



Taking Charge of Your Stroke Recovery

A SURVIVOR'S GUIDE TO THE CANADIAN STROKE
BEST PRACTICE RECOMMENDATIONS

BE INFORMED | BE INVOLVED | TAKE ACTION



HEART &
STROKE
FOUNDATION

CANADIAN
Stroke
BEST PRACTICE
RECOMMENDATIONS

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The *Canadian Stroke Best Practice Recommendations* were developed by Canadian medical experts who reviewed research from around the world to identify the best ways to prevent and treat stroke.

This guide outlines key recommendations for providing the best care and contributing to the best possible outcome for someone who has had a stroke. It also stresses the importance of taking into consideration each person's individual circumstances and needs in planning for treatment, rehabilitation, prevention, and recovery.

When these recommendations are followed, the impact of stroke can be reduced.

You can read all of the recommendations and learn more about stroke care in Canada at strokebestpractices.ca.

BE INFORMED

Learn about stroke:

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

BE INVOLVED

Be part of the process:

Make your voice heard when it comes to goal setting and care planning; ask questions and get answers.

TAKE ACTION

Do what needs to be done to get better:

Follow your recovery plan. Practice your exercises; take your medication; make lifestyle changes. Achieve your goals. Celebrate success.

BE INFORMED

- Stroke is a medical emergency. Know the signs and act fast.
- People can have a stroke while they are asleep, and wake up with stroke symptoms. This is also a medical emergency that requires immediate action.
- Stroke doesn't just happen to the elderly; in fact, up to 10 percent of strokes happen in people aged 18 to 54. Infants and children can experience stroke too.
- The sooner a stroke patient gets to the hospital, the better his or her chance of receiving treatment that could help reverse or minimize the effects of the stroke.
- There is hope. Stroke can be prevented and treated.

THE SIGNS OF STROKE



Weakness

Sudden loss of strength or sudden numbness in the face, arm, or leg, even if temporary.



Trouble speaking

Sudden difficulty speaking or understanding or sudden confusion, even if temporary.



Vision problems

Sudden trouble with vision, even if temporary.



Headache

Sudden severe and unusual headache.



Dizziness

Sudden loss of balance, especially with any of the above signs.

Note: In this guide, the term *caregivers* refers to a more informal network of care that supports a person who has had a stroke such as family, friends, and neighbours.

Healthcare team refers to medical and other healthcare professionals and providers who provide care for people who have had a stroke and their caregivers.

Best Practices For EMERGENCY RESPONSE TO STROKE

Call an ambulance if you think you or someone around you is having a stroke. Never drive yourself or the person having a stroke to the hospital.

Take immediate action by calling 9-1-1 or your local emergency number. The paramedics will know the closest hospital that has a specialized program for stroke care and can call ahead so hospital staff are prepared for your arrival.

Be seen quickly. You should receive medical attention soon after you arrive. If you don't, let the emergency department staff know. Time is of the essence when it comes to stroke.

The type of stroke matters. A brain scan should be done soon after you arrive at the hospital, to find out if the stroke was caused by a blood clot (ischemic stroke) or by bleeding in the brain (hemorrhagic stroke).

tPA may help. If there is a blood clot, you may benefit from a clot-busting drug called tPA that can help re-open blocked arteries. tPA can reduce the severity of a stroke and reverse some of the effects, helping you recover more fully. However, it is not right for everyone. It depends on the type of stroke, how much time has passed since symptoms started, and results of the brain scan (CT or MRI).

Urgent! tPA must be given as soon as possible and within four and a half hours from the start of symptoms. The longer the wait, the smaller the possible benefit.

Ask when you will be seen at a stroke clinic if you are not admitted to hospital. If you had a TIA (transient ischemic attack or "mini-stroke"), you should seek immediate treatment to prevent a major stroke.



Best Practices For STROKE CARE IN THE HOSPITAL

First and foremost, being cared for by stroke experts makes a difference. You should be looked after by a team of healthcare professionals who are experts in stroke, preferably in a specialized stroke unit dedicated to the care of people with stroke.

