

Taking Action for Optimal Community and Long-Term Stroke Care

A resource for healthcare providers

Updated April 2020

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OVERVIEW



The goal of **Taking Action for Optimal Community and Long-Term Stroke Care (TACLS)** is to provide information to support healthcare providers as they work together with people who have had a stroke to help them achieve optimal outcomes, regain their best level of functioning, and live meaningful lives.

SCOPE

This resource provides guidance and information to healthcare providers about how to care for people who have had a stroke who are living in community settings, such as their own home, a rehabilitation centre, a long-term care setting, or other community facility.

The care described in this resource is applicable throughout recovery and resuming activities of daily life, a process that may continue for months and years after a stroke has occurred. It focuses on the care needed after the hyperacute (generally the hours immediately following the stroke) and acute phases (usually the first week following the stroke) have passed. Information on caring for people in the hyperacute and acute phases of stroke can be found in other resources developed by the Heart and Stroke Foundation of Canada, available at www.strokebestpractices.ca.

The layout of this resource follows the International Classification of Functioning, Disability and Health (ICF), the World Health Organization's framework for measuring health and disability. The ICF provides a standard language and framework to talk about functioning, disability, and health, using four domains: Body Structures, Body Functions, Activities and Participation, and Environmental Factors. This document is structured around the first three, with environmental factors being integrated throughout rather than addressed in a separate section.

This resource updates and replaces *Tips and Tools for Every Day Living: a Guide for Caregivers*. It includes updated information on specific areas of caring for people who have had a stroke, and more closely links to the Heart and Stroke Foundation's Canadian Stroke Best Practice Recommendations.

TARGET AUDIENCE

This resource is written primarily for healthcare providers such as Personal Support Workers, Health Care Aides, Home Care Attendants, Rehabilitation Assistants, and others who are providing paid care, in any setting across the continuum of care, to people who have had a stroke. The focus is on rehabilitation and recovery.

Other healthcare professionals working with people who have had a stroke and their families may also find the content helpful. They may also wish to read *Taking Action Towards Optimal Stroke Care: An Overview*, *Taking Action in Stroke Prevention: A Quick Response Guide*, and *Taking Action Towards Acute Inpatient Stroke Care*, all available from the Heart and Stroke Foundation Canadian Stroke Best Practices at www.strokebestpractices.ca.

Caregivers, family members, and friends who provide informal support and care may find this resource useful. They may also wish to read *Your Stroke Journey: A Guide for People Living with Stroke* and *Taking Charge of Your Stroke Recovery: A Survivor's Guide to the Canadian Stroke Best Practice Recommendations*, available from the Heart and Stroke Foundation at www.strokebestpractices.ca

CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

The information in this resource is based on the Canadian Stroke Best Practice Recommendations, which outline the best ways to prevent, diagnose, treat, and care for people who have had a stroke. The recommendations are developed and updated every 2-3 years under the leadership of the Heart and Stroke Foundation of Canada. Canadian healthcare professionals from many disciplines with expertise in stroke care review current research, evidence, and information from Canada and around the world to create the best practice recommendations.

The best practice recommendations represent the gold standard in stroke care. Meeting all of the recommendations is a challenge; however, they serve as goals that healthcare professionals and healthcare systems can strive toward in a spirit of continuous quality improvement.

Following the best practice recommendations narrows the gap between what is known about the best ways to treat stroke (evidence) and how stroke care is actually delivered on a daily basis (practice). Ultimately, implementing stroke best practices decreases the impact of stroke on individuals, families, communities, and the healthcare system.

Some of the best practice recommendations are included in this resource. The full content can be found at www.strokebestpractices.ca. In addition to the recommendations, the website also includes information on the types of services that should be available for people who have had a stroke; ways to measure how well stroke care is being delivered; and lists of tools, checklists and questionnaires that can be used to guide care for people who have had a stroke.

DISCLAIMER

Taking Action for Optimal Community and Long-Term Stroke Care 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.

THANK YOU

The Heart and Stroke Foundation of Canada acknowledges and thanks the dedicated group of healthcare professionals who gave their time, energy, and expertise to write and review this resource. Their commitment to improving stroke care in Canada represents interprofessional collaboration at its best. We also thank the many thousands of healthcare providers, family members, and caregivers who provide invaluable assistance to people who have had a stroke.

Your comments, suggestions, and inquiries regarding this resource are welcome and appreciated. Share your comments with us by email strokebestpractices@hsf.ca

GLOBAL STROKE BILL OF RIGHTS

In 2014, following widespread consultation with stroke survivors and caregivers around the world, the World Stroke Organization (www.world-stroke.org) released a bill of rights for stroke patients. It highlights the care and treatment patients and families consider most important to their recovery. As healthcare providers, we all have a responsibility to provide people who have had a stroke the best care possible within available resources and geographic capacity.

AS A PERSON WHO HAS HAD A STROKE, I HAVE A RIGHT TO:



Receive the best stroke care

- A rapid diagnosis so I can be treated quickly
- Receive treatment by a specialized team at all stages of my journey (in hospital and during rehabilitation)
- Receive care that is well coordinated
- Access treatment regardless of financial situation, gender, culture or place that I live
- Receive treatment that is right for me as an individual considering my age, gender, culture, goals and changing needs over time

Be informed and prepared

- Be informed about the signs of stroke so I can recognize one if I am having one
- Be fully informed about what has happened to me and about living with stroke for as long as I require it

Be supported in my recovery

- Be provided with hope for the best possible recovery I can make now and into the future
- Receive psychological and emotional support in a form that best meets my needs
- Be included in all aspects of society regardless of any disability I may have
- Receive support (financial or otherwise) to ensure I am cared for in the long term
- Be supported to return to work and/or to other activities I may choose to participate in after my stroke
- Get access to formal and informal advocacy to assist me with access to the services I need
- Be connected to other stroke survivors and caregivers so I may gain and provide support in my recovery from stroke

CHAPTER 1

The Stroke Care Team

Providing care for people who have had a stroke and their family and caregivers, involves a team of specialized health care professionals and care providers.

IN THIS CHAPTER

Roles and Responsibilities
Client-Centred Care
Team Members



CHAPTER 1

The Stroke Care Team



IN THIS CHAPTER

- Roles and responsibilities
- Client-centred care: “Nothing about me without me”
- The team members
- The team approach
- Your role as part of the stroke care team

YOUR ROLE AS A HEALTHCARE PROVIDER

People who have had a stroke experience a wide range of physical, cognitive, and emotional challenges that require different types of healthcare expertise. Each member of the stroke care team contributes to the care and recovery journey. As a member of this team, you can make a big difference in the quality of life of someone who has had a stroke.

ROLES AND RESPONSIBILITIES

Providing care for people who have had a stroke, and their family and caregivers, involves a team of specialized healthcare professionals and care providers, defined here as the **stroke care team**. Each team member has unique knowledge and skills to add to overall care. The team approach helps ensure that people who have had a stroke get the best and most up-to-date care.

The stroke care team is made up of the person who has had a stroke, their family, friends and caregivers, and various healthcare providers, depending on availability and the person’s health status. Recovery is much more successful when everyone works together to communicate with each other and coordinate treatment and services.

The roles and responsibilities of the stroke care team are to:

- **Help** the person who has had a stroke achieve the best possible outcomes
- **Develop** individualized care plans that specify client centered goals, strategies, and approaches
- **Prevent** or reduce the risk of complications, and quickly address complications that do occur
- **Educate** the person and their family about stroke and its effects
- **Help** the person learn strategies to cope and adapt to changes caused by the stroke
- **Provide** assistance during recovery and on an ongoing basis
- **Be flexible** and respond to changing needs of the person who has had a stroke
- **Communicate** with each other about the needs and wishes of the person who has had a stroke
- **Communicate** with each other about the person’s progress, and concerns or issues
- **Regularly review** the care plan and update it as needed in accordance with the person’s medical status, progress, and preferences

The team works together so that people who have a stroke can recover in a safe, supportive environment that helps them heal, receive care that includes support and education, and have their physical, cognitive, social, and emotional needs met.

CLIENT-CENTRED CARE: “NOTHING ABOUT ME WITHOUT ME”

Following the principles of patient- or client-centred care means healthcare providers put the client at the centre of everything that is done — sometimes described as “nothing about me without me.”*

When you and your colleagues provide client-centred care, you:

- Respect each person as an individual, taking the time to get to know them and understand them
- Maintain their dignity at all times
- Encourage independence without pushing them beyond their limit or holding them back
- Include them in decision making to the extent that they wish to be involved, because they are the expert on their life
- Ask about their goals, preferences, and values, and work as a team to incorporate their needs into the care plan

Always remember that the recovery journey is different for everyone. Your goal is to help people who have had a stroke learn to cope with the changes they are facing, and improve the quality of life for them and their families.

THE TEAM MEMBERS

The composition of the team varies based on the stroke severity, the strengths and limitations of the person who has had a stroke, the stage in the stroke journey, the place where care is being provided, healthcare site, and the availability of healthcare expertise. It usually includes the following:

- **The person who has had a stroke, also called the stroke survivor**, is the focus of the team’s efforts and a member of the team. As much as possible, they and their family members should have input into decisions about the care plan, the goals, and the care that is provided.
- **Caregivers** are family and friends who provide ongoing care, emotional support, and social contact to the person who has had a stroke. They often book and take the person to appointments and services, provide assistance with activities of daily living such as dressing and toileting, and participate in rehabilitation programs. They can provide valuable insights about the person’s needs and preferences, especially if the ability to communicate has been affected by the stroke.
- **Healthcare support workers** include Personal Support Workers, Health Care Aides, Rehabilitation Assistants, Home Care Attendants, and/or others depending on the work setting. These team members provide hands-on care to the person who has had a stroke, always in accordance with the individualized care plan. They may help with activities of daily living, such as personal hygiene, feeding, and toileting; positioning and transfers; and household tasks such as meal preparation, laundry, or cleaning.

* Excerpt from Valerie Billingham, from a session at the Salzburg Global Seminar, (session 356) in 1998, “Through the Patient’s Eyes.”



- **Doctors (Physicians)** are responsible for overall care. They monitor the person's medical, physical, cognitive, and emotional well-being; treat issues that arise; make referrals to other specialists; prescribe medications; and support the person who has had a stroke and their family. Some of the many different types of doctors who look after people who have had a stroke include:
 - ♦ A **family medicine** physician
 - ♦ A **neurologist**, who specializes in disorders of the nervous system
 - ♦ A **physiatrist**, who specializes in rehabilitation
 - ♦ A **psychiatrist**, who specializes in mental health
 - ♦ A **cardiologist**, who specializes in heart problems
 - ♦ A **urologist**, who specializes in urinary tract problems
- **Nurses** play many roles in helping to manage health issues and prevent complications for someone who has had a stroke. Nurses monitor medication management, blood pressure, breathing, bowel and bladder control, nutrition, meal time care, oral health, and skin health, as well as address other medical issues as they arise. Through education, nurses help the person who has had a stroke and their family and caregivers understand the effects of stroke, coordinate activities of the team, and ensure care plans remain current.
- **Case managers/coordinators/stroke navigators** may be involved in planning for the person's discharge from hospital; determining housing, equipment, and support service needs in the community; providing education and support to the person who has had a stroke and their family; and advocating for ongoing needs so the person can remain safely at home for as long as possible. They remain involved with the person in the community and plan necessary services to support care needs as new challenges arise. They help find community resources that will help the person once discharged from hospital.
- **Physiotherapists** have an advanced understanding of how the body moves, how stroke impairments interfere with movement, and how to restore mobility. They help the person who has had a stroke maximize recovery through exercises, activities, and strategies to help with motor and sensory recovery, balance, mobility, and independence. They may recommend mobility aids to decrease the risk of falls and keep people as safe as possible, and provide skills training to help people become more independent.

- **Occupational therapists** work with people who have had a stroke to maximize their independence and quality of life. They assess and provide treatment for many issues related to stroke including mobility, strength, hand function, sensation, vision, perception, cognition, and mood. Occupational therapists focus on improving a person's ability to participate in meaningful activities such as bathing, dressing, driving, making a meal, taking the bus, returning to leisure activities, and working. They also help improve someone's ability to fulfill their role as a parent, spouse, or employee. They help the person set goals, practice daily activities and exercises, adapt their environment to increase safety and function, and identify special equipment to promote success in problem areas. They also provide caregiver training on how to care for and support the person who has had a stroke.
- **Speech-language pathologists** help people who have had a stroke improve their understanding of what others say, their articulation (clarity of speech), their oral and written language (order of the words, difficulty finding words), and their understanding of what they read. They may help the person maximize their communication abilities and/or teach them other ways to communicate. They assess dysphagia (swallowing difficulties) and help identify risks for people with dysphagia, and they may recommend exercises to improve swallowing ability and ways to alter food and liquid consistencies if necessary.
- **Dietitians** provide assessment, diagnosis and recommendations to deal with dietary and nutritional issues that the person who has had a stroke may be experiencing. Dietitians use the most up-to-date public health and scientific research on food, health, and disease and then educate the person who has had a stroke and their family members about how to plan meals and snacks. They also enable people to make appropriate lifestyle and food choices to be healthier and minimize the risk of another stroke.
- **Pharmacists** fill prescriptions, provide education on reasons for taking prescribed medications, and check for potential drug interactions and side effects. They also teach people about medication schedules and help prepare the medication so it is easy to remember the right time to take it.
- **Psychologists** provide counseling and support for a person who has had a stroke, especially if the person is having problems with thinking, memory skills, or emotional issues.
- **Recreation therapists** work with people who have had a stroke to maximize their quality of life. Recreation therapists focus on a person's ability to participate in meaningful leisure activities safely and independently. Recreation therapists provide knowledge, support, advocacy and resources to persons with stroke and their families to assist them in returning to previously enjoyed leisure activities and explore new ones. Recreation therapy services may take place in an institution, in the person's home or within their community.
- **Rehabilitation assistants** provide rehabilitation care to people following a stroke, and assist people with their exercises and activities of daily living to promote recovery and independence. They carry out these rehabilitation programs as developed, assigned and supervised by a speech-language pathologist, physiotherapist, and/or occupational therapist. Services provided may take place in an institution, in the person's home, or in the community.
- **Social workers** provide support, advocacy, and resource connections. They help the person who has had a stroke cope with feelings such as fear, anger, sadness, depression, confusion, and anxiety. Social workers may help coordinate services, help with discharge planning, and act as an advocate to ensure the person and their caregiver have access to services and benefits. They may help with managing crises, such as ensuring someone has a safe environment to live, or connecting people with protective or emergency services. They can contact community services about issues such as caregiver support, respite care, housing, finances and eligibility for benefits, job and career counseling, legal matters, addictions, or moving to long-term care or other living settings.

BEST PRACTICE RECOMMENDATIONS

All patients admitted to hospital with acute stroke should have an initial assessment, conducted by rehabilitation professionals, as soon as possible after admission. The core rehabilitation professional team should include physiatrists, other physicians with expertise/core training in stroke rehabilitation, occupational therapists, physiotherapists, speech-language pathologists, nurses, social workers and dietitians. The patient and family are also included as part of the core team.

THE TEAM APPROACH

Providing the best care for the person who has had a stroke and their family requires assessment, diagnosis, care planning, implementation, and evaluation.

Assessment: Your careful observation and insights about the person you are caring for can contribute to the team assessment. Be sure to report what you see.

Diagnosis: The team doctors identify medical problems based on the assessment.

Care planning: The team develops a care plan based on the assessment, diagnosis, and the person's goals.

Implementation: Your knowledge of and close contact with the person who has had a stroke can help determine the best way to implement the plan.

Evaluation: Your observations help the team judge how well the care plan is working and if changes are needed.



YOUR ROLE AS PART OF THE STROKE CARE TEAM

As a healthcare provider, you know the important role you play in helping people recover from illness and injury, both physically and emotionally. This is challenging and rewarding work. Everyone you care for deserves personalized care that fits their health condition, needs, abilities, and preferences.

The sudden and dramatic effect of stroke often causes people to feel fragile, vulnerable, frustrated, and extremely sad. Your support can help everyone — the person who has had a stroke, and their family and caregivers — adjust to the changes that stroke brings, and find new ways to thrive as they learn to accept “the new normal” that is life after stroke.

As someone who works very closely with the person who has had a stroke and their family, you are in a good position to learn about their needs and monitor their physical, mental, and emotional well-being. You can share this information with the rest of the team to help with planning and determine if adjustments to the care plan are necessary.



GET TO KNOW EACH PERSON

Throughout this resource, you will be reminded to get to know each person as an individual — beyond the effects of the stroke. This makes it easier for you to adapt your care and techniques to suit their needs and preferences.

As the team member who has a great deal of contact with the person and their family in their daily lives, you can empathize with their challenges and celebrate the successes. Also, you may be the first to notice changes. Your observations and your ability to communicate these effectively to the team are vital to helping the person get the best possible care and experience the best possible recovery.

HOW YOU CAN HELP



- Take the time to ask questions about their life, and listen to their stories. What are their likes and dislikes, their interests, their concerns, their hopes and fears?
- Talk to their family and friends. What was the person like before the stroke?
- Have team discussions. Learn about the person from others who are providing care.

KNOW THE CARE PLAN AND FOLLOW IT

Each person will have an individualized care plan that specifies the treatments, medications, and therapies they should receive. The care plan is like a road map that guides them to their best possible level of functioning, whether physical, cognitive, emotional, communicative, or social.

You must always be familiar with each person's care plan and know what parts of it is your responsibility. The plan will be updated as the person's condition changes, so monitor it regularly. Knowing the care plan is the best way to make sure that each person gets the right care for their individual circumstances.

COMMUNICATE WITH YOUR TEAM

Throughout this resource, you will be reminded to consult with your team if you are unclear about any aspect of the care plan and how to implement it, or if you have concerns about the health of the person you are caring for. Make sure you know who your direct contact on the team is — most likely the nurse, the physiotherapist, the occupational therapist, or the case manager.

Clear, timely, and regular communication is key to a team approach to effective stroke care. Follow your workplace guidelines for communicating with the team and do so in a timely manner. Do not delay if a situation requires immediate attention — contact the appropriate team member as quickly as you can.

FOLLOW DIRECTION FROM YOUR ORGANIZATION AND YOUR TEAM

People who have had a stroke receive the best care when their care plan follows the Canadian Stroke Best Practice Recommendations, as these are the most up-to-date and effective ways to treat people who have had a stroke. This resource is based on those recommendations.

However, there may be times when the information in this resource differs from the instructions or care plan that have been developed by the organization you work for or by the stroke care team.

In these cases, always follow the direction from your employer, your team, and the care plan. You may want to ask about a best practice recommendation if you notice differences, but the care plan and your organization's policies and procedures must always take priority.

KEY MESSAGES OF THE STROKE CARE TEAM

- ❑ **You are part of a team of healthcare providers**, family members, and caregivers who are working together to help the person who has had a stroke recover to the greatest possible extent.
- ❑ **You are an important support and source of information** for the person who has had a stroke and their family members.
- ❑ **You can help people who have had a stroke relearn daily activities** or learn new ways to be independent, to help them decrease frustration and develop more confidence in their abilities.
- ❑ **You can talk to the stroke care team** about the person's progress and about any concerns you or they may have.



CHAPTER 2

Body Structure

Within the International Classification of Functioning, Body Structure refers to anatomical parts of the body such as organs, limbs and their components. (WHO, 2001).

IN THIS CHAPTER

- 2.1 The Brain
- 2.2 Stroke and its Effects



2.1 The Brain



IN THIS SECTION

- How the brain works
- Brain hemispheres
- The lobes of the brain

YOUR ROLE AS A HEALTHCARE PROVIDER

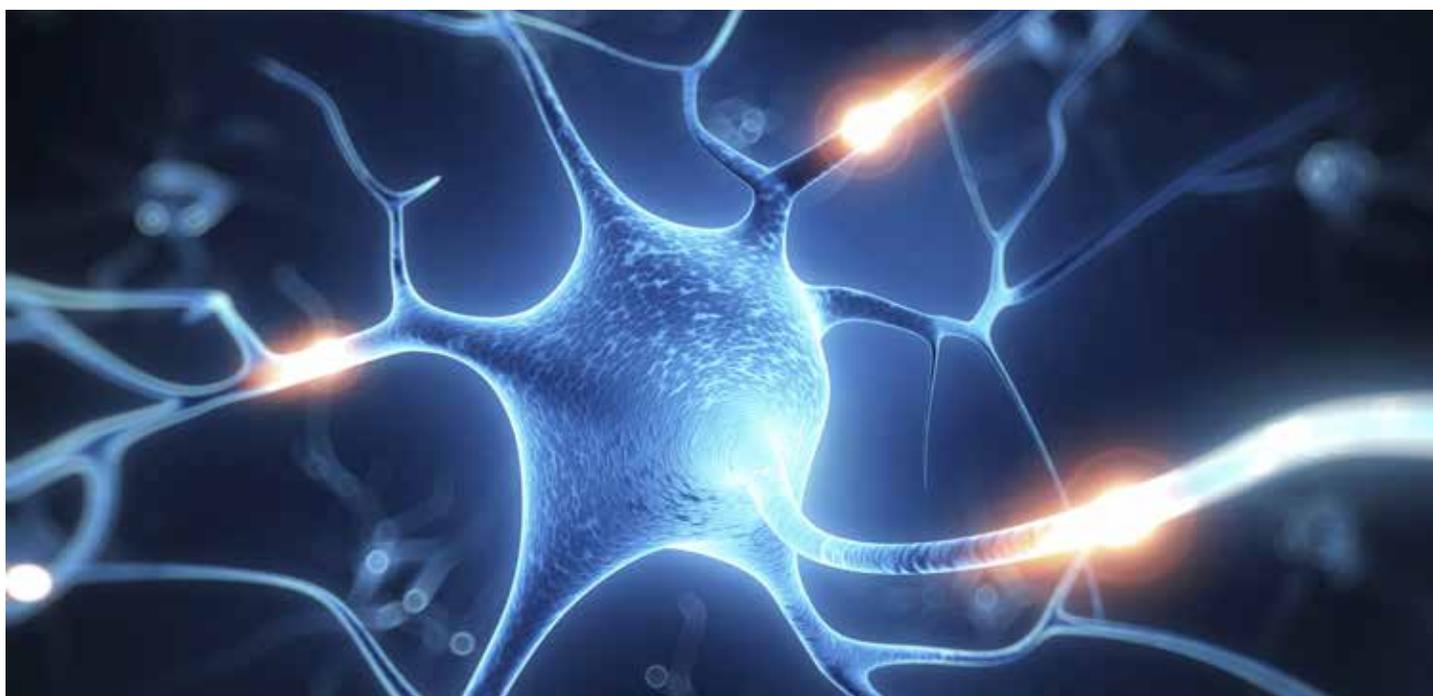
When you understand how the brain works and the effects of a stroke, you can provide better care and support to the person who has had a stroke and their family.

