



Your Stroke Journey

A guide for people living with stroke



HEART &
STROKE
FOUNDATION

CANADIAN
Stroke
BEST PRACTICE
RECOMMENDATIONS

Acknowledgements

Sincere thanks to the many people who helped create this resource:

To those living with stroke — your willingness and openness to share your personal journey has given this guide a foundation in real life.

To their care partners — your experiences and support have added incredible value.

To the healthcare providers and experts — your expertise, insight and caring have helped provide the most current, accurate information.

It really takes a village to create a resource. Thank you for your time, energy, and talent.

*Do you want us to keep you up to date on new stroke information, and do you want to provide input into our work? Sign up at **heartandstroke.ca/connect***

We will stay in touch with research news, tips and strategies to help you manage your recovery, educational webinars and requests for your opinion.

Survivor to survivor:

WORDS OF HOPE AND ADVICE



“ *You can't compare your stroke to someone else's.* - Lindsay

“ *The stroke is with me every day and affects everything I do. Life has become a series of adjustments to make daily life work for me. I have grown as a person and fully appreciate the simple things in life. I now live my life more for today and enjoy and appreciate the many things I once took for granted.* - Lou



“ *You are more than your stroke.* - Carol

“ *Be positive, attitude is everything.* - Dawn



Survivor to survivor:

WORDS OF HOPE AND ADVICE



You are always trying to balance hopeful and realistic, realizing there is no magic.

- Luis



Do something! If I do nothing, contribute nothing, at what point do I become nothing? Do something, anything to keep going.

- John



Stroke leaves you feeling vulnerable for sure. You have to believe you have a strength you never knew existed. Let that strength surface and you will be able to overcome even some of the toughest obstacles. - Patrice



How *to use* this guide

This guide is written for adults who have had a stroke. We also hope that your care partners, family and friends find it helpful.

We have designed this guide to:

- help you understand stroke and its effects
- give you tips and strategies for living your life fully
- help you know that you are not alone in your recovery
- tell you about the support services, healthcare providers and networks of stroke survivors that can help you on your journey.

You may want to read this guide from cover to cover, or you may just seek out certain topics. Take from it information that is important to you. Apply it to your recovery plan. Share it with family, friends and your healthcare team.

We use the term **care partners** to describe those in your life (family and friends) who support you most in your recovery.

Stroke can happen at any age. If your child has had a stroke, you may find **A Family Guide to Pediatric Stroke** helpful.

When you and the people around you better understand the journey you are on, you can move through it with more confidence and support.

If you need information on pediatric stroke, read **“A Family Guide to Pediatric Stroke”** available at strokebestpractices.ca

Your journey

Stroke is a major life event for you and those close to you. The common goal for everyone — you, your care partner, your family, your friends and your healthcare team — is your recovery.

Recovery means regaining as much function and independence as possible. This may mean a life different than the one you had before stroke. Part of the recovery process is building a life with your current abilities that includes things that you find meaningful and fulfilling.

How *to use* this guide - *continued*

Recovery can take a lot of work and has its ups and downs. Reaching out for support can help.

There are three things that you can do to make your journey easier:

1. Be informed

Know the facts. Be aware of best practices for care and how you can be involved in your care and recovery.

2. Be part of the process

Make your voice heard when it comes to setting goals and care planning. Ask questions and get answers.

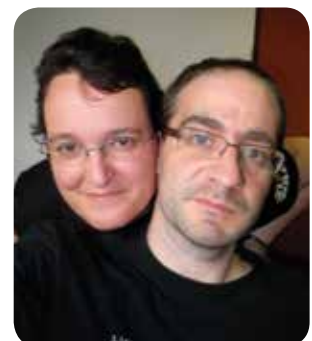
3. Do what needs to be done to get better

Practice your exercises. Take your medication. Make lifestyle changes. Achieve your goals.

Roles and relationships

Each family has its own routines, and each member has their own roles and responsibilities. A stroke can change your natural family balance. Family roles may change. The same can be true of your relationships with close friends. Part of the recovery journey is to work out a new balance.

“*My family’s support was key. When my downs were deep, they lent me a hand to get up again.* - Luis



There are three things that you and each person close to you can do to help with your recovery:

1. Communicate

Talk positively, clearly and practically. Listen carefully. Always consider how the other person is feeling.

2. Support each other

Know what type of support you want and ask for it. Is it practical help? Is it encouragement? Is it helping figure out new ways to do things?

3. Reach out

It is a big help if there is a broader support network of friends outside of your family and your care partner. Sometimes, just knowing they are there — even if you do not need to turn to them — can be helpful.



Keep people who are positive around you - it will make a difference.

- Wayne



Asking for help is NOT a sign of weakness. - Carol

A message for care partners:

Look after your own physical and emotional health

Stroke recovery can take a toll on everyone. Care partners are particularly vulnerable. You may tend not to take a break or look after your own health. Juggling roles and providing daily support can be taxing and tiring for even the most devoted person, no matter how happy you are to take on this role.

To prevent burnout, it helps to eat well, stay active, get a good night's sleep and take time for an enjoyable activity.

Care partners and family members should watch themselves and one another for signs of burnout. Look for ways to reduce your load and take a break. Reach out for support to family, friends, support groups or programs and the healthcare team if you see signs like these:

- feeling unusually tense or edgy
- being angry with the stroke survivor or others
- feeling sad, tearful or dissatisfied with life in general
- feeling very tired and saying things like, “It is too much”
- no longer seeing friends
- losing interest or energy for activities you enjoy
- getting sick more often and taking an unusually long time to recover (*lowered immunity*)
- showing an increased need for drugs or using alcohol too much
- feeling out of control, with no sense of how to regain that control
- having trouble sleeping or having disturbing dreams
- not eating well.

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Understanding STROKE



Louise and John

1. *Understanding* STROKE

The brain is the control centre of your body. It controls how you think, feel, communicate and move. Knowing how your brain works can help you understand your stroke.

The brain

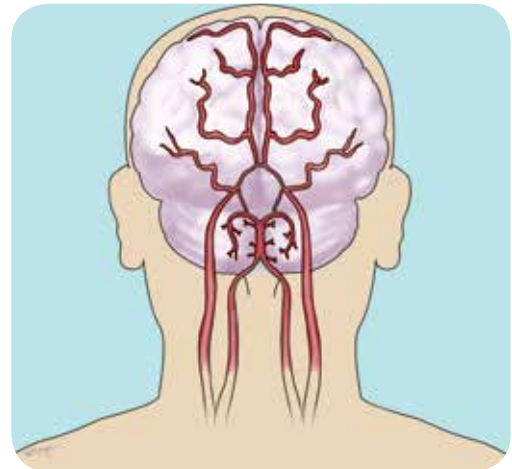
Brain cells

The brain is full of specialized cells called neurons. These neurons make the brain work. To work properly — and even to survive — they need to be fed by a constant supply of blood.

Blood vessels of the brain

Arteries and veins are types of blood vessels in your body. Arteries carry blood, rich in oxygen and nutrients, to your organs. Veins carry waste products away from your organs. Cerebral arteries are the arteries of the brain. Normal brain function needs a constant supply of oxygen and nutrients.

When a stroke happens, the blood flow is disrupted. Some brain cells do not get the oxygen and nutrients they need. When the cells die, that area of the brain cannot function as it did before.

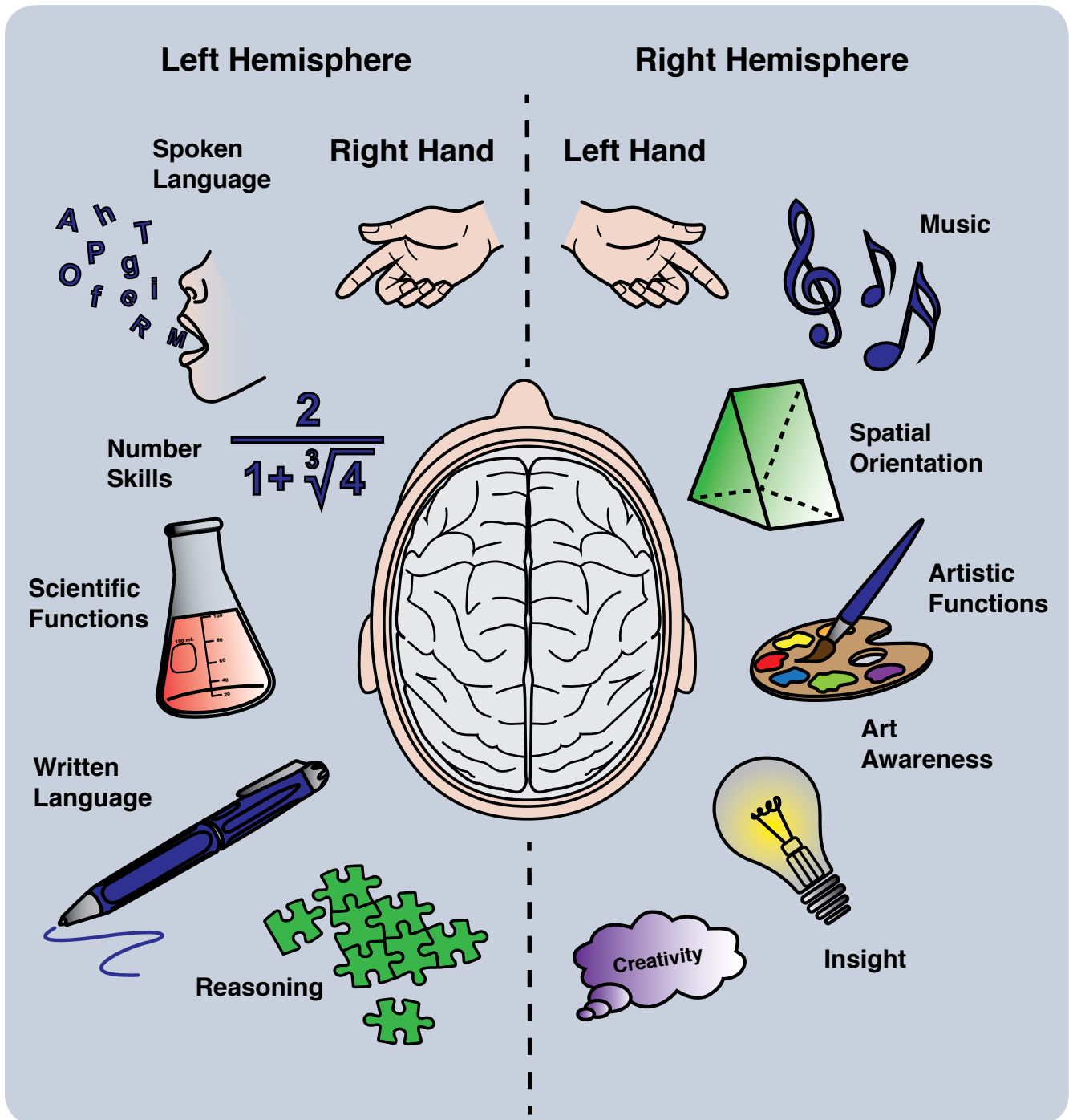


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Hemispheres

The brain is divided into two parts called hemispheres, the right and the left. The right hemisphere of your brain controls the left side of your body. The left hemisphere of your brain controls the right side of your body. Some functions are controlled by both.

Functions of the two hemispheres of the brain



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Regions of the brain and what they control

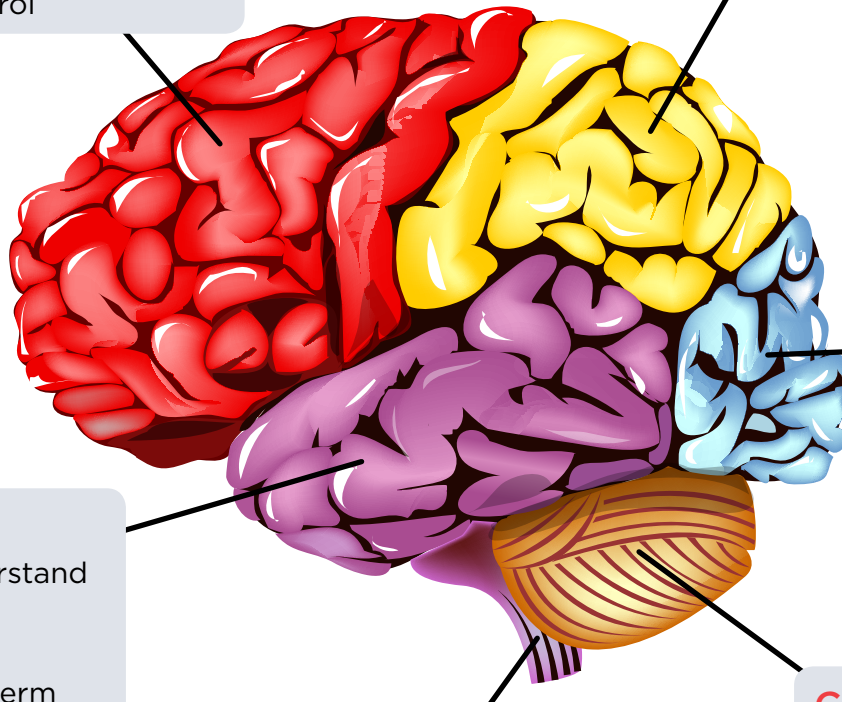
Each hemisphere is divided into six regions or lobes that control different functions. This chart shows the names of the lobes and their functions:

Frontal

- Personality
- Emotions and arousal
- Intelligence
- Ability to concentrate, make decisions, plan, put things in order, solve problems
- Awareness of what is around you
- Voluntary movement
- Ability to speak and write
- Behaviour control

Parietal

- Sensations: pain, touch, temperature
- Understanding and interpreting sensory information, such as size, colour and shape
- Understanding space and distance
- Math calculations



Occipital

- Vision
- Interpreting what you see

Temporal

- Ability to understand language
- Hearing
- Memory, long-term storage of memories
- Organization and planning
- Behaviour and emotions

Brain stem

- Breathing
- Heart rate control
- Consciousness, alertness, wakefulness
- Swallowing
- Blood pressure
- Sweating

Cerebellum

- Balance
- Motor (movement) coordination
- Posture
- Fine motor skills

What happens during a stroke

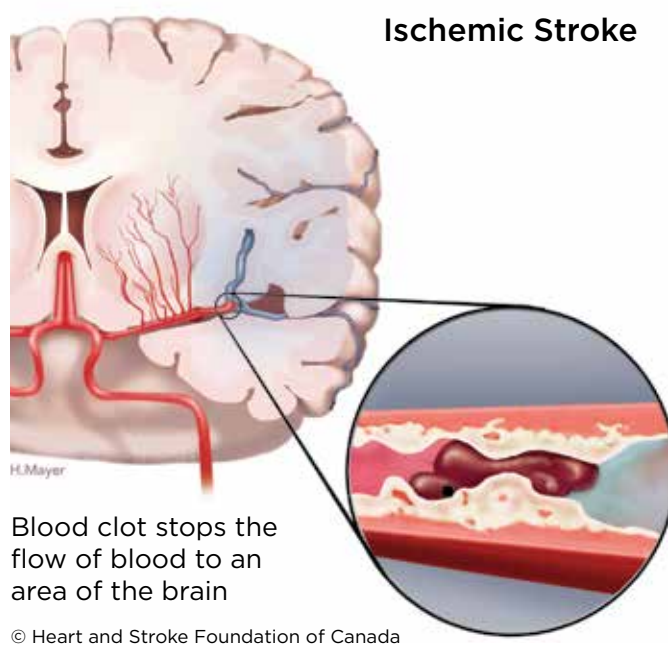
A stroke happens when blood stops flowing to any part of your brain. This interruption causes damage to the brain cells which cannot be repaired or replaced. The effects of your stroke depend on the part of the brain that was damaged and the amount of damage done.