You should receive the following care in the hospital:

- **Blood pressure:** Your blood pressure should be checked to see if it is too high. High blood pressure is the leading cause of stroke.
- **Heart rhythm:** Your heart rhythm should be checked to see if it is irregular. Irregular rhythms such as atrial fibrillation may have contributed to your stroke. It may also increase your risk of another stroke.
- **Diabetes:** Your blood sugar should be checked to find out if you have diabetes. Diabetes is a risk factor for stroke.
- **Swallowing:** You should be checked to see if you have trouble swallowing. This is common after stroke and can lead to choking and pneumonia. Your dietary needs should also be assessed.
- **Leg clot prevention:** Stroke can often result in not being able to move your leg. Paralysis can lead to clots. You may be given medication to stop clots from forming before you are able to start walking again.
- **Antiplatelet or anticoagulant medication:** If your stroke was caused by a clot, you should be given a blood thinner medication such as ASA (commonly referred to as Aspirin™) to help prevent more clots.
- **Neck scan:** If your stroke was caused by a blood clot, a carotid scan of your neck should be done to find out if blood vessels in your neck are narrowed or blocked. If so, surgery may be required and this should be done as soon as possible.
- **Falls:** People are more likely to fall after a stroke. You should know the risk and you and your family and caregivers should be taught how to avoid falls.



TAKE ACTION

Get involved in planning for your recovery and rehabilitation. Once you are medically stable, planning should begin for treatment, rehabilitation, and discharge. Your healthcare team should involve you in this process and make sure your wishes and needs are reflected in the plan.

Get moving. With advice and support from your healthcare team, you should start moving as soon as you can, to prevent complications such as pneumonia and blood clots in your legs. With guidance, gradually increase your activity from moving in bed to sitting, standing, and walking. Ask for help if it is difficult to move or if you are worried about falling.

Best Practices For STROKE REHABILITATION

Rehabilitation should start as soon as possible after your stroke, while you are still in the hospital, and will likely continue after you leave. There are many forms of rehabilitation, all designed to help you improve and recover your physical, emotional, cognitive, and communication skills and well-being.

Rehabilitation can happen in many places, including a specialized stroke rehabilitation unit in the hospital, a separate rehabilitation hospital, an outpatient rehabilitation centre or community program, or your own home. The place where you receive your rehabilitation may change as you progress.

Rehabilitation therapy is important.

If the stroke has affected your ability to walk, use your arms, think, see, or speak, you will need rehabilitation to help you recover. As much as possible, advocate on your own behalf for access to rehabilitation therapy.

Specialized is best. You should receive rehabilitation therapy in a specialized stroke rehabilitation unit or from a specialized community stroke rehabilitation team.



You are part of the team. Your healthcare team should involve you in determining what kind of rehabilitation you need and work with you to develop realistic expectations and achievable goals for your recovery.

It's your plan. Work with your healthcare team to develop a personalized plan to achieve your goals. Share what you want to accomplish during rehabilitation and include this in the plan. The team should work with you to update your plan as you progress, so it always fits your current needs and improving abilities.

Practice, practice, practice. To achieve the best recovery, it is important to practice the exercises and activities you are taught in your rehabilitation therapy sessions. The healthcare team should work with you and your family and caregivers to identify activities you can safely do on your own, between sessions. Be sure you understand their instructions. Ask questions until you do.

Keep at it. Everyone's recovery from stroke is different. Rehabilitation and reintegration into the community will happen at your own pace, and improvement is often seen for weeks, months, or even years after the stroke occurred.

Best Practices For DISCHARGE AFTER STROKE

When you leave the hospital, there are things you and your healthcare team should do so you can feel confident in your health, your abilities, and your surroundings.

LEAVING THE HOSPITAL

Share your concerns. Your healthcare team should work with you to answer all your questions and help you identify and address your physical and emotional needs.

Be assessed. Before you leave, your ability to communicate, use your limbs, walk by yourself, take care of yourself, and carry out daily tasks should be assessed. Your healthcare team should talk to you about the results and help you understand what activities you can safely do after you leave.

Have your discharge plan. You should be given a list of your medications, follow-up appointments, and contact numbers for your healthcare team in the community and at the hospital. Take this with you to all your medical appointments.

Take your medications. Continue to take all medications that have been prescribed for you, and do not stop taking any medication unless your doctor tells you to. You should regularly review your medications with your healthcare team.

IF YOU ARE GOING HOME

Plan ahead to make it safe. If changes are needed to make your home safe and accessible, have them done before you are discharged.

Plan ahead for extra help. You may need extra help and care once you are home. Make arrangements for these, including talking to family and friends and contacting community resources if necessary, prior to leaving the hospital.