HOW THE BRAIN WORKS

To understand how stroke affects people, it's helpful to know how the brain works and how brain functions are organized.

The brain is like a control centre. It manages physical, sensory, mental, and emotional functions, including:

- **Motor functions:** Movement, coordination
- **Sensory functions:** Sight, sound, smell, touch, taste, and pain
- **Perception:** Interpreting information from the senses, making sense of the surrounding environment
- **Cognition:** Thinking, remembering, planning, reasoning, problem-solving
- **Communication:** Understanding language, speaking
- **Emotions and behaviour**



BRAIN HEMISPHERES

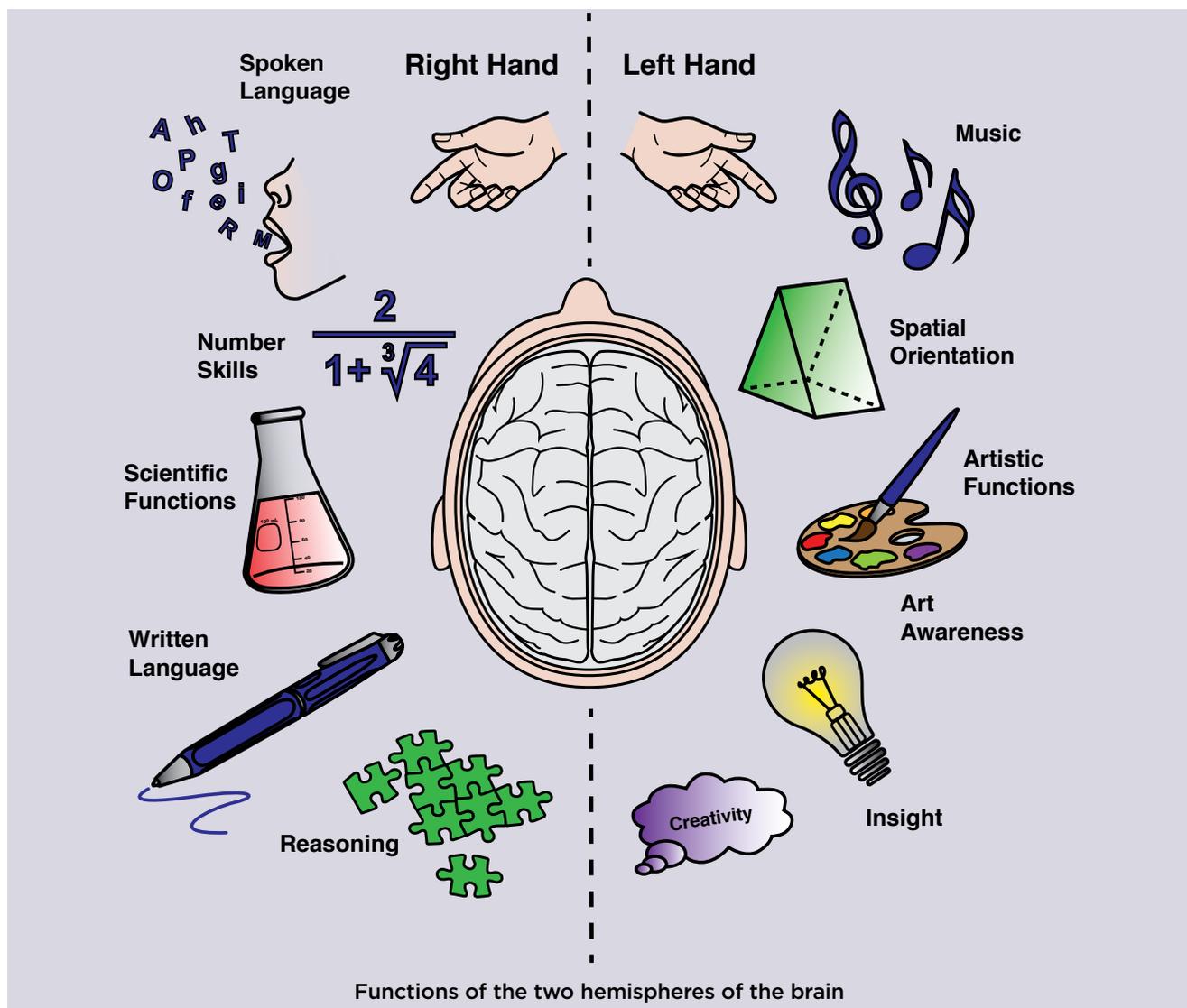
The brain is divided into two sides called the **left hemisphere** (considered the dominant hemisphere) and the **right hemisphere** (non-dominant hemisphere), each controlling different functions. Some functions are controlled by both.

The left hemisphere controls:

- Movement (motor functions) and feeling (sensory functions) on the right side of the body
- Reading, writing, speaking
- Math and number skills
- Logical reasoning

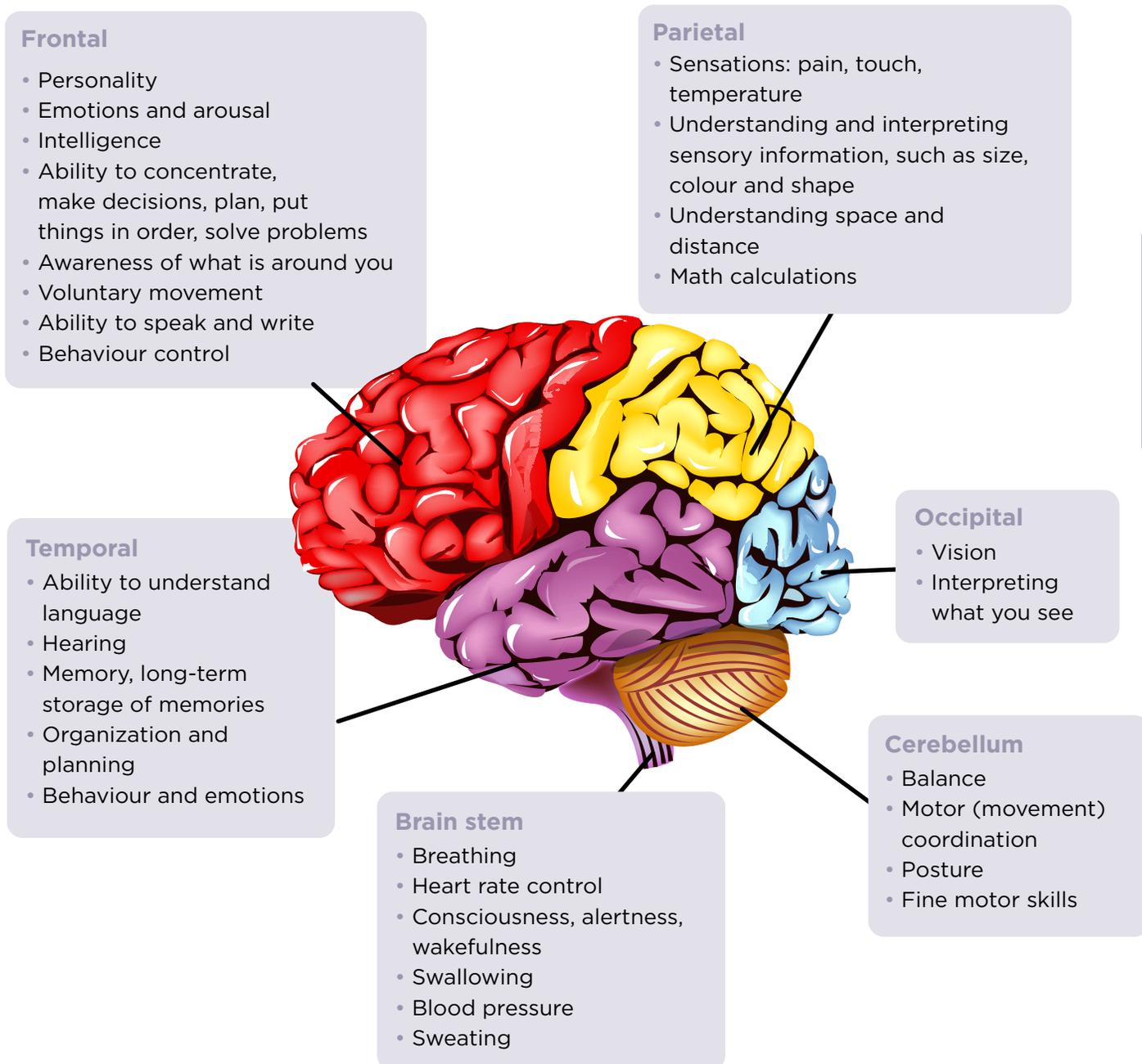
The right hemisphere controls:

- Movement and feeling on the left side of the body
- Creativity and artistic abilities such as music or drawing
- Insight
- Being aware of and making sense of the surrounding environment (perception)
- Reasoning and judgment



THE LOBES OF THE BRAIN

Each hemisphere has six lobes that control different functions.



KEY MESSAGES OF THE BRAIN

- ❑ **To understand how stroke affects people**, it's helpful to know how the brain works and how brain functions are organized
- ❑ **The brain is divided into a left and right side**
- ❑ **The brain has 6 lobes** that control different functions of the body.



2.2 Stroke and its Effects



IN THIS SECTION

- What is stroke?
- Types of stroke
- Stroke is a medical emergency
- Risk factors
- Effects of stroke
- Recovery and rehabilitation

YOUR ROLE AS A HEALTHCARE PROVIDER

People who have had a stroke are at risk of having another, so it's important to know the signs of a stroke and to call the local emergency number immediately. They will also be working with their stroke care team to decrease their risk of another stroke. Your knowledge of the risk factors for stroke and how they can be controlled can help.

WHAT IS STROKE?

The brain is made up of specialized cells called **neurons**. To work properly — and even to survive — neurons need a constant supply of oxygen and nutrients. Blood vessels called **arteries** carry oxygen and nutrients to all parts of the brain, with each artery supplying a specific area.

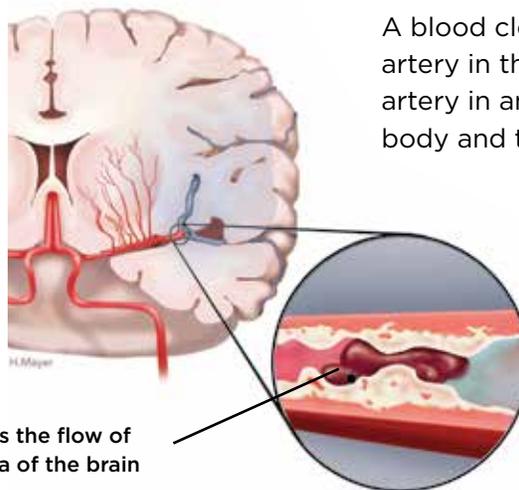
A stroke happens when blood flow in an artery stops, either because the artery is blocked (**ischemic stroke**) or it bursts (**hemorrhagic stroke**). The part of the brain supplied by the artery is then deprived of oxygen and nutrients, damaging the neurons and the functions they control. If blood flow is not restored within minutes, the damaged neurons start to die.

TYPES OF STROKE

Ischemic stroke

About 80 percent of strokes are caused by a blockage or clot in an artery in the brain. A stroke caused by a clot is called an ischemic stroke.

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



Blood clot stops the flow of blood to an area of the brain

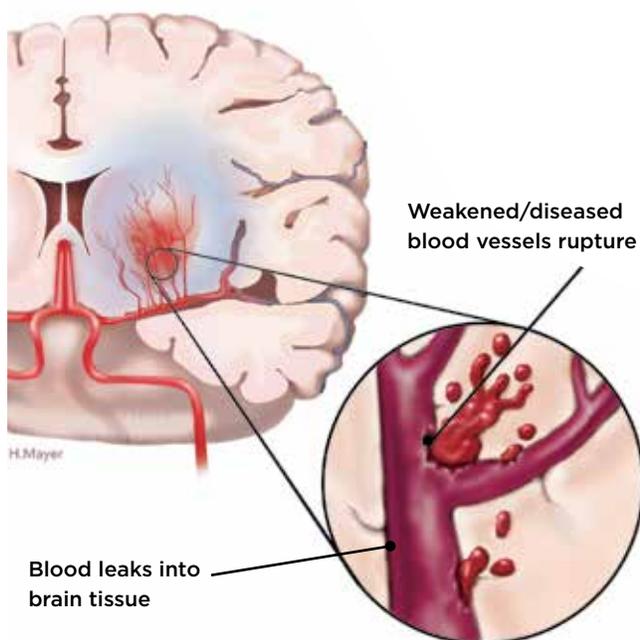
A blood clot can form in an artery in the brain, or in an artery in another part of the body and travel to the brain.

Ischemic Stroke

Transient ischemic attack

A **transient ischemic attack (TIA)** sometimes called a “mini-stroke” or “warning stroke,” is caused by a small clot that briefly blocks an artery. The symptoms are similar to a stroke, but they last only a few minutes or hours and cause no lasting damage. A TIA is different from a mild stroke. A person who has had a mild stroke will have some impairment that remains beyond the first few minutes or hours.

A TIA is a warning that a more serious stroke may occur soon. It should be treated as an emergency and medical help should be sought right away. Call 9-1-1 or your local emergency number, even if the symptoms go away.



Hemorrhagic Stroke

Hemorrhagic stroke

About 20 percent of strokes are hemorrhagic. A hemorrhagic stroke is caused when weak spots in the arteries, called **aneurysms**, stretch too far and break open. This interrupts blood flow and damages the brain. High blood pressure weakens arteries and is a major cause of hemorrhagic stroke.

OTHER CAUSES OF STROKE

In rare cases, a tumor, an infection, or swelling in the brain due to injury or illness can cause a stroke. Some people have irregularities in their arteries at birth that can eventually cause a stroke. Additionally, recreational drug use (such as cocaine) can sometimes lead to a stroke.

STROKE IS A MEDICAL EMERGENCY

Stroke and TIAs are a medical emergency that requires immediate medical attention. Getting treatment quickly can improve the chances of survival, reduce the damage in the brain, and lead to a better recovery. Therefore, it is crucial to recognize the signs and respond immediately.

FAST SIGNS OF STROKE

The Heart and Stroke Foundation of Canada's FAST campaign helps Canadians recognize the signs of stroke and act FAST. Recognizing the signs of stroke and acting quickly can mean the difference between life and death, or the difference between a better recovery and a less successful outcome.

Learn the signs of stroke

Face is it drooping?

Arms can you raise both?

Speech is it slurred or jumbled?

Time to call 9-1-1 right away.

Act **F A S T** because the quicker you act, the more of the person you save.

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If you or someone with you experiences any of these signs, call 9-1-1 or your local emergency number immediately. Acting quickly can improve survival and recovery.

Do not drive yourself or the person having a stroke to the hospital. An ambulance will get to the best hospital for stroke care safely and more efficiently.

BEST PRACTICE RECOMMENDATIONS

All members of the public should be educated that stroke is a medical emergency. Public education should focus on recognizing the signs and symptoms of stroke. Public awareness campaigns and education should include use of the FAST (Face, Arms, Speech, Time) acronym to facilitate memory of these symptoms. Public education should emphasize the need to respond immediately by calling 9-1-1 or their local emergency number.

All members of the public should be educated that stroke is a medical emergency. Public education campaigns should focus on:

- Recognizing signs and symptoms of stroke
- Use of the FAST (Face, Arms, Speech, Time) acronym to help remember stroke symptoms
- The need to respond immediately by calling 9-1-1 or a local emergency number.

TIME IS OF THE ESSENCE

If the stroke is ischemic (caused by a blood clot), a clot-busting drug called tissue Plasminogen Activator (tPA) may be used. tPA must be given within four and a half hours after the stroke symptoms began, and the sooner after the symptoms began the better. The doctor will determine if tPA is appropriate and when it may be administered.

People experiencing a severe stroke caused by larger clots may be eligible for new endovascular treatments, which remove the clot using a tiny device inserted via the blood vessels. This treatment must take place within six hours for most patients.

RISK FACTORS

Risk factors for stroke are divided into two categories:

- **Modifiable risk factors** can be managed through lifestyle changes, treatment, and medication
- **Non-modifiable risk factors** cannot be changed

Modifiable risk factors	Non-modifiable risk factors
<p>Medical conditions</p> <ul style="list-style-type: none"> • Hypertension (high blood pressure) • Atrial fibrillation (irregular heart beat) • Diabetes • Blocked carotid arteries • Hypercholesterolemia (high blood cholesterol) • Sleep apnea (breathing starts and stops during sleep) • Taking birth control pills or hormone replacement therapy <p>Lifestyle</p> <ul style="list-style-type: none"> • Unhealthy diet • High salt intake • Being overweight or obese • Physical inactivity • Smoking • Excessive alcohol consumption • Recreational drug abuse (e.g., cocaine) • High stress levels 	<ul style="list-style-type: none"> • Previous stroke or TIA: The risk is higher if the person has already had a stroke or TIA. It is greatest immediately after the stroke and stays high for five years. More than 30 percent of stroke survivors have a second stroke. • Family history: The risk is higher if a parent or sibling had a stroke before age 65. • Age: Stroke can occur at any age, but most happen to people over 65. • Gender: Before menopause, women have a lower risk than men, but more women than men die of stroke. • Ethnicity: First Nations people and those of African or South Asian descent have an increased risk because of higher rates of high blood pressure and diabetes in these populations.

MANAGING RISK FACTORS

The risk of another stroke can be reduced by controlling modifiable risk factors. Even controlling just one risk factor can significantly reduce the risk.

Healthcare providers play an important role in helping people identify and manage their risk factors for stroke. Appendix A provides detailed information about managing stroke risk factors.

Refer to Appendix A for additional information on managing stroke risk factors, page 169.



BEST PRACTICE RECOMMENDATION

Secondary prevention of stroke should be aggressively managed and risk factor reduction strategies optimized in all living settings (e.g., long term care). They (patients) should receive information and counseling about possible strategies to modify their lifestyle and risk factors. Referrals to appropriate specialists should be made where required to provide more comprehensive assessments and structured programs to manage risk factors.

HOW YOU CAN HELP



- Be aware of the person's risk factors
- Understand their goals for dealing with the risk factors
- Discuss how you can help them decrease the impact of their risk factors
- Reinforce the recommendations that have been made to decrease the impact of their risk factors
- Help them set realistic goals that fall within the care plan, to motivate them to keep trying
- Help them deal with obstacles
- Help them track their progress
- Provide support and encouragement
- Talk to the stroke care team about problems or issues

EFFECTS OF STROKE

Some common effects of a stroke include:

- Paralysis or weakness on one side of the body
- Vision problems
- Communication problems
- Fatigue
- Incontinence (loss of bladder or bowel control)
- Changes in how the person perceives or interprets the world
- Neglect (decreased or no awareness of the affected side of the body, or the environment)
- Personality changes (depression, loss of emotional control)
- Cognitive difficulties that make it hard to remember things, solve problems, and handle everyday tasks

Some effects occur no matter where the stroke took place in the brain, while others are characteristic of a left or right hemisphere stroke.

IMPAIRMENT AND DISABILITY

Most people who have had a stroke will have some impairment, even if it is only temporary.

- **Impairment** is a change in function caused by the stroke.
- **Disability** is a change in the ability to do things because of the impairment.

About 60 percent of people who have had a stroke will have some long-term impairment that can affect their ability to participate in everyday activities. The effects of stroke are different for each person, and the severity of the impairment and disability depends on several factors:

- The type of stroke (ischemic or hemorrhagic)
- The side of the brain where the stroke occurred (right or left hemisphere)
- The part of the brain (lobe) affected by the stroke
- The size of the affected area in the brain
- The amount of time the brain area had no blood flow
- The amount of time it took to get to the hospital
- Whether there are other blood vessels in the affected area of the brain that can keep delivering oxygen and nutrients (**collateral circulation**)
- How quickly healthy brain areas take over the functions affected by the stroke (**neuroplasticity**)

RECOVERY AND REHABILITATION

Everyone's recovery journey is different. It happens at the person's own pace. It may happen quickly for some, while it may take months or even years for others. The pace of recovery is most rapid in the first few months after a stroke, although it often continues for months or years.

Researchers used to believe that brain pathways (for sending messages between the brain and the body) were fixed or unchangeable. This meant if a function was performed by a certain area of the brain it could only be performed by that area. Therefore, any brain damage that was not repaired within a few months would be permanent.

It is now being found that the brain and the pathways can change at all stages of life. This is called **neuroplasticity**. It means that some people who have had a stroke may be able to retrain their brain by learning to use different parts of the brain to regain function during rehabilitation.

There are number of factors that affect recovery:

- Age and general health
- The type and location of the stroke and the extent of the damage
- Personality, coping abilities, and emotional state
- Amount and type of support available from family and friends
- Access to required rehabilitation
- Ability and motivation to take part in rehabilitation

THE IMPORTANCE OF FOLLOWING THE REHABILITATION PLAN

Rehabilitation is a key component of comprehensive stroke care. It may be provided in acute care settings, rehabilitation centres, outpatient clinics, home, and community based rehabilitation programs such as early supported discharge services and private services.

How long rehabilitation lasts varies depending on the type of service needed, the nature of the disability, the needs of the person who has had a stroke, and their family's willingness to participate and be involved. The most intensive rehabilitation generally takes place within the first six months after the stroke. Rehabilitation is an ongoing process that may continue from inpatient care into the community.

Carefully following the rehabilitation plan makes a big difference to how well people recover. You can remind the person how important it is to follow their rehabilitation plan and help them practice what they were taught.

KEY MESSAGES OF STROKE AND ITS EFFECTS

- ❑ By learning about stroke, you can help the person who has had a stroke **understand what has happened to them.**
- ❑ **Stroke and TIA are medical emergencies** that require immediate medical attention.
- ❑ **Learn the signs of stroke – FAST:**
 - Face** – is it drooping?
 - Arms** – can you raise both?
 - Speech** – is it slurred or jumbled?
 - Time** – to call 9-1-1 right away.
- ❑ **Stroke can happen at any age.**
- ❑ **Know the risk factors for stroke.** Some can be changed, some can't.
- ❑ **Recovery from stroke** is very individual and depends on many factors. It can continue for months and even years.



CHAPTER 3

Body Function (Physical)

Body function refers to physiological functions of body systems (WHO, ICF 2001).

It includes all areas of care that help people recover and manage mobility, nutrition, self-care and personal hygiene, sensory functions, pain, emotions, thinking, and memory.

IN THIS CHAPTER

- 3.1 Movement and Motor Recovery
- 3.2 Nutrition and Swallowing
- 3.3 Hydration
- 3.4 Bladder and Bowel Control
- 3.5 Skin Integrity



3.1 Movement and Motor Recovery



IN THIS SECTION

- Factors affecting movement after a stroke
- Using the affected limbs in recovery

YOUR ROLE AS A HEALTHCARE PROVIDER

Stroke frequently affects a person's ability to move parts of their body, as well as to move around safely in their environment. Limitations in these areas can be frustrating and confining. There are many techniques to help a person who has had a stroke move without causing further injury or pain, as well as improve their ability to move safely on their own. By being aware of the typical changes in movement that occur after a stroke you can help the person be safer, more comfortable, and more independent. You need to use proper positioning and safe transfer techniques, and provide support as they adjust to the changes.

