# Understanding Stroke







# **Your Stroke Prevention Plan**

$oldsymbol{\mathbf{p}}$	Medicines:	Blood Pressure Control
D	Blood pressure range:	
	Reduc	ce Cholesterol, Fats and Salt
	Medicines:	Foods:
K		□ low cholesterol □ low fat □ low salt
	LDL:	Your target goal:
	Antio	coagulants/Antithrombotics
$ \mathbf{A} $	☐ apixaban (Eliquis®)	□ aspirin □ heparin □ warfarin (Jantoven®) □ enoxaparin (Lovenox®) □ clopidogrel (Plavix®) □ rivaroxaban (Xarelto®) □
1	Call your health care pro if you have black or tarry	vider or go to the Emergency Department right away v-looking stools.
		Increase Activity
	How will you increase yo suggest?	our activity level? What did your health care team
	No	Tobacco Use/Drug Abuse
	What is your plan to quit	using tobacco or drugs?
	Medicines:	Blood Glucose Control
	Hemoglobin A1c:	Your target A1c range:

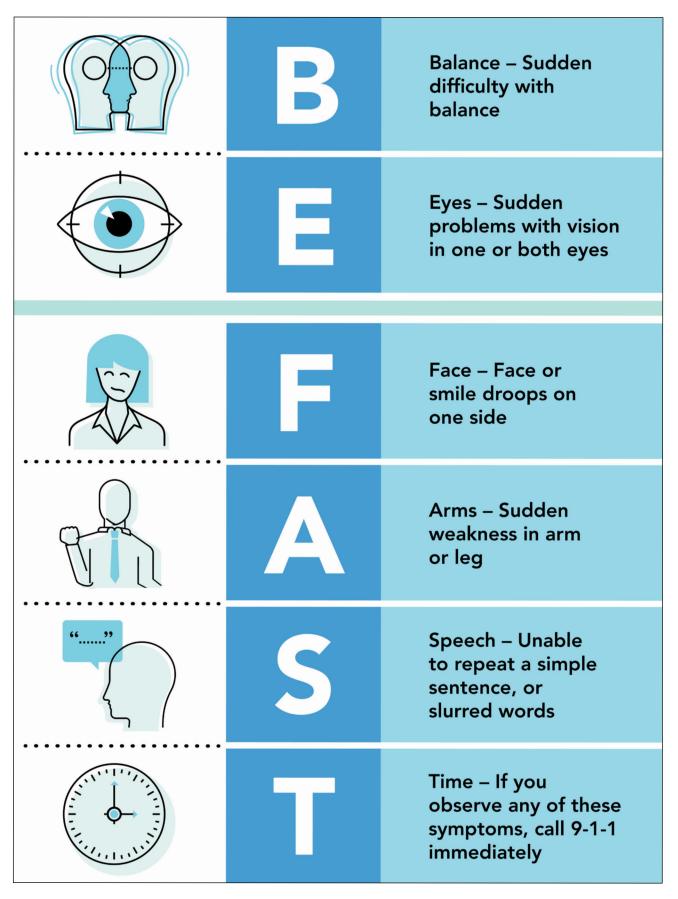
Questions or Notes		

# **Your Stroke Risks**

See Chapter 2 to learn about risks you can and cannot control.

Risks you can control. Check all that apply:				
☐ high blood pressure	☐ extra weight			
☐ tobacco use	☐ physical inactivity			
□ atrial fibrillation	☐ carotid artery disease			
(irregular heartbeat)	☐ peripheral artery disease (PAD)			
☐ heart disease	☐ diabetes			
☐ high cholesterol	□ food □ street drugs			
□ alcohol use				
Risks you cannot contr	ol. Check all that apply:			
□ race	☐ family history (genetics)			
□ age	□ stroke or transient ischemic			
☐ gender	attack (TIA)			

Questions or Notes	5		



# **Understanding Stroke**

# Fifth edition

Developed by Allina Health.

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The publisher believes that information in this manual was accurate at the time the manual was published. However, because of the rapidly changing state of scientific and medical knowledge, some of the facts and recommendations in the manual may be out-of-date by the time you read it. Your health care provider is the best source for current information and medical advice in your particular situation.

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#### Disclaimer

This publication is for general information only and is not intended to provide specific advice or recommendations for any individual. The information it contains cannot be used to diagnose medical conditions or prescribe treatment. The information provided is designed to support, not replace, the relationship that exists between a patient and his/her existing physician.

For specific information about your health condition, please contact your health care provider.



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# Welcome

#### Did You Know?

Your **care circle** is your family, friends and others close to you. This term will be used in this book.

You are being treated for a stroke. The information in this book will help you better understand strokes. You will learn about:

- types of stroke
- causes of stroke
- effects of stroke
- stroke risks
- warning signs
- rehabilitation (rehab) and recovery
- how members of your care circle can help.

By learning about strokes, you and members of your care circle can work toward a better recovery. This information may also help prevent a future stroke.

This book is meant as a guide. It does not replace medical or professional advice.

The way your body responds to a stroke is unique. If you have any questions about your rehab, recovery or general health, talk with your doctor or health care provider, such as your registered nurse, pharmacist or physical therapist.

Because the stroke has put you in a new situation, reading all of this information at once can be overwhelming. Look at the sections that apply to where you are right now in your recovery.

# **Your Recovery Team**

Members of your health care team may include any of the following:

#### ■ Advance practice provider

An advance practice provider can treat illnesses and diseases such as cancer. An advance practice provider and doctor work together as a team. Advance practice providers include:

- ☐ clinical nurse specialists
- nurse practitioners
- physician assistants.

#### ■ Dietitian

A dietitian will look at your food needs. He or she will work with the health care team to create a meal plan for you. He or she will also provide education about your meal plan.

#### **■** Hospitalist

A hospitalist is doctor who specializes in adult medicine.

#### **■** Intensivist

An intensivist is a doctor who specializes in intensive care.

#### **■** Internist

An internist is a doctor who specializes in adult medicine.

#### ■ Neurologist

A neurologist treats brain, spinal cord and nervous system problems and conditions.

#### Nurses

Nurses will closely watch your ability to eat, swallow and move (helping you change positions in bed and helping you get in and out of a chair or bed). They check your skin and check to make sure you have no problems going to the bathroom. Nurses will give you medicine and help with therapy.

They will educate you and your care circle about stroke and medicines. Nurses will also work with the rest of the health care team to make sure you and the members of your care circle have your emotional needs met.

Nurses will provide and coordinate your care. They will watch for neurological changes (speech, vision) that show your symptoms are getting better or worse.

#### ■ Occupational therapist (OT)

The occupational therapist will look at your ability to do everyday activities. These include eating, brushing your teeth, getting dressed, bathing, doing housework and going to the bathroom.

He or she will also look at and treat problems related to your stroke. This includes problems with vision and thinking, such as memory, judgment or safety. The OT helps you gain arm strength and coordination. He or she will let you know if you need special equipment after you leave the hospital.

#### ■ Pharmacist

The pharmacist will supply the medicines ordered by your doctor. He or she will watch to make sure your medicines work together and help manage your side effects.

#### **■** Physiatrist

A physiatrist is a doctor who works in rehab.

#### ■ Physical therapist (PT)

The physical therapist treats problems with your balance, coordination, strength, walking and transfers (getting yourself in and out of a chair, bed or car). If needed, he or she will help you learn to use aids such as canes, walkers or wheelchairs. He or she will let you know if you need special equipment after you leave the hospital.

The PT will teach you balance and strength exercises and help you practice walking and transfers. He or she will also teach members of your care circle how to help you walk, transfer and do exercises.

#### **■** Social worker

The social worker looks at your social and emotional needs and helps plan for your needs when you are ready to leave the hospital (at discharge). He or she will provide supportive counseling and information about community resources.

He or she will help you and members of your care circle with decisions about a new living place if needed. The social worker can also help get financial and insurance information for you.

#### ■ Speech-language pathologist (SLP)

A speech-language pathologist treats your problems with swallowing, speaking, understanding, reading and writing.

He or she will help you regain language skills or teach you other ways to communicate. He or she may also help you with your attention span, problem-solving and memory skills.

#### ■ Stroke outreach volunteer

A volunteer who is a stroke survivor may meet with you on a one-to-one basis. Ask your social worker for more information.

■ Therapeutic recreation specialist (recreational therapist)
A therapeutic recreation specialist helps improve your independence and everyday activities. He or she will provide recreation resources and opportunities to improve your health and well-being.

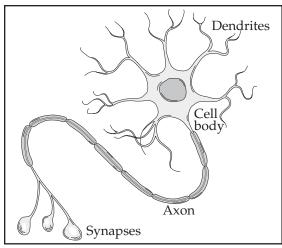
He or she will help you return to the leisure activities you enjoy and to learn how to get around in your community.

# Chapter 1: What Is a Stroke?

A stroke occurs when the flow of blood and oxygen to the brain is stopped or interrupted. This happens because of a burst (ruptured) or blocked blood vessel.

A stroke can cause serious disability and can be life-threatening.

# The Role of Your Brain and Central Nervous System



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The different parts of a nerve cell.

Nerve cells in the brain (neurons) send signals to the rest of your body. These signals control your speech, movement, thinking process and senses (hearing, sight and touch).

The part of your brain affected by a stroke determines how your body is affected.

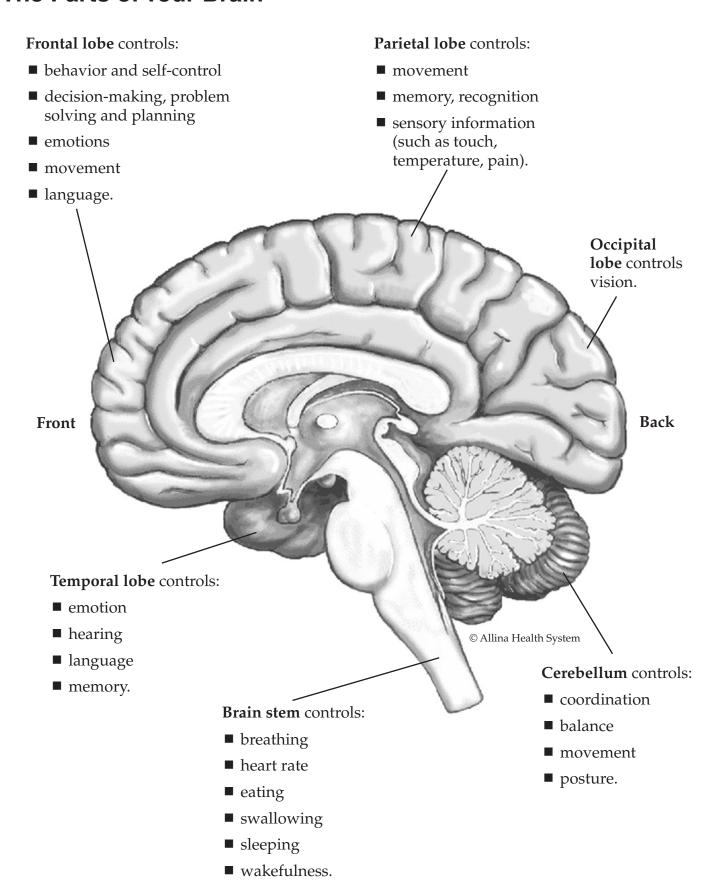
The right side of your brain controls the left side of your body. Usually, the right side of your brain controls the ability to pay attention, be aware of your own body, or recognize things you see, hear or touch.

The left side of your brain controls the right side of your body. Usually, the left side of your brain controls the way you talk and understand speech.

The base of your brain (brainstem) is connected to your spinal cord. The brainstem controls specialized functions, including:

- your eye movements
- swallowing
- breathing
- alertness.

# The Parts of Your Brain



# **Causes and Types of Stroke**

#### Did You Know?

Blood carries oxygen and nutrients through your body.

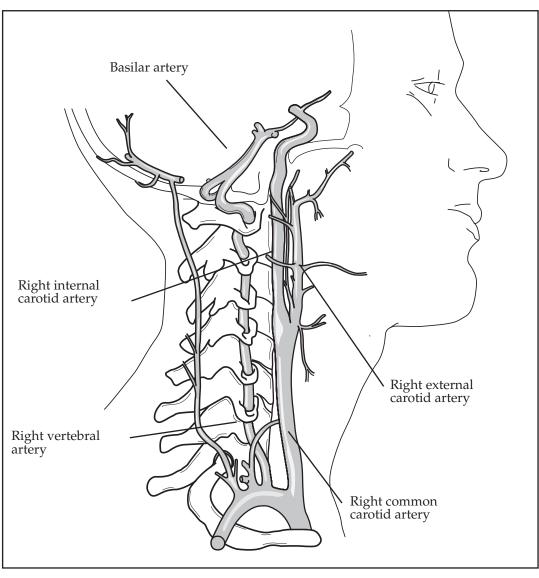
Your brain gets blood mainly through:

- 2 arteries in your neck (carotid arteries)
- 2 arteries near your spine (vertebral arteries).

These 4 arteries branch into other blood vessels that supply your brain with blood.

If blood cannot flow to your brain, your brain cells will start to die. Stroke symptoms will start to appear.

There are two types of stroke: ischemic and hemorrhagic.



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A stroke may occur if an artery bursts or is blocked. This may prevent blood flow to the brain.