Types of stroke

Ischemic stroke

Most strokes are caused by a blockage or clot in a blood vessel in your brain. This is called *ischemic stroke*.

The blockage can be caused when a substance called *plaque* builds up on the inside wall of an artery. The blockage or clot grows as blood cells and fat cells stick to the plaque. Gradually, it grows big enough to block normal blood flow.



The blockage or clot can form in an artery in your brain. Or, it can form in an artery in another part of your body and travel to the brain.

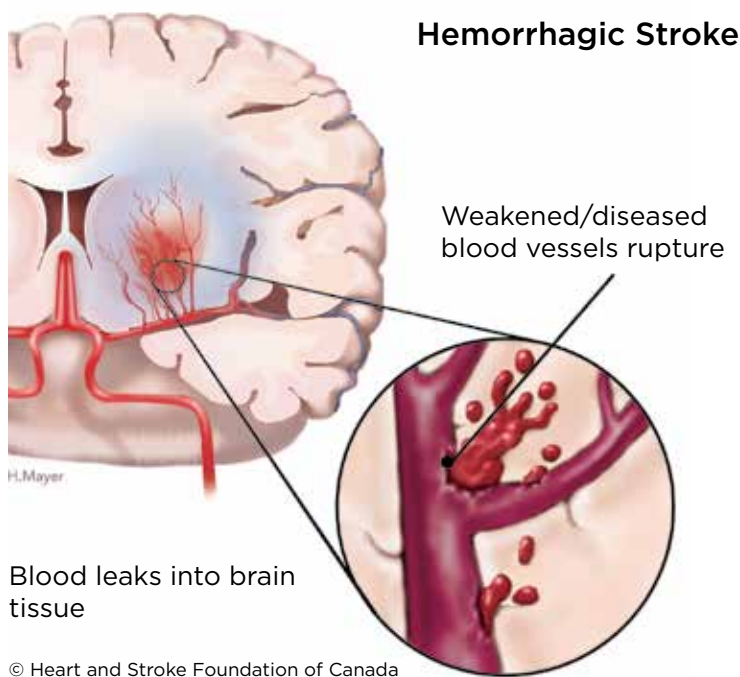
Transient ischemic attack (TIA)

A transient ischemic attack (TIA) is caused by a small clot that briefly blocks an artery. It is sometimes called a mini-stroke or warning stroke. TIA symptoms might last only a few minutes or hours. No lasting damage occurs, but TIAs are an important warning that a more serious stroke may occur soon. They are a medical emergency — call 9-1-1.

A transient ischemic attack (TIA) is sometimes called a mini-stroke or warning stroke. TIAs are a warning that a more serious stroke may occur soon. TIAs are a medical emergency — call 9-1-1.

Hemorrhagic stroke

Hemorrhagic stroke is caused when an artery in the brain breaks open. The interrupted blood flow causes damage to your brain.



High blood pressure makes arteries weak over time. It is a major cause of hemorrhagic stroke. Weak spots in the arteries called aneurysms can stretch too far and eventually burst.

Other causes

In rare cases, a tumour, an infection, or brain swelling due to an injury or illness can cause a stroke. Some people have irregularities in their arteries at birth that can cause a stroke later in life.

How can a stroke affect my body?

The effects of stroke are different for each person. They can be mild, moderate or severe. The severity depends on factors such as:

- the type of stroke (ischemic or hemorrhagic)
- the side of the brain where the stroke occurred (right or left hemisphere)
- the lobes of the brain affected by the stroke
- the size of the damaged area in the brain
- the body functions controlled by the affected area
- the amount of time the brain area had no blood flow
- the time it took to get to hospital.

TIA >>>>>>>> Mild Stroke >>>>>>>>> Moderate Stroke >>>>>>>>>>>>>>> Severe Stroke



No Permanent Damage >>>>>>>> Some Damage >>>>>>>>> Significant Permanent Damage

Help us make this guide better!

There is a brief survey at that back of this book. Please fill it out once you have read it. You can also fill it out online at heartandstroke.ca/feedback



2. *Stroke* CARE

Your stroke recovery team

When you have a stroke, a team of healthcare providers works with you and your family, whether in hospital or at home, to:

- help you recover from or adapt to the changes caused by stroke
- teach you about stroke, its effects and strategies to use in daily life.

Get to know each team member and their role in supporting you in your recovery. Keep a list of names, roles and ways to contact them.

Your role working with the team

You, your care partner and those close to you are at the centre of your stroke recovery team. Teams usually meet regularly. Ask when they will be meeting to discuss your care. Make sure you are included. If you are not up to it, have your care partner or a family member attend on your behalf.

Overcoming language barriers

Translation services are available in most medical centres in Canada. If needed, ask what is available to you.



YOU ARE THE CAPTAIN OF YOUR OWN SHIP. The many doctors, nurses, social workers, navigators and therapists are there to give advice and support but it is up to you to decide where you are sailing. If your way is blocked, try a new direction. – John

What to tell the team

Help the team get to know you by sharing information about:

- Your background: What kind of work you do and your hobbies.
- Your living situation: Do you live in a house, apartment or condo? Are you in a city, town or rural community?

- The support available to you: Do you live alone or with a spouse or friend? What kind of supports are in your community? How are your finances?
- Your needs and goals: In the short term, do you want to focus on daily tasks, like bathing on your own? In the longer term, do you want to go back to work? Travel?

Making the most of team meetings

Most of us remember only a small part of what we are told in healthcare team meetings. So go prepared. Make a list of the questions you want to ask. Make notes of each meeting – who was there, what was discussed and what the next steps will be.

Bring someone with you who can take notes and help you to remember and understand what happened at the meeting.

Keep a journal or calendar of all your appointments, meetings and tests.

“ I can't stress enough the importance of keeping a journal. - Louise, John's care partner

Team members and their roles

The makeup of your stroke recovery team will depend on your needs and the healthcare providers available in your community. You may not meet all of the specialists in this list.

Neurologists are experts on brain issues.

Physiatrists are doctors expert in rehabilitation – the medicine of physical recovery.

Neuropsychologists assess the impact of stroke on your cognitive or thinking abilities. This expert can teach you how to help your brain recover and carry out cognitive tasks.

Family doctors are experts in your general health.

Nurses work closely with you and your family during all stages of recovery both in and out of hospital. They provide physical care, assessments and coordination of care.

Occupational therapists work with you to make a plan to resume your daily tasks, like dressing, bathing, eating and leisure activities.

Physiotherapists work with you on recovering your physical abilities, strength and balance, for tasks such as walking and getting around.



Speech-language pathologists help you with swallowing, speaking and communication.

Social workers may help you with social and emotional problems. They may also work with you and your family to plan your care after discharge. Other types of people who help with planning your next step of care include **case managers** and **discharge planners**.

Dietitians assess your ability to eat. They identify foods and meals that will help recovery by taking into account your nutritional needs, swallowing challenges and food preferences.

Pharmacists teach you about your medications, how to take them safely and what side effects to watch for.

Educators help you learn about your stroke and its effects. They also teach you, your care partner and family members about caring for you and themselves. Any member of the team involved in your care might take on the role of educator.

Recreational therapists support you in finding and adapting leisure activities.

Telestroke: Stroke care from a distance

Thanks to technology, people who live far away from stroke specialists have options for long-distance care. Healthcare providers in one area can link with consultants and specialists in another area for real-time assessments and treatment. This can give you access to treatments and services at any stage from the first few hours after a stroke, to rehabilitation, to care in the community. Find out if this is an option for you.

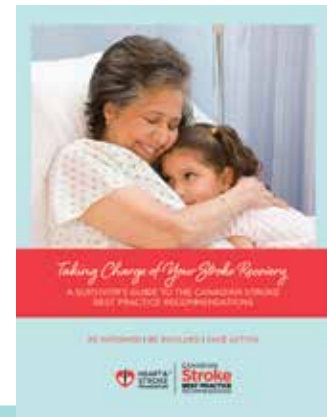
The first days

The first hours at the emergency department

The first hours after stroke can be very scary and fast-paced. The healthcare team will be working quickly to figure out the type of stroke you have had so that they can take action to prevent further damage to brain cells.

There are three goals for treatment in the first few hours after a stroke:

- **To stabilize you** by managing breathing, heart function, blood pressure, bleeding, swallowing and other symptoms.
- **To make a diagnosis:** You should receive a brain scan soon after you arrive at the hospital. This is usually a CT (*computed tomography*) scan. The scan may show the type of the stroke (a clot or a broken artery). A CT scan also finds the location of the stroke. Scan results help your healthcare team choose the best treatment options. Blood tests may be a part of your assessment.
- **To provide early treatment:** The type of treatment depends on the type of stroke. Ideally, treatment takes place in a special stroke unit in the hospital.



Learn about stroke best practice from **Taking Charge** – go to strokebestpractices.ca

Early treatment for ischemic stroke (clot)

If a clot caused the stroke, doctors will decide whether you could benefit from a clot-busting drug called tPA (*tissue Plasminogen Activator* – also known as *Activase*®). This medication can help reopen blocked arteries in some people with ischemic stroke. It must be given as soon as possible, within 4½ hours after stroke symptoms started. tPA can reduce the severity of the stroke and reverse some stroke effects. Not everyone who has an ischemic stroke can receive tPA.

After you receive tPA, the healthcare team will be watching extra closely for the first day. To make sure the tPA worked, a repeat CT scan will be done within a day or two after the stroke.

Early treatment for hemorrhagic stroke (bleed)

Hemorrhagic stroke can be very serious and cannot be treated with tPA. It has a longer recovery time than ischemic stroke.

A neurosurgeon will determine with the team if an operation is needed. This might be needed to control the bleeding in your brain, to fix the damaged artery or to lower the pressure in your brain.

The team will check often to make sure symptoms are not getting worse. They will monitor blood pressure and check for alertness, headache, weakness or paralysis, and other stroke symptoms.

The first days in hospital

Two-thirds of people with stroke are admitted to hospital. Each person recovers at his or her own pace. Your care and length of stay is based on your needs. A team of healthcare providers will work with you. Here is what your in-hospital care will focus on:

Understanding what happened

During the first few days after your stroke, you might be very tired and need to recover from the initial event. Meanwhile, your team will identify the type of stroke, where it occurred, the type and amount of damage, and the effects. They may perform more tests and blood work.

Monitoring and managing risk factors

If you had an ischemic stroke, you may be prescribed **blood thinners** (anti-platelet medication such as *ASA, acetylsalicylic acid* or *Aspirin®*) to prevent more clots.

Your **blood pressure** will be checked regularly. If it is high, medication may be prescribed.

If the team suspects your stroke was caused by blocked **carotid arteries** in your neck, they may do scans. If necessary, they will have you see a surgeon.



Atrial fibrillation or irregular heart rhythm is a significant risk factor for stroke. You may be tested for this during hospitalization.

If you have **diabetes** – a risk factor for stroke – the team will review how you manage it.

The team will review **other risk factors** for stroke and work with you to set goals and make a plan to prevent another stroke. (Learn more in Chapter 3 – Preventing another stroke.)

Preventing complications

The team will be checking for some of the more common complications of stroke. Starting treatment early helps to prevent further complications.

If you are unable to move around in bed, the team will be working to **prevent clots** (*deep vein thrombosis*) from forming in your legs. They will also try to prevent **pressure sores** on your skin. As soon as you are able, the team will work with you to get you sitting, standing and walking safely.



Weakness and balance problems may put you at **risk of falling**. The team will assess your risk. They will work with you to make sure you understand the risk and how to prevent falls. If the team gives you a mobility device such as a walker, it is important to use it.

You should have a **swallowing** test before you are given any liquids, food or medication. Problems swallowing, if not identified, can lead to complications such as:

- pneumonia
- not getting enough to eat (*malnutrition*)
- not drinking enough (*dehydration*).

The team will want to identify any problems with **bowel and bladder control** early so that training programs can start as soon as possible.

Starting your recovery

Recovery starts once you are stabilized. The team will work with you to assess your abilities and start developing strategies and therapies to begin your recovery.

Planning for your discharge

Team members will be looking to see how the stroke has affected your ability to resume day-to-day life. They will start working with you to plan for the next step in your recovery — whether you are going home, to rehabilitation, or to long-term care.

What questions should you and your family ask?

