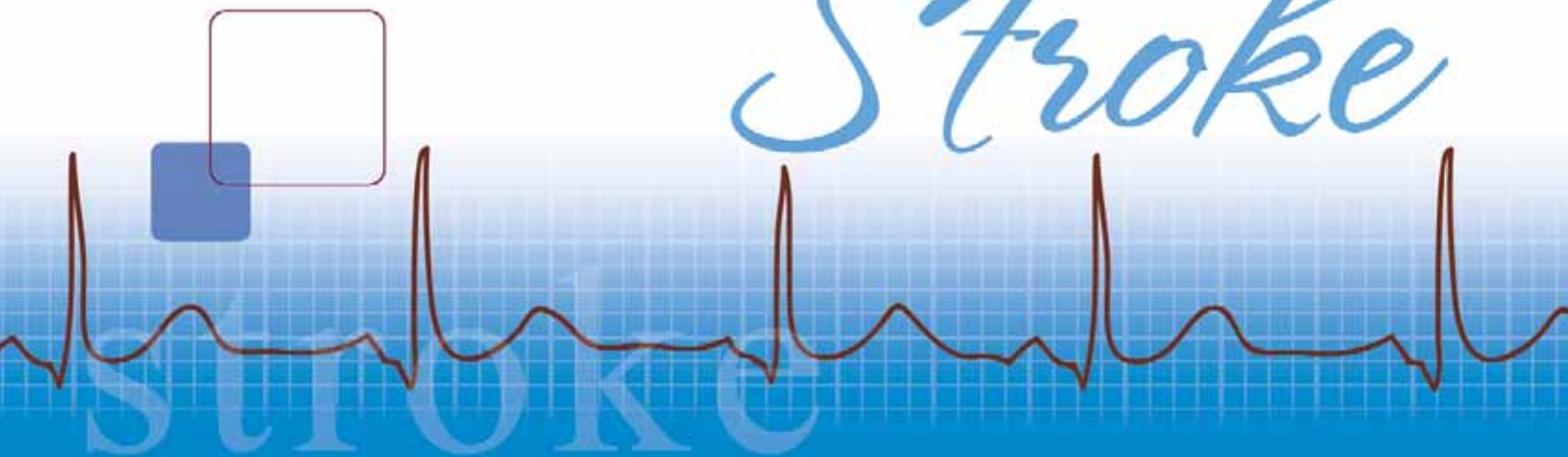




Recovering
from a

Stroke



“

My stroke took away things I'll never get back. But it has given me things, too—important things. Gratitude for my family and friends. Confidence that I can keep getting better. A second chance to live each day fully. It seems odd to say it, but some days I feel like the luckiest person alive.

—*Richard, 59,*
one year after a stroke

AFTER A STROKE, you and your loved ones may feel uncertain and overwhelmed. You probably have many questions about what lies ahead, and what you need to know and do.

This booklet can help. Along with your doctors and other healthcare providers, the information here can guide you through your initial recovery period, and help you prepare for better days ahead.

As you read, keep in mind that this booklet doesn't replace the specific instructions you may receive from your healthcare providers. Always follow the specific instructions of your own doctors, nurses, and other care providers—and go to them with any questions or concerns.

For *family*
and friends

This booklet is for you, too.

Read it to learn more about stroke, stroke recovery—and what you can do to help your loved one heal.

Throughout these pages, look for the *For family and friends* boxes for reassurance, tips, and information just for you. For more advice about caring for your loved one, see the section titled, *Caring for a Loved One After a Stroke*, pages 35 to 37.

WHAT'S INSIDE

5	Understanding Strokes	
	What is a stroke?	5
	What causes a stroke?	6
	What are the different types of stroke?	7
	What are the effects of a stroke?	8
	Why does it matter where in my brain the stroke happened?	10
	What does the future hold?	11
13	Diagnosing and Treating Strokes	
	How are strokes diagnosed?	13
	How are strokes treated?	14
	How does the brain heal?	18
	What is stroke rehab—and why is it important?	19
21	Recovering in the Hospital	
	Beyond the ER: what to expect	21
	Before you go home	22
	Your stroke rehab team	23
25	Recovering at Home: <i>your checklist</i>	
	Keep follow-up appointments	26
	Give your home a safety upgrade	26
	Take your medications	27
	Monitor your health	28
	Balance rest and activity	29
	Eat healthy	30
	Return to work and driving as your doctor recommends	31
	Care for your mental and emotional health	32
	If you smoke, STOP	33
35	Caring for a Loved One After a Stroke	
	What may change after a stroke	35
	How you may feel	36
	Dos and don'ts for communication and care	37
38	Stroke Resources	
39	Know Your Stroke: <i>a worksheet</i>	
41	Follow Up: <i>phone numbers and appointments</i>	
42	Medication Chart	

“

At the hospital, they told us it was a stroke. I thought I was too young. I didn't think it could happen to me.

—*Anna, 39,*
one month after a stroke

I tried not to show it, but I was scared. What was going to happen to her, to our kids? My mind couldn't accept the fact that things could change in an instant.

And though it doesn't make sense, I felt guilty, too. Was she working too hard? Did she know how much I loved her? You think you can protect the people you love. You wish you could.

—*Robert, 42,*
Anna's husband



UNDERSTANDING

Strokes

EACH YEAR, MORE THAN 750,000 AMERICANS HAVE STROKES. This section gives some basic information about stroke, its causes, and what it may mean for your health today—and in the future.

What is a stroke?

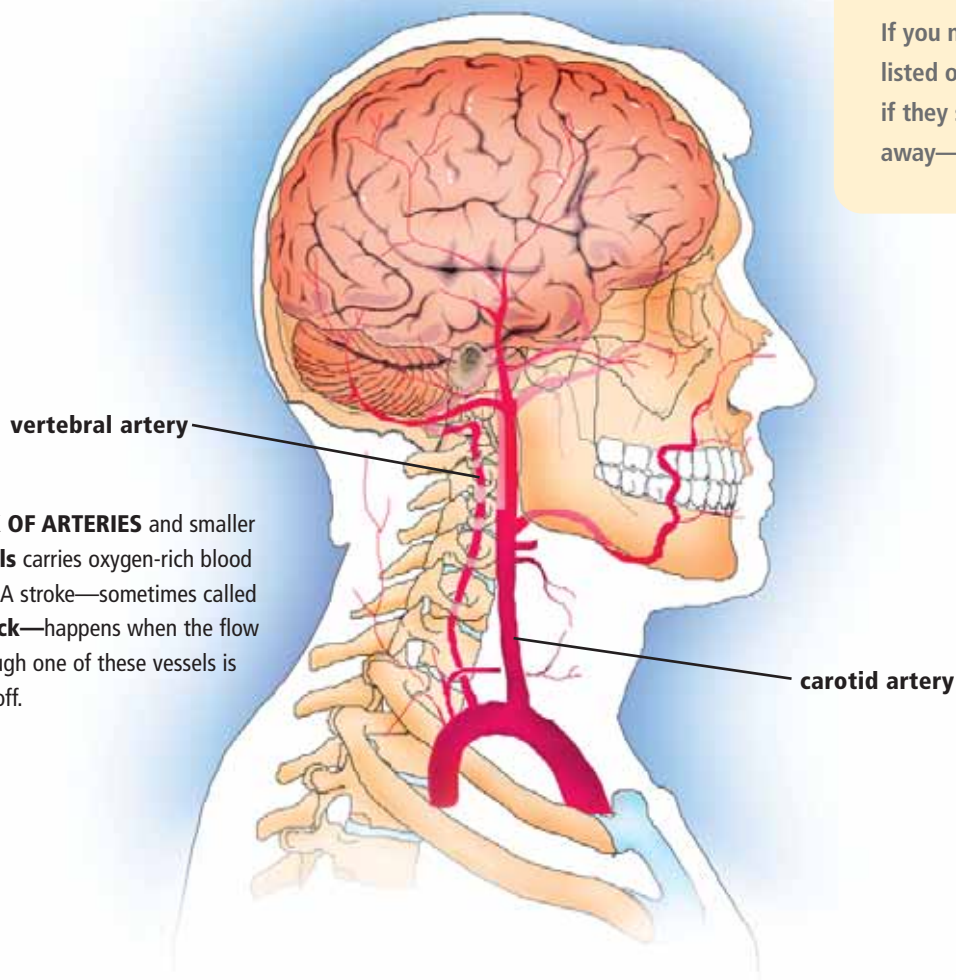
A stroke is when blood flow to part of your brain suddenly stops. Your brain cells need the oxygen and nutrients carried by the blood—so when a stroke happens, brain cells begin to die within minutes. And since the brain controls many parts and functions of your body, the effects of a stroke can be widespread. A stroke can change how your body moves, how your mind works, even how you feel and express yourself.

Transient ischemic attacks (TIAs)

A transient ischemic attack (or TIA for short) happens when a blood clot temporarily blocks an artery leading to your brain. Sometimes called a “mini-stroke,” a TIA can cause some of the same warning signs as a stroke (like weakness, vision or speech problems, dizziness, and headache). With a TIA, however, these effects usually last only a few minutes.

Don’t ignore a TIA! It may not cause lasting brain damage, but it often happens before a major stroke.

If you notice any of the signs listed on the back cover—even if they seem to have gone away—CALL 911 RIGHT AWAY.



A NETWORK OF ARTERIES and smaller **blood vessels** carries oxygen-rich blood to your brain. A stroke—sometimes called a **brain attack**—happens when the flow of blood through one of these vessels is suddenly cut off.



What causes a stroke?

A stroke is caused by a problem with one of the blood vessels that carry blood to the brain. Most commonly, the problem is a **blood clot** that gets stuck in a damaged blood vessel, blocking blood flow. Another possible problem is a **broken blood vessel**, which leads to bleeding in the brain. But whether the vessel is blocked or bleeding, the result is the same: blood can no longer reach the part of the brain that was normally fed by that vessel.

What leads to these problems? It depends—and in some cases, it's not known. A stroke can happen to anyone, at any age. Still, studies show that strokes are more likely to happen to people with the risk factors listed below. Each of these factors can damage your blood vessels.