FACTORS AFFECTING MOVEMENT AFTER A STROKE

There are many factors that affect how well a person can move after a stroke. First, the stroke itself often affects motor function (the ability to move parts of the body), usually on the opposite side from where the stroke occurred (i.e., a left brain stroke can affect motor function on the right side of the body). Brain stem stroke can affect motor function on both sides of the body.

In addition, the following effects of a stroke can make movement more difficult.

FATIGUE

Healing the brain and relearning the tasks of daily living take a great deal of energy. People who have had a stroke often feel very tired, especially during their initial recovery. Some fatigue is a normal part of stroke recovery. Even simple tasks may be exhausting. Being so tired all the time can lead to frustration, sadness, and anger. The rehabilitation specialists are able to suggest ways that the person can save their energy, so they can better manage fatigue and participate in recovery. Severe and persistent fatigue is a serious issue that should be reported to the stroke care team.

BEST PRACTICE RECOMMENDATION

Post-stroke fatigue is a common condition, and can be experienced after TIA and stroke at any point during the recovery process. Post-stroke fatigue is often under-recognized; thus healthcare professionals should anticipate the possibility of post-stroke fatigue, and prepare patients and families to mitigate fatigue through assessment, education, and interventions at any point during the stroke-recovery continuum.

LOSS OF SENSATION

Sensation means being able to feel, be aware of touch and temperature, and know where the body is in space. A person who has had a stroke may have limited or no sensation in the part of the body affected by the stroke.*

CHANGES IN MUSCLE TONE (SPASTICITY OR FLACCIDITY)

Muscle tone is the slight tension always present in normal muscle, even when the muscle is at rest. Normal muscle tone stops muscles from being pulled down by gravity. Stroke can cause muscles to become low tone (flaccid) or high tone (spastic) leading to movement and mobility problems.

- **Flaccidity:** A flaccid or low-tone limb appears heavy and limp. It must be handled carefully at all times (lying down, sitting, standing, and when transferring), to prevent joint and soft tissue injury and pain. The occupational therapist or physiotherapist can recommend ways to safely position and manage a flaccid limb.
- **Spasticity:** A spastic or high-tone limb appears stiff or tense. Careful and gentle handling and positioning, as well as doing prescribed range of motion exercises and stretching can help prevent spasticity from getting worse. Spasticity can cause muscle contractures or shortening of the muscles, and reduce the **range of motion** (how far a person's joints can be moved in different directions) in a joint. Splints are sometimes prescribed to provide a prolonged stretch to tight muscles and soft tissues. Splints should always be worn according to the schedule provided and skin should be checked regularly for irritation or breakdown.

BEST PRACTICE RECOMMENDATION

Spasticity and contractures can be prevented or treated by antispastic pattern positioning, range of motion exercises, and/or stretching. Routine use of splints is not recommended. In some select patients, the use of splints may be useful and should be considered on an individualized basis.



* Refer to Section 4.5 for more information on sensory loss.

CHANGES IN MUSCLE STRENGTH

Muscle strength can be affected by stroke. Muscle groups in the trunk and in the arm and leg on the side of the body affected by the stroke can have decreased strength after a stroke. This can lead to difficulty moving around and completing activities of daily living and/or a painful shoulder. Because certain arm and leg movement patterns are common after a stroke, therapists often work with stroke survivors to strengthen weakened muscles and help the person return to more normal and functional movement.

POOR BALANCE

Problems with sensation, motor control, and vision can affect balance, whether sitting or standing, and increase the risk of falls. Therapists will often evaluate the person who has had a stroke in their home and community environments and recommend modifications and/or equipment to minimize the risk of falls.

BEST PRACTICE RECOMMENDATION

Based on risk assessment findings, an individualized falls prevention plan should be implemented for each patient.

IMPROPER POSTURE

Proper standing posture means that the shoulders, hips, and feet are vertically aligned, with the head upright in the middle. Stroke may cause people to put more weight on the unaffected side. This can cause the affected shoulder (**shoulder girdle**) and hip (**pelvic girdle**) to become misaligned, and this asymmetrical or uneven posture may lead to muscle tightness, pain, and difficulties with movement.

PERCEPTUAL PROBLEMS

Changes in perception may affect mobility and make it harder to move around safely. Changes in perception caused by stroke include:

- Visual neglect (decreased awareness of the environment on the side of the body affected by stroke)
- Body neglect (decreased awareness of the body on the side affected by stroke)
- Apraxia (difficulty planning and carrying out purposeful movements, even when the person has normal movement required to perform the task)
- Impaired depth and distance perception, often a result of double vision or partial loss of vision in one or both eyes
- Visual field loss (being unable to see the full scope of what is in front and to the side)*

* Refer to 4.1 for more information about vision and visual perception impairments caused by stroke.

USING THE AFFECTED LIMBS IN RECOVERY

Although recovery is often greatest in the first several months following a stroke, recovery from impairment and the resulting improvements in function and participation can go on for years. Our understanding of neuroplasticity, the brain's ability to reorganize by forming new neural connections, has led to more treatment options to promote optimal recovery. Intense practice of relevant and challenging tasks has been shown to affect neuroplasticity and improve functional recovery.

To promote recovery, people who have had a stroke are encouraged to incorporate their affected limbs into daily activities as soon as possible. Even small movements can be used to help accomplish tasks. There was a time when people who had a stroke were encouraged to use their stronger arm to complete tasks; however, it has been found that this does not encourage positive brain changes and in fact can interfere with learning new skills and improving function. For this reason, ongoing intense, goal-directed therapy is very important in the early months and should be practiced daily. Therapists often work with the person who has had a stroke to develop a home program of challenging tasks and activities that should be completed daily.

KEY MESSAGES OF MOVEMENT AND MOTOR RECOVERY

- ❑ **Know how stroke** affects a person's ability to move.
- ❑ **Make your safety** and theirs a priority. Use proper positioning and safe transfer techniques.
- ❑ **Provide support** as people who have had a stroke adjust to the changes.
- ❑ **Motor recovery takes energy**; ensure people who have had a stroke balance exercise and rest periods.
- ❑ **Provide assistance** with the goal of helping the person who has had a stroke regain as much independence as possible.
- ❑ **Stroke recovery** happens over many months, and in some cases years.



3.2 Nutrition and Swallowing



IN THIS SECTION

- Eating and swallowing problems
- Dysphagia
- Oral hygiene
- Adapting food textures and special diets
- Assistive devices

YOUR ROLE AS A HEALTHCARE PROVIDER

Eating and drinking are necessary and pleasurable parts of life. Stroke can leave people unable to feed themselves or swallow food or liquid safely. Food textures often need to be modified. You play a critical role in helping people eat and drink enough to stay healthy, avoid the dangers caused by swallowing problems, and enjoy their meals.

EATING AND SWALLOWING PROBLEMS

Eating: A stroke can interfere with getting food from the plate to the mouth in a number of ways. The person's arm and hand movement may be affected, the cognitive abilities that help them know how to chew and swallow may be affected, or they may not see some of the food on their plate due to neglect. Also, stroke can change how food smells or tastes to the person. All of these can make mealtimes challenging, frustrating, and less enjoyable.

Swallowing: Swallowing requires the coordination of many muscles to move food and liquid through the mouth, throat, and esophagus to the stomach. A stroke can affect these muscles, resulting in dysphagia (difficulty swallowing). Decreased alertness and attention from a stroke may further impact the ability to swallow safely.

Some effects on these muscles are easy to see, such as weakness in facial muscles and drooling. Other effects may be invisible and unrecognized. These include lack of a cough reflex when food or liquid enters the airway (silent aspiration), or preventing food from moving quickly through the esophagus into the stomach.

DYSPHAGIA

People who have had a stroke will have their swallowing abilities assessed by a member of the team. This could be the speech-language pathologist, occupational therapist, dietitian, nursing assistant, or a healthcare support worker.

COMMONLY OBSERVED SIGNS AND SYMPTOMS

- Coughing, throat clearing, or choking during or after meals
- Shortness of breath
- Difficulty moving food to start the swallow
- Drooling
- Poor lip closure, loss of food from mouth
- Altered voice quality, such as a wet, gurgling, or weak voice

- Watery eyes or runny nose when eating or drinking
- Spitting food out
- Pocketing food in cheeks, under the tongue or the side of the mouth
- Slow, effortful chewing
- Rapid, uncontrolled eating

Additionally, the person may report:

- A tight throat
- Food sticking in their throat or chest
- Difficulty swallowing solids
- Reflux or heartburn
- Feeling full after eating very little
- Feeling anxious about mealtimes

Carefully monitor the person for any of these signs and symptoms. If you observe them, talk to your team for advice and strategies. If a person's condition and swallowing abilities change at any time, they should be screened and possibly re-assessed by team members with expertise in dysphagia management.

CONSEQUENCES OF DYSPHAGIA

Dysphagia often stops people who have had a stroke from getting enough nourishment, especially during early recovery, and may lead them to avoid mealtimes.

Dehydration: Not drinking enough fluid can result in dehydration. Dehydration can cause dry mouth, constipation, urinary tract infection, confusion, severe illness, or even death. It can make some swallowing difficulties even more difficult to manage.

Malnutrition: Not eating enough can result in malnutrition, weight loss, reduced energy, skin breakdown, impaired wound healing, and lower resistance to infection.

Aspiration: The entry of saliva, food, liquid, or refluxed stomach contents (stomach contents coming back up) into the airway can cause respiratory problems, and pneumonia.

Choking: A piece of food may become lodged in the airway, making it difficult or impossible to breathe.

Impaired quality of life: Eating is often a social activity. Swallowing and eating problems can make the person reluctant to eat with a group. This can increase social isolation and decrease their quality of life. Changes in taste and smell can also affect the person's enjoyment of food.

Other consequences of dysphagia may include:

- Spikes in temperature shortly after meals
- Dry mouth
- Weight loss or weight gain due to malnutrition
- Respiratory infections
- Poor air intake or weak cough
- Chronic heartburn

HOW YOU CAN HELP



Always use proper positioning

- Get the person out of bed to eat whenever possible.
- Seat the person upright in a wheelchair or straight-backed chair.
- Position someone who is unable to get out of bed at 60 to 90 degrees, and stabilize them with pillows.
- Keep the head in the midline and flexed forward slightly.
- Encourage them to stay upright for 30 minutes after meals, or elevate the head of the bed 30 degrees, to prevent reflux.

Reduce distractions

- If the person is easily distracted, remove all non-essential items from the table or tray, avoid busy dining rooms, and present one food at a time.
- Serve meals in a quiet environment. For example, turn off the television or radio, minimize conversation, and discourage them from talking with food in their mouth.
- Encourage visitors to come outside of mealtimes.
- Have the person take medications before and after meals, rather than during.

Monitor feeding rate and amount

- Provide small, frequent meals.
- Feed small amounts using a teaspoon or even a half teaspoon, not a tablespoon.
- Encourage them to swallow twice. To check for a complete swallow, watch for laryngeal elevation, which is the movement of the Adam's apple up and down.
- Ensure the mouth is clear before introducing more food.
- Cue them to the whole plate or tray if they have neglect or tend to miss food.
- Encourage them to eat slowly, and never rush them.

Teach the person to

- Monitor self-feeding with a mirror.
- Remove pocketed food with their tongue.
- Be aware of drooling and use a napkin if necessary.
- Cough to clear the throat.
- Wear loose-fitting clothes and avoid tight belts, to avoid reflux.

ORAL HYGIENE

Poor oral hygiene, dental problems such as loose or decayed teeth, and poorly fitting dentures can cause problems with eating and swallowing safely.

A clean mouth and teeth are essential to comfort and good health. Gum disease is linked to heart disease, pneumonia, and stroke. Bacteria from diseased gums may travel through the bloodstream and cause infections. Bacteria and food particles in the mouth can be especially dangerous if aspirated into the lungs, potentially causing aspiration pneumonia.

A clean mouth and teeth are important even for people who are fed through a tube.

BEST PRACTICE RECOMMENDATION

Patients, families and caregivers should receive education on swallowing and feeding recommendations. To reduce the risk of aspiration pneumonia, patients should be permitted and encouraged to feed themselves whenever possible. Patients should be given meticulous mouth and dental care, and educated in the need for good oral hygiene to further reduce the risk of pneumonia.

HOW YOU CAN HELP



Help the person practice good oral hygiene:

- Encourage or help the person perform mouth care before and after meals
- Remove dentures after each meal so food particles can't collect and cause irritation
- Check the mouth for food debris after each meal

At least once a day, check that the person's mouth and tongue are pink and moist. If the mouth is dry with patchy white areas, or the tongue is white and coated, tell your team.

Help the person brush their teeth, gums, and tongue using a soft toothbrush and toothpaste. Do not use oral swabs, as they do not clean the mouth properly.

Clean dentures when required, not just at bedtime. Remove and soak dentures overnight. Gums and mouth tissues will be healthier when allowed to "breathe" for four to six hours every night.

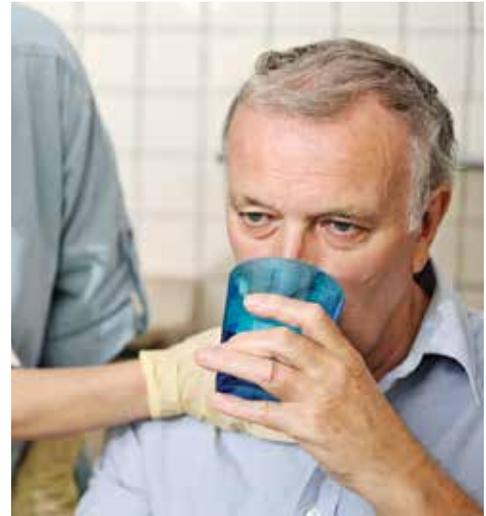
Encourage the person to get regular dental check-ups.

ADAPTING FOOD TEXTURES AND SPECIAL DIETS

To eat safely, stroke survivors with dysphagia often need their food textures adapted. The type of swallowing problem they have determines which food textures are safer for them. If food textures cannot be adapted sufficiently, the person may need to be fed through a tube, which can still provide them with the calories and nutrients they need. If their swallowing ability improves, they can often return to a soft or regular diet.

Many healthcare professionals (speech-language pathologists, dietitians, occupational therapists) are involved in assessing and monitoring someone's ability to chew and swallow. They also recommend safe food textures and strategies for feeding.

- A speech-language pathologist will identify the specific problems with swallowing
- A dietitian ensures that the diet texture or tube feeding meets nutrition and hydration needs
- An occupational therapist recommends seating and positioning strategies
- An occupational therapist recommends appropriate adaptive equipment



Always follow the food and diet instructions in the care plan. Never adapt a food texture or change a person's diet on your own.

If the person should have...	
Puréed food	<p>Serve:</p> <ul style="list-style-type: none"> • Mashed and blenderized foods • Dense, smooth foods of pudding consistency
Minced or moist minced food	<p>Serve:</p> <ul style="list-style-type: none"> • Foods that are the texture of ground beef • Finely chopped foods
<p>Thickened fluids</p> <p>(From thickest to thinnest: pudding, liquid honey, nectar.)</p>	<p>Serve:</p> <ul style="list-style-type: none"> • Fluids thickened to the consistency specified in the care plan <p>If you are not sure how thick a fluid should be, ask the person on the team who is trained in dysphagia to show you. Commercial and pre-mixed thickeners (available through pharmacies and some hospitals) can be used with hot or cold beverages. If these are recommended, follow the instructions for use on the box or can.</p>

If the person should NOT have...

Dry particulates	Avoid: <ul style="list-style-type: none"> • Dry and crumbly foods, breads, muffins, cookies • Peanut butter, dry crumbly cheeses
Bread products	Avoid: <ul style="list-style-type: none"> • Breads, cakes, pastries, and sandwiches • Any meals prepared with bread
Mixed consistencies	Avoid: <ul style="list-style-type: none"> • Foods combining liquids and solids (i.e., cereal with milk, chicken/vegetable soups, etc.)
Thin fluids	Avoid: <ul style="list-style-type: none"> • Water • Unthickened beverages • Broth-based soups • Commercial supplements • Ice cream, ice, cold jellied products
Foods that may cause reflux	Avoid: <ul style="list-style-type: none"> • Spicy, seasoned foods • Citrus products and other acidic foods • Peppermint and spearmint • Caffeine (e.g., coffee, tea, chocolate, cola) • High-fat and fried foods

Other problematic foods include rice, stringy food, raisins, nuts, and seeds. If these cause chewing or swallowing difficulties, avoid them.

If the person's sense of smell or taste has been affected, but they don't have reflux or swallowing problems, you can try different spices and flavour enhancers to increase their enjoyment of food and mealtimes.



ASSISTIVE DEVICES

An occupational therapist can recommend assistive devices for eating and swallowing problems. These might include:

- Rimmed plates
- A gripper pad to prevent dishes from slipping
- Cup or glass holders
- Modified utensils with built-up or bent handles
- Cutting utensils for one-handed use, such as a rocker knife, cheese knife, and pizza cutter
- Modified cups with a cut-out or partial lid



BEST PRACTICE RECOMMENDATION

Stroke patients with suspected nutritional concerns, hydration deficits, dysphagia, or other comorbidities that may affect nutrition should be referred to a dietician for recommendations to meet nutrient and fluid needs orally while supporting alteration in food texture and fluid consistency recommended by a speech-language pathologist or other trained professional.

KEY MESSAGES OF NUTRITION AND SWALLOWING

- ❑ **Know whether the person** you are working with has had a swallowing assessment and whether they have any swallowing issues.
- ❑ **Problems with swallowing** could lead to complications and interfere with recovery.
- ❑ People with dysphagia may need **foods of specific textures** for safety. They are at risk of poor nutrition and need to be carefully monitored.
- ❑ **Report any changes** in nutrition and swallowing to the stroke care team.



3.3 Hydration



IN THIS SECTION

- Daily fluid requirements
- Dehydration
- Hydration and urinary incontinence

YOUR ROLE AS A HEALTHCARE PROVIDER

Water is critical to life. Dehydration occurs when the body loses more fluid than it takes in. You play a key role in making sure the person who has had a stroke drinks enough to stay healthy, and letting the team know right away if you notice signs of dehydration.

DAILY FLUID REQUIREMENTS

The average adult can live for weeks without food, but only a few days without water.

We all need at least six to eight cups of fluids daily to stay hydrated. The amount of fluid the person who has had a stroke needs should be specified in the care plan. This chart shows equivalent amounts in ounces, litres (L), and millilitres (mLs):

Measure	Amount	
Cups	6	8
Ounces	48	64
Litres	1.5	2
Millilitres	1500	2000

Types of fluids include:

- Beverages such as water, juices, and milk
- Frozen liquids such as a popsicle or frozen juice bar
- Some foods, such as jellied desserts, pudding, ice cream, soup, and canned fruit

This chart gives examples of the amount of fluid in some common foods:

Food	Serving Size	Fluid content
Jellied dessert	½ cup	120 mL
Pudding	½ cup	100 mL
Ice cream or sherbet	½ cup	120 mL
Popsicle	1 popsicle	90 mL
Yogurt	½ cup	90 mL
Canned Fruit	½ cup	100 mL
Soup	1½ cups	165 mL
Simple conversion for daily fluid requirement		
1 cup = 250 mL	½ cup = 125 mL	

DEHYDRATION

Dehydration can quickly become life-threatening. When people are dehydrated they may lose physical, mental, and cognitive function. It also increases their risk of infection, constipation and fecal impaction, and urinary tract infection.

Stroke survivors with swallowing problems may avoid drinking fluids for fear of choking. Those who worry about incontinence may drink less to try to prevent accidents.

People who have had a stroke are more likely to become dehydrated if they:

- Are on a thickened fluid diet and do not take all the fluids provided
- Have swallowing difficulties known as dysphagia
- Refuse fluids at meals or snacks
- Need help with eating and drinking
- Do not feel thirsty (this is common among older adults)
- Are unable to communicate that they are thirsty
- Have memory problems or are forgetful
- Have an illness that increases fluid loss, such as vomiting, diarrhea, or fever and sweating, so that their fluid loss becomes greater than their intake

SIGNS OF DEHYDRATION

Report any of these signs to the nurse.

- Decreased urine output
- Dark, concentrated, or strong-smelling urine
- Frequent urinary tract or bladder infections
- Thick, stringy saliva
- Constipation
- Dizziness when sitting up or standing
- Confusion or a change in mental status
- Weight loss of 3.5 pounds (1.5 kg) in less than seven days
- Fever and sweating
- Decreased skin elasticity (To check, gently pinch the skin on the person's hand. If it stays pinched up when you release it, the person may be dehydrated.)



HYDRATION AND URINARY INCONTINENCE

Some people with urinary incontinence believe if they drink less they won't need to urinate as often. The reverse is actually true.

Low fluid intake decreases urine production. This results in concentrated dark urine that irritates the bladder lining. As a result, the person needs to release small amounts more often.

Adequate fluid intake flushes the bladder and helps prevent bladder irritation and urinary tract infection. A hydrated person has clear, light yellow urine. Cloudy, smelly urine is usually a sign of inadequate fluid intake, not a urinary tract infection.

In addition, normal, healthy bowel function depends on adequate fluid intake. The normal frequency of bowel movements is anywhere from three times a day to three times a week. Low fluid consumption can result in hard stools that are difficult to pass.*

HOW YOU CAN HELP



- Try to ensure the person gets the amount of fluid specified in the care plan by giving frequent, gentle reminders to drink. (If no amount is specified, aim for six to eight cups a day.)
- Water is the preferred fluid, but you can offer a variety such as juices, popsicles, and puddings. Ask what the person's favorite fluids are and make them available.
- Encourage them to sip fluids throughout the day rather than drinking large amounts all at once.
- You may want to put the required amount of fluid in a container each day, so you both know how much is left to drink.
- If the person has neglect, put the container on the unaffected side.
- Limit caffeinated drinks such as coffee, tea, and cola to two or three servings per day. Caffeine promotes urination and fluid loss, and should be limited. They are counted as part of the daily fluid intake.
- Give the fluid at the temperature the person prefers. Some people prefer room temperature, while others like drinks that are ice cold.

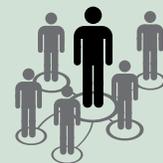
* Refer to 3.4 for more information on Bladder and Bowel Control.

BEST PRACTICE RECOMMENDATION

Stroke patients with suspected nutritional concerns, hydration deficits, dysphagia, or other comorbidities that may affect nutrition should be referred to a dietitian for recommendations to meet nutrient and fluid needs orally while supporting alteration in food texture and fluid consistency recommended by a speech-language pathologist or other trained professional.

