

Partners in Stroke Recovery

A guide to help you begin your journey



Kingston General Hospital

Outstanding care, always™

This Guide Belongs to:

Name:

Contact Person:

Phone Number:

Email:



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Always seek advice from a doctor or other qualified healthcare professional about your medical concerns.

Welcome to the Acute Stroke Unit

Stroke is a sudden and traumatic event in a person's life. It is also the start of a life-long recovery journey. We know that you and your family are worried about what is happening to you. As part of your team, we will support you, your family, and your caregivers. If you have questions, please talk to anyone on the healthcare team. We hope that this guide will help answer some of those questions and help you on your stroke recovery journey. It is built in chapters to make it easy for you to find what you are looking for. It is yours to keep, so please take it with you when you leave Kingston General Hospital.

The Acute Stroke Unit is on Kidd 7. While you are here, the stroke team will offer expert care and work with you on your recovery plan. We also want your family to be part of your care. This includes being with you any time, which is why we do not limit visiting hours. If someone you love wants to stay with you in your room, any staff member can help to arrange this.



The acute stroke unit on Kidd 7

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Chapter 1

Introduction

This guide is for you, your family, and your caregivers to use during your recovery in hospital and as you continue your recovery journey after discharge. Family is anyone you choose to call family. This guide has different chapters that you can read in any order you like. We hope that it will answer some of the questions that you have.

You should use this guide to keep track of your recovery journey after your stroke. You and your family can use it as a journal to write down any thoughts or questions you have, keep track of your medications and all your appointments. Take it with you when you go to appointments. You can also keep track of things like your blood pressure, blood sugar, and tests. It is also helpful to write down what goals you might be working on.

This guide will help you and your loved ones learn the skills to be involved and to take charge of your health. We call this self-management. Self-management will help you feel more involved and in control of your health and wellness.

This Chapter at a Glance:

- Partners in care

Partners in Care



Many people are partners in your care. This picture shows just a few. Along the way, you may meet some or all of us. We are all here to work with you during your recovery even if you don't always see us. You can ask us questions or for help at any time. "Nothing about me, without me" is a statement that tells everyone that you are the centre of your team (MacLeod & Kushner, 2013).

This part of the guide will tell you all about who we are and what we do. With the help of your care partners, you and your caregivers will learn how to manage your health and keep a positive outlook. This is the best way to recover and live well after your stroke.



Members of your care team look at a CT scan

Doctors

The doctor involved in your care is a neurologist. You will also meet medical students and residents. Residents are doctors doing more training to become specialists.

Nurses

Registered nurses (RN) and registered practical nurses (RPN) will help with your day-to-day needs. Your nurses will also give your medications, check your temperature, blood pressure, blood sugar and many other important things. They talk with all your other healthcare partners every day. Your nurses work with patient care assistants (PCA) to help you with bathing, meals, getting in and out of bed and to the bathroom. You may also meet nursing students.

Physiotherapist

Your physiotherapist (PT) thinks about how your body moves and what keeps it moving well. The PT will work with you to improve how you move. The physiotherapist will meet you within the first few days after your stroke. The PT will review your health history and look at your movement, strength, and balance. They will make sure that you are using your muscles as normally as possible. The PT will have you do exercises and practice things like walking to help you get back your strength and balance. The PT might give you exercises that you can do between therapy sessions and may give you a cane or a walker to help you with your walking. Sometimes a physiotherapy assistant will also work with you.

A session with a Physiotherapist



www.physiofunction.co.uk

Occupational Therapist

The occupational therapist (OT) is interested in finding out more about what you do in your everyday life. For example, what you do or did for a living, what activities you do on a day-to-day basis, and what your home is like. The OT will meet you within the first few days, often with the physiotherapist. The OT looks at your vision, thinking, and memory. They may also work with you to help you do things for yourself, like showering, dressing, and cooking. The OT may also get you a special chair if you need one. Both the occupational therapist and the physiotherapist will help with your plan for discharge from Kingston General Hospital.

A session with an Occupational Therapist



Burke Rehab Center

Speech-Language Pathologist

A speech-language pathologist (SLP), also called a speech therapist, is an expert in communication and swallowing problems. The SLP will meet you if you have one of these problems. These problems are common after a stroke. Your SLP may suggest things to make it easier for you to swallow safely. If the SLP finds that it is not safe for you to eat or drink they may suggest that you have a naso-gastric tube (NG tube) put in so that you can get nutrition and medications. This tube goes through your nose and into your stomach. The SLP will continue to check your swallowing during your stay in hospital. They will also work closely with your dietitian.

Learn more from The Canadian Association of Speech-Language Pathologist and Audiologists at: <http://www.caslpa.ca/public/home>

Dietitian

A registered dietitian may be part of your team on the acute stroke unit. The dietitian is an expert on diet and nutrition. Good nutrition will help give you the strength and energy you need for your recovery.

Below are some examples of how a dietitian may be part of your care:

- Speak with you about tube feedings
- Review how much you are eating
- Talk with you about your special diet and healthy eating
- Talk with you about foods that may interact with your medication

If your SLP finds that you can't swallow safely your dietitian will make sure you are getting the fluids and nutrition that you need through your tube feeding.

Social Worker

The stroke team social worker (SW) can meet with you to talk about how you are coping after your stroke and to help you or your loved ones get used to the changes that you are facing. You may want to talk about the emotions you are feeling, decisions you need to make, or ask questions about how you will manage your finances. The SW may speak with you or your family about where you will go when you are ready to leave Kingston General Hospital. The SW has information about community supports, financial help, and Powers of Attorney. The social worker may stop by and introduce him or herself, or, you can tell anyone on the healthcare team that you would like to speak with the social worker.

Community Care Access Centre (CCAC) Care Coordinator

If you need help when you leave the hospital, you will have a CCAC care coordinator. This person will do an assessment of your healthcare needs and decide what services you need. The care coordinator will meet with you and your family to talk about your plan. The care coordinator will arrange, coordinate, and monitor your services. They will make sure that your services keep pace with your changing health needs and that you get the highest quality of services possible. The care coordinator will talk with you about stopping services when you no longer need them. You will have the name and contact information for the care coordinator in the community so that you can call whenever you have a question or concern.

To learn more go to the Community Care Access Centre website at www.ccac-ont.ca



Pharmacist

Your Pharmacist is someone who works with you and your team to make sure that the medications you are taking are safe and right for you. He or she will do this by checking the medications we give you while you are in the hospital. They will work with you to get the "best possible medication history". They do this to make sure that:

- None of your home medications are missed while you are in the hospital
- We continue any home medications that are still needed
- All the medications you were taking at home are written in your chart

Your hospital pharmacist can give you up-to-date drug information and teach you how to take your medication. They will also monitor how your medications are working for you. Your pharmacist is always keeping track of your medications. They may suggest changes to your medications while you are in hospital. If you have any questions about your medications while in hospital, please ask to speak to your pharmacist.

Stroke Specialist Case Manager (SSCM)

This person is a Registered Nurse who works only with patients and their families after a stroke. She or he may meet you at any time during your stay in hospital. The SSCM is happy to work with you on your plan of care, and will be in touch with other members of your health team often. You can ask this person any questions or talk about your worries. She will help make sure that the right person is available to help you work through any of these things. The SSCM will help you and your family get ready to leave the hospital and will work hard to make sure that we have done everything we can to support you after discharge.

Chapter 2

You or Your Loved One Had a Stroke



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We know that it may be hard for you and your loved ones to keep up with and understand all the things that happen right after your stroke. This guide will help.

This Chapter at a Glance:

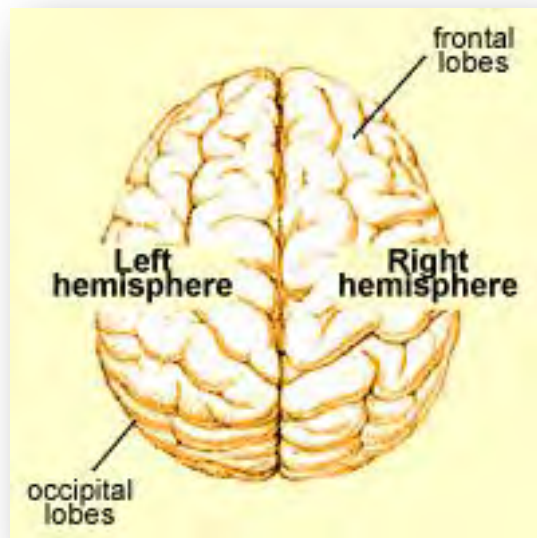
- How Does the Brain Work?
- What is a Stroke?
- Your Stroke
- What is a Transient Ischemic Attack (TIA)?
- Changes to Your Body Caused by a Stroke

How Does the Brain Work?

Your brain has two sides, called cerebral hemispheres. Each hemisphere takes care of one side of your body, but the controls are crossed: the right hemisphere takes care of your left side, and vice versa. If each hemisphere were unfolded, it would be the size of an extra-large pizza! For this reason, your brain must fold over on itself many times to fit into your skull.

The brain accounts for only about 2% of the total weight of your body, but accounts for about 20% of its blood and oxygen use. Thanks to the one billion nerve cells we can think, plan, talk, imagine, move, and much more.

The brain seen from the top



© <http://thebrain.mcgill.ca>

Different areas of your brain control the many things you can do. That is why damage to different parts of the brain causes different stroke symptoms.

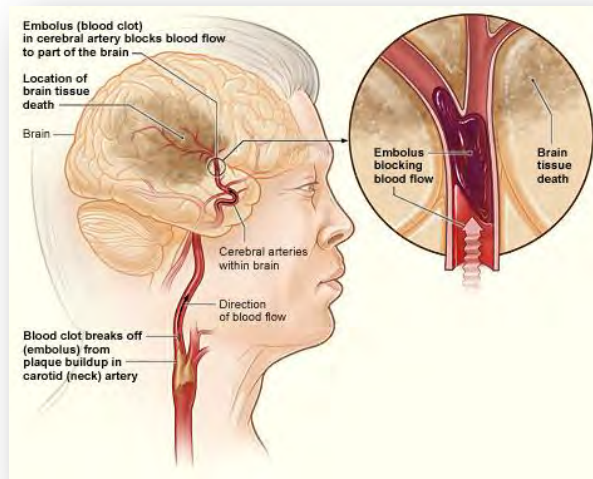
What is a Stroke?

Arteries are special tubes that carry blood through your body. When an artery is suddenly blocked and blood can't reach your brain, or when an artery breaks and blood leaks out, your brain is damaged and changes how it works. This is a stroke.

What is an Ischemic Stroke?

A blocked artery causes most strokes. This is an ischemic stroke. Several things can block one of your arteries. A buildup of yellow fat in the artery is called plaque. Plaque causes your arteries to narrow and blocks the flow of blood. It's like a pinched garden hose; the water doesn't flow properly. If a blood clot tries to get past the narrow part of your artery it can get stuck and totally block that artery. A blocked artery means that part of your brain is not getting the blood and oxygen that it needs to work properly. If that part of your brain stays without oxygen for too long, it will die and parts of your body will not work properly.

A blocked artery causes an ischemic stroke

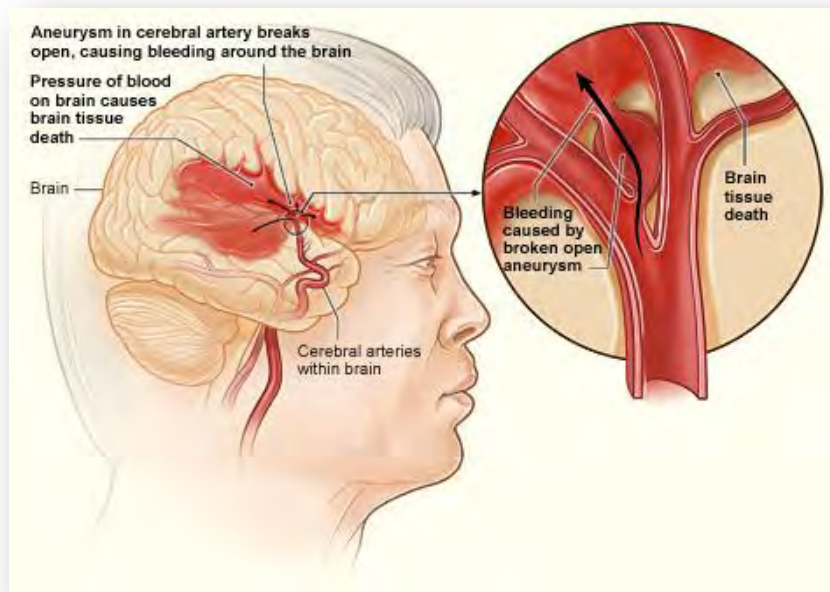


Source: National Heart, Lung, and Blood Institute; National Institutes of Health; U.S. Department of Health and Human Services.

What is a Hemorrhagic Stroke?

When an artery in your brain leaks or bursts it causes bleeding into your brain. This bleeding changes the normal flow of blood and floods the brain, killing brain cells. This is a hemorrhagic stroke. High blood pressure or weak spots in your arteries can cause bleeding in your brain.

An artery bursts causing a hemorrhagic stroke



Source: National Heart, Lung, and Blood Institute; National Institutes of Health; U.S. Department of Health and Human Services.