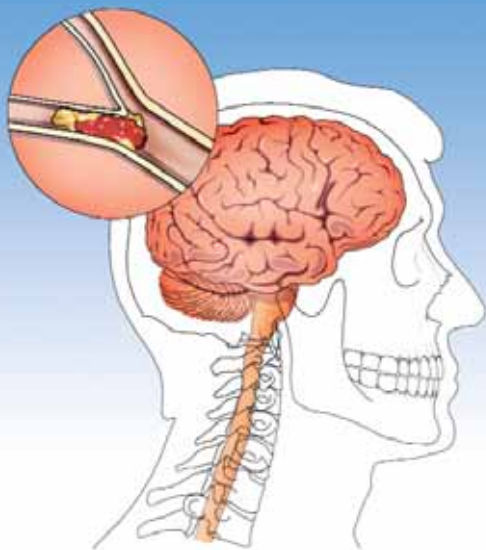
Risk factors for stroke

- **Atherosclerosis.** Fatty plaque can build up in your arteries, hardening and narrowing them. Arteries with atherosclerosis are more likely to become clogged and blocked by a blood clot.
- **High blood pressure (hypertension).** High blood pressure—140/90 or higher—is the biggest risk factor for stroke. It can weaken and damage your blood vessels. This makes them more likely to rupture or develop atherosclerosis.
- **Cholesterol problems.** Problems with the cholesterol in your bloodstream can lead to atherosclerosis. For example, your levels of LDL cholesterol (“bad cholesterol”) or triglycerides may be too high—or your HDL cholesterol (“good cholesterol”) level too low.
- **Diabetes.** People with diabetes are more prone to atherosclerosis. Also, the disease can interfere with the body’s ability to break down blood clots. Together, these factors put people with diabetes at a much higher risk for stroke than the general population.
- **Obesity and physical inactivity.** Being overweight or inactive—or both!—increases your chance of having all of the risk factors listed above.
- **Atrial fibrillation or other heart disease.** Atrial fibrillation is when the heart’s upper chambers quiver, rather than pump strongly as they should. This can cause blood to pool and form clots. And if the clots travel to your brain, they may get stuck in a blood vessel and cause a stroke. Other heart problems—like heart failure—also raise your risk of stroke.
- **Smoking.** Smoking makes your heart work harder and can promote high blood pressure. It also speeds up the fatty buildup of atherosclerosis.
- **Drug or alcohol abuse.** Many street drugs have been linked to stroke. So has binge drinking. And even drinking more than a moderate amount of alcohol—one drink a day for women, or one to two drinks a day for men—can raise blood pressure.
- **Use of birth control pills.** Although today’s lower-dose pills bring a much lower risk than in previous years, they do still increase your risk of stroke. This risk is greatest if you’re over age 35 or if you smoke.
- **High homocysteine levels.** Homocysteine is a substance in your blood. It’s normal to have some homocysteine. But if you have too much, you’re more likely to develop blood clots and atherosclerosis.
- **Ethnicity, age, and family and medical history.** Some stroke risk factors are beyond your control. For example, the older you are, the more likely you are to have a stroke. You’re also more likely to have a stroke if you’re African American, or if others in your family have had a stroke. The same is true if you’ve had a stroke or TIA in the past.

It’s important to know your risk factors. Managing them will be an important part of your recovery and your future healthy lifestyle. You may not be able to change all of them—your age, for example—but you can focus on the others.

What are the different types of stroke?

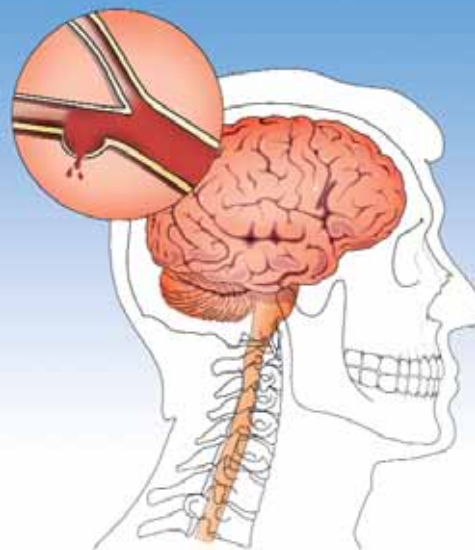
There are two main types of stroke: ischemic stroke and hemorrhagic stroke.



Ischemic strokes

Ischemic strokes are the most common type of stroke. About 85% of all strokes are of this type. In an ischemic stroke, blood flow to the brain is cut off (or greatly reduced). The cause depends on the type of ischemic stroke you've had:

- **A thrombotic stroke** happens when a blood clot (thrombus) forms inside an artery leading to the brain, blocking blood flow. It often forms in an artery that's already damaged by **atherosclerosis** (fatty buildup).
- **An embolic stroke** is also caused by a blood clot. But in this case, a blood clot that forms elsewhere in your body—often in your heart—travels in your bloodstream toward your brain. (A blood clot that's carried in your bloodstream is called an embolus.)
- **Systemic hypoperfusion** means low blood flow, and it happens when the heart's pumping action fails. A heart attack can cause this kind of stroke.



Hemorrhagic strokes

Hemorrhagic strokes happen when a blood vessel that feeds the brain ruptures (bursts). When this happens, blood floods into the surrounding tissue. This bleeding means that the part of your brain that's normally fed by this vessel no longer receives blood. It can also cause dangerous swelling in your brain.

Ruptures tend to happen at weak spots in the brain's network of blood vessels. Often, the artery ruptures at a weakened place in the wall of the vessel, called an **aneurysm**, that balloons out from the artery (see the picture above). Other times, it happens at the site of an **arteriovenous malformation (AVM)**, an abnormal tangle of thin-walled blood vessels. There are two kinds of hemorrhagic stroke, classified by where they happen in your brain:

- **A subarachnoid hemorrhage** happens when a blood vessel on the surface of the brain ruptures. Blood floods into the space between your brain and your skull.
- **An intracerebral hemorrhage** happens when a blood vessel breaks deep inside your brain. The bleeding there can cause tremendous pressure.

Complications after a stroke

A stroke can sometimes trigger other health problems, such as seizures, brain swelling, or infections. These may add to the effects of your stroke, or prolong your recovery.

That's why, after a stroke, your medical team will work hard to prevent and treat complications. See pages 14 to 17 for more information on treating a stroke and its complications.

What are the effects of a stroke?

The effects of a stroke vary a lot from person to person. They range from mild to severe, and can be temporary or permanent. The changes you see will depend on the location of your stroke, how quickly you received treatment, and whether you've had any complications. Still, one thing is certain: the effects of a stroke are greatest in the first days and weeks after the stroke happens. If you're like most people, you will improve with time. In fact, you may continue to improve for many months—and even years—after your stroke. The sections below describe some of the more common effects of a stroke.

Loss of movement, strength, or sensation

Weakness and paralysis, usually on one side of your body, are common after a stroke. You may hear the medical terms **hemiparesis** (for weakness) or **hemiplegia** (for paralysis) used to describe these one-sided effects. Sometimes they can cause **"one-sided neglect,"** which is when you ignore or forget one side of your body. Trouble swallowing (**dysphagia**) is also common.

Trouble communicating

Trouble expressing your thoughts is quite common after a stroke. So is mixing up words or having trouble understanding other people's speech. **Aphasia** is the general term for these kinds of problems. But other stroke effects may also interfere with your ability to communicate. For example, if the muscles used in talking or swallowing are affected, your speech can be slurred, slow, and difficult to understand.

For *family*
and friends

Knowing the stroke

Your loved one's treatment and recovery may depend on the type of stroke, where it happened in the brain, and the risk factors involved. Work with the medical team to record this important information on *Know Your Stroke: a Worksheet*, on pages 39 and 40 of this booklet.

Problems thinking and remembering

You might have trouble making decisions or solving problems. You might become forgetful, or feel like your memory is playing tricks on you.

Changes in vision

Your field of vision may be smaller than normal. (Some people liken this to a shade being pulled across or over part of their field of vision.) You might have trouble coordinating or controlling your eye movements. Or, you could have trouble with **depth perception**—with judging how close things are to you. Blurred vision is also common after a stroke.

Changes in your behavior, perceptions, and emotions

After a stroke, you may feel sad, angry, or depressed for a time. Your emotions may change rapidly, and you may find yourself crying or laughing uncontrollably or at inappropriate times. In some cases, people feel that their basic personality has changed. They find that they're more or less friendly, spontaneous, cautious, bold, and so on.



Feeling tired

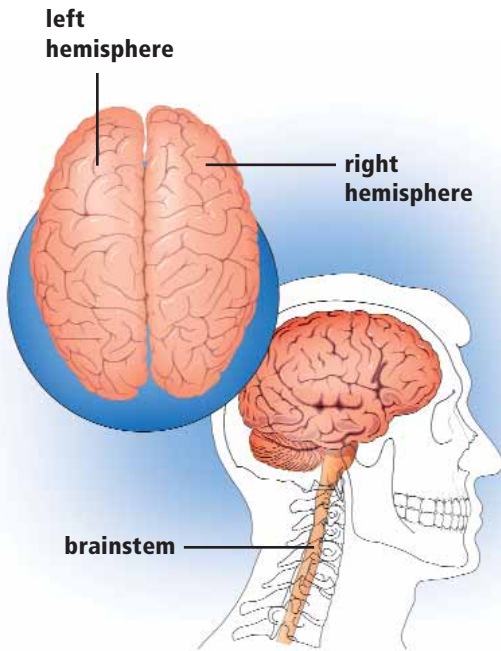
After a stroke, you may feel tired for a while. Fatigue may be an effect of your stroke, and it may be increased by other factors:

- **Changes in routine.** Poor sleep, little exercise, and new medications may leave you with less energy.
- **Daily activities that require more effort.** The effects of your stroke may require you to work much harder to walk, talk, pay attention, and so on.
- **Frustration and worry.** These feelings are common after a stroke. They can be exhausting!
- **Clinical depression.** If you have symptoms of depression, they should be treated.

Your energy should slowly come back as you recover. If it doesn't, talk to your doctor. Together you can determine the cause of your fatigue—and whether you need treatment.



Why does it matter where in my brain the stroke happened?

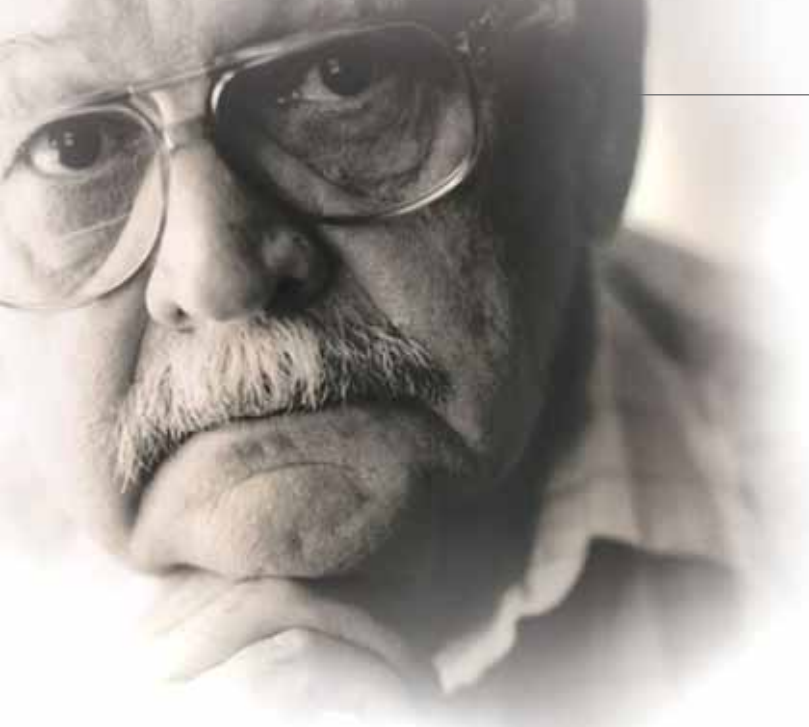


Your brain is divided into two sides (**hemispheres**). The right and left sides of your brain work together, but each side controls different things. For example, the left side of your brain controls the right side of your body, and vice versa. The two sides have other distinct jobs as well. This is why a stroke in the left side of your brain will affect you differently than if it had happened in the right side.