KEY MESSAGES OF HYDRATION

- ❑ **Maintaining good hydration** is very important after stroke.
- ❑ **Monitor the amounts of fluid** the person who has had a stroke takes in each day.
- ❑ **Find strategies** to help the person remember to take in enough fluids.
- ❑ **Report changes** in hydration status to the stroke care team.



3.4 Bladder and Bowel Control



IN THIS SECTION

- Incontinence after stroke
- Normal bladder function
- Identifying urinary problems
- Strategies to manage urinary incontinence
- Normal bowel function
- Identifying bowel problems
- Factors that increase the risk of incontinence
- The team approach to managing incontinence.

YOUR ROLE AS A HEALTHCARE PROVIDER

Bladder incontinence, or loss of bladder control, is common after stroke. Bowel incontinence is less common but can also result from stroke. Incontinence is a key factor in determining whether someone who has had a stroke can remain at home. By learning strategies to help people manage bladder and bowel incontinence, as well as constipation, you can make a big difference to their quality of life, comfort, dignity, and self-esteem.

INCONTINENCE AFTER STROKE

A person who has had a stroke and their family members are often devastated by the loss of bladder or bowel control. Incontinence dramatically affects feelings of self-worth and well-being, as well as lifestyle and social interactions. The person may feel the need to stay close to a toilet, and their activities may be interrupted by frequent bathroom visits. They may socialize less and stop taking part in activities or travel in case of accidents. Sexual activity may decrease. Depression, a common complication of stroke, can make the person less able to manage incontinence.

Having to help someone who has had a stroke go to the bathroom can strain family relationships. It may limit family visits and reduce social outings.

Incontinence can result in skin breakdown and infection, urinary tract infection, pain, falls and injuries from hurrying to the toilet and dehydration from restricted fluid intake. In addition, it is one of the main reasons that someone who has had a stroke goes to a long-term care home or other facility rather than being able to live at home.

Almost half of stroke survivors who have problems with incontinence had the same problems before the stroke. With lifestyle changes and good support, about 80 percent of incontinence problems can be resolved.

NORMAL BLADDER FUNCTION

The normal adult bladder holds between 500 and 600 millilitres (mLs) of urine. People start feeling the urge to urinate when the bladder is about half full (250 to 300 mLs). A person with normal bladder function can suppress this urge for up to one to two hours, until the bladder is full.

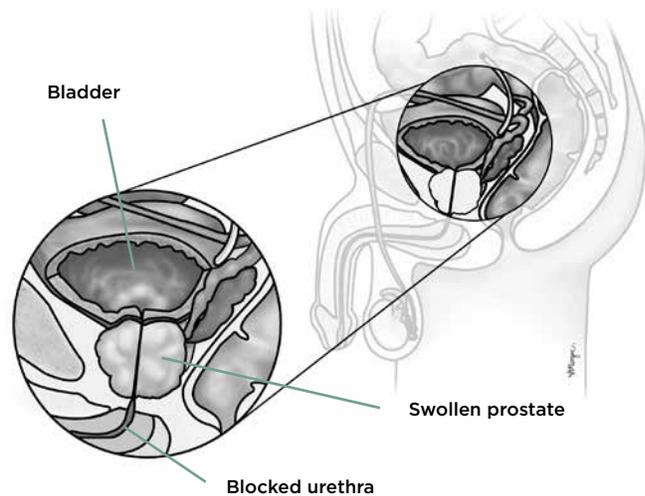
Normal bladder function requires coordination between the nervous system and the lower urinary tract. The lower urinary tract is made up of the bladder, urethra, and sphincters. The urethra is the tube that the urine passes through. The sphincters are muscles that close to hold urine in or open to let it pass through the urethra.

As a person ages, the bladder shrinks. An aging bladder holds only 250 to 300 mLs of urine, which is about half what a younger bladder holds. While most people urinate three to six times during the day and possibly once or twice during the night, older people need to empty smaller amounts from their bladders more frequently. In addition, as the bladder wall becomes thinner and muscle tone decreases, the urine stream weakens and the bladder does not empty completely.

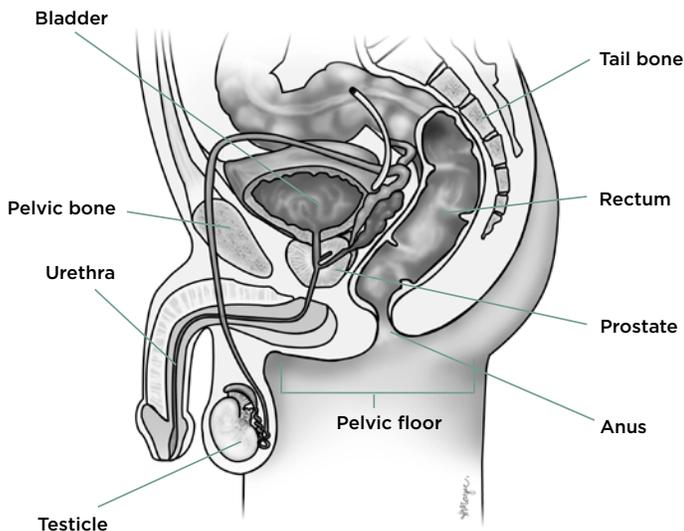
Men may have even more trouble emptying their bladder if they have an enlarged prostate (a small gland that surrounds the urethra) that blocks the flow of urine.

After menopause, women may have urine leakage. This is because a drop in estrogen can weaken the muscles that normally stop the flow of urine. This often happens during coughing or laughing, and is called **stress incontinence**.

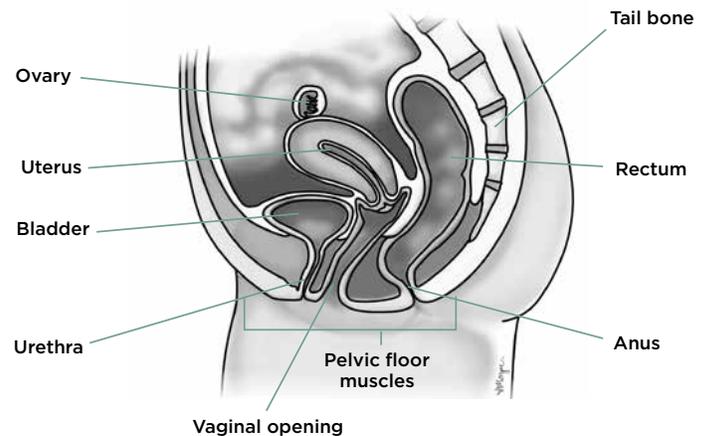
Some older people have involuntary bladder wall contractions that make them feel like they need to urinate. This is called **urge incontinence**.



MALE ANATOMY



FEMALE ANATOMY



IDENTIFYING URINARY PROBLEMS

Because bladder problems can have such serious health and emotional consequences, they need to be identified quickly.

Urinary problems that can arise after stroke include:

- **Urinary incontinence:** The person who has had a stroke may lose the ability to identify and respond to the need to urinate, especially right after the stroke happens. Many regain this function within a couple of months. For some, incontinence may come and go, or it may be permanent.
- **Urinary retention** causes urine to back up. Stroke can interrupt the nerve pathways that control bladder emptying. If this happens, the person does not feel an urge to urinate. So even though the bladder fills, they are unable to empty it. Urinary retention increases the risk of urinary tract infection and damage to the kidneys. The urine may need to be removed with a **catheter**, a tube inserted into the urethra that empties the urine into a bag.

Watch for these signs and symptoms of incontinence and notify the nurse as soon as possible if you see:

- Changes in the person's normal pattern of going to the bathroom.
- Loss of small amounts of urine (dribbling). This might happen when the person does something physical, such as lifting, coughing, or sneezing (stress incontinence), or even without any movement.
- A sudden urge to urinate, followed by loss of large amounts of urine (urge incontinence). You might notice unsuccessful rushes to the bathroom. The person might become aware of the need to urinate only seconds before the bladder empties, and it may be difficult or impossible to stop the urine stream.
- Urinating more than eight times per day or twice per night.
- A weak or interrupted urine stream.
- Reporting that their bladder still feels full, even after urinating (urinary retention).
- Frequent urinary tract infections.

COMPLICATING FACTORS IN INCONTINENCE

Vision problems: The person may be unable to find the bathroom or see enough to use the toilet independently.

Decreased mobility: The person may be unable to get to the bathroom independently or quickly enough, as their balance and gait may be impaired. Or they may not be able to transfer to the toilet independently and have to wait for assistance.

Lack of movement: The person may have difficulty managing clothing, continence products, or wiping, especially if one or both arms are affected.

Changes in time of urine production: More urine may be produced during the night, requiring the person to get up more often.

URINARY TRACT INFECTION

A lower urinary tract infection (UTI) is also called a bladder infection. Untreated, it can move up the urinary tract to the kidneys and cause serious health problems.

Watch for these signs and symptoms.

Temperature above 37.9° C

Blood in the urine

Any new:

- Burning or pain with urination
- Chills or shaking
- Delirium or confusion — any rapid change in cognitive abilities, such as a sudden inability to focus

Any new or worsening:

- Urinary urgency
- Urinary frequency
- Urinary incontinence
- Pain in the lower abdomen or side
- Change in urine colour or odour
- Urethral or vaginal discharge

HOW YOU CAN HELP



- Report signs and symptoms of a urinary tract infection to the nurse.
- Ensure the person has an adequate fluid intake (six to eight cups per day, or as prescribed in the care plan).
- Encourage the person to drink more fluids if they have a burning feeling during urination.
- Limit caffeinated drinks to two cups per day.

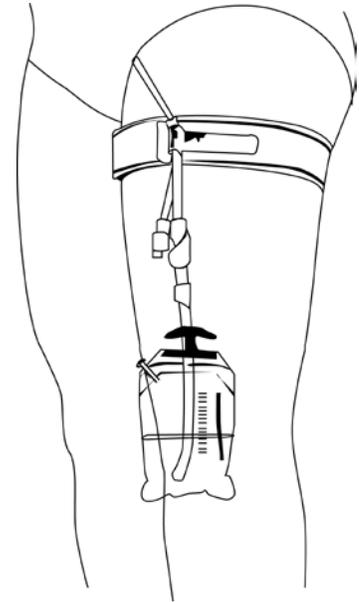


URINARY CATHETERS

A urinary catheter or other external device may be needed on a temporary or permanent basis.

A catheter increases the risk of urinary tract infection. Appropriate catheter use and care can reduce this risk.

- Ensure the person drinks at least six to eight cups of fluid daily (1,500 - 2,000 mLs) to keep the catheter draining well and free of sediment.
- Position the drainage bag below the bladder, to prevent urine from backing up into the bladder.
- Position the catheter tubing so it does not kink or pull on the catheter.
- Secure tubing to leg to prevent accidents.
- Empty the drainage bag every eight hours.
- Prevent tubing contamination. Follow your employer's procedures for disconnecting and connecting tubing.
- Ask how long the tube needs to stay in, with the goal of leaving it in only as long as necessary



Report any of the following signs and symptoms to the nurse:

Changes in urine output

- Any change in output over a four-hour period
- Decreased output, especially if the person reports a feeling of a full bladder

Pain

- In the abdomen, pelvis, or at the catheter insertion site
- Restlessness or agitation (this could be a sign of pain or discomfort)

Urine

- Change in colour or consistency
- Blood
- Foul-smelling drainage around the catheter
- Urine leakage around the catheter
- Any signs or symptoms of urinary tract infection

STRATEGIES TO MANAGE URINARY INCONTINENCE

Prompted voiding can help treat urinary incontinence and constipation. This strategy has three parts: monitoring, prompting and redirecting, and positive feedback.

Monitoring

- At regular intervals, ask if the person would like to use the toilet. People who have lost the ability to identify and respond to the need to urinate may benefit from a toileting schedule, with regular reminders and physical help. Always try to stay on the schedule.
- Watch for behaviour that shows a need to urinate. Someone who has difficulty communicating may be more agitated because of worry about incontinence, or when they are wet.
- Note the usual times the person urinates or has a bowel movement. Take them to the toilet on that schedule, whether or not they have an urge to go.
- Keep a voiding diary.

Prompting and redirecting

- At regular intervals, prompt the person to use the toilet.
- Between those times, encourage them to stay on schedule. Redirect or distract them by suggesting they read, watch television or listen to the radio, or meditate.
- Work with the nurse to adjust the schedule as needed to reduce the chance of incontinent episodes.

Positive feedback

- React in a positive way when the person stays dry and uses the toilet when needed.
- Manage incontinent episodes without comment.

Bladder retraining gradually increases the times between trips to the bathroom. This reduces frequent voiding, increases bladder capacity, and helps suppress the feeling of urgency.

The nurse usually puts the bladder retraining protocol in the care plan. The plan may include **pelvic floor exercises**. These exercises involve tightening and relaxing the muscles of the pelvic floor, which are the muscles that control urination and bowel movements. The plan should include a schedule for urinating. For instance, you might be asked to periodically increase the interval between voids by 15 minutes (or less if needed), until the time between voids is three to four hours.

BEST PRACTICE RECOMMENDATIONS

Stroke patients with urinary incontinence should be assessed by trained personnel using a structured functional assessment to determine causes and develop an individualized management plan. A bladder-training program should be implemented in patients who are incontinent; including timed and prompted toileting on a consistent schedule.

HOW YOU CAN HELP



- Know the care plan strategies that are being used to help with bladder control and follow them.
- Remind and encourage the person to practice pelvic floor exercises if they are part of the care plan.
- Write down the toilet schedule, and physical assistance and equipment required to help the person and other healthcare providers keep track.
- Encourage and praise them for staying on schedule. If they can't, be positive about trying again the next time.

NORMAL BOWEL FUNCTION

The bowels absorb nutrients and fluid from the food we eat and drink. They also remove solid waste (stool) from the body. There are two parts to the bowel:

- **Small bowel** (small intestine): The small bowel absorbs nutrients. It is about 20 feet long. It begins at the stomach and ends at the large bowel.
- **Large bowel** (large intestine or colon): The large bowel absorbs fluids. It is about five or six feet long. It begins at the end of the small bowel and ends at the rectum.

A healthy bowel depends on a number of factors, including how well the muscles and nerves work together, eating a high fibre diet, and drinking six to eight cups of fluids each day.

Usually, bowel movements occur anywhere from three times a day to three times a week.

IDENTIFYING BOWEL PROBLEMS

Constipation or other bowel problems may be part of a serious, underlying health condition. If you see any of these signs, tell the nurse:

- Sudden change in bowel pattern or stool
- No bowel movements in at least three days
- Constant straining with bowel movements
- Abdominal pain
- Rectal bleeding
- Liquid stools
- Fever
- Weight loss



CONSTIPATION

Stroke can weaken the muscles that expel stool from the colon, causing constipation or making it worse. Constipation happens when the bowels don't move often enough. Stools become hard and dry and difficult to pass. This is the most common bowel management problem for people who have had a stroke. It reduces quality of life, comfort, functional ability, and social life.

It is critical to identify and treat constipation early.

Symptoms of constipation include:

- Fewer than three bowel movements per week
- Straining
- Hardened stools
- Feeling of incomplete stool evacuation
- Feeling of blockage or obstruction
- Need for stool evacuation

COMPLICATIONS OF CONSTIPATION

Fecal impaction: Fecal impaction is a mass of hard, clay-like stool lodged in the rectum. It can cause bowel obstruction, ulcers in the bowel, and an enlarged colon. The person may need enemas and laxatives to clear the bowel. Once normal bowel function is restored, they will need strategies to prevent constipation.

Fecal incontinence: Fecal incontinence occurs when a person cannot prevent fecal material from passing through the body. It can be liquid stool that soils undergarments, or a loss of control of solid stools. Often, fecal impaction causes incontinence, as liquid stool seeps around the bowel obstruction.

Straining: When a constipated person strains to pass stools, it can cause hemorrhoids, and heart problems. It can also cause **rectal prolapse**, when part of the bowel slips or falls out of place.

Constipation can also create urinary incontinence by increasing pressure on the bladder, making it harder to maintain normal bladder function.

DIARRHEA

Diarrhea is marked by frequent, watery stools. Causes can range from viral infections, such as the flu, to more serious medical problems, such as Crohn's disease. Sometimes, fecal incontinence can be mistaken for diarrhea, when in fact the person has severe constipation.

FACTORS THAT INCREASE THE RISK OF INCONTINENCE

Environmental

- Poor access to a toilet, such as long distances to the bathroom
- Limited room for a wheelchair and other equipment to help with transferring in the bathroom
- Lack of equipment such as bedside commodes, transfer belts
- Lack of privacy
- Lack of adaptive clothing (clothing that is easy to put on and take off)

Health and stroke-related

- Conditions such as diabetes, depression, or dementia
- Some medications
- Limited mobility, needing more time and help to reach the toilet and remove clothing
- Communication problems that make it hard to express an urgent need to use the bathroom
- Loss of the ability to identify and respond to the urge to go to the bathroom

Lifestyle

- Not getting enough fluids, especially if the person is avoiding fluids to try to prevent urinary incontinence
- Not eating enough, or not eating enough fibre
- Not getting enough exercise
- Ignoring the urge to go to the bathroom

THE TEAM APPROACH TO MANAGING INCONTINENCE

Managing bladder and bowel problems is critical. Avoiding even one episode of incontinence a day can greatly increase self-esteem and quality of life, as well reduce complications and the risk of falls and injury. It also saves you time as a healthcare provider and cuts down on the use of continence products such as pads or diapers.

The team approach to managing bladder and bowel problems requires assessment, diagnosis, care planning, implementation, and evaluation.

Assessment

Your careful and accurate observations will provide much of the information needed for assessment. You may want to keep a voiding diary to organize the information for the team, with details such as:

- Urination habits
- Bowel habits, stool colour, and consistency
- Straining and discomfort with bowel movements
- Diet and fluid intake
- Mobility, activity, or exercise
- Signs of skin breakdown such as swelling, redness, oozing or crusting around the anus, scrotum, vulva, or **perineum** (the skin between the genitals and the anus)
- How well the person transfers from the bed or wheelchair to the commode chair
- Problems with undressing and dressing
- The person's behaviour and response to care
- Any impact from the environment (i.e., is the bathroom too far away?)
- Whether you think a home assessment might be helpful, to determine need for adaptation and supportive equipment (e.g., over arm toilet bars (versa frame), raised toilet seats)

The nurse on the team can show you how to collect this information and tell you what information should be reported right away. The speech-language pathologist can identify the best communication method for each person.

If you notice any of the following symptoms, report them immediately:

- Not passing urine for more than four hours
- Unable to have a bowel movement
- Fever
- Increasing confusion or agitation
- Pain in the lower abdomen or lower back
- Skin breakdown or discomfort in the perineal area

Diagnosis

The team doctor will diagnose urinary incontinence and bowel problems and their causes. An urologist may be consulted as well.

Care planning and implementation

Based on the diagnosis, the team develops a care plan. Your observations about and knowledge of the person can help the team tailor the plan to the person's needs and determine the best way to implement it.

The plan may address:

- Medications and laxative use
- Activity levels
- Equipment needed for easy and safe toileting
- Fluid intake and diet (e.g., adding more fibre for constipation.) People who cannot move or who do not get enough fluids should not take fibre supplements.
- Strategies to manage bladder and bowel incontinence, some of which are described in this section. They may include **habit training** where a routine toileting schedule is followed, **prompting** the person about scheduled trips to the bathroom, or **redirection** (particularly for those with cognitive impairment), where the person is distracted with other activities.



Evaluation

Observe the person's response to the care plan and report it to the team. Note what the person tells you and their non-verbal reactions. For example, during a wheelchair-to-toilet transfer, you may notice them frown or become agitated. Talk to the team. This could mean the person is in pain and may need pain treatment.

BEST PRACTICE RECOMMENDATION

A bowel management program should be implemented for stroke patients with persistent constipation or bowel incontinence.

HOW YOU CAN HELP

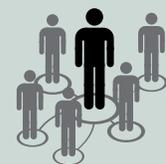


- Be alert to any behaviour that may communicate the need to urinate or have a bowel movement, such as restlessness, agitation, or grimacing.
- Observe and record bowel and bladder habits.
- Report any changes or new problems with mobility to the nurse.
- Move furniture or other obstacles to getting to the toilet.
- Place a night light near the bed to orient the person to the room at night.
- Allow privacy but stay close so you can help if they call for assistance.
- Encourage the person to use a commode or toilet rather than a bedpan. A commode or toilet promotes more complete bladder emptying, because of gravity and increased abdominal pressure. Tell them to lean forward during urination if possible, with their feet flat on the floor or on a stool, to help the bladder empty.
- If the person uses a urinal, keep it where it can be easily seen and reached. It may help to keep a urinal on each side of the bed.
- If the person uses a bedpan, make sure the head of the bed is as upright as possible to allow the person to sit as normally as possible when using the bedpan.



KEY MESSAGES OF BLADDER AND BOWEL CONTROL

- ❑ **Bladder incontinence**, or loss of bladder control, is common after stroke. Bowel incontinence can also be a problem after stroke.
- ❑ **Understand issues of bladder and/or bowel control** in the persons you are caring for
- ❑ **Follow-through** on bladder and bowel programs consistently.
- ❑ **Monitor carefully** for skin breakdown, infection, or other complications.
- ❑ **Maintain a safe physical environment** for people who need to go to bathroom often and urgently.
- ❑ **Provide emotional support** and reassurance to people experiencing incontinence.



3.5 Skin Integrity



IN THIS SECTION

- Movement and skin health
- Skin and skin breakdown
- Protect bony and compromised areas
- Reduce friction and shear injuries
- Pressure-redistribution devices
- Cleaning a spastic (contracted) hand
- Hygiene and incontinence

YOUR ROLE AS A HEALTHCARE PROVIDER

The skin is the largest organ in the body. Skin maintains body temperature and hydration, and intact skin keeps us safe from infection. You can help keep the stroke survivor's skin healthy and reduce the risk of skin breakdown through many care activities, such as careful positioning, frequent movement as appropriate, good hygiene and skin care, maintaining good nutrition and hydration, and careful monitoring.

MOVEMENT AND SKIN HEALTH

When someone sits or lies in the same position for a long time, circulation to their skin is reduced. This increases the risk of skin damage, pressure sores, or ulcers. The risk is greatest for those who cannot move without help. Follow the care plan for moving the person regularly, usually at least every two hours for people who are in bed, and repositioning people who are in a wheelchair or other seats for long periods of time during the day.

The more someone can move and maintain or improve their current activity level, mobility, and range of motion, the lower the risk of skin breakdown.

People who are unable to reposition themselves in bed should be turned at least every two hours. Those who are unable to shift their weight while sitting should be repositioned at least every hour, or according to the care plan.

SKIN AND SKIN BREAKDOWN

The skin consists of three layers called the epidermis, dermis, and subcutaneous tissue.