#### **Medical Term**

A blood clotting disorder occurs when you have abnormal amounts of different proteins in your blood that can:

- change the way your blood clots
- increase your risk of stroke.

Certain diseases and medicines can also affect how blood clots.

#### **Medical Term**

Atrial fibrillation is an irregular heartbeat. Your heart's upper chambers quiver instead of beat in a regular rhythm. Blood pools in your heart and can form blood clots. This increases your risk of having a stroke.

#### **Ischemic strokes**

This type of stroke happens when a blood vessel in the brain is blocked. This may be caused by a blood clotting disorder. There are two types of ischemic stroke:

#### ☐ Thrombotic

Over time, fatty deposits (plaque) attach inside the artery walls. The plaque may narrow or close the artery. This may reduce blood flow to the brain.

A thrombotic stroke is caused by plaque build up and the sudden formation of a blood clot.

- Large vessel: This is the most common type of stroke.
   This stroke occurs when a larger artery in the brain is blocked.
- **Small vessel (lacunar):** This type of stroke occurs deep in the brain when a smaller artery in the brain is blocked.

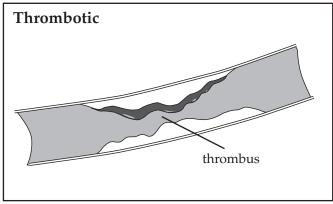
#### □ Embolic

This occurs when a small blood clot forms in any part your body and travels in the bloodstream to the brain. This clot becomes stuck and blocks a blood vessel.

The blood clot often travels from the heart. A common cause of an embolic stroke is atrial fibrillation.

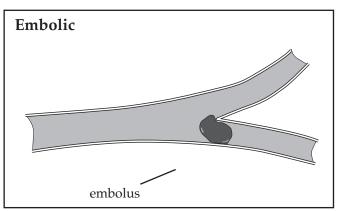
In more severe strokes, the large arteries in your brain or neck may be blocked. This blockage may cause permanent injury to a large part of the brain.

Ischemic strokes may lead to widespread brain injury. This injury can cause swelling in the brain. This swelling may lead to severe disability or death.



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A thrombotic stroke occurs when plaque narrows artery walls and reduces blood flow to the brain.



© Allina Health System

An embolic stroke occurs when a small blood clot blocks a blood vessel.

### Warning

Do not ignore symptoms of a TIA.

Call 911 right away.

#### Transient ischemic attacks (TIAs)

A thrombotic or embolic ischemic stroke may be called a TIA.

TIAs have the same symptoms as a stroke but they do not cause brain injury. They are sometimes called mini-strokes. If you had a TIA, your stroke risk is higher.

**Important:** TIAs require the same immediate attention as a stroke.

#### Hemorrhagic strokes

This type of stroke happens when a blood vessel in the brain ruptures and bleeds. This may be caused by a blood clotting disorder. There are two types of hemorrhagic stroke:

#### ☐ Subarachnoid hemorrhage

It happens when blood leaks into the space between the brain and middle membrane that covers it. This is called the subarachnoid space.

Common causes include:

#### — Aneurysm

This happens when an artery or blood vessel becomes weak and bulges. A brain aneurysm is found on the arteries that supply blood to the brain. The aneurysm may become large and break (rupture).

#### — Arteriovenous malformation (AVM)

This occurs when blood flows directly from the arteries to veins, rather than passing through the capillaries first.

#### ☐ Intracerebral hemorrhage

This occurs when a small blood vessel in the brain bursts and leaks. This causes bleeding in the brain. This is often caused by high blood pressure.

# Chapter 2: Your Risks, Prevention and Stroke Signs and Symptoms

## Stroke Risks and Prevention

Certain risks increase your chance of having a stroke. There are two types of risks: those you can control and those you cannot.

Your health care provider can help you learn what your risks are and how you can control them.

#### What you can control

According to the American Stroke Association, the following stroke risks are those you can control:

#### ☐ High blood pressure

This is the leading cause of stroke. High blood pressure puts stress on your blood vessel walls. This silent condition (known as hypertension) can lead to a stroke.

Your blood pressure is checked with two numbers. The top number (systolic) shows the pressure in your arteries when your heart beats. The bottom number (diastolic) shows the pressure in your arteries when your heart rests.

— Prevention: Ask your health care provider about what blood pressure is right for you. Have regular appointments with your health care provider to help manage your blood pressure. Together, you and your health care provider will decide on a treatment plan.

#### ☐ Tobacco use

Tobacco use doubles your stroke risk. It damages blood vessel walls, lowers the level of oxygen in your blood, makes plaque form more quickly in your arteries, raises your blood pressure and makes your heart work harder. Your risk of stroke greatly increases if you smoke and use a birth control method that changes your hormones.

 Prevention: If you use tobacco products, stop. See the resource list on page 66 or ask your health care provider for how to quit.

#### ☐ Atrial fibrillation (irregular heart beat)

This is a heart rhythm that increases your risk for stroke. Your heart's upper chambers quiver instead of beating in a regular rhythm. Blood pools in your heart and can form blood clots. These blood clots can travel through your bloodstream to your brain. Your risk for stroke increases if you have sleep apnea and atrial fibrillation.

 Prevention: Talk with your health care provider about how to treat atrial fibrillation and reduce your risk of blood clots forming in your heart.

#### ☐ Heart disease

There are many types of heart disease, including heart failure and heart valve disease. Heart disease increases your risk for stroke.

— Prevention: You can help prevent heart disease by managing stress, eating healthful foods, exercising regularly, and doing strength and stretching exercises. Do not use tobacco products. Talk with your health care provider about how to prevent and treat your heart disease.

#### ☐ High cholesterol

Cholesterol is a fat-like substance made by your liver and found in the food you eat.

High density lipoprotein cholesterol is also called HDL (the "good" cholesterol). HDL helps to get rid of extra cholesterol from your blood. Higher levels of HDL may decrease your risk of stroke and heart disease.

Low density lipoprotein cholesterol is also called LDL (the "bad" cholesterol). When too much LDL builds up on your artery walls, plaque forms and blocks blood flow in vessels. Higher levels of LDL may increase your risk of stroke and heart disease.

Triglycerides are a type of fat in your bloodstream. High levels of triglycerides can increase your risk of stroke and heart disease.

 Prevention: Ask your health care provider about what cholesterol level is right for you. Together, you and your health care provider will decide on a treatment plan. Have regular appointments with your health care provider to manage your cholesterol.

#### ☐ Alcohol use

Drinking too much alcohol can lead to a stroke.

Prevention: If you are a man, drink no more than 2 alcoholic drinks each day. If you are a woman, drink no more than 1 alcoholic drink each day. Do not drink alcohol if you are pregnant. Ask your health care provider for help if needed.

#### ☐ Extra weight

Carrying extra weight strains your circulatory system. It also makes you more likely to have high cholesterol, high blood pressure and diabetes.

— **Prevention:** Talk with your health care provider about how to lose weight.

#### ☐ Physical inactivity

Lack of exercise increases your risk for heart disease, stroke, high blood pressure, high cholesterol and diabetes.

 Prevention: Talk with your health care provider before you start a regular exercise routine.

#### ☐ Carotid artery disease

Your carotid arteries carry blood to your brain. When plaque builds up in these neck arteries, you are at risk for an ischemic stroke (see page 18).

— Prevention: Your health care provider may order tests to find out how much plaque you have. Removing the plaque may help prevent stroke in some cases. A procedure called angioplasty may be used to place tubes (stents) in the artery to help keep it open. Surgery may be needed to remove the plaque.

### ☐ Peripheral artery disease (PAD)

In PAD, cholesterol and plaque build up in your blood vessel walls and cause your blood vessels to narrow. This may reduce blood flow.

 Prevention: Talk with your health care provider about how to manage and treat PAD.

#### ☐ Diabetes

Having diabetes increases your risk for heart disease and stroke.

 Prevention: Follow your health care provider's treatment plan if you have diabetes.

#### ☐ Food

Eating foods high in saturated fat, trans fat and cholesterol can make your blood cholesterol levels go up. Eating foods high in sodium (salt) can raise your blood pressure. Eating foods high in calories can make you gain weight.

 Prevention: Cut down on saturated fats, trans fats, salt and foods high in cholesterol. Eat at least 5 servings of fruit and vegetables each day. See nutrition on pages 56-57 or visit choosemyplate.gov to learn more.

#### ☐ Street drugs

Using street drugs changes your blood pressure and increases your risk for stroke.

 Prevention: If you use street drugs, stop. Ask your health care provider for how to quit.

#### What you cannot control

According to the American Stroke Association, the following stroke risks are those you cannot control:

#### ☐ Race

Rates of stroke vary among races. Lifestyle and environment can have an effect. Blacks, Latinos and Asians are at higher risk for stroke than Caucasians.

#### ☐ Age

A stroke can happen to anyone. It is more common in adults older than age 55. Your chance of having a stroke increases with your age.

#### ☐ Gender

Women have more strokes than men.

### ☐ Family history (genetics)

A history of heart disease or stroke can increase your stroke risk.

#### ☐ Stroke or transient ischemic attack (TIA)

If you have already had a stroke or TIA (see page 19), you have a higher risk of having another stroke.

# **Stroke Signs and Symptoms: Call 911**

# Tip

You may notice stroke symptoms when you wake up.

Call 911 right away if you have any of the symptoms listed on this page.

#### ■ Balance

Sudden loss of balance or coordination, trouble walking or dizziness

#### **■** Eyes

Sudden blurred, double or loss of vision in one or both of the eyes

#### ■ Face

Face or smile droops on one side

#### ■ Arms

Sudden weakness, numbness or paralysis in an arm, hand or leg, usually only on one side of the body

#### ■ Speech

Sudden trouble speaking or understanding language, including confusion, slurred words or being unable to repeat a simple sentence

#### ■ Headache

sudden severe headache (the worst headache of your life) with no known cause

Signs and symptoms may last a short time and disappear. Do not delay in getting help. A stroke is a medical emergency.

Call 911 right away if you have any of these symptoms.

# **Chapter 3: Emergency Department**

#### Tip

Call 911 right away if you have symptoms of stroke.

Treatment started within the first few hours is important to prevent brain injury. Treatment begins in the Emergency Department. The Emergency Department may use a "stroke code." This code calls a specialized stroke team to your bedside. This process helps you quickly get care.

Members of your stroke team will determine if you are having a stoke by reviewing your:

- health history
- symptoms
- physical exam
- test results.

They may talk with members of your care circle about treatment options.

### **Tests**

#### **Blood tests**

You will have a blood test. This helps your stroke care team identify your available treatment options.

### Imaging tests

#### ■ CT (computed tomography) scan

You will have a CT scan. This scan uses X-ray and a computer to get an in-depth look at your brain. The result is an image that provides a clear and detailed picture.

A CT scan will be done to rule out hemorrhage (bleeding) as the type of stroke.

The scan usually takes less than 5 minutes.

### ☐ CT angiography (CTA)

This painless test uses CT technology to get a 3-D view of your blood vessels. Like a CT scan, a CTA uses X-ray and a computer. It provides an in-depth look at your blood vessels. You will have an intravenous (IV) contrast injection to help see your blood vessels better.

A CTA may be done to identify your possible treatment options.

The scan usually takes less than 5 minutes.

# Tip

Members of your stroke team will talk with you if you need other tests.

#### ☐ MRI (magnetic resonance imaging)

This is a painless way to look inside your body without using X-rays. MRI does not use radiation.

MRI uses a magnetic field to make three-dimensional (3-D) images of your brain. These images show the injured area of your brain.

The scan usually takes 45 to 90 minutes.

#### **Heart test**

#### ☐ Electrocardiogram (EKG)

This is a painless heart rhythm test done at the bedside. An EKG may be done to find the cause of your stroke and identify treatment options.

The scan usually takes less than 5 minutes.

#### **Treatment**

Your treatment will depend on your type of stroke. There are several types of treatment.

#### ☐ Ischemic stroke treatment

Your stroke care team may start treatment to dissolve or remove a blood clot.

#### Medicine

# ☐ Thrombolytic (tenecteplase or alteplase)

This medicine is used to treat strokes caused by blood clots. It works by quickly dissolving the clot and allowing blood to flow through the artery.

You can only get this medicine in the hospital. You will receive it through an intravenous (IV) line in your hand or arm. This medicine should be given as soon as possible after the start of stroke symptoms.

This medicine may cause bleeding (including bleeding into the brain). Your health care provider will determine if a thrombolytic medicine is right for you.

#### **Procedure**

☐ Mechanical thrombectomy (intra-arterial treatment)
This procedure is done to open a large artery that is blocked.

A long, narrow tube (catheter) is inserted through a large artery in your groin and guided to the blood clot. The goal is to remove the remove the clot and restore blood flow.

# ☐ Hemorrhagic stroke treatment

Your stroke care team will start treatment to stop the bleeding in your brain. Your treatment may also help reduce pressure on your brain.

#### Medicine

#### ☐ Blood pressure medicine

High blood pressure may lead to more bleeding in your brain. You may receive medicine through an intravenous (IV) line to quickly manage your blood pressure.

#### **Transfusion**

#### **☐** Transfusion

If you are taking anticoagulant medicine (known as blood thinners), your blood will not clot as quickly. During a stroke, this medicine may lead to more bleeding in your brain.

