse
☐ Drug use	☐ Clotting disorder
☐ Sleep apnea	☐ Previous stroke/TIA
☐ Contraceptives/hormone replacement therapy	☐ Family history of stroke before age 65

☐ Other risk factors: _____

_____

My Stroke Prevention Medications

See page 25 for a list of common stroke medications.

Medication	What is it for?

My Action Plan

Goal blood pressure: _____

Goal cholesterol:

HDL _____ LDL _____ Total _____

Hemoglobin A1C:

Current _____ Goal _____

Mobility: _____

_____

_____

Communication: _____

_____

_____

Self-care:

Other risk factors: _____

_____

_____

Other personal goals: _____

_____

_____

Daily Blood Pressure Log						
Mon	**Tues**	**Wed**	**Thurs**	**Fri**	**Sat**	**Sun**

My Follow-Up Appointments

Follow-Up Appointment Information will be located on your discharge paperwork.

You can expect a follow-up appointment with (circle all that apply):

Cardiology Neurology Neurosurgery Primary Care Provider (PCP) Other_____

Questions for Follow-Up Appointment

_____

_____

_____

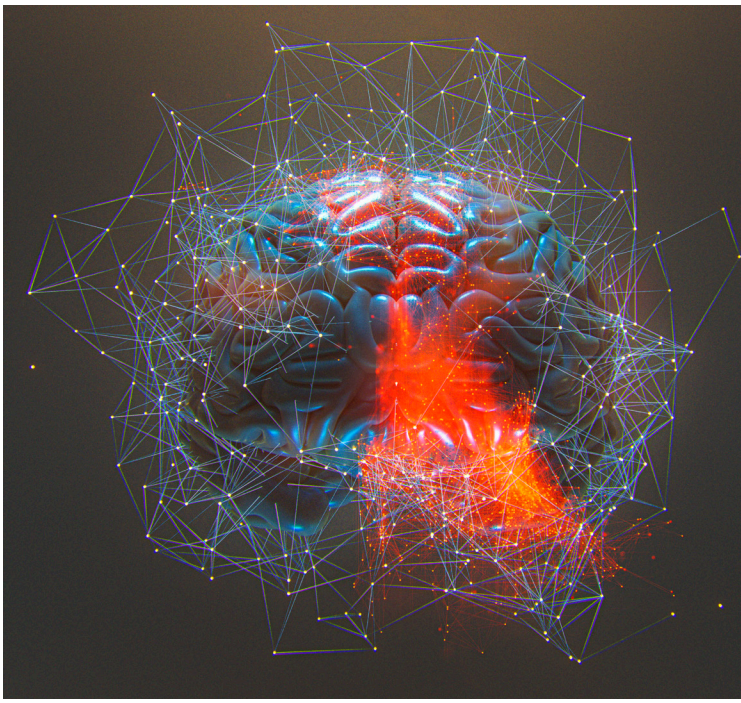
_____

_____

_____

_____

What is a Stroke?



A stroke is an event that affects the blood flow in the brain. This happens when a blood vessel bringing blood to the brain is blocked or bursts, and the area involved can't get oxygen or the nutrients it needs. Without these things, the nerve cells begin to die.

Your brain is complex! It helps control everything about you. Brain injury from a stroke can affect how you move, speak, think and behave.

This booklet has important information to help you through your hospital stay and beyond. Use this booklet to help guide conversations with your health care team and caregivers.

What Happened?

When you come to the hospital, we quickly try to figure out what is happening to you or your loved one. Through testing, we determine what type of stroke you are having.

Ischemic Stroke

- The **most common** kind of stroke.
- Happens when a blood clot blocks a blood vessel in the brain.

Hemorrhagic Stroke

- **Less common**. Only around 20% of strokes are hemorrhagic.
- Happens when a blood vessel bursts or tears and causes bleeding in the brain.

Transient Ischemic Attack (TIA)

- Seen as a warning sign.
- Stroke symptoms quickly resolve themselves with no deficits.

A note about TIAs

A TIA, sometimes called a "mini stroke," occurs when a blood clot blocks an artery for a short time. The symptoms are similar to those of an ischemic stroke, but they usually last only a few minutes. TIAs are strong predictors of future strokes. Roughly 33% of patients with a TIA will have a stroke in the future.

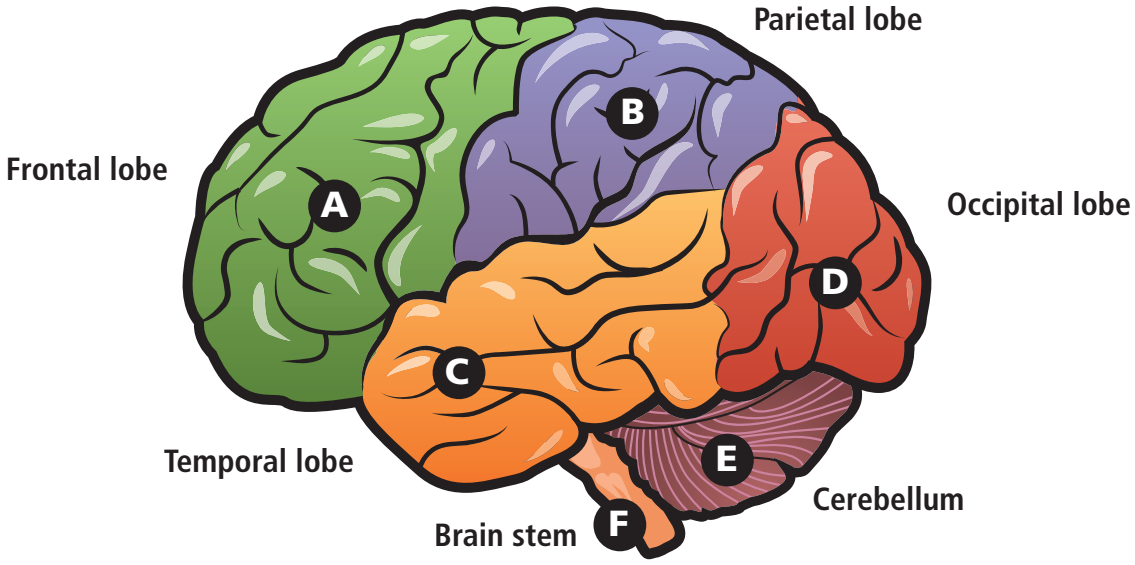
Intracerebral Hemorrhage (ICH)

Occurs when a blood vessel in the brain breaks open and blood leaks into the brain tissue.