The **epidermis** is the outermost layer and it is mostly made up of dead skin cells. These cells are constantly being shed and replaced with more cells from underneath. The second layer is called the **dermis** and it has sweat glands, oil glands, nerve endings, small blood vessels called capillaries, and collagen. The nerves ending in this layer transmit sensations of pain, itch, touch and pleasure. The deepest layer of skin has **subcutaneous adipose tissue**. It is the layer of fat and collagen that contains nerves and blood vessels. This inner layer helps control the temperature of the skin and the body, and protects the body from injury by acting as a cushion.

Skin breakdown or **ulceration** (sores) can be very painful and may result in serious infection or even death if it is very severe. People who have had a stroke face skin breakdown because of:

- Decreased ability to relieve pressure due to weakness and limited mobility
- Decreased or no sensation
- Increased moisture from incontinence or perspiration
- Poor nutrition, dehydration, and dry skin
- Inability to communicate pain and discomfort
- Improper positioning, causing friction and shear injuries

Proper skin care is very important, especially for people who cannot move on their own. Follow turning and sitting schedules determined by stroke care team members, including changing their position frequently, and getting them out of bed and onto supported seating as described in the care plan.

HOW YOU CAN HELP



Inspect and report

- Check the person's skin carefully every day for redness, blisters, skin openings, or breakdown. This is particularly important for people who have impaired sensation. Some organizations use specific tools (such as the Braden Scale) to guide how you should examine the skin.
- Skin checks should be done at least once a day, during regular grooming activities (bathing, dressing), during toileting, or at other convenient opportunities.
- Skin checks should include looking for signs of redness, blisters, discharge or breakdown; feeling the skin for moisture, heat, swelling, induration; and smelling the skin for foul or unusual odour.
- Pay special attention to **bony prominences**. These are areas that tend to stick out, like elbows, heels, ankles, hip bones, the sacral area (tailbone), and **ischial tuberosities** (sitting bones). When a person is seated, their weight typically rests on the ischial tuberosities which bear the majority of their weight.
- Report concerns or signs of skin irritation immediately to the right person — the nurse, case manager, physician, or a family member.

Clean

- Wash skin gently and regularly, using mild cleansers. Do not scrub.
- Rinse thoroughly.
- Dry thoroughly using soft cloths, especially in skin folds. Pat the skin dry rather than rubbing it to avoid further irritation.
- Always wash soiled skin promptly, to remove irritants and maintain the skin's natural barrier.

Moisturize

- Treat dry skin with moisturizers. Dry, flaky or scaling skin can lead to skin irritation, pressure sores and pressure ulcers, and possible infection.
- Discuss the most appropriate type of cream or ointment for each person with the stroke care team. Some have barrier ingredients such as urea creams, some are scent-free to further reduce the risk of irritation, and others have medication such as cortisone.
- Do not massage bony prominences or reddened areas. A reddened area is an early sign of tissue irritation and the mechanical forces of massage can result in greater tissue damage.
- Some people may have skin that is already very moist due to excess sweating or urine leakage. Good hygiene is important for these situations, and moisturizers should only be used on the advice of the stroke care team. In these cases, barrier-type creams may be preferred to other types of moisturizers.

Protect

- Sources of moisture on the skin that can cause skin breakdown include urine or stool, perspiration, and/or fluids from a draining wound. These fluids contain chemical irritants that can damage the skin.
- Protect skin from contact by gently cleansing at time of soiling, or using wound dressings or barrier creams as specified in the care plan.
- Promote good bladder and bowel routines and follow bladder and bowel training programs to reduce the risk of skin breakdown.*
- Minimize the use of continence products as they may increase skin temperature, and prevent good air circulation which helps keep skin dry and healthy.

Reposition

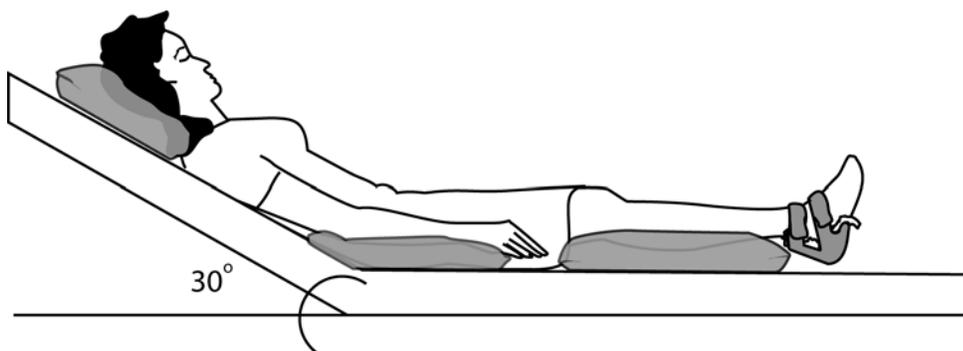
- Repositioning is important for people who cannot move on their own.
- Change their position according to the care plan, and get them out of bed and onto supported seating (e.g., using special cushions) whenever possible.
- People who are unable to reposition themselves in bed should be turned at least every two hours.
- Those who are sitting should shift their weight at least every 15 minutes if they are able; if not, they should be repositioned at least every hour.
- When repositioning the individual, move them and use repositioning equipment (e.g., sliders (friction reducing devices), mechanical lifts) as required, avoiding friction that may be caused if the person is pulled or dragged across surfaces. (See Friction Injuries below).

* Refer to 3.4 for more information about incontinence.

PROTECT BONY AND COMPROMISED AREAS

When positioning a person who has had a stroke, your goal is to maintain proper body alignment while reducing pressure on bony prominences.

Position the person who has had a stroke in a 30 degree side-lying position in the bed. Do not put the person completely on their side. Lying directly on the hip increases the risk of a pressure ulcer. Change the position regularly.



- Use foam wedges or pillows to support the person in the proper position.
- Use pillows between the knees and the ankles to separate bony prominences.
- Use a water pillow, thick foam, or specialty boot to relieve pressure on the heels.
- Use wedges and padding. Donut devices should not be used as they can decrease blood flow and increase tissue breakdown.
- If the person has a pressure ulcer, avoid positioning them directly on it. If it's unavoidable, keep them there for as little time as possible.
- If lying on the unaffected side, ensure the affected arm is supported by pillows.
- When positioning on the back, ensure the head, affected arm and affected hip are supported with pillows. A pillow under the knees may help take pressure off the sacral area.
- If you are unsure how to position someone, check with the nurse or occupational therapist.*



REDUCE FRICTION AND SHEAR INJURIES

Friction injury occurs when the skin moves over another surface. A friction injury can happen when you move someone in bed or they move themselves. These injuries happen often on the sacrum (tailbone), heels, and elbows.

Use sliders (friction reducing devices) when you move someone. Use sliders as prescribed and follow the care plan. Never pull or drag the person.

* Refer to 6.2 for more information on positioning.

Shear injury occurs when the body moves without the skin moving. For example, raising the head of the bed allows the body to slide down, while the skin remains pressed against the sheet. Shear injuries reduce blood supply to the skin.

Prevent shear injuries by lifting the head of the bed no more than 30 degrees and limiting the amount of time in this position.

PRESSURE REDISTRIBUTION DEVICES

Devices that help prevent skin breakdown include:

- Pressure-redistribution mattresses (e.g., alternating pressure air mattress or high density foam)
- Elbow pads
- Heel pads or booties, devices that relieve pressure on the heels and bony prominences of the feet
- Specialized wheelchair cushions (gel or air-filled); do not add extra covers on top of the wheelchair seat cushions as they destroy the pressure reducing benefits/properties of the cushion.
- Bath seats and commode chairs with friction and pressure reducing surfaces

Do not use donut devices or products that localize or increase pressure to other areas.

The nurse or occupational therapist may recommend one of these devices, based on the person's needs. Follow the care plan for using the device. Discuss any other new devices with the stroke care team before using them.

CLEANING A SPASTIC (CONTRACTED) HAND

A person who has had a stroke may develop high tone in their affected hand due to spasticity. Constant spasticity can lead to **contractures**, where the muscles and tendons shorten, and the hand becomes clenched and very difficult to open and keep clean.*

A spastic or contracted hand often sweats, and poor air circulation can cause skin damage, odour, and infection. Good hygiene is important to prevent skin damage. Once it is open, wash it gently and clean and trim the nails. Dry the hand thoroughly. This also provides essential sensory input. If the hand is painful, the person may prefer to clean it themselves.



* Refer to 6.2 for how to open the hand safely.

HYGIENE AND INCONTINENCE

People with urinary incontinence have a higher risk of developing perineal skin problems and urinary tract infections. Proper hygiene and good skin care can help avoid these problems:

- Wipe from front to back after voiding
- Change underwear daily or more often if soiled
- Always provide thorough **peri-care** (care of the perineum or genital area) after urinary or fecal incontinence. Wear gloves when completing peri-care
- Use barrier creams if recommended in the care plan
- Wash your hands and those of the stroke survivor after peri-care
- Do not use deodorant sprays, powder, or perfumes on perineal skin

CONTINENCE PRODUCTS

Continence products should only be used when absolutely necessary. If required, always use continence products rather than menstrual products. Continence products draw urine away from the surface of the pad and promote healthy skin. Replace pads and linens when they are damp. Watch for leaking, tight fitting products, skin irritation, or rash, and report any signs of redness, irritation, or skin breakdown to the nurse.

KEY MESSAGES OF SKIN INTEGRITY

- ❑ **Good skin care** is important for someone who has had a stroke.
- ❑ **Regularly monitoring skin** can help identify skin breakdown early, preventing more serious problems from developing.
- ❑ **Proper positioning** and frequent adjustments can significantly decrease the risk of skin breakdown.



CHAPTER 4

Body Function (Sensory)

Sensory Function within the ICF model describes functions related to hearing, seeing, tasting, smelling, touch, feeling pain, and proprioception which is the sense of the relative position of your body (WHO, ICF 2001).

IN THIS CHAPTER

- 4.1 Vision and Visual Perception
- 4.2 Unilateral Spatial Neglect
- 4.3 Body Scheme
- 4.4 Praxis
- 4.5 Sensation
- 4.6 Pain



4.1 Vision and Visual Perception



IN THIS SECTION

- Visual processing skills
- Hierarchy of visual processing
- Vision and visual perceptual problems

YOUR ROLE AS A HEALTHCARE PROVIDER

You can help someone who has vision and visual perception problems after stroke to stay safe and become more independent by using recommended strategies to deal with these difficulties. Your patience and support can help them become more aware of their environment and compensate for the impairment they may be experiencing.

VISUAL PROCESSING SKILLS

Vision plays a very important role in our everyday lives. It is the main sensory system that we use to obtain information from our surroundings. It helps us detect danger and make choices and decisions. Our vision tells us if there is an oncoming car as we cross the street, what colour and style of clothing we want to wear, and in which aisle we might find a certain food at a grocery store. It helps us know how to interact with people and objects in our environment, such as understanding facial expressions and gestures, and knowing which route to take when walking in our neighbourhood.

Vision affects how we physically react to stimuli. If someone throws us a ball, we move in a certain direction and reach out our hand to catch it. Vision also affects our posture and balance. If we see a step or curb, we automatically change our posture and adjust our balance to take that step.

Visual processing is a combination of how accurately our eyes see things and how we process or make sense of what we see. This in turn impacts our ability and the speed in which we make decisions, and react and respond to our environment.

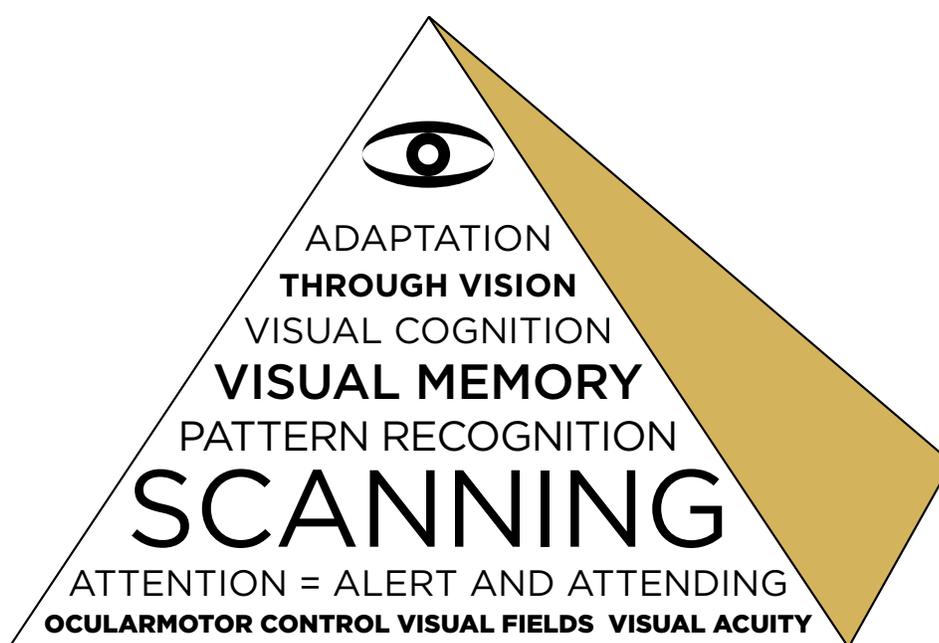
HIERARCHY OF VISUAL PROCESSING

The ability to use vision to interact with our environment depends on how well our eyes see, and our brain's ability to take what we see and make it meaningful. There are different ways and levels (hierarchies) that our brain makes sense of what we see. Each level is dependent on the previous level. How we perceive and understand what we see may not be accurate if there are problems at any level in the hierarchy.

The first and most important level depends on how well our eyes function. Our eye muscles need to work together to move and focus our eyes (**oculomotor control**), our retina needs to display a clear image (**visual acuity**), and our eyes need to see everything surrounding us (**visual fields**).

Next, it is important that we are alert and attentive so that we can scan our environment thoroughly. When scanning, we need to recognize shapes, patterns, and details in order to put together the features of an object. We need to be able to store these features in our visual memory so we can retrieve that memory later to recognize what we see. Once we recognize and make sense of what we see, we can respond appropriately. This is known as adaptation.

A problem at any of these levels affects the next higher level. For example, problems focusing on a person's face will result in a blurry image and difficulty seeing details of the face. When the person cannot see the details and features of the face, they will not be able to access their memory of faces to see if that face is of a person they know. If it is not a face they recognize, then they may choose not to interact with that person.



Adapted with permission: Mary Warren Phd, OTR/L, SCLV, FAOTA - visABILITIES Rehab Services Inc.

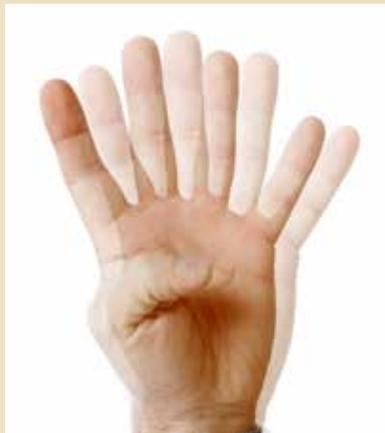
VISION AND VISUAL PERCEPTUAL PROBLEMS

Visual perceptual problems are invisible barriers, and the person may not appear to have any impairment. Family and friends often find it hard to understand visual perceptual problems and may expect too much of the person who has had a stroke. They may become frustrated and angry, believing the person is acting this way on purpose or is not trying hard enough to get better.

You can help family members understand that visual perceptual problems are a result of the stroke, and some can improve or be managed. Once the problem is identified, then strategies to improve function can be developed. This may reduce frustration for everyone.

Problems related to vision and visual perception as a result of a stroke may include:

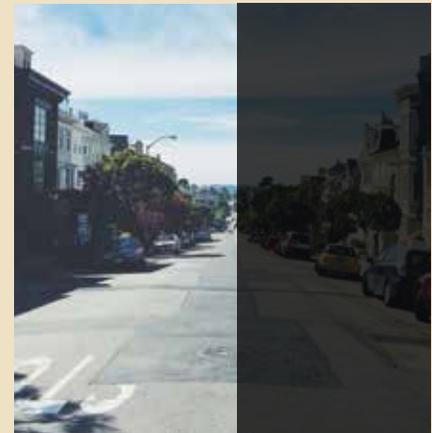
- **Visual acuity loss:** Objects are not sharp and clear (blurred vision). The person may read with the paper close to their eyes, shift the paper around, or squint or close one eye when reading.
- **Loss of binocular vision (double vision):** Unable to put together images from each eye into one image.
- **Loss of accommodation:** Unable to focus vision between objects at different distances.
- **Loss of ocular motility:** Eyes cannot move together in a smooth and coordinated manner.
- **Visual field loss:** When looking straight ahead, the person is unable to see the entire space around them normally (panoramic view). A person will only see part of what is in front of them. An activity like reading may be confusing as the person may only see half a letter, word, or sentence.
- **Loss of spatial relations:** Inability to orient oneself in relation to other objects.
- **Impaired sense of position in space:** Inability to understand the concepts such as under, above and below, in front and behind.
- **Loss of topographical orientation:** Inability to find one's way from one place to another.
- **Loss of contrast sensitivity:** Difficulty seeing contrast between an object and its background, which may result in an inability to distinguish objects in the foreground from objects in the background (often called **figure ground perception**). For example, a person can't find a white towel on top of a white bed sheet.
- **Decreased depth perception:** Difficulty perceiving the world in three dimensions, making it hard to judge distance.
- **Visual agnosia:** Difficulty recognizing objects (hairbrush, fork, phone), faces (may not recognize a familiar person), or letters, despite being able to see clearly. The person has lost the meaning of what the object or face represents.



Double Vision



Blurred Vision



Visual Field Loss

Additional examples of what a person who has had a stroke may experience as a result of visual and visual perceptual problems include:

- Difficulty reading, understanding what is read, or reading for long periods of time
- Headaches when reading, watching television, or being in busy environments
- Anxiety in crowds or in busy, unfamiliar environments
- Difficulty finding items in drawers, fridge, closet, rooms, or the grocery store
- Inability to locate arm sleeve or pant leg when dressing
- Getting lost or having difficulty finding their way around
- Not seeing objects on one side, such as the brake on their wheelchair
- Overfilling a water glass
- Missing food with the fork, or missing their mouth with the toothbrush
- Dizziness and balance problems
- Unsafe transfers and difficulty moving around, creating an increased risk of falls
- Misjudging distance and the location of transfer surfaces
- Tripping on steps, curbs, or uneven ground
- A person with visual field loss may:
 - ◆ Bump into doors, people, walls, and objects on the side of the visual field loss
 - ◆ Not be able to find their toothbrush or cutlery located on the side of the visual field loss
 - ◆ Walk or move along the side of a wall, using the wall as a guide
 - ◆ Not move out of the way when something is coming in their direction

MANAGING VISION AND VISUAL PERCEPTUAL PROBLEMS

Vision problems may improve on their own in the weeks after a stroke. If problems persist, team members trained to address vision and visual perception (such as occupational therapists and ophthalmologists) will provide therapy to reduce the severity and impact and provide strategies to adapt to the impairments.

HOW YOU CAN HELP



- Talk with the appropriate team member such as the occupational therapist about the best ways to deal with a specific vision problem and encourage the person to use the strategies recommended.
- Reduce obstacles and clutter.
- Ensure there is good lighting.
- Supervise transfers and encourage the person to use walking aids if prescribed.
- Encourage the person to use the handrail and to go slowly when climbing steps.
- Be consistent about taking the same route to a location every time (i.e., from bedroom to cafeteria or therapy department), noting landmarks along the way.

- Place items in the same location.
- Keep drawers, closets, cupboards and counters uncluttered, and organize items into categories or sections so they are easy to find.
- Have the person do activities that require sustained vision (reading, watching television) for small amounts of time and with lots of rest breaks.
- Identify yourself when coming up to a person who has difficulty recognizing faces.
- Use reference points or colour contrasts, such as red tape on the edge of a table or along the stairs.
- Use a dark placemat under light dishes and cutlery or a light cup for dark drinks and a dark cup for light drinks.

For visual field loss

- Encourage the person to look toward the affected side when necessary.
- Place items on affected side and/or walk on the affected side to increase awareness of that visual space.
- Encourage the use of an eye patch or prism glasses, if prescribed.
- Point to objects and ask the person to look at what you are pointing to, for example, food items on plate, grooming aids at sink.
- When reading, use a coloured ruler or paper as a line guide, or place a guide under each line as it is read or along the side of the paragraph where the person has visual field loss.

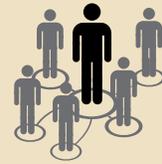
Case example

Mr. Shamji has a left visual field loss, impaired depth perception, and problems recognizing colour contrasts. Mr. Shamji bumps into people in the hallway, and hits walls and doors with his wheelchair on the left hand side. When dressing he cannot find his shirt in his drawer and doesn't know how to place his arm in the sleeve. He has a hard time finding his razor on the sink where it is kept with the rest of his toiletries.

Elena, his healthcare provider, helped Mr. Shamji by encouraging him to turn his head to the left while moving in his wheelchair, to find his grooming objects in the bathroom and when scanning his environment. She organized his clothes in the drawers so that shirts and pants were in different locations, and put shirts in the drawer by alternating colour. Elena also used the techniques suggested by the occupational therapist to position and orient Mr. Shamji's clothes so he could find the sleeve.

KEY MESSAGES OF VISION AND VISUAL PERCEPTION

- ❑ **Vision and visual perception** are the ability to see your surroundings and make sense of what you see.
- ❑ It is not always obvious that a person has **visual perceptual problems**.
- ❑ It is important to **be aware of this issue** and monitor the patient for signs of vision problems.
- ❑ **Safety is a significant issue** for a person who has vision or visual perception problems following a stroke.
- ❑ **Set up the living space** so the person with stroke can move around and know the location of obstacles such as furniture.
- ❑ **Communicate with the stroke care team** and know the plan to address vision and visual perception problems.



4.2 Unilateral Spatial Neglect



IN THIS SECTION

- Defining spatial neglect
- Personal neglect
- Near extrapersonal neglect
- Far extrapersonal neglect

YOUR ROLE AS A HEALTHCARE PROVIDER

With spatial neglect the person who has had a stroke loses awareness of one side of their body and their surroundings on that side. You can help the stroke survivor stay safe by helping increase awareness of their affected side and the surrounding area, and working through neglect concerns during your daily care and interactions with the person.

DEFINING SPATIAL NEGLECT

Following a stroke, a person sometimes loses the ability to be aware of stimuli on one side of their body and personal space. It is usually on the side opposite to where the stroke occurred in the brain. Most commonly, it will be noticed on the left side. This is often referred to as left body neglect or visual spatial inattention. Sometimes a person also has a visual field loss along with unilateral spatial neglect and/or body neglect. This makes it even more difficult for the person to orient properly to their surroundings as there is a visual component to their neglect.

There are three categories of unilateral spatial neglect.