You can also have a stroke in your **brainstem**. The brainstem is the part of the brain that connects the brain to the spinal cord. A stroke here usually affects movement more than the other brain functions—and may leave more severe effects overall.

The table below describes some common effects of stroke in the left side of the brain, the right side of the brain, and the brainstem. Keep in mind that these are general descriptions—they may not match your experience.

Realm affected	LEFT side stroke	RIGHT side stroke	BRAINSTEM stroke
Movement and sensation	<ul style="list-style-type: none"> ■ Loss of strength, feeling, or movement on the right side of the body ■ Forgetting about or neglecting to use the right side of the body ■ A droop on the right side of the face 	<ul style="list-style-type: none"> ■ Loss of strength, feeling, or movement on the left side of the body ■ Forgetting about or neglecting to use the left side of the body ■ A droop on the left side of the face 	<ul style="list-style-type: none"> ■ Loss of strength, feeling, or movement on one or both sides ■ Trouble swallowing ■ Jerky movements ■ Poor balance, coordination
Communication	<ul style="list-style-type: none"> ■ Trouble speaking or understanding speech ■ Trouble reading and writing 	<ul style="list-style-type: none"> ■ Talking too much, or having trouble staying on topic or taking turns in conversation ■ Slurred, monotonous speech 	<ul style="list-style-type: none"> ■ Weak mouth and tongue muscles making speech difficult (slurred)
Thought and memory	<ul style="list-style-type: none"> ■ Trouble planning, organizing ■ Confusing left/right, up/down, over/under, etc. ■ Trouble solving problems and connecting thoughts 	<ul style="list-style-type: none"> ■ Trouble learning and remembering ■ Poor judgment ■ Trouble focusing, paying attention ■ Confusion about time and date 	<ul style="list-style-type: none"> ■ Decreased level of alertness or consciousness (may cause coma)
Vision	<ul style="list-style-type: none"> ■ Loss of the right visual field 	<ul style="list-style-type: none"> ■ Loss of the left visual field ■ Poor eye contact 	<ul style="list-style-type: none"> ■ Double vision or other changes in vision ■ Drooping eyelids, or trouble closing the eye all the way
Behavior, perception, and emotion	<ul style="list-style-type: none"> ■ Being more cautious, passive, and slow than before the stroke ■ Being more easily frustrated ■ Lack of motivation 	<ul style="list-style-type: none"> ■ Being more impulsive, stubborn, sarcastic, and irritable ■ Trouble recognizing familiar faces or others' moods ■ Denial of the effects of stroke, unrealistic expectations for recovery 	<ul style="list-style-type: none"> ■ Usually not affected



What does the future hold?

Right now, you and your family are eager to know what to expect for the future. You probably wish someone could tell you exactly which stroke effects will linger, and which will go away.

Your doctors and other caregivers can explain your specific condition. They can also tell you a lot about your recovery. But there will still be many unknowns. As with any brain injury, stroke recovery can take many possible courses—and they can be difficult to predict. As you go forward in your treatment and recovery, it's important to keep in mind the following:

- **The effects of a stroke are greatest in the first few days after the stroke.** Don't assume you'll always feel as you do today. You may improve dramatically in the days, weeks, and months to come.
- **With time, care, and effort, most people do improve.** Healing may not happen the way you think it will, but it does happen.
- **Rehabilitation activities can play a huge role in recovery.** Stroke rehabilitation (stroke rehab) may include physical, occupational, and speech therapy. It may also include counseling for mental health concerns.
- **Your healthcare providers are important to your recovery—but YOU are the most important person on your care team.** Your commitment and energy will be vital factors in your recovery.

For *family* and friends

What you can do today

Someone close to you has just had a stroke. You may find yourself wondering what you can do to help—or how you can feel more in control of things right now. If so, look below for ideas to help you through this difficult time:

- **Learn as much as you can.** Read all of this booklet. Ask the medical team about anything that worries you. The more you know, the less frightened you may feel.
- **Anticipate changes.** Even if it was very mild, the stroke will bring changes to your loved one—and to you. These changes can happen in different areas of your life. They may not be permanent, but it helps to anticipate them—and to be as patient and flexible as you can be as they unfold in the days to come.
- **Ask for help.** What do you need help with? What do you want to know? Ask others to help you right now. Some examples:
 - Friends or family members can mow your lawn, bring you dinner, or pick up groceries.
 - A hospital social worker can help you arrange care, find medical supplies, sort out financial and legal issues, and so on.
 - Nurses and rehab staff can help you set up a medication schedule, show you how to prepare healthier meals, and find other ways for you to support your loved one at home.
- **Take care of yourself—starting today.** Caring for a stroke survivor can be demanding, and you need to pace yourself to avoid exhaustion and burnout.

For more information on all of these topics, see pages 35 to 37.



“

I thought it was just a really bad headache—a migraine. The pain was terrible, and I was seeing funny. I guess I was talking funny, too, because my wife could tell that something was really wrong. She called an ambulance. And you know, thank goodness! I was able to get treated pretty quickly, and my doctor says that made a big difference.

—*Oscar, 68,*
two months
after a stroke

I stayed with Oscar the whole time—in the ambulance and in the hospital. I made everyone explain what was happening. I had questions about everything, every step of the way.

Even when things were happening fast, the doctors and nurses never made me feel like I was in the way. They answered all my questions. That meant a lot to me. When everything is spinning around you, you need information to feel a little more in control.

—*Delia, 68,*
Oscar's wife

DIAGNOSING AND

Treating Strokes

THE FIRST MINUTES AND HOURS AFTER THE STROKE'S ONSET MAY SEEM LIKE A BLUR TO YOU NOW. You may not remember what happened, or fully understand what your doctors did. This section can fill in a few gaps, and explain some of the treatments you've received or will receive.

Common SIGNS of a stroke

- Sudden numbness or weakness of the face, arm, or leg—especially on one side of the body
- Sudden confusion or trouble speaking or understanding speech
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, or loss of balance or coordination
- Sudden severe headache with no known cause



How are strokes diagnosed?

When a stroke is suspected, doctors must work quickly to confirm this diagnosis. They'll also try to determine the type and location of the stroke—these are important factors in treatment. Here are some common steps in this process:

- **Medical history.** The goal of a medical history is to better understand your condition. To do this, your healthcare providers ask you about previous health problems and about any medicines you take. (If you can't talk, they'll ask a family member.) They also ask about your symptoms and when you first noticed them. Are they getting worse, or better? Are they changing, or staying the same? The list at left gives some common stroke symptoms.
- **Physical exam.** Providers examine different areas of your body, and check for stroke risk factors like high blood pressure. They test your muscles and nerves, and assess your strength, coordination, and reflexes. They ask you questions to check your memory, speech, and thinking.
- **Other tests as needed.** To rule out other causes of your symptoms—or to pinpoint the type, cause, and location of the stroke—doctors often order tests such as these:
 - **Blood tests** to see if your blood is clotting normally, and to check for infections and immune problems.
 - **Imaging tests** of your head, such as a CT (computerized tomography) or MRI (magnetic resonance imaging). Such tests can check for bleeding, pinpoint the location of a stroke, and suggest the extent of the brain injury.
 - **Heart function tests** (such as echocardiograms) and **blood flow tests** (angiography or carotid ultrasound, for example). These may help show the cause of a stroke.

For *family* and friends

Medication management

Make sure that the medical team knows about all the things your loved one takes for health:

- ◆ Prescription medications
- ◆ Over-the-counter medications
- ◆ Herbal or nutritional supplements
- ◆ Vitamins and minerals

Sharing this information will help the team determine the best short-term and long-term treatments for your loved one.

Also realize that many stroke survivors go home with new medications. You may need to help your loved one keep track of these medications. For more on medication management, see page 27.



How are strokes treated?

Very often, stroke treatment must first include **basic life support**. This could include helping you breathe and keeping your airway open.

Besides basic life support, you may also need **treatment for stroke symptoms and complications**. For example, you may need medication to relieve headache pain or to help prevent a seizure. To **help protect your brain**, your medical team will also work to keep your blood glucose and temperature within normal ranges.

Beyond these measures, treatment for a stroke depends on the type of stroke you had—**ischemic** or **hemorrhagic**—and when it started. It can also depend on its specific cause and its location in your brain.

Treatments for ischemic strokes

For an ischemic stroke, the goal is to restore normal blood flow through the blood vessel. Medication and surgical or catheter procedures are common ways to do this.

Medication

The types of medication listed below are used to treat an ischemic stroke:

- **“Clot-busting” medication** put into your blood vessels—such as a **tissue plasminogen activator (tPA)**—can quickly dissolve a blood clot that’s blocking blood flow to your brain. These medications are used as emergency treatment—that is, within 3 hours of the onset of stroke symptoms. Outside this 3-hour time window, however, clot-busting medication may not help.
- **Antihypertensives** are medications to lower high blood pressure (hypertension).
- **Statins**, a type of cholesterol medication, may protect and support inflamed blood vessels during a stroke. They may also help prevent another stroke.
- **Antiplatelets and anticoagulants** work in different ways, but they both help prevent blood clots from forming inside your blood vessels. Doctors sometimes give antiplatelets during a stroke. More often, they prescribe antiplatelets and anticoagulants *after* a stroke, to help prevent another one.

Surgical and catheter procedures

Surgical or catheter procedures can also open up blocked blood vessels.

Here are some common choices for treating ischemic stroke:

- **Cerebral angioplasty** can widen an artery narrowed by fatty buildup (plaque). To begin, a doctor opens a blood vessel through your skin, and threads a small, balloon-tipped catheter (tube) through the blood vessels. When the catheter reaches the narrowed area in the artery, the doctor inflates the balloon. This presses the plaque against the side of the artery. At this point, the doctor will sometimes place a hollow tube (**stent**) inside the artery. Once the catheter balloon is deflated and removed, the stent remains in place to help keep the vessel open.
- **Carotid endarterectomy** is a surgery to clear away plaque in your carotid artery. The doctor reaches the artery through a small incision (cut) in your neck, and removes the plaque inside. Blood will flow more easily through this newly “cleaned” artery.
- **The MERCI Retriever** device is a catheter (tube) with a coiled tip. A doctor puts it into your blood vessel through the skin in your groin, then guides it up through your body until it reaches the site of your stroke. There the doctor uses it to “grab” a blood clot that’s blocking blood flow to your brain. The clot is removed from your brain as the catheter is pulled back out the way it came.

Which treatment?