To learn more go to:

<http://www.strokecenter.org/patients/about-stroke>

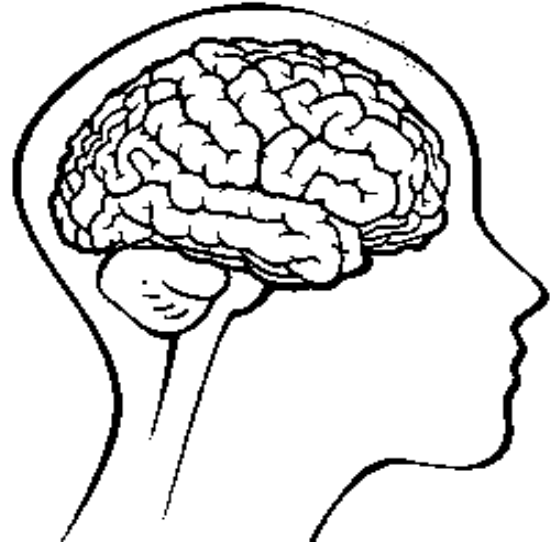
<http://www.heartandstroke.com>

<http://strokengine.ca/family>

Your Stroke



Looking at my brain from the left side



Looking at my brain from the right side

<http://www.nlm.nih.gov>

Circle or have your healthcare professional circle the area of your brain where your stroke happened.

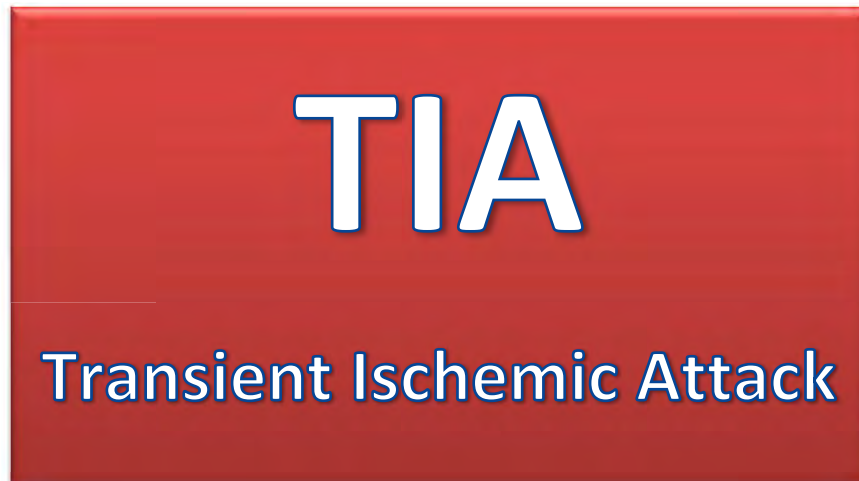
The date of my stroke was:
The type of stroke I had was:
My stroke was located:

What is a Transient Ischemic Attack?

A transient ischemic attack (TIA) sometimes called a “mini-stroke” is a serious warning sign of stroke risk. It is a temporary loss of blood supply to part of your brain. Even though your symptoms may last a short time, from a few seconds to several minutes, you should never ignore a TIA! Your chance of stroke following a TIA is high.

If you have, any of these symptoms don't ignore them, call 911 immediately!

- Sudden weakness
- Sudden trouble speaking
- Sudden vision problems
- Sudden headache
- Sudden dizziness



Take Immediate Action

Changes to Your Body Caused by a Stroke

Your brain controls how you move, feel, communicate, think and act. So, when you have a stroke some of these things may change. Some changes are common when a stroke happens on either side of your brain. Some are based on the side of the brain injured by your stroke.

What are the Most Common Changes after a Stroke?

Swallowing Problems

Many people have swallowing problems after a stroke. This is called dysphagia. Swallowing is very complicated. It involves several areas of your brain and many muscles working together. Swallowing problems may cause a number of complications, such as pneumonia. It is important to know if you have a swallowing problem so we can reduce the chance of complications (see “Helpful Information” on page 81, in Chapter 5, for more on complications).

Watch for these common signs of swallowing problems after a stroke:

- Coughing during or right after eating or drinking
- Wet or gurgly sounding voice during or after eating or drinking
- Extra effort or time needed to chew or swallow
- Food or liquid leaking from the mouth or getting stuck in your mouth
- Chest congestion after eating

Communication Problems

After a stroke you may have problems with language that make it difficult to communicate, this is called aphasia.



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After a stroke, aphasia can make it difficult to read, write, use numbers. Most people with aphasia find it very frustrating. No two people will experience aphasia in the same way.

You or your family may notice that you are having some of these problems:

- Problems putting words together
- Trouble switching topics
- Problems keeping up with what others are saying

Sometimes the muscles that help your mouth form words may not work properly after a stroke. This is dysarthria. If you have dysarthria, you may notice some of these problems:

- Muscles of your lips and tongue may be weaker
- Your speech may not be clear or you may not be able to speak loud enough to be heard

Weakness

Having a stroke may cause one side of your body to be weaker than the other. Weakness on one side of your body is called hemiparesis. Hemiplegia is paralysis of one side of your body. How much your strength and movement improves is different for each person. Everyone recovers at a different rate and to a different degree.

Changes in Your Vision

Vision problems are also common after a stroke. They may include problems focusing, double vision, trouble moving your eyes, or blind spots. Vision problems after stroke happen because of damage to your brain, not your eyes.

vision-problems

To learn more go to

<http://healthtalkonline.org/peoples-experiences/nerves-brain/stroke/changes-vision>

Changes in How Your Body Feels

Having a stroke may change the way your body feels, or your sensation. Your face, arms or legs may feel numb or feel like pins and needles. You could also be less aware of temperature on parts of your body. Some people notice that they are more aware of things such as taste, sound and touch.

Changes in Your Balance

Problems with balance are common after a stroke. If your balance has changed, you may feel dizzy or unsteady. Your balance could be affected by weakness, changes in your vision and changes in how your body feels. This could lead to a fall when walking or moving around and may reduce your confidence when walking. You might also feel nauseous, which can make you unable to work with your healthcare team. This will get better with time but in the meantime, we can give you medication to help.

Changes in Memory, Thinking, and Understanding

After a stroke, you may have difficulty with your memory, attention, and understanding. These are problems that are harder to see than things that affect you physically. Every day your brain needs to sort through large amounts of information. Your brain must figure out, organize, and store this information so that you can go about your day. A stroke can affect any part of this process.

If your stroke was in the left side of your brain, you may find that you are unsure about things and want to take your time. You may find that you need to have tasks broken down into steps. You may need lots of practice to do those tasks.

If your stroke was in the right side of your brain you may have problems with things like judging distance, size and how your body parts on the left relate to the rest of your body. You may try to do some things too quickly. You may think that you can do things that you can't or shouldn't, such as driving.

Chapter 3

In the Hospital



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This Chapter at a Glance:

- What to Expect From One Another
- What Tests Could I Have While in the Hospital?
- What is the Treatment for Stroke?
- Fatigue and Sleep
- Pain after Stroke
- Communicating After a Stroke
- Feelings You Might Have and Coping with Emotions

What to Expect from One Another

Your stay in the acute stroke unit at Kingston General Hospital is a care partnership. We invite you and your family to join us as active members of your care team.

We will:

- Treat you with respect and compassion
- Tell you our names and what we do
- Coordinate your care
- Involve you in your care
- Explain your care and treatment in language you understand
- Ask if you have questions or concerns
- Listen to your questions or concerns and take steps to address them
- Ask you if you have an advanced directive. These written instructions tell us your healthcare wishes
- Clean our hands often

We ask you or a loved one to:

- Be clear and complete about your medical history, including current medications
- Appoint one loved one to be the family contact
- Ask questions
- Speak up if you are concerned about a test, procedure, or medication
- Tell us if you don't understand something
- Clean your hands often, and ask your visitors to do the same
- Remind us if we don't do the things we said we would

What Tests Could I Have While in Hospital?

CT scan (CAT scan)

The first test you will have is a CT scan to look at your brain. A CT scan is a special X-ray test. It can give clear pictures of the inside of your body. It is good for looking at the brain, which does not show up on regular X-rays. This will happen very quickly when you first get to the emergency department. Using a CT scan, we may see where your stroke is and what kind of stroke you are having. We need to know if your stroke was ischemic (from a blockage) or hemorrhagic (from bleeding in the brain). This will help us decide what we do next. We will need to remove any glasses, earrings, and necklaces you are wearing. The CT scan is a very quick test and takes only a few minutes. Because a CT scan uses X-rays you cannot have anyone in the room with you, but your healthcare professionals will be watching through a window. They can hear you if you ask for help. You may have more than one CT scan while you are at Kingston General Hospital.

The CT scanner at Kingston General Hospital



MRI

An MRI (magnetic resonance imaging) scan is a test that uses powerful magnets and radio waves to take pictures of your brain. It does not use radiation like other X-rays or scans.

Because the MRI uses strong magnets, we will ask you to wear a hospital gown and remove anything made of metal, such as jewelry. Metal objects are not allowed in the scanner room.

You will lie on a narrow table, which slides into a large tunnel-shaped scanner. During the MRI, the person who operates the machine will watch you from another room. The MRI does not cause any pain, but the machine makes loud thumping and humming noises when it is on.

There is an intercom in the room so you can speak to someone at any time.



Discovery.com

A patient having an MRI of the brain

Swallowing Screen

Problems swallowing after a stroke are common. If you are having problems swallowing (this is called dysphagia) it may not be safe for you to eat or drink. A nurse will do a special test to check if you are having problems swallowing. This is a simple test that is done at your bedside. If this test shows that you have a problem swallowing, we will call a speech-language pathologist to do an assessment. This will give us more information about your swallowing problems.

VFSS

A VFSS (Videofluoroscopic swallowing study), sometimes called a cookie swallow, is a swallowing test done with your speech-language pathologist (SLP). During this test, you will try different foods and liquids. This test is done in the X-ray department. The VFSS lets your SLP see if food is going into your airway instead of your stomach. This is called aspiration.

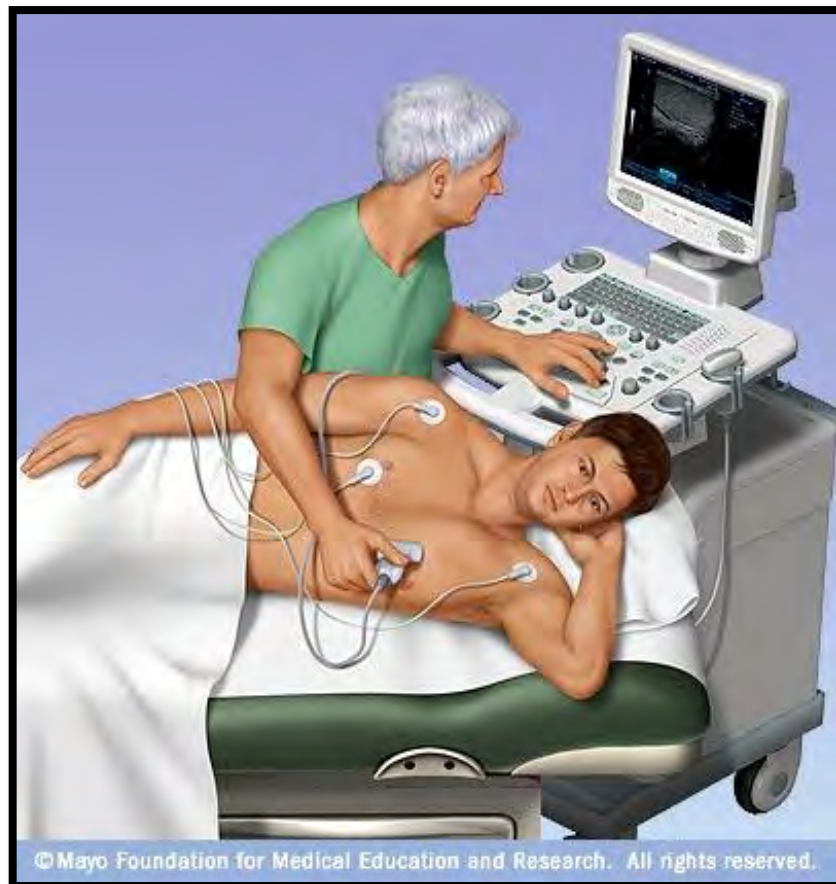
A VFSS will also tell us which parts of your mouth and throat may not be working well, what kinds of food are safest for you to swallow and how to help you swallow better.

Your SLP will share the video with you and your family so you can see what happens for yourself. Your SLP will use the test results to decide what diet texture and treatment is right for you.

Echocardiogram

An echocardiogram checks how your heart is pumping blood through your body. It uses an ultrasound to see how blood moves through your heart. The echocardiogram is a painless test. It takes about 45-60 minutes. It can help your doctor to see if a heart condition may have caused your stroke.

