Patient, Caregiver and Family Guide to the Stroke Quality Standard

August 2022



This material has been reviewed and approved by patient partners with the Patient Voices Network.





Working Together. Accelerating Improvement.

The Stroke Quality Standard was developed by the BC Patient Safety & Quality Council.

The Council's work leads to better health care for British Columbians. Using evidence-informed strategies, it advances person and family-centred care, shifts culture and improves clinical practice to support high-quality care for every person in the province.

If you want to improve BC's health care system, visit **BCPSQC.ca** to access programs and resources that can help you start today.



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About the Stroke Quality Standard

About the Stroke Quality Standard

Quality standards are tools for helping our health care systems deliver consistent, high-quality care to support the health of patients and the population.

They describe key aspects of high-quality services for a condition or topic, focusing on specific areas where improvement can lead to better health outcomes.



About the Stroke Quality Standard

The Stroke Quality Standard was developed to advance high-quality stroke care across British Columbia.

It features nine quality statements to guide improvement efforts where they are needed most. These future-focused statements serve as common goals to which the BC health care system can aspire.

To see the Stroke Quality Standard, go to **BCPSQC.ca**.



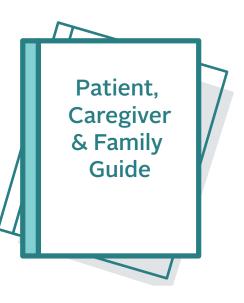


About this guide

About this Guide

The Patient, Caregiver and Family Guide to the Stroke Quality Standard has been developed as a helpful resource for people with stroke, as well as friends and family members who are involved as caregivers.

It describes key aspects of high-quality stroke care for people when they are at risk of having a stroke, experiencing a stroke or recovering from a stroke.







About this Guide

This guide is for:

People with stroke

If you are a **person with stroke**, the guide can help you understand your stroke care and support you to make informed decisions in collaboration with your health care team.

Caregivers and/or family members

If you are a chosen caregiver or family member (relative, partner, friend or member of the community), this guide will help you understand the care available and how you will be included. 6

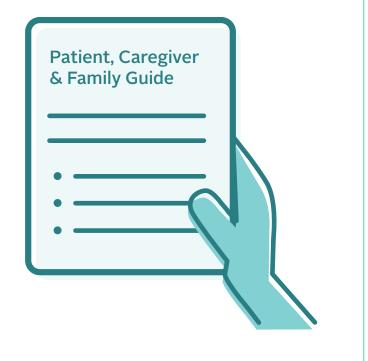
About this guide

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This guide features an **aphasia**-friendly design for people with stroke who may have difficulty reading and understanding its content.

This includes: increased whitespace, clear icons, a horizontal layout and separation of concepts for an easy-to-read resource.

See bold text like "**aphasia**" above? That means we've included a definition for that term in our glossary on page 47.







What is a stroke?

What is a stroke?

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A **stroke** happens when the normal blood supply to the brain is interrupted or reduced. This starves brain cells of oxygen and causes damage.

Types of stroke include:

Ischemic stroke - when a blockage or clot in a blood vessel stops blood flow to the brain.

Hemorrhagic stroke - when a blood vessel inside the brain breaks open because it is damaged or weakened.

Transient Ischemic Attack (TIA) - when a small clot briefly blocks blood flow to the brain. This is sometimes called a mini-stroke or warning stroke because it is a warning sign that a more serious stroke may occur soon.¹





What is a stroke?

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A stroke is a medical emergency and anyone having a stroke, including a Transient Ischemic Attack (TIA), needs urgent medical treatment.

The effects of a stroke can vary depending on which area of the brain is affected and the amount of brain tissue that is damaged.¹

Some people recover fully, but others may have long-term or lifelong disabilities.





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The quality statements

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Quality statements focus on specific areas of the patient journey where improvement can lead to better health outcomes. They include indicators to measure progress and guide improvement work.

There are 9 quality statements in this guide.