Subarachnoid Hemorrhage

Occurs when a blood vessel tears or bursts in the outside layer that surrounds the brain.

Understanding My Brain



Area of Brain and Function		Possible Impact of Injury
A	**Frontal lobe:** In charge of self-awareness, judgement, problem-solving, language and movement	• Changes in personality or mood • Difficulty thinking clearly or problem-solving • Language deficits or paralysis
B	**Parietal lobe**: In charge of processing sensory information, such as touch, pain, hot and cold	• Problems with recognizing where your body is in a space • Trouble with purposeful movements • Problems with math
C	**Temporal lobe**: Helps with understanding language and forming new memories	• Difficulty understanding what people are saying • Memory issues
D	**Occipital lobe**: Controls depth perception and vision	• Problems with reading, writing and recognizing words or pictures • Vision trouble
E	**Cerebellum**: Controls balance, coordination and movement	• Difficulty with fine motor coordination and balance • Trouble with walking and standing upright • Dizziness and slurred speech
F	**Brain stem**: Controls breathing, heart rate, reflexes, swallowing, eye movement and level of alertness	• Problems with basic functions • Breathing and swallowing difficulties • Changes in sleep cycles

Treatment Options:
Ischemic Stroke

Every minute counts with stroke. Our treatment options depend on an accurate and precise time of "last-known well" – this is the date and time at which you were last known to be without the signs and symptoms of the current stroke. Your health care team likely asked you or a witness for the last time you were "normal."

There are a few timelines your health care team considers when choosing a treatment option for you or your loved one experiencing **ischemic stroke**.

- 4.5 hours from last known well for **intravenous thrombolytics**. These drugs are commonly known as "clot busters." They work by breaking up the clot so that blood flow can return to the affected area of the brain.
- Up to 24 hours for **mechanical thrombectomy**. This is also known as "clot retrieval." If you are a candidate, a neurosurgeon takes a small catheter up to the clot and removes it to return blood flow. This involves a small puncture in either the groin or wrist to thread the catheter.
  - This technique can only be done in the largest blood vessels in the brain. Your health care team may refer to this type of stroke as a large vessel occlusion.

Both treatments (intravenous thrombolytics and mechanical thrombectomy) can be done in certain patients.

Why Didn't I Get Treatment?

Technology has come a long way in recent years, and stroke care has improved greatly. Unfortunately, there are still limitations to what we can do. As with any medical procedure, your health care team will look at risk versus benefit. As time passes from your last-known well, risk increases.

There may be other medical issues that would exclude you from receiving these kinds of treatments, such as excessively high blood pressure, certain medical conditions or use of medications to thin out the blood.

- Your health care team will discuss your personal risk factors for treatment soon after you arrive at the hospital.
- The goal for treatment is to save undamaged brain tissue. As time passes, damage cannot be reversed and intervention at this point may increase your risk of **hemorrhagic conversion**. This is where you can develop bleeding at the site of your stroke where there previously was none.

Treatment Options: Hemorrhagic Stroke

Hemorrhagic strokes, or "brain bleeds," have different treatment challenges than ischemic strokes. For many brain bleeds, we monitor lab work and manage blood pressure carefully. Our focus goes to rehabilitation to help the patient regain function.

- Some patients with hemorrhagic strokes may need much more invasive treatment or surgery.
- Depending on the cause of bleeding and other risk factors, your neurosurgery team will choose the best treatment for you.

Types of Testing

After a stroke, you and your health care team will work to figure out why. During your hospital stay, you will have several tests to determine the cause of your stroke. They may include:

Brain Imaging

- Computed tomography(CT)/computed tomography angiogram (CTA)
- Magnetic resonance imaging (MRI)

Ultrasound

- Echocardiogram (echo)
- Doppler
- Transesophageal echocardiogram (TEE)

Computed Tomography

A CT scan is likely to be the first test you get when you come in.

- Helps your health care team determine what options they have for treatment
- Very important imaging for determining the presence of blood in the brain

Types of Testing

Computed Tomography Angiogram

A CTA is another test done in the CT scanner to look at the blood vessels in the brain.

- Helps your health care team determine if you have a **large vessel occlusion**
- Done with **intravenous (IV) contrast**, a medication administered through an IV line to help "light up" the images and get the best look at your blood vessels

Magnetic Resonance Imaging

An MRI uses large, powerful magnets to get a very precise image of your body.

- While a better image, an MRI takes longer to do. This is why you will get a CT scan first.
- If you have any implanted devices or metal anywhere in your body, you may not be able to complete this test.

Echocardiogram

An echo is an ultrasound of your heart. It looks at how your heart moves, fills and empties with each beat.

- Can also identify clots or issues with the heart valves
- Limited in that it cannot see the back of the heart

Doppler

This test uses sound waves to look for stenosis, or narrowing, of your blood vessels.

You may have two types of dopplers, depending on your diagnosis:

- Carotid – Looks at the vessels in your neck
- Transcranial – Looks at the vessels in your brain

Transesophageal Echocardiogram

A TEE uses a scope down your throat to allow us to see the back of your heart.