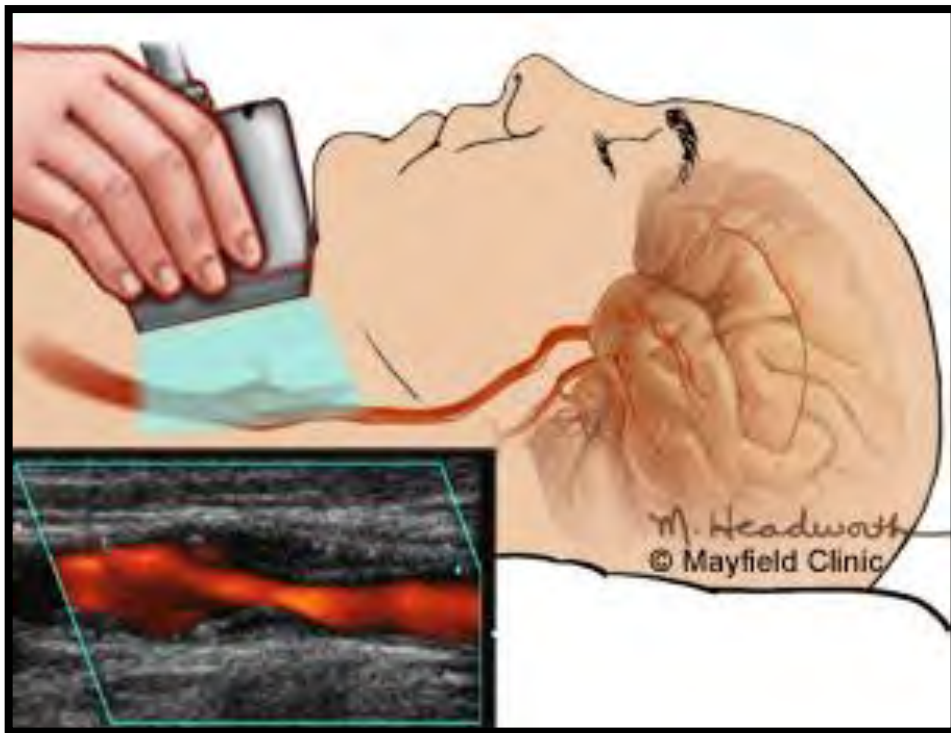
A man having an echocardiogram



Carotid Doppler

Carotid Doppler allows your doctor to measure the speed of blood flow through your carotid arteries. It also gives us images of your carotid arteries. Your carotid arteries are those big arteries that go up each side of your neck. They take blood and oxygen to the front and side parts of your brain. During the Doppler you may hear a whooshing sound timed with your heartbeat. This is the sound the Doppler machine makes when blood moves through the artery. The Doppler test will take about 20 minutes.

A man having a carotid Doppler



www.mayoclinic.ca

ECG

An ECG (electrocardiogram) monitors your heartbeats for problems. Electrodes taped to your arm, legs, and chest record your heart's electrical signals. These electrical signals are what make your heart beat. The signals show up as waves on an attached computer monitor or printer. An ECG takes just a few minutes. You will need to lie very still and breathe normally during the test. An ECG will give us a quick snap shot of how your heart is beating at that moment.

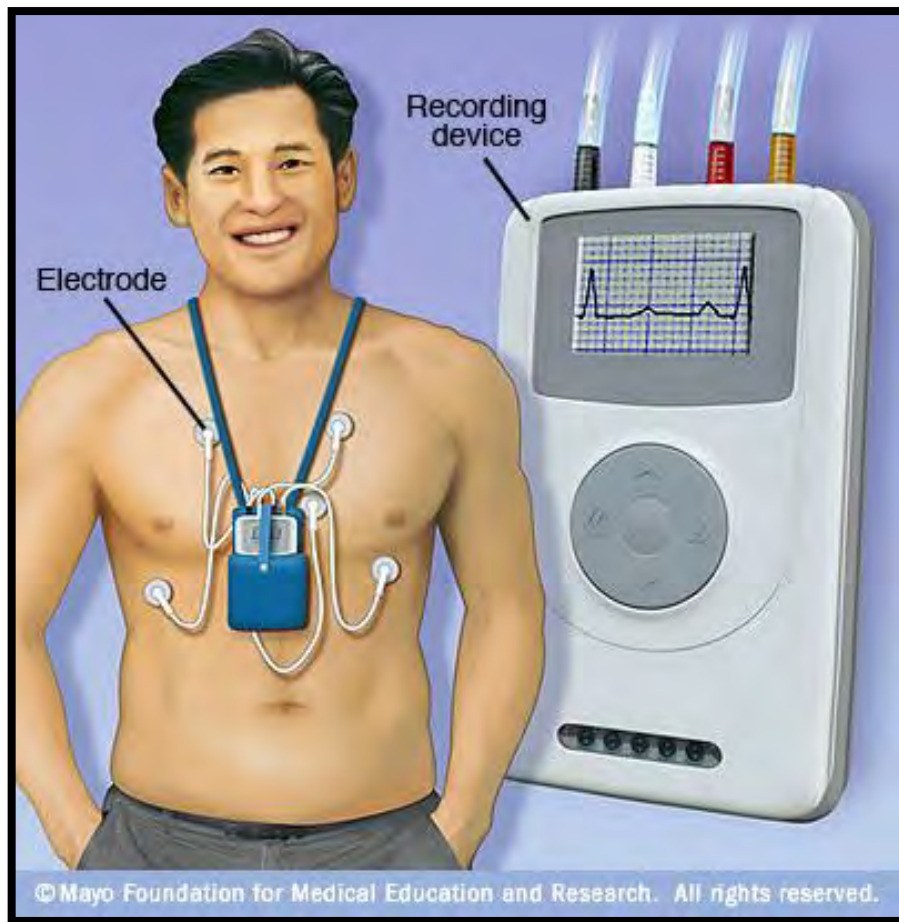
A man having an ECG



Holter Monitor

A Holter monitor uses electrodes and a small recording device to record your heart beats for 24 to 72 hours. Your doctor can use the information on the recording device to see your heart beats during the time you wore the monitor. It can help your doctor to know if your heart has a problem with the way it beats. Sometimes an irregular heartbeat can cause a stroke.

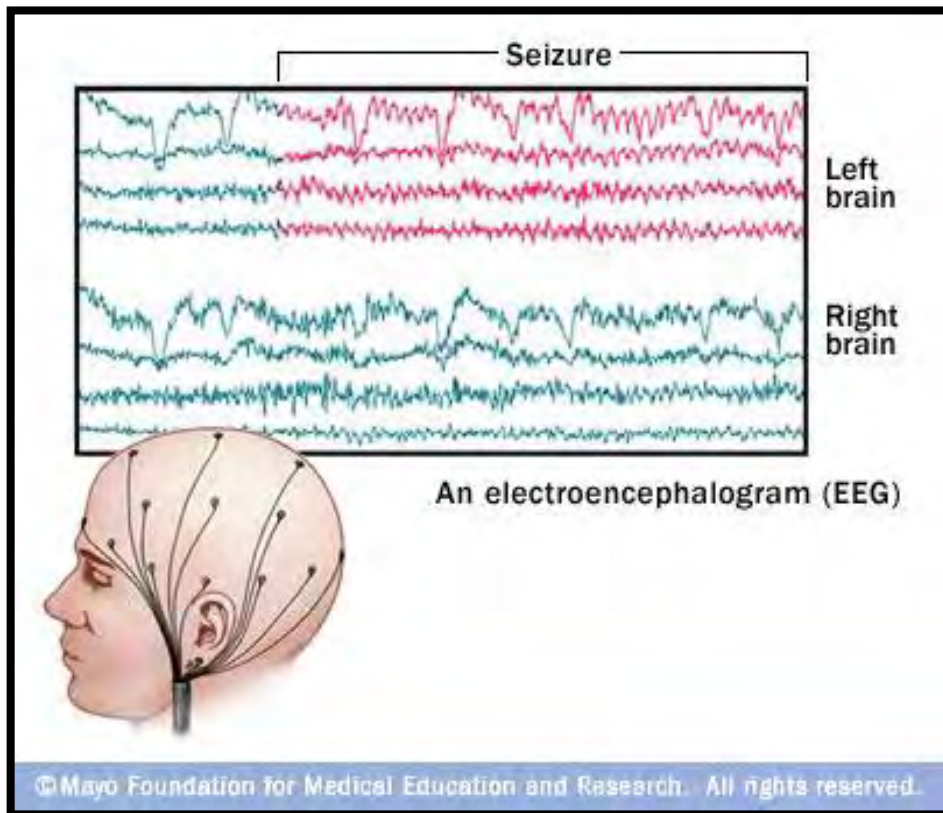
A man with a Holter monitor



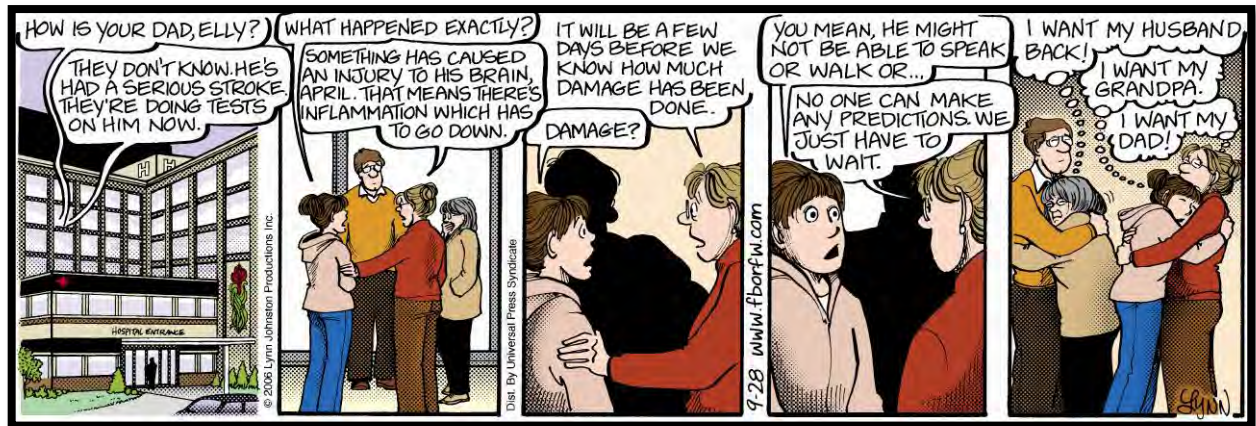
EEG

An EEG (electroencephalogram) records electrical activity of your brain by electrodes attached to your scalp with sticky paste. An EEG can show changes in your brain waves that might help in pinpointing brain problems. An EEG is often done in your room, and will take about 40 minutes.

EEG electrodes and brain waves



What is the Treatment for Stroke?



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Treatment after your stroke will depend in part, on what kind of stroke you had. You may remember from earlier in this guide that you can have a stroke from a blocked artery or from an artery bleeding into your brain. The treatments will be different for each. We also want to know why you had a stroke. Then we can decide what treatment we can use to reduce the risk that you might have another stroke.

When you first arrive at the hospital, the main goal of treatment for an ischemic stroke is to get blood flowing to your brain again. If you had an ischemic stroke (one caused by a blocked artery), we may have given you a medication called tPA (Tissue Plasminogen Activator). This medication is given in hopes of breaking up a clot that may have blocked your artery. If you got tPA then you spent the first 24 hours in the critical care unit before coming to the acute stroke unit. After that 24 hours is up the stroke team will meet you to start on your plan of care. Your healthcare team will talk with you about any plans.

Fatigue and Sleep

Fatigue is very common after a stroke. This may be due to damage to your brain and mental and physical activity. There are two types of fatigue after a stroke.

1. Body Fatigue:

- You need extra effort because of problems with things like walking and talking
- Your body needs time to heal itself and so you use your energy differently
- Being in the hospital will sometimes make it difficult for you to sleep
- If you already have chronic pain this may drain your energy
- You may be feeling the side effects of medication
- You will have tests, therapy, and visitors during the day

2. Brain Fatigue:

- Your brain may have trouble sorting out the things around you, such as music, people talking, television, and bright lights
- You may be swamped with feelings that cause you to be tired
- You may need to think longer in order to do things
- You may feel more tired because of depression. Depression is common after a stroke

Fatigue can be a problem for several reasons. Fatigue may make some of your stroke symptoms seem worse. It may make you feel weaker, your speech more slurred, and your swallowing weaker. It can also make you more emotional than usual. You and your family can talk about any of these things with your healthcare team.

To learn more go to Let's Talk About Stroke, page 41, at www.heartandstroke.com
or <http://www.strokeassociation.org/>

These are tips to help you feel less tired:

- Eat healthy and drink plenty of fluids
- Try taking naps during the day. Rest as long as you need to feel refreshed
- Do something you enjoy every day. Interact with friends, family, and other people
- Break up big tasks into smaller tasks
- Make a plan for your day and your week. If you know you have a busy day today, plan for a rest day tomorrow
- Stay physically active. As you become physically active you will have more energy
- Celebrate your successes. Give yourself credit when things are going well

Sleep

Good sleep is being able to fall asleep and stay asleep. It is important to your recovery because it helps your brain to heal. It gives your mind and your body energy. If you have poor sleep you have trouble falling asleep and may not stay asleep. You will feel tired during the day and have more trouble concentrating. There are things that can help, such as medications and relaxation therapy. Ask your healthcare professional.

Sleep Apnea

Some people have poor sleep because of a medical condition called sleep apnea. This is when there are pauses in your breathing while you sleep. When your breathing pauses you wake up because your body is not getting enough oxygen. Sleep apnea is a risk factor for stroke. You should talk to your doctor if you or your family notices these signs of sleep apnea:

- You snore loud enough to disturb your sleep or others
- You wake up feeling short of breath or with headaches
- You feel very tired and get sleepy during the day

Pain after Stroke

Pain can be a common problem after stroke. There are different types of pain you could experience after a stroke. Weakness on one side of your body is one of the most common effects of stroke. This can lead to painful conditions such as muscle stiffness (spasticity) and shoulder problems. Pain may last for some time, but things such as medication and physiotherapy can often help.

We can teach you and your family how to position your weak arm to lessen pain, stiffness, and prevent injury to your shoulder. Correct positioning is important because it can help reduce the strain on your ligaments and your shoulder joint. We can support your arm on pillows.

Physiotherapy will help to stretch your muscles and keep them flexible. The physiotherapist may give you some passive exercises that you can do with your family. If you find you are still having stiffness, you may be given medication to help reduce this stiffness and the pain that goes along with it.

To learn more go to

Let's Talk About Stroke, page 38, at www.heartandstroke.com

Communicating After a Stroke

We usually think of communication as talking with someone. It also involves reading, writing, and understanding what others are saying. After a stroke, you may find it hard to find the right word or notice your speech is garbled. You may even have trouble reading and writing.