Your doctors will move quickly to choose and begin the right treatment for you. The faster treatment begins, the less brain damage there may be.

Keep in mind, however, that stroke treatment is NOT “one size fits all.” Your doctor must carefully consider the following:

- **Will it help?**
Some treatments may have no effect on your condition.
- **Will it hurt?**
Depending on your condition, a treatment that helps another stroke patient may hurt you.
- **Is it safe for you?**
Allergies, other illnesses, or the severity of your condition may rule out a particular treatment.
- **Do the risks outweigh the benefits?**
Every treatment carries risks. Your doctors must determine that the potential benefits are greater than these risks.





New studies... new options

Medical scientists are working hard to find better ways of treating strokes, and recent successes are exciting. For example, several studies looked at the effect of adding ultrasound to treatment with clot-busting medication. The combination seems to speed the breakup of a clot in ischemic stroke. Another emerging therapy is cooling the body to help protect the brain during stroke. These new possibilities—and many more on the horizon—offer hope for anyone whose life has been touched by a stroke.

Treatments for hemorrhagic strokes

For a hemorrhagic stroke, the goal is to stop the bleeding in the brain and to relieve any extra pressure on the brain. As with ischemic stroke, treatment options include medication and surgical or catheter procedures.

Medication

Medications used to treat a hemorrhagic stroke depend on the factors that cause or accompany the stroke. Here are a few commonly used medications:

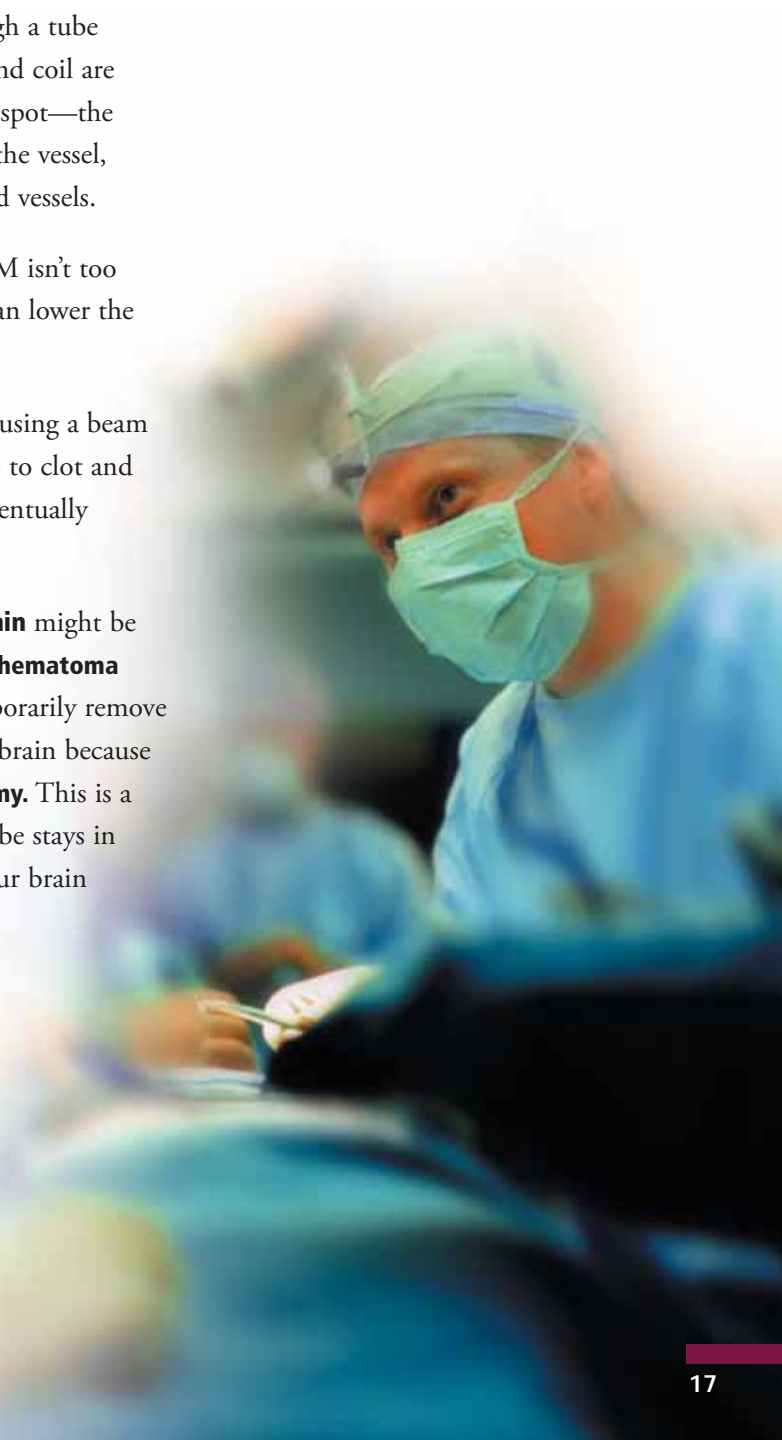
- **Antihypertensives** are medications to lower high blood pressure (hypertension). Hypertension is a common cause of stroke—and it can also worsen the bleeding from a hemorrhagic stroke.
- **Statins**, a type of cholesterol medication, may help protect the brain during a stroke. They may also help prevent another stroke.
- **Hyperosmotic agents** are medications that help reduce swelling in the brain tissue caused by the bleeding.
- **Substances to help your blood clot.** These can help stop the bleeding in your brain. If you've been using anticoagulant medication such as Coumadin, your doctors may give you something to reverse its effect.



Surgical and catheter procedures

These procedures can help correct the source of the bleeding, or reduce its effects on the brain:

- **Aneurysm clipping** may be an option if a ruptured aneurysm has caused the stroke. A surgeon can place a small clip on the blood vessel “upstream” from the aneurysm. This can help prevent re-bleeding or rupture of the aneurysm.
- **Coil embolization (coiling)** may be used if the stroke was caused by a ruptured aneurysm or an **arteriovenous malformation (AVM)**. In this procedure, a doctor pushes a tiny platinum coil in through a tube (catheter) placed inside your blood vessel. The catheter and coil are threaded up through the blood vessel toward the trouble spot—the aneurysm or AVM. Once there, the coil opens up to fill the vessel, causing it to clot and seal itself off from connecting blood vessels.
- **Surgery to remove an AVM** may be an option if the AVM isn’t too large or too deep inside the brain. Removing the AVM can lower the chance of another stroke.
- **Stereotactic radiosurgery** can eliminate an AVM by focusing a beam of radiation on the tangled vessels. This causes the vessels to clot and seal themselves off. Without a blood supply, the AVM eventually disappears, lowering the chance of another stroke.
- **Procedures to reduce pressure and irritation in the brain** might be needed. For example, you may have surgery to remove a **hematoma** (a collection of blood), clear away dead tissue, or to temporarily remove part of your skull. If cerebrospinal fluid builds up in the brain because of bleeding, your doctor may need to do a **ventriculostomy**. This is a surgery to place a small, soft tube into your skull. The tube stays in until the excess fluid has drained, and the pressure on your brain is relieved.



How does the brain heal?

Some of the damage done by a stroke can never be undone. But some of it can. Here's how it works in both cases:

- **The stroke kills some brain cells.** Your body clears away these dead brain cells, and they can't be re-grown or replaced. The function they controlled may be permanently lost.
- **The stroke limits (impairs) the function of other, undamaged brain cells.** Often this happens because the undamaged brain cells have lost normal communication with a damaged area of the brain. After some time, the functioning may return, as communication is "re-routed" inside your brain. Another possibility is for undamaged areas to take on new tasks. Since most activities—like talking or walking—require a coordinated effort between different parts of the brain, there are many possible ways for the brain to make up for a missing "player."

Right now, you still don't know what your recovery will look like. But there are ways that you and your family can help the healing process. One of the most important of these is to take part in **stroke rehabilitation (stroke rehab)** activities. See the facing page for more information on stroke rehab.

For *family*
and friends

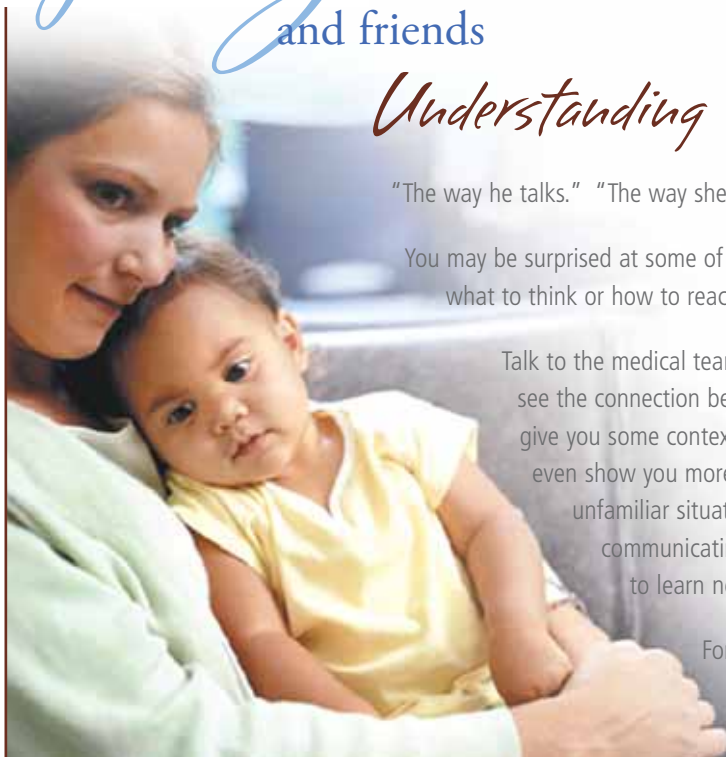
Understanding and coping with change

"The way he talks." "The way she sees me." "How hard it seems."

You may be surprised at some of the changes you see in your loved one. You may not know what to think or how to react. It can be disturbing.

Talk to the medical team. They may be able to explain these changes—to help you see the connection between the brain injury and the behaviors you see. They can give you some context, help you take things a little less personally, and perhaps even show you more of your loved one's "same old self" in this new and unfamiliar situation. Just as important, they can offer tips for communicating with your loved one. Like your loved one, you may need to learn new ways of doing things for a while.

For more information for family and friends, see pages 35 to 37.



What is stroke rehab— and why is it important?

Stroke rehab is a general name for a variety of therapies and services.

Stroke rehab can make a big difference in your recovery. It can help your brain learn new ways of working—and help you regain more of the abilities you lost when you had your stroke. It can also help you feel safer and more supported as you go about the hard work of recovery.

Stroke rehab may start when you're still in the hospital, and can continue after you've been discharged. Depending on your needs, it can include education, guided exercise, and support for any of the following:

- **Skills for daily living**, such as bathing, dressing, using the toilet, and so on
- **Mobility skills**, such as moving about in a wheelchair or walking
- **Communication skills**, such as finding the right word or speaking it aloud
- **Cognitive skills**, such as solving problems or remembering things
- **Social skills** to help you interact with others
- **Coping skills** to help you handle your emotions and get the help you need for depression or other mental illness

Page 23 of the next section introduces you to the people you may meet as part of your stroke rehab team.