- Done under light sedation
- Shows problems, such as clots or valve issues, at the back of the heart

What Happened to My Brain?

Damage from strokes, regardless of type, comes from areas of your brain suddenly losing blood flow. Without proper blood flow, that area begins to die.

When the tissue becomes damaged, the area no longer functions.

- When the tissue becomes damaged, you start to have deficits, or symptoms of your stroke.
- Rehabilitation through different therapies taps into your brain's neuroplasticity, or ability to reorganize its pathways after an injury such as stroke.

Understanding your deficits is essential to creating a plan for rehabilitation.

Effects Explained: Hemiparesis and Hemiplegia

Hemiparesis

Hemiparesis refers to weakness, but not total paralysis, of one side of the body.

- You may barely notice the weakness, or it may be more moderate in severity.
- It can affect your stamina, balance and coordination with both large and small movements.

Hemiplegia

Hemiplegia refers to complete loss of strength or paralysis on one side of the body

- While very scary, paralysis can change over time. You may see improvements with physical therapy.

Effects Explained: Trouble Swallowing

Dysphagia refers to difficulty with your ability to swallow.

- Some strokes affect the area of the brain in charge of controlling this.
  - Having dysphagia can increase your risk of developing **aspiration pneumonia**. This is when food, drink or even saliva goes into your lungs rather than down your esophagus into your stomach.
  - You may need to work with a speech therapist to strengthen your swallowing ability.
  - Stroke patients are screened for dysphagia on admission to determine if they should have speech therapy.
- A speech therapist may recommend a change in food texture or thickness for you to safely eat and drink.
- In the most severe cases, your health care team may talk to you about alternative ways to get nutrition.

Effects Explained: Difficulty With Expression and Understanding

Aphasia is a communication disorder that affects the way you communicate. There are three types of aphasia, which are explained on the following page.

Effects Explained: Difficulty With Expression and Understanding

Expressive Aphasia	Receptive Aphasia
• The lack of ability to use expressive speech • Being unable to express thoughts through language • Also known as Broca's aphasia due to the area of the brain it affects	• The lack of ability to comprehend speech in verbal or written form • Also known as Wernicke's aphasia due to the area of the brain it affects
Global Aphasia	
• The most severe form of aphasia that results from large strokes affecting the language centers of the brain • Difficulties with both using and understanding language	

Like any physical limitation, your therapy team will help work with you to create a plan to improve your ability to communicate.

Effects Explained: Trouble Speaking

Dysarthria is the medical term for slurred speech. It is caused by a weakness of the muscles responsible for speech.

- It is different from aphasia because it deals with the motor action of speech and is not an expressive or receptive issue.
- Your therapy team will work with you on exercises to strengthen your speech ability.

Effects Explained: Neglect

Neglect can be hard to explain. With certain strokes, the area of the brain that gives us awareness of where our body is in space can be damaged. This can result in not using one side of your body with varying degrees of severity.

- Neglect may be as subtle as only eating food on one side of your plate or as severe as not recognizing one half of your body.
- This condition can be difficult to rehabilitate, but your therapy team will help identify neglected areas and do exercises to help you improve.

Simple Ways to Help Neglect

- Place pictures of loved ones on the affected side.
- Have visitors sit on the affected side.
- Place the nightstand on the affected side.
- Write notes to encourage your loved one to remember to use the affected side.

Effects Explained: Vision Loss

Your brain in responsible for processing information it receives from your eyes. This means that, even though your eyes are okay, the part of the brain that works with vision can be damaged with a stroke.

Visual deficits are a bit different from other changes with strokes. Because the nerves from each eye travel together in the brain, **both** eyes will have vision loss. **Hemianopia** is the loss of one half of the visual field in each eye. **Quadrantanopia** is the loss of a quarter of your visual field.

- Your brain is great at adapting, and you may not initially notice a problem.
  - You may notice that you can only see part of the clock on the wall or, while reading, part of a sentence may disappear.

My Vision Loss			
Left		**Right**	

Your health care team will help you determine if you have vision loss. If you do, they may need to discuss the need for driving tests in the future.

Effects Explained: Memory and Mood Changes

It is not uncommon to have changes in cognition, or understanding, and behavior after having a stroke. For some patients, these effects are temporary, while others will have changes long term.

Certain parts of our brain control our memory and personality, and those areas can be damaged by stroke.

You may notice:

- Forgetfulness
- Mixing up details of an event
- Trouble learning new information
- Out of the ordinary behavior
- Frequently changing emotions
- Anxiety
- Depression

These symptoms can be troubling for you or your loved ones. Your health care team can provide you with resources to help you after discharge.

Other Complications: Seizure and Vasospasm

Unfortunately, depending on the type of stroke and where it occurs in your brain, you may have a seizure or vasospasm.

Seizure refers to abnormal electrical activity in the brain. This activity can cause abnormal movements and altered consciousness and breathing.

- A seizure may be a one-time event or something that needs to be followed as an outpatient. You will have additional testing and start taking antiseizure medications.

Vasospasm occurs when a blood vessel in the brain narrows. It causes reduced blood flow to the brain tissue.

- If you have a brain bleed, specifically a subarachnoid hemorrhage, you are at greater risk of vasospasm.
  - Nimodipine is a medication used to prevent vasospasm and protect the brain.

Both of these complications can be very scary for patients and their loved ones. Your health care team will help develop treatment and prevention plans for these issues if they arise.

Stroke Risk Factors

You may hear your medical team talk about risk factors for stroke. These are things that may make us more likely to have a stroke. We have control over some risk factors but others we do not.