When your family and friends are speaking with you, they should:

- Be patient by listening and waiting for you to speak
- Accept speech or grammar that isn't perfect
- Avoid correcting you if your idea is clear
- Focus on your tone of voice, body language, and the topic to help figure out what you mean
- Ask yes or no questions or offer a choice of two answers ("are you hot or cold?")
- Use short sentences
- Speak slowly and use plain and simple words
- Be patient and relaxed while communicating with you
- Allow extra time for you to process the information and work out a response
- Help you with a word you appear to be stuck on, by asking what it looks like, where it is found and what it is for
- Encourage you to write down a word or draw if you can

To learn more go to

The Aphasia Institute at www.aphasia.ca

or York-Durham Aphasia Centre at <http://www.marchofdimes.ca>

Feelings You Might Have and Coping with Emotions

Right after a stroke, your feelings may make you respond one way, yet weeks later respond in a different way. You may react with sadness or be cheerful. These emotions may happen because of changes due to your stroke. Some changes are because of the actual injury and chemical changes to the brain. These changes may vary over time.

There are some common emotions after stroke:

- Breaking into tears that suddenly stop, for no obvious reason
- Laughing or crying when it doesn't match your mood or at unusual times
- Frustration
- Anger
- Depression or sadness
- Lack of motivation

What can help you cope with changing emotions?

- Don't feel guilty about how you feel
- Talk to people who understand.
- Ask the staff about a support group
- Celebrate your gains, both small and large
- Get enough rest
- Ask for help

Chapter 4

Getting Ready to Leave the Hospital



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Getting ready to leave the hospital can be confusing and stressful. This chapter of the guide will help you get ready for next steps.

This Chapter at a Glance:

- Warning Signs of Stroke
- Risk Factors for Stroke
- Nutrition after Stroke
- My Health Action Plan
- Medication after Stroke
- Discharge Destinations
- Getting Ready for a Successful Discharge
- Driving After a Stroke

Warning Signs of Stroke

The warning signs of stroke are the brain's way of telling you that it is under attack. The warning signs will be different depending upon what part of your brain is in trouble. Not everyone will have the same warning signs.

If you or someone else, has any of these signs call 911 immediately!

Warning signs of stroke

RECOGNIZE A STROKE & REACT, CALL 911!
Someone's life could be in your hands.

Sudden dizziness
Perte soudaine de l'équilibre

Sudden weakness
Faiblesse soudaine

Sudden trouble speaking
Difficulté soudaine d'élocution

Sudden vision problems
Problème de vision soudain

Sudden headache
Mal de tête soudain

SI VOUS RESSENTEZ UN DE CES SIGNES, COMPOSEZ LE 9-1-1!
La vie d'une personne pourrait être entre vos mains.

Risk Factors for Stroke

A risk factor is something that may increase your chance (risk) of having a stroke.

We can't change some risk factors:

- A family history of stroke
- Being over 55
- Race
- Gender – men have a higher risk of stroke than women

After your stroke, we will work with you on your risk factors. We call this secondary prevention. We hope to lower your risk of having another stroke in the future. There are some risk factors we can work on together:

- High blood pressure
- Smoking or being around second hand smoke
- High cholesterol
- Diabetes
- Being overweight
- Heavy drinking
- Obstructive sleep apnea (a problem with sleep that makes your oxygen levels drop on and off during the night)

While you are in the hospital, we will talk with you more about your risk factors and start your action plan to help you manage them.

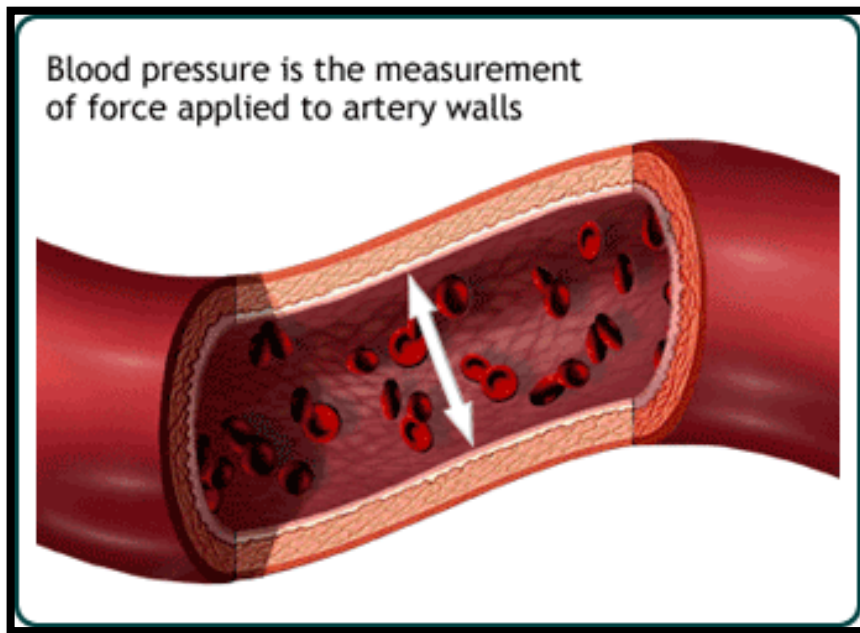
Let's look at some of those risk factors

Blood Pressure

Let's look at the facts about blood pressure, so that you can understand how your body works and why it is a good idea to start protecting yourself.

Your brain needs oxygen to survive. Blood carries oxygen to your brain. When your heart beats, it pushes your blood through special tubes, called arteries. Blood pressure is the force of blood pushing out on your artery walls. The pressure happens in two stages, the first is when blood pumps out of your heart into your arteries, the top number of your blood pressure. The second happens when your heart rests in between beats, the bottom number of your blood pressure. This is what we call blood pressure.

Blood pressure is the force pushing on artery walls



<http://www.cdc.gov/bloodpressure/about.htm>

High Blood Pressure

High blood pressure, also called hypertension, means there is too much pressure in your arteries. Over time, high blood pressure can damage your arteries. By keeping your blood pressure healthy, you are doing several things:

- Lowering the risk of your arteries becoming stretched and injured
- Making sure that your entire body gets blood that is rich in oxygen
- Lowering the amount of work your heart must do
- Lowering your risk of stroke and heart attack

You may not feel any different when you have high blood pressure. However, if your blood pressure gets very high, you may have a headache or feel anxious. While in the hospital, we will give you some medication to help manage your blood pressure.

You will need to keep taking your medication and get your blood pressure checked on a regular basis once you leave the hospital. If you have a reaction to your medication, call your doctor. Do not stop taking your blood pressure medication unless the doctor tells you to.

There are things you can do to prevent or lower high blood pressure. You will find information about many of those things in this guide.

To learn more go to <http://www.hypertension.ca/chep/>

Blood Pressure Numbers

DIAGNOSIS	STSTOLIC READING (TOP NUMBER)	DIASTOLIC READING (BOTTOM NUMBER)
NORMAL	LESS THAN 120	LESS THAN 80
PREHYPERTENSION	120 - 139	80 - 89
HYPERTENSION	STAGE 1 140 - 159 STAGE 2 160 & HIGHER	STAGE 1 90 - 99 STAGE 2 100 & HIGHER
HYPERTENSION EMERGENCY *GET MEDICAL ATTENTION NOW*	GREATER THAN 180	GREATER THAN 120

It is important to know your blood pressure numbers. There is a place on page 105 of this guide for you to keep track of your blood pressure numbers. Visit your family doctor to have your blood pressure checked on a regular basis, and take this guide with you. Your doctor or other healthcare professional can write your blood pressure numbers in it for you. Talk to your doctor about how you can check and keep track of your blood pressure at home.

Smoking

Smoking or being around second-hand smoke can increase the stickiness of your blood. This makes it hard for your heart to move the blood through your body. It makes your heart work harder and can lead to high blood pressure. The chemicals from smoking cigarettes cause cholesterol to stick to the walls of your arteries. This is sometimes called “hardening of the arteries”. Nicotine in cigarettes can cause clots to form in your blood. Smoking lowers the amount of oxygen in your blood, so less blood gets to your brain.

You will lower your risk of stroke right away if you quit smoking and are no longer around second-hand smoke. If you are thinking about quitting while you are in the hospital we can help you get started. So let someone on your healthcare team know.

Here are a few tips that might help:

- Figure out when you tend to smoke
- Once you figure out when you tend to smoke, you can keep your hands and mouth busy by drinking water, eating a healthy snack or taking a walk
- Make your home and car smoke free zones
- Ask for help

To learn more go to

<http://www.smokershelpline.ca>

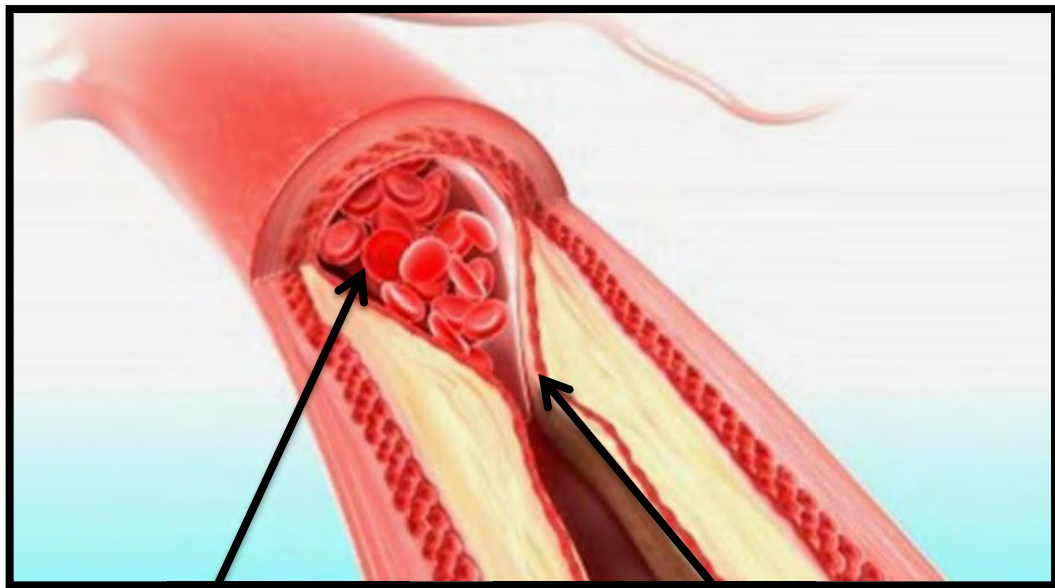
<http://www.heartandstroke.com>

<http://www.lung.ca>

High Cholesterol

Cholesterol is a waxy material made by your liver and put into your blood. Your body uses cholesterol for its building blocks, called cells. Cholesterol is stored in special proteins. There is “bad” cholesterol or LDL proteins (think L for lousy), which build up in your arteries when your blood levels are high. This can lead to high blood pressure. “Good” cholesterol or HDL proteins (think H for healthy) helps carry cholesterol away from your blood and artery walls. Triglycerides are a type of fat found with cholesterol in your blood and stored in fat all over your body. While you are in the hospital, we will measure these things by a blood test. When blood, fats like cholesterol, and other things build up on your artery walls this is atherosclerosis. Over time, deposits called plaques may form. The deposits may narrow, or block, your arteries.

Over time cholesterol builds up in your arteries and blocks blood flow.



<http://www.whydontyoutrythis.com>

Blood Cells

Cholesterol

What can you do to help manage your cholesterol?



1. Get your cholesterol tested
2. Be smoke free
3. Get physically active (check with your doctor before starting any exercise program)
4. Get to, and stay at your healthy body weight
5. Lower how much fat you eat. Limit your intake of fats found in red meat and high-fat dairy products (saturated fats)
6. Choose healthy fats mainly found in vegetable oils, nuts, and fish. These fats are called poly and monounsaturated fats
7. Use Canada's Food Guide to plan your healthy diet



Diabetes

Diabetes is a disease that causes your body to have trouble moving blood sugar or glucose out of your blood and into your body's cells. Your body uses blood sugar for fuel.

There are two main types of diabetes. Type I diabetes is usually diagnosed in children. It happens when your body is not able to make enough insulin. Insulin is what moves sugar out of your blood. About ten percent of people have type I diabetes. Most people have type II diabetes. This type of diabetes usually starts when you are an adult. In type II diabetes, your body makes enough insulin but is not able to use the insulin the way it should so your blood sugar levels go up.

Signs and symptoms of diabetes:

- Unusual thirst
- Frequent urination
- Sudden weight change
- Blurred vision
- Cuts and bruises that are slow to heal
- Frequent infections
- Tingling or numbness in your hands or feet

If you or your family notices, any of the signs of diabetes contact your healthcare

How is diabetes a risk for stroke?

When your blood sugar level goes up it causes your blood to become thicker or stickier. This makes it hard for your heart to pump your blood through your arteries.

Many people who have diabetes also have other health problems that increase their risk for stroke. Two out of three adults with diabetes also have high blood pressure and high cholesterol.

To learn more go to

www.diabetes.ca/diabetes-and-you/what/facts/

www.ontario.ca/diabetes

Maintaining a Healthy Body Weight

Being overweight can put a strain on your heart. It can also make you more likely to have high cholesterol, high blood pressure, and diabetes. All of these things can increase your risk for stroke. Maintaining a healthy weight by eating healthy, being active and following your action plan are important ways you can lower your risk of having another stroke.

Alcohol Intake

Studies have found that drinking lots of alcohol can play a part in stroke. For example, having more than two drinks in a day may increase your stroke risk. Scientists are still figuring out just how drinking alcohol may increase your risk of stroke. Ask your healthcare professional about drinking and your risk of stroke.