See your family doctor. You should see your primary healthcare provider (family doctor, nurse practitioner) soon after you leave the hospital. Ask the hospital to send your primary healthcare provider a summary of the care you received in the hospital, including test results and recommended treatments so they can continue the treatment plan.



Best Practices For PREVENTING ANOTHER STROKE

Once you have had a stroke or TIA (transient ischemic attack or “mini-stroke”), your chances of having another are higher. Know the signs and be prepared to act quickly.

Your healthcare team should work with you to develop a plan to deal with the issues that put you at risk of stroke.

Know your risk factors. Find out as much as you can about your risk factors for stroke. Some common risk factors are:

- High blood pressure
- Irregular heartbeat (such as atrial fibrillation)
- Lifestyle — Lack of exercise, unhealthy diet, unhealthy weight, excessive alcohol use
- Smoking
- Diabetes
- High cholesterol (lipids)
- Sleep apnea
- Hormone replacement therapy



TAKE ACTION

Reduce your risk. A combination of lifestyle change and medication may be necessary to control some of your risk factors. These might include taking antiplatelet medication every day, quitting smoking, and losing weight.

Whatever is needed, your healthcare team should work with you to find programs and treatments and develop a plan of action that works for you and that you can follow.

Best Practices For ADJUSTING TO YOUR NEW NORMAL

As you begin to face the reality of daily life after your stroke, you will likely need to make some small adjustments or big changes to help you find a “new normal.”

Pay attention. There are common issues that many stroke patients encounter, and they can occur at any time. You, your healthcare team, and your family and caregivers should watch for:

- **Depression:** Feeling very overwhelmed or sad and having emotional mood swings is common. If these feelings don't get better, or are accompanied by other symptoms such as changes in appetite or sleep or feelings of hopelessness, then you may have depression. Depression can slow your progress by affecting your ability to fully participate in your recovery.
- **Cognitive problems:** You may notice changes in your ability to remember things, concentrate, or manage your daily activities.
- **Fatigue:** Post-stroke fatigue is tiredness that does not seem to go away, and short rest times do not seem to help. It is very different from just feeling tired.
- **Pain:** Pain, particularly in the shoulder on the side affected by your stroke, is common and can make it difficult to dress yourself or sleep.
- **Changes in relationships:** You may find some of your relationships and interactions with others difficult at times as you and those around you learn to cope after your stroke.



- **Difficulties with sexuality:** Stroke can have a negative effect on your sexual desires and functions.
- **Changes in lifestyle and activities:** You may find you are isolating yourself and not taking part in activities you used to enjoy.
- **Driving after your stroke:** People who have had a stroke usually have to wait before driving again. You may need vision tests, occupational therapy, or other assessments before driving. Discuss your goals for driving with your healthcare team.

Best Practices For ADJUSTING TO YOUR NEW NORMAL

TAKE ACTION

Talk about it. If you notice problems like the ones mentioned in this guide, especially if they are getting worse or not going away, tell your healthcare team or your family or caregivers. There are coping strategies and adjustments that can help.

Write about it. Keep a journal so you can monitor your achievements and progress, record information about your medications or therapy, keep track of medical appointments, and write down questions to ask at your appointments.

The *Post-stroke Checklist* found at the end of this guide can help you start a conversation about issues you may be experiencing. Fill out a new one before every medical appointment. It gives you an ongoing record of your progress and makes it easier for your doctor or others on your healthcare team to understand how you are doing and work with you to get additional help if you need it.



Best Practices For PATIENT-CENTRED CARE

You need information to be involved in your own care. You have the right — and the responsibility — to find out as much as you can about your stroke and your recovery.

Your healthcare team should give you answers and information at every stage of the process. If they don't, ask and keep asking. Write down the answers in your journal.

BE INVOLVED

Ask your healthcare team:

- What type of stroke did I have? Was it caused by a blood clot or by bleeding into the brain?
- What long-term effect has the stroke had on my body?
- What do you expect my recovery will be like?
- What can I expect to be able to do in the next few months and one year from now?
- What skills will I need to take care of myself?
- What services and resources are available to help me and my family? How can I access them?
- What can I do to prevent another stroke?

BE INFORMED

There are many resources to help you be informed, involved, and take action.