The role of repetition • The role of repetition • The role of repetition • The role of repetition

The role of repetition

Once the immediate crisis of a stroke is over, rehab can help you to:

- Regain skills you lost when your brain was injured
- Learn new skills and new ways of doing things
- Be more independent
- Have the best possible quality of life

Repetitive practice—doing certain movements and exercises again and again—is an important part of most rehab programs. Studies show that repetition is key to learning. If you've ever worked hard to gain a skill—to play the piano, or perfect your golf swing, for example—you know this is true!

“

The stroke was a shock. And it made me angry! We were both about to retire, and then I got hit with that. I just felt like it was unfair, and it took me a long time to get past that frustration.

—*David, 74,*
ten years after his stroke

The stroke was a setback, but it wasn't an ending. It was hard work, and it took a long time, but David did get better. And we're still doing the things we like to do. We do them slowly—but we do them, and we enjoy them.

—*Cora, 74,*
David's wife



RECOVERING IN THE

Hospital

YOUR RECOVERY FROM A STROKE BEGINS WHILE YOU'RE IN THE HOSPITAL, and continues after you leave. This section is your guide for your time in the hospital.

For *family*
and friends

*How you can help
in the hospital*

- ◆ **Limit visitors.**
Friends may be eager to visit—but ask them to wait. For now, keep the guest list to just one or two close family members. This will help your loved one rest, and lower the chance of infection.
- ◆ **Help your loved one rest.**
Hospitals are busy places, and they can be noisy. Help your loved one rest by staying quiet and relaxed yourself. Just being there is enough.
- ◆ **Share your observations.**
You know your loved one best, so your insight can be helpful to the team.

Beyond the ER: what to expect

After the emergency room (ER), you may go to the intensive care unit (ICU) or another unit of the hospital. Once there, your care will focus on assessing the injury to the brain, preventing complications, and monitoring and treating symptoms. Here's what your care may require:

- **Medication** given through a vein (intravenously, or “IV”), by mouth, or by other methods
- **Monitoring**, including frequent checks of your vital signs (blood pressure, heart rate, and so on)
- **Frequent blood draws** for laboratory tests
- **Imaging tests** such as an x-ray or echocardiogram (“echo”)
- **Bed rest**, with limited bedside and self-care activities as directed by your medical team
- **Other equipment, monitoring, or support**—for example, extra oxygen, a **feeding tube**, or a **ventilator** (breathing machine)



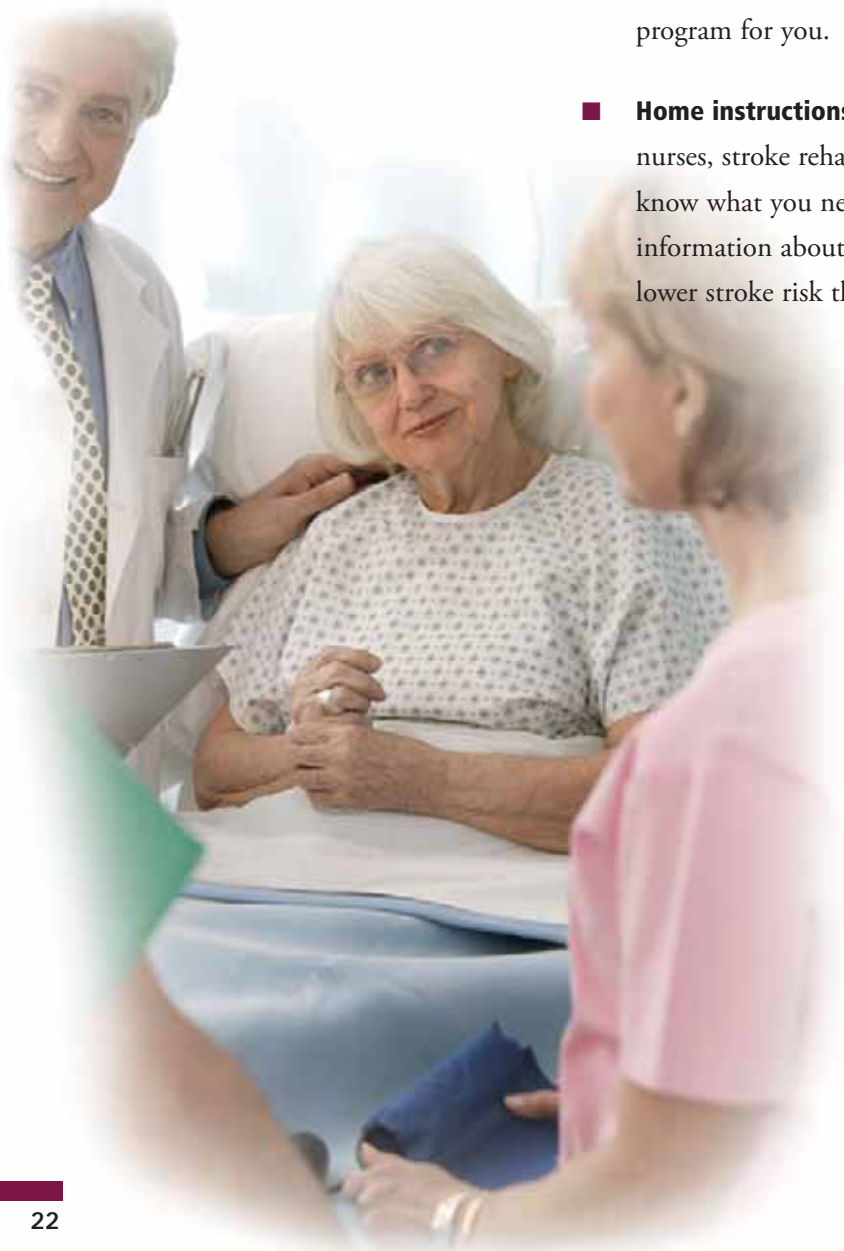
Bells and whistles... don't be alarmed

In the ICU—and in other units of the hospital as well—machines will help monitor your condition. Some of these machines have alarms that will go off from time to time. In this case, don't panic. An alarm doesn't always mean there's an emergency. Sometimes a machine makes noise to remind the medical team to check something, or do some other routine task.

Before you go home

Once your health is stable, you'll enter a new phase of your treatment. You'll still receive the monitoring, medication, and other medical support you need. But your medical team will now begin to help you and your family plan for the future. Here's what you can expect in this part of your hospital stay:

- **Stroke rehab evaluation and activities.** Rehab staff (see the next page) will visit you. Working with your doctors, they'll determine how the stroke has affected you, and what type of rehab might help. They may begin some rehab activities with you before you go home. As they work with you, staff will monitor your response and give feedback to your doctors. If needed, they'll also help arrange an outpatient rehab program for you.
- **Home instructions.** Small-group and one-on-one teaching from your nurses, stroke rehab staff, and others will help you and your family know what you need to do after you're discharged. This includes information about the immediate recovery period as well as how to lower stroke risk throughout your life.



Your stroke rehab team

You may work with a number of new people in the days and weeks to come. As you begin stroke rehab, your care team may now grow to include some of these specialists:

- **Rehab nurses** have special training to help stroke survivors. They can teach you about strokes, risk factors, and healthy living after a stroke. They may also help you relearn basic skills, such as using the toilet and bathing.
- **Physical, occupational, speech, and recreation therapists** can help you gain the skills you need for greater independence and a more satisfying life after a stroke. Which of these therapists you see depends on your condition and your goals.
- **Social workers and vocation counselors** may help you make adjustments for life at home or at work.

Doctors specializing in...

Your stroke rehab team may include one or more doctors specializing in these areas:

- ◆ Neurology
- ◆ Internal medicine
- ◆ Physical rehabilitation
- ◆ Mental health

As you work with these specialists, remember that your effort and commitment matter. Stroke rehab is rewarding—and sometimes even fun! But it can also be tiring and frustrating. Do your best, and stick with it. Rehab can play a big role in how fast and how well you recover.



I'm better than I was right after the stroke. But things still don't work like I want them to. My brain is blurry, and my arm feels heavy. Lynn is helping and I don't like being a problem for her. I'm trying to be patient.

—Gordon, 66,
three weeks after his stroke

“

He recognizes people when they come to visit, but then sometimes he can't remember that they came. He's laughing and joking one minute—just like he was before—and then the next minute he's withdrawn, frightened.

It's getting better, but I wish I knew where this journey was leading. At least I have my friends and the support group. They keep me going. They keep *us* going.

—Lynn, 59,

Gordon's wife and caregiver



RECOVERING AT HOME

Your Checklist

For *family*
and friends

Helping at home

This checklist is for you, too. As your loved one leaves the hospital, you may find yourself with a long list of new jobs. You may need to drive to rehab appointments, organize daily medications, and learn to cook healthier meals. As you review this recovery checklist, you'll probably find many other tasks that you can help your loved one accomplish.

Try to take things slowly. Give yourself credit for everything you're doing to help your loved one. And if you find that it has become too much, call your social worker or your loved one's doctor. You can also turn to one of the resources listed on page 38.



YOU'RE PROBABLY EAGER TO LEAVE THE HOSPITAL. But you may have some questions and concerns, too. Things have changed for you and your family, and you probably want some clear directions about your care in the months to come.

This section can help. It gives general guidelines to follow when you go home. A few of these guidelines—like when to follow up with your medical team—apply specifically to your initial recovery period, or about the first 12 months after your stroke. The rest of the guidelines are meant to be ongoing. Use them to help prevent another stroke and live a healthier life every day.

Before you leave the hospital, your nurses will go over each of these topics with you and your family. They'll also answer any questions you have. Always follow the advice of your medical team, even if it's different from the guidelines in this booklet.

If you're not able to go home

Everyone needs a little extra help after a stroke. Some people can get this extra help at home from their family, or from **home health nurses or aides**. For other people, the best place is at a facility such as the following:

- **Nursing facility.** This is for people who need more (or different) medical care than they can get at home. Also, a nursing facility can give around-the-clock care by skilled nurses and aides.
- **Assisted living facility.** Assisted living is for people who can manage most things on their own, but still need some extra support and care. For example, an assisted living facility may offer a service to help you manage your daily medication.

These are just two broad types of facilities that you and your family may consider. In fact, there are many different kinds of facilities, providing differing levels of care and services. Ask your medical team or social worker to help you explore your options.

Safety supplies?

To make your home safer—or just a little easier to get around in—you might need a few new items. Check a medical supply store. They have handles, grab bars, commode chairs, and other things listed below.

✓ Keep follow-up appointments

You'll probably be asked to make several follow-up appointments. Your neurologist, primary care, and rehab team may all want to see you within the first few weeks. These appointments are important! Use the chart on page 41 of this book to remind yourself to make and keep them.