During your hospital stay, ask lots of questions to make sure you understand what has happened, what to expect and your role in recovery. Most of us remember only a small part of what we are told in healthcare team appointments and meetings. That's why it is important to keep track of the answers in a journal.

Here are some questions to ask:

- What type of stroke did I have? Was it caused by a blood clot or by bleeding into the brain?
- What part of my brain is affected? What damage has the stroke done?
- What will my recovery be like? What treatments will I receive? Will I need medication?
- What are the results of my tests? What do they mean?
- Did I receive tPA?
- Did the stroke affect my ability to swallow?
- What are my risk factors for another stroke in the next few months? (This is especially important if you had a transient ischemic attack or mini-stroke.)
- What is the next step in my care? Will I be admitted to hospital or discharged home?
- Will I be assessed to see if I need rehabilitation?

- Will I be given an appointment at a stroke clinic or with a stroke specialist when I leave the hospital?
- What will I be able to do in the next few months?
- What can I expect one year from now?
- What skills will I need to take care of myself?
- What services and resources can help me and my family? How do I access them?

Discharge – Preparing for the next step

Moving to the next step in your recovery can be a stressful time. You may be moving to a rehabilitation unit, going home or going into long-term care. It helps to be prepared and to have a good discharge plan. You and your family play the most important role in making your plan.

To find the right place, you and your team need to consider these factors:

- the effects of your stroke on your mobility and ability to care for yourself
- the effects of your stroke on your thinking, speech and ability to communicate
- how much you have recovered so far
- your living situation. Do you live alone? Do you have family who can stay with you when you come home?



Use the **Post-stroke checklist** to help make sure you receive the care you need - go to strokebestpractices.ca

Planning to go home

Many people with stroke are able to return home, either from the emergency department or eventually from inpatient hospital care or rehabilitation. If you

are going home, it helps to have family members and friends available to support you.

You may be able to go home for a trial visit of a day or two before you leave hospital. This visit helps you to decide if you are well enough to go home. Use this time to start building new routines to help you live with the effects of your stroke. Think about changes that need to be made to your home. For example, you may need to have furniture in some rooms moved for safety.

If you are being discharged home from the emergency department, make sure you have appointments for:

- a stroke specialist
- a stroke clinic where they will look at the risk factors that played a role in your stroke
- any further tests needed
- a rehabilitation assessment, if needed.

Planning for rehabilitation (rehab)

Rehab soon after a stroke helps you recover best. Many people need some rehabilitation. This could involve:

- a move to a specialized rehabilitation hospital
- going home and attending a community program
- having rehab at home.

What you need will guide your rehabilitation plan.

Planning for long-term care

Some people have a stroke with more severe damage. They may need the extra help with personal care that long-term care provides.

Making your discharge plan

Your role in making a good transition

Before you leave any level of care you need to have a plan for the near future. Your team should work with you and your family to set realistic goals for the



Wayne

next weeks and months. Make sure all of your questions and those of your care partner and family have been answered. You should have all of the following information written down.

Where you are going

- home, in-patient rehabilitation, long-term care or some other location

Your healthcare contacts

- list of your appointments, the reason for each appointment, the location, contact name and phone number
- names of your therapists, their contact information and why you are seeing them
- who to contact if you have any questions.

Recovery and rehabilitation needs

- your recovery needs – what do you need to continue to recover?
- list of devices that may help you and where to find them
- any safety concerns
- description of the types of rehab you need and where you will receive it
- what you can do on your own
- a list of services in your community for people with stroke and their care partners.

A plan to prevent another stroke

- a review of your risk factors
- your goals and plan for reducing risk
- a follow-up appointment about managing your risk factors
- a list of signs of stroke and what to do if they occur.

A list of your medications including

- names
- what they are for
- when to take them

- how to take them
- possible side effects
- foods you might need to avoid.

Daily life routines

- a list of assistive devices to help you
- a list of strategies you can use right now for daily routines such as getting around, eating, bathing and going to the toilet.

Tips for recovery

- Know your abilities and limitations.
- Decide on your goals and priorities.
- Ask your therapist what you can do on your own to help you keep moving forward. When your therapy sessions end, ask when you should consult a therapist again. Remember to balance your activity and get rest to avoid fatigue.
- Keep track of your progress.
- Celebrate success!



Stay positive. Do your best.
– Wayne

The first weeks

Starting rehabilitation (rehab)

Your recovery starts as soon as you are stabilized. Rehab is the process and approach that helps you to recover as many abilities as possible. It can be a formal program, or it might include exercises and routines that you do at home.

Recovery is a long-term process and varies from one person to the next. For some, it can take several months. For others, it may take years.

Start rehab as soon as you can. Over time, you will learn new skills, activities and exercises to “retrain your brain”. You will receive help with physical abilities, such as hand use, and cognitive abilities, such as memory and thinking. It will also address communication problems and emotional issues.

In the first few weeks after stroke, some abilities may start to return as your brain naturally recovers, including:

- swallowing
- speaking
- understanding what people are saying
- moving an affected arm or leg.

Recovery includes both body and mind. Your desire to get better and to work hard are important in reaching your recovery goals.



Where does rehab take place?

Rehabilitation can occur in many places including:

- a special floor of a hospital known as a rehabilitation stroke unit
- a rehabilitation hospital
- a clinic or office in your community
- your home, with home care services.

Why does rehab work?

The brain is able to make up for functions lost in damaged areas. It does this by reorganizing and rewiring itself. This ability is called *neuroplasticity*. The goal of stroke rehabilitation is to help you recover as much function as possible.

To make these changes in the brain you need to train it by repeating specific exercises and activities. The type of rehab you do depends on:

- how severe your stroke was
- the part of your brain that was damaged
- the effects of the stroke on your body, mind and emotions
- your general health
- how hard you are able to work to reach your recovery goals.



How long will it take?

There is no schedule for stroke recovery. Your stroke is unique to you and your recovery will move at your own pace, based on your own situation.

You will likely find that you keep making progress for many months and even years after your stroke. The more you practice doing the tasks of everyday life, the easier they become over time.

Be prepared to work through plateaus

Your recovery may slow down or seem to stop for a time. You may even feel you are getting worse. This is a common feeling. Your therapist may say you have reached a plateau and may reassess your abilities. Do not despair. Recovery often continues if you keep working on your therapy.

Treat a plateau as a signal to reassess, not an end to recovery. Look at what you have achieved. Figure out what you need to change to move forward. Do you need to change your goals or do you need to change your strategy? Talk with your therapist about this and make a plan to move forward together.

“*Whatever you put into your recovery, you get out of it.*
– John

Preventing ANOTHER STROKE



Wayne

3. *Preventing* ANOTHER STROKE

Having a stroke or TIA (transient ischemic attack or mini-stroke) puts you at a higher risk of having another one. You can reduce that risk. Here's how:

- Know the **signs of stroke** so that you can get help quickly.
- Learn your **risk factors** for another stroke.
- Learn what you can do to **lower your risk**.
- Find out how to make **healthy** choices in your life.

Know the signs of stroke

Stroke is a medical emergency. Recognize and respond immediately to any of these signs. Call 9-1-1 or your local emergency number.

LEARN THE SIGNS OF STROKE

FACE is it drooping?
A RMS can you raise both?
S PEECH is it slurred or jumbled?
T IME to call 9-11 right away

ACT **F A S T** BECAUSE THE QUICKER YOU ACT,
THE MORE OF THE PERSON YOU SAVE.

© Heart and Stroke Foundation of Canada, 2014

Some treatments that can help reduce the effects of a stroke are time sensitive. For example, a person having a stroke caused by a blood clot can receive a clot-busting drug within four and a half hours after symptoms

begin. That makes it important to know the signs of stroke and to call 9-1-1 right away. Do not drive — an ambulance will ensure you get to a hospital most able to treat stroke.

If you are alone at home, carry a portable phone or wear a medical alert system device button around your neck that you can press when help is needed.

Know your risk factors

Each person has their own risk factors for stroke. If you know what yours are, you can take action to manage them and reduce your risk. Talk to your healthcare team about your risk factors. Together, you can identify the actions you can take to improve your health.

Factors you can change

- unhealthy diet
- a diet high in salt
- being overweight
- physical inactivity
- smoking
- excessive alcohol intake
- recreational drug abuse.
- high stress level

Try these e-tools to help you identify and manage your risk:

Go to **heartandstroke.ca/risk** for a 10 minute quiz that gives you a personal report on how to reduce your risk.

The e-tool at **heartandstroke.ca/bp** helps you to learn how to manage your high blood pressure.

Medical conditions that are risk factors

Some medical conditions increase the risk of stroke, but you can manage them with medication, treatment and by making healthy choices.

High blood pressure (hypertension)

High blood pressure can weaken your artery walls, increasing your chances of a stroke. If you keep your blood pressure below target levels, you can lower your risk of stroke by 30-40%.

Learn about hypertension at **heartandstroke.ca/bloodpressure**

Atrial fibrillation (Afib)

This is an irregular heart rhythm. It can cause small clots to form in your heart and travel to your brain. It increases your risk of ischemic stroke three to five times.

Learn about Afib at
heartandstroke.ca/AFGuide

Diabetes

This disease can affect your blood vessels and in turn increase blood pressure. Diabetes also increases the chance of plaque forming in your blood vessels.

Learn about diabetes at
diabetes.ca

Blocked carotid arteries

The large arteries in your neck become narrowed, making it difficult for the blood to flow to your brain.

High cholesterol

This can lead to a buildup of plaque in the artery walls (*atherosclerosis*). The plaque makes it harder for blood to flow through your body, putting you at increased risk of stroke.

Learn about cholesterol at
heartandstroke.ca/cholesterol

Sleep apnea

When people have interrupted breathing during sleep, it lowers the amount of oxygen reaching the brain. It can also cause high blood pressure.

Birth control pills or hormone replacement therapy

Women who take drugs containing the hormone estrogen have an increased risk of clot formation and therefore stroke.

Factors you cannot change

- having had a previous stroke or TIA or mini-stroke
- family history of stroke or blood vessel problems
- age — the older you are, the higher your risk of stroke
- sex — until women reach menopause, they have a lower risk of stroke than men

- ethnicity — First Nations people and people of African or South Asian descent are more likely to have high blood pressure and diabetes. You are at greater risk of heart disease and stroke than the general population.

Make healthy choices

Small, healthy changes in your daily routine can decrease your risk for another stroke. Making changes is always challenging. Your healthcare team can help you figure out what risk factors you should focus on first and set goals that you can reach.

Don't try to change yourself overnight. Start with something that is relatively easy and build on your successes.

Healthy food choices

Even small changes to your diet can add up to big health benefits. Balanced meals and healthy snacks will help you:

- increase your intake of healthy foods
- manage your weight
- keep your blood pressure down
- control your blood sugar levels
- lower your cholesterol
- increase your energy level.

All of these factors reduce your risk of stroke. If you need help making healthy choices, consult a dietitian. Here are some tips on healthy eating:

Eat more vegetables and fruit

Vegetables and fruit are rich in vitamins, minerals and fibre. They are low in

Learn about healthy food choices at
heartandstroke.ca/recipes
heartandstroke.ca/dash



calories, fat and salt (*sodium*). They help to reduce cholesterol, lower blood pressure and maintain a healthy weight.

Choose foods high in fibre

The best sources of fibre are vegetables, fruits, whole grains and legumes such as lentils. Fibre will help to reduce your cholesterol, lower your blood pressure and maintain a healthy weight.

Lower sodium intake

Reducing salt (*sodium*) in your diet can bring down your blood pressure and cut your risk of stroke and heart disease by about a third. Most sodium comes from packaged food and eating out. Here are some tips to help reduce salt.

Choose:

- foods with less than 200 mg of sodium per serving. Read labels to check the sodium amount.
- seasonings other than salt and soy sauce to flavour your food. Use garlic, lemon juice or herbs instead.
- unsalted nuts as a healthy alternative to snack foods.
- low-salt (140gm per serving) recipes to cook at home.

Limit or avoid:

- processed and packaged food such as canned soups, bacon, pickles and sandwich meats
- take-out food
- salty snacks like potato chips.

Choose healthy fats

Fats are not all the same. *Saturated* and *trans fats* raise cholesterol levels. Other types of fat or oil called *unsaturated fats* can help prevent plaque from building up in your blood vessels.

Choose:

- lean meats and more fish
- low-fat dairy products
- unsaturated fats, such as olive oil, soybean oil, canola oil and peanut oil
- foods with less than 3 grams of total fat and less than 2 grams of saturated fat per serving. Read food labels to check for amounts of both types of fat.

Limit or avoid:

- deep-fried foods
- foods with saturated and trans fats
- ghee and butter.

Eat less added sugar

Added sugar provides energy in the form of calories, but it has no other nutritional value. If we do not use the calories, we store them in the form of fat. There is no specific amount of sugar recommended as a part of a healthy diet. Eat less sugar to maintain a healthy weight.

Choose:

- water or unsweetened tea
- lower sugar options. Check the amount of added sugar on food labels. There are 4 grams of sugar in one teaspoon.




Limit or avoid:

- baked goods
- sweetened beverages, including pop and fruit juice.

Eat moderate portions

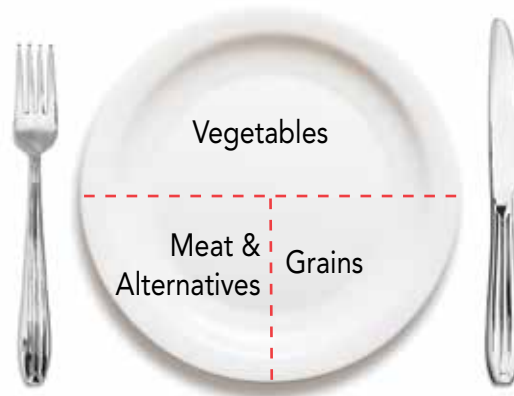
Limiting your portion size is a good idea, whether you are at home or in a restaurant.

Let your hands help you measure healthy portions.