To control your blood clotting, you may need a blood transfusion. This may help your blood clot quicker and lead to less bleeding in your brain. You will receive a blood product that is compatible with your blood type.

# **Chapter 4: Hospital Stay and Recovery**

## **Medicines**

### **Important**

Call your health care provider if you have severe or unusual reactions to your medicine(s). Taking your medicine as directed is important. Your health care provider will decide which medicines you should take. This depends on your:

- medical history
- cause of stroke
- allergies.

The following are some medicines you may take. Your health care provider will give you more information about your medicine.

#### Medicines to help prevent blood clots

You may have other medicines prescribed during your hospital stay not listed here. Take them as directed.

#### ☐ Anti-platelets

Platelets circulate (move) in your blood and help form blood clots. Anti-platelet medicines help keep the blood from clotting. These medicines are known as blood thinners. Some types of anti-platelets include:

#### ☐ Aspirin

Aspirin is often the first choice to prevent another stroke. Over-the-counter medicines like Tylenol®, Advil® or Aleve® do not keep the blood from clotting. Only aspirin can keep your blood from clotting.

If aspirin upsets your stomach, you may take a coated aspirin.

☐ Extended release dipyridamole and aspirin combination (Aggrenox®), clopidogrel (Plavix®), ticlopidine (Ticlid®) and others

Like aspirin, these medicines keep your blood from clotting. You can only get these medicines with a prescription. Your health care provider will decide if any of these medicines will work better for you than aspirin.

# Tip

Your health care provider will tell you how to get your medicine. You can buy some medicine over-the-counter. You will need a prescription to get other types of medicine.

#### ☐ Anticoagulants

Other parts of your blood (besides platelets) can cause blood clots. Anticoagulant medicines keep you from getting blood clots and help break up blood clots that form. These medicines are known as blood thinners. Some types of anticoagulants include:

#### ☐ Warfarin (Jantoven®)

Warfarin is a common medicine to prevent stroke. You will need to have a blood test called the international normalized ration (INR) to decide the best dose for you.

You will need to have regular blood tests to determine the best dose for you. If you have questions about warfarin, ask your health care provider.

#### ☐ Other anticoagulants

If warfarin is not the best anticoagulant medicine for you, your health care provider may recommend a different anticoagulant. Other common anticoagulants include apixaban (Eliquis®), dabigatran (Pradaxa®) or rivaroxaban (Xarelto®).

You do not need to have a blood test with these medicines.

#### **Medicines to lower cholesterol**

#### ☐ Anti-hyperlipidemics

These medicines lower the cholesterol levels in your blood. This has many benefits. One group of these medicines, known as "statins," has been shown to help reduce the risk for stroke in people who have high cholesterol.

Common statins include atorvastatin (Lipitor®), fluvastatin (Lescol®, Lescol XL®), rosuvastatin (Crestor®), simvastatin (Zocor)®.

If you are taking a different anti-hyperlipidemic medicine and have a stroke, a statin medicine might be added to your current medicines to help prevent another stroke.

### **Medicine Dos and Don'ts**

#### What to do

- Learn the generic and brand names of your medicines. For example, acetaminophen is the generic name and Tylenol<sup>®</sup> is the brand name.
- Understand why you are taking your medicines.
- Ask your doctor or pharmacist if there are foods or other medicines you should not have while taking this medicine. Some foods and medicines may affect your medicine.
- Take your medicine at about the same time each day.
- Have all of your medicines filled at one pharmacy.
- Talk with your doctor, nurse or pharmacist if you have any questions about your medicine.
- Use a pill box or guide to manage your medicines.
- Ask your health care provider or pharmacist what to do if you miss a dose.
- Keep **all** medicines (prescription, over-the-counter, herbals and vitamins) out of reach of children and pets.
- Keep all medicines in their original bottles or in a pill box.
- Keep all medicines away from heat, light and humidity. Do not keep medicines in the bathroom or near the kitchen sink.
- Plan ahead for vacations. Check how much medicine you have and call your pharmacy to refill your prescription, if needed. Do not be caught without enough of your medicines when you are away from home.
- Allow extra time for refills if you use a mail order pharmacy.
- If you are flying, check with your airline for details about bringing medicines on board.
- If you are seeing more than one health care provider, be sure to tell each one which medicines you are taking.

#### What not to do

- Do not let your medicines run out. Make sure you call your pharmacy at least 1 week before you need a refill.
- Do not take medicines prescribed for someone else.
- Do not take any more or less than the prescribed dose of any medicine.
- Do not keep outdated medicine.
- Do not stop taking your medicines unless you have talked with your health care provider.

# **Bring Your Medicines to Your Doctor Appointments**

#### Tip

Keep a current list of your medicines in your wallet or purse.

Bring all of your medicines or a list of them to your doctor appointments. Put your medicine bottles and boxes into a bag and bring it with you to your appointments or use the *My Medicine List* (see pages 107-108).

#### Include all:

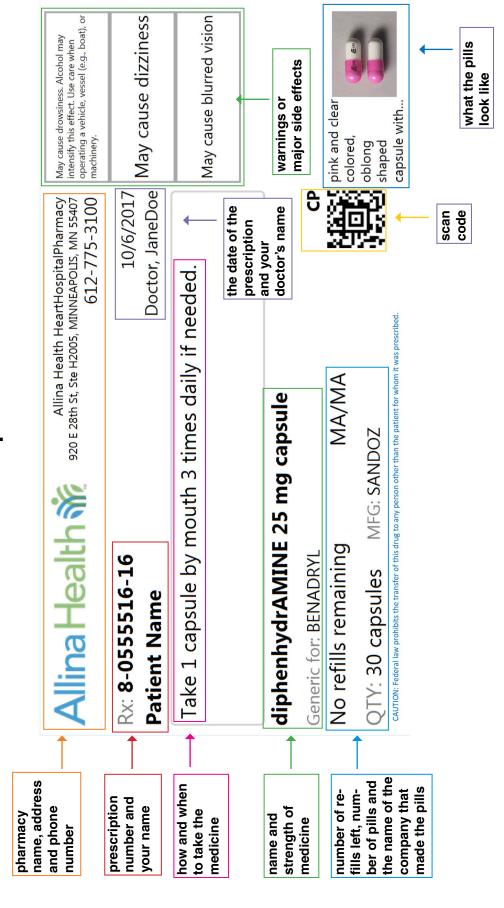
- prescription medicines
- over-the-counter medicines
- herbals
- natural products.

Medicines can work against each other so your health care provider needs to know what you are taking.

# **How to Read Your Prescription Label**

The label on your prescription medicine has a lot of information on it. To learn how to read it, see the label on the next page.

# How to Read Your Prescription Label



#### **Tests**

The following are some of the tests you may have during your hospital stay.

#### **Blood tests**

These tests are used to look for stroke risks or conditions that may have led to your stroke. Blood tests are done to check:

- your cholesterol levels
- how your blood clots, such as partial thromboplastin time test (PTT) and international normalized ratio (INR)
- if you have diabetes by looking at your blood glucose levels
- the level(s) of medicine in your blood.

#### **Swallow tests**

You may have problems with swallowing or moving your mouth. This can make you cough or choke on food or drinks. Swallow tests are used to help find the cause of these problems.

There are two types of swallow tests:

#### ■ at your hospital bed:

A speech-language pathologist or nurse will watch you eat foods and drink liquids. This will help tell if other tests are needed or what foods and liquids are safest for you.

#### ■ video swallow:

You will swallow some barium (a white liquid that shows up on X-ray) to simulate "normal" eating. A video X-ray is taken as you swallow the barium.

A radiologist and speech-language pathologist can study your ability to swallow. He or she will check for aspiration (if food and liquids are going into your windpipe).

#### Tip

Members of your health care team will make you as comfortable as possible. Tell someone if you are uncomfortable in closed-in spaces.

#### **Imaging tests**

These are done to find the area of the brain affected by the stroke, make an early prognosis and rule out other medical conditions.

#### ☐ MRI (magnetic resonance imaging)

This is a painless way to look inside your body without using X-rays. MRI does not use radiation.

MRI uses a magnetic field to make three-dimensional (3-D) images of your brain. These images show the injured areas of your brain. This can help your health care team determine how serious your stoke was.

If you have a pacemaker or if you have metal fragments in your head, you may not be able to have this scan.

#### ☐ Carotid ultrasound

This painless, safe test uses high-frequency sound waves to create an image of your arteries and blood flow on a computer screen. This lets your health care provider see if your arteries are narrowed or damaged.

Ultrasound is most often done on the carotid arteries in your neck. Ultrasound does not use radiation and has no side effects.

#### ☐ Trans cranial doppler

This is an ultrasound that measures blood flow through the major vessels in your brain.

### ☐ Magnetic resonance angiogram

This test uses MRI technology to get a 3-D view of your blood vessels.

# □ Angiogram

This uses X-ray to see your blood vessels. A radiologist (doctor of X-ray) inserts a tube (catheter) into an artery in your groin and threads it to the arteries in your neck and head. He or she injects contrast into your blood vessels to help them show up on the X-ray. This test helps rule out problems with blood vessels in the neck and brain.

#### **Heart tests**

Heart problems increase your risk of having a stroke. Common heart problems include:

- atrial fibrillation (irregular heartbeat)
- heart attack
- heart failure
- if you have an artificial heart valve.

Some of the most common tests used to check your heart are:

#### **□** Blood tests

Certain enzymes and proteins are released when your heart is damaged. Your health care provider can use these tests to tell if you had a heart attack.

### ☐ Echocardiogram (echo)

This is an ultrasound study of your heart muscle, heart valves and pericardium (the sac surrounding your heart). This painless test uses sound waves to see how well your heart is working.

A wand-like instrument makes the sound waves. As the ultrasound wand is moved over your chest, pictures of your heart appear on a screen and are recorded.

### ☐ Electrocardiogram (EKG)

This test records the electrical activity of your heart. Small patches (discs) attached to your chest "pick up" the electrical activity from your heart. This activity goes through wires to the EKG machine where it is recorded on a moving strip of paper. This test is painless.

### ☐ Transesophageal echocardiogram (TEE)

This records ultrasound images of your heart. The transducer, about the size of a normal piece of food, is mounted on the end of a flexible tube, about the size of your index finger. The tube is placed in your mouth and guided down your esophagus (swallowing tube).

You will be given medicine to help numb the back of your throat. This will make swallowing the tube easier.

The TEE gives excellent pictures of your heart because your heart is next to your esophagus.

## Tip

After the TEE, members of your health care team will make sure you can safely swallow before you can eat or drink.

### Contrast echo (bubble study)

Saline (salt water) solution is injected into an arm vein. Ultrasound tracks the solution as it flows through your heart. This will let him or her see if there is an abnormal opening between the right and left sides of your heart. This test is painless.

### **Procedures**

### ☐ Carotid endarterectomy

This surgery is done to help prevent a stroke by improving blood flow to your brain. It involves removing plaque from a carotid artery in your neck.

Your surgeon makes an incision along the side of your neck, opens the artery and removes the plaque. He or she then closes the incision. You will not be awake (unconscious) during the surgery.

### ☐ Clipping

This surgery is done to stop the blood flow to a brain aneurysm. A metal clip is placed across the base of the aneurysm. This stops blood flow to the aneurysm and makes it less likely for the aneurysm to bleed. You will be unconscious during surgery. This clip does not need to be removed.

### ☐ Coiling (embolization)

This procedure is done to prevent bleeding in your brain by closing off an aneurysm. An aneurysm occurs when an artery or vein in your brain becomes weak and bulges.

A long, narrow tube (catheter) is inserted through an artery in your groin and guided to the aneurysm in your brain. Your doctor then threads small coils through the catheter into the aneurysm. These coils fill the aneurysm and help prevent it from bleeding. You will be unconscious during this procedure. The coils do not need to be removed.

### ☐ Craniotomy

This is a surgery to remove part of the skull (the bone flap) to reach the brain. The location and size of the craniotomy will depend on your stroke. You will not be awake (unconscious) during surgery.

☐ Mechanical thrombectomy (intra-arterial treatment)	
This p	ocedure is done to open a large artery that is blocked
in you	brain.

A long, narrow tube (catheter) is inserted through a large artery in your groin and guided to the blood clot. Your health care team will use a device to grab and remove the blood clot. This will open the blood vessel and restore normal blood flow.

### ☐ Radiosurgery

This procedure is done to treat an AVM. Radiosurgery uses a "pencil-like" beam of high dose radiation to destroy the AVM. Radiosurgery does not harm the normal brain tissue around the AVM. You will be conscious during surgery.

Radiosurgery will take 20 minutes to 2 hours. It is not painful.

### **□** Ventriculostomy

This procedure uses gravity to drain excess fluid from your brain. A catheter is inserted into your ventricle (a chamber in your brain) and drains into a collection bag. This helps reduce pressure on your brain.

# **Chapter 5: Rehabilitation and Recovery**

## The Goal of Rehabilitation

The brain heals more slowly than many other parts of the body. Recovery from a stroke is different for each person. It can often take months or years to recover.

Your goal is to be as independent as you can. You may learn new skills, improve your physical condition and learn how to do tasks in different ways.

Because a person with a stroke has specific needs, recovery will be different for each person. The recovery often includes medical care, natural recovery, rehabilitation and the gradual return to your everyday activities.