Cross-continuum

Quality Statement 1:

People with a stroke diagnosis experience a care journey in the health care system that feels respectful and culturally safe.

What it means to you:

You should expect your stroke care to be professional and respectful.

You should receive the same access to and quality of care, regardless of aspects of your personal identity such as race, ethnicity, colour, ancestry, place of origin, religion, marital status, family status, physical or mental disability, gender identity and expression, sex, sexual orientation and age.







Cross-continuum

Quality Statement 1:

People with a stroke diagnosis experience a care journey in the health care system that feels respectful and culturally safe.

What it means to you:

Cultural safety is an important concept in BC's health care system. Culturally safe health care services are free of racism and discrimination.

Health care professionals show **cultural humility** in their interactions with you and seek to work with you in a way that respects your culture, circumstances, history, needs and preferences.







Cross-continuum

Quality Statement 2:

People with stroke and their chosen caregivers and/or family collaborate with the care team to develop a **care plan** and work together to evaluate and update it throughout the patient journey.

What it means to you:

The care plan is part of your medical record. It documents important information to help guide your stroke care and recovery.

In addition to providing medical details about you as a patient – such as your stroke diagnosis, treatments and rehabilitation needs – the care plan is also a place where you can share your personal preferences, priorities and goals for recovery with everyone involved in your care.





Cross-continuum

Quality Statement 2:

People with stroke and their chosen caregivers and/or family collaborate with the care team to develop a **care plan** and work together to evaluate and update it throughout the patient journey.

What it means to you:

Your care plan will help ensure that you are at the centre of decision making about your care and that your needs are communicated and honoured. This may also include a formal **advance care plan**, which provides guidance about your wishes in the event you are not able to communicate them yourself.

As you progress along your care journey, you and the care team will have the opportunity to evaluate how well the care plan is working for you and make adjustments if needed.





Cross-continuum

Quality Statement 3:

People with stroke and their chosen caregivers and/or family actively take part in available stroke education and training, from the onset of their stroke and throughout their recovery.

What it means to you:

Learning about stroke and building your skills are important ways to help with your stroke recovery and to maintain your health and well-being.

You should be provided with education on stroke risk factors, treatment and recovery, as well as practical training in daily living skills to help you manage successfully at home.







Cross-continuum

Quality Statement 3:

People with stroke and their chosen caregivers and/or family actively take part in available stroke education and training, from the onset of their stroke and throughout their recovery.

What it means to you:

The education and training you receive should reflect your goals for recovery. It should also be tailored to your learning needs.

Your chosen caregivers and/or family are encouraged to participate in your stroke care education.







Early Recognition

Quality Statement 4:

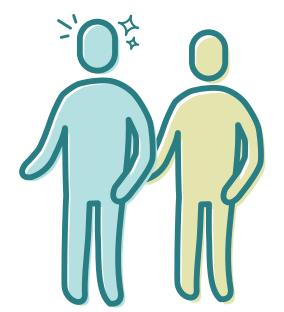
People with symptoms of a stroke are recognized early and offered timely transport to the most appropriate care.

What it means to you:

Stroke is a medical emergency. When someone shows signs of a stroke, a rapid response can reduce the risk of permanent disability or death.

This requires:

- Early recognition of the signs of stroke
- Rapid assessment by a trained health care professional
- Quick transport to appropriate stroke care





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Early Recognition

Quality Statement 4:

People with symptoms of a stroke are recognized early and offered timely transport to the most appropriate care.

What it means to you:

It is important that everyone can recognize the signs of a stroke.

If you or another person experiences any of the following FAST signs, call 9-1-1 immediately.²







Early Recognition

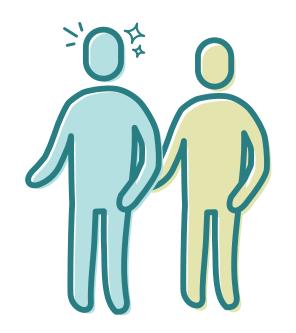
Quality Statement 4:

People with symptoms of a stroke are recognized early and offered timely transport to the most appropriate care.