	Grains, Starches & Fruits: Your FIST can measure a serving of grains such as quinoa or rice, starch such as potatoes and fruit such as melon or apple.
	Meat and Alternatives: The PALM of your hand can measure a serving of meat such as chicken or meat alternatives such as tofu.
	Vegetables: Your HANDS held together can measure a serving of vegetables such as kale or broccoli.
	Fats: Your FINGERTIP can measure a serving of fat such as margarine or ghee.

Adapted from the "Portion Guide" with permission of the Canadian Diabetes Association

- Use smaller plates, bowls, and cups.
- Fill up half of your plate with vegetables (not counting potatoes). Fill a quarter of the plate with whole grains such as brown rice or whole grain pasta. The last quarter of the plate is for meat or meat alternatives such as beans, tofu or low-fat cheese.



- Avoid supersized portions and second helpings.
- In restaurants, you can choose appetizer portions. You can also ask for a small portion or plan to take some home.

Try new recipes

For healthy recipes go to heartandstroke.ca/recipes.

Be more active

Regular physical activity for 150 minutes or more a week is a great way to maintain a healthy weight, reduce high blood pressure, lower cholesterol levels, manage diabetes and manage stress. It can cut the risk of heart disease and stroke by 30%.

Talk to your healthcare team about the right way for you to get active. The team will factor in your abilities, your health and your interests. They will help you to come up with a plan that is enjoyable and safe. Ask about programs in your community that would meet your needs and abilities.



Dawn



John

No matter what your state of health, there is something you can do to stay active. Maybe you can do yoga or tai chi. Maybe you can go for more walks. There are exercises you can do from a chair or in bed.

Start with 10- to 15-minute sessions. Increase the time, frequency and intensity as you grow stronger. Eventually, you can work toward the recommended 150 minutes total per week.

Quit smoking

Smoking and exposure to second-hand smoke increase the risk of stroke. Twenty minutes after your last cigarette your blood pressure and heart rate will drop reducing your risk. Quitting will decrease the plaque in your blood vessels.

Quitting is one of the best things you can do to reduce your risk of another stroke. You might be afraid that quitting will be too hard, but there is lots of help available to you when you are ready. Here are some tips to get started:

- Think through the pros and cons of quitting. Try to imagine how much better you would feel and how proud you would be if you could quit.
- Understand your smoking habits. Smoking is an emotional as well as a physical habit. What are the triggers that give you the urge?
- Make a plan for quitting. Your healthcare team can tell you about programs to support you. Call **1-866-366-3667** to talk to someone about quitting. There are lots of helpful booklets and online programs.
- Your health-care team can help with nicotine replacement and other therapies.
- Involve your family and friends for support.

Drink less alcohol

Heavy drinking and binge drinking are risk factors for high blood pressure and stroke. Alcohol may also cause problems by interacting with your medications.

Follow the guidelines for moderate drinking:

- 10 drinks a week for women, with no more than 2 drinks a day most days
- 15 drinks a week for men, with no more than 3 drinks a day most days
- Always consider your age, body weight and health problems that might suggest lower limits.

“A drink” means:

**341 mL / 12 oz (1 bottle)
of regular strength beer
(5% alcohol)**

**142 mL / 5 oz wine
(12% alcohol)**

**43 mL / 1½ oz spirits
(40% alcohol)**

Be aware of your drinking habits. Plan non-drinking days each week. Track the number of drinks you have every day.

Talk to your healthcare team if you would like to find a program to help you deal with alcohol problems.

Quit recreational drug use

Recreational drug use increases your risk of another stroke. Talk to your healthcare team about programs in your community to help you quit.

Manage stress

We know that some people who have high levels of stress or prolonged stress have higher cholesterol or blood pressure. They may be more prone to narrowing of the arteries (*atherosclerosis*), a stroke risk factor.



Music helps me to relax and feel good.
- Carol

Here are some tips for managing stress:

- Ask yourself what causes your stress. If you are aware of its cause, can you eliminate it? If not, find ways to manage it?
- Talk about your feelings to family, friends or a healthcare team member.
- Do things that you find relaxing, such as listening to music, reading, walking or meditation.

Make a plan for healthy changes

The key to making changes is developing **healthy habits that stick**. The change should become a habit that you do every day without thinking, like brushing your teeth. Here are seven tips for planning a change.

1. Set a goal

Your health-care team can help you decide which lifestyle changes would have the greatest impact on your overall health and risk of

another stroke. Make sure it is a change that you feel confident you can achieve.

Choose one goal that you can achieve in a short period. For example, “I will walk around the block once a day for a week.” Make the goal specific and realistic. Set yourself up to succeed!

Your goal should also be something you can measure, so that you will know you achieved it. For instance, “I will eat seven servings of vegetables and fruit each day.” Instead of “I will try to eat more vegetables and fruit.”



I always make short-term, easy goals so I can succeed. Long-term goals can be discouraging. - Lindsay

2. Figure out how you will achieve your goal

Planning how you will achieve your goal is one of the most important steps to success. Ask yourself, “What do I need to do to reach my goal?”

Make a plan that sets out specific steps to success. For example, if your goal is to eat seven servings of vegetables and fruit every day, you could break it down this way:

How many servings do I eat now?

I eat four per day. I will need to add three to reach my goal.

Ideas to add servings each day:

- Eat salad for lunch.
- Have a smoothie for a snack.

- Add one serving of steamed vegetables, for a total of two, at dinner.
- Make vegetable soup for lunches.
- Have a piece of fruit for an afternoon snack.
- Eat a piece of fruit for breakfast each morning.
- Choose a vegetable stir-fry when out for dinner.



What I can do to make it happen

- Plan my meals for the week.
- Shop with a list that includes extra fruit and vegetables.
- Wash and cut up fruit and vegetables ahead of time.
- Keep track of the fruit and vegetables I eat each day.

3. Prepare for obstacles

Try to think ahead about the challenges you might face. Develop a plan to meet them. For instance, you may have to miss a morning walk if you have a doctor's appointment. Plan to walk after lunch or dinner instead.

4. Get support

Ask family and friends for support. If you have a partner, ask them to adopt the change as well. Here are some more tips on reaching out for support:

- Ask a family member, friend or neighbour to go for a walk with you.
- Ask for help to cut up vegetables and fruit.
- If you do not buy the groceries, ask whoever does to buy only healthy snacks.
- Ask your healthcare team for information and coaching. For instance, your physiotherapist can give you a safe exercise routine. Your dietitian can help with healthier food choices.



My wife learned how to buy groceries a different way. Making healthier choices for all of us. – Ken

5. Track your progress

The more you track your progress, the greater your chances of achieving your goal. Keep a log or record of what you are doing to work toward your goal.

If your goal is to eat seven servings of vegetables and fruit each day, this simple log will track your vegetable and fruit servings for each day of the week.

Date	Vegetables and fruit
Monday	Breakfast - 2 Lunch - 2 Snack - 1 Dinner - 2 Total - 7
Tuesday	Breakfast - 2 Lunch - 1 Snack - 1 Dinner - 2 Total - 6

You only need to track the changes until you feel that they have become a regular habit. That usually takes three to six weeks.

6. When things go off plan, keep going!

It can be hard to stick to a plan if you are tired, stressed, or not feeling well. Setbacks are a normal part of the process — they are not a failure. Don't give up. Here are some tips to help you turn a setback around:

- Remind yourself why you want to make the change. Think about how important it is.
- Look at what you've achieved so far. It is human nature to focus on the things we don't get right, but try instead to give yourself credit for what you have accomplished.
- Start keeping a log again.

- Look at what caused the setback. What can you do if it happens again? Look for support. Ask your family to help you get back on track.
- Check your goals again. Are they specific, realistic and measurable? Do you need to change them?
- Do you need to change your plan?

7. Celebrate success!

Whenever you make a small step toward your goal, pat yourself on the back and congratulate yourself. Reward yourself with something you like — time with a friend or a favourite movie.

Work with your healthcare team

Know your numbers

Your healthcare team uses numbers as one way to track your health — numbers such as your blood pressure reading and your blood test results. Get to know what these numbers mean. Talk to your team about the targets they feel are right for you. Ask about your results and track your progress.



Take your medications as prescribed

Managing your medications properly will help you to avoid another stroke.

- Take all medications unless your doctor tells you to stop. If you have to stop on your own for some reason, tell your doctor or nurse practitioner right away.
- Mark your calendar when your prescription runs out. Make sure you have an appointment to renew your prescription before you run out.

- Make sure your doctor knows about all of the medications that you take. This includes prescription drugs, over the counter drugs, and herbal remedies.
- Always check with your pharmacist when you buy anything over the counter, to make sure there are no problems taking it with your other medications.
- Keep a complete list of the names of your medications. Record the dose (how much) and how many times a day you take it. Keep this list in a handy spot in case your family or emergency personnel need the information.

Tips for keeping your medications organized:

- Get a pill container (*dosette*) and fill it weekly.
- Ask your pharmacist to prepare your medications in a blister pack with individual doses. This only works well if you are able to open the blister packaging on your own.
- Take your medication at the same time every day.
- Use visual reminders. Keep your pills where you will see them often, such as on the counter. Or put a sticker on the bathroom mirror to remind you.
- If you are going out, make sure you have your medication with you.



Stay in touch with your healthcare team

Make regular appointments with your doctor or nurse practitioner. Report any changes in your condition. Ask questions. Be sure to ask for any prescription renewals you need.

Living WITH PHYSICAL CHANGES



Mathew and John

4. *Living* WITH PHYSICAL CHANGES

Stroke is a major life event. It affects each person differently. There may be changes in how you live day-to-day. You may need to find new ways to do things — your new normal.

This is a time to be creative in how you go about your daily life. Talk to people around you about how you feel as you adjust. Get ideas from other people with stroke. They can be a helpful support.

Communication

We communicate our thoughts, ideas and feelings to others in many ways. We do it with words — spoken or written. We communicate through the use of voice, hand gestures, face and body movements.

After a stroke, communication problems are common. You may find yourself using the wrong word or not able to create sentences. Or you may repeat yourself. You may misunderstand what people are saying. You may find that you are unable to read and write. *Aphasia* is the term given to these problems with communication.

You may also find yourself having slurred speech. *Dysarthria* is the term given to this problem with speech.

Aphasia

There are two types of aphasia:

Expressive aphasia

You know what you want to say but the words come out wrong. The words may:

- be jumbled

“*My biggest frustration today is knowing what I want to say and not being able to say it, I now need a script or notes to communicate, I can't be spontaneous.* – Lou

To learn more about aphasia go to:
aphasia.ca

- not make sense
- be totally different from the words you wanted to say.

Receptive aphasia

- You can hear spoken words and see written words, but have a hard time knowing what they mean.
- You may also take word meanings very literally and be unable to understand some forms of humour.

Some people with stroke may have both expressive and receptive aphasia. Either type makes it hard to read, write, work with numbers, join in conversation, or share thoughts and feelings.

Aphasia can be mild or severe, depending on your stroke. It may be temporary and improve quickly. For some people, it is long-lasting or permanent.

Aphasia can be very frustrating. You may find it hard to enjoy time with family and friends, or even to ask for what you want or need. You may find that some people treat you differently.

Try to let people know how you feel. Make sure they know you are still able to join in conversations in your own way. Get those closest to you to read this section. This will help them understand what you are experiencing and give them ideas for how to communicate with you.

Your first goal may be to find a way to communicate with your family and team. Right after the stroke, you may need to use other forms of communication such as picture boards, hand signals, or using a pencil and paper to draw or write words.

Strategies for communicating

Find out what part of your communication is affected. The therapist on your healthcare team who can help you with communication is called a *speech language pathologist*. If you are not seeing one, get a referral.



Your therapist will help identify what type of communication and speech problem you have. Then they will develop a plan to help you regain communication skills. Here are some areas they may work on:

- improved understanding in conversation — asking you to match pictures to a spoken phrase
- improved ability to use the right words — asking you to name things you see in pictures
- improved ability to read — working with you to read a short paragraph and answer questions about it
- improved ability to write — practicing skills needed to write
- improved ability to speak clearly — exercises to strengthen the muscles involved in speech.

Make a plan with your therapist. They can show you how to practice to improve your communication skills. Make sure your family and friends know about your plan and how they can help you communicate with them.

Tips for staying connected

Here are some strategies that people with aphasia use to communicate:

- Focus on one task. Don't try to multi-task.
- Write things down before saying them. Try using short written notes. Keep a pencil and paper handy.
- Try using flashcards with keywords and pictures, like TOOTHBRUSH.
- When people communicate with you in writing, they should use markers that make it easy for you to see the words. When you are writing, using a pencil is easiest.
- Use Scrabble™ tiles to spell out words.
- Not able to write? Try gestures, hand signals and simple picture boards to point at.
- If you have trouble finding words, try looking around to find clues from your environment.



- Computers and smartphones have apps to help with aphasia. They speak words that are typed. Or they may help you find the name of an object.

Tips for family and friends

- get the person's attention
- speak slowly and clearly
- give one idea at a time
- use yes or no questions
- avoid open-ended questions. Instead of asking, "What would you like to drink?" ask, "Would you like tea or coffee?" Ask "Can you show me?" Gesture or point to an item
- repeat or re-word sentences.
- write down your message with a black marker
- don't interrupt
- pay attention to body language

“ At work, people often bombard me with things to do for them, it sends my stress level through the roof, even today. Let me do it my way at my own pace. – Keitha

Where to get support:

Speech language pathologists are the team members who specialize in helping you communicate.

Check if there are aphasia support groups that meet in your community.

Challenges with arms and legs

The effects of stroke can leave one side of your body paralyzed or weakened. This poses challenges to your independence.

Problems with muscles

Stroke can affect muscles in your arms, legs, hands and feet. The muscles can shorten and become very tight. This is called *spasticity*. Or they might become limp and soft (*flaccid*).

These muscle changes can cause problems with the joints they support. When there is low muscle tone around the shoulder joint, it can lead to *shoulder subluxation* – a partial dislocation of the shoulder joint. This can be prevented with proper movement and positioning. You should never force an affected limb to move. Talk to your team about strategies.