It is important to follow your health care provider's instructions about recovery.

Rehabilitation usually starts in the hospital. You may continue with it after your hospital stay. Together, you and members of your health care team and care circle will make rehabilitation choices before you leave the hospital.

## **Rehabilitation Program**

Your program may include:

- learning about your stroke
- learning ways to help you safely eat, brush your teeth, get dressed, bathe, do housework and go to the bathroom
- strengthening exercises for arms and legs
- receiving emotional support
- testing and treatment for problems with:
  - vision
  - swallowing and eating
  - communication
  - reading and writing
  - memory, attention span and problem-solving skills

- learning how to:
  - take medicines
  - regain bowel and bladder control
  - get in and out of a chair, bed or car
  - position yourself in bed or chair
  - get around your home and community
  - enjoy your favorite leisure activities.

## **Planning for Care After Your Hospital Stay**

Making plans for when you leave the hospital is an important part of your recovery. Your health care team will work with you and members of your care circle to plan for your discharge. This planning begins early during your hospital stay.

Depending on your needs, your plan for discharge may include rehabilitation after your hospital stay. There are different types available.

The type of rehabilitation you will need depends on:

- your ability to take part in therapy
- your medical and nursing needs
- your care circle
- the resources available in your community.

Possible options for after your hospital stay are listed on page 51. A social worker or other member of your health care team will talk with you while you are in the hospital to help decide which option is right for you.

## **Rehabilitation Options**

### Tip

You may not need rehabilitation after your hospital stay. Talk with your social worker about your options.

Not everyone needs rehabilitation after a hospital stay. If you do, you have options. The type of rehabilitation you receive depends on your ability to take part in therapy, your medical and nursing needs, and your caregiver.

### ☐ Hospital programs

These are for people who need doctor and nurse care every day. These programs are done in special rehabilitation hospitals or in "acute care" hospitals. You will stay in the hospital where you have therapy. The length of time you stay in a hospital program depends on your needs and goals.

### ☐ Skilled nursing facility

This care is for people who need 24-hour care. You will receive short-term or long-term care for your health needs. Your stay will depend on your needs.

### ☐ Transitional care unit (TCU)

This care is for people who need more help and health care services every day than what they can get at home. Most people stay in a TCU for 2 to 4 weeks. Your stay will depend on your needs.

### ☐ Outpatient programs

These are for people who live at home. They go to the hospital for care during the day.

#### ☐ Home care

These programs let people receive services in their own homes.

## **Role of Your Care Circle**

### Tip

See Chapter 7 for information just for members of the care circle.

Members of your care circle are important to your recovery. They need to understand what you are going through and how the stroke has affected you.

The adjustment may be easier if your care circle knows how to handle problems that may come up after you leave the hospital. Your care circle can also help by giving you support and encouragement.

Members of your care circle can help by:

- taking care of themselves (eating well, getting rest, doing things they enjoy, and dealing with their own feelings such as anger, anxiety or resentment)
- knowing that your progress may be slow
- visiting and talking with you
- sitting with you in silence
- letting you know you are still needed and important
- supporting your rehabilitation decisions
- becoming educated about your condition and recovery
- asking to go along to therapy sessions
- supporting and encouraging you to meet your milestones during your recovery
- showing confidence in your improvement
- working with members of your health care team to create a healing environment at home
- sharing responsibilities
- being realistic in knowing you may have recovery limits.

## **Tips for Reducing Stress During Your Recovery**

- Take your recovery one day at a time. Be hopeful for a successful recovery.
- Create a regular routine or write lists of what needs to be done to help plan and organize your day.
- Appreciate each small gain. Your emotions and ability to do things may vary from day-to-day because of fatigue. You may need to learn how to do things in different ways or try new ways of doing tasks, talking, speaking and organizing your social life.
- Expect that members of your care circle will improve their skills and knowledge. They are learning right along with you.
- Plan for breaks so you and members of your care circle are not together all the time. Time apart is important for both you and these individuals. Try to do activities that get you both out of the house.
- Ask family members and friends to help.
- Try relaxation, massage or meditation to cope with your stress.
- Join a support group.

Be patient with and kind to others. You may feel irritated or upset some times, but do not blame anyone. Do not take your frustrations out on others. Talk with a family member, friend, professional or support group about your feelings.

## **Progressive Muscle Relaxation**

Progressive muscle relaxation is a short and easy exercise to help you relax and relieve some of your pain.

### **Getting started**

Find a relaxing position. You may sit down or lie on your back in bed. Be sure your legs and hands are not crossed.

You may close your eyes. If you prefer, you can keep your eyes open, but focus on one spot in front of you.

Bring your attention to your breathing. Think about where your breath comes in and out of your nose or mouth. Think about how your chest moves up and down with each breath.

Imagine a gentle, safe wave of relaxation that will slowly and warmly flow through your body. The wave can help you find those places that need to relax and give them permission to relax.

You can also imagine this wave in any way you find most comfortable. You may see it as light, water or just a feeling.

If your mind wanders, gently bring it back to your breathing.

### Relax from your head to your feet

- Bring your attention to the top of your head and begin to imagine a wave.
- With your next breath out, feel the wave flow through your head. Feel your jaw soften and relax.
- Breathe in.
- With your next breath out, focus on the back of your neck. Let it soften and relax.
- Breathe in.
- With your next breath out, imagine the wave moving through each arm all the way to your hands. Feel your hands become slightly heavier where they are lying.
- Breathe in.
- With your next breath out, imagine the wave of relaxation roll gently and safely down your spine. Let all of your back muscles relax and soften.
- Continue to breathe. Feel the wave flow as you breathe out.
- Let the wave flow through your pelvic area and hips into your upper legs and thighs.
- Breathe in.
- With your next breath out, allow the wave to find those areas in your legs and knees that need to relax. Give them permission to relax.
- Breathe in.
- With your next breath out, feel the wave move into your calves, then your feet. Feel your feet become a little heavier.
- Take two deep breaths. Imagine any remaining stress gently flowing out the bottoms of your feet.

Take a moment to observe the still place you created. With practice, relaxation will become easier.

## **Nutrition**

## Tip

According to the United States Department of Agriculture, you should:

- eat smaller portion sizes
- make half of your grains whole
- make half of your plate vegetables and fruits
- drink fat-free or low-fat milk
- eat lean proteins.

Visit choosemyplate.gov for more information about nutrition.

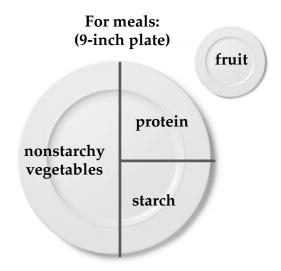
## **Important**

If you have questions about your nutrition and recovery, ask your health care provider.

Good nutrition is essential for your recovery. Eating well-balanced meals and snacks will help you recover quickly and help you feel your best. What you eat after your brain injury affects your well-being.

If you do not eat enough of the right foods, you will become tired and less able to take care of yourself. Be sure you make time to eat — even if you do not feel hungry.

When you are planning your meals and snacks, try to think about what your plate should look like.

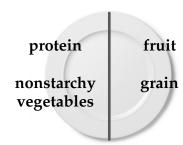


## Tip

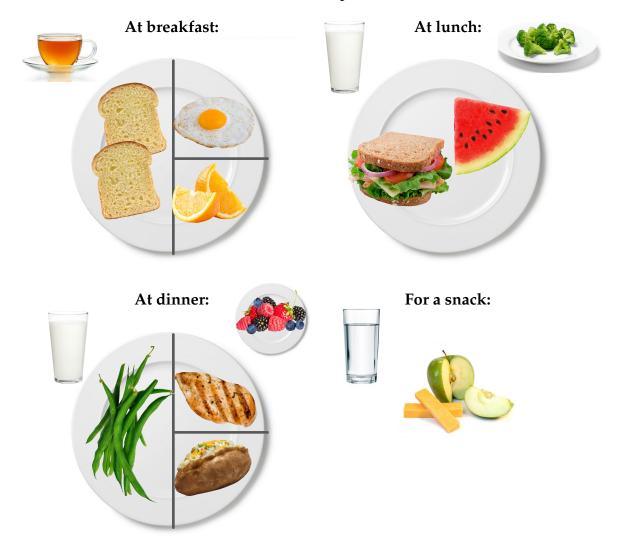
It is important you get enough water every day. Drink when you feel thirsty and with your meals.

Ask your health care provider how much water you need every day. Follow any special directions if you have fluid restrictions or if you have had weight loss surgery.

#### For snacks:



Here are some examples of well-balanced meals and a snack.



## Tip

Eat foods high in vitamin C to help absorb the iron that comes from plants such as spinach.

For instance, drink a glass of orange juice with an iron-fortified cereal.

Good sources of vitamin C are oranges, broccoli, tomatoes, kiwi, strawberries, peppers, potatoes and cabbage.

## **Nutrients important for your recovery**

Eating foods rich in the following nutrients are important for your recovery.

### ■ Protein:

Protein helps repair and build healthy tissue.

### ■ Iron:

Iron works in each of your body's cells to help make energy.

#### ■ Vitamin C:

Vitamin C helps your body repair damaged tissues, keeps your bones and teeth strong, and helps your body absorb iron.

#### ■ Calcium:

Calcium helps build and maintain your bones, your muscles move, your blood clot, and your nerves send messages.

### ■ Fiber:

Fiber helps your body produce regular bowel movements.

Use the chart on the next page to help you choose foods for building well-balanced meals and snacks.

## **Your Exercise Program**

### Why exercise is important

Getting regular exercise will help:

- prevent another stroke, if you had one
- maintain a healthy weight
- reduce the risk for heart disease, diabetes, obesity, certain cancers and joint conditions
- reduce levels of anxiety and stress
- improve your self-esteem and confidence
- improve concentration and memory
- maintain good blood pressure and cholesterol levels
- give you an overall feeling of well-being
- build endurance and increase your metabolism
- you relax and sleep better
- provide healthy blood flow to your brain
- improve your mood
- improve your thinking and memory
- improve your walking ability
- treat your pain.

## Your goals

- Your general goal is 30 minutes of exercise at least 3 to 5 days each week. Aerobic exercise uses large muscle groups and raises your heart rate (like biking, walking and swimming).
- During aerobic exercise you should be able to talk (singing would be hard).
  - Your rate of perceived exertion (how hard you are working) should be between light and somewhat hard (at left).

## How you can exercise

- Follow your exercise prescription from your therapist or doctor:
- aerobic exercise
- strength training
- ☐ flexibility and balance.
- If you do not have an exercise prescription or you are having a hard time starting one, ask your doctor for a referral to physical therapy.
- 6 No exertion at all 7 Extremely light 8 9 Very light 10 11 Light 12 13 Somewhat hard 14 15 Hard (heavy) 16 17 Very hard 18 19 Extremely hard 20 Maximal exertion
- Borg-RPE-skalan® © Gunnar Borg, 1970, 1985, 1994, 1998

The scale with correct instructions can be obtained from Borg Perception, see the home page: www.borgperception. se/index.html.

- Do what you can based on your abilities.
- Walk around your house.
- Walk around your neighborhood.
- Do something you enjoy. Walk with a friend or with a walking group.
- Join a fitness center (if you are able).
- Start small.
  - Exercise for 5 minutes 5 times a day.
  - Add 1 to 3 minutes each day as you are able.

### Signs you are doing too much

As you exercise you should be aware of your body's response. Signs you are doing too much include:

- feeling dizzy or lightheaded
- nausea (upset stomach) and vomiting (throwing up)
- cold sweat
- being short of breath (unable to have a conversation)
- exhaustion or unusual fatigue (very tired)
- feeling as if your heart is suddenly racing or pounding
- any chest pain or pressure in your teeth, arm, jaw, ear, neck or between your shoulder blades.

Call your doctor if the symptoms do not go away after resting. Call 911 if you cannot reach your doctor. Do not drive yourself to a clinic or Emergency Department.

## **Tobacco Use is Dangerous**

#### Did You Know

Smoking doubles your risk for stroke.

(Source: Illinois Department of Health)

#### Did You Know

- Smoking causes nearly 1 out of every 3 deaths from heart disease and stroke.
- Heart disease and stroke cause 1 out of 3 women's deaths.

Source: Centers for Disease Control and Prevention



Tobacco products include cigarettes, electronic nicotine delivery systems (ENDS, includes e-cigarettes and JUUL®), smokeless tobacco (dip or chew), cigars, hookahs and pipes.

Tobacco use is especially dangerous to your blood vessels and arteries. It can cause atherosclerosis, a build-up of plaque (fatty substances found in your blood). Over time, the plaque hardens and narrows your blood vessels and arteries.

Smoking also makes the blood vessels and arteries sticky. This leads to "obstructions" in blood flow, meaning that your blood cannot flow easily. The side effects of using tobacco can result in needing stents, coronary artery bypass surgery or both to keep your blood vessels and arteries open. It can also lead to stroke or heart attack.

#### Tobacco use:

- causes stroke and heart disease
- increases your heart rate
- increases your blood pressure
- lowers your good (HDL) cholesterol
- makes your heart work harder (adding stress to scarred or weakened blood vessels and arteries)
- can interfere with how well your heart medicines work.