What it means to you:

Also, watch for these other possible signs of stroke that may suddenly appear:

- Weakness, numbness or lack of coordination on one side of the body
- Vision loss (cannot see) in one or both eyes
- Severe headache
- Memory loss or confusion
- Episode of dizziness and unsteadiness





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Acute Care

Quality Statement 5:

When presenting to the emergency department, people with acute stroke are offered rapid assessment and treatment appropriate for their type of stroke as outlined by the **Canadian Stroke Best Practice Recommendations.**

What it means to you:

Once you arrive at the emergency department, you should be assessed without delay. If the health care professional suspects stroke, you should be sent immediately for a brain scan.

The brain scan can confirm a stroke and show what type of stroke you have.







Acute Care

Quality Statement 5:

When presenting to the emergency department, people with acute stroke are offered rapid assessment and treatment appropriate for their type of stroke as outlined by the **Canadian Stroke Best Practice Recommendations.**

What it means to you:

The treatment that is recommended for you will depend on the type and severity of your stroke:

If you have an ischemic stroke (caused by a blood vessel blockage or clot), your health care professional will look at ways to restore blood flow in the brain. Treatment may include medication to dissolve the blockage/clot (thrombolysis) or a procedure to remove the blockage/ clot (endovascular thrombectomy or EVT).¹





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Acute Care

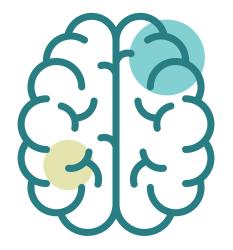
Quality Statement 5:

When presenting to the emergency department, people with acute stroke are offered rapid assessment and treatment appropriate for their type of stroke as outlined by the **Canadian Stroke Best Practice Recommendations.**

What it means to you:

The treatment that is recommended for you will depend on the type and severity of your stroke:

 If you have a hemorrhagic stroke (caused by a burst blood vessel in the brain), your health care professional will consider how to stop the bleeding and relieve pressure in the brain. Treatment options may include surgery, managing your blood pressure and controlling how your blood clots.¹





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Acute Care

Quality Statement 5:

When presenting to the emergency department, people with acute stroke are offered rapid assessment and treatment appropriate for their type of stroke as outlined by the **Canadian Stroke Best Practice Recommendations.**

What it means to you:

These treatments may not be appropriate for everyone. The care team will discuss their recommendations with you and ask for your consent to provide treatment.

If you are unable to make medical decisions due to the stroke, the health care professional will attempt to identify a **temporary substitute decision maker** to provide consent on your behalf. In emergency situations this is not always possible. If you have an advance care plan, your wishes will be known and can be used to guide decisions.



Acute Care

Quality Statement 6:

A person with stroke is offered **stroke unit care** as defined by the **Provincial Stroke Unit Care Definition.**³

What it means to you:

If you require hospitalization for stroke, you should be offered stroke unit care.

A stroke unit is a specialized hospital unit staffed by a team of health care professionals with stroke expertise, such as physicians, nurses, occupational therapists, physiotherapists, speech-language pathologists, pharmacists, social workers and dietitians.

Members of the stroke unit team may see you in person or they may see you virtually.





Acute Care

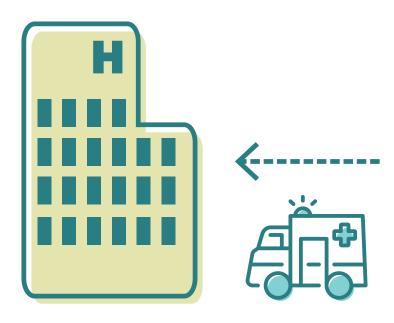
Quality Statement 6:

A person with stroke is offered **stroke unit care** as defined by the **Provincial Stroke Unit Care Definition.**³

What it means to you:

Not all hospitals have a stroke unit on site. Depending on your needs and preferences, you may be transferred to another hospital to receive stroke unit care.