Muscle problems can also cause *shoulder or hand syndrome* – a stiff, swollen and painful shoulder or hand and wrist.

Treatment for muscle problems may involve:

- proper positioning
- using splints or orthotics – special devices that help position joints
- physiotherapy
- exercise
- injecting botulinum toxin (Botox®, Xeomin®)



Muscle spasticity is increased muscle tone or stiffness, and an increased resistance which may lead to uncontrolled, awkward movements. It may also lead to a tight closed fist. It is important to make sure the hand stays clean and dry, and that the nails are well trimmed. Good hygiene can prevent skin damage. Talk to your healthcare team about the best way to manage your spasticity and take care of your contracted hand.

Where to get support:

The members of your healthcare team who can help may include a:

- physiatrist (rehabilitation doctor)
- occupational therapist
- physiotherapist
- nurse.

Getting around (mobility)

Getting around your home and community is an important part of your independence. After a stroke, muscle, strength and balance problems may make it hard to get around independently. Some people may need assistive devices such as a walker or wheelchair. No matter how you get around, it is important to keep safe.

Mobility aids

A mobility aid is any assistive device that helps you get around. Make sure it meets your needs, both inside and outside of your home. All devices need to be fitted to you. You will also need instructions on how to use them safely. Your physiotherapist or occupational therapist can help with this.

Orthotics and braces

Orthotics or braces can be helpful for people who have weakened or spastic muscles after a stroke. They can support and stabilize the limb to help it function.



Walkers

Walkers can provide you with support when walking. Some have no wheels, two wheels or four wheels. Your physiotherapist will make sure you get the one that is right for you and will show you the correct posture when using it.

Canes

There are different types of canes. Some have a single prong at the end. Some canes are balanced with three prongs. Some have a rubber tip, with a claw you can attach for walking in winter.



Wheelchairs

There are two types of wheelchairs: manual and electric. A manual chair is fine if you have the strength to wheel it yourself, or if someone will be pushing you. Electric wheelchairs are an option if they fit in your home and you are able to operate one safely.

If you need a wheelchair, you should be fitted by a member of your healthcare team. They will show you how to sit properly and check to see if you need a seat cushion or back rest. Proper positioning prevents injury and pressure sores. You will need to learn to transfer or move safely from your wheelchair to the toilet, bed or another chair.

You will need to plan how to get around your home in a wheelchair. Is there enough room to pass through doorways and turn around?

Make sure that your wheelchair has a seatbelt — and use it. A team member will help you learn how to transfer in and out of the chair safely.

An electric scooter may be an option for you.

Where to get support:

Your occupational therapist and physiotherapist will help you choose and fit your mobility devices. They will train you to use them safely.

Provincial or private insurance plans may fund mobility devices.

Local service groups sometimes lend equipment.

Swallowing problems (dysphagia)

A problem with swallowing food and drink is called dysphagia. This happens when you have trouble using the muscles in your throat or your mouth to move food and drink around. Or, you may have lost feeling in your mouth. Dysphagia can put you at risk of choking or inhaling food (*aspiration*). This can lead to pneumonia. Dysphagia can also put you at risk for not getting enough to eat (*malnutrition*) and not getting enough to drink (*dehydration*).

If you have dysphagia, the speech language pathologist, dietitian or occupational therapist on your team will work with you. They will help develop a plan to make sure you are able to safely eat and drink.

The plan will tell you what the best food consistency is for your swallowing abilities. For some, softer foods with a finer consistency are easier to swallow. Examples are mashed potatoes, ground meat or stewed legumes such as lentils or dhal.



The swallowing problems were the scariest part of my recovery. I had to experiment to find foods that worked for me. – John

Some people find thickened liquids easier to swallow. Each person is different — ask your team what is best for you.

Here are some safe eating tips:

- Make sure you are sitting up straight.
- Remove distractions, such as TV, radio or cell phone.
- Do not talk when chewing. Ask people not to ask questions or distract you when you are eating.
- Cut food into small bites. Use a teaspoon instead of tablespoon to make sure you are not putting too much in your mouth at once.
- Chew food completely on the stronger side of your mouth. Swallow before taking the next bite.



Getting enough liquids

Sometimes when drinking is challenging, people avoid it. This can lead to problems like dehydration or constipation. Make sure you drink six to eight cups a day of non-caffeinated, non-carbonated fluids that are easiest for you to swallow. Keep a water bottle or travel mug filled with the right liquid close by at all times. Take sips often throughout the day to stay hydrated.



Where to get support:

Speech language pathologists, dietitians and occupational therapists can help assess your eating and swallowing problems.

Dietitians can help you find healthy food choices that fit your situation.

Bladder and bowel problems

Incontinence means poor control of the bladder and bowel. It affects many people after a stroke. Sometimes incontinence is caused by your brain having trouble communicating with your body. Also, you may have difficulties getting to the bathroom or taking clothes off in time. If you already had bowel or bladder problems before the stroke, the incontinence may have become worse.

Sometimes medication can affect your bladder and bowel. If that is the case for you, speak with your doctor about it. Do not stop any medication without first speaking with your doctor.

Many people recover control of their bladder and bowel function soon after stroke. Some may still have problems several months later.

Bladder problems

There are several types of bladder problem:

- **Urinary incontinence** is the loss of control of your bladder.
- **Urinary frequency** is the need to use the toilet more often.
- **Urge incontinence** is the sudden need or urge to urinate.
- **Functional incontinence** means trouble getting to the toilet in time or trouble getting clothes off soon enough.
- **Night time (nocturnal) incontinence** is the need to use the toilet several times during the night, or wetting the bed at night.
- **Stress incontinence** is loss of bladder control due to pressure on the abdomen. For example, wetting yourself after sneezing or exercise.



I am still struggling somewhat with my bladder. Two and a half years later. Again, embarrassing. – Keitha

Urinary tract infection

Problems with emptying the bladder can lead to urinary tract infection. Contact your doctor if you see signs of infection. Symptoms include:

- needing to use the toilet often, even if the bladder is empty
- having accidents

- pain or burning while urinating
- stomach cramps
- cloudy urine or urine with a strong smell
- fever or increased body temperature
- for people with aphasia, a change in behaviour, such as agitation.

Bowel problems

Bowel problems can occur after a stroke:

- **Constipation** develops when bowel movements do not occur as often as they used to or you have trouble passing stools.
- **Diarrhea** is loose bowel movements.
- **Bowel incontinence** is the loss of control of the muscles around your lower bowel.
- **Functional bowel incontinence** means trouble getting to the toilet in time or trouble getting clothes off soon enough.

Strategies for dealing with bladder and bowel problems

Talk to your healthcare team about what is causing your problem. They can help you understand the cause and suggest strategies to deal with it. Here are some common strategies:

Make getting to the bathroom easier

- Clear a path. Remove any items, such as furniture or mats that block your way to the toilet.
- Install a night light.
- Use a raised toilet seat. These come with or without armrests and make it easier and safer to get on and off.
- If getting on or off the toilet is too hard or unsafe, use a commode (portable toilet) or urinal. This can be particularly helpful at night.



Commode

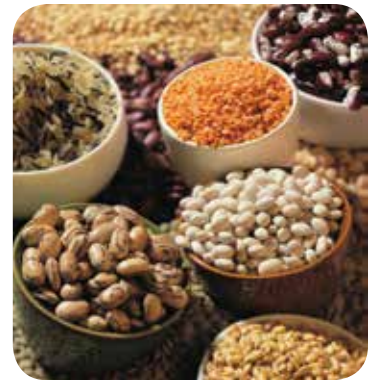
When control is lost

If you are unable to control your bladder, continence products will help keep you dry. Be sure to use continence products, not menstrual pads. Continence products are better at drawing the urine away to promote healthier skin.

Constipation

To help prevent constipation:

- Make sure you drink enough liquids (6 to 8 cups per day).
- Increase the amount of fibre in your diet. Whole grains and legumes such as lentils and kidney beans, are good sources of fibre.
- If water and dietary fibre do not help prevent constipation, speak to your healthcare provider about over-the-counter products that may be helpful.
- Keep as active as you can.



Retraining

Your healthcare team may suggest retraining. This involves going to the toilet on a regular schedule, for example every two hours for bladder, every morning for bowel.

Refusing liquids is not a good strategy

No matter the cause of your problems, it is very important to drink enough liquids to prevent dehydration — six to eight cups per day.

Where to get support:

Physiotherapists can teach you pelvic floor exercises that strengthen the muscles you need for control.

Occupational therapists can help make it easier to get to and use the toilet.

Nurses can help with skin care and tips for retraining.

Dietitians can help you choose high-fibre foods and plan ways to drink more liquids.

5

LIVING WITH *Changes* TO EMOTIONS, ENERGY, COGNITION AND PERCEPTION



Ramona and Ramon

5. LIVING WITH *Changes* TO EMOTIONS, ENERGY, COGNITION, AND PERCEPTION

Stroke has effects that you cannot see. Changes to the way you feel and think can have a big impact on your life.

Emotional changes

The emotions you have throughout your recovery can be intense and change quickly. Intense feelings are a normal reaction to a big health event, but they can also be a result of brain injury from a stroke.

“It is sometimes harder to deal with the invisible deficits such as depression, emotional changes, problem solving as they are not apparent to the outside world. – Lou

Your care partner and close family and friends will likely go through many emotions too. They are on a parallel journey with you.

Feelings you may experience after stroke:

Anger: Thinking “Why has this happened to me?” or “What did I do to deserve this?”

Anxiety: Worrying about the future or how well you will recover.

Denial: Acting as if there is nothing wrong because it hurts too much to face it.

Embarrassment: Feeling awkward and ashamed that you are not able to function as you did before.

Fear: Worrying about having another stroke.

Frustration: Losing patience with yourself for not being able to do things you used to do. Losing patience with others for treating you differently, or not understanding how you feel or what you want.

Grief and sadness: Feeling sorrow about your loss of ability, or sadness about not having the same future you once saw for yourself.

Guilt: Feeling guilty about the changes your stroke has caused in the family, or about your need for more support. Also, a stroke can sometimes make people feel guilty about things that happened a long time ago.

Loneliness: Feeling that you are all alone and that no one understands what you are going through.

Controlling emotions after a stroke

Damage to the brain from a stroke may also affect your ability to control your emotions. This is called emotional incontinence or lability. You may find that you cry suddenly or frequently for no reason. Or you may respond in a different way than you want to. For example, you may laugh at a sad time.

Depression

There is a difference between sadness and depression. Sadness comes and goes. It is normal to feel sadness and a sense of loss after a stroke. Sadness that doesn't go away may mean depression. It is common for stroke survivors or their care partners to develop a true clinical depression. Know the signs of depression and contact your doctor if you see them. Depression can slow down your recovery. There are treatments that can help.



My faith has provided me with strength in accepting my new normal. – Ramon

Some physical signs of depression:

- changes in your sleep pattern (not sleeping well, or sleeping more than normal)
- changes in appetite
- gaining or losing weight without trying
- feeling tired, having much less energy
- feeling restless
- persistent headaches
- chronic pain or digestive problems (such as stomach aches, nausea, constipation or diarrhea).



Some emotional signs of depression:

- feeling sad, anxious, irritable, nervous, guilty, worthless or hopeless
- not feeling interested in doing things you used to enjoy
- finding it hard to focus, remember things or make decisions
- changes in your work style or zest for work
- constant thoughts of death.

If you believe someone is in danger because of their thoughts of suicide, call a distress line or 9-1-1 right away.

If you have any of these symptoms for more than two weeks, contact your doctor. Treatment can involve speaking to a trained mental health professional, taking medication or both.

The difference between sadness and depression:

The blues or sadness	Clinical depression
You feel sad or unhappy. (We all feel this way sometimes).	Clinical depression is a medical illness.
You know why you feel sad or blue (because of a sad event).	You do not know why you feel the way you do.
You find that the feeling of sadness goes away on its own.	Clinical depression does not go away without treatment.
You notice that your sad mood is temporary — it lasts a few days or weeks.	Clinical depression can last months or years.

Emotional issues are part of your journey

You may naturally want to hide your feelings. You may not want to share feelings of sadness or

“ I keep a journal of one positive thing that happens everyday, so when I am down it shows me that there are good parts in my life. – John

depression. But keeping emotions inside can interfere with your recovery. Sharing your feelings, as hard as it may be, is a step toward meeting your recovery goals.

Find people you can talk to about your feelings. This might be family, friends, other stroke survivors, someone from your faith community, or a member of your healthcare team. Join or start a support group. If any of your feelings become overwhelming, talk with a healthcare professional right away.

Where to get support:

Talk about how you are feeling to a member of your healthcare team you are comfortable with. A psychologist or social worker might also help.

Speak with people in your life that you are close to and trust.

Look for support groups or peer visiting programs. Talking to others who live with stroke can help.

Low energy (*fatigue*)

One of the invisible effects of stroke is fatigue, both in body and mind. It is tiredness that does not go away with a good night's sleep. It can leave you feeling like you have no energy. You may get tired after just a short period of activity, even just getting up to eat breakfast.

Feeling tired for a few weeks is normal. Post-stroke fatigue is a sense of intense tiredness that does not get better with rest. It can lead to depression and isolation. It is important to tell your team you are having post-stroke fatigue.

Recovering from a stroke takes a lot of energy and thought. Here are some tips for managing and maximizing your energy.

“As a mom, wife and child of elderly parents I wanted to still be able to do everything I did before. Without pacing myself I would become too exhausted by mid-day. And end up missing important activities. Plan ahead!! – Patrice

Structure your day

- Keep a schedule of daily activities.
- Know your high and low energy times.
- Plan your activities a day in advance. Anticipate the energy needs for each one.
- Schedule rest periods. Plan higher-energy activities in the morning or after a rest.
- Balance your activity level to make sure you have the energy you need to get through the day.
- If the day's tasks will take more energy than you have, pick your priorities. Be sure to include things you enjoy.
- Talk about your energy level and need for rest with your family and friends. Ask for help with high-energy tasks.