Smoking even 1 cigarette a day:

- causes your heart rate and blood pressure to increase, and your major blood vessels to become smaller, causing your heart to work harder
- causes your blood to clot faster; tobacco users have a higher chance of stroke and heart attack
- reduces the amount of oxygen in your bloodstream, making you short of breath
- slows your ability to heal.

Cigarette smoke contains more than 7,000 chemicals. More than 70 can cause cancer. The human body was not designed to smoke.

### Secondhand Vape

Dangerous and harmful chemicals have been found in secondhand vape.

### Did You Know

The risk of dying from major tobacco-related diseases is higher among former cigarette smokers who switched to spit tobacco after they stopped smoking than among those who quit using all tobacco.

Source: Illinois Department of Health



### Secondhand smoke

Secondhand smoke is a mixture of smoke coming from the burning tips of cigarettes, pipes and cigars and smoke exhaled by smokers.

Anyone around secondhand smoke breathes in the chemicals from the tobacco smoke. Secondhand smoke causes death and disease in people who do not smoke.

Even briefly breathing secondhand smoke can damage the lining of blood vessels and cause your blood to become stickier. These changes can cause a deadly heart attack.

No amount of secondhand smoke is safe. According to the Centers for Disease Control and Prevention, secondhand smoke exposure causes more than 8,000 deaths from strokes.

### **Smokeless tobacco**

Smokeless tobacco products (snuff, chewing tobacco, snus and tobacco products that dissolve) are not a safe alternative to smoking. Any form of tobacco contains many toxic chemicals and high levels of nicotine.

For example, the nicotine levels in 1 tin of smokeless tobacco is roughly equal to 4 packs of cigarettes. These chemicals move from your mouth to all parts of your body through your bloodstream. It affects your heart by increasing your heart rate and blood pressure. This can lead to a stroke.

Smokeless tobacco also contains *a lot* of sugar. This can make it harder to control your glucose levels.

## E-cigarettes

Electronic cigarettes (e-cigarettes or e-cigs), JUUL®, hookah pens, vapes, vaporizers, vape pens, e-hookah, e-pens, e-pipes, e-cigars and disposables are all known as electronic nicotine delivery system (ENDS).

E-cigarettes have become very popular very quickly. This means there has not been time to get results from long-term studies on the safety or health effects of e-cigarettes.

■ A 2018 public health research report supported by the FDA confirms that using ENDS products is harmful. Use causes health and safety problems and greatly increases tobacco addiction among adolescents.

- The name of the report is "Public Health Consequences of E-cigarettes" by the National Academies of Science, Engineering, Medicine (NASEM)."
- The FDA has not approved e-cigarettes as a way to quit smoking. According to the 2018 NASEM report, there is "limited" evidence that e-cigarettes help some people to quit smoking. Many people return to smoking, continue to use the e-cigarette, or use both. None of these options is healthful.

## **Benefits Of Quitting Tobacco**

### Within...

#### ■ 8 hours:

The carbon monoxide level in your blood drops to normal and the oxygen level in your blood increases to normal. Your breathing starts to improve.



#### **■** 24 hours:

Your chance of a heart attack decreases.

### ■ 48 hours:

Nerve endings start to grow again. Your senses of smell and taste improve.

#### ■ 2 weeks:

Your circulation improves and your lung function increases.

#### ■ 1 to 9 months:

Your cough, stuffy nose and shortness of breath decrease. Your energy level increases.

#### **■** 1 year:

Your chance of heart disease is cut in half.

#### ■ 4 to 5 years:

Your chance of a stroke is the same as someone who does not use tobacco. Your chance of dying from lung cancer is cut in half.

### ■ 5 to 10 years:

Pre-cancerous cells are replaced with normal cells.

#### **■** 10 years:

Your risk of cancer, stroke, and heart disease is close to the same of someone who has never used tobacco.

(Source: World Health Organization)

#### Did You Know?

In 1 year of quitting smoking, your risk of heart disease is reduced by more than half. Quitting also reduces the risk of a second heart attack if you've already had one.

(Source: National Institutes of Health)

## **Behavioral Tips and Coping Skills for Quitting Tobacco**

### **Getting started**

- Make a list of reasons for quitting.
- Think positively.
  - Believe you can.
  - Remind yourself,
     "I'm choosing not to smoke today."
  - Remember that it's "not that I can't smoke, it's that I'm choosing not to."



- Tell yourself often: "I can do this."
- Visualize yourself as someone who doesn't use tobacco.
- Use relaxation breathing.
  - Inhale to count of eight.
  - Hold to count of four.
  - Exhale to count of eight.
- Substitute items for cigarettes.
  - Chew gum.
  - Suck on hard candy.
  - Chew on straws or toothpicks.
  - Eat low-calorie snacks.
- Keep your hands busy.
  - Play cards.
  - Read books.
  - Put together puzzles.
  - Play with rubber binders.
  - Make crafts.
  - Write letters.
  - Draw.
  - Paint.
- Concentrate on the good things in your life!

- Change your environment:
  - Change your routine to help avoid temptation. Even small changes can lower the craving to smoke.
  - Get rid of all cigarettes, ashtrays and lighters in your home, car, desk or office.
  - Change your favorite smoking areas to make them remind you less of smoking.
  - Make your home and vehicles smoke free.
- Get support from others:
  - Talk to your family, friends or coworkers about how to support you while you quit.
  - See if others you know would like to quit with you.
     This way you can support each other through the tougher times of quitting.
- Plan your reward for each day you do not smoke. Think about small, pleasurable activities you can do during your day that give you joy. Long-term rewards are helpful as well, but the small rewards are just as important.
- Remember that even the most intense craving lasts only 5 to 10 minutes. Wait it out. Tell yourself, "This too shall pass."

### Avoiding a relapse

- Think about what you are gaining from quitting tobacco, instead of focusing on what you've given up. For example, "It's easier to play with my kids or grandkids."
- Have a plan for how you will deal with unexpected urges. (Take a walk, make a call.)
- Think your way through difficult situations ahead of time whenever you can.
- Think about past quitting attempts and what was helpful to you. Reuse them again if possible or try something new.
- Explore ways to move your body with safe and realistic expectations. Increasing your physical activity can help you manage weight gain and work through emotions that otherwise would make you want to smoke.
- Avoid foods high in calories and fat. Sugar can increase cravings to smoke. Limit large amounts of sugar.

- Drink lots of water. Ice water may be helpful in getting rid of a craving.
- Reward yourself when you reach milestones: 1 day, 1 week, 2 weeks, 1 month, etc.
- Go to places where you cannot smoke stay away from the places you used to smoke.
- Think about the money you saved!
- Think of quitting as an act of love for those you care about and for yourself!

## **Resources for Quitting Tobacco**

\*There may be a cost to you.

Check with your insurance

provider.

### **Allina Health**

- Tobacco Intervention Program at Abbott Northwestern Hospital
  - **—** 612-863-1648
- Tobacco Intervention Program at Mercy Hospital
  - **—** 763-236-8008
- Tobacco Intervention Program at River Falls Area Hospital
  - **—** 715-307-6075
- \*United Hospital Lung and Sleep Clinic Tobacco Cessation Program
  - **—** 651-726-6200
- \*Penny George™ Institute for Health and Healing (LiveWell Center) tobacco intervention coaching





### **Other**

- Quit Partner
  - 1-800-QUIT-NOW (1-800-784-8669) or quitpartnermn.com
- Minnesota Department of Health
  - health.state.mn.us/quit
- online tobacco cessation support
  - smokefree.gov
- American Lung Association/Tobacco Quit Line
  - 651-227-8014 or 1-800-586-4872
- Chantix<sup>®</sup> GetQuit Support plan
  - 1-877-CHANTIX (1-877-242-6849) or get-quit.com
- financial aid for Chantix® or Nicotrol® inhaler
  - 1-866-706-2400 or pfizerrxpathways.com
- \*Mayo Clinic Nicotine Dependence Center's Residential Treatment Program
  - 1-800-344-5984 or 1-507-266-1930
- Plant Extracts aromatherapy
  - **—** 1-877-999-4236
- \*There may be a cost to you. Check with your insurance provider.

# **Chapter 6: Effects of Stroke**

## **Effects on Everyday Activities**

### Tip

Your stroke and recovery are unique to you. You may have one or more changes that affect your ability to do everyday activities.

Talk with your health care provider about your changes and recovery.

## **Important**

Some everyday activities may be dangerous.

Ask your health care provider what activities are no longer safe for you and how to live a healthy lifestyle.

Your health care provider may want you to keep track of the activities that are and are not safe for you to do during your recovery. Your stroke may affect how you think, move, feel, or a combination of these ways. Changes after your brain injury may be short-term or long-lasting. Changes may range from mild to severe.

Your changes will depend on:

- the area of your brain affected by the injury
- how bad your injury is (from mild to severe).

Some everyday activities may be more difficult or may not be safe for you. Your brain injury may affect your ability to:

- eat
- bathe
- get dressed
- use the toilet
- do housework
- cook
- use the phone
- handle money
- write
- speak
- coordinate your body movements
- drive or get around the community
- take care of children
- interact with other people.

## **Effects of Stroke: Physical Changes**

Stroke usually affects one side of the brain. Movement and sensation for one side of the body is controlled by the opposite side of the brain.

This means that if your stroke affected the left side of your brain, you will have problems with the right side of your body. If your stroke affected the right side of your brain, you will have problems with the left side of your body.

Changes that may happen after a stroke on either side of the brain include the following.

### ☐ Abnormal muscle tone

This is a nerve problem that can make your movements slow and jerky. There are different stages of muscle tone recovery.

- Your arm, leg or joint may be limp and floppy.
- Your arm, leg or joint may move on its own when your muscle tone starts to return. It does not always do what your brain tells it to do.
- Your arm, leg or joint begins to respond to your brain.

### □ Bladder changes

You may have problems urinating or controlling your urine (incontinence). You might also have a bladder infection.

## □ Bowel changes

Constipation is the most common problem after a stroke. This may be caused by lack of liquids or limited physical activity. Your doctor or nurse can help you regain your regular bowel pattern.

## **☐** Cognitive problems

You may have problems with memory, thinking, attention or learning. For example, you may have trouble:

- concentrating
- following directions
- interacting with other people
- organizing or prioritizing your day
- making decisions
- understanding what is safe
- problem-solving such as:
  - thinking of all the steps needed to solve problems
  - coming up with other solutions if the first does not work
- doing everyday activities when a routine is changed or stopped
- remembering information or events such as:
  - what someone just told you
  - the current time and date
  - what you have read
  - if you took your medicine.

## □ Coordination problems

You may have reduced hand-eye coordination. When reaching for an object, your arm may waver or your hand may overshoot the object.

## □ Dysarthria (dis-AR-three-a)

Dysarthria is a motor speech problem. This means you are not able to coordinate the movement of your mouth to form words or sounds.

It is caused by weakness, lack of coordination, or loss of feeling in your lips, tongue and mouth muscles. You know the right words, but you have problems saying them. Dysarthria may affect your:

- word pronunciation
- voice
- speech rate
- rhythm
- resonance (how deep and clear your voice sounds)
- breath control for speaking.

### Signs of Aspiration

Call your health care provider if you have any of these signs:

- a wet-sounding voice
- breathing you can hear
- struggling when breathing or swallowing
- shortness of breath
- rattling sound in your lungs
- higher body temperature.

## ☐ Dysphagia (dis-FAY-ja)

Dysphagia is a swallowing problem usually caused by weakness or loss of feeling in your tongue, lips, throat or palate (roof of your mouth).

It may cause problems with:

- moving food around your mouth
- having food stick in your throat
- coughing or choking on liquids or solids (aspiration).

If you have swallowing problems, you may need to have a video swallow study. (See page 42 for more information.)

A member of your health care team will recommend the correct diet for you. He or she may recommend some ways to help your swallowing. These include:

- correct body and head positions
  - Stay as upright as you can.
  - If you are in bed, make sure the head of the bed is as high as it can go.
  - Bend your knees so you will not slide.
  - Put pillows behind your back.
  - Keep your head slightly bent downward. This will keep food and liquid from going into your lungs (aspiration).
- correct food texture
- correct food quantity
- correct feeding utensils and containers.

If you cannot eat or drink by mouth, you will need to get your nutrients by a tube. This will keep food and liquids from getting into your lungs.

- A nasogastric feeding tube is passed through your nose and esophagus to your stomach. This will be used for short-term tube feedings.
- A gastrostomy tube is put through your abdominal wall into your stomach. This will be used for long-term tube feedings when your recovery is slow.

The dietitian will suggest which tube feeding product will fit your schedule. Members of your health care team will closely watch your tube feeding for any problems or adjustments.

Your ability to swallow may return during recovery.

You will receive updates on your progress.

To reduce your risk of choking during your recovery:

- Check with your doctor if you cough when you swallow.
- Do not try to stop a cough. A cough is your body's natural protection against choking.
- Stop eating if you cannot stop coughing or if you cannot clear your airway. Call 911 right away.
- Drink thickened liquids to slow down coughing or choking. Gelatin, pudding powder or potato flakes can thicken liquids. The texture of food and the utensils you use will affect your ability to swallow.

## □ Emotional changes

Please see the section on emotional effects on pages 78-80.

## **☐** Endurance problem

You may find you are unable to do a task or activity for a long period of time. This should get better as you get stronger.