✓ Give your home a safety upgrade

After a stroke, you're more prone to accidents. But making a few small changes around the house can help prevent them. Try the room-by-room suggestions below to make your home safer.

ALL rooms, stairs, and hallways:

TO HELP PREVENT FALLS:

- Remove rugs or tape them down with non-skid tape.
- Put sturdy handrails along stairs—even small flights as on a porch.
- Keep pathways clear of electrical cords or other clutter.
- Add nightlights to your hallway and bedroom, and a table lamp by your bed and favorite chair.

Bedroom

- Keep your bedspread up off the floor.
- Keep a telephone within easy reach of your bed.
- If you have trouble getting to the bathroom during the night, get a commode chair. (This is a seat with grab bars on both sides, and a little removable bucket beneath it. You can use it at night, then empty it in the morning.)

Bathroom

To steady yourself in the tub or shower:

- Put grab bars on the wall.
- Use a special seat or bench to sit in while you bathe. (If you bathe seated, a hand-held showerhead is helpful.)
- Put non-skid decals on the floor of the bath or tub.

Also, if you find it difficult to adjust the water temperature, replace the faucet handles with bigger, lever-type handles.

Kitchen

- Create a clear surface near the stove. This will give you a space to put pans that are too heavy—or too hot—to hold on to.
- If you've become more forgetful, you may want to install automatic shut-off valves on the stove.

✓ Take your medications

A big part of your recovery is managing your stroke risk factors. For most people, this includes taking medications. Always follow your doctor's instructions for taking your medications—as well as these basic guidelines:

- **Know your medications—and get organized!** Medication mistakes are common, and can be dangerous. So listen carefully to your doctor's or pharmacist's instructions. Ask questions. Write down **what** you're taking, **why** you're taking it, and **how** to take it. Use a pillbox or chart to help organize your medications and track what you've taken. And if you need help, just ask your pharmacist or rehab therapist.
- **Only take medications that your doctor has approved or prescribed for you.** Tell your doctor about all the things you take for your health, including vitamins, herbs, over-the-counter medicines, and so on.
- **Don't stop taking any medication—unless your doctor tells you to.** You may leave the hospital with a small supply of medication. You'll probably need to refill this supply at your local pharmacy. Make sure you have all the instructions and prescriptions you need—and that you order refills before you run out.



Use a medication chart—like the one on page 42—and a pillbox to help manage your medication.

If you're taking Coumadin (warfarin)...

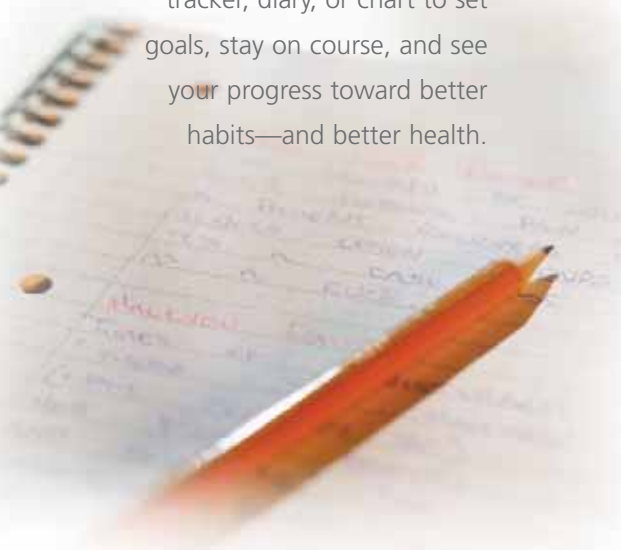
- **Follow instructions for getting your blood tested regularly.**
These tests, called PT/INR tests, tell your doctor if your blood is clotting at the right level.
- **Regulate your eating habits.**
Avoid drastic changes. It's especially important to be consistent in the amount of dark green, leafy vegetables (like spinach) you eat from day to day. These are high in vitamin K, which affects how Coumadin works in your body.
- **Don't eat grapefruit (or drink grapefruit juice) at the same time you take your Coumadin.**
Allow about 4 hours in between. Grapefruit can interfere with the absorption of Coumadin.
- **Talk to your doctor before taking aspirin or arthritis medications.**
Acetaminophen (Tylenol) is best for pain.
- **CALL YOUR DOCTOR**
if you notice bleeding from your gums, or blood in your urine or stools.

Keep on trackin’

After a stroke, most people need to make lifestyle changes to help control their risk factors.

Lowering blood pressure, losing weight, and getting more exercise are some common goals. What can help you get there? Tracking your progress regularly.

Many different studies have shown the power of written records to help people make healthier choices. So use a tracker, diary, or chart to set goals, stay on course, and see your progress toward better habits—and better health.



✓ Monitor your health

After a stroke, you need to pay special attention to your body, how you feel—even what you do each day. In fact, your medical team may ask you to keep a record of some of these things. For example, you may need to track the following:

- **Blood pressure.** High blood pressure is a major risk factor for stroke. If you have this problem, take your blood pressure regularly. Write down your numbers. If you find you can’t meet your blood pressure goals, call your doctor.
- **Weight.** Are you staying at a healthy weight? Making progress on that weight loss plan? The best way to know is to step on the scale—and write it down.
- **What you eat and drink.** Your medical team may have asked you to change some of your eating habits. For example, if you have high blood pressure, you need to limit sodium (salt) in your diet. If you’re taking Coumadin (warfarin), you need to stay consistent with the amount of vitamin K-rich foods you eat.
- **Minutes of physical activity.** Daily exercise is even more important after a stroke. Set goals with your medical team, and track your progress every day.
- **Other rehab activities.** Your rehab providers may give you exercises to do on your own. For example, they may ask you to work on strengthening your weak side, practice repeating words, or work on puzzles.

Be alert to signs of a stroke or TIA

Unfortunately, once you’ve had a stroke or transient ischemic attack (TIA), you’re at higher risk for another. So besides monitoring the things above, you and your family must also ALWAYS watch for these warning signs:

- Sudden numbness or weakness of the face, arm, or leg—especially on one side of the body
- Sudden confusion or trouble speaking or understanding speech
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, or loss of balance or coordination
- Sudden severe headache with no known cause

If you notice any of the above, **call 911 right away.**



✓ Balance rest and activity

Both rest and activity are important for healing. Here are a few guidelines for getting enough of each:

- **Rest.** Try to get at least 8 hours of sleep every night. Steer clear of things that you find stressful. Even if you don't find yourself unusually tired—as many people do after a stroke—you need extra rest right now.
- **Activity.** Physical activity may be a big part of your stroke rehab. It's definitely a big part of healthy living for the rest of your life. Even if you can't move as well as you used to, you can still exercise. So talk with your medical team about creating a plan. For most people, a good goal is **30 to 60 minutes of moderate exercise every day**. For better all-around fitness, try to do activities that help improve your strength, balance, flexibility, and endurance.

Getting a feel for fitness

Wonder whether you're exercising too hard, or not hard enough? Here's what moderate exercise feels like:

- You can talk during exercise, but you can't sing.
- You're breathing harder than usual, but not gasping for air.
- You're sweating lightly, not dripping wet.
- You feel invigorated right after—not exhausted.

Exercise Ideas

Ask your medical team to help you devise an exercise program. They can help you decide what activities to do, how often to do them, how hard, and how long.

STRENGTH

- **Arm raises**
Lift light hand weights, no more than 2 pounds. (You can use cans of soup.)
- **Knee bends**
Holding onto the back of a sturdy chair, bend down and up with both legs.
- **Tummy crunches**
Lying on your back on the floor with your knees bent, tuck in your chin and lift your shoulders up toward your knees. Stop when your shoulder blades are just off the floor. Hold for a moment, then roll back down.
- **Wall push-ups**
Standing a few feet away from the wall, place your palms against the wall at shoulder level and do "push-ups" into the wall.

BALANCE

- **Side leg raises**
Holding onto the back of a chair, lift one leg 6 to 12 inches out to the side, keeping both legs straight and foot facing forward (not pointed). Repeat on the other side.
- **Hip extensions**
Standing 12 to 18 inches away from a table and holding on for support, lean forward at the hips and lift one leg straight out in back (no pointed toe). Repeat on the other side.
- **Heel-to-toe walk**
Walk so that you're placing the heel of one foot down directly in front of the toes of the other foot.
- **Stand up and sit down**
without using your arms.

FLEXIBILITY

- **Triceps stretch**
Holding the end of a dishtowel in your hand, raise your arm over your head, then bend it so the towel is draped down your back. Reach behind your lower back with the other hand to grab the bottom of towel. Slowly work your hands closer together for a good stretch. Hold for 10 seconds. Repeat on the other side.
- **Hip rotation**
Lying on your back on the floor with your knees bent, gently lower your legs to one side as far as you can without pain (keep your knees together). Hold for 10 seconds. Repeat on the other side.

ENDURANCE

- Walking
- Swimming
- Gardening, mowing, raking
- Cycling on a stationary bike
- Bicycling outdoors
- Running or jogging
- Playing tennis
- Climbing stairs or hills
- Playing golf (walking)

IF YOU HAVE PHYSICAL DISABILITIES... The National Center on Physical Activity and Disability (www.ncpad.org) offers personalized tools and resources to help you meet your goals for physical activity—regardless of your disability.

Doing the DASH (Dietary Approaches to Stop Hypertension)

The DASH Eating Plan can help you lower your blood pressure—and eat healthier all the way around. The DASH Plan includes the following advice:

- **Limit your sodium (salt) intake.** Don't cook with salt, and don't add salt later. Also, read food labels. The label will reveal any hidden sodium, as well as other sneaky ingredients like trans fat.
- **Eat plenty of fruits and vegetables.** Don't rely on juices or canned versions. Fill up on whole fruits and vegetables—fresh or frozen—instead. Try for lots of dark green, orange, and yellow vegetables.
- **Go for whole grains.** Whole-grain bread, brown rice, and oatmeal are healthier than white bread and rice or processed cereals.
- **Choose unsaturated fats**—and stay clear of saturated and trans fats.
- **Get your protein from heart-healthy sources.** Fish, nuts, beans, and lean poultry and meat are best.
- **Pick nonfat or low-fat dairy products.** Milk, cheese, and yogurt are healthiest when they're low in fat.