Arrange your space

- As much as you can, arrange your home so that it is easy to move around in.
- Reduce the need to climb stairs.
- Put frequently-used items where they are easy to reach.
- Sit rather than stand when doing chores such as ironing or washing dishes.
- Use energy-saving equipment and technology. For example, try shopping online.

Eating, sleeping and staying active

- Eat a healthy diet to maximize your energy levels.
- Establish good sleep patterns. Go to bed and get up at the same time every day.



- Include down time, rest periods or naps in your day.
- Avoid sedating drugs and excessive alcohol.
- Take part in exercise and leisure activity you can tolerate. Talk to your healthcare team about what is safe for you.
- Set goals to gradually increase the intensity and duration of exercise.

Where to get support:

An occupational therapist can work with you on a plan for reducing the energy needed for your daily tasks.

A physiotherapist can help you plan exercises and safely increase the amount of exercise you do.

Your family and friends can help you get things done.

Cognitive problems (*thinking*)

Understanding problems you have with thinking or cognition can help you develop strategies to manage daily life. Talk about your problems with your healthcare team. They will help you make a plan you can share with your family and friends.

Areas of cognition that can be affected by stroke

Attention: Being able to concentrate on one thing for the time needed.

Examples: You become easily distracted when performing a task - like getting dressed or eating take longer.

Tips and strategies

- Find a quiet space when you are trying to do something.
- Turn off all distractions, such as radio or TV.
- Keep clutter to a minimum.
- Take your time and do a task one step at a time.

Areas of cognition that can be affected by stroke

Tips and strategies

Orientation: Being aware of time, place and who you are.

Examples: You may think it is time for lunch soon after breakfast.

- Keep a calendar and cross off the days as they go by.
- List the times for your daily activities and check them off once you finish.
- Try to establish a routine, doing the same thing at the same time of day.

Memory: Being able to remember personal experience, information and skills.

Examples: Stroke can affect your ability to learn new things or remember old information to help you with everyday tasks. You may forget the names of ordinary things. Or you might forget the exercise instructions you get from your physiotherapist.

- Writing down important information in a journal can be helpful.
- Put signs and labels on things you keep forgetting or want to remember.
- Store items in the same place every time you use them.
- Try memorizing the words to songs or poems you like.
- Use on-line memory games.
- Read anything that interests you.

Sequencing: Being able to arrange things or perform actions in the right order.

Examples: It may be hard to get a task started or remember what the next step is. This can cause trouble with things like getting dressed — for instance, forgetting to put socks on before shoes.

- Break down a task into very short, numbered steps.
- Follow the steps every time you need to do the task.
- Write the steps down and keep them where you can see them.

Areas of cognition that can be affected by stroke

Tips and strategies

Problem solving: Figuring out how to solve a problem takes many parts of cognition.

Example: You may not realize that you are having trouble putting toothpaste on your brush because you have forgotten to take the cap off. Solving this problem requires memory skills, sequencing skills and insight.

- Break the problem into small parts.
- Brainstorm possible solutions.
- Get family and friends to help if needed.
- Practice solving problems with word and number puzzles.

Insight and judgment: Knowing what we can do and understanding our limits; making good choices based on our understanding.

Example: You may not understand that you have poor balance and should ask for help when getting up. You may try to get up on your own and risk falling.

Post reminders such as:

- Don't stand up without help.
- Put on your coat when you go outside.

Where to get support:

Occupational therapists can help you adapt tasks to your abilities.

Talk to your healthcare team and your family and friends about your thinking skills. Let them know if you think you are having more difficulties.

Changes in perception

Perception is the way your brain tells your body about what is going on in the space around you. Here are some areas of perception that may be affected by stroke and some tips for dealing with them:

Areas of perception	Tips and strategies
<p>Vision: may be affected several ways.</p> <p>Examples:</p> <ul style="list-style-type: none">• double vision• partial loss of vision in one or both eyes• blurred vision• loss of visual field (blind spots).	<ul style="list-style-type: none">• Lighthouse strategy: This means that you turn your head from side to side using the visual field you still have, in a sweeping motion to look at the whole room. This makes up for the loss of visual field.• Put signs on the doors, such as “bathroom” to help you find your way.• Use tools such as prism glasses and patches as recommended by your healthcare team.
<p>Sensation: feeling may be lost on the side of your body affected by stroke. This can put you at risk for injury.</p> <p>Example: you may not be aware of a shoe rubbing or hot liquid in a cup.</p>	<ul style="list-style-type: none">• Use a silicone glove when handling hot pans.• Adjust the water heater to a safe temperature.• Check the skin on the affected side for red marks.
<p>Spatial relations: estimating or judging the space between things around you.</p> <p>Examples: you might:</p> <ul style="list-style-type: none">• misjudge the height of steps or bathtubs.• trip over rugs, steps or uneven pavement.• miss the chair when sitting down.	<ul style="list-style-type: none">• Understand and identify safety issues in your environment.• Tape the edges of tables and stairs to provide a point of reference.• Always make sure you can feel the seat of the chair you are about to sit on.

Areas of perception

Tips and strategies

Time awareness: recognition of time passing.

Example: you may feel that time is passing more slowly or quickly than it really is. For instance, you may think it is time for lunch soon after breakfast.

- Keep clocks and calendars handy.

Unilateral body neglect: a decreased awareness or failure to attend to one side of the body.

Example: you may be unaware or less aware of the side of your body affected by stroke, so you do not take care of it. You might put only one arm into a shirt.

- Learning to scan the neglected side with your eyes (visual scanning). Or use a mirror to remind yourself of the affected side.
- Include your affected side in any task.
- Rub the affected arm and leg. Post reminders such as, “Rub your left arm.”

Visual neglect: seeing only part of what is in front of you.

Example: you may only recognize or perceive part of the table or plate.

- Have people approach you from your neglected side to increase awareness.
- Place articles you use frequently such as phone or remote on your neglected side.

Pain: shoulder pain is common after a stroke. This happens when poor muscle tone moves the joint out of place (*shoulder subluxation*).

Damage from a stroke can also cause burning or stabbing pain in an arm or leg. It can be made worse by touch or cold temperature.

- Always lie, sit and walk in recommended positions.
- Change positions often. Avoid long periods of time in one position.
- Monitor and track your daily pain levels.
- Follow your plan for pain control.
- Sometimes physio, massage or pain medication can help.

Where to get support:

Talk about your perception problems with your healthcare team and find out who can provide the best support for each problem. Make sure your care partner, family and friends understand where you are having challenges, so they can support you.

Help us make this guide better!

There is a brief survey at the back of this book. Please fill it out once you have read it. You can also fill it out online at heartandstroke.ca/feedback



Dawn and Shani

6. Relationships

Stroke recovery can take a toll on everyone. Care partners have a critical role to play in their partners' recovery. But new roles and providing daily support can be tiring.

Pages 4 to 6 of this guide outlines the need for care partners and family members to watch themselves and one another for signs of burnout. Make sure that you are familiar with the message for care partners and that you are aware of the signs of burn out.

Connecting with family and friends

Connecting socially is not just enjoyable — it is essential for your health and recovery.

Having a stroke may change the way you connect with people. Changes in the way you look and feel may have affected your confidence. These feelings sometimes stop you from doing things that once mattered to you. You may avoid social activities, family and friends.

If you are finding it hard to connect, talk to your family, friends and healthcare team about what you are feeling and how you can get help.

For some friends and family, the changes caused by the stroke may make them uncomfortable, so they do not connect with you as often as before. Some may think that it is better not to intrude on your recovery. Some might not know how to connect with you anymore.

Think about asking them why they are not connecting. It might help them if they understand your experience better, your need for connection and the best way to do that.

“Not all your friends will understand what you are going through and some will drift away. In fact quite a few of our current friends never knew us pre-stroke. – Frank, Lou's care partner

Parenting after a stroke when you still have younger children

A stroke creates physical and emotional demands on both parents and children. It affects each member of the family differently.

The parent who has had the stroke needs to focus on recovery and may be less able to be the parent they were. Others in the home often take on extra roles and responsibilities.

Some children may develop behaviour problems or show signs of depression after a parent has a stroke. Here are some tips to keep connected to your children:

Communicate. Make sure to give children a chance to express their feelings and concerns. Be open, sensitive and honest.

Be yourself. Do not let the stroke be the focus of your relationship with your child.

Make time. Plan time in each day for your child.

Be supportive. Try not to let the situation overwhelm you and the children. Plan to cope as a family with each problem as it occurs.

Use your children's talents. Empower them by hearing what they have to say and by using their ideas to solve problems.

Maintain routines. Include having fun as part of the routine. It helps to cope with uncertainty.

Make children part of the team. Involve them in parts of your therapy. Teach them how to handle emergencies. Make sure they know how to respond if another stroke occurs.

Talking to children

Children often blame themselves when something bad happens in a family. They need to know that no one caused the stroke and no one is to blame.



“ My son Mathew helped with my physio, it helped him understand what I am going through. – John

Explain that a medical problem caused the stroke. Make sure they understand and accept that it did not happen because of anything they said or did.

Here are some tips for talking to children about stroke:

- Explain what a stroke is by using words your child can understand. You could say: “A blood vessel taking blood to my brain was not healthy. It started to bleed. That meant my brain did not get enough blood for a while.”
- Talk about the stroke: what caused it, how it feels — the good and the bad.
- Explain the results of having a stroke. Explain the changes you are experiencing and that you may not be able to do the same things as before, or you may do them differently.
- Talk about the effects that cannot be seen such as fatigue and memory problems.
- Explain that you may need a lot of rest to get better and it may take a long time.

Where to get support:

Talk with your doctor, nurse, social worker or someone from your faith community.

Family and child services in the community may offer counselling and play therapy for children.

Sex and intimacy

Being intimate with someone you care about can be an important part of a relationship. The effects of stroke can affect intimacy with your partner. Here are some possible problems:

- The stroke may have damaged the part of your brain that controls your sex drive.
- You may feel emotionally overwhelmed and find it hard to focus on intimacy.

- Fatigue and depression may affect your desire and sex drive.
- You may fear that you will have another stroke during sex.
- You may have lost feeling on one side of your body.
- You may have trouble communicating with your partner.
- Men may have trouble getting an erection or ejaculating.
- Women may have less feeling in the vagina and more dryness.



Tips to help with intimacy

Timing

There is no defined time for resuming sexual relationships. It is up to you to know when you are ready.

You may want to start slowly with other ways to show intimacy and gradually work up to sexual intercourse.

Set the scene

Talk with your partner about the best times for getting together. Choose times when you are both rested and will have no interruptions. Set aside plenty of time. That way, if your sexual responses are slow, you are less likely to feel frustrated.

Relax together before you begin. Have a massage, listen to music or soak in a bath.

“*It is so important for both of you to reestablish the intimate side of your relationship. Seek support from healthcare providers who are open and willing to find answers. – Millie*

Before sex:

- Do not drink large amounts of liquid for two hours before sex.
- Empty your bladder.
- Avoid alcohol.

Try new things

If your stroke has caused loss of movement or feeling, experiment with new ways of having sex that make it as easy and comfortable as possible.

Use a lubricating jelly that is water-based to help with vaginal dryness. Avoid lubricants such as oils or petroleum jelly because they do not dissolve in water and can lead to infection in your vagina.

You and your partner may enjoy sharing sexy books or movies. Talk with your partner to see if this would be helpful.

There are many ways to show love and affection. Hugs, kisses, touch and massage are just a few. Take time to talk to your partner to discover different ways to please each other.

During intimacy, focus on the feelings on the side of your body not affected by your stroke.

Medication and your sex drive

After a stroke, your doctor may prescribe pills to lower blood pressure or antidepressants. These medications can affect your urge or ability to have sex. Never stop taking a medication without consulting your doctor first. Talk to your doctor about how the medication is affecting you.

You may hear about herbal remedies that claim to boost your sex drive or sexual function. Natural and herbal products can interact with medication you are taking. Talk to your doctor or pharmacist first.

Where to get support:

Your family doctor, social worker, nurse or counsellor may be able to help if you have questions about intimacy or need to talk about it. They may recommend a therapist who specializes in sexual issues.

7

EVERYDAY *Tasks:* YOUR NEW NORMAL



Luis

7. EVERYDAY *Tasks:* YOUR NEW NORMAL

After a stroke, it can take time to figure out how to do the tasks that make up daily life — tasks such as washing, dressing, preparing and eating meals.

The healthcare team will use different approaches to help you meet your personal recovery goals in doing everyday tasks. Some of the therapies include:

Constraint induced therapy: This involves confining your stronger arm, to make you practice using your weaker arm.

Task-oriented training: This involves practising an everyday task with the goal of getting a skill back or gaining a new skill to replace it. The therapist might also ask you to imagine doing the task before trying it.

Strength training: These are exercises that increase muscle strength.

Compensatory therapy: This approach works by changing the environment, finding another way to do a task or using an assistive device such as a bath seat.

Assistive devices can help

There are many devices to support you in your everyday tasks. For example, there are devices to help with grooming and devices that can help with cooking. A member of your healthcare team, such as an occupational therapist, physiotherapist or nurse, can guide you in choosing devices. They will help to select devices that fit you and are useful and safe.

Try it out before you buy it. Make sure you get instructions that you can easily follow.

“*Embrace change, things are different, there are new rules. You have to learn how to play with new rules.* – Luis

You may be able to get devices at the hospital or rehabilitation center where you receive treatment. If not, ask for a list of companies that supply these devices in your area. You may also find local companies by searching on the internet.

“ Find the tools and knowledge to help you keep progressing forward. – Carol

General tips for any task

Arrange your living space to make it safe and convenient:

- Ensure there is good lighting and a clear path.
- Get rid of distractions like the radio or TV.
- Remove all area rugs and loose mats — these are tripping hazards. Add non-slip pads under larger carpets. Use two sided tape to make sure all corners and edges are stuck to the floor.
- Arrange furniture so that you have clear paths for walking and moving.
- If there are stairs, install railings on both sides. Consider installing an electric chair lift.