## □ Fatigue

Fatigue is a feeling of tiredness that can keep you from doing the things you normally do or want to do. It is common to feel tired more quickly after a brain injury. You may need more sleep or rest.

Fatigue may cause you to:

- be unable to do a task or activity for a long period of time
- need more concentration or effort to do things
- feel more tired when you are stressed or anxious.

You may also have more trouble with coordination, vision, speech, movement, controlling your emotions or other problems when you are tired.

## ☐ Hemiparesis (hem-ee-par-Ee-sis) or Hemiplegia (hem-ee-PLEE-ja)

You may have weakness, partial or complete paralysis of one side of your body or just one arm or one leg.

- If the stroke was on the left side of your brain, the right side of your body will be affected.
- If the stroke was on the right side of your brain, the left side of your body will be affected.

### □ Impulsivity

You may act without planning ahead.

## Judgment

You may not know your own limits. You may act without thinking about the consequences of your actions. You may misinterpret situations. You may be unable to judge, problem-solve, organize, use "abstract" reasoning skills or all of these.

## ■ Memory problems

You may have poor memory. This may lead to problems retaining, blending and recalling information.

## □ Sensation changes

You may have numbness or loss of feeling in different parts of your body. This may cause you to have trouble knowing where you place or how you position a part of your body (such as your hand or foot).

## ☐ Sexuality concerns

It is rare that a medical concern would keep you from sexual activity. Fear may keep you from being intimate with your partner. You may feel anxiety about:

- how you look
- changes in your relationship
- rejection.

Talk with your partner about how you feel. Talk about how the two of you can become close and tender again. Talk with your doctor if you are having intimacy concerns.

## □ Vision changes

You may ignore or not be able to see anything toward your right. You may only eat from the left side of your plate or read from the left side of a page.

Some problems that happen after stroke are more common with stroke on one side of the brain than the other. In most people, the left side of the brain controls the ability to speak and understand language. The right side of the brain controls the ability to pay attention, recognize things you see, hear or touch, and be aware of your own body.

In some left-handed people, language is controlled by the right side of the brain and awareness by the left side of the brain.

The following information is for the most common situation of language control on the left side of the brain.

## □ Effects of Left-sided Stroke

#### □ Anomia

You may not recall the names of everyday objects.

### □ Aphasia (a-FAY-zha)

Aphasia is a language problem that affects your ability to:

- speak
- read
- write
- listen
- deal with numbers
- understand speech or written words
- think of words when talking or writing.

How much trouble you have with aphasia depends on the type and severity of your brain injury.

Aphasia means you have problems speaking and understanding language. You may be unable to find the words you need or put sentences together. This is like having a word "on the tip of your tongue." Not all strokes cause aphasia.

To know why a stroke can cause so many different problems, it is helpful to understand how speech works. Communicating a message means you think about what you want to say, put your thoughts into words and say the words aloud. Understanding a message means you know someone wants to say something, you keep the words in mind and put the words together.

Your brain controls the complex steps needed to speak and understand language. That's why injury to the brain — such as lack of blood flow during a stroke — can get in the way of your ability to do these steps. Different problems result depending on the location and severity of the stroke.

If you have aphasia, you should have your speech and language checked. A speech-language pathologist (or speech therapist) must see how well you can speak and understand. The exam includes:

- speaking aloud
- writing
- listening comprehension
- reading comprehension.

You may have problems in some or all four areas. For example, you may have problems reading and writing but not in talking. This exam can also show which areas of speech and language have been least affected.

See pages 92-95 for information about how to communicate with someone who has aphasia.

### □ Apraxia (motor apraxia)

You may not be able to do purposeful movements even though your muscles and senses are working normally.

## □ Verbal apraxia (a-PRAX-ee-a)

Verbal apraxia is a motor speech problem. This means you are not able to coordinate the movement of your mouth to form words or sounds.

It is not caused by loss of feeling or muscle weakness. You know the right words, but you have problems forming words or putting sounds together.

You may have problems with word pronunciation:

## saying words clearly

You may substitute (or replace) a correct sound with an incorrect sound. For example, a "cup of coffee" may come out as "a puck of pappy" or a "bup of foppe."

## — saying sentences clearly

You may repeat a single syllable or phrase. For example, "I dunno" may come out as "do-do-do."

## □ Effects of Right-sided Stroke □ Agnosia You may not be able to recognize objects, faces, voices or places. □ Anomia You may not recall the names of everyday objects. ☐ Attention span You may be unable to focus attention on a conversation or tasks for long periods of time. □ Denial You may deny that you had a stroke. Some people even deny that their paralyzed arm or leg belongs to them. They look at the paralyzed arm or leg and believe it belongs to someone else. ■ Neglect You may ignore the left side of your body or your environment. This means you may not turn to look toward your left side or you may not recognize things that are on your left. □ Perseveration You may have difficulty following instructions or answering many questions asked one right after the other. You may repeat answers or movement even though a new instruction was given or a new question asked. □ Visual/spatial problems You may have problems judging distance, size, position and rate of movement and how parts relate to a whole.

## □ Changes to Mental Health, Emotional Health or Both

You may have emotional, behavioral or other mental health changes. Talk with your health care provider if your emotional changes become severe or if they do not go away. You may find help by talking with a social worker or psychologist.

You may have one or more of the following changes.

### □ Anxiety

Anxiety is a strong feeling of fear and may involve constant worry. Intense anxiety is a temporary reaction to the stresses of everyday life. Some anxiety is normal.

You need to get help when you have physical symptoms that keep you from feeling healthy and affect your work or social life. Severe and chronic (long-lasting) anxiety needs treatment.

Common symptoms of anxiety include:

- dizziness or feeling lightheaded
- racing or pounding heartbeat
- trouble breathing (too rapid, short of breath or unable to breathe)
- feeling like you will throw up
- tense muscles or shaking
- worrying a lot
- irritability or restlessness
- trouble concentrating
- problems sleeping due to worrying
- avoiding situations that make you uncomfortable.

# Thoughts of Death or Suicide

Depression can include feelings of hopelessness or worthlessness and even thoughts of suicide.

**Call** your health care provider or the national Suicide Prevention Hotline at 1-800-273-8255 if you are having thoughts of death or suicide.

### □ Depression

Clinical depression is a serious medical illness. It is not something you have made up in your head. It is more than just feeling "down" or "blue" for a few days. It is normal for you to feel sad after a brain injury. But there is a deeper sadness that may show up right after a brain injury or many weeks later.

You may have feelings of helplessness, hopelessness and poor self-esteem. These feelings can go on for weeks or months. Depression can even affect how often you become ill or how well you heal after your stroke.

You need to call your doctor right away if you have any of the following symptoms:

- feeling sad, blue or down in the dumps
- losing interest in things you used to enjoy
- feeling sluggish, restless or unable to sit still
- feeling worthless or guilty
- having an increase or decrease in appetite or weight
- having problems concentrating, thinking, remembering or making decisions
- having trouble sleeping or sleeping too much
- losing energy or feeling tired all the time
- having headaches
- having aches and pains
- having digestive problems
- having sexuality problems
- feeling pessimistic or hopeless
- being anxious or worried
- having relationship problems with members of your care circle
- having thoughts of death or suicide.

# ☐ Emotional lability (limited control over your feelings and reactions)

You may have limited control over your feelings and reactions. You may laugh, cry or get upset more easily or at the wrong times.

### □ Loss of inhibition

You may have changes in how you interact with other people. You may have these types of behaviors:

- aggression or violence
- impulsiveness or no self-control
- temper outbursts (verbal or physical)
- inappropriate social behavior
- inappropriate sexual behavior
- inappropriate use of alcohol, street drugs (heroin, marijuana, methamphetamine) or both.

## ■ Mood swings

You can go from being happy to being sad or angry without warning. Your mood swings may vary.

### **□** Self-centeredness

You may be focused on your needs and not be paying attention to members of your care circle.

## **□** Posterior Stroke

A posterior circulation stroke means the stroke affects the back area of your brain. This includes your brain stem, cerebellum (the area responsible for balance and coordination) and occipital lobes (the area responsible for vision).

Changes that may occur include the following.

### □ Ataxia

You have a loss of coordinated arm or leg movements.

### □ Double vision

You may have problems with your vision because your eye movement is limited in one or both eyes.

## □ Vertigo

You have dizziness that makes you feel like you are spinning.

### ☐ Visual field loss

You may not be able to see anything toward your left or right.

## □ Brainstem Stroke

The brainstem connects the brain and the spinal cord. It controls many important functions, such as breathing, blood pressure and heart rhythm. Changes that may occur after a stroke in the brainstem include the following.

### □ Breathing problems

### □ Coma

You are unable to wake up or move.

## □ Dysphagia

You have a swallowing problem caused by weakness or loss of feeling in your tongue, lips, palate, throat or all. See pages 72-73 for more information on dysphagia.

## ☐ Heart problems

## ☐ Hearing loss

## ☐ Hemiparesis or hemiplegia

You have weakness, partial or complete paralysis on your left side or right side or both.

### ☐ "Locked in" state

You appear to be aware of your surroundings, but are unable to speak or respond in a meaningful way.

## □ Sensation changes

You have numbness or loss of feeling on your left side or right side or both.

## □ Multiple Stroke (Pseudobulbar State)

A multiple stroke means several small (lacunar) strokes happen in a short time on both sides of your brain. You may feel weakness or loss of feeling on either side of your body.

In addition to changes that occur in the left and right sides, you may also have confusion, dementia or both.

# **Chapter 7: For the Care Circle Members**

## What to Consider About Visitors

Your loved one may or may not want to have visitors during his or her hospital stay. Respect your loved one's wishes about when he or she would like to see members of his or her care circle.

Each hospital has different visitor rules. Ask your loved one's health care team about rules for your area.

### How to help your loved one

- Limit visitors to no more than 2 at a time.
- Limit visits to 10 to 15 minutes, unless you are just sitting with your loved one and not talking or doing an activity.
- Keep your conversations brief and clear. Give just 1 piece of information at a time.
- Speak slowly with a calm, quiet voice. Give your loved one time to respond.
- You may put up a few family photos in your loved one's room. Limit cards, balloons and flowers. Consider putting photos and cards in a small album.
- Do not use your phone when your loved one is in the room. If you need to use your phone, go into the hallway.
- If the room phone keeps ringing, talk with a nurse about options.
- Keep the television, music and computer off unless you know your loved one enjoys it. Limit screen and music time to no more than 20 minutes.
- Remove clutter in your loved one's room.
- Check with staff before giving your loved one anything to eat or drink.
- Share these tips with others who visit.
- Talk with any member of your loved one's health care team if you have any questions or concerns.

# **Just for the Caregiver**

Your loved one will have specific needs after a stroke. This means you may need to learn new skills or change your role with him or her.

It is important that you learn about your loved one's safety, physical and emotional needs.

Here are some tasks you may do:

- Keep notes about discharge plans. Ask about anything that is not clear.
- Help to make sure your loved one takes his or her medicines the right way at the right time.
- Help to make sure your loved one eats well, exercises and rests.
- Help your loved one practice the skills learned in rehabilitation.
- Help your loved one solve problems and learn how to do things.
- Help your loved one with tasks done before the stroke. This includes using tools, buttoning a shirt and doing housework.
- Help your loved one with personal care if needed.
- Help your loved one's speech if needed. Include him or her in family activities even if he or she cannot actively participate.
- Arrange for any needed community services.

# **Preparing to Care for Your Loved One**

Think about how your role may change with your loved one. This can help you prepare to provide care. Ask yourself the following questions:

- What are my loved one's needs?
- Who can best help meet my loved one's needs?
- Am I ready to help my loved one recover from the brain injury?
- Will this care need to be scheduled around my work or other activities?
- If others are helping care for my loved one, who will be the main person providing care?

You will have time to talk with your loved one's health care team before discharge (leaving the hospital) to make plans for his or her care after discharge.

Your loved one's brain injury and needs are unique. It is important that you learn about your loved one's safety, physical and emotional needs.

Your loved one's health care team will help you decide what type of care and how much care your loved one needs. You may need to learn new skills or change your role with your loved one.

# **Your Role in Providing Care**

Below are some tasks you may need to do.

- Keep notes about your loved one's care plan after leaving the hospital. Ask about anything that is not clear.
- Help make sure your loved one takes his or her medicines correctly and on time.
- Help make sure your loved one eats well, exercises and rests (see pages 53-59).
- Help your loved one practice the skills learned in rehabilitation.
- Help your loved one solve problems.
- Help your loved one learn or relearn how to do things.
- Help your loved one as needed with personal care such as bathing or using the toilet.
- Help your loved one with tasks he or she did before the brain injury. This may include using tools, buttoning a shirt and doing housework.
- Help your loved one communicate if needed. Include him or her in family activities even if he or she cannot actively participate.
- Arrange for any needed community services.
- Learn all you can about brain injury symptoms, treatment and care.
- Check out education classes or information in your community.
- Talk to your loved one's health care team if you have any questions or concerns.

# **Taking Care of Yourself**

To take care of your loved one, you also need to take care of yourself.