Nutrition after Stroke

Healthy food habits can help you reduce three risk factors for stroke. These are high cholesterol levels, high blood pressure, and excess weight. Diets that are high in saturated fat, or trans-fat and cholesterol can raise blood cholesterol levels. Diets high in salt can add to increased blood pressure and high calorie diets can add to weight gain. A diet with five or more servings of fruits and vegetables per day may reduce the risk of stroke. Follow Canada's Food Guide for help.

Some stroke survivors have a loss of appetite. Others may have problems swallowing or limited hand or arm movement. While you are in the hospital, you can speak with the dietitian to help teach you about a brain healthy diet. Research shows a brain-healthy diet is rich in the following foods:

- Beans and legumes
- Vegetables
- Fruits
- Fish (salmon, albacore tuna, mackerel, herring, or trout, all are rich in omega 3 fatty acids)
- Whole-grain, high-fiber foods
- Dairy: Fat-free and low-fat (1%) products
- Lean meats like skinless poultry

To learn more go to

www.hc-sc.gc.ca www.healthcheck.org,

www.sodium101.ca www.dietitian.ca

Important Nutrition Information from Health Canada



Using the Nutrition Facts Table: % Daily Value

How to CHOOSE

The Nutrition Facts table gives you information on calories and 13 core nutrients. Use the amount of food and the % Daily Value (% DV) to choose healthier food products.

Follow these three steps:

1 LOOK at the amount of food
 Nutrition Facts are based on a specific amount of food (also known as the serving size). Compare this to the amount you actually eat.

2 READ the % DV
 The % DV helps you see if a specific amount of food has a little or a lot of a nutrient.

5% DV or less is a **LITTLE**
 15% DV or more is a **LOT** } This applies to all nutrients.

3 CHOOSE
 Make a better choice for you. Here are some nutrients you may want...

- | | |
|---|---|
| less of | more of |
| <ul style="list-style-type: none"> • Fat • Saturated and trans fats • Sodium | <ul style="list-style-type: none"> • Fibre • Vitamin A • Calcium • Iron |

Here is an example of how to choose:
 You are at the grocery store looking at yogurt. The small container (175 g) of yogurt you pick has a **little** fat (4% DV) and a **lot** of calcium (20% DV) – this is a better choice if you are trying to eat less fat and more calcium as part of a healthy lifestyle!

Yogurt

Nutrition Facts	
Per 3/4 cup (175 g)	
Amount	% Daily Value
Calories 160	
Fat 2.5 g	4 %
Saturated 1.5 g + Trans 0 g	8 %
Cholesterol 10 mg	
Sodium 75 mg	3 %
Carbohydrate 25 g	8 %
Fibre 0 g	0 %
Sugars 24 g	
Protein 8 g	
Vitamin A 2 %	Vitamin C 0 %
Calcium 20 %	Iron 0 %



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 Également disponible en français sous le titre : Utilisez le tableau de la valeur nutritive : % de la valeur quotidienne.
 HC Pub.: 100539
 Cat.: H164-127/2011E-PDF
 ISBN: 978-1-100-19881-1



How to COMPARE

Use the amount of food and the % Daily Value (% DV) to compare and choose healthier food products.

Follow these three steps:

1 LOOK at the amounts of food

Compare the amounts of food (also known as the serving sizes) in the Nutrition Facts tables.

Cracker A has 9 crackers and weighs 23 grams.

Cracker B has 4 crackers and weighs 20 grams.

Because the weights are similar, you can compare these Nutrition Facts tables.

Cracker A

Nutrition Facts			
Per 9 crackers (23 g)			
Amount	% Daily Value		
Calories 90			
Fat 4.5 g	7 %		
Saturated 2.5 g			
+ Trans 0 g	13 %		
Cholesterol 0 mg			
Sodium 280 mg	12 %		
Carbohydrate 12 g	4 %		
Fibre 1 g	4 %		
Sugars 0 g			
Protein 3 g			
Vitamin A 0 %	Vitamin C 0 %		
Calcium 2 %	Iron 8 %		

Cracker B

Nutrition Facts			
Per 4 crackers (20 g)			
Amount	% Daily Value		
Calories 90			
Fat 2 g	3 %		
Saturated 0.3 g			
+ Trans 0 g	2 %		
Cholesterol 0 mg			
Sodium 90 mg	4 %		
Carbohydrate 15 g	5 %		
Fibre 3 g	12 %		
Sugars 1 g			
Protein 2 g			
Vitamin A 0 %	Vitamin C 0 %		
Calcium 2 %	Iron 8 %		

2 READ the % DVs

Since you are comparing crackers, you may want to look at the % DVs for saturated and trans fats, sodium and fibre.

Cracker A has 13% DV for saturated and trans fats, 12% DV for sodium and 4% DV for fibre.

Cracker B has 2% DV for saturated and trans fats, 4% DV for sodium and 12% DV for fibre.

Remember: 5% DV or less is a little and 15% DV or more is a lot. This applies to all nutrients.

Did you know?

You may be able to compare products that don't have similar amounts of food.

For example, you could compare the % DVs of a bagel (90 g) to the % DVs of 2 slices of bread (70 g) because you would most likely eat either amount of food at one meal.

3 CHOOSE

In this case, **Cracker B** would be a better choice if you are trying to eat less saturated and trans fats, less sodium and more fibre as part of a healthy lifestyle.

Use the Nutrition Facts table and *Eating Well with Canada's Food Guide* to make healthier food choices.



 **DAILY VALUE** healthy Canadians.gc.ca/dailyvalue

My Health Action Plan

Good health doesn't just happen. It is the result of healthy living each day. You can use the information in this guide to decide where you would like to make changes in your life. Then follow three simple steps to design your Health Action Plan.

Step 1

List the areas you would like to work on.

Step 2

Write a **SMART** goal to reach your target. **SMART** goals are:

Specific - Be clear about what you want to accomplish

Measurable - You need to be able to measure what you want so that you can manage it

Achievable - Set goals that you can reach

Realistic - Choose goals that mean something to you

Time-bound - Set a time line, have a start and a stop date

Step 3

Start your Action plan.

For example; if you are interested in fitness, instead of saying, "I want to be more active," write...

- Specific: I will get 20-30 minutes of moderate activity, 3-5 days a week

- Measurable: I will log my daily activity and do at least 120 minutes of activity a week
- Achievable: I will use my friend as an exercise buddy
- Reward: If I meet my goal for 6 weeks, I will treat myself to a relaxing massage
- Time-bound: After 8 weeks, I'll look at my goals and make changes as needed to meet my goal of 3 hours of exercise each week

My **SMART** Health Action Plan

Specific:

Measurable:

Achievable:

Realistic:

Time-bound:

Tips to help reach your goals:

1. Focus on one goal at a time. Taking on too much can lead to failure
2. Pick something you are ready to tackle
3. Start with small steps. Set goals you think you can reach
4. Keep track of your progress daily
5. Be optimistic. You can do it

MEDICATIONS REVIEW

After your stroke, you may start taking new medication. We use some of these medications to help lower the risk of having another stroke. We call this secondary prevention. Below you will see a list of some of those medications. You may not be taking all of these medications, or may be taking different ones, so please ask your healthcare professional which medications you are taking.

Types of Medication	What does it do?	Side Effects
<p>Platelet Inhibitors</p> <ul style="list-style-type: none"> • Acetylsalicylic acid, ASA (Aspirin, Entrophen, Novasen) • Clopidogrel (Plavix) • Dipyridamole XR/ASA (Aggrenox) 	<p>Stops platelets from sticking together</p>	<p>Increased risk of bleeding</p>
<p>Anticoagulants</p> <ul style="list-style-type: none"> • Warfarin (Coumadin) • Dabigatran (Pradax) • Rivaroxaban (Xarelto) • Apixaban (Eliquis) 	<p>Used to prevent blood clots</p>	<p>Increased risk of bleeding</p>
<p>Ace Inhibitors</p> <ul style="list-style-type: none"> • Enalapril (Vasotec) • Perindopril (Coversyl) • Quinapril (Accupril) • Ramipril (Altace) 	<p>Lowers risk of stroke and heart attack</p> <p>Lowers high blood pressure</p>	<p>Dry cough</p> <p>Rarely, an allergic reaction can happen causing swelling and shortness of breath</p>

Types of Medication	What does it do?	Side Effects
Angiotension II Receptor Blockers <ul style="list-style-type: none"> • Candesartan (Atacand) • Irbesartan (Avapro) • Losartan (Cozaar) • Valsartan (Diovan) 	Lowers high blood pressure Lowers risk of stroke and heart attack	Rarely, an allergic reaction can happen causing swelling and shortness of breath
Beta Blockers <ul style="list-style-type: none"> • Atenolol (Tenormin) • Carvedilol (Coreg) • Metoprolol (Lopressor) • Bisoprolol (Monacor) 	Lowers blood pressure and heart rate Keeps your heart beat regular Helps prevent and treat angina Helps prevent future heart attacks	Dizziness or light headedness Slight drowsiness Trouble sleeping Unusual tiredness or weakness Vivid dreams
Calcium Channel Blockers <ul style="list-style-type: none"> • Amlodipine (Norvasc) • Diltiazem (Cardizem, Tiazac) • Nifedipine (Adalat) • Verapamil (Isoptin) 	Lowers high blood pressure Helps prevent and treat angina May keep your heart beat regular	Headache Constipation Ankle Swelling
Diuretics <ul style="list-style-type: none"> • Hydrochlorothiazide (Apo-Hydro/Novo-Hydraside) • Indapamide (Lozide) 	May lower risk of stroke Lowers high blood pressure	May lower potassium levels in your blood
Lipid Lowering Agents <ul style="list-style-type: none"> • Atrovastatin (Lipitor) • Pravastatin (Pravachol) • Simvastatin (Zochor) • Rosuvastatin (Crestor) 	Lowers total cholesterol, bad cholesterol (LDL), and triglycerides	Rarely, may cause muscle pain & weakness or liver problems

Discharge Destinations and Planning

Shortly after you come into hospital, the healthcare team will begin to work with you and your family to plan for your discharge. We will gather information that will help us get to know you and to set your discharge goals. Once your doctor feels you are medically ready to be discharged, you, your family, and the healthcare team will make the best plan possible based on your needs. Below you will find information about all the possible discharge destinations.

Home

You could be discharged home with or without Community Care Access Centre services, based on your needs. The healthcare team will always include you and your family in planning your discharge destination.

Rehabilitation

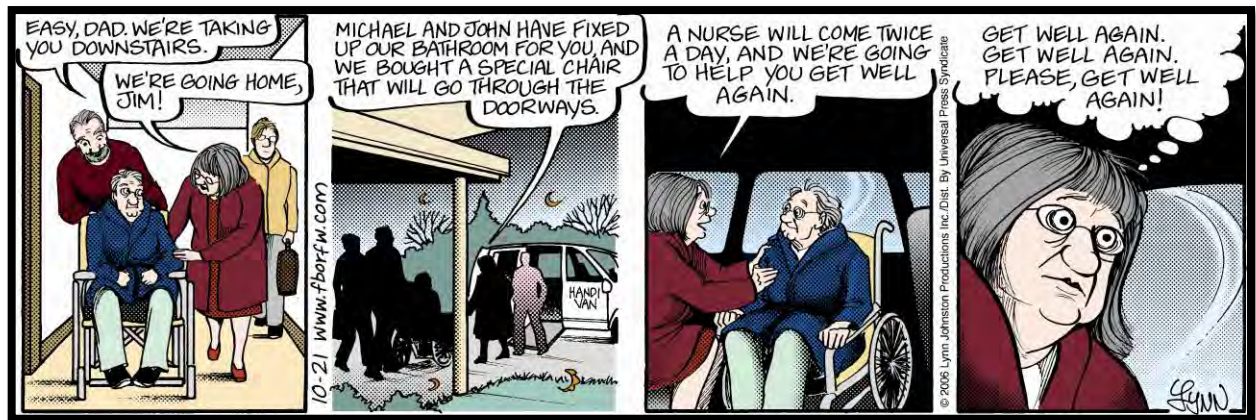
Inpatient Criteria

- You must be medically stable
- You are making progress with PT and OT in the hospital
- You can show an ability to learn
- You are able to take part in 2-3 hours of therapy daily
- You are interested and willing to take part in rehabilitation

Long Term Care

- You require personal care and/or 24-hour supervision
- You are unable to return home or to another residential setting
- You are unable to meet the criteria for an active inpatient rehabilitation program

Getting Ready for a Successful Discharge



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A successful discharge involves many things:

1. You are medically stable (that means no serious illness)
2. You have somewhere to live that you can get into and out of and have access to all the areas of the home that you need (such as the bathroom)
3. You have the care and support you need available
4. You know about the equipment you need, such as a walker or grab bars in the bathroom.
5. Equipment is ordered
6. You will have started to work on gaining back your strength
7. You and your family will have started learning about the way your body has changed
8. You know who to call if you have questions
9. You or a loved one have completed the discharge checklist on page 67

Your healthcare partners will start planning your discharge with you and your family very early in your hospital stay. Part of what we do is helping to prepare you to get back to your life.

After a stroke, many people expect that they will stay in hospital until they are completely better. You may think that you won't leave the hospital until you have fully recovered. Actually, that is not the case. When you leave, you will still be recovering. Since recovery can continue for a long time after a stroke, you are likely to continue to gain abilities after you leave hospital. When you return to the community, you will find yourself applying the skills you learned in hospital to everyday activities. You will continue to grow in terms of strength, skill, knowledge, and confidence.

Will you feel completely ready to go?

Maybe not

Will you have some worries and doubts?

Probably

Will it be hard to give up the security of having a healthcare team on hand?

Possibly

Will there be some challenges once you leave hospital?

Very likely

Will you and your family feel uncertain about how you will all cope?