Plan in advance to make sure that the task is manageable:

- Make sure you have the energy needed for the task.
- Break the task into steps.
- Make a list of everything you will need for the task.
- Write the steps down and keep them close by when doing the task.
- Start with steps you know you can do and get help with the rest. Slowly work up to doing the whole task when you feel confident.
- Stay seated for a task if you have balance problems or are feeling tired.

If you are alone, make sure you have a way to communicate if a problem arises. This might be a portable telephone, a cell phone or a safety call button service.

Talk to your healthcare team for more tips, strategies and assistive devices for your tasks.

Bathing, grooming and dressing

Daily tasks like showering, shaving and brushing your teeth make you feel good. Here are some assistive devices that can help you perform these tasks safely on your own.

Bathing or showering

- special bath or shower chair or bench
- hand-held shower head
- tap handle extenders
- grab bars
- non-slip surfaces, such as rubber mats or appliqués to roughen a smooth surface
- soap on a rope or liquid soap in a pump bottle
- long-handled brush
- face cloth made into a mitt
- terry cloth robe instead of a towel



Shower chair with safety bars



Long-handled brush

Dental care

- built up toothbrush handle that is easier to hold
- electric toothbrush
- flip cap toothpaste instead of a screw top or a pump top
- floss picks instead of dental floss
- brush on a suction cup for dentures



Denture brush on suction cups

Shaving

- electric shaver
- magnifying mirror

Nail care

- nail brush on suction cup
- one-handed nail clippers

Dressing

- clothing with elastic waists and zippers or Velcro™ closings instead of buttons
- button hook
- front-closing bras
- clip or key ring to help pull up zippers
- suspenders instead of belts
- clip-on ties and earrings
- sock aid for pulling on socks
- long-handled shoe horn

Where to get support:

Look for organizations and businesses in your community that provide services in your home, such as:

- hairdressers and barbers
- nail services and foot care
- support in bathing.

Your occupational therapist can help you:

- decide which devices you need
- get the devices you need
- learn how to use them properly and safely
- organize your bathroom to make it safe and accessible.



Nail clippers on suction cups



Button hook



Long-handled shoe horn

Preparing meals, eating and drinking

Both physical and cognitive changes after stroke can pose problems in planning and preparing meals. For example, problems with a hand or arm can make it difficult to bring food and drink to your mouth. Cognitive changes may mean that you need to relearn how to do some kitchen routines safely.

An occupational therapist can help you find devices and strategies to manage meal times more independently.

Preparing meals

Planning

- Plan your meals a week ahead.
- Make a shopping list.
- Write down the steps needed to get a meal ready.
- Try to make double batches and freeze extras for another day.
- Set up a routine for preparing meals. Practice the routine often to help you remember the steps.
- Ask family and friends to get involved in meal preparation.

“ You need to find equipment that works for you in the kitchen. Look in regular stores, not just those that sell adaptive equipment. – Millie

Safety in the kitchen

The kitchen can be an unsafe place. Safety awareness is important for someone with stroke.

- Always wear protective, heat-proof gloves when handling pots and pans. This is especially important if you have lost feeling in your hands or if you might forget that something is hot.
- Arrange your kitchen to make it easier for you to reach things. Move frequently used ingredients to lower shelves. Keep dishes and pots within easy reach.

- Put rubber mats or wet cloths under plates and cutting boards to prevent them from slipping during food preparation and meals.
- When possible, use a microwave oven or toaster oven instead of the stove or oven.



Conserving your energy

- Sit in a chair when working at the kitchen counter.
- Change the knobs on doors to handles that are easier to grasp.
- Use cooking utensils and cutlery that are specifically designed for people with stroke.



A cutting board with a peg that can hold what you are cutting



A rocker knife or pizza cutter can be easier to use than a regular knife



A one-handed electric opener can help you open cans more easily

Eating and drinking

Assistive devices can help you if you have trouble coordinating your muscles while you eat and drink. These devices include:

- plates with big rims to hold food in
- dishes with gripper pads on the bottom so they don't slip
- modified utensils with built-up or bent handles



Plate with gripper pad

- one-handed cutting utensils
- cups with a cut-out or partial lid.

Dental health

Dentures, partial plates and other dental devices sometimes lose their fit after a stroke. Visit your dentist or denturist to have the devices assessed and altered as needed.

Good oral hygiene is especially important if you have swallowing problems (*dysphagia*). Clean your teeth after each meal.



Utensils with built-up handles

Where to get support:

Occupational therapists: can help you find devices to make cooking and eating easier. They can also help you organize your kitchen to help you cook and eat safely.

Dietitians can help you find healthy food choices that fit your situation.

If you cannot prepare meals on your own, here are some alternatives:

- community meal services such as Meals on Wheels
- grocery stores and private companies that sell complete, balanced, prepared, healthy meals
- grocery stores that deliver telephone or on-line orders
- healthy frozen meals. Read the labels to check for nutritional content. Make sure there are vegetables and protein. Some frozen packaged meals are high in sodium and fat and are less nutritious.

“A program in our community has frozen complete meals you can purchase at a very reasonable price. – Keitha

Driving

Many people see driving as an important part of regaining independence. Your ability to drive after a stroke depends on your vision, judgment, attention and physical abilities. About half of people with stroke can drive again. The loss of driving privileges can be very hard to accept as it means a loss of independence.

After a stroke, you are not allowed to drive until you have been assessed and cleared to operate a car by your healthcare team and provincial transportation department.

Before you get behind the wheel again

Driving is a complex activity. Driving safely uses all of your abilities — physical, cognitive and perceptual, as well as communication abilities. Stroke can affect these areas.

People are not allowed to drive after a stroke until they are assessed as capable. In many provinces and territories, doctors must notify the Ministry of Transportation when someone has a stroke. That means your licence will be suspended. Check the status of your licence and find out what is required to reinstate it.

Get assessed by an occupational therapist to see if you are ready to start driving again. If you have a physical problem, such as a weak arm or leg, you may still be able to drive. You may need to learn new skills and adapt your vehicle to drive safely.

Depending on your initial driving assessment, you may need to complete a written test and a road test before you can drive again. The provincial driving evaluator will work with you to figure out if you are ready to drive. If you have problems communicating (*aphasia*), he or she may use aids, such as picture cards, to support communication needed for the written and road test.

Be patient if driving is a goal. Give yourself time to recover from your stroke and prepare to drive again. Rushing into driving could put you and others at risk. And if you do not follow the assessment process, it could result in permanent loss of your license.

Accessible parking

Ask your healthcare team if you need to have an accessible parking pass. Find out how to apply in your province/territory.

Where to get support:

Your occupational therapist is the key team member to support your return to driving.

The transportation ministry in your province can help you figure out the process for getting your licence back.

Find out your transportation options. Some examples are accessible transit, taxis, volunteers, driving services, friends and family.

Household chores

Living at home is important to your quality of life. But mobility challenges and fatigue can make household chores difficult.

Get started with a plan

- Make a list of chores that need doing, when they need to be done and how often.
- Set priorities. Which chores are the most important?

“ *It took me a year and a half to get my licence back - but it was worth it. - Joe*



- Identify the chores you are able to do yourself and where you need some help.
- Talk to your healthcare team about what support is available in your community. Do an internet search of agencies in your area that can help.
- Share your list with your family and friends who have offered to help. Accept their help.



Shopping tips

- Write a list of the items you need to buy before you go to the store. Take the list and a pen with you. Cross off the items as you find them.
- If getting out is not possible, shop online or call in a telephone order to your grocery store.
- Try to do small shops more often. Getting too many items at once can be tiring. It means pushing a heavy shopping cart and carrying a lot of bags.
- Allow yourself plenty of time to do the shopping — do not rush.
- Ask a family member or friend if they can go to the grocery store with you.
- Ask for help if you cannot reach an item.
- Use credit or debit cards to pay, so that you don't have to count out cash.

Doing laundry

- Make sure you can get to the laundry area easily.
- Keep small, light laundry hampers in the bathroom and bedroom. Line them with shopping bags. This will make it a little easier to get the clothes out of the hamper and to the washer.
- Have a chair next to the washer so you can sit when loading.



- Clearly mark the settings on the washer and dryer. You can use coloured stickers or labels.
- Push buttons or large dials on laundry machines are easier to use than small knobs. You can add a tap turner to get better leverage with small knobs.
- Make sure detergents and laundry supplies are within easy reach — at waist level.
- Clearly label your laundry detergents and supplies. Keep them sealed securely.
- Pour liquid laundry detergent into smaller, easy-to-use containers, such as pump-action or squeeze bottles.
- Fold washing while sitting. Use a table or low counter to avoid having to bend over.
- An iron that shuts off automatically helps prevent burns to clothing and skin.
- Avoid clothing that requires special care.



Keeping the house clean

- Look for cleaning products that are simple to use, such as disposable wipes and multi-purpose cleaners.
- Use light cleaning tools and small containers. Avoid lifting large, heavy objects like buckets of water.
- Use long-handled brushes, mops and dusters to clean hard-to-reach areas.
- Put cleaning liquids in easy-to-use containers such as pump-action, spray or squeeze bottles.
- Keep cleaning materials within easy reach.



- Sit whenever you can while cleaning.
- Clean only one small area at a time. Take frequent breaks.

Yard work and gardening

- Use hand tools with cushioned, thick or built-up handles that are easy to hold.
- Use long-handled tools to get to spots that are difficult to reach.
- Protect your hands with gardening gloves. Wear an apron with pockets, where you can store small gardening tools.
- Keep a phone with you in case you need help while you are outside.
- Be aware of tripping hazards such as steps, objects lying on the ground or uneven ground. Keep equipment such as garden hoses organized and out of the way so that you do not trip over them.
- Raised garden beds, vertical gardens and high pots are easier to reach than garden beds at ground level.
- When working on the ground, use a sturdy garden seat with kneeler cushioning. You can lean on the seat when you stand up.
- Keep a drink of water in a plastic bottle nearby.
- Sit down when you can. For instance, you could sit at a table or bench to pot or prune plants.
- Keep tools that you use often within easy reach.



Where to get support:

Your occupational therapist can help you to adapt tasks to your abilities.

Support services in the community can help with household chores. Some charge fees. Others rely on volunteers or are part of a government-funded home care program. These services are usually aware of each other and can refer you to a service if they don't provide it themselves.

Call on your family members and friends who have offered help.

Help us make this guide better!

There is a brief survey at the back of this book. Please fill it out once you have read it. You can also fill it out online at

heartandstroke.ca/feedback

8

GETTING THE *Most* FROM LEISURE TIME



Millie

8. GETTING THE *Most* FROM LEISURE TIME

Leisure activities refresh the body, mind and spirit. They do much more for our health than we realize. This is especially true after a stroke. Doing things you enjoy and connecting with friends can reduce depression and relieve stress. Leisure activity provides structure in your day. It increases independence and improves self-confidence. Our physical and mental abilities improve while we are doing things we enjoy.

Find things to do that you enjoy. An occupational or recreational therapist can help you adapt an activity you love to your current abilities or help you find a new one.



Ken

Adapting your activities

Here are ways to adapt some popular activities.

Reading

Tools that can help you read include book holders, large-print books and talking books. Electronic readers allow you to control the print size and operate it with one hand.



Games

Card holder stands let you play cards with one hand. Large-faced cards and card shufflers can make a card game easier.

You may find it easier to use computer card games and other game apps. There are many programs and devices that can provide hours of entertainment. Game controllers that can be used with one hand are available.

Jigsaw puzzles

There are large-piece jigsaw puzzles that are age-appropriate. Special mats can ensure that the pieces do not fall off or get lost. They also make pieces easier to pick up.

Knitting, sewing and needlework

Special devices help you knit with one hand. Frames and clamps can hold your needlework so you can sew with one hand. Other tools include needle threaders and finger grippers so the needle is less likely to slip.



Woodworking

Safety is a very important concern in your workshop. Make sure all power tools have automatic shut-offs and safety catches. Have a family member or friend help you if you need to use an electric saw, drill press or router. Use clamps to hold projects in place so you can drill, carve, sand and paint with one hand.



Sports

Physical activity helps you stay healthy and avoid another stroke. Sports such as tennis, golf and swimming are a great way to stay active. Your physiotherapist, occupational therapist and recreational therapist can help you get ready for sports. You may need to

“ I tee off by driving with one arm, pick up the ball and putt out on the green.
- Lou

start slowly and build the strength and energy you need.

You can adapt the handles of sports equipment to make them easier and more secure to hold.

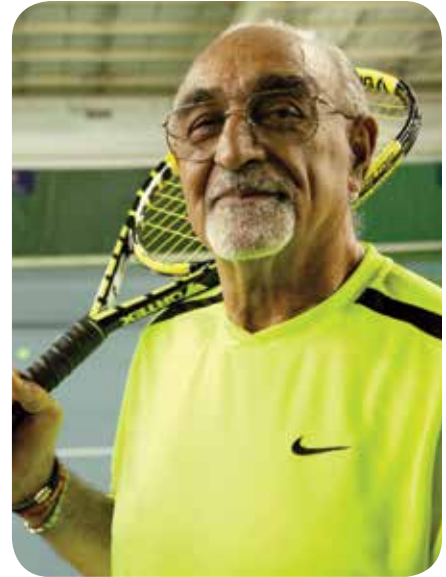
Where to get support:

Recreational and occupational therapists can help you select and adapt activities you enjoy.

There are numerous outdoor and recreational clubs and groups in your community that accommodate physical and mobility issues.

Maybe you are interested in sailing, hiking, kayaking, horse riding or travel. Look in seniors and recreational guides or on the internet.

Get tips and inspiration from the Active Living Coalition for Older Adults at alcoa.ca.



Marco



Ken

9. *Returning* TO WORK

There may come a time in your recovery when you consider returning to work. You may be asking yourself if you are able to do the job you used to do. Or you may be considering changing jobs or volunteering.

An occupational therapist and vocational counsellor can help you decide if you are ready to get back to work and help you plan for it.