- Take time each day to be by yourself, or take 1 or 2 days off during the week. This can refresh you and help you provide better care.
- Take time to do activities you enjoy.
- Do not be afraid to ask your loved one's care circle for help.
- Ask about community agencies, volunteer groups, churches, respite care or nursing agencies that can help you.
- Talk to a psychologist about how your life has changed.
- Join a support group.

### **Support Groups**

Support group members share common experiences about caring for a loved one. Members "lend an ear" so you can share your feelings with others who may have similar needs and feelings.

Support groups can also give you ongoing education, helpful tips and sources of help in the community. Support group members can become your new friends or give you support.

# **Tips for Reducing Stress**

- Take stroke recovery one day at a time. Be hopeful for a successful recovery.
- Appreciate each small gain your loved one makes. Your loved one's emotions and ability to do things may vary day to day because of fatigue. He or she may need to learn how to do things in different ways or try new ways of doing tasks, talking, speaking and organizing his or her social life.
- Expect that your skills and knowledge of how to provide care will improve. This is a time of learning for both you and your loved one.
- Plan for breaks so you and your loved one are not together all the time. Time apart is important for both you and your loved one. Try to do activities that get you both out of the house.
- Ask your loved one's care circle to help.
- Try relaxation, massage or meditation to cope with your stress. Ask a nurse about your options.
- Learn from others who have had similar experiences. Read about them or join an in-person or online support group.
- Be patient with and kind to each other. You may feel frustrated some times. Do not take your frustrations out on others.
   Talk with a family member, friend, professional or support group about your feelings.

# **Progressive Muscle Relaxation**

Progressive muscle relaxation is a short and easy exercise to help you relax.

#### **Getting started**

Find a relaxing position. You may sit down or lie on your back in bed. Be sure your legs and hands are not crossed.

You may close your eyes. If you prefer, you can keep your eyes open, but focus on one spot in front of you.

Bring your attention to your breathing. Think about where your breath comes in and out of your nose or mouth. Think about how your chest moves up and down with each breath.

Imagine a gentle, safe wave of relaxation that will slowly and warmly flow through your body. The wave can help you find those places that need to relax and give them permission to relax.

You can also imagine this wave in any way you find most comfortable. You may see it as light, water or just a feeling.

If your mind wanders, gently bring it back to your breathing.

#### Relax from your head to your feet

- Bring your attention to the top of your head and begin to imagine a wave.
- With your next breath out, feel the wave flow through your head. Feel your jaw soften and relax.
- Breathe in.
- With your next breath out, focus on the back of your neck. Let it soften and relax.
- Breathe in.
- With your next breath out, imagine the wave moving through each arm all the way to your hands. Feel your hands become slightly heavier where they are lying.
- Breathe in.

- With your next breath out, imagine the wave of relaxation roll gently and safely down your spine. Let all of your back muscles relax and soften.
- Continue to breathe. Feel the wave flow as you breathe out.
- Let the wave flow through your pelvic area and hips into your upper legs and thighs.
- Breathe in.
- With your next breath out, allow the wave to find those areas in your legs and knees that need to relax. Give them permission to relax.
- Breathe in.
- With your next breath out, feel the wave move into your calves, then your feet. Feel your feet become a little heavier.
- Take two deep breaths. Imagine any remaining stress gently flowing out the bottoms of your feet.

Take a moment to observe the still place you created. With practice, relaxation will become easier.

# **Guided Imagery**

You can use your imagination to help you breathe easier. Guided imagery helps manage distress and gives you a better sense of well-being.

- Think about a pleasant or restful place. It can be anywhere: a beach, a cabin, the woods or a safe place at home.
- Let happy thoughts of your favorite scene or place relax you.
- Close your eyes and picture that scene or place.
- Focus on the sights, sounds and smells of your favorite scene or place as you relax.
- Let your body relax and your breathing become deeper.

# How Aphasia Affects Your Loved One's Speech and Understanding

#### **Medical Term**

**Aphasia** (a-FAY-zha) is a language problem.

Aphasia means your loved one has problems understanding language and speaking. He or she may be unable to find the right words or put sentences together. Not all strokes cause aphasia.

This means your loved one's brain may have problems with:

- speaking
- listening
- reading
- writing
- dealing with numbers.

Just because your loved one has problems using language, does not mean he or she cannot think clearly. Most people know what they want to say, they just have trouble putting their thoughts into words. It's like when you have a word "on the tip of your tongue."

Some people with aphasia:

- are unable to use nouns or verbs while others have trouble with little words like *the* and *of*
- speak easily while others struggle to make a sound (Sometimes they are hard to understand.)
- speak mainly in jargon but do not know they are not speaking clearly
- have trouble retrieving the right words they want to say
- know the right words but cannot form them with their lips, tongue and teeth (may cause stuttering)
- have problems understanding simple commands and more complex material.

# **Tips to Help You and Your Loved One Communicate**

	Do not assume your loved one cannot understand what is being said. Never say anything you would not want your loved one to hear.
	Work closely with the speech-language pathologist. You can help improve and maintain your loved one's communication skills by following the home program.
	Learn when is the best time of day to work on communication skills. Try to use that time whenever you can.
	Set up a routine.
	Let your loved one rest several times each day.
	Respect your loved one's wishes about when he or she would like to see members of their care circle. Your loved one may want to wait until he or she has adjusted to the injury or improved his or her communication skills. Slowly get your loved one back into social situations.
	Include your loved one in communication even if he or she seems unable to speak or understand.
	Let your loved one share in life-affecting decisions.
	Encourage your loved one to be as independent as he or she can.
Н	lelping your loved one listen
	Reduce distractions. Close the door. Turn off the TV or radio. Pull the curtains.
	Limit the number of people in the conversation. Try to avoid large groups.
	Sit down so your loved one can see you. This will help him or her be more relaxed.
	If your loved one wears hearing aids, make sure he or she wears them, has them turned on, and the batteries are working

Helping you speak
☐ Speak slowly.
☐ Use short, simple sentences.
☐ Pause between sentences to give your loved one time to "digest" what you have said.
☐ Give your loved one directions, question or piece of information at a time.
☐ Talk about things your loved one can see. Use photos, hand movements or facial expressions.
☐ Write down any request you have for your loved one. This way he or she can read what you are asking.
☐ Watch for signs your loved one understands you. Repeat or rephrase what you are saying if needed.
☐ Do not ask your loved one to talk and do another task at the same time.
☐ Try not to switch topics too quickly or often.
☐ Keep conversations short and to the point.
Helping your loved one speak
☐ Allow at least 30 seconds for your loved one to respond, follow a direction or to tell you something.
☐ Remind your loved one to:
— speak slowly
— speak clearly.
☐ Encourage your loved one to use other ways of communication such as:
<ul> <li>— write it first and read it out loud</li> </ul>
<ul> <li>gesture the meaning or what someone would do with it</li> </ul>
— draw a picture
<ul> <li>point to the picture, object or word on a chart</li> </ul>
<ul><li>describe it in other words.</li></ul>
☐ If your loved one tries 2 or 3 times and gets frustrated, ask him or her to take a short break. Have him or her try again in a few minutes.

#### Helping you listen

- ☐ Be patient.
- ☐ Do not interrupt. Give your loved one at least 30 seconds to respond. Try to look relaxed while you wait.
- ☐ Let your loved one know when you do not understand. For example try saying, "I am not understanding you."

# **Aspiration**

After a brain injury, some people are more likely to cough or choke on liquids or solids. This is called aspiration. It is common for people who have dysphagia (see pages 72-73) to also have aspiration.

Watch your loved one for signs of aspiration:

- a wet-sounding voice
- breathing you can hear
- struggling when breathing or swallowing
- shortness of breath
- a rattling sound in his or her lungs
- fever.

If you think your loved one has aspiration:

- do not try to stop the coughing. Coughing is the body's natural protection against choking.
- have your loved one stop eating and drinking until he or she stops coughing and the airway is clear
- make sure you or your loved one talks about aspiration with a speech-language pathologist or doctor. He or she can check for aspiration and may give tips to reduce the risk of choking.

#### When to call 911

Call 911 if your loved one:

- has a blue or purple tinge to his or her skin color
- is not breathing for more than 30 seconds
- is unable to speak.

# **Sexual Behavior and Sexual Activity**

#### **Important**

Talk honestly with your loved one's health care provider about your questions or concerns.

If the health care provider does not know there is a problem, he or she cannot help. It is common for people with brain injuries to have a change in sexual behavior or sexual activity.

There are two common types of changes: hyposexuality and hypersexuality.

#### **Hyposexuality**

Your loved one may lose interest in sex, feel depressed or have emotional lability (crying or getting upset more easily or at the wrong times). This may be the result of sexual dysfunction or physical changes caused by the brain injury.

The most common types of sexual dysfunction are:

- lack of arousal and orgasm
- erectile dysfunction (ED or impotence). This is the inability to get or keep an erection long enough for sexual intercourse.

Fear about physical changes may keep your loved one from being intimate. He or she may feel anxious about:

- how he or she looks
- changes in his or her relationship
- rejection.

It is important for you to know how to deal with hyposexuality.

- Talk openly with your loved one's health care provider about your loved one's hyposexuality. Talk about any questions or concerns you have.
- If your loved one is also your sexual partner, it may be helpful to talk with a licensed family or marriage counselor about any concerns you may have.

#### **Hypersexuality**

Your loved one may have increased sexual thoughts, feelings or behaviors.

Hypersexuality may cause inappropriate sexual behavior such as:

- talking explicitly about sex
- making offensive or bad sexual comments or gestures
- touching others.

It is important for you to know how to deal with inappropriate sexual behavior.

- Talk with your loved one's health care team about what to do if there are inappropriate sexual behaviors. Common questions include:
  - what do I do if he or she touches someone inappropriately?
  - how should I react if he or she starts talking sexually?

Talk openly with your loved one's health care provider about any other questions or concerns you have.

- Talk with your loved one's care circle about what kinds of sexual behavior are appropriate and what are not.
- If your loved one is also your sexual partner, it may be helpful to talk with a licensed family or marriage counselor about any concerns you may have.
- Talk with your loved one's health care provider about the risks of sexually transmitted infections.

# **Reducing Brain Over-stimulation**

#### Over-stimulation

To help your loved one recover from a brain injury, it's important to help him or her not get over-stimulated.

His or her brain is unable to make sense of all of the information coming in such as sounds, lights, touches and smells.

In the early stages of rehabilitation, it is important to provide an environment that reduces brain over-stimulation so he or she can participate in rehab.

Members of the health care team will work to keep your loved one on a regular schedule and plan his or her care in a quiet, dimly lit environment. Without this, your loved one may become overwhelmed and more confused. He or she may withdraw and shut down or even become aggressive.

The amount of stimulation your loved one receives will increase as he or she improves.

#### Signs to Watch for

Signs your loved one may be over-stimulated:

- being restless or trying to move around
- repeating the same words or sounds
- having a lack of attention
- being easily distracted
- being confused, irritated or being verbally aggressive
- being physically aggressive
- not wanting to be touched or withdrawing from interactions with staff or visitors.

Tell a member of the health care team if you think your loved one is over-stimulated.

#### **How To Help Your Loved One**

- Limit visitors to no more than 2 at a time.
- Limit visits to 10 to 15 minutes, unless you are just sitting with your loved one and not talking or doing an activity.
- Keep your conversations brief and clear. Give just one piece of information at a time.
- Do not use your phone when your loved one is in the room. If you need to use your phone, go into the hallway.
- If the room phone keeps ringing, talk with a nurse about options.
- Keep the television, music and computer off unless you know your loved one enjoys it. Limit screen and music time to no more than 20 minutes.
- You may put up a few family photos in your loved one's room. Limit cards, balloons and flowers. Consider putting photos and cards in a small album.
- Remove clutter in your loved one's room.
- Speak slowly with a calm, quiet voice. Give your loved one time to respond.
- Check with staff before giving your loved one anything to eat or drink.
- Please share these tips with others who visit.

Talk with any member of your loved one's health care team if you have any questions or concerns.

(over)

#### **Environmental Management System**

Courage Kenny Rehabilitation Institute uses a system of communication that identifies how the environment should be managed for each person based on where he or she is in the rehabilitation process. This is called the environmental management system (EMS). The system is based on a traffic light:

- red light: full restrictions
- yellow light: some restrictions
- green light: limited or no restrictions.

The level may change based on your loved one's needs and health care team's advice.

	Red Light	Yellow Light	Green Light
Lighting	<ul><li>dim/dark at night</li><li>natural light during the day</li></ul>	as he or she can tolerate	■ no restrictions
Noise	■ completely quiet	<ul><li>avoid loud, annoying, or ongoing noises</li></ul>	■ no restrictions
Room décor	■ none or very limited	<ul> <li>a small amount is OK</li> <li>avoid violent or sexual content</li> <li>avoid busy or active posters</li> </ul>	■ no restrictions
TV, video, music	■ none	no more than 20 minutes at a time (not during scheduled rest breaks)	■ no restrictions
Visitors	<ul> <li>family only</li> <li>1 visitor at a time</li> <li>limit visit to</li> <li>10 minutes or less</li> </ul>	<ul> <li>family, close friends, and clergy</li> <li>no more than 1 or 2 visitors at a time</li> <li>limit visits to 15 minutes or less</li> </ul>	<ul><li>no restrictions</li><li>must follow the hospital visitation policy</li></ul>
Touch, handling	<ul> <li>limit touch and handling except as absolutely needed for medical care</li> </ul>	as he or she can tolerate	■ no restrictions
Treatment location	■ in the room or in a private treatment area	■ in a private or semi- private treatment area	■ anywhere
Notes	These help prevent agitation later, help your loved one tolerate and benefit from rehabilitation therapies and keep your loved one safe and comfortable.	Red light restrictions will be used at the first sign(s) of agitation or withdrawal.	These provide cues to help your loved one recognize symptoms of overload, understand what adds to it and understand how to reduce stimulation.