Perhaps

Remember that there is always help available when you leave the hospital. You are not alone.

Discharge Planning Checklist

This checklist is for you and your family to use as you get ready to leave the hospital. Use this checklist early and often during your stay. Talk to your healthcare team and look at the items on this checklist together.

Action Items	Notes
<input type="checkbox"/> I have been involved in decisions about what will take place after I leave Kingston General Hospital.	
<input type="checkbox"/> Have we talked about advanced care planning? <input type="checkbox"/> Have I made my wishes known? <input type="checkbox"/> Have I asked someone I trust to be my substitute decision maker? <input type="checkbox"/> Do I have my wishes written down?	
<input type="checkbox"/> I understand where I am going after I leave hospital and what will happen once I get there.	
<input type="checkbox"/> I have asked my healthcare team about what I can do to help myself.	
<input type="checkbox"/> I understand what problems to watch for and what to do about them.	
<input type="checkbox"/> I have listed my medication in chapter 7. I have included prescriptions, over-the-counter drugs, vitamins, and herbal supplements.	
<input type="checkbox"/> I have circled the things I need help with and have talked to my healthcare team about them. <ul style="list-style-type: none"> • Bathing, dressing, using the bathroom, climbing stairs. • Cooking, food shopping, house cleaning, paying bills, picking up medication. • Getting to appointments. 	

<input type="checkbox"/> The healthcare team has shown me tasks that require special skills. I have practiced these skills.	
<input type="checkbox"/> I have asked for written discharge instructions (that I can read and understand), and a copy of my discharge summary. I will bring this information and this guide to all my follow-up appointments.	
<p>When I go to any healthcare appointment I will ask these 3 questions:</p> <input type="checkbox"/> What is my main problem? <input type="checkbox"/> What do I need to do? <input type="checkbox"/> Why is it important for me to do this?	
<p>I have asked about driving:</p> <input type="checkbox"/> When can I drive again? <input type="checkbox"/> What do I need to do to drive again?	
For Your Caregiver	Notes
<p>Can I give my loved one the help he or she needs?</p> <input type="checkbox"/> What tasks do I need help with? <input type="checkbox"/> Do I need any education and training? <input type="checkbox"/> I have talked to the healthcare team about getting the help I need. <input type="checkbox"/> I understand the plan. <input type="checkbox"/> I have a name and phone number to call if I have questions.	
<input type="checkbox"/> I have prescriptions so I can go directly home.	
<input type="checkbox"/> Members of the healthcare team have answered my questions.	
<input type="checkbox"/> I have a booked follow-up appointment with the doctor. <input type="checkbox"/> Neurologist <input type="checkbox"/> Family doctor	

Driving After a Stroke

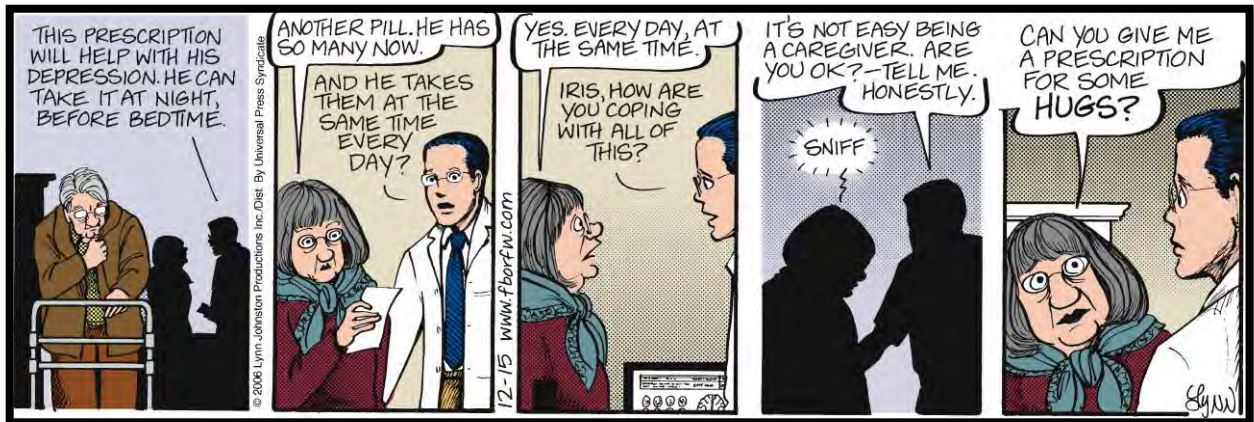
Driving is a means of independence that many people value. It is a skill that is physically and mentally demanding. It calls for concentration, attention, quick judgment, vision, and endurance. A stroke can affect any or all of these things. It can affect your ability to be safe while driving.

What You Should Know About Driving After a Stroke?

- You cannot drive for at least one month
- Your doctor must assess your readiness to drive before you can drive again
- There are ways that you could modify your vehicle so that you might be able to drive after your stroke, if your doctor says you are ready
- You can drive again if you have no major changes in:
 - Your vision
 - Your physical skills
 - Your thinking, such as problem solving or judgment

Chapter 5

Taking Care While Caregiving



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This chapter at a glance:

- You are not alone
- Lessons learned by past caregivers
- Be ready for a visit to the emergency room
- Support for caregivers
- Caregivers' bill of rights
- How to talk to healthcare professionals
- Training for caregivers
- Helpful information
- What your loved one may be feeling
- Websites you can rely on

You Are Not Alone

One becomes a caregiver suddenly and the adjustment to that role is often rocky. It can take a long time and in fact may never be complete for some. Your role as a caregiver is important to the health of your loved one. As a caregiver, you may find this role rewarding and satisfying. You may feel pride in all that you have accomplished or pleasure in being able to maintain your loved one's dignity, and a sense of strength. It can also be challenging and frustrating and you may feel angry, and uncertain.

Always remember that you are not alone.

As a caregiver, you are strong and courageous. You will be expected to take on new and challenging responsibilities. It is important for everyone, including you to know that this role is valuable. You will have a big impact on your loved one's care and comfort. Sometimes, accepting this can be difficult as attention is directed towards the person with stroke.

The needs of your loved one will probably take up most of your thoughts. But, as a new caregiver, you must learn the number one rule of caregiving - **you need to look after yourself**. Otherwise, the quality of care that you are able to give, your relationship with the person you are caring for, and the quality of your own life may suffer. If you make a point of looking after your own needs as well as the needs of others you will be happier and healthier. You will also be a better caregiver.



Most caregivers learn “on-the-job”. Here are some lessons learned and shared by past caregivers.

1. Join or start a support group.
2. Educate yourself and your family. Learn all that you can. Arming yourself with knowledge will help you to anticipate and prepare for changes that might happen.
3. Know your rights as a caregiver.
4. Prepare a list of questions for your healthcare professionals.
5. Focus on quality of life. Plan activities in which you can both participate. Remain positive. This allows you to connect with each other outside the caregiver role.
6. Stay organized. Keep a dedicated calendar that can easily go with you to all your appointments. Keep track of appointments, start, and stop dates for medication, and what they are for. Include any allergies.
7. Make a list of phone numbers and addresses in case of an emergency. List phone contacts and indicate who to call first.
8. Ask for help! No one is able to care for someone 24 hours a day by himself or herself. Put together a list of family and friends that you can rely on to relieve you.
9. Take care of yourself. Eat healthy and get plenty of rest. Don't stop enjoying life. Resume your previous life as much as possible, while you discover your new life together.

Be Ready for a Visit to the Emergency Room

1. Know when to go to the emergency room.
2. Pack a “just in case” bag for your loved one with personal items, extra clothes, books etc. Keep it tucked away in a closet and ready for use.
3. Pack a caregiver bag with a change of clothes and your personal items, pad of paper and pen, books etc. Keep it ready to use.
4. Bring all your loved one’s current medications.
5. Bring this guide to record what is happening, and show it to the healthcare professionals so that they can know what has happened already.
6. Be prepared to speak up for your loved one. You know what is normal for them. Share your concerns and information. Be polite but firm and be cooperative.
7. Ask questions and write the answers down.
8. Remain calm and patient.
9. Call a friend or family member to let them know where you are going.

Before you leave the emergency room make sure that you have clear discharge instructions (such as your prescription for any new medications, how and when to take those medications, and any follow-up appointments). Read any instructions before you leave and ask questions if you don’t understand something.

Support for Caregivers

While being a caregiver to your loved one you may need different types of support. You might need information, someone to talk to, and training for things you need to do as a caregiver.

Here are some tips that might help:

- Get help early, so that your loved one will get used to having other people around
- Involve other family members from the beginning
- Learn as much as possible about stroke
- Learn to accept your feelings, they come from being tired and from the losses you are experiencing
- Join a support group as soon as you can, remember that you are not alone
- Accept that you are not perfect
- Look after yourself and be kind to yourself
- Take one day at a time

This list might set you on the path to thinking about your support needs:

- What supports do you need right now?
- Where can you get this support? Get a list of resources available. Ask friends, family, or your healthcare professional. Check the list on page 108 in this guide
- What should you try first? Start with trying just one thing
- How did the support you tried work for you?
- If this didn't work what else should you try? Try another resource on your list

What Can You Do to Deal with Your Feelings?

Feelings can be very complicated and you can feel overwhelmed by them. Your feelings are real. As a caregiver, you need to express your feelings in a setting that is safe and where you don't feel like you are being judged.

- Accept your feelings for what they are
- Release your feelings in a way that suits you; try to enjoy your hobbies
- Talk to your healthcare professional: your doctor, social worker, or nurse
- Talk to friends, family members or your spiritual advisor
- Add yourself to the list of people you care for

Allow yourself to feel all of your emotions, good and bad, and share these with your loved one. This may help you to understand what it is like for both of you and may make it easier for you to talk. Tell your other family members about your loved one's progress often. Tell them about things that you are having trouble with and why. Ask for help.

You can get support by talking with other caregivers. This can be done by joining a support group or by having a telephone buddy. Having someone to share your feelings with may improve your ability to cope with your day-to-day role. Peer support can be a good way to:

- Give you a chance to focus on yourself
- Relieve your stress
- Give you hope as you hear how others have coped
- Give you a chance to help others with your suggestions

Caregiver Bill of Rights

This powerful message first appeared in Jo Horne's book "Caregiving: Helping an Aging Loved One" (AARP Books, 1985). These points can be a source of comfort for any caregiver.

I have the right:

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one
- To seek help from others, even though my loved one may object. I recognize the limits of my own endurance and strength
- To maintain facets of my own life that do not include the person I provide care for, just as I would if he or she were healthy. I know that I do everything I reasonably can for this person and I have the right to do some things just for myself
- To get angry, be depressed and express other difficult feelings occasionally
- To reject any attempt by my loved one [either conscious or unconscious] to manipulate me through guilt, anger or depression
- To receive consideration, affection, forgiveness and acceptance for what I do for my loved one for as long as I offer these qualities in return
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full time help
- To expect and demand that as new strides are made in finding resources to aid persons living with illness, physical or mental challenges, similar strides will be made toward aiding and supporting caregivers

How to Talk to Healthcare Professionals

Past caregivers have said that right after the stroke they most wanted to know about:

- What has just happened?
- What does this mean for the health of my loved one?
- How is this going to change our lives?

Your need for information and support will change over time.

Here are some ideas that might help when you talk with your healthcare professional:

- Write down what you want to talk about, or get someone else to write it down for you
- Put the most important things first
- Give a copy of your list to your healthcare professional; don't wait for them to ask if you have any questions
- Write down the answers to your questions
- Take someone with you to your appointments if you think that you might not understand or remember everything that was said
- Let the healthcare professionals know if you are having problems

“Don't make assumptions. Find the courage to ask questions and to express what you really want. Communicate with others as clearly as you can to avoid misunderstandings, sadness, and drama”. Don Miguel Ruiz

Training for Caregivers

As a caregiver, you may need to:

- Help with doctor's appointments, medications, and exercises
- Look after banking and transportation
- Provide your loved one with physical, mental and emotional help
- Help your loved one with things such as personal care and bathing
- Plan your loved one's care, by setting routines and working with the care team
- Think about medical needs, talk with healthcare professionals, and ask for help



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Don't let this list frighten you. Remember you are not alone. When your loved one goes home, you can get help if you need it. The Community Care Access Centre (CCAC) may be able to help you plan and make informed choices about managing your health needs when you leave hospital. Not everyone will need CCAC services. The healthcare team at the hospital will speak with you and your loved ones and if needed, make a referral before discharge. Anyone, including you can make a referral to CCAC. See page 108 of this guide for CCAC contact information.

Helpful Information

This part of the guide will give you some information about things to be aware of once you leave Kingston General Hospital. Our hope is that once you are at home and continue to recover from your stroke, you stay there. But, sometimes people have problems that may mean a trip to your doctor or to the emergency room. If you know more about these problems, you may be able to avoid a hospital admission by going to your doctor or the emergency room as soon as you see signs of a problem. This list tells you about some of the most common reasons to get medical help.

Urinary Tract Infections

A urinary tract infection happens when bacteria grows in your urine. After a stroke a urinary tract infection can quickly turn into something more serious. Urinary tract infections can also cause an infection of the blood. After a stroke you could get a urinary tract infection for many reasons. You may not empty your bladder properly because you are not up and about as usual or maybe you are having trouble telling your caregiver that you need to go to the bathroom. Some people have problems controlling and emptying their bladder after a stroke. Symptoms of a urinary tract infection that mean you should call your doctor:

- Pain or burning feeling when going to the bathroom
- Needing to go to the bathroom often
- Urine that looks cloudy or smells bad
- Fever (temperature of 37.5°C or 99.5°F) with or without chills
- Drowsiness, confusion, or agitation
- Nausea and vomiting

Pneumonia

After a stroke, you have a higher risk of getting pneumonia. Pneumonia is a lung infection that can make you very sick. Swallowing problems after stroke can sometimes result in things 'going down the wrong way'. We call this aspiration. Aspiration can lead to pneumonia. Pneumonia causes breathing problems.