Looking at your abilities

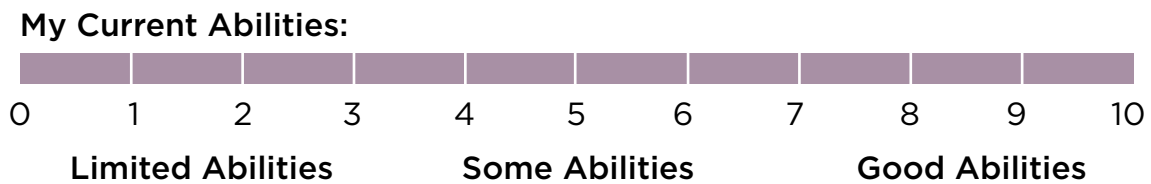
Here are five key areas to consider when looking at your ability to do a job:

<i>Physical ability</i>	<ul style="list-style-type: none">• use of arms• use of legs• eye-sight• fatigue.
<i>Communication ability</i>	<ul style="list-style-type: none">• speech• listening• writing• reading.
<i>Cognitive ability</i>	<ul style="list-style-type: none">• memory• attention• problem solving• thinking speed• fatigue• planning and organizing.

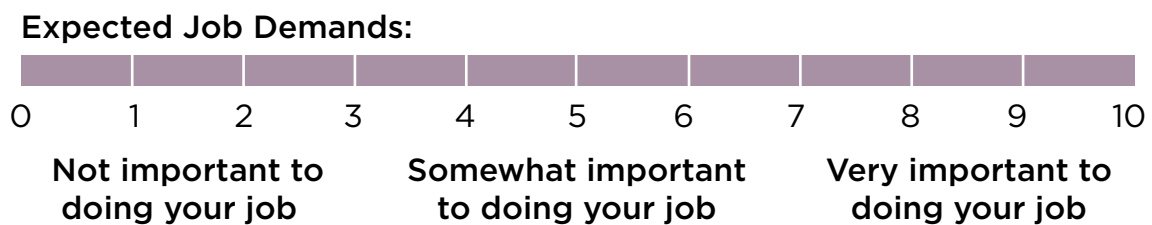
<i>Emotional ability</i>	<ul style="list-style-type: none"> • level of frustration • level of stress • ability to manage • confidence.
<i>Ability to get around</i>	<ul style="list-style-type: none"> • driving ability • access to transportation.

Rate your abilities

Use this chart to estimate your strengths and challenges related to the abilities listed above.



Use this chart to see if your abilities match the demands of the role you are considering.



Planning your return to work

Once you, your healthcare team and your employer agree that it is time to return to work, figure out what your return will look like.

- How many hours a week are you able to work with your current abilities and energy?

- Can you return gradually, building up hours as you are able?
- Can you work part time?
- Can you work flex hours?
- What adaptations need to happen in your workspace?

Changing careers

There are national and provincial/territorial programs to support people returning to a different kind of work. For example, the Canada Pension Plan Disability Vocational Rehabilitation Program offers vocational counselling, financial support for training, and job search services to recipients of Canada Pension Plan (CPP) Disability Benefits.

Where to get support:

Occupational therapists, vocational counsellors, social workers or psychologists can help you determine if you are ready to go back to work. They can also help adapt your workplace to your abilities. They will likely be aware of local vocational and employment programs that provide retraining and support.

Your doctor will be able to help with some of the documentation required.

The human resources department at your workplace can help with workplace adaptations.

There are many local resources that help with return to work. They are listed under Employment or Vocational Counselling in community resource directories or on the internet.

“*When I went back to work I put in half days. I tried to work every day but that was exhausting, so I worked until 2 or 3 – remember the energy needed for the commute home.* – Keitha



Mark

Volunteering

Volunteer opportunities can benefit your recovery by:

- helping you maintain and improve your skills
- offering the chance to try out a new role or gain experience
- building confidence
- energizing and relaxing you
- providing networking opportunities.

Here are some questions to ask yourself when choosing a volunteer opportunity:

- What are my strengths and abilities?
- What skills would I bring to this volunteer role?
- Would I like to work with people or would I rather work alone?
- Am I better behind the scenes or do I want to be out in front of people?
- How much time am I willing to commit?
- How much responsibility am I ready to take on?
- What causes are important to me?



You lose sense of purpose. The world is moving fast and leaves you behind. Volunteering has given me purpose and carried me past my stage of depression. – Ramon



Wayne

Once you know what kind of experience you want, you can search the internet for opportunities in your community. Ask friends and neighbours for ideas. Some communities have volunteer bureaus or list opportunities in local newspapers.

Protecting your benefits

Make sure your volunteer efforts will not affect your eligibility for disability payments. Check your insurance policy to make sure.

Information in this chapter has been adapted from the Southwestern Ontario Stroke Network's website on the "return to work" journey. For more information, go to swostroke.ca

Help us make this guide better!

There is a brief survey at the back of this book. Please fill it out once you have read it. You can also fill it out online at heartandstroke.ca/feedback

TAKING CARE OF *Business:* ADVANCE PLANNING



10. TAKING CARE OF *Business:* ADVANCE PLANNING

A stroke can affect your ability to earn a living. It can also bring on new expenses. Figuring out what support is available might take some time.

That's why it is a good idea to get started on taking care of your finances sooner rather than later. While you are recovering from your stroke, family and friends, as well as workplace contacts, can look into what benefits you qualify for.

It may also be a good time to think about the choices you would make if you became very seriously ill. Advance planning is a way of helping your loved ones by making your choices formally known.

Your sources of income

Paid employment leave

If you were employed at the time of your stroke, contact your human resources department to find out what benefits are available to you. These may include:

- sick leave
- vacation
- short-term disability
- long-term disability.

Ask these questions:

- What do I need to do to apply?
- What are the eligibility criteria?
- How long will the benefit last?

“*Get help understanding your disability policy - the do's and don'ts.* - John

- What is the amount of my benefit?
- Is the benefit taxable or non-taxable?
- What deductions will be taken off?

Provincial/territorial disability programs

Each province/territory has its own way to support people with a disability. This might involve income benefits, tax credits or deductions, job retraining, or programs that help adapt homes and purchase equipment to increase independence.

To find out about programs in your province:

Go to **canadabenefits.gc.ca**

Click **“I am a person with a disability”**

Select **your province/territory**

Canada Pension Plan Disability Benefit

If you have paid into the Canada Pension Plan, you may qualify for a disability pension. Look into this benefit as soon as it becomes apparent that you might not be able to return to work.

Employment Insurance (EI) sickness benefits

These benefits are for people who are unable to work because of sickness. They are available once your employer benefits are exhausted. For example, if you have used all of the sick leave and vacation available to you, you may qualify for EI sickness benefits for a limited time.

Apply as soon as you decide that you will not be able to work in the short term. EI will ask for the following information:

- your employment record for the last 52 weeks
- amount of EI payments
- proof of inability to work from your doctor.

To find out about programs in your province:

Go to **servicecanada.gc.ca**

Click **“Employment Insurance”**

or

Call **Service Canada at 1-800-622-6232**

Personal insurance

Some people have disability insurance through a private plan or through their mortgage insurance or credit card insurance. Check your records carefully to see whether you have any insurance coverage that you can claim.

Savings on your taxes

The following tax credits and deductions are available nationally. In addition, check to see if your province also has opportunities to save on taxes.

Disability tax credit

This non-refundable tax credit reduces your taxes. You will need a proof-of-disability certificate completed by a qualified professional such as a doctor. This must be approved by Canada Revenue Agency (CRA) before you can receive the credit. To learn more:

To learn more:

Go to **cra-arc.gc.ca**

or

Call **1-800-959-8281**

Medical expenses

You or your spouse can claim medical care expenses that are not covered by health plans. There is a limit to the amount you can claim. Keep all medical receipts and claim them at tax time.

Expenses related to medical care that may be tax deductible include:

- payments to medical practitioners, testing facilities and hospitals
- transportation expenses
- medical devices and equipment such as wheelchairs or orthotics
- premiums paid to a private health insurance plan
- expenses for adapting your home to your disability
- costs of rehabilitation therapy
- preventive, diagnostic and other treatments
- medications
- dental costs
- alternative or complementary treatments.

To learn more:

Go to cra-arc.gc.ca/medical/

or

Call **1-800-959-8281**

Covering your medical expenses

Your healthcare team may recommend the purchase of equipment or additional therapy sessions. There may be programs available to help with these costs.

Extended health benefits

You may have extended health benefits through your employer or your own personal extended health care plan. Be sure to ask:

- What benefits are available and what are the funding criteria?
- What are the funding limits?
- Will it cover costs of equipment? If so what equipment and how much?
- Will it cover costs of therapy? What kind (for example, physiotherapy, occupational therapy, massage therapy, speech therapy)?

Provincial/territorial programs

Some provinces/territories have programs that pay for assistive devices such as walkers, wheelchairs and canes. Find out what is available in your province/territory. To learn more:

- check your province or territory's website
- ask members of your healthcare team.

Where to get support:

The social worker on your team.

The human resource contact with your employer.

Your financial planner or accountant.

Community organizations with volunteer tax preparers.

Your bank.

Advance planning

Having a stroke raises difficult life issues. You may feel that it is time to do some advance planning. Advance planning means setting out how you would like your personal care and finances managed, should you be unable to communicate your wishes in the future. It requires that you talk with

family and friends, as well as your healthcare team, your financial advisor and a legal professional.

Each province/territory uses different terms and has different legal requirements for advance planning. There are many resources available to help you and your family through this process.

There are three things that you can put in place in case you have another stroke or a condition that is more disabling or life limiting:

1. Select a representative or substitute decision maker for health care and financial decisions.
2. Create a plan for your health and personal care should you be unable to communicate your wishes (*a living will*).
3. Make a will for the distribution of your estate if you die. This is called *estate planning*.

1. Select a representative or substitute decision maker

This is a person you trust (or it could be more than one person) whom you ask to act on your behalf, should you be unable to communicate or make decisions about your health care and finances.

It is up to you to decide who you could ask to carry out this responsibility. Choose someone who will honour and respect your wishes.

You can ask the same person to make all decisions, or you may ask different people to carry out different decisions. For example, you might ask one person to carry out your wishes about your healthcare and a different person to handle your finances.

Once you decide who will represent you, it is important to communicate your wishes clearly with that person and make sure you are understood.

Once you decide who will represent you, it is crucial to share your wishes clearly until you feel you are understood.

2. Create a living will for your personal care

Advance care planning is a process of reflection and communication. It is a time for you to reflect on your values and wishes, and to let others know your future health care preferences in the event that you are not able to communicate them. This might start as a conversation, but you should put your wishes in writing. Here are some helpful steps.

- Think about what is right for you. Ask yourself: what are my values and beliefs? What do I know about end-of-life care? What is important to me?
- Learn more about the medical procedures that might be offered near the end of life. Some might improve your quality of life. Others might only prolong life. Different people have different thoughts about these procedures. Decide what you think.
- Talk about your wishes with your representative, family members and friends who are important to you.
- Write down your wishes or make a recording or video. There are also forms available in most provinces and territories. Each of your substitute decision makers should have a copy. Share your written wishes with your healthcare team, your family and close friends.
- Review your plan regularly to make sure it reflects your wishes, especially if something in your life changes. Communicate any changes to your representative.

“*Planning is crucial, don't procrastinate. Have the conversation with your family it is important.*
- Millie

3. Plan your estate

Estate planning means writing down how you would like to transfer your property, money and other assets at the end of your life. This usually takes the form of a legal document such as a will. You may need the help of a lawyer to finalize it.

Where to get support:

Advancecareplanning.ca

Search for “advance care planning” on your provincial/territorial government’s website

Consult a lawyer, bank professional and doctor for advice in the various areas.

Checklist for your personal documents

Use this checklist to help you collect and organize important records, documents and instructions that you and your representative may need:

- Legal will
- Advance care plan or living will
- Name and contact information for your substitute decision makers
- Birth certificate
- Social Insurance Number
- Life insurance policy
- Health insurance policy
- Bank account information and passwords
- Safe deposit box location
- Real estate or rental papers
- Car insurance and registration

This publication is for informational purposes only and is not intended to be considered or relied upon as medical advice or a substitute for medical advice, a medical diagnosis or treatment from a physician or qualified healthcare professional. You are responsible for obtaining appropriate medical advice from a physician or other qualified healthcare professional prior to acting upon any information available through this publication.

Was this guide helpful?

Please help us make sure that we are providing helpful information and strategies to people living with stroke and their families. Take a few minutes to complete the following survey and mail it to:

Heart and Stroke Foundation
Attn: Health Information Team
2300 Yonge Street, Suite 1300
PO Box 2414, Toronto, ON M4P 1E4

OR

Complete this questionnaire online at
heartandstroke.ca/feedback

Circle one number for each statement:

	Strongly disagree		Strongly agree		
The information is easy to understand	1	2	3	4	5
This information is useful to me	1	2	3	4	5
I feel better informed about stroke because of this guide	1	2	3	4	5
With this information, I feel I can make better decisions about stroke recovery	1	2	3	4	5
I would share this guide with others	1	2	3	4	5

What did you find most useful or helpful in this guide and why?

What would make this guide more useful or helpful to you? _____

Other comments and suggestions:

Please tell us who you are:

Stroke survivor

Care partner (person most involved in caring for the survivor)

Other family member or friend

Other (please specify) _____

Would you like to be contacted by the Heart and Stroke Foundation with additional resources related to stroke prevention and recovery? If so, please provide the following information:

Name: _____ E-mail address: _____

Thank you!

JOIN US!

For more than 60 years, Canadian families have looked to the Heart and Stroke Foundation to help them improve their health every day. Thanks to millions of Canadians like you, we have made tremendous progress — but we will not stop until all Canadians live healthy lives free of heart disease and stroke. We hope you want to be part of our shared success as we work to achieve our vision and mission outcomes. We invite you to:



Spread the message among your family, friends and community.



Volunteer to help us extend the reach of our activities.



Donate to help fund critical life-saving research.



Lend your voice to our campaigns for healthier government policies.



Be the first to know about our latest research breakthroughs.



Live better with the help of our health eTools and resources.

Learn more at heartandstroke.ca



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