You and your chosen caregivers and/or family will be involved in any decisions about transferring to another hospital.





Secondary Prevention

Quality Statement 7:

At the time of diagnosis, people with stroke (including **TIA**) are assessed for risk of recurrent stroke and offered preventive treatment and education.

What it means to you:

If you have a stroke (including TIA), you are at risk of having another stroke. This could lead to more disability or death. Secondary stroke prevention is an important part of your stroke care.

In addition to the urgent care you receive immediately following a stroke, you should be assessed for your risk of having another stroke. This may require further diagnostic tests.





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Secondary Prevention

Quality Statement 7:

At the time of diagnosis, people with stroke (including **TIA**) are assessed for risk of recurrent stroke and offered preventive treatment and education.

What it means to you:

If you are admitted to hospital, your inpatient care will include treatments for secondary stroke prevention. You will also learn about how to reduce your risk by making changes to your diet, exercising or taking medicines.

If you do not require hospitalization, you may receive an urgent referral to a health care professional who specializes in secondary stroke prevention. Together, you will decide on treatment options and discuss ways to minimize your risk of another stroke.



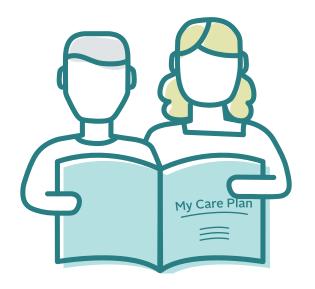
Secondary Prevention

Quality Statement 7:

At the time of diagnosis, people with stroke (including **TIA**) are assessed for risk of recurrent stroke and offered preventive treatment and education.

What it means to you:

You may wish to talk to your chosen caregivers and/or family, as well as a health care professional, about advance care planning. This allows you to express your beliefs, values and wishes to guide decision making if you are unable to communicate your wishes.







Rehabilitation & Recovery

Quality Statement 8:

Throughout their care journey, people with stroke have access to interdisciplinary rehabilitation that aligns with the **Canadian Stroke Best Practice Recommendations**.

What it means to you:

Rehabilitation is a process to help you regain skills that were lost due to stroke. Rehabilitation may occur at any point of the stroke recovery journey, and can be offered in hospitals, outpatient clinics, community programs and more.





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Rehabilitation & Recovery

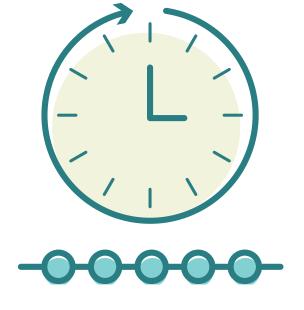
Quality Statement 8:

Throughout their care journey, people with stroke have access to interdisciplinary rehabilitation that aligns with the **Canadian Stroke Best Practice Recommendations**.

What it means to you:

If you are hospitalized for stroke, your care will include an initial rehabilitation review to determine your rehabilitation needs. This usually happens within the first 48 hours, depending on your condition.

You may need support from a range of health professionals with expertise in stroke rehabilitation, including **physiatrists**, other physicians, occupational therapists, physiotherapists, speech-language pathologists, nurses, social workers and dietitians.





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Rehabilitation & Recovery

Quality Statement 8:

Throughout their care journey, people with stroke have access to interdisciplinary rehabilitation that aligns with the **Canadian Stroke Best Practice Recommendations**.

What it means to you:

Depending on the hospital, some health care professionals may meet with you virtually rather than in person.

If you do not require admission to hospital, you should be screened to see if you need a referral to an outpatient or community-based rehabilitation service.





The quality statements

Community Integration

Quality Statement 9:

Within the first year after hospital discharge, people with stroke receive a health and social care needs review initiated by their primary health care provider.

What it means to you:

The decision to discharge you from hospital care will be guided by an assessment of your readiness to return to the community.

In addition to assessing your health, your stroke care team will determine whether you and your chosen caregivers and/or family will require additional skills, knowledge or services to support you to live safely in the community.