What I Can Control

- Blood pressure
- Cholesterol
- Diabetes (Type 2)
- Sleep apnea
- Coronary artery disease
- Atrial fibrillation (aFib)
- Weight
- Inactivity
- Smoking
- Alcohol use
- Drug use
- Contraceptives/hormone replacement therapy

What I Can't Control

- Age
- Sex
- Family history
- Genetic risk factors
- Clotting disorders
- Race/ethnicity

Risk Factors Explained:
Blood Pressure

High blood pressure, also called hypertension, is the number one cause of stroke in adults. The good news: It is also modifiable, which means you can improve this risk factor with the help of your health care team.

- Your team will help you form blood pressure goals.
- In addition to medication, your team may recommend changes to diet and exercise to help you reach your goal.

Monitoring your blood pressure is important to prevent further strokes! Keeping a careful log will help you meet your goal.

My blood pressure goal is:_____

Risk Factors Explained: Cholesterol

High cholesterol causes strokes by leading to build up of something called plaque. Plaque narrows the blood vessels and can also break off, leading to stroke.

- Evidence has shown that when you experience a stroke or TIA, cholesterol medication can help protect the brain and prevent further issues.
- You and your health care team will find the best choice for you in order to reach your goal.

Risk Factors Explained: Diabetes

Diabetes occurs when the body does not have enough of a substance called insulin. Insulin helps the body use the energy from food we eat. Without insulin, those energy molecules, glucose, build up in the body. High blood glucose, also called blood sugar, damages the tissues and blood vessels in the brain and body. This process increases your risk of stroke.

- Hearing the word "diabetes" can be scary, and that's okay. Ask questions. Your health care team can help you get answers.
- Your health care team will talk to you about your **hemoglobin A1C**. This refers to a blood test that tells the team what your blood sugar levels have been over the last three months.
- Many patients with diabetes have success with medication and lifestyle changes.

After discharge, it is important to follow up with your primary care provider to monitor your diabetes and figure out what works for you.

Risk Factors Explained: Sleep Apnea

Sleep apnea is a common sleep disorder that causes you to stop breathing for short periods of time. These are known as apneic episodes and can double your risk of stroke.

- Sleep apnea can occur at any age.
- You may have sleep apnea if:
  - People have told you that you snore.
  - You wake up tired even after a normal night's sleep.

Your health care team may recommend a sleep study be done to determine if you have apnea. This involves being monitored overnight to track apneic episodes.

- The most common treatment is use of a continuous positive airway pressure (CPAP) machine while sleeping.
- Your team will help you find a set up that is most comfortable for you.

A majority of patients report a better night's sleep after treatment of sleep apnea!

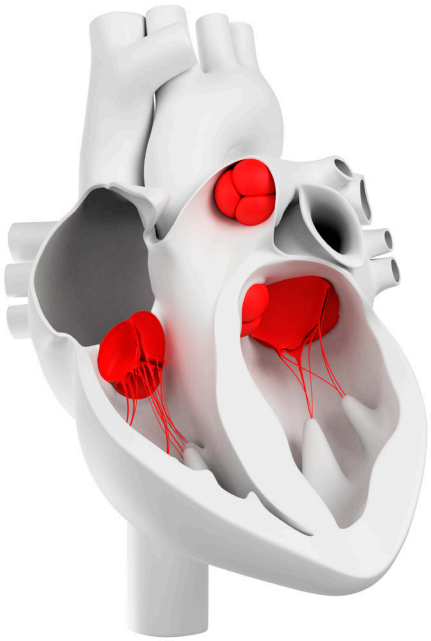
Risk Factors Explained: Coronary Artery Disease

Coronary artery disease happens when the blood vessels in the heart become narrowed. This prevents them from providing the heart with enough oxygen-rich blood. Your health care team may call this a type of heart disease.

- The leading cause of coronary artery disease (CAD) is plaque, which is a fatty buildup of cholesterol in blood vessels. This leads to increased risk of heart attack or stroke.
- While there isn't a cure for CAD, it can be managed.
  - Your provider may want additional testing while you are in the hospital or once you leave.
  - A cardiologist may talk with you. Cardiologists specialize in the heart and its vessels.
  - You might start taking cardioprotective medications to keep things working as smoothly as possible.

Your heart and brain are connected! Protecting the heart can reduce stroke risk!

Risk Factors Explained: Irregular Heartbeat (Atrial Fibrillation)



Atrial fibrillation, or aFib, is an irregular heart rhythm. It happens when the upper chambers of the heart, called atria, begin to beat very rapidly, while the bottom chambers, called ventricles, beat at a slower rate.

- If your heart is not beating as it should, clots can form and travel to your brain, causing a stroke.

Many patients do not know that they have aFib until they have symptoms. Treatment after detection is critical to prevent future strokes.

- Your provider may prescribe medication.
- A cardiologist may talk to you about more invasive measures if you have a very fast type of aFib called rapid atrial fibrillation or if your aFib is not well managed on oral medication.

Risk Factors Explained: Excess Weight and Inactivity

Extra weight, along with inactivity, can put a strain on your entire body.

The good news is, you can change things! Small steps can dramatically change your overall health.

- 30 minutes of physical activity five days a week can reduce your stroke risk by 25%.

Don't overthink it! Do what you love!

- Find activities you love to do, or try something new.
- It doesn't have to be fancy to be effective.
- Start small, and build up to more strenuous activity.

Risk Factors Explained: Smoking

Smoking doubles your risk for stroke. When you smoke, you reduce the amount of oxygen in the blood. This makes your heart work harder to make up for the lack of oxygen.

- When your heart works harder, it puts you at greater risk of forming a clot that could travel to your brain.
- Smoking also damages the walls of your blood vessels, which can reduce blood flow and make it easier for a clot to block your vessels.

If you are willing to make the change, your health care team will provide you with education and resources to stop smoking.