PERSONAL NEGLECT

Personal neglect is neglect of one side of the body (body parts), such as:

- A man only shaving half of his face
- Washing or dressing only half of the body
- Brushing only half the teeth
- Leaving an affected limb dangling over the bed or the side of the wheelchair without noticing

NEAR EXTRAPERSONAL NEGLECT

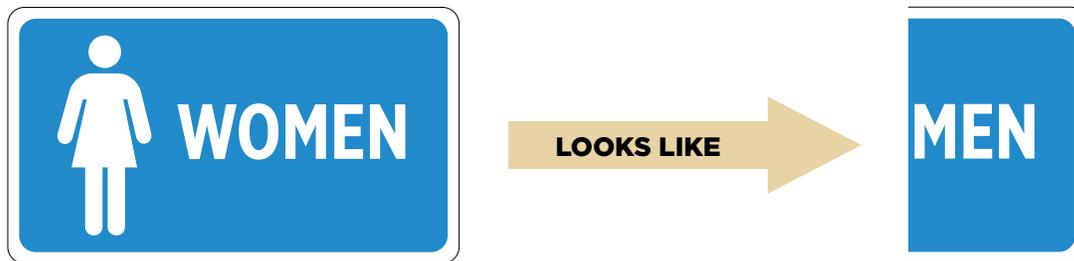
Near extrapersonal neglect is neglect of the space within reaching distance, such as:

- Eating only half the food on a plate
- Not finding cutlery placed on one side of the plate
- Difficulty reading; a person might only see half of the words in a sentence on the page, and as a result the information doesn't make sense
- Writing on one half of a page
- Only using clothing from one half of a dresser drawer or closet, without knowing there is another half to look in
- Filling the sink with only cold water to wash, neglecting to see the hot water tap
- Not noticing the television remote, a book, or a water glass placed on a side table located on the neglected side of the body

FAR EXTRAPERSONAL NEGLECT

Far extrapersonal neglect is neglect of the space beyond reaching distance, such as:

- Walking past the bedroom or washroom door if it is on the neglected side
- Not noticing someone or something approaching on the neglected side
- Bumping into objects, doorways, and walls on the affected side
- Experiencing unsafe transfers because they miss the transfer surface, as they only see half of it
- Only reading half a sign and possibly misinterpreting what the sign says



HOW YOU CAN HELP



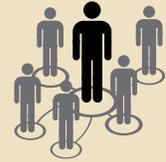
- Talk with the occupational therapist about how to best use the neglected limb in daily activities.
- Position or help the person position the affected limb so they can see it.
- Talk to the person on the neglected side.
- Use cues to draw attention to the affected side. Ask, “Where is your arm?”
- Have the person use a mirror to provide feedback when dressing or grooming.
- Place items on the person’s unaffected side, so they are easy to find.
- Always use the same technique and order for dressing, starting with the neglected side.
- Place your hand on top of their neglected limb or gently rub the limb to offer sensory feedback to help them notice the affected body part.
- Practice taking the same route to a place every time, so the person becomes familiar with the route.

Case example

Mrs. Brown initially had a problem leaving her affected left arm hanging over the side of her wheelchair. Her healthcare provider got her a lap tray and reinforced the importance of keeping her left arm on the lap tray where she could see it. Her family and all her healthcare providers always reminded her about her left arm. Over time, Mrs. Brown placed her affected arm on the tray without being reminded.

KEY MESSAGES OF UNILATERAL SPATIAL NEGLECT

- ❑ After a stroke, **a person can lose awareness** of the affected side of their body.
- ❑ **They may not pay attention** to the affected side, which may create safety issues.
- ❑ **Frequent reminders** and education will help the person with stroke become more aware of their affected side and care for it during daily activities.



4.3 Body Scheme



IN THIS SECTION

- Defining body scheme disorders
- Autotopagnosia
- Personal (body) neglect
- Right-left discrimination

YOUR ROLE AS A HEALTHCARE PROVIDER

A person who has had a stroke may lose the ability to name body parts or be aware of their location on the body or position within their environment. You can help a person who has body scheme issues by including education and awareness of body into your regular care activities.

DEFINING BODY SCHEME DISORDERS

Body scheme is defined as an awareness of one's body parts, as well as the position of the body and its parts in relation to each other and objects in the environment. Body scheme is affected by sensory input including pressure, touch, joint position, vision, sound, and balance.

Following a stroke, a person might show problems with body scheme, related to impairments of various sensory systems. They might be able to find a body part on another person but not on themselves. Or they might be able to name a body part, but not be able to say where it is in relation to other body parts. For instance, they can identify the nose, but not know that it is between the eyes.

AUTOTOPAGNOSIA

Autotopagnosia is when a person does not recognize his own body parts and their relationship to each other, and they do not have a good sense of their body structure. They may not be able to localize a body part ("mouth" for example) but they can show you the part of the body that they "eat with." They may have difficulty using both hands together to do a task, or they may confuse the sides of the body, so that if you ask them to move their left foot during a transfer, they are not sure which foot is left. Or they may try to put the right sleeve of a shirt on their left arm, or their arm through the neck hole.

A person with autotopagnosia may have difficulty with:

- Dressing (they may have a dressing apraxia)
- Mobility and transfers
- Identifying body parts during personal care
- Differentiating between right and left
- Using both hands for two-handed activities

HOW YOU CAN HELP



- Reinforce or name the parts of the body during personal care activities. For example say “You are washing your left arm now”.
- Touch the limb you are referring to, to provide sensory input. For example, if you ask the person to move their left foot during a transfer, touch their left foot with your foot.
- Reinforce the strategies recommended by the occupational therapist in the care plan during your interactions with the person.

RIGHT-LEFT DISCRIMINATION

A person who has problems with right-left discrimination cannot tell the difference between right and left on their body or in relation to other objects or their environment. This can lead to problems with:

- Dressing, as the person cannot match the right pant leg with the right leg
- Mobility, as they cannot respond to “turn left” or “turn right”
- Cuing, as they have difficulty responding when you ask them to turn their head further to the left to compensate for a visual field deficit (they may not know which way to turn their head)

HOW YOU CAN HELP



- Follow the suggestions provided by the occupational therapist to help the person re-orient to right and left.
- Mark objects with tape or writing to identify difference between right and left.
- When giving instructions do not use the words “right” or “left.” Instead either point to the body part you are referring to, or refer to an object by its location, by saying “the washroom door is just before your bedroom door” instead of “the washroom door is on your right.”

Case example

Mrs. Sinclair has problems with her body scheme. Jana, her healthcare provider, often gets frustrated because Mrs. Sinclair will not cooperate during her bath. When asked to move a body part closer to Jana so she can wash it, Mrs. Sinclair doesn't respond, or she offers a completely different body part. When Jana asks Mrs. Sinclair to wash her own face, she tries to wash her hair instead. Jana is learning that if she refers to the body part by name and touches it at the same time, Mrs. Sinclair will move the correct body part closer for washing. Jana is also providing hand over hand guidance of the cloth to her face to help her wash her face, while verbally reinforcing that this was her face.

KEY MESSAGES OF BODY SCHEME

- ❑ Following a stroke, **a person might show problems** with body scheme, related to impairments of various sensory systems.
- ❑ **Include strategies** for reinforcing body parts and functions during daily activities and interactions.



4.4 Praxis



IN THIS SECTION

- Defining apraxia
- Ideomotor apraxia
- Ideational apraxia
- Dressing apraxia

YOUR ROLE AS A HEALTHCARE PROVIDER

Apraxia may occur in people who have had a stroke, and causes difficulties in controlling purposeful movements. It can be a very frustrating experience. You can help the person by using different strategies suggested by the occupational therapist to overcome issues. You can also provide reminders on how to approach tasks, and give frequent and consistent encouragement. It is important not to take over the tasks; rather be patient and help the person to work through the challenges with your assistance.

DEFINING APRAXIA

Apraxia is difficulty carrying out purposeful movements even though the person has the physical ability to perform the task. It means messages from the brain to the muscles are not being processed properly. Apraxia can also affect the muscles responsible for the ability to speak.

Apraxia can affect movement on both sides of the body, not just the affected or weak side. For example, the person may have trouble performing simple, everyday tasks like hair brushing, eating or getting dressed using their unaffected limb.

There are different types of apraxia that you may see in someone who has had a stroke:

IDEOMOTOR APRAXIA

Ideomotor apraxia is the inability to imitate gestures or perform a purposeful motor task on command, even though the person understands the idea or concept.

For example, you might say to someone “please pass me the shampoo bottle.” Even though the person has the physical ability they will not be able to initiate this task. They might look at the shampoo bottle, understand it is shampoo and what it is used for, but not be able to figure out how to reach for it and hand it to you. Or you might show someone how to put on the wheelchair brake yet they are not able to copy what you do.

IDEATIONAL APRAXIA

Ideational apraxia is the loss of the idea and knowledge of how to perform a task. The person has lost the “concept” of how to do a task, rather than being unable to start or complete the task. They may use an object incorrectly, such as using a toothbrush to brush their hair or a knife to eat their soup. Or they might pick up their razor and not know what to do with it, just turning it over and over in their hand trying to figure out what it is used for.

DRESSING APRAXIA

Dressing apraxia occurs when a person has difficulty dressing themselves, even though they are physically capable of doing so. They make mistakes orienting their clothing and might put their clothes on backwards, upside down, or inside out. They might try to put two legs into one pant leg, or their arm into the wrong sleeve or the neck hole of a shirt. Once they notice the clothing is not fitting properly, they have a hard time figuring out what is wrong and how to fix it.

HOW YOU CAN HELP



- Talk with the occupational therapist about the best strategies to use. These may include physical or verbal cues, and/or demonstrations.
- You will need to use different strategies depending on the type of apraxia, as cues for one apraxia may not work for another type of apraxia.

For ideational and ideomotor apraxia

- Use short and simple instructions to limit confusion and break the task into simple steps
- Encourage repetition and practice and use the same steps every time the task is performed
- Do activities in as normal an environment as possible (i.e., brush teeth in the bathroom at the sink after eating, not at the bedside in the middle of the day)
- Encourage the person to close their eyes and visualize the movement or task
- Instead of telling the person what to do, help move their limbs through the necessary motion by providing **hand-over-hand guidance**, where you guide the person with your hand over theirs, but you don't perform the task for them. Examples of when this could be done include:
 - ♦ To put on the wheelchair brakes
 - ♦ To cut food with knife and fork
 - ♦ To brush teeth
- Avoid commands like “brush your hair,” “put on your brake,” “do up your button.” Instead say “here’s your hair brush,” and hand them their hairbrush, lock your wheelchair before standing,” or “you haven’t done up your shirt buttons yet.”



Hand-over-hand guidance

Case example

Initially, Mr. Black would try to use his toothbrush to comb his hair. Each day, his healthcare provider guided his hand as he used his toothbrush to brush his teeth. After a few weeks, Mr. Black was able to pick up his toothbrush and use it correctly without assistance.

For dressing apraxia

- Cue the person to use labels to orient clothing to front and back
- When buttoning a shirt, encourage a person to find the bottom button and match it up to the bottom button hole, and then continue matching the rest of the buttons upward from there
- Encourage the use of pull over shirts if buttoned shirts seem too difficult
- Dress using the same recommended technique and order every time—practice and repetition is important

Case example

Mrs. Wong couldn't figure out how to put on her pants, often putting them on backwards. Each day Jessica, her healthcare provider, had her sit in an armchair to dress, and then placed her pants on her lap. Jessica encouraged her to find the tag and orient the pants so that the tag was facing up on her lap, and then cued her to “put your right leg in first” and then “put in your left leg.” After several weeks of practice using this technique, Mrs. Wong was able to put on her pants independently.

BEST PRACTICE RECOMMENDATIONS

Patients with suspected perceptual impairments (visual-spatial impairment, agnosias, body scheme disorders and apraxias) should be assessed using validated tools.

Treatment of neglect can include visual scanning techniques, phasic alerting, cuing, imagery, virtual reality, hemispheric (limb) activation and trunk rotation.

Remedial based techniques could include prisms, eye patching, transcranial magnetic stimulation, and neck muscle vibration.

Rationale: Visual perceptual disorders are a common clinical consequence of stroke. They include unilateral neglect, which has a major impact on rehabilitation outcome. Visual perceptual disorders result in processing changes in the integration of visual information with other systems. These changes decrease a patient's ability to adapt to the basic requirements of daily life. The incidence of unilateral spatial neglect is estimated to be approximately 23%. The presence of neglect has been associated with both severity of stroke and age of the individual.

Limb apraxias are more common in those with left hemisphere involvement (28 - 57%) but can also be seen in right hemisphere damage (0 - 34%) (Donkervoort et al., 2000). While apraxia improves with early recovery, up to 20 percent of those initially identified will continue to demonstrate persistent problems. Severity of apraxia is associated with changes in functional performance.

KEY MESSAGES OF PRAXIS

- ❑ **Apraxia may occur** in people who have had a stroke and causes difficulties in controlling purposeful movements.
- ❑ **Work with the stroke care team** to develop different strategies to help address the specific issues the person is experiencing.
- ❑ **Be clear and specific** when providing reminders on how to approach tasks.
- ❑ **Provide encouragement** and reassurance to the person experiencing Apraxia.



4.5 Sensation



IN THIS SECTION

- Defining sensation
- Touch
- Temperature (hot and cold)
- Joint position
- Risks

YOUR ROLE AS A HEALTHCARE PROVIDER

A person who has had a stroke may have limited or no sensation in the part of the body affected by the stroke. This creates safety issues. You may be the first to notice the loss of sensation. You can help the person with changes in sensation by monitoring and ensuring proper positioning of the affected side, ensuring dangers in their surrounding environment are avoided (such as being too close to a hot stove), and providing verbal cues as reminders of what is happening on the affected side.

DEFINING SENSATION

Sensation is the ability to feel touch, temperature, and pain, and know where our body and body parts are in space. Nerves carry the feeling of sensation from our body parts to our brain, which then interprets what we feel or sense. Then our brain tells our muscles and organs to respond appropriately. A stroke can cause a problem in the brain where the sensations are interpreted.

A person who has had a stroke may have limited or no sensation in the part of the body affected by the stroke. Sensory changes following a stroke may be slight or severe, and can include full loss of a specific type of sensation. A person with sensory loss may not realize their shoe is too tight, that they are developing a blister or pressure sore, or that their arm is hanging over the side of the wheelchair. Sensation may improve over time but not in all cases.

Common sensory impairments that may result from a stroke can include problems with:

- Touch (ability to feel touch)
- Temperature (ability to discriminate between hot and cold)
- Joint position (knowing where a body part is in space)
- Pain (altered sensation of pain)

TOUCH

A person may lose the ability to feel light or deep pressure touch. They may be unable to feel something touching their body/skin like a blanket, clothing, or an object. They may have difficulty moving objects in their hands, like a button on a shirt, or they might seem clumsy or drop things. Some people say it feels like they are wearing a pair of thick gloves at all times.

Sometimes a person loses the ability to identify an object by feel (without looking at it). Others may be hypersensitive to touch. For example, a person might complain of pins and needles or a sharp twinge when they touch something, or clothing on their skin might feel uncomfortable.

TEMPERATURE (HOT AND COLD)

A person who has had a stroke may have difficulty feeling the difference between hot and cold or be unable to recognize the temperature they are feeling. For example, they are unable to tell you if the bath water was hot or cold. Sometimes hot and cold sensation is just reduced, so that very hot water, for example, feels lukewarm.

JOINT POSITION

After having a stroke, it is possible that the person may lose the ability to feel the position of where their joints are in space. They cannot tell where their body parts are without looking at them. Unless they look at the joint they are moving, they cannot tell if they are swinging their leg when walking or if their arm has reached and grasped a cup on the table. They might leave a leg behind during a transfer, not grasp their walker properly, or not realize their arm is hanging over the side of the wheelchair.

When you are working with them, remember that problems with sensation put a person at risk of injury. If someone can't feel a sensation, they are less likely to be aware of an injury or remove themselves from a dangerous situation.

Potential risks:

- Burns from hot water, spills, burners, or curling irons
- Cuts from knives or razors
- Blisters or pressure sores
- Falls during mobility or transfers
- Injury to limbs (twisted or hanging)

HOW YOU CAN HELP



- Be aware of sensory problems the person might have.
- Take steps to ensure they remain safe during personal care and day-to-day activities.
- Provide verbal cues or touch the limb when providing instructions for transfers or movement (i.e., “Your right knee is bent,” or “Your left leg has not moved yet,” or “Your hand has fallen off the walker.”)
- Follow the care plan recommendations to increase sensory awareness made by the occupational therapist or physiotherapist.

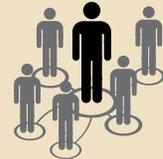
Case example

Since her stroke, Mrs. Columbo has difficulty sensing touch and temperature, and recently a burn was found on her hand. She is having trouble doing up buttons on her shirt. She also frequently drops her toothbrush when brushing her teeth, as she can't feel it in her hand. The occupational therapist has provided her with therapy activities to help improve sensation.

Linh, her healthcare provider, takes extra care to ensure Mrs. Columbo's soup is cool before she eats it, and transfers warm coffee to a spill-proof mug before giving it to Mrs. Columbo. When dressing, she encourages Mrs. Columbo to look at what she is doing, telling her to look down at her shirt when fastening the buttons. Linh also encourages Mrs. Columbo to look in the mirror when she is brushing her teeth.

KEY MESSAGES OF SENSATION

- ❑ A person who has had a stroke may have **limited or no sensation** in the part of the body affected by the stroke.
- ❑ **The person may lose the ability** to feel sensations of touch, pain, temperature and awareness of position of arm and leg.
- ❑ **Safety is an important issue** with loss of sensation.
- ❑ **Frequent verbal cues** and managing the environment are important as part of daily care.



4.6 Pain



IN THIS SECTION

- Defining pain
- Common types of post-stroke pain
- Identifying pain

YOUR ROLE AS A HEALTHCARE PROVIDER

Pain after stroke is very common and may become chronic. You may be the first to notice signs of pain. There are many different kinds of post-stroke pain as well as different techniques to ease the pain. This can make a big difference to the person's quality of life. You can help reduce the pain by following the strategies outlined in the care plan. If you notice new pain or the pain appears to be getting worse, tell the team right away so it can be assessed and managed. Identifying the type of pain can lead to the right treatment.

DEFINING PAIN

Pain is a sensation in the body that causes discomfort, and it can negatively affect mood and recovery. It is usually described by how long it has been present (duration) and what caused it (source).

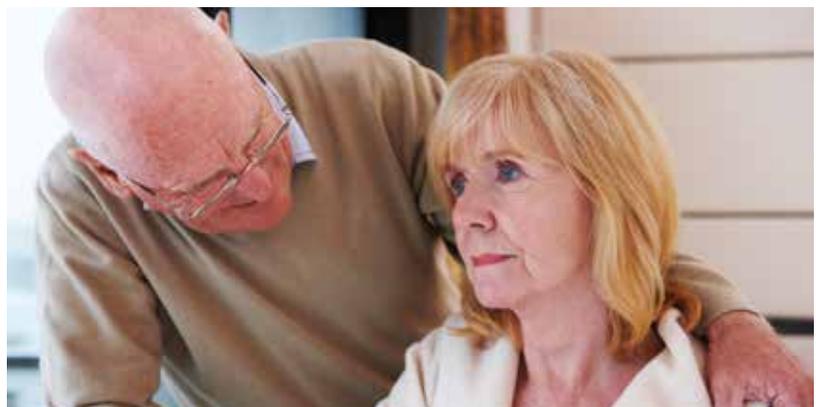
Pain is either acute or chronic. **Acute pain** is usually short-lived and comes from an event, such as an injury.

Chronic pain may arise from an initial stroke and its impact on the body, or there may be an ongoing cause that is persistent. However, there may also be no clear cause. Chronic pain usually lasts more than three to six months.

Pain can be described in many ways: sharp, dull, aching, burning, shooting, tingling, pricking, cutting, piercing, stabbing, numbing, or like a sudden shock. Some find that pain can be triggered even by a light touch.

Some things to know about pain:

- Pain may be present even in parts of the body with impaired movement or sensation
- People with dementia or cognitive impairment experience pain
- Pain may be present even if the person is not conscious
- Among seniors who have had a stroke and who live in long-term care facilities:
 - ◆ One in two has ongoing and frequent pain.
 - ◆ One in four has pain daily
 - ◆ Seven in ten have untreated pain



UNTREATED PAIN

- Can cause anxiety, sleep disturbances, memory problems, reduced appetite, poor posture, and even depression
- Interferes with daily activities like going to the bathroom, dressing, and grooming
- Reduces the ability to move and participate in activities
- Increases irritability and makes people more likely to refuse care
- Can cause people to become isolated and cut off from others, especially when the pain is chronic

When it comes to pain — **prevention is key.**

COMMON TYPES OF POST-STROKE PAIN

Post-stroke pain can take several forms and may include:

- **Peripheral neuropathic pain:** A type of nerve sensitivity that causes muscle aches, painful cramps, and other symptoms
- **Shoulder subluxation:** Low muscle tone and weakness in the shoulder muscles results in what appears to be shoulder joint dislocation; the shoulder and arm are no longer aligned in correct positions
- **Spasticity:** Stiff and rigid muscles that often result in hemiplegic shoulder pain
- **Shoulder-hand syndrome:** A complication of stroke
- **Central post-stroke pain or thalamic pain syndrome**
- **Other Body Pain or Pain from Previous Conditions**

SUBLUXATION AND HEMIPLEGIC SHOULDER PAIN

People who have had a stroke often experience shoulder pain on the side affected by stroke. The pain may begin within a few days, weeks, or months after the stroke.

Muscles affected by stroke may no longer be able to keep the arm and the shoulder joint in a good position. This can cause pain and movement problems such as shoulder subluxation. This is when the shoulder joint is partially dislocated. Early supportive positioning and correct handling can help prevent shoulder pain.

Identifying and treating shoulder pain early is important. Treatment is more difficult after the pain is established and has become chronic.

BEST PRACTICE RECOMMENDATION

Treatment of hemiplegic shoulder pain related to limitations in range of motion includes gentle stretching and mobilization techniques, and typically involves increasing external rotation and abduction.

Rationale: The incidence of shoulder pain following a stroke is high. As many as 72 percent of stroke patients report at least one episode of shoulder pain in the first year after stroke. Shoulder pain may inhibit patient participation in rehabilitation activities and contribute to poor functional recovery. It can also mask improvement of movement and function. Hemiplegic shoulder pain may contribute to depression and sleeplessness and reduce quality of life.

HOW YOU CAN HELP



- Watch for signs that may indicate the person is in pain
- Acknowledge the person's pain
- Report the person's pain to your team so an assessment can be completed
- Handle and move the affected shoulder and arm carefully in all care activities to prevent painful stretching of muscles and ligaments
- Support the arm when the person is sitting, standing, or walking*

SPASTICITY

Spasticity results from abnormally high muscle tone as a result of stroke. It can lead to stiff, rigid muscles, decreased range of motion, and pain in limbs and joints.