The quality statements

Community Integration

Quality Statement 9:

Within the first year after hospital discharge, people with stroke receive a health and social care needs review initiated by their primary health care provider.

What it means to you:

Once in the community you will work with your primary care team (such as your family doctor and community-based rehabilitation specialists) to develop a plan for follow-up and support after hospital discharge. You will also receive information on who to contact if you need to talk to someone about your health before your next scheduled review.







Advance care planning

A process of reflection and communication, where a person will reflect on their values and beliefs, and then let others know their future health and personal care preferences in the event that they become incapable of consenting or refusing care.⁴

Aphasia

Aphasia is a condition which can affect your ability to read and understand information. It often results from damage to the brain following a stroke or head injury.

Care plan

A plan to outline a person's stroke care journey. It is developed with the person with stroke, their chosen caregivers and/or family and the health care team. It includes specific therapy goals, upcoming investigations and daily therapy activities.



Cultural humility

A process of self-reflection to understand personal and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience.⁵

Cultural safety

An outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care.⁵



Dimensions of quality

Quality is defined by seven dimensions that span the full continuum of care:⁶

- **Respect:** honouring a person's choices, needs and values
- **Safety:** avoiding harm and fostering security
- Accessibility: ease with which health and wellness services are reached
- **Appropriateness:** care is specific to a person's or community's context
- Effectiveness: care is known to achieve intended outcomes
- **Equity:** fair distribution of services and benefits according to population need



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Endovascular thrombectomy (EVT)

A surgical procedure used to remove a blood clot in a blood vessel.⁷

FAST signs

FAST is an acronym used to highlight the most common signs of a stroke:

- Face is it dropping?
- Arms can you raise both?
- **Speech** is it slurred or jumbled?
- Time to call 911 right away.²



Health care professionals

Health care professionals provide essential services to promote health, prevent diseases and deliver health care services based on the needs of the person.⁸

Hemorrhagic stroke

A stroke which occurs when a blood vessel in the brain breaks open because it is damaged or weakened. The interrupted blood flow causes damage to the brain.¹

Interdisciplinary team

A team of health care professionals dedicated to the care of a person with stroke. The team will include physicians, nurses, allied health professionals such as physiotherapists, speech-language pathologists, pharmacists, social workers and dietitians, to name a few.⁹



Ischemic stroke

A stroke which occurs when the blood supply to the brain is disrupted, normally due to a blood clot.¹

People with stroke

People who are having or have had a stroke, including TIA.

Physiatrist

A physician who specializes in the field of physical medicine and rehabilitation.¹¹



Recovery

Stroke recovery is a process which includes seven steps: exercise and mobility; communication and language; social interaction; thinking, memory and perception; support; healthy lifestyle; and navigating the health care system.¹²

Rehabilitation

A process in the stroke recovery journey to help regain skills that were lost due to stroke.¹³

Spontaneous intracerebral hemorrhage (hemorrhagic stroke)

Bleeding in the brain without a known specific cause.¹



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Stroke

A disruption of blood supply to the brain – either through a blockage due to clot (ischemic) or bleeding (hemorrhagic).

The amount of brain affected by the stroke and the type of symptoms a person experiences depends on where the blockage or bleed occurs. In both cases, if the blood supply is not restored quickly, the affected part of the brain dies, causing disability or death.¹

Stroke unit care

A stroke unit is a specialized, geographically defined hospital unit dedicated to the management of stroke patients and staffed by an experienced interdisciplinary stroke team.¹⁴



Temporary substitute decision maker

An adult chosen by a health care professional from a list of family and/ or friends of someone who is unable to speak for themselves. This person must be willing and able to make decisions about health care treatments of the person who cannot communicate.

Thrombolysis

Medication used to break up a blood clot to allow blood to begin flowing properly again.¹²

Transient ischemic attack (TIA)

A "mini-stroke" when blood flow to the brain stops for a short period of time. A TIA is an important sign of a problem with blood flow to the brain and should be treated as an emergency.¹





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