Risk Factors Explained: Alcohol

While an occasional drink can be fun and even have certain health benefits, drinking excessive amounts of alcohol increases your risk of stroke.

- Alcohol can increase your risk of developing abnormal heart rhythms, like aFib.
- Drinking alcohol changes the way your blood clots. This leads to increased risk for hemorrhagic stroke.
- Excessive alcohol use also increases blood pressure, which is the number one risk factor for stroke.
- Long-term alcohol use can also lead to other risk factors, such as weight gain and diabetes.

If you need help to stop drinking, your health care team will help you get the resources you need.

Risk Factors Explained: Drug Use

The three most harmful and commonly abused illegal drugs in the United States are cocaine, methamphetamine and heroin. Even occasional recreational use of these drugs can have irreversible effects on your body.

- Use of illegal drugs can increase your risk of abnormal heart rhythms, such as aFib or more fatal heart rhythms.
- Intravenous drug use can introduce bacteria to the blood that can grow on the valves of your heart. This is called **endocarditis**. This growth can break off and travel to your brain.
- Illegal drugs can harden blood vessels and increase blood pressure.

Addiction is a disease. If you need help, your health care team will give you options and connect you with the resources you need.

Risk Factors Explained: Contraceptives and Hormone Replacement Therapy

Hormone therapy and various birth control medications have been shown to affect the way our body forms clots. While studies show newer generations of these medications have a decreased risk compared to older generations, there is still an increased risk of forming a clot that can lead to a stroke.

Ask your health care team about your current contraceptive medication or hormone therapy. They can help develop the best treatment plan for you to meet your care goals.

Risk Factors You Can't Control

While there are many risk factors we are able to change, there are a few that we can't do much about. Knowing those risk factors is critical for you and your health care team to develop a plan to prevent strokes in the future.

- Age
- Sex
- Genetic risk factors
- Family history of stroke before age 65
- Clotting Disorders

You checked your uncontrollable risk factors on the stroke worksheet at the beginning of this guide.

Managing Risk: Medication

While there are many risk factors that can be affected by changing behaviors, there are times when you will need medication.

Antiplatelets and Anticoagulants

- These medications work by making it harder for clots to form.

Blood Pressure

- Each of these medications use different methods to lower arterial blood pressure.

Cholesterol-Lowering

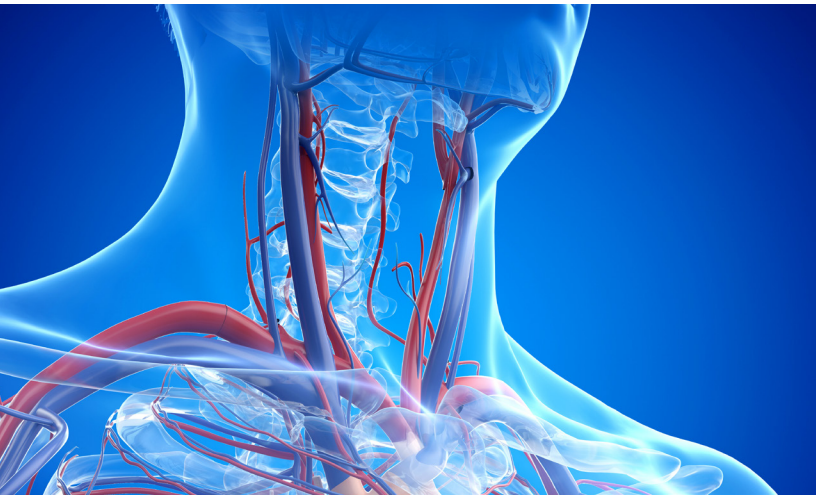
- These medications lower cholesterol in the blood and prevent plaque buildup.
- These medications can be prescribed even if cholesterol is in the normal range.
- Studies have found that cholesterol-lowering medications can be neuroprotective, meaning they can protect the blood vessels of the brain.

Managing Risk: Medication

Common medications for managing stroke risk include:

Cholesterol-Lowering	Antiplatelets
• Atorvastatin/Lipitor • Rosuvastatin/Crestor	• Aspirin 81 mg • Clopidogrel/Plavix • Ticagrelor/Brilinta • Acetylsalicylic acid/Dipyridamole/Aggrenox
Blood Pressure	**Anticoagulants**
• Hydrochlorothiazide • Chlorthalidone • Losartan • Metoprolol • Nicardipine	• Apixaban/Eliquis • Dabigatran/Pradaxa • Enoxaparin/Lovenox • Rivaroxaban/Xarelto • Warfarin/Coumadin/Jantoven
Antiseizure	
• Levetiracetam/Keppra	

Managing Risk: Surgical Options



Testing may reveal that you have dangerous amounts of plaque in the arteries that lead directly to your brain. Depending on the circumstances, a neurosurgeon may speak with you about more invasive options.

In-Hospital Therapies

Studies have shown that early intervention with physical, occupational and speech therapy can dramatically change the recovery of patients long term.

Physical Therapy

Physical therapy focuses on body movement, such as how you walk, called "gait," and balance. Your care team will:

- Evaluate the need for more rehabilitation after your discharge from the hospital
- Help you find the best mobility tool for you, such as canes, walkers, crutches, etc.

Occupational Therapy

Occupational therapy focuses on confidence in and ability to do daily tasks, such as getting dressed or your brushing teeth. Your care team will:

- Evaluate your need for more rehabilitation after discharge from the hospital
- Help you find adaptive tools that help with daily tasks, such as grips for silverware or a tool to help you put on socks

In-Hospital Therapies

Speech Therapy

Speech therapy focuses on the actual ability to speak and the motor ability to swallow and eat, as well as your attention, information retention, word fluency, expression and problem-solving. Your care team will:

- Evaluate your need for more rehabilitation after discharge from the hospital
- Help create exercises to strengthen your speech and swallowing abilities
- Recommend different food and beverage thickness to prevent aspiration pneumonia, if needed.