The physician and therapists help manage spasticity. The physician may recommend injections of botulinum toxin (Botox™) or muscle relaxants to reduce spasticity, and a therapist may recommend stretches, exercises, and /or splints to maintain optimal muscle length.

HOW YOU CAN HELP



- If you notice increased joint stiffness or pain, report it to a team member
- Handle and position the affected limb carefully and according to the care plan
- Don't force the limb to move
- Refer to positioning guidelines that may be recommended for a specific person
- Apply prescribed splints properly and for the correct amount of time*

* Refer to 6.2 for detailed information on proper positioning and handling of an affected shoulder.

SHOULDER-HAND SYNDROME

On occasion, a person with shoulder pain may develop a stiff, swollen, discoloured, and extremely painful hand and wrist, which may be diagnosed as shoulder-hand syndrome or reflex sympathetic dystrophy. This may also be called **Complex Regional Pain Syndrome**. The person may demonstrate a very limited range of motion in the shoulder and hand and limited use of the arm.

HOW YOU CAN HELP



- Watch for signs that may indicate the person is in pain.
- Acknowledge the person's pain.
- Use recommended positioning to protect the affected arm and hand.
- Help the person do their prescribed exercises.
- Always handle an affected arm, shoulder and hand carefully to prevent painful stretching of muscles and ligaments.
- Support the arm, shoulder and hand when the person is walking, standing, or sitting.
- Report any increase in shoulder, arm, hand, and wrist pain, swelling, or discoloration.

CENTRAL POST-STROKE PAIN

Up to 10 percent of people who have had a stroke may develop chronic pain syndromes. One type of pain that is often undertreated or misdiagnosed is **central post-stroke pain (CPSP) syndrome or thalamic pain syndrome**. It is different from other types of pain and tends to be harder to treat. It can occur when a stroke affects the thalamus or parietal lobe — two parts of the brain that process sensory stimuli like heat, cold, and touch. As a result, sensory neurons (brain cells) in these areas of the brain misfire, so the brain no longer interprets information correctly and registers all sensation as pain. This can lead to chronic and sometimes disabling pain.

The pain is sometimes described as a burning, pins-and-needles, or even a sudden stabbing sensation that can be intolerable. It can be felt throughout the body or focused on a specific body part, such as the hands or feet. The pain can come and go, or be continuous.

OTHER SHOULDER AND ARM CONDITIONS

Other arm and shoulder conditions that can cause pain may have been present before the stroke, or may have developed from injuries afterwards. These include:

- **Rotator cuff injury:** The muscles surrounding the shoulder are injured.
- **Tendonitis:** Inflammation of a tendon.
- **Bursitis:** A bursa is a small, fluid-filled sac that reduces friction and allows tendons around a joint to glide more easily. Bursitis is inflammation of a bursa sometimes caused by pinching of the shoulder bursa.
- **Upper arm fracture:** Fractures of the upper arm can result from a fall or osteoporosis.

If you have questions or concerns about pain that someone is having, or are unsure about care strategies, talk to a specialist on the team, such as a physiotherapist, occupational therapist, or physiatrist.

OTHER BODY PAIN OR PAIN FROM PREVIOUS CONDITIONS

The stroke survivor may experience pain in their back, hips, knees, or feet. This could be new since the stroke, such as from altered posture/poor positioning in bed or in a wheelchair. Pain may have developed due to their altered gait pattern. Their pain could be stemming from pre-existing conditions such as Osteoarthritis, Chronic Low Back Pain, Fibromyalgia, or other condition.

HOW YOU CAN HELP



- Watch for signs that may indicate the person is in pain.
- Acknowledge the person's pain.
- Ask questions to better understand the type and intensity of the pain.
- Report any new experiences of pain to the healthcare team.

IDENTIFYING PAIN

Pain is subjective. The person experiencing pain is the only one who can describe the severity.

People may not report pain because they:

- Believe pain is part of aging
- May not want to be a burden
- Have impairments that make it hard to communicate

People may express pain in various ways, not all of them spoken. Be alert to body language and movement, especially if the ability to communicate is impaired. This is especially true of people with aphasia. If they can't tell you, ask a family member how the person usually shows pain. There are a number of ways a person may show pain including:

Verbally

- Telling you: "That hurts! Ouch! Stop that!"
- Using pain-related words: burning, itching, throbbing
- Making sounds: moans, groans, grunts, cries, gasps, sighs

Physically

- Rubbing or massaging the painful area
- Bracing, holding, or guarding an area, especially when they move
- Frequent shifting, restlessness, rocking, or not being able to stay still
- Impaired bowel and bladder function

Through facial expressions

- Frowning
- Grimacing
- Wincing

Through behaviour change

- A usually restless person is quiet, or a usually quiet one is restless
- Anger or irritability
- Changes in appetite

PAIN SCALES

A **pain scale** is a way to measure the intensity of someone's pain. There are a number of different types of pain scales including:

- “0” for no pain and “10” for the worst possible pain
- Pictures of faces representing “no pain” to “worst pain possible.” This type of scale may be beneficial when someone is unable to communicate verbally.

Check with your team to find out if you should be using a scale to detect or monitor pain. To use a pain scale, ask the person to tell you (or point to) the number or description on the scale that corresponds to the pain they are feeling.

COMPARATIVE PAIN SCALE CHART (Pain Assessment Tool)										
										
0 Pain Free	1 Very Mild	2 Discomforting	3 Tolerable	4 Distressing	5 Very Distressing	6 Intense	7 Very Intense	8 Utterly Horrible	9 Excruciating Unbearable	10 Unimaginable Unspeakable
No Pain	Minor Pain			Moderate Pain			Severe Pain			
Feeling perfectly normal	Nagging, annoying, but doesn't interfere with most daily living activities. Patient able to adapt to pain psychologically and with medication or devices such as cushions.			Interferes significantly with daily living activities. Requires lifestyle changes but patient remains independent. Patient unable to adapt pain.			Disabling; unable to perform daily living activities. Unable to engage in normal activities. Patient is disabled and unable to function independently.			

HOW YOU CAN HELP

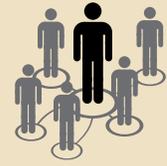


Your knowledge of the person who has had a stroke is an important tool in identifying and assessing their pain. When you are talking to them about pain:

- Ask yes or no questions.
- Use simple words to help identify the problem.
- Point to areas that may be painful, and ask about them.
- Ask about pain during or after movement.
- Be patient. They may need more time to explain what they feel.
- Use a pain scale if recommended by the team. Even people whose pain is being treated may still experience pain.
- Discuss pain and pain management with the team, to ensure that pain management strategies and medication are adequate.

KEY MESSAGES OF PAIN

- ❑ **Pain after stroke** is very common and may become chronic.
- ❑ **There are several different types** of pain that the person can experience.
- ❑ **It often occurs in the affected shoulder**, and can also occur in other parts of the body. Acknowledge the person's pain, provide reassurance and empathy.
- ❑ **Monitor pain intensity**, and activities that increase pain, as well as the effect of strategies to reduce pain.
- ❑ **Communicate with other members** of the stroke care team about the pain experience and management.



CHAPTER 5

Mental Function And Emotional Responses

Mental function and emotional responses are important considerations after stroke. They involve how the brain interprets, processes and reacts. This may include consciousness, energy and drive, as well as specific functions such as memory, language, cognitive and intellectual functioning, interpersonal skills, sleep, memory, attention and emotions (WHO, ICF 2001).

Three areas will be the focus of this section most relevant to caring for people who have had a stroke and are living in the community:

IN THIS CHAPTER

- 5.1 Behaviour Changes
- 5.2 Mood and Depression
- 5.3 Cognition



5.1 Behaviour Changes



IN THIS SECTION

- The impact of stroke on behaviour
- Social isolation
- Anger and aggression
- Apathy
- Social judgment

YOUR ROLE AS A HEALTHCARE PROVIDER

The loss of or damage to brain cells due to a stroke can change how a person feels and behaves. They may have difficulty controlling their emotions, and may react or behave in ways that are unlike their pre-stroke personality. You can help the person who has had a stroke and their family members understand why these changes are happening, and help them adapt.

THE IMPACT OF STROKE ON BEHAVIOUR

While some people who have had a stroke may show little or no change in behaviour, others may experience extensive changes. Damage to the brain can decrease emotional control and change the way people behave and relate to others. The extent of the change depends on:

- Where the stroke was in the brain
- How severe the stroke was
- How long ago the stroke occurred
- The person's cognitive abilities, personality, and behaviour before the stroke
- Whether the person is experiencing a clinical mental health issue such as depression or anxiety

Some behaviour changes stem from damage in the areas of the brain that control cognitive, perceptual, or other abilities. Others may be related to frustration the person is feeling from being unable to communicate or function the way they used to. In some cases, the person may not be aware of the changes in their personality or behaviour, although their loved ones might notice them.

Changes in behaviour are not always consistent. Someone may have good days and bad days, or even good and bad times during the course of the same day.

It is important to remember that most behaviour changes are due to the stroke. Some of the possible effects include:

- Their behaviour may not match how they feel. For example, someone may laugh at a sad story.
- They may not realize how their behaviour affects others. For example, they may not know when they say or do things that hurt or upset a family member.
- Extreme mood swings, such as being upset one minute and laughing the next.
- Losing interest in things they used to like to do. For example, a person who used to read regularly may no longer pick up a book.
- Appearing stubborn, selfish, or demanding to others.

Practice the techniques outlined here and use patience, common sense, and a problem-solving approach regardless of the behaviour observed. The person is struggling to cope, and that takes time and patience.

ANGER AND AGGRESSION

Anger and aggression can be caused by the area of the brain that was damaged by the stroke. With this, it is important to remember that people who have had a stroke sometimes cannot control these feelings. Coping with the changes that stroke brings can also be frustrating and difficult. This can lead to **anger** and, occasionally, **aggression**. The person may also have a hard time working through their anger, making it difficult to get past it.

Sometimes the stroke-related deficits themselves can make managing an angry outburst difficult. For example, the person may not be able to follow instructions, tell you their perspective or feelings, or understand your point of view.

Anger is a normal human reaction to a perceived threat or irritation. It is important to identify the causes of angry outbursts. They may be a result of:

- Frustration, which can stem from the person knowing what they want to say but can't get the words out, or being rushed to perform a task
- Embarrassment, from something like a toileting accident
- Lack of independence/autonomy, where others do things for them rather than helping them be independent
- Feeling helpless or hopeless, perhaps from uncontrolled pain

If anger and aggression seem out of control or is distressing the person or their loved ones, discuss it with the team and consider whether referring the person to outside services such as social work or counseling might be necessary.

HOW YOU CAN HELP



- **Look for causes (“triggers”)**
 - ◆ When you know the cause of the anger, you can help find solutions. Once you have identified triggers, avoid them if possible. For example, you know the person gets agitated and angry in large crowds, so you learn to avoid environments like these.
 - ◆ If it's because of pain, help them identify the pain so it can be managed.
- **Prevent outbursts**
 - ◆ Predictability can help prevent outbursts. Know the person's daily routines and preferences and follow them whenever possible. Processing or problem solving a lot of new information, especially when routine is lacking, is a common trigger.
 - ◆ Explain what you are doing, so they are prepared for what will happen next.

- ◆ Approach from the unaffected side. Coming up to someone on the affected side can cause alarm and possibly an angry outburst.
 - ◆ Help them feel successful by alternating between easy and more difficult tasks.
 - ◆ Offer support or assistance as needed during activities that cause frustration.
 - ◆ Talk to the person and their loved ones to try to identify and understand their triggers.
- **During an outburst**
 - ◆ If you can do it discreetly, take the person away from the situation or activity that triggered the outburst.
 - ◆ Redirect their attention elsewhere, such as to a favourite activity.
 - ◆ Always use a calm approach.
 - ◆ Stay safe. If the person becomes violent, give them space and seek help from others if necessary.

SOCIAL ISOLATION

A stroke can bring on many changes — physical, emotional, and cognitive — that can be difficult to adjust to. When these changes negatively affect how people see themselves (their **self-image**), or feel about themselves or their self-worth (their **self-esteem**), they are at risk of depression. This could leave them with a lack of confidence, loss of purpose, and sadness or despair. Sometimes people cope with feelings like this by isolating themselves from social activities and/or their loved ones.

Social isolation can also be brought on by other stroke-related changes, such as being unable to safely leave their home (e.g., due to stairs), or being unable to drive or access transport.



HOW YOU CAN HELP



Helping someone who has had a stroke participate in life again is one of the most important things you can do.

- **Find out their interests and social history.**
 - ◆ Talk with the person and their caregivers about their life experiences and memories. What interests did they have before the stroke? What activities did they like?
 - ◆ Look for ways to help them overcome barriers and return to doing what they used to enjoy, or to find new activities. Work with the team to help the person and their family return to favourite activities.
 - ◆ Support them in contacting and participating in their faith community or other activities they used to enjoy.
 - ◆ Speak with the healthcare team about referring them to a recreation therapist who can assist them with returning to their activities of interest.
 - ◆ Remember that family members and caregivers can also become socially isolated as a result of their caregiving duties. Talk to them about their interests and hobbies too, and encourage them to continue participating in their social activities.
- **Promote independence to help achieve a more positive self-image and self-esteem.**
 - ◆ Encourage the person to participate in their own care as much as possible.
 - ◆ Include them in discussions and decisions about their personal care.
 - ◆ Arrange their personal items in a way that gives the best access, and thus gives the person more independence.

BEST PRACTICE RECOMMENDATIONS

Patients should be given the opportunity to discuss pre-stroke leisure pursuits and be assessed for rehabilitative needs to resume these activities. Participation in leisure activities should be encouraged. Patients should be offered information regarding leisure activities in the community and/or be referred to relevant agencies. Use of peer support groups should be encouraged.*

Case example

Mrs. Rosen had a stroke 18 months ago. She has some weakness on the right side and the right side of her face droops. She is very self-conscious about the way she looks and speaks, and as a result is reluctant to go out. Her healthcare provider encourages her to go out, first to quiet, familiar places. Little by little, Mrs. Rosen is becoming less self-conscious and more able to be part of her community again.

* Refer to 5.2 and 6.6 for more information.

APATHY

People who have damage to the right side of the brain may develop apathy or a lack of interest in daily activities or leisure activities. Also, they may be unwilling to try to complete a task or activity or, if they have tried and failed, they may refuse to try again.

HOW YOU CAN HELP



- Learn what interests them and make it as easy as possible for them to participate.
- Reinforce and support any interest that they show in activities. Use praise and encouragement.
- Encourage them to try again if an initial attempt to do something fails.
- Do not embarrass or force someone who refuses. Instead, try again later.*

Case example

Harry had a stroke almost a year ago. He experienced very little loss of mobility, but he has lost interest in his previous pastimes because he cannot do as much as he used to because of difficulty with memory and concentration. Kelly, his healthcare provider, is helping him regain interest in activities by encouraging him to attend social events. To reduce the risk of frustration, she encourages him to take part in activities he can easily do. For example, Harry was an avid bridge player before his stroke; now he and Kelly play Hearts, an easier card game, instead.

SOCIAL JUDGMENT

Social judgment is saying and doing the right thing in a social situation. The personality changes and cognition problems caused by stroke may lead to poor social judgment, irrational behaviour, or behaviour that is out of character for the person. For instance:

- A shy person may now want to be the centre of attention
- A talkative person may become quiet
- An easygoing person may become rigid and unyielding in their opinions
- A previously neat and fastidious person may become sloppy about personal grooming and appearance
- Someone may start missing or misinterpreting social cues or non-verbal communication, when they never had trouble with this before
- Someone who was very controlled may make impulsive decisions

Sometimes the person who has had a stroke does not realize that how they are responding is inappropriate, or that these changes may be results of stroke-related changes in the brain. Family and friends may draw the wrong conclusions when they see behaviour that is out of character as well.

* Refer to 6.6 for more information.

HOW YOU CAN HELP



- **Recognize limits**
 - ◆ Avoid situations that require the person to make decisions beyond their capabilities.
 - ◆ Give time and choice.
 - ◆ Use patience.
- **Give feedback and cues**
 - ◆ Privately and tactfully, and as soon possible after the behaviour occurred, tell the person how their behaviour was inappropriate. Be gentle and straightforward rather than critical.
 - ◆ Offer alternatives, or ask the person to come up with alternatives.
 - ◆ Reinforce appropriate behaviour with praise and encouragement.
 - ◆ Remind the person and their family that fatigue can intensify changes in behaviour. Encourage the person to stay well-rested.

BEST PRACTICE RECOMMENDATION

Patients with cognitive impairment and evidence of changes in mood (e.g., depression, anxiety), or other behavioural changes on screening could be referred to and managed by an appropriate mental healthcare professional.

Rationale: Emotional and related behavioural changes are known to occur following stroke, with specific behaviours linked to the affected hemisphere and stroke location. Disorders such as apathy, anxiety, labile laughing and crying, and other behaviours such as disinhibition, denial, indifference, overt sadness, and aggressiveness can occur following stroke.

KEY MESSAGES OF BEHAVIOUR CHANGES

- ❑ The **loss of or damage to brain cells** due to a stroke can change how a person feels and behaves.
- ❑ **Changes in behaviour** are not always consistent. Someone may have good days and bad days, or even good and bad times during the course of the same day.
- ❑ Sometimes **people cope with feelings** like this by isolating themselves from social activities and/or their loved ones.
- ❑ **Talk with the person** and their caregivers about possible behaviour changes so they understand it is part of having a stroke.
- ❑ **Encourage the person** to participate in their own care as much as possible, and engage them in meaningful activities.



5.2 Mood and Depression



IN THIS SECTION

- Emotional lability
- Depression

YOUR ROLE AS A HEALTHCARE PROVIDER

In addition to the physical and emotional challenges stroke brings, it can also have a serious impact on mood (mental health). Depression is very common among people who have a stroke. This makes the recovery journey even more difficult for the person and for those around them. Your observations can help determine if someone is becoming depressed and your support can help them cope with the depression as well as the effects of the stroke.

THE IMPACT OF STROKE ON FEELINGS AND SOCIAL LIFE

Stroke affects people's mental health and self-image, as well as their relationships. After a stroke, many people feel fear, anxiety, frustration, anger, and sadness, and grieve for their losses. These feelings are a natural response. They often feel that they are on an emotional roller coaster, experiencing anger one minute and sadness the next.

The damage to the brain caused by stroke can lead to emotional disturbances and personality changes. These changes may or may not be caused by depression. A medical assessment is usually necessary to find out if the person is depressed or just having a normal reaction to the upheaval in their life caused by stroke.

FIRST REACTIONS

There is a grieving process associated with the losses and changes that stroke causes. Shock is usually the first emotion people feel after they have a stroke. They may find it hard not to ask "Why did this happen to me? How did it happen? What could I have done to prevent it?"

They may wonder if they will survive and worry about having another stroke. They may worry about what life will be like from now on, and wonder how their family will cope. They may be concerned about whether they will return to activities from their pre-stroke life such as working, driving, and social or leisure activities. Anxiety is a normal reaction to these concerns and changes. It usually decreases as the person learns to accept and adapt. Your support can help them through this process.

AS TIME GOES BY

As time passes the person may feel:

- Frustration about physical limits, memory loss, and difficulties speaking or communicating
- Fatigue from the effects of stroke and the increased effort needed to do routine tasks

- Embarrassment about how they look and how they sound when they speak
- Sadness related to how they feel about themselves and how they believe others feel about them, feeling like a burden to their loved ones.

These challenges often lead to social withdrawal, isolation and, in some cases, depression and/or anxiety.

EMOTIONAL LABILITY

Emotional lability, sometimes referred to as emotional incontinence, is a lack of emotional control. You may observe responses that appear excessive, such as uncontrollable sobbing, or responses that do not match what you might expect, such as laughing at bad news.

Emotional lability can be upsetting for everyone. It can also be embarrassing to the person who has had a stroke and to those around them. It may take time for everyone to adjust to this change. Communication difficulties may result when people misinterpret a stroke survivor's emotional responses.

HOW YOU CAN HELP



- Ask the person if the feelings they are showing match what they are feeling on the inside.
- Do not tell the person to stop the behaviour, as that could lead to further frustration.
- Try distraction. Call the person's name or ask an unrelated question, to help them regain control and get on with an activity.
- Encourage the person to slow down and take deep breaths.
- Reassure the person who has had a stroke and their loved ones that loss of emotional control is common after stroke.

Case example

Since his stroke, Mr. Buraka has found it hard to control his emotions. He cannot watch the evening news without crying uncontrollably. This upsets him and those around him. Carmela, his healthcare provider, can often distract him by asking if he would like a snack or reminding him that his favourite show is coming on. This sometimes helps Mr. Buraka stop crying.



DEPRESSION

It is normal for people to feel sadness and a sense of loss after a stroke. However, about one-third to one-half of people who have had a stroke develop clinical depression during the year following the stroke. While depression is most likely to start within three to four months afterwards, as the new reality sets in, it can happen at any time, even years later.

Depression is a chronic, overwhelming sense of sadness, loss of interest, and despair that interferes with a person's ability to function. A person living with depression may feel a significant lack of energy. It can slow physical and mental recovery, and the person may lose interest in taking part in rehabilitation or in caring for themselves.

Depression can be treated. The sooner it is treated, the better the outcome may be.

THE “BLUES” OR CLINICAL DEPRESSION?

Only a doctor can diagnose clinical depression. Your ability to recognize how a person who has had a stroke is feeling and share that information with the team is an important part of identifying depression early.

The “blues” or just feeling sad	Clinical depression
Everyone feels sad sometimes.	About 10 to 15 percent of people experience clinical depression. About 30 to 50 percent of people who have had a stroke experience depression.
There is a definite beginning. People know when it started and why they feel sad.	The beginning is gradual. People don't really know when or why it started.
The sad feelings are an emotional response to an event.	Depression is a medical illness resulting from chemical changes in the brain.
The sad feelings go away without treatment.	Depression does not go away without treatment.
The mood lasts a few days or weeks.	Depression can last months or years.

SIGNS OF DEPRESSION

Depression affects people physically as well as emotionally. Some of the most common signs are:

Physical

- Changes in sleeping patterns: Sleeping more or less than usual or having a broken sleep
- Changes in eating habits: Eating more or less than usual, weight loss or gain
- Decreased energy
- Easily fatigued
- Unexplained aches and pains
- Tearfulness

Attitudes

- Not caring about anything
- Loss of interest in things that were previously enjoyed
- Negativity: Feeling that everything is gloomy and dark
- Self-focus on me, myself and I
- Self-loathing
- Difficulty connecting with others, withdrawing from people or activities that they previously enjoyed

Emotions

- Feelings of hopelessness, worthlessness, and guilt
- Sadness and despair
- Anxiety or nervousness
- Irritability or anger
- Thoughts of death and suicide
- Difficulty coping, easily overwhelmed

Mental functions

- Difficulty concentrating
- Difficulty making decisions
- Feelings of confusion or a sense of living in a fog
- Difficulty remembering things, especially short-term events

Watch for these symptoms and take note of patterns. Share your observations with members of your team if you are noticing that the symptoms are consistent over time.