Signs of pneumonia to watch for are:

- Cough like when you have the flu or a cold
- Fever with or without chills
- Shortness of breath
- Chest congestion
- Changes in thinking or delirium
- Increased weakness
- Muscle or joint pain

If you or your family notices, any of these signs call your doctor immediately or go to the emergency room.

Dehydration

Sometimes after a stroke, you may not be eating or drinking the way you usually do. This means you can get dehydrated. When you are dehydrated, you are using more water than you are taking in. It is important to make sure that you take drinks often throughout the day.

Symptoms of mild to moderate dehydration include:

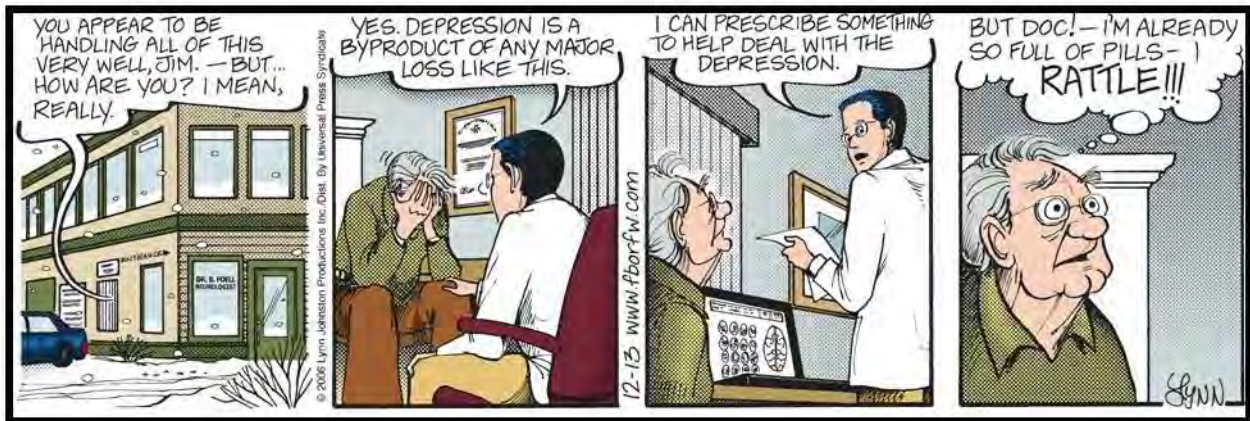
- Thirst and a dry, sticky mouth
- A drop in how much urine your body is making
- Dry skin
- Headache
- Constipation
- Dizziness or feeling light headed

Symptoms of severe dehydration include:

- Extreme thirst and a very dry mouth
- Your body has made little or no urine
- Skin is shriveled and very dry
- Fast heartbeat and breathing
- Fever
- Delirium (a sudden change in how you are thinking, usually temporary)

You can usually treat mild to moderate dehydration by drinking more fluids. If you have symptoms of severe dehydration, you need to get immediate medical care. Do this by going to the nearest emergency room or calling 911.

Depression



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Depression can be common after a stroke. It is a state of low mood. This may come from the loss of your previous self, work and social life, and the changing roles in your family.

You may have anxiety because your healthcare team can't tell you exactly what your future will be like. There are different degrees of depression. Often medication can help, and counseling is available. Tell your healthcare professionals; don't hesitate to ask for help.

Some of the symptoms of depression include:

- Loss of interest or no pleasure in activities
- Trouble sleeping at night, or sleeping a lot during the day
- Feelings of worthlessness or excess guilt
- Thoughts of death or suicide

Risk of Falling

Moving around safely and easily is not something you may think about, until you have a stroke.

Statistics show that 40 percent of all stroke survivors suffer serious falls within a year after their stroke.

The following tips may help you avoid falling and injuring yourself at home:

- Use nightlights in bedrooms, bathrooms, and hallways
- Make sure light switches are easily accessible
- Use bathmats with suction cups and non-adhesive strips in the tub
- Sit on a bench or stool in the shower and use a hand-held showerhead
- Don't walk around in stocking feet. Wear shoes or slippers that fit snugly
- Remove throw rugs and secure area rugs with double-sided tape
- Review medications with your doctor as some may cause dizziness and imbalance
- Ask for help
- If your physiotherapist has given you a mobility aid, such as a walker or a cane, use it
- Slow down and take all the time you need when walking

To learn more go to

http://www.thehealthline.ca/pdfs/OntarioFallsPreventionCommunityofPractice_Brochure.pdf



What Your Loved One May be Feeling

Just like you, your loved one is probably having many different feelings. This is because of the changes that are happening to them and to your family. To understand these feelings you need to know what they are. Talk to one another.



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Your loved one may be feeling:

- A sense of sadness and loss because of changes to their body
- A sense of losing control over life
- Anger and frustration towards their condition
 - These feelings may be directed at you
- Fear of losing friends
- Fear of being isolated, as they can't get around as easily and they once did

Websites You Can Rely On

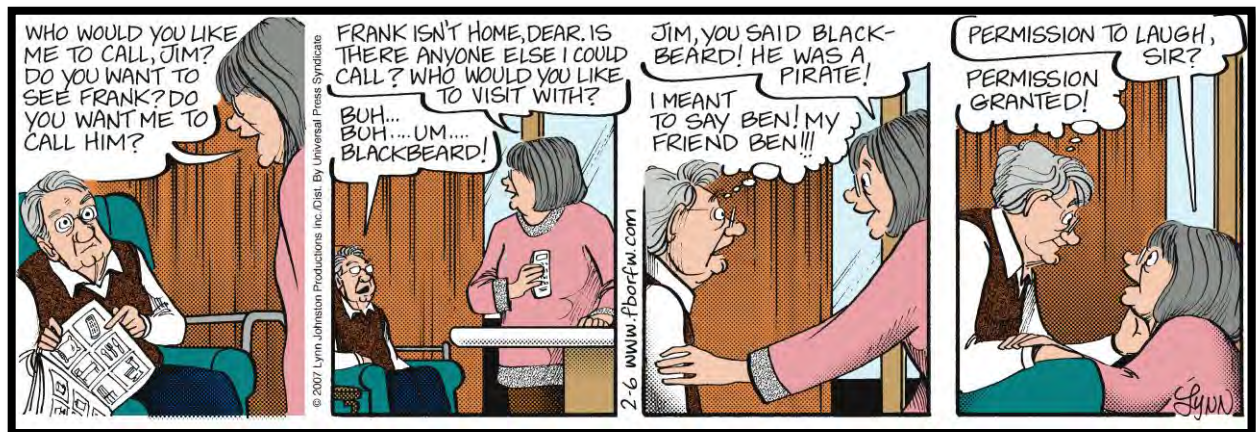
As time goes on you will think of more and different questions to ask. There are websites on the Internet that you can trust and that might have answers to some of those questions.

Below is a short list of websites that might help.

1	Canadian Best Practice Recommendations for Stroke Care	www.strokebestpractices.ca
2	Drug coverage.ca	http://www.drugcoverage.ca
3	Canada's Economic Action	http://actionplan.gc.ca
4	Community Care Access Centre	www.ccac-ont.ca
5	The Internet Stroke Center	http://www.strokecenter.org
6	Canadian Stroke Network	http://www.canadianstrokenetwork.ca
7	Heart and Stroke Foundation of Canada	http://www.heartandstroke.ca
8	National Family Caregivers Association	http://www.thefamilycaregiver.org
9	Stroke Recovery Canada	www.strokerecoverycanada.com
10	March of Dimes Canada	http://www.marchofdimes.ca
11	Life after stroke	http://www.lifeafterstroke.ca
12	Stroke Link (IPad app)	http://strokelink.ca/
13	Stroke Engine	http://strokengine.ca/
14	Victorian Order of Nurses	http://www.von.ca/en/caregiver

Chapter 6

Finding the Beauty in Life after Stroke



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“Whatever life takes away from you let it go. When you surrender and let go of the past, you allow yourself to be fully alive in the moment”. Don Miguel Ruiz

This Chapter at a Glance:

- Intimacy
- Leisure Activities
- Returning to Work
- Peer Support

Intimacy

Given all the things facing you as a stroke survivor, sexual intimacy may not seem important at the beginning. However, as you recover, sexual activity may once again be an important part of pleasure, relaxation, and intimacy.

There is no evidence to suggest that having sex will cause you to have another stroke. Having said that, you will find that your relationship with your partner has changed. You will need to explore this part of your relationship. You could look at this as a chance to reignite the spark between the two of you. Try to be creative and have fun.

Fatigue after stroke and a busy rehabilitation schedule may leave you feeling that a sexual relationship is not a priority. It takes a stroke survivor much more energy to do the everyday things like walking and dressing. You need to balance your activities and your rest carefully. You have the rest of your lives ahead of you, so take it one day at a time.

Some medications you are taking may affect your ability to have intercourse. If this is a problem, speak with your healthcare professional.

It is important to talk to your partner about how you feel about yourself and the way your body has changed. A stroke need not be a barrier to an active and fulfilling sexual relationship. If you have concerns about resuming your sexual activity consult your healthcare professional.

To learn more go to www.stroke.org.nz/resources/Sexuality-Booklet.pdf

Leisure Activities

Leisure is more than just the things we do in our spare time. It is an enjoyable and important part of our lives. There is life after a stroke. You can put the pieces back together. Life may be different but it can still hold pleasure and fun.

It is possible for you to do leisure activities, even if you still have some problems caused by your stroke. Sometimes it may be hard for you to do the exact same leisure activities that you enjoyed before your stroke. You may have to change your way of doing these things so that they are easier. Your occupational therapist can help you find devices that might help.

You may want to try something new. Support groups are a good way to share your experiences and learn new ideas. Speak with the members of a support group for ideas about how they spend their leisure time. Always talk to your healthcare professional before trying any new and strenuous activities.

Are you looking for ways to spend your leisure time?

Here are a few ideas:

- Arts and crafts – drawing or painting
- Days out – visiting art galleries or museums
- Gardening
- Music – listening to music or going to concerts
- Puzzles and games – jigsaw, crosswords, Sudoku or computer games
- Join a support group or volunteer as a peer support visitor at your local hospital
- Photography – taking photos or visiting galleries

Here are some steps to follow to help you find leisure activities that you might enjoy:

Step 1	<p>Think about the role of leisure in your life.</p> <ul style="list-style-type: none"> • Ask yourself how important your leisure activities are to you. • What was fun before your stroke? What makes you smile?
Step 2	<p>Decide how much enjoyment you get from your leisure activities.</p> <ul style="list-style-type: none"> • Look at how much pleasure you get and how you spend your free time.
Step 3	<p>Think about your leisure activities.</p> <ul style="list-style-type: none"> • What activities do you enjoy? • What activities do you do? • What activities did you used to do that you would like to start doing again? • When do you like to do activities, during the day or at night?
Step 4	<p>Think about what you want from the leisure activities.</p> <ul style="list-style-type: none"> • Why do you like one activity more than others?
Step 5	<p>Decide where, how and with whom you will spend your time.</p> <ul style="list-style-type: none"> • What problems do you have to deal with to be able to do the leisure activities? • Are there others who like the same things? Who do you like to do things with? • Can you call ahead to where you are going so they can be ready for you?
Step 6	<p>Look for different ways to carry out your leisure activities.</p> <ul style="list-style-type: none"> • Do you need special equipment? • Can you find another place for your leisure activity? • Did you talk to your healthcare professional for help?
Step 7	<p>Figure out other activities you might enjoy.</p> <ul style="list-style-type: none"> • The important thing may not be the activity but the enjoyment it brings to you!
Step 8	<p>Stick with it!</p> <ul style="list-style-type: none"> • Talk to your family and friends to tell them what you can and cannot do. They may need to learn new ways to do leisure activities with you.

Returning to Work

It's common for people to want to return to work after a stroke. There's the financial motivation, but there is also an emotional pull. A stroke can rob you of some of your self-worth. You may feel you are not the whole person you once were. But, if your work provides you with a lot of satisfaction, and your job is important to you, getting back to work can restore your self-worth. Always talk to your doctor before you try to go back to work.

If you return to work with an impairment that you didn't have before, things will be different. If you do return to work, have an honest discussion with your employer and co-workers so that they understand that you are easing back into work.

Help your employer prepare. Talk to them about what is happening. Several things that you might ask your employer to do could help you to continue to work:

- Allowing phased in return to work or "work hardening" programs
- Changing your work hours or allowing flexibility with your hours
- Part-time work or job sharing
- Arranging to work from home or doing a different job
- Helping to provide transport to and from work
- Changes to your work environment

Rather than thinking of changes made for you at work, as negative, understand that your employer thinks enough of you to find you a worthwhile place in the organization.

To learn more go to: <http://swostroke.ca/rtw-introduction/>



Peer support programs offer a chance for stroke survivors and their families to learn about stroke, stroke recovery, and things that help you cope, while meeting people who understand. Stroke survivors and caregivers have a chance to build skills that help them make decisions about their health and recovery. This is what we call self-management.