Care Coordination

Care Coordination consists of registered nurse case managers and registered social workers who work behind the scenes to set up all of the services you may need outside of the hospital. They are an essential role in discharge planning. Care Coordination helps balance the needs and wants of patients and families with the realities of insurance and regulatory hurdles.

Care Coordination can help with:

- Insurance issues, whether with existing insurance or if you need medical assistance
- Requesting insurance authorization for:
  - Home health
  - Long-term care
  - Inpatient rehabilitation
  - Outpatient services
  - Assistive devices and equipment
- Social issues, such as:
  - Lack of housing
  - Need for court-ordered guardianship

Penn State Health care coordinators are in constant communication with the rest of your health care team. As issues arise, they will work to best prepare you for discharge.

Discharge Planning

Behind the scenes, your health care team begins planning for what happens when you leave the hospital on the first day you are admitted. It is not always possible to go directly home after discharge and, even if you can, you may need a little extra help. There are a variety of programs or services designed to aid in your recovery outside of the hospital. Your health care team will work with you to find the best options for you after discharge.

Discharge options and therapy include:

- Inpatient rehabilitation
- Skilled nursing facility
- Outpatient therapy
- Long-term acute care hospital
- Home health
- Community paramedicine and follow-up phone calls

You will also have follow-up appointments. There is information on support groups in the "Life After Stroke" section of this guide.

Discharge planning can be overwhelming and complicated at times. Your health care team will help determine what services you or your loved one qualify for and help you through the process.

Inpatient Rehabilitation

The therapy that you receive in the hospital may not be enough to get you where you need to be to go back home. Inpatient rehab provides more intensive therapy in order to get you closer to your baseline.

What to Expect

Rehab hospitals have a specialized health care team that will help build an individualized plan to help you gain as much independence as possible.

Therapy is much more than the physical therapy gym:

- Occupational and speech therapy are also available services at rehab hospitals.
- Your team may also involve you in emotional and cognitive therapy as part of your recovery journey.
- Advanced technology can also be used to help recover functionality and rebuild neural pathways lost to stroke.
- Therapy is much more intensive, at least three hours a day of active therapy for five or six days a week.
- The average stay at a rehab facility is two to three weeks.

Depending on insurance and other factors, you may have a choice of rehabs to go to. Care Coordination will work with you, your insurance and the rehab facility to find the best option for you.

Long-Term Acute Care Hospital

Sometimes you may have a more serious medical concern related to your stroke that can't be managed at a rehab or nursing facility. Long-term acute care hospitals provide high-level medical care while starting the rehabilitation process.

What to Expect

These types of hospitals provide specialized care for medically complex or critically ill patients. They have many of the features of a full-sized hospital, while providing early rehabilitation.

- These hospitals are capable of a much higher level of medical care than other facilities outside of a hospital.
- They provide 24/7 access to physicians and on-site respiratory therapists.
- You will see a physician daily, much like in a hospital setting.
- Respiratory therapists help to manage patients needing long-term tracheostomy and ventilator care.
- Nurses are capable of providing high-level medical care.
- Length of stay is 30 days on average.

Home Health and Outpatient Therapy

It can be possible to go immediately home after discharge while still receiving the medical help you need. Home health agencies provide medical care a few days a week. This is ideal for patients who can function at home by themselves or with the assistance of a loved one.

If mobility and travel are not issues, your provider may send you home with a prescription for therapy at an outpatient center.

Services available include:

- Physical therapy
- Occupational therapy
- Speech therapy
- Intravenous medication infusions
- Medical supplies
- Social services

Your health care team will work with you and your insurance to find the best option for you to move forward. Even if you don't go home immediately, home health can be a valuable part of your care plan after rehab or a long-term acute care hospital.

Follow-Up Appointments

Organized follow-up is extremely important to reduce your risk of a stroke happening again. Most patients will be asked to follow up at discharge from the hospital.

Depending on your needs after discharge, you will review different parts of your care plan, such as driving privileges, returning to work, follow-up imaging and medications. These follow-up visits also allow your provider to evaluate any deficits and determine whether you need additional support or therapy.

Ideally, these appointments will be scheduled before you leave the hospital. If not, you will receive a phone call to schedule shortly after discharge.

Life After Stroke

Finding Support

Whether your stroke is big or small, mild or severe, you have experienced a life-changing event. You are now a stroke survivor. In the immediate aftermath, you may feel confused or angry. Feelings of "why me?" and "what do I do now?" are normal and valid.

The way you cope may look a little different than someone else, and that's okay. Finding support for you and your loved ones is essential to recovery. At the back of this guide is more information about local support organizations and groups that can help you and your loved ones after this life-changing event.

Stroke support groups

A support group can be a great way to meet other survivors and caregivers going through similar experiences. Having a sense of community can go a long way toward your recovery. You and your loved ones can swap ideas and get help with issues from other survivors who have picked up tips and tricks along the way. Penn State Health offers a monthly support group:

Penn State Health Stroke Support Group
Meets second Wednesday of every month at 3 p.m.
Penn State Rehabilitation Hospital
1135 Old West Chocolate Ave.
Hummelstown, PA 17036

Managing Fear, Frustration and Hopelessness

For many, this may be the most serious health event they have ever experienced. It is very common to feel fear and frustration in the initial hours and days after a stroke. It can feel like everything is falling apart, and you don't know if you will be able to find a way out.

Depression and anxiety are caused by chemical changes in the brain and are not uncommon in the weeks after having a stroke. Early treatment of these conditions is available and can improve your recovery dramatically. Social support, as well as the help of an experienced clinician, can help you cope and overcome the challenges associated with your recovery.