# **Chapter 8: Resources**

#### **Allina Health Resources**

- Allina Health Home Health 651-635-9173
- Courage Kenny Rehabilitation Institute 612-863-4200 or 1-866-880-3550
  - Adaptive Sports & Recreation:
     612-775-2277 of allinahealth.org/ adaptivesports
  - Aquatics, fitness and wellness: 612-775-2306
  - Driver Assessment and Training: 612-262-7855
  - Vocational Services:612-775-2569

- Financial assistance 612-262-9000 or 1-800-859-5077
- Mental Health & Addiction Connection 1-866-603-0016
- Penny George<sup>TM</sup> Institute for Health and Healing 612-863-3333
- **■** Transportation
  - Allina Health Emergency Medical Services:
     651-241-4400
  - non-emergency medical transportation: 651-222-0555

### **Community Resources**

#### ■ Adaptive recreation

- Capable Partners: 763-439-1038
- Reach for Resources, Inc.: 952-200-3030
- Wilderness Inquiry: 612-676-9400
- Parks and Recreation Department:
   You can find information on local
   programs through your city. Visit your
   city's website to learn more.

#### ■ Adult day care programs

- Minnesota Department of Human Services:
   Visit mn.gov/dhs to learn more about local licensed service providers.
   Click General public and then Licensing.
- Wisconsin Adult Day Services Association: wadsa.org

#### ■ Adult protective services

- Minnesota Adult Abuse Reporting Center: 1-844-880-1574
- Wisconsin:
   Visit dhs.wisconsin.gov/aps to learn more about adult protective services.
   Click Wisconsin Adult Protective Services
   Response Systems and then Elderly Adultsat-Risk Helplines to find your county agency and contact information.

#### ■ Brain Injury Alliance

- Minnesota:612-378-2742 or 1-800-669-6442
- Wisconsin: 262-790-9660 or 1-800-882-9282
- Courage Kenny Rehabilitation Institute Adaptive Sports & Recreation: 612-775-2277 or allinahealth.org/adaptivesports

#### **■** Crisis services (Minnesota)

- Crisis Connection:612-379-6363 or 1-866-379-6363
- TXT4Life Text "Life" to 61222
- National Suicide Prevention Lifeline: 1-800-273-8255

#### **■** Crisis services (Wisconsin)

- HOPELINE: Text "HOPELINE" to 741741
- Prevent Suicide Wisconsin:
   Visit preventsuicidewi.org to find a suicide
   prevention coalition or crisis line near you.
   Click Wisconsin Coalitions & Crisis Lines to
   find information for your county.

#### ■ Resource centers (Minnesota)

- Disability Linkage Line®: 1-866-333-2466
- Senior LinkAge Line<sup>®:</sup>
   1-800-333-2433

#### ■ Resource centers (Wisconsin)

 Aging and Disability Resource Centers: dhs.wi.gov/adrc

#### ■ Respite care

 Call your local nursing homes, home health agencies, adult day care centers or county Department of Social Services.

#### **■** Stroke associations

- American Heart Association/ American Stroke Association<sup>®</sup>: 1-888-478-7653
- Minnesota Stroke Association: 763-553-0088
- National Institute of Neurological Disorders and Stroke: ninds.nih.gov
- National Stroke Association<sup>®</sup>: 763-553-0088

#### **■** Transportation (Minnesota)

Metro Mobility:
 Call 651-602-1111 or visit mnhelp.info
 to find local transportation services.
 Type "medical appointment
 transportation" in the search bar.

#### **■** Transportation (Wisconsin)

- Medicaid and BadgerCare Plus non-emergency medical transportation: 1-866-907-1493
- Tender Care Transport:715-835-2435

#### **■** Transportation (National)

- Independent Living Research Utilization: ilru.org
- United Way:211 or 651-291-0211

#### **■** Department of Veterans Affairs

- Minnesota:1-888-546-5838
- Wisconsin:1-800-947-8387

#### ■ Disability parking permits (Minnesota)

Driver and Vehicle Services:
 Call 651-297-3377 or visit dmv.org to learn more about disability parking permits. Click Registration & Title and then Disability Plates and Placards.

 Select Minnesota.

#### ■ Disability parking permits (Wisconsin)

- Wisconsin Division of Motor Vehicles: Call 608-264-7169 or visit dmv.org to learn more about disability parking permits. Click Registration & Title and then Disability Plates and Placards. Select Wisconsin.
- **Discover Abilities Expo** (every April): account.allinahealth.org/services/879

#### ■ Meals on Wheels (Minnesota)

- Metro area: 612-623-3363
- Greater Minnesota:

Visit meals-on-wheels.com to learn more about home-delivered meals. Click *get meals* and then *Check Address* to learn if you are within their service area.

#### ■ Meals on Wheels (Wisconsin)

 Visit gwaar.org to learn more about home-delivered meals. Click For Seniors and Families and then Elderly Nutrition Program. Select Contact someone to find your local agency and contact information.

#### Vocational rehabilitation services (Minnesota)

- Minnesota Employment and Economic Development:
  - Metro area: 651-259-7114
  - Greater Minnesota: 1-800-657-3858 or 651-642-0363

#### ■ Vocational rehabilitation services (Wisconsin)

Wisconsin Division of Vocational Rehabilitation: 608-261-0050 or 1-800-442-3477

# **Allina Health Support Groups**

#### ■ Abbott Northwestern Hospital:

- second Wednesday of the month
- 2 to 3:30 p.m.
- Room E1220
- 612-863-4317 or 612-863-4576

# ■ Abbott Northwestern Hospital YESS (Young Enthusiastic Stroke Survivors):

- second Tuesday of the month
- 6 to 7:30 p.m.
- Room E1220
- **—** 612-863-4896

#### ■ Buffalo Hospital:

- second Wednesday of the month
- -1 to 2 p.m.
- **—** 763-684-3855

#### ■ Cambridge Medical Center:

- third Thursday of the month
- 4-5 p.m.
- Dining Room B
- **—** 763-688-7782

# ■ Courage Kenny Rehabilitation Institute – Golden Valley Campus:

- second and fourth Wednesday
- 3 to 4:30 p.m.
- Boardroom
- **—** 612-863-4872

#### ■ Mercy Hospital:

- third Wednesday of the month
- 1:30 to 3 p.m.
- lower level room 0149
- -763-236-8910

#### ■ New Ulm Medical Center:

- second Tuesday of the month
- 10 to 11 a.m.
- Board Room
- 1-507-217-5685 or 1-507-217-5686

#### ■ United Hospital:

- second Thursday of the month
- 2 to 3:30 p.m.
- Bentson Conference Room
- **—** 651-241-4823

# **Other Support Groups**

For other support groups, call the:

- Courage Kenny Rehabilitation Institute Stroke Program coordinator at 612-863-4317
- American Stroke Association at 1-888-478-7653
- National Stroke Association at 1-800-787-6537 or go to portal.stroke.org and click on support groups. Enter your city or state for more support groups.

# My Medicine List Fold this form and keep it with you

Name:	Date of Birth:	Allergic To: (Describe reaction)
Emergency Contact/Phone numbers:		
Doctor(s):		
Pharmacies, other sources:		
Immunization Record (Record the date/year of last dose taken)	uken)   Flu vaccine(s):	

	,		
Pneumonia vaccine:	Tetanus:	Hepatitis vaccine:	Other:
List all medicines you are currently	i <b>ly taking.</b> Include prescriptic	/ taking. Include prescriptions (examples: pills, inhalers, creams, shots), over-the-counter medication	shots), over-the-counter medications

rs).									
amples: ginseng, gingko). Include medications taken as needed (example: nitroglycerin, inhalers).	<b>'ES</b> r taking?)								
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unpies. gins	<b>DIRECTIONS</b> <i>How do you take it? When? How often?)</i>								
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# **Directions for My Medicine List**

- 1. ALWAYS KEEP THIS FORM WITH YOU. You may want to fold it and keep it in your wallet along with your driver's license. Then it will be available in case of an emergency.
- Write down all of the medicines you are taking and list all of your allergies. Add information on medicines taken in clinics, hospitals and other health care settings — as well as at home.
- 3. Take this form with you on all visits to your clinic, pharmacy, hospital, physician, or other providers.
- 4. WRITE DOWN ALL CHANGES MADE TO YOUR MEDICINES on this form. When you stop taking a certain medicine, write the date it was stopped. If help is needed, ask your doctor, nurse, pharmacist, or family member to help you keep it up-to-date.
- 5. In the "Notes" column, write down why you are taking the medicine (Examples: high blood pressure, high blood sugar, high cholesterol).
- 6. When you are discharged from the hospital, someone will talk with you about which medicines to take and which medicines to stop taking. Since many changes are often made after a hospital stay, a new list may be filled out. When you return to your doctor, take your list with you. This will keep everyone up-to-date on your medicines.

# How does this form help you?

- This form helps you and your family members remember all of the medicines you are taking.
- It provides your doctors and other providers with a current list of ALL of your medicines. They need to know the herbals, vitamins, and over-the-counter medicines you take!
- With this information, doctors and other providers can prevent potential health problems, triggered by how different medicines interact.



For copies of the My Medicine List and a brochure with more tips, visit the Minnesota Alliance for Patient Safety's Web site at www.mnpatientsafety.org or call (651) 641-1121.



2277 Highway 36 West, Ste 200 | Roseville, MN | 55113-3830 | 612-378-2742 | 800-669-6442

#### Authorization to Participate in Resource Facilitation

As part of your rehabilitation, we offer follow-up services through the Minnesota Brain Injury Alliance/Minnesota Stroke Association Resource Facilitation Program. This confidential and voluntary telephone follow-up service DOES NOT REPLACE any medical or rehabilitation follow-up care that you may need. It is intended to provide you and your family with information about brain injury or stroke and assistance in accessing services and supports. Participation begins on the date signed. A Resource Facilitator will contact you by telephone approximately six (6) weeks from the time you return this form. If you prefer contact

sooner, prease can the number liste	d above.	
I,	, give permission for mys nnesota Brain Injury Alliance/Minno	elf or my child to be part of the Resource Facilita
Tonow op Frogram with the Wil	mesota Bram mjury rmanec/wimic	Sou office Association.
Name:	Telep	phone:
Address:	Emai	l:
City:	State: Zip:	Best Time to Call:
Date of Birth:	Gender: Male □ Female □	Language Spoken
□ Brain Injury Cause: □ Stroke		
Date of Incident:	Date of Hosp	oital Discharge:
Caregiver or Guardian of Patient/I	ndividual:	Relationship:
Address (if different then Patient/I	ndividual):	
Email:	Telephone:	
Signature of Patient/Individual o	or Guardian	Date
Professional Completing this Refe	ral (Social Worker, Discharge Planner,	, Health Care/Rehabilitation Professional, etc):
Name/Title of Professional	Organization	Email/Phone
Send Completed Form to: Minne	esota Brain Injury Alliance / Minnesota	a Stroke Association

Attn: Resource Facilitation

2277 Highway 36 West, Suite 200 Roseville, MN 55113-3830

Fax to: 612-378-2789 or Scan and E-mail to: info@braininjurymn.org [subject line: RF Referral]

# Get better communication and faster answers online with your Allina Health account.

Health is a journey that happens beyond the walls of your clinic or hospital and we will be there to help you – whether it's a question that pops into your head at midnight or recalling the date of your last tetanus shot. When you sign up for an Allina Health account online, you get better communication with your clinic, hospital and provider; faster answers and your (and your loved one's) health information organized and at your fingertips anytime.







# Nondiscrimination in Health Programs and Activities

Affordable Care Act – Section 1557

Allina Health complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, gender identity or sex. Allina Health does not exclude people or treat them differently because of race, color, national origin, age, disability, gender identity or sex.

#### Allina Health:

- provides free aids and services to people with disabilities to communicate effectively with us, such as: 
  ◊ qualified sign language interpreters, and
  - ♦ written information in other formats (large print, audio, accessible electronic formats, other formats)
- provides free language services to people whose primary language is not English, such as:
  - ♦ qualified interpreters, and
  - ♦ information written in other languages.

If you need these services, ask a member of your care team.

If you believe that Allina Health has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, gender identity or sex, you can file a grievance with:

Allina Health Grievance Coordinator P.O. Box 43 Minneapolis, MN 55440-0043 Phone: 612-262-0900

Fax: 612-262-4370

GrievanceCoordinator@allina.com

You can file a grievance in person or by mail, fax or email. If you need help filing a grievance, the Allina Health Grievance Coordinator can help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at https://ocrportal.hhs.gov/ocr/portal/lobby.jsf, or by mail or phone at:

U.S. Department of Health and Human Services 200 Independence Avenue, SW Room 509F, HHH Building Washington, D.C. 20201 1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at http://www.hhs.gov/ocr/office/file/index.html.





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