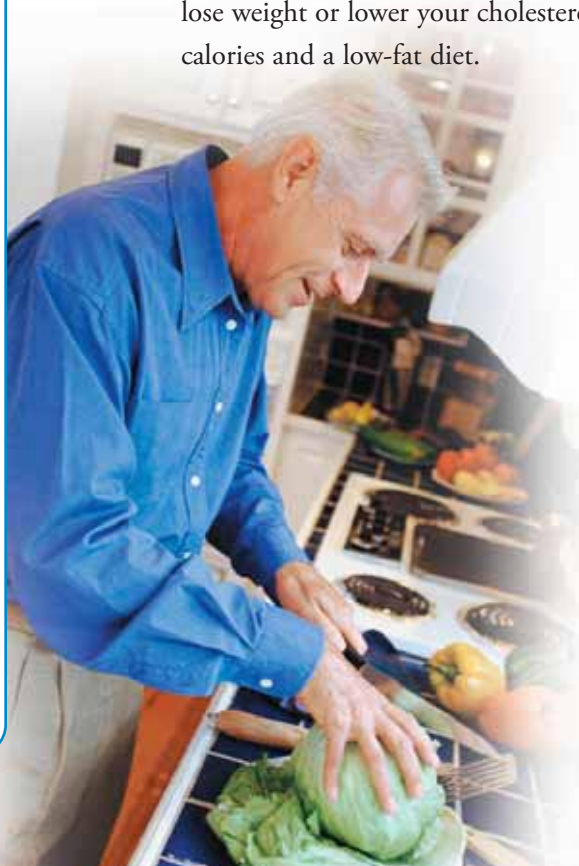
For more information on the DASH Plan, visit this website at the National Institutes of Health (NIH):

www.nhlbi.nih.gov/health/public/heart/hbp/dash/index.htm

✓ Eat healthy

For the first few weeks after your stroke, you may not have much of an appetite. But you need to keep eating to keep up your strength and speed your recovery. At the same time, you might need to make a few changes in your diet to help control your stroke risk factors. Your medical team will have specific instructions, but here are a few general guidelines.

- **Eat a wide variety of healthy foods.** Vegetables, fruits, and whole-grain foods are good choices. If you aren't hungry, ask your rehab team or dietitian to recommend a nutritional drink to add to your daily meals. This may help you get the nutrients and energy you need while you heal.
- **If you have dysphagia (trouble swallowing), take it slowly.** Eat smaller bites. Chew them slowly. If you have a lot of trouble swallowing, try soft foods like applesauce and soup. Liquids thickened with honey are another possibility. Ask your rehab team or dietitian for more ideas. (Or, if your rehab team has given you a special diet because of your dysphagia, follow it faithfully.)
- **Start a healthy eating plan as recommended by your medical team.** For example, if you have high blood pressure, you may need to cut down on sodium (salt) in your diet. If you need to lose weight or lower your cholesterol, you may need fewer calories and a low-fat diet.



Rx for an RD

Your healthcare providers may refer you to a **Registered Dietitian (RD)**. An RD can help you make changes in your eating habits by:

- Teaching about nutrition and how diet affects your stroke risk factors
- Helping you choose foods and plan menus
- Helping you track progress toward goals
- Encouraging and supporting your family's efforts to eat healthier

✓ Return to work and driving as your doctor recommends

After a stroke, you may be eager to return to work or start driving again. But for your health and safety, you'll need to wait a while. There are several important factors to consider before you go back to your old routines, and you need to follow the advice of your medical team. The boxes on this page and the next page list some things to talk over with your doctor and loved ones.

Driving

- **Even with very few stroke effects, most people should wait** at least a week before driving again. This gives time for you and your medical team to know your limits.
- **Driving after a stroke may not be safe**—for you or for others. A stroke can change your perception, judgment, and reaction times. And since many people don't realize all the effects of their stroke, it's vital to involve your doctor and rehab staff in your decision to start driving again. Talk to your family, too.
- **Driving against your doctor's advice may be illegal.** In some cases, the law requires your doctor to alert the state that you've been advised against driving.
- **If you have any concerns** about your ability to drive safely after a stroke, contact your state's drivers licensing office. They can give you a medical evaluation form for your doctor to fill out. As part of this evaluation, your doctor may refer you to someone who can test your driving ability, or to a driver's training program that can help you get back on the road.
- **If you do start to drive again,** have your family watch for warning signs of unsafe driving. If they see any of these in your driving, you need to have your driving tested:
 - Driving too fast or too slow
 - Ignoring traffic signs or signals
 - Getting lost or confused easily
 - Drifting across lanes
 - Driving and stopping too close to, or too far from, other cars

For *family*
and friends

The decision to drive

To many people, driving means freedom and independence. Even thinking about giving it up can be very difficult.

As you talk over the issues below with your loved one, try to be patient. If your loved one does begin to drive again, help out by watching for signs of unsafe driving. And keep in mind that safety—for your loved one and others—is the most important thing.



The bottom line...

There's no single, set time frame for returning to work and driving after a stroke. It depends on many individual factors. **So ALWAYS follow your own medical team's advice on resuming work or driving.** Your actions can affect your health and safety—and the safety of others as well.

Work

- **Your body needs time to heal.** Even with very few stroke effects, most people should wait at least a week before returning to work.
- **The stroke may have affected your ability to work**—temporarily or permanently. It depends on your condition and the type of work you do. And since many people don't realize all the effects of their stroke, it's wise to involve other people in your decision to return to work.
- **Talk to your family, employer, doctor, and rehab team about the mental and physical demands of your job.** Can you meet the demands, or can the job be adjusted? Have you had enough rest, and are you emotionally ready to take the plunge?
- **Explore occupational therapy.** An "OT" can help you relearn work skills or make other adjustments to help you stay in the workforce.
- **Suggest a trial period at work** to test out your job readiness.
- **Start back gradually.** Try lighter-duty assignments and shorter days at first.

✓ Care for your mental and emotional health

Emotional changes are common after a stroke. They may be a direct effect of your stroke—a result of the injury to your brain. But they can also come from the loss and uncertainty that a stroke may bring to your life. Many people report feeling anger, sadness, and hopelessness as they adjust to the reality of life after a stroke.

Often these feelings are temporary. But they can be quite painful, and they may get in the way of your rehab and recovery. To prevent this, try the following things to care for your mental and emotional health:

- **Go easy on yourself.** Be patient, and let the feelings come. Don't beat yourself up about the way you're feeling.
- **Join a support group.** Other stroke survivors know what you're going through, and they can help you feel more connected and hopeful. See page 38 for information on joining a stroke support group.
- **Stick to your exercise plan.** Being physically active can boost your mood and speed your recovery.
- **Talk to your doctor.** Depression and anxiety can be treated. Your doctor can discuss the best treatment for you.

✓ If you smoke, STOP

Smokers have three times the risk of heart attack and stroke as nonsmokers. The good news is that if you quit smoking now, your risk goes down right away—even if you’ve smoked for many years.

Talk to your medical team. They can help you plan a way to quit smoking, and can suggest programs and methods to help you cope with the stress of quitting. They may also offer medications to help reduce your craving for cigarettes and ease your withdrawal symptoms. You can also check out one of the resources below.

Worried you can’t quit smoking? Keep trying!

Most people try several times before they finally quit smoking for good. So keep at it. It’s never too late to be healthier—and past failures do NOT mean you can’t succeed this time.

■ Smoke Breakers (801) 442-5599

Smoke Breakers is a class-based smoking cessation program available at these Intermountain Healthcare Hospitals:

- **Cottonwood or LDS Hospital**
(801) 314-2702
- **Logan Regional Hospital**
(435) 716-5310
- **McKay-Dee Hospital**
(801) 387-3075
- **Utah Valley Regional Medical Center**
(801) 357-7162
- **Dixie Regional Medical Center**
(435) 251-1653

For all other Intermountain Healthcare locations call (801) 442-5599.

This program is available to SelectHealth members for a deposit, which is refundable after completion of the program. Non-SelectHealth members may participate for a non-refundable fee.

■ Free & Clear 1-800-292-2336

www.freeclear.com

The Free & Clear program is a 12-month, confidential, phone-based smoking cessation program. You will receive one-on-one telephone support from a smoking cessation specialist, a quit guide and workbook, and a stress management tape and workbook. This program is available at no charge to all SelectHealth members.

■ Freedom From Smoking 1-800-586-4872

www.ffsonline.org

Freedom From Smoking is an 8-week, class-based smoking cessation program offered by the American Lung Association.

■ Utah Tobacco Quit Line

In English: 1-888-567-TRUTH (1-888-567-8788)
En Español: 1-877-2NO-FUME (1-877-266-3863)

www.tobaccofreeutah.org

The Utah Tobacco Quit Line is a free, phone-based service available to all teens, uninsured adults, or adults on Medicare and/or Medicaid in the state of Utah. In addition to other services, the Quit Line provides support and information for pregnant women trying to quit smoking.

I think the first year is the hardest. You're working so hard to relearn things and get stronger—and your brain is still healing. Your emotions are all over the place. It's frustrating and exhausting.

I tell everyone who's had a stroke: take it one day at a time. Don't give up. Keep challenging yourself. Sometimes your progress will slow down for a while. You just have to be patient. When you get tired, rest. But don't give up. There's still more ahead if you reach for it.

Yes, life is different, but you are still you. You still have a life to live, and you still have something to give to the people you love.

—*Marya,*

70, five years after a stroke

“

At first, caring for Mom was just... totally stressful. There was so much to do, and I had no experience with caregiving, and I worried I wasn't doing it right. On top of that, she hated needing my help. Sometimes she'd lash out. You try not to take it personally, but it's hard. I did lose my temper with her a couple of times.

Things are different now. Mom's gotten better, and I've learned to manage things better, too. All in all, I really value the time I have with her. Caring for Mom has been the hardest thing I've ever done, but it's also been the most rewarding.

—*Tomas,*

Marya's son



For *family* and friends

Caring for a loved one after a stroke

AFTER A STROKE, YOU'RE FOCUSED ON HELPING YOUR LOVED ONE. That's how it should be. But believe it or not, taking care of yourself will be just as important. This section tells you a little about what you might expect as a stroke caregiver, and how you can help your loved one—without losing yourself.

What may change after a stroke

If you live with—or spend a lot of time with—someone who has recently had a stroke, you may already sense that changes are on the way for you, too. Strokes affect health, but they also affect daily living and relationships. According to other stroke caregivers, you may see changes in these areas:

- **Time for yourself.** You probably won't have much of this. Helping with daily activities, driving to rehab and doctor appointments, helping your loved one rest and recover—all this takes time. And if your loved one has become clingy or demanding, you may feel as if you scarcely have a minute to yourself.
- **Roles and responsibilities.** Strokes often shift the dynamics of a relationship. Maybe you need to “parent” your mother or father now. Or maybe you have to start doing things your spouse usually handled—driving, paying bills, supporting the family financially, and so on. Expect to re-think your role in your relationship with your loved one.
- **Daily habits.** To control stroke risk factors, your loved one may need to make some lifestyle changes. Such changes often require a team effort. For example, you may need to cook and eat in a new way, become more active, or stop smoking, too. It can be a real challenge!
- **Social life.** Going out to see people will be more difficult, at least for a while. Entertaining at home? You probably won't feel like it. And after the first few weeks, you'll probably get fewer visitors. The truth is, a stroke can isolate you. Expect to work harder to keep your social ties from unraveling.
- **Sex life.** If your spouse or partner has had a stroke, your sex life may change. At least for a time, you may need to find other ways to stay close.