Checklist for Stroke-Related Anxiety and Depression

Anxiety	Depression
☐ Feeling restless or wound up	☐ Feelings of sadness, tearfulness or hopelessness
☐ Having feelings of impending doom or feeling in danger	☐ Loss of interest or enjoyment in activities you once loved
☐ Irritability	☐ Out-of-character outbursts of anger and frustration
☐ Difficulty controlling feelings of worry	☐ Changes in eating habits leading to weight loss or weight gain
☐ Difficulty concentrating	☐ Changes in sleep habits, such as sleeping too much or not enough
☐ Difficulty falling asleep or staying asleep	☐ Mental fog
☐ Feeling easily fatigued	☐ Feeling easily fatigued
☐ Trouble concentrating	☐ Trouble concentrating
☐ Physical symptoms, such as upset stomach, rapid heartrate or trembling	☐ Physical symptoms, such as headaches and muscle aches

Caregiver Support

Moving Forward After Stroke

Finding their way after a stroke can be difficult for both the patient and those around them. Caregivers represent an important member of the health care team. You act not only as caregiver but advocate for your loved one as they move forward from stroke. However, this role is often one that comes as a surprise and can feel overwhelming at times.

Documents to Think About

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

Additional Information and Support Services

- **Family Caregiver Alliance: Caregiver resources for specific health conditions** caregiver.org/resources-health-issue-or-condition
- **Brain Aneurysm Foundation** bafound.org

Financial and Prescription Resources

Recovery after stroke can sometimes be expensive, even with insurance. Both local and national resources are available. Your social worker and care coordinator can help you navigate some of the immediate issues you may have while you are still in the hospital. After discharge, you may be able to work with a social worker and care coordinator through your primary care office.

You can also refer to the following list of national resources:

- **AARP Money Management Program:** Daily money management service to help low-income, older or disabled individuals who have financial difficulties.
- **AARP Foundation Tax-Aide Program:** Aims to help provide assistance in completing tax forms for individuals age 50 and older.
- **American Association of Daily Money Managers**: Daily money managers help with personal monetary affairs, such as organizing and keeping track of financial and medical insurance papers and maintaining bank accounts.
- **Social Security Disability Insurance (SSDI):** Talk to a social worker about applying for SSDI as soon as possible if you're not already on Social Security. Stroke survivors often don't get approved the first time they apply and, if they do, it's a long process.
- **Supplemental Security Income:** Federal income program to help people with disabilities who have little or no income.
- **The Patient Advocate Foundation:** Provides free, direct advocacy services, including helping obtain health insurance, solving medical debt issues and working to keep survivors in rehab.
- **Veterans Health Administration:** Veterans 65 and older may qualify for a tax-free benefit called Aid and Attendance Pension, which can help pay for in-home care, a nursing home or assisted living.

Financial and Prescription Resources

Even with insurance, there may be ways to help save money:

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

Health Insurance Issues

- If you have issues with your insurance or need coverage, your social worker and care coordinator may be able help while you are still in the hospital.
- Calling your insurance company to determine what services are and are not available can help you move forward with planning what the future will look like for you and your loved ones.

Words to Know

Advance directive: A legal document signed by a competent person. Provides guidance for medical and health care decisions, such as the termination of life support or organ donation, in the event the person becomes unable to make such decisions.

Anticoagulant: A medication that prevents the clotting of blood.

Antiplatelet: A medication that prevents platelets from adhering to each other or makes it more difficult.

Anxiety: An abnormal and overwhelming sense of apprehension and fear, often accompanied by physical signs, such as tension, sweating and increased pulse rate.

Aphasia: The loss or impairment of the ability to use or comprehend words resulting from an injury to the brain, such as stroke or head injury.

Apnea: A temporary pause in breathing.

Aspiration pneumonia: An infection of the lungs caused by breathing in foreign bodies.

Atria: The uppermost chambers of the heart.

Atrial fibrillation: An irregular heartbeat caused by the atria (upper chambers) beating very rapidly, while the bottom chambers (ventricles) beat at a slower rate.

Blood pressure: The pressure of blood on the walls of blood vessels.

Brainstem: A structure that controls breathing, heart rate, reflexes, swallowing, eye movements and level of alertness.

Cardioprotective: Medications or substances that serve to protect the heart.

Carotid endarterectomy: A surgical procedure to remove the inner layer of an artery that has been thickened or occluded by plaque.

Cerebellum: The part of the brain that controls balance, coordination and movement.

Community paramedicine: An emergency medical services group that meets with recently discharged stroke patients to go over medications, check on living situations and review symptom management.

Computerized tomography (CT): A scan that combines a series of X-ray images taken from different angles around the body. Uses computer processing to create cross-sectional images, called "slices," of the bones, blood vessels and soft tissues inside the body.

Computerized tomography angiography (CTA): A type of medical test that combines a CT scan with an injection of a special dye to produce pictures of blood vessels and tissues in a specific part of the body.

Coronary artery disease: A condition where the major blood vessels supplying the heart are narrowed. The reduced blood flow can cause chest pain and shortness of breath.

Deficits: The "symptoms" of a stroke, such as weakness, visual or sensory loss, or paralysis.

Depression: A condition caused by a chemical imbalance in the brain. Includes feelings of hopelessness, sadness, loss of interest, fatigue and sleep changes. Common after stroke.

Diabetes: A metabolic disorder in which the body has high sugar levels for prolonged periods of time.

Doppler: A test that uses sound waves to look for stenosis, or narrowing, of blood vessels.

Dysarthria: The medical term for slurred speech. Caused by a weakness of the muscles responsible for speech.

Dysphagia: Difficulty swallowing.