Heart and Stroke Foundation, Canada

heartandstroke.ca/stroke

Canadian Stroke Best Practice Recommendations

strokebestpractices.ca

A Family Guide to Pediatric Stroke

strokebestpractices.ca - **Pediatric Stroke**

The Post-stroke Checklist (see pages 11-12)

POST-STROKE Checklist



Developed by the Global Stroke Community Advisory Panel [2012], endorsed by the World Stroke Organization, adapted by the Heart and Stroke Foundation Canadian Stroke Best Practice Recommendations development team [2014]

Patient Name: _____ **Date Completed:** _____

COMPLETED BY: HEALTHCARE PROVIDER PATIENT FAMILY MEMBER OTHER

SINCE YOUR STROKE OR LAST ASSESSMENT

1 Secondary Prevention

Have you received medical advice on health-related lifestyle changes or medications to prevent another stroke?

NO

Refer patient to primary care providers for risk factor assessment and treatment if appropriate, or secondary stroke prevention services.

YES

Continue to monitor progress

2 Activities of Daily Living (ADL)

Are you finding it more difficult to take care of yourself?

NO

Continue to monitor progress

YES

Do you have difficulty:
 dressing, washing, or bathing?
 preparing hot drinks or meals?
 getting outside?

If **Yes** to any, consider referral to home care services; appropriate therapist; secondary stroke prevention services.

3 Mobility

Are you finding it more difficult to walk or move safely (i.e., from bed to chair)?

NO

Continue to monitor progress

YES

Are you continuing to receive rehabilitation therapy?

No. Consider referral to home care services; appropriate therapist; secondary stroke prevention services.
 Yes. Update patient record; review at next assessment.

4 Spasticity

Do you have increasing stiffness in your arms, hands, or legs?

NO

Continue to monitor progress

YES

Is this interfering with activities of daily living?

No. Update patient record; review at next assessment.
 Yes. Consider referral to rehabilitation service; secondary stroke prevention services; physician with experience in post-stroke spasticity (e.g., physiatrist, neurologist).

5 Pain

Do you have any new pain?

NO

Continue to monitor progress

YES

Ensure there is adequate evaluation by a healthcare provider with expertise in pain management.

6 Incontinence

Are you having more problems controlling your bladder or bowels?

NO

Continue to monitor progress

YES

Consider referral to healthcare provider with experience in incontinence; secondary stroke prevention services.

7 Communication

Are you finding it more difficult to communicate?

NO Continue to monitor progress

YES Consider referral to speech language pathologist; rehabilitation service; secondary stroke prevention services.

8 Mood

Do you feel more anxious or depressed?

NO Continue to monitor progress

YES Consider referral to healthcare provider (e.g., psychologist, neuropsychologist, psychiatrist) with experience in post-stroke mood changes; secondary stroke prevention services.

9 Cognition

Are you finding it more difficult to think, concentrate, or remember things?

NO Continue to monitor progress

YES Is this interfering with your ability to participate in activities?

- No.** Update patient record; review at next assessment.
- Yes.** Consider referral to healthcare provider with experience in post-stroke cognition changes; secondary stroke prevention services; rehabilitation service; memory clinic.

10 Life After Stroke

Are you finding it more difficult to carry out leisure activities, hobbies, work, or engage in sexual activity?

NO Continue to monitor progress

YES Consider referral to stroke support organization (local/provincial support group, Heart and Stroke Foundation of Canada Living with Stroke program); leisure, vocational, or recreational therapist.

11 Personal Relationships

Have your personal relationships (with family, friends, or others) become more difficult or strained?

NO Continue to monitor progress

YES

- Schedule next primary care visit with patient and family member(s) to discuss difficulties.
- Consider referral to stroke support organization (local/provincial support group, Heart and Stroke Foundation of Canada); healthcare provider (e.g., psychologist, counsellor, therapist) with experience in family relationships and stroke.

12 Fatigue

Are you experiencing fatigue that is interfering with your ability to do your exercises or other activities?

NO Continue to monitor progress

YES

- Discuss fatigue with Primary Care provider.
- Consider referral to home care services for education and counselling.

13 Other Challenges

Do you have other challenges or concerns related to your stroke that are interfering with your recovery or causing you distress?

NO Continue to monitor progress

YES

- Schedule next primary care visit with patient and family member(s) to discuss challenges and concerns.
- Consider referral to healthcare provider; stroke support organization (local or provincial support group, Heart and Stroke Foundation of Canada).