How you may feel

“Stroke caregiver” is a job you probably didn’t expect to have. Here’s what you may feel as you begin your on-the-job training for this new role:

- **Worried.** You worry that you won’t be able to handle caregiving, or that you won’t do a good job. You worry that your loved one will die.
- **Overwhelmed.** You feel exhausted—physically and emotionally.
- **Sad.** You mourn the “good old days” before the stroke. You feel discouraged. You have trouble making decisions, enjoying things, or sleeping.
- **Guilty.** You play the “what-if?” game—wondering if you should have done something different to protect your loved one. Or, you feel guilty for being frustrated and impatient with your loved one.

All these feelings are normal. But they can be hard to handle. See below for ideas on coping.

Coping: Tips from other caregivers

You won’t be much help to anyone if you let yourself get overwhelmed by the new demands—and strong emotions—that can come with caregiving. Here are a few tips for coping:

- **Join a support group.** Other caregivers can be a great source of information, ideas, support, and hope. See page 38 for ways to connect—online, over the phone, or face to face.
- **Talk it out.** Don’t let your worries build up inside. Talk to your loved one, your friends, and the hospital social worker. They can offer you support and help you prepare for whatever the future may bring.
- **Get help.** Never refuse an offer of help. Create a “job list” so that if people ask what they can do, you can show them the list and have them take their pick. And if people aren’t offering to help, call them up and ask for it. There’s no shame in it—everyone needs a hand at times.
- **Get relief.** Most communities have resources that can give you a break from caregiving. See page 38 for ideas.
- **Try on a new perspective.** For a moment, imagine that the stroke has happened in someone else’s family. Would you blame or judge any of them? Wouldn’t they deserve your sympathy and compassion? Try to give yourself the same kindness you would show to someone else in your situation. And try not to dwell on the past. Instead, focus on making healthy changes for the future.
- **Hold on to hope.** It’s normal to grieve a little right now. Try to be patient with your feelings of loss or sadness. Things should improve with time. But if the feelings are stopping you from doing what you need to do every day, call your doctor. You may need treatment for depression.

Dos and don'ts

for communication and care

Because of the stroke's effects, you and your loved one may need to find new ways to connect. As you work with your loved one to give care and comfort, try these tips:

Do

- ◆ Keep conversations simple and brief. "Yes" or "no" questions may be easiest to understand and answer.
- ◆ Use your face and body to help communicate. Point at things, nod your head, shrug, guide with your hands, etc. You can also try using pictures to help get your point across.
- ◆ Break down tasks into steps—and guide your loved one through them one at a time.
- ◆ Make a daily schedule—and stick to it. A predictable routine will reassure your loved one.
- ◆ Give your loved one plenty of time to answer questions and do things.
- ◆ Remember that chatting isn't the only way to relate to your loved one. Share a cup of tea, take a walk, play checkers, or work in the garden together.

Don't

- ◆ Don't use baby talk or speak more loudly or softly than normal.
- ◆ Don't keep the radio or TV on when you're helping your loved one do an activity. The radio or TV may be too distracting.
- ◆ Don't wait until later to give feedback on a task. It's easier to learn from mistakes if they are corrected immediately.
- ◆ Don't leave your loved one alone to do a new task or stay in an unfamiliar environment.
- ◆ Don't ignore your loved one, or exclude them in conversations with others.
- ◆ Don't get upset if your loved one acts or talks inappropriately. Stay calm and continue doing what you were doing.

The search for a “new normal” for everyday life can be long and difficult.

So celebrate each small victory.

Laugh when you can.

Be patient with your loved one—and with yourself. You may be new to this caregiving job, but you'll learn it. And since you do it with love, there's no one better qualified.

STROKE

Resources

Below you'll find a few of the many organizations that support people who've had a stroke—and their friends and families.

Intermountain Healthcare, Intensive Medicine and Cardiovascular Clinical Programs

In Ogden, McKay-Dee Hospital Center:
801.387.3073

In Salt Lake City, LDS Hospital:
801.408.8305

In Provo, Utah Valley Regional Medical
Center
801.357.7522

Call the phone number of the facility
nearest you to find out how to connect
to local resources, including:

- Stroke rehab
- Home health aides
- Stroke support groups
- Community resources for respite care, adult day care, and meal programs (like Meals on Wheels)

[www.intermountainhealthcare.org/
stroke](http://www.intermountainhealthcare.org/stroke)

Visit the Online Stroke Center for
physician directories, web resources, and
drug information related to stroke.

National Institute of Neurological Disorders and Stroke (NINDS)

[www.ninds.nih.gov/
disorders/stroke/stroke.htm](http://www.ninds.nih.gov/disorders/stroke/stroke.htm)

Visit this website for stroke information
and research from the National
Institutes of Health.

Utah Department of Health, Heart Disease and Stroke Prevention

1.866.887.8765 (1.866.88.STROKE)

Call this toll-free phone number to get
a free stroke prevention kit that
includes:

- A brochure, symptoms magnet, and bookmark
- Blood pressure wallet card
- DASH diet eating plan book

www.hearthighway.org

Visit this website to learn about stroke
and what you and your family can do
to live healthier lives.

American Stroke Association

1.888.478.7653 (1.888.4.STROKE)

Call this toll-free phone number to:

- Find out about stroke support groups in your area
- Talk with other stroke survivors and caregivers
- Sign up to get Stroke Connection, a free magazine for survivors and caregivers

www.strokeassociation.com

Visit this website to learn more about
stroke, healthy habits to control stroke
risk factors, and stroke rehab and
recovery. You can also read other
people's stories and find out what's
new in stroke research.

National Stroke Association (NSA)

1.800.787.6537 (1.800.STROKES)

Call this toll-free number if you want
the association to:

- Send you a copy of HOPE: The Stroke Recovery Guide, or send other informational brochures and fact sheets
- Help you find helpful products and services for stroke survivors
- Help you find a support group
- Send you a free copy of StrokeSmart Magazine
- Help you get involved in the fight against stroke

www.stroke.org

Visit this website for any of the
reasons listed above—as well as
online stroke information and a
chance to link to Lotsa Helping Hands,
a new program that helps families
identify their needs and organize the
support of friends and family.

The National Center on Physical Activity and Disability

www.ncpad.org

Visit this website to access personalized
tools and resources to help you meet
your goals for physical activity—
regardless of your disability.

KNOW YOUR STROKE:

A Worksheet

Your treatment and recovery may depend on the type of stroke you've had, where it happened in your brain, and the risk factors you have. Use these two pages to record this important information.

Type of stroke:

Ischemic

- thrombotic (clot forming in vessel that feeds the brain)
- embolic (blood clot traveling to brain from another part of the body)
- systemic hypoperfusion (low blood flow)

Hemorrhagic

- subarachnoid (bleeding into space between brain and skull)
- cerebral hemorrhage (bleeding inside the brain)

Cause:

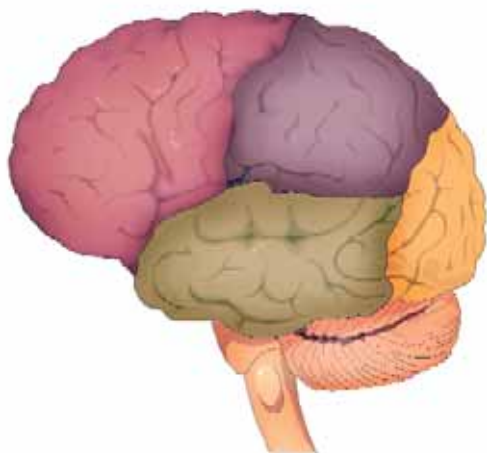
Location of stroke:

- LEFT side RIGHT side brain stem

Initial stroke effects, deficits

- LEFT sided RIGHT sided

Mark where your stroke occurred:



Risk factors I can't change:

- Ethnicity
- Age
- Family and medical history

Risk factors I can change:

My goals:

High blood pressure (hypertension)

Atherosclerosis

Cholesterol problems

Diabetes

Obesity

Physical inactivity

Atrial fibrillation or other heart disease

Smoking

Drug or alcohol abuse

Use of birth control pills

High homocysteine levels

Other: _____

Other: _____

Follow Up

PHONE NUMBERS AND APPOINTMENTS

















In the first few weeks after your discharge, you'll need to see members of your medical team. Use the chart below to keep track of these important appointments.

An appointment with...	is usually recommended	and MY appointment is...
Primary care provider: Name: _____ Phone: _____	1 to 7 days after you leave the hospital	Date: _____ Time: _____
Neurologist: Name: _____ Phone: _____	2 to 3 weeks after you leave the hospital	Date: _____ Time: _____
Rehab therapists (physical therapist, speech therapist, etc.): Name: _____ Phone: _____	As early as your first day home	Date: _____ Time: _____
Other provider: Name: _____ Phone: _____		Date: _____ Time: _____
Other provider: Name: _____ Phone: _____		Date: _____ Time: _____

Medication

CHART

You may need to take daily medication to help control your stroke risk factors and improve your health in other ways. Use this chart to help keep track of what you take, why you take it, and how to take it. Include everything you take for health—both new medications and the medications, vitamins, etc. you were taking before you came to the hospital.

Medication	How to Take	 Breakfast 7-9 a.m.	 Lunch 11-1 p.m.	 Dinner 5-7 p.m.	 Bedtime 9-11 p.m.
Name: _____ Dose: _____ <i>Taking this before admission?</i> Yes / No <i>At the same dose?</i> Yes / No What it's for: _____ What it looks like: _____ <small>color/shape</small>	<input type="checkbox"/> With food <input type="checkbox"/> NO food _____ <small>special instructions</small>				
Name: _____ Dose: _____ <i>Taking this before admission?</i> Yes / No <i>At the same dose?</i> Yes / No What it's for: _____ What it looks like: _____ <small>color/shape</small>	<input type="checkbox"/> With food <input type="checkbox"/> NO food _____ <small>special instructions</small>				
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Name: _____ Dose: _____ <i>Taking this before admission? Yes / No</i> <i>At the same dose? Yes / No</i> What it's for: _____ What it looks like: _____ <small>color/shape</small>	<input type="checkbox"/> With food <input type="checkbox"/> NO food _____ <small>special instructions</small>				

Call **911** if...

You see any of these stroke warning signs:

- Sudden numbness or weakness of the face, arm, or leg—especially on one side the body
- Sudden confusion or trouble speaking or understanding speech
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, or loss of balance or coordination
- Sudden severe headache with no known cause

You have any of these signs of heart attack:

- Strong or long-lasting pressure or pain in your chest, back, neck, shoulder, jaw, or arms
- Shortness of breath
- Extreme weakness or fatigue
- Dizziness
- Fainting

Call your primary care *doctor* if...

- You notice side effects from your medication that worry you
- You notice stroke effects or other problems that weren't discussed in the hospital
- You're taking Coumadin (warfarin), and you notice bleeding from your gums, or blood in your urine or stool
- You feel so sad and down that you can't do what you need to
- You're having trouble sleeping
- You (or your caregiver) are struggling to manage day-to-day activities.



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