Echocardiogram: An ultrasound of the heart. Looks at how the heart moves, fills and empties with each beat. Can also identify clots or issues with the heart valves. Limited in that it cannot see the back of the heart.

Words to Know

Endocarditis: Caused by bacteria in the blood that can grow on the valves of the heart. This growth can break off and travel to the brain.

Expressive aphasia: This is the inability to express thoughts through language. Also known as Broca's aphasia due to the area of the brain it affects

Follow-up appointments: Post-stroke appointments with Neurology at 30 and 90 days. For discussing progress, making medication changes and evaluating the need for more intervention.

Frontal lobe: The area of the brain in charge of self-awareness, judgement, problem solving, language and movement.

Global aphasia: The most severe form of aphasia that results from large strokes affecting the language centers of the brain. This can cause difficulties with both using and understanding language.

Health Insurance Portability and Accountability Act of 1996 (HIPAA) Representative Form: A form that patients sign to give permission to the health care team to release medical information to a trusted family member or support person.

Heart disease: Conditions that affect the structures or function of the heart. This is also called cardiovascular disease.

Hemianopia: The loss of one half of the visual field in each eye.

Hemiparesis: A weakness, but not total paralysis, of one side of the body.

Hemiplegia: The complete loss of strength or paralysis on one side of the body.

Hemoglobin A1C: A blood test that tells the team what a patient's blood sugar has been over the last three months.

Hemorrhagic conversion: Bleeding at the site of the stroke where there previously was no blood.

Hemorrhagic stroke: Less common type that accounts for approximately 20% of strokes. This happens when a blood vessel bursts or tears and causes bleeding in the brain. Also called a brain bleed.

Hyperlipidemia: A condition used to describe elevated lipid levels in the blood. This can also be called dyslipidemia.

Hypertension: The medical term for high blood pressure.

Inpatient rehabilitation (rehab): An inpatient facility where patients get intensive physical, occupational and/or speech therapy for several weeks before discharge.

Insulin: A hormone produced by the pancreas that regulates the amount of glucose in the blood. This also refers to the medication used to treat diabetes (either animal-derived or synthetic)

Intravenous thrombolytics: Drugs commonly known as "clot buster/clot dissolvers" Work by breaking up a clot so blood flow can return to the affected area of the brain.

Ischemic stroke: The most common kind of stroke. This happens when a blood clot blocks a blood vessel in the brain.

Large vessel occlusion: The obstruction of large, proximal cerebral arteries. It accounts for many ischemic strokes.

Last-known well: The last time a patient was seen in a usual, or "normal," state of health.

Last will and testament: A patient's clear statement of wishes about health care. This helps avoid disputes about treatment options and gives direction to health care providers.

Long-term acute care hospital (LTACH): Provides specialized care for medically complex or critically ill patients. It has many of the features of a full-sized hospital while providing critical early rehabilitation.

Magnetic resonance imaging (MRI): A scan that provides precise details of your body parts, especially soft tissues, with the help of magnetic fields and radio waves.

Mechanical thrombectomy: Also known as "clot retrieval." A neurosurgeon takes a small catheter up to the clot and removes it to return blood flow. Involves a small puncture in either the groin or wrist to the catheter.

Modifiable risk factor: Individual risk factors that a patient is able to change. Examples include blood pressure, diet and activity level.

Neglect: Occurs with certain types of strokes that damage the area of the brain that gives us awareness of where our body is in space. Can result in not using one side of the body to varying degrees of severity.

Neuroplasticity: The brain's ability to reorganize its pathways after an injury such as stroke.

Neuroprotective: A substance or medication that serves to protect nerve cells from injury or degeneration.

Occipital lobe: The part of the brain that controls depth perception and vision.

Occupational therapy: Therapy that focuses on confidence and ability to do daily tasks, such as getting dressed or brushing teeth.

Outpatient therapy: Physical, occupational or speech therapy in an office or outpatient center.

Parietal lobe: The area of the brain in charge of processing sensory information, such as touch, pain, hot and cold.

Physical therapy: Therapy that focuses on body movement, such as gait and balance.

Plaque: A buildup of cholesterol and other substances that causes the blood vessels to narrow. This can break off and cause a blockage in the brain.

Power of attorney: A legally binding document put in place to designate a person to be in charge of a person's medical or financial affairs if they become unable to make decisions.

Quadrantanopia: The loss of a quarter of the visual field.

Rapid atrial fibrillation: A very rapid type of atrial fibrillation where the ventricles also beat quickly. A heart rate above 100 beats per minute that is more dangerous than normal aFib and requires intervention.

Receptive aphasia: The lack of ability to comprehend speech in verbal or written form. It also known as Wernicke's aphasia due to the area of the brain it affects.

Risk factor: Something that increases the chance of stroke. This can be controllable factors, such as diet and exercise, or uncontrollable, such as age or genetics.

Seizure: Abnormal electrical activity in the brain. It can cause abnormal movements and altered consciousness and breathing.

Sleep apnea: Temporary periods of time where a person's breathing stops while asleep.

Speech therapy: Focuses both on the actual ability to speak as well as the motor ability to swallow and eat.

Support group: A group of people who have experienced a common event, such as stroke, either directly or as a family member or support person. Regular meetings may be held to discuss feelings or share ideas and education related to the similar experience.

Transesophageal echocardiogram (TEE): An echocardiogram that can see the back of the heart.

Temporal lobe: The part of the brain that helps to understand language and form new memories.

Transient ischemic attack (TIA): Stroke symptoms that quickly resolve themselves with no deficits. This is seen as a warning sign.

Vasospasm: Occurs when a blood vessel in the brain narrows. This causes reduced blood flow to the brain tissue.

Ventricle: The bottom chambers of the heart. This also refers to the middle open spaces of the brain where cerebral spinal fluid flows.

Notes

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NEU_230950_0823