There are several goals of peer support programs. Some of those goals are to:

- Provide hope as you continue to recover
- Educate and support you as you gain self-management skills
- Help you to build ties with others who have lived through a stroke
- Share tips and tools with people who face similar challenges
- Help guide you through the healthcare system
- Learn and gain confidence in order to take charge of your life
- Help you to reach and continue with healthy lifestyles to prevent future strokes
- Provide information about community resources and updates as those resources change

To learn more go to:

www.heartandstroke.com

www.canadianstrokenetwork.ca

<http://strokenetworkseo.ca>

Each support group has a trained facilitator; this may be a social worker. A facilitator is someone who helps the group work together to support one another. The facilitator is a neutral person who does not take sides and can help the group be open and fair. The group facilitator can also help you to find your way through community services. The facilitator can help with referrals and make sure that the services are helping. Support groups are an excellent way to make sure that you are getting the right services from the right people.

Stroke support groups push people to get beyond their limitations. Social contact and feeling connected to others helps ease the feelings of being alone after stroke. One of the greatest benefits of a stroke support group is the chance to be around people with great attitudes. Stroke survivors often find that the can-do attitude of a strong stroke group is contagious and changes their experiences.

Some of the good that a support group does happens simply by people getting out of their homes. It helps just to see different faces and to hear different voices. If you have problems getting out of the house there may be monthly telephone support and possible home visits.

If you would like to be part of a support group you can contact the facilitator yourself when you are ready or we can pass on your telephone number to the facilitator for you and he or she will contact you in a few weeks' time.

To learn how to get in touch with your area support programs see page 108 of this guide.

Chapter 7

Notes and Other Resources

This section is for you or your family to make notes about questions, comments, or thoughts that you may have. This section may be useful to make a list of questions you wish to ask members of your healthcare team.

This section is also for you to plan and schedule appointments, keep track of tests and medications.

It also includes a list of resources available in the Kingston area.

This Chapter at a Glance:

- Notes
- Appointments
- Medication List
- My Blood Pressure Numbers
- Making an Emergency Plan
- Community Resources
- Glossary of Terms
- References










Appointments

Date	Time	Place	With Whom	Reason

MEDICATIONS REVIEW 	What does it do?	How to take it	When to take it			
			Morning	Noon	Evening	Bedtime
<i>Example: Aspirin</i>	<i>Reduces clotting of my blood</i>	<i>1 pill (81mg) once a day</i>	<i>X</i>			

My Blood Pressure Numbers

My blood pressure (BP) should be less than _____/_____mm/Hg.

Date	Time	BP reading # 1 (mmHg)		BP reading # 2 (mmHg)	
		systolic	diastolic	systolic	diastolic
<i>Example:</i>	<i>8:00am</i>	<i>128</i>	<i>76</i>	<i>126</i>	<i>68</i>

Making an Emergency Plan

An emergency plan is a back-up plan to use if you can't care for your loved one. It may be needed because:

- You get sick
- You have other important things to do
- You need a break from caregiving
- You have a personal emergency
- You need help managing
- Something you didn't plan happens, such as car trouble

Your back up plan will help you think about what you can do when the unexpected happens. A good plan will help to lower your worry during an emergency. It will name your back up person and how to reach them. It will also help you to think about things you may not have time to think about later (such as letting the dog out).

Make your plan with your loved one and talk to your emergency contacts a head of time.

My Emergency Plan

Name of Family Doctor: _____

Phone #: _____

Name of CCAC Care Coordinator:

Phone #: _____

Emergency (back up) contacts & supports:

Name: _____ Relationship: _____

Phone #: _____

Name: _____ Relationship: _____

Phone #: _____


Name: _____ Relationship: _____

Phone #: _____

Important things that my emergency contacts need to know:



Community Care Access Centre			
Brockville Office	613-283-8012 1-800-267-6041	Northbrook Office	613-336-8310
Kingston Office	613-544-7090	Selby Office	613-388-2488
Foot Care Providers			
Caracare Community Health Services			613-384-7557
Victorian Order of Nurses, Greater Kingston Location			613-634-7810
Help with Transportation			
Bryden Transportation Services for Seniors			613-541-9916
Kingston Access Bus Services			613-542-2512
Gananoque Wheels of Care			613-382-4831
Seniors Association Kingston Region			613-548-7810
Kingston Frontenac Lennox & Addington Public Health Services 613-549-1232 or 1-800-267-7875			
Dial-a-dietitian Free nutrition information over the phone, speak with a registered dietitian			Ext. 1224
Good Food Box Non-profit vegetable and fruit distribution system. Prices \$5-\$15			Ext. 1440

<p>Stay on Your Feet Injury prevention Information about fall risk and strategies to prevent falls, educational sessions for seniors and caregivers</p>	Ext. 1209
<p>Meals on Wheels</p>	
Land O'Lakes Community Services	613-336-8934
Meals on Wheels	613-634-0123
Seniors Association Kingston Region	613-548-7810
 StrokeUnderstood Support Groups	
Brockville and Area Support Group	613-342-3693 ext 2154 1-800-465-7646 ext 2154
Community Care for South Hastings Stroke support groups for South Hastings and Prince Edward counties	613-969-0130 www.ccs.h.ca
Kingston and Area Greater Kingston Site, VON	613-634-0130 ext 469 Kathleen.pratt@von.ca www.von.ca
Perth and Smith Falls Area Stroke Survivor and Caregiver Support Group	613-342-3693 ext 2154 1-800-465-7646 ext 2154



GLOSSARY

This is a list of some of stroke and medical terms you might hear during your stroke recovery.

Activities of daily living (ADLs): Activities a person performs for self-care (feeding, bathing, dressing), work, homemaking, and leisure.

Acute: Developing over minutes to hours.

Advanced directives: Legal documents that allow you to spell out decisions about your care ahead of time. They give you a way to tell your wishes to family, friends, and healthcare professionals and to avoid confusion later on.

Aneurysm: A permanent abnormal balloon-like bulging of an arterial wall. The bursting of an aneurysm in a brain artery causes a hemorrhagic stroke.

Anticoagulant: Medication used to reduce blood clotting.

Aphasia: A problem with communication because of damage to an area of the brain. A person with aphasia may find it hard to talk, read, write or understand others when they speak

Apraxia: Being unable to do a body movement because the brain has difficulty planning that movement.

Aspiration: When food, fluid or saliva goes into the windpipe.

Ataxia: Uncoordinated movements caused by a stroke.

Atherosclerosis: Hardening or narrowing of the arteries. It is a disease of the blood vessels. It is caused by the build-up of fatty deposits that reduces blood flow through the artery.

Atrial fibrillation: Also called A Fib. A heart disorder when the heart beats irregularly. Sometimes the heart may also beat too quickly. This is a risk for stroke.

Arteriovenous Malformation (AVM): This is a tangled mass of blood vessels in the brain that can cause a hemorrhagic stroke.

Carotid Doppler: An ultrasound test that looks at the arteries in the neck that supply the brain. This is to see how well the blood flows through these arteries.

Carotid Artery: The major arteries on either side of the neck that supply blood to the brain.

Carotid Endarterectomy: An operation to unblock narrowed carotid arteries in your neck.

Cerebral hemisphere: One side of the brain.

Cerebral angiogram: A cerebral angiogram is when a dye is injected into the blood vessels (arteries and veins) of the brain. This outlines them for the x-ray machine to take pictures.

Cerebral infarct: An area of dead cells in the brain caused by a loss of blood supply to that area (an ischemic stroke).

Cholesterol: A fatty substance present in blood. If the cholesterol level becomes too high it can build up along artery walls.

Cognition: A word used to explain our thinking ability. Cognition includes things such as remembering things, paying attention, solving problems and making decisions.

Continence: Automatic control of bladder and bowel function. Loss of one or both may happen for a time after stroke. This is called incontinence.

CT (CAT) Scan: CT stands for computerized tomography. A test that uses X-rays to produce an image of the brain.

Delirium: Abnormal mental state that appears as confusion, fear, irritability, agitation.

Diastolic pressure: The lower number in a blood pressure reading. This is the pressure against the artery walls when the heart is at rest.

Dysarthria: A type of speech problem where speech becomes slurred or a person is unable to say things clearly. Dysarthria is caused by weakness in the muscles used for speaking and may occur after a stroke.

Dysphagia: This means difficulty swallowing. Dysphagia can occur after a stroke because of weakness in the muscles needed for swallowing.

Early supported discharge: If right for you, your healthcare team will aim to help stroke patients return home from hospital as early as possible and receive rehabilitation at home.

Echocardiogram: An ultrasound test of the heart to get a picture of the structure of the heart.

Edema: Swelling of cells in the brain after a stroke.

Electrocardiogram (ECG): This shows the pattern of electrical activity in the heart.

Electroencephalogram (EEG): A test that records the electrical activity of the brain from electrodes attached to the scalp.

Embolic stroke: A stroke caused by a blood clot that has come from somewhere else in the body (an embolus).

Embolus: A fragment of a blood clot that breaks away and gets stuck in an artery blocking blood flow.

Emotional lability: Uncontrollable outbursts of emotion (such as laughing to crying) without real cause. It may only last a few weeks or continue for a long period.

Epilepsy: A brain disorder where there are chronic seizures.

Family meeting: A formal meeting between you, your family and members of the stroke team.

Gait: The characteristics of walking unique to an individual.

Goal setting: The process of the healthcare team and the patient and family working together to decide on main objectives of care.

Hemorrhagic stroke: A type of stroke where a blood vessel in the brain bursts and causes bleeding into the brain.

Hemianopia: The loss of vision to one part of the visual field. This can lead to trouble seeing on one side of your body.

Hemiparesis: Weakness on one side of the body. Hemiparesis can affect the arm, the leg or both.

Hemiplegia: Paralysis (no movement) on one side of the body. Hemiplegia can affect the arm, the leg or both.

Holter monitor: Device that records electrical activity of heart over a period of time, usually 24-72 hours.

Hypertension: High blood pressure; a risk factor for stroke.

Infarct: An area of tissue death due to lack of oxygen.

International normalized ratio: Also called INR. A laboratory test which measures the time it takes for blood to clot and compares it to an average.

Intracerebral hemorrhage: A type of hemorrhagic stroke caused by bleeding into the brain.

Ischemic stroke: A type of stroke where a blood clot blocks a blood vessel in the brain.

Lipid: Another word for “fat”.

Lobe: One of four major parts of the brain named after the skull bones that are underneath them: frontal, parietal, temporal, and occipital.

Mobility: The ability to move e.g. walking, standing up, moving from one chair to another.

MRI scan: MRI stands for magnetic resonance imaging. It is a scan that gives a detailed picture of the brain.

Naso-gastric tube: A tube that is passed through the nose down the throat into the stomach usually to allow feeding when a person has swallowing problems.

Neglect: After damage to one side of the brain the person with stroke is unable to recognize one side of their body or the environment.

Neurologist: A doctor who specializes in assessing and treating conditions of the brain and nervous system.

Obstructive sleep apnea: A problem with breathing that includes heavy snoring and interrupted breathing during sleep; a risk factor for stroke.

Paralysis: The loss of motor function in a body part.

Perception: The way our brain interprets what our eyes see.

Perseveration: Being stuck on one idea, action, or response.

Physiatrist: see rehabilitation physician.

Plaque: A fatty buildup of cholesterol, calcium, and other things inside an artery.

Power of attorney: Also called POA. A legal agreement so you can appoint someone you trust to make financial, property, and health decisions for you if you are not able.

Rehabilitation physician: A doctor who specializes in the rehabilitation of patients.

Rehabilitation unit: A dedicated unit that helps to restore the skills of a person who has had a stroke or other event or injury.

Respite care/services: Short-term and temporary care for stroke survivors to allow caregivers time away from their caring responsibilities.

Shoulder subluxation: This is a common occurrence after stroke and can be due to muscle weakness in the arm. It is when the upper arm bone drops out of the shoulder socket.

Spasticity: Increased muscle tone often resulting in stiffness and pain.

Statins: Medication used to lower cholesterol.

Stenosis: Narrowing of an artery due to the buildup of plaque on the inside wall of an artery.

Stroke: A sudden loss of brain functions because of a blocked or broken artery to the brain.

Stroke support group: A group of stroke survivors and caregivers who meet regularly and provide support to each other.

Stroke unit: A set area in a hospital where an expert stroke team looks after people with stroke.

Subarachnoid hemorrhage: A type of hemorrhagic stroke where there is bleeding over the surface of the brain.

Tissue Plasminogen Activator (tPA): The drug most commonly used to break up a clot in an artery.

Thrombolysis: The process of administering the drug tPA intravenously to break up a blood clot.

Thrombotic stroke: A stroke caused by a blood clot that has formed in the brain (a thrombus).

Transcranial Doppler: Also called a Doppler. This is an ultrasound that measures the speed of the blood flow in the brain arteries.

Transient ischemic attack (TIA): This refers to a transient ischemic attack. A 'mini-stroke', symptoms last for less than 24 hours.

Visual fields: Entire area visible to an eye that is looking straight ahead

References

The following organizations' websites helped shape the content of this Guide.

Aphasia Institute	www.aphasia.ca
Canadian Best Practice Recommendations for Stroke Care	www.strokebestpractices.ca
Canadian Stroke Network	www.canadianstrokenetwork.ca
Community Care Access Centre	www.ccac-ont.ca
For Better or For Worse	www.fborfw.com
Health Canada	www.hc-sc.gc.ca
Heart and Stroke Foundation of Canada	www.heartandstroke.com
Hypertension Canada	www.hypertension.ca/chep
Mayo Clinic	www.mayoclinic.com
Readability-Score.com	www.readability-score.com
Registered Nurses Association of Ontario	http://rnao.ca/bpg
Stroke Engine	www.strokengine.ca
Stroke Foundation of New Zealand	www.stroke.org.nz
The Family Caregiver	www.thefamilycaregiver.org

To read more of the For Better or For Worse comic strips entitled “Grandpa Jim’s Stroke” go to: <http://catalog.fborfw.com/indexstoryline.php?q=Stroke>.

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