Some of these symptoms may also be caused by stroke without the person being depressed. For instance, a stroke may cause someone to be fatigued, but they are not depressed. These symptoms can indicate depression, but are not conclusive of depression.

RECOGNIZING DEPRESSION

It is not always easy to recognize depression. In fact, fewer than half of those with post-stroke depression are identified. Often, people may not know that they are depressed. In addition, there is a stigma in society around mental illness (including depression). Common misconceptions about depression include it being a sign of weakness or a character flaw, or that treatment may require drugs which have too many side effects, are addictive, or could change a person's personality.

In addition, healthcare professionals may not know when someone who has had a stroke is depressed. It is easy to put the signs and symptoms of depression down to the effects of the stroke, or to aging. And it is difficult to assess someone with communication or cognitive problems for depression.



HOW YOU CAN HELP



- **Build a connection with the person**
 - ◆ When you get to know someone, you are better able to see patterns in their change of mood that may signal depression, rather than just a sad day or two.
 - ◆ Ask the person how they are feeling and actively listen to their response. This will help build rapport. It may also help you identify any other causes for their low mood, such as pain.
 - ◆ Always communicate with care and empathy, and be accepting, not judgmental.
- **Offer support**
 - ◆ Remind the person and their family members that depression is a medical illness. This may help reduce the stigma they have around mental illness and treatment.
 - ◆ Find out what resources are available and share them with the person and their family.
 - ◆ Help them plan and structure each day. Routine can help people adjust.
 - ◆ Remain hopeful. Remind the person that help is available and depression can be treated.
 - ◆ Ask if you can share your concerns with a team member who could help.
- **Encourage them to stay as active and involved as they can**
 - ◆ Find out what activities they enjoy and help the person access them.
 - ◆ If appropriate, encourage friends and family to spend time with them, maybe playing cards or board games.
 - ◆ Suggest activities that might help them relax. Sometimes listening to music, watching television, reading, or meditation can take the focus off feelings of sadness.
- **Encourage them to talk about their emotions**
 - ◆ Help the person feel comfortable expressing their grief and sadness about the stroke and what they feel they have lost. You can be an important support, especially if these conversations seem to be difficult for family members.
 - ◆ Give them realistic hope about the future. Remind them that most people who have had a stroke continue to improve for weeks, months, and even years.
 - ◆ Respect their privacy as necessary, but share relevant information about what the person is feeling with the relevant members of the team.

CATCH IT EARLY

The goal is to recognize feelings of sadness and despair and help the person cope so they don't slip into a clinical depression.*

HOW YOU CAN HELP



- Gently encourage the person to be as independent as possible. Help them only if the task they are trying to do becomes too hard or tiring.
- Always be alert for signs of depression.
- Be positive. When you notice improvements or that the person is doing better, say so. Track their successes and remind them often.
- If you ever have reason to believe someone is thinking of harming themselves or ending their life, get help immediately.

BEST PRACTICE RECOMMENDATIONS

All patients with stroke should be considered to be at high risk for post-stroke depression, which can occur at any stage of recovery. Patients and families should be given information and education about the potential impact of stroke on their mood and that of family and caregivers; patients and families should be provided with the opportunity to talk about the impact of stroke on their lives at all stages of care. Patients and their caregivers should have their psychosocial and support needs assessed as part of ongoing stroke management.

KEY MESSAGES OF MOOD AND DEPRESSION

- ❑ After a stroke, **many people feel fear**, anxiety, frustration, anger, sadness, and grieve for their losses... They often feel that they are on an emotional roller coaster, experiencing anger one minute and sadness the next.
- ❑ **A person living with depression** may feel a significant lack of energy. It can slow physical and mental recovery, and the person may lose interest in taking part in rehabilitation or in caring for themselves.
- ❑ **Reassure the person** who has had a stroke and their loved ones that loss of emotional control is common after stroke.
- ❑ **Encourage the person** to be as independent as possible.
- ❑ **Communicate changes in mood** to other members of the stroke care team.



* Refer to 6.6 for more ideas and suggestions on ways to help keep people engaged and involved in meaningful activities.

5.3 Cognition



IN THIS SECTION

- Defining cognition
- Attention
- Orientation
- Memory
- Insight
- Judgment
- Impulsivity
- Sequencing
- Problem solving

YOUR ROLE AS A HEALTHCARE PROVIDER

Once you understand how stroke can affect a person's ability to think, plan, remember and organize information, you can better help them stay safe and learn to be more independent. Someone who has had a stroke may require help to perform tasks, remember instructions, and make safe decisions. As these abilities improve they feel more self-sufficient, confident, and motivated, which helps reduce their frustration and that of family members, friends, and caregivers.

DEFINING COGNITION

Cognition refers to how we know things and how we think. There are many aspects to cognition.

- Attention: Being able to concentrate
- Orientation: Being aware of time, place, and self
- Memory: Being able to recall experiences, information, and skills
- Insight: Knowing and understanding our abilities and limitations
- Judgment: Making good choices and decisions
- Impulsivity: Doing something too quickly without careful thought or planning
- Sequencing: Being able to arrange things or perform actions in the right order
- Problem solving: Recognizing a problem and finding a solution

When people have trouble with tasks related to cognition, they are said to have **cognitive problems** or **cognitive impairment**. Unlike a physical impairment, problems with cognition are often subtle and more difficult to see. However, these problems have a major impact on how well the person functions and their level of independence. Cognitive skills may improve to some extent over time, but some problems may persist and require strategies to promote a person's safety.

Family and friends of the person who has had a stroke can sometimes overestimate the person's abilities, which can lead to frustration and anger. They may believe that the person is acting this way on purpose, is unmotivated, or is being stubborn. More likely, it means they are expecting too much. Helping the family to create a supportive environment is important.

Cognitive problems related to stroke are not the same as dementia. Although some people who have had a stroke may also have dementia, it's important to understand the difference to provide the right care. For example, a stroke may cause a person to have poor short term memory, but this may not indicate that the person also has dementia.

ATTENTION

People who have had a stroke may have a short **attention** span. They can find it hard to concentrate and are easily distracted. This limits their ability to focus on a task, and consequently they may need more time to complete it.

HOW YOU CAN HELP



- Reduce distractions, including television, radio, and separate conversations.
- Give short, simple, step-by-step instructions. Ask if the person understands the instructions before you continue.
- Help the person focus on one thing at a time by gently bringing their attention back to the task.
- Make eye contact as you speak. This can help them focus on what you are saying and follow your instructions.
- Slow down so the person doesn't feel pressured and has more time to think.
- Remember that the person who has had a stroke is not acting this way on purpose.

ORIENTATION

Orientation is the ability to be aware of time, place, other people, and ourselves. People who have had a stroke may lose their sense of orientation in one or more of these areas. For instance, they may think it is 1975 instead of the current year, or it is fall when it is summer, or that they are in school instead of at home. They may not know their date of birth or how old they are.

HOW YOU CAN HELP



- Gently give them the correct information, without making them feel foolish.
- Mention the date when you arrive. "Good morning, Mrs. Smith. It's Wednesday, October 13th today."
- Put up a calendar to help the person keep track of the day and date. Cross each day off.
- Post personal information (address, phone numbers) and family pictures on a bulletin board where the person can see them easily.
- Keep to a regular schedule of meals and activities to minimize confusion.

MEMORY

Memory means being able to retain and recall experiences, information, and skills. Problems with memory make it hard to learn and use new information and skills.

There are different types of memory. Short-term memory refers to something quite immediate, such as the name of someone we just met. Recent memory might be what we ate for breakfast yesterday, or where we went last weekend. Long-term memory is memories from childhood and earlier adulthood. Sometimes people have difficulty remembering verbal instructions, so other types of cues may be helpful.

HOW YOU CAN HELP



- Encourage the person to use memory aids such as a daily planner (electronic or written), calendar, and sticky notes.
- Repeat information to help them remember it.
- Store items in the same place. Label drawers and cupboards to show what is in them.
- Provide information clearly and without too much detail, to help the person focus on the key points.
- Present new information one step at a time, so the person can concentrate on one piece of information before moving to the next.
- Use signs or pictures as memory cues. Put signs on the doors in the home, and post family pictures on the bulletin board.

Case example

Mrs. Wright has experienced memory problems as a result of her stroke. She becomes upset when she cannot remember where familiar items are stored or what she did the day before. Fiona, her healthcare provider, helps Mrs. Wright by jotting down the day's activities in a journal. When Mrs. Wright can't remember when something happened, she looks it up in the journal. To help Mrs. Wright find things, Fiona always puts them back in the same place. She has also labeled the cupboards so Mrs. Wright can find things more easily.

INSIGHT

Insight means recognizing and understanding our abilities and limitations. A lack of insight may lead a person who has had a stroke to do things that aren't safe, or be impulsive. For example, they may not recognize that their weak leg makes it unsafe to walk alone.

HOW YOU CAN HELP



- Make the environment as safe as possible.
- Have mobility aids and other assistive devices close by.
- Gently remind the person about limitations they may have. Be honest but not critical about the limitations.
- Provide sufficient supervision to ensure the person's safety.
- Post reminders such as “use your cane”, or “do not cook or use the stove.”

Case example

Mr. D'Angelo had a stroke three years ago, but he continues to think that he is safe to transfer to and from the toilet independently. However, he has poor balance and limited movement on his left side which places him at high risk of a fall. When his healthcare provider John was first assigned to assist Mr. D'Angelo, he discussed this issue with Mr. D'Angelo's wife and the occupational therapist. Together, they developed strategies to reinforce with Mr. D'Angelo. They encouraged him to call for assistance during all wheelchair-to-bed and toilet transfers, and made sure the proper equipment such as mobility aids and grab bars were available and used correctly, to help prevent injuries.

JUDGMENT

Judgment means making the right choices and decisions and being aware of one's own capabilities. People who have had a stroke may demonstrate impaired judgment and make choices that aren't safe, such as attempting to get into a tub on their own, or trying to cook a meal when they shouldn't be using the stove alone.

HOW YOU CAN HELP



- Discuss your concerns about safety with the team.
- With your team, develop strategies to help the person be as independent and safe as possible.
- Try to make sure the person does not end up in challenging situations where they may be unable to decide what actions are safe.
- Make the environment as safe as possible. If the person uses a wheelchair, make sure brakes are always locked before rising and sitting down. Remove obstacles and loose mats that could be a tripping hazard. If they use a walker, keep it within reach with the wheels locked until they are ready to move.

IMPULSIVITY

Impulsivity is acting quickly, without thinking things through. Problems with insight and judgment after stroke often lead to impulsivity. The person may act on sudden urges that could result in injury. For example, someone using a wheelchair may attempt to get up quickly without locking the brakes.

HOW YOU CAN HELP



- Remind the person to slow down.
- Give clear and specific instructions.
- Divide tasks into small steps. This lets them focus on one part of the task at a time.
- Make sure they perform one step before moving on to the next. For example, say to the person, “Swallow that mouthful of food first. Then take another bite.”
- Make the environment as safe as possible. Keep walking aids and other assistive devices close by.

SEQUENCING

Sequencing means being able to perform steps and actions in the right order. Some people who have had a stroke are unable to start a task because they don't know where to begin. Or they may do things in the wrong order. For example, they may forget that underwear goes on before pants, and socks go on before shoes.

HOW YOU CAN HELP



- Give clear step-by-step instructions to help the person understand the task.
- Plan the task together. Encourage the person to think it through, explaining the next step if needed.
- Give the person lots of time to practice the task, even if it takes a long time or seems difficult for them.
- Remind them to do the task the same way each time. For instance, the sequence to put on a sweater might be to:
 1. Put the affected arm into its sleeve first.
 2. Put the unaffected arm into its sleeve.
 3. Pull the sweater over their head.
 4. Pull the sweater down in back.

PROBLEM SOLVING

Problem solving is being able to recognize a problem and find a good solution. Difficulties with insight, sequencing, and memory can affect problem-solving abilities. For example, someone may try to get toothpaste out of the tube without realizing the cap is still on.

HOW YOU CAN HELP



- Break tasks into small steps.
- Focus on one step at a time to help the person think about one part of the problem before moving to the next.
- Give verbal cues when needed, but as much as possible let the person find a solution.
- Work together to identify different ways of solving the problem. Talk about ways to approach the problem.

Case example

Mrs. Johansen appeared to have poor compliance with taking her medication. Her healthcare provider labeled her blister packs with the correct dates. This helped provide structure and made it easier for her to take her medication properly.

BEST PRACTICE RECOMMENDATIONS

Interventions for cognitive impairment should be tailored according to the following considerations:

- Goals should be patient-centred and sensitive to the values and expectations of patient, family and caregivers.
- Goals and interventions should take into account the strengths and weaknesses of the cognitive profile and communication abilities.
- Patients with communication or cognitive issues may require additional support (e.g., family involvement) to optimize patient participation in goal-setting and/or engagement in rehabilitation.
- Interventions should be individualized, based on best available evidence, and have the long-term aim to facilitate resumption of desired activities and participation (e.g., self-care, home and financial management, leisure, driving, return to work).
- Severity of impairments: If the level of impairment has reached the moderate dementia stage, it is reasonable for interventions to be more focused on providing education and support for the caregiver in addition to, or in lieu of, cognitive rehabilitation with the patient.

KEY MESSAGES OF COGNITION

- ❑ When people have trouble with tasks related to cognition, they are said to have **cognitive problems or cognitive impairment**. Unlike a physical impairment, problems with cognition are often subtle and more difficult to see.
- ❑ **Cognitive difficulties** may include such things as inattention, awareness of place and time, problems with short or long term memory, and problem solving.
- ❑ As a healthcare provider with the person on a regular basis, you may be able to **notice these behaviours** or challenges better than other team members.
- ❑ **Communicate changes** in cognitive abilities to other team members and follow the care plan and strategies to support the person with cognitive impairment.



CHAPTER 6

Activities And Participation

Activities are described as the execution of a task or action by an individual. Participation refers to involvement in life situations (WHO, ICF 2001).

IN THIS CHAPTER

- 6.1 Communication
- 6.2 Positioning
- 6.3 Transfers
- 6.4 Mobility
- 6.5 Activities of Daily Living
- 6.6 Leisure and Social Activities
- 6.7 Caregivers, Family, and Friends



6.1 Communication



IN THIS SECTION

- How stroke affects communication
- Dysarthria
- Aphasia
- Cognitive communication impairments
- General post-stroke problems that can affect communication
- Strategies for effective communication

YOUR ROLE AS A HEALTHCARE PROVIDER

Stroke often impairs a person's ability to communicate and connect with others. It can be difficult to determine what the person who has had a stroke understands, or what they are trying to say. When you understand the communication challenges they face, and learn strategies and techniques to help them communicate, you can help meet their needs and keep them connected to the world around them.

HOW STROKE AFFECTS COMMUNICATION

Communication is the exchange of ideas through speech, language, gestures, or writing. It's a basic human need. It helps us stay connected to each other, and builds our sense of self-worth and well-being. Clear communication helps us get our needs met.

Stroke can cause communication impairments. The location and severity of the stroke determines the type and the extent of the impairment.

Some common communication impairments that result from stroke are:

- **Dysarthria:** Slurred speech, problems making the sounds of speech
- **Aphasia:** Difficulty understanding language and/or using language
- **Cognitive communication impairments:** Problems forming and organizing thoughts; problems communicating clearly

In addition, muscle weakness may alter facial expressions or prevent the person from turning to face someone who is speaking, and make their voice weak and hard to hear.

Communication impairments often limit people's sense of connection with others and can lead to social isolation and depression.

Communicating with a person who has had a stroke requires:

- A belief that every person can be reached
- Creativity in expressing your feelings and message
- Understanding the effect stroke has on communication
- Patience to slow down, listen, watch, and wait for a response
- Skill and practice to get your message across, and understand what they are trying to say.

BEST PRACTICE RECOMMENDATION

All healthcare providers working with persons with stroke across the continuum of care should be trained about aphasia, including the impact of aphasia; methods to support communication such as Supported Conversation for Adults with Aphasia (SCA™); and other communication disorders that may result from stroke including: dysarthria, apraxia of speech and cognitive communication deficits.

NON-VERBAL COMMUNICATION

Can you think of a time when you understood someone's feelings without that person saying a word? How did they convey the message?

Whether we are aware of it or not, just about everything we do (or do not do) sends a message to others. We all learn to interpret spoken (verbal) and unspoken (non-verbal) messages. While we may think of communication as talking, it's important to remember that speech is only one form of communication. In fact, it is estimated that up to 70 percent of communication is non-verbal.

We communicate without words in many ways. Our posture, our movements, our facial expressions, and our tone of voice are all part of non-verbal communication. A raised eyebrow, a shrug, crossed arms, or a frown can contradict the meaning of spoken words. Most importantly, we usually tend to believe the non-verbal message over the verbal one.

For instance, if someone says they are not angry, but they are frowning and using a clipped, harsh tone of voice, which would you believe – their words or their expression and tone?

COMMUNICATION PARTNERSHIPS

Every communication involves at least two partners, both of whom send and receive messages. For effective communication to take place, each has to understand the messages the other sends.

People who communicate with each other frequently develop communication partnerships, where they learn to read each other's facial expressions and body language. This makes their communication easier and more successful.



Someone who has had a stroke may not be able to be an equal partner in communication. You may need to take more responsibility for the conversation than you normally would.

ATTITUDES OF OTHERS

People may assume that someone who has had a stroke is not intelligent because they cannot communicate very well. They may treat the person rudely or ignore them, on the assumption that they cannot think or speak for themselves. For instance, staff in stores or restaurants may ignore people using wheelchairs and speak to their companions instead.

As you might expect, these experiences frustrate and offend the person who has had a stroke. They may lose confidence and stop socializing or going out. In turn, this can cause those around them to think they cannot or do not want to communicate.

The person who has had a stroke deserves respect. Their values, interests, concerns, opinions, strengths, and weaknesses are important and reflect a lifetime of experience.

HOW YOU CAN HELP



You may be one of the person who has had a stroke's most frequent communication partners. Develop a good communication partnership by:

- Creating opportunities to communicate
- Being willing to put in the time and effort required to overcome communication problems
- Sending clear and simple messages.
- Showing that you want to understand what the person is trying to say.
- Respecting the message the person sends.
- Trusting that the person wants to understand what you are saying.
- Showing you understand the difficulties they may be having.

When communication breaks down or is not easy:

- Stay hopeful that the message will eventually be understood.
- Be patient and persistent.
- Be creative. There is more than one way to get your message across. Try drawing, writing things down, gesturing/acting it out or using different words.
- Tell the other person when you do not understand something.
- Admit if you are frustrated.
- Be honest about the problem. Ignoring it sends the message that you do not respect the other person.
- Don't pretend to understand things you don't.
- Don't change the topic to avoid the problem.

DYSARTHRIA

Those who have **dysarthria** have trouble speaking clearly. It is a motor problem caused by weakness and/or lack of coordination in the muscles of the mouth, throat, and chest.

Dysarthria may cause the person's voice to be soft, or their words to be slurred as if they were drunk. Other people do not always realize that only the person's speech is affected, and that they can still:

- Understand spoken language
- Communicate through computers or other devices
- Read and write
- Think, plan, make decisions, and reason

People who are unfamiliar with dysarthria may misjudge the person's mental abilities, make incorrect guesses about their desires, and exclude them from decisions, on the assumption that they are incapable of understanding, thinking, or reasoning.

HOW YOU CAN HELP



- Communicate in a quiet place.
- Ask the person to speak slowly and loudly. Explain that this is the best way to make speech easier to understand.
- Speak slowly to encourage them to speak slowly, but do so in a normal voice. Speaking unusually loudly or exaggerating your intonation makes the person think you are questioning their intelligence.
- Repeat what you have understood. Ask the person to explain anything you have not understood.
- Make notes, especially if the dysarthria is severe. Written notes make it easier for both of you to keep track of the conversation.
- Provide paper and a pen, a white board and marker, or a communication board with pictures, words, or phrases. It may be easier for the person to write or point than to talk. Keep these communication aids nearby at all times.
- Consider using a computer, tablet, or a teletypewriter (TTY or TDY; a device used by people with hearing impairments, so they can type rather than talk on the telephone).
- Use an alphabet board to communicate more complex ideas. Write the words as the person spells them.
- Make sure the person is rested when you communicate about important issues. Fatigue makes communication harder or impossible.

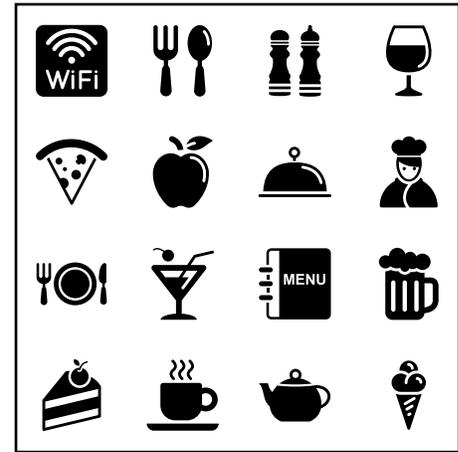
APHASIA

Aphasia is the loss of language, including sounds, meanings, and rules for combining words into sentences. For most of us, the left side of the brain deals with language. A stroke in the left side of the brain can injure areas that control understanding and the production of words and sentences, causing aphasia. Aphasia may affect the ability to talk, read, write, or understand language.

Fluent aphasia is a type of aphasia where someone may talk constantly without making much sense, and their speech may contain made-up words or phrases with no real content. They often don't realize their speech is incomprehensible. Tell them you are having trouble understanding them. Focus on non-verbal strategies, like pictures and printed words.

Many people link communication skills with mental ability. They may misjudge the mental abilities of someone who has aphasia, when the person can in fact think, plan, decide, and reason. They can also produce some clear words, and understand facial expressions, gestures, and non-verbal communication.

In other words, people with aphasia are able adults who know more than they can say.



COMMUNICATION BOARD

HOW YOU CAN HELP



- **Set the stage**
 - ◆ Talk face-to-face in a quiet room.
 - ◆ Give small amounts of information at a time.
 - ◆ Tell the person that you know that they know what they want to say.
 - ◆ Introduce topics clearly. For example, say “I want to talk to you about your family.”
- **Be patient**
 - ◆ Speak slowly. Give the person time to respond.
 - ◆ When someone is struggling for a word, don't jump in too quickly. Supply the word if the person seems to be getting frustrated.
 - ◆ Allow them to express themselves to the best of their ability.
- **Provide specific choices, avoiding open-ended questions**
 - ◆ Ask yes/no questions such as, “Are you hungry? Are you feeling ill?” instead of a more general question like “What's wrong?”
 - ◆ Ask “Would you like an apple or an orange?” instead of “What would you like to eat?”
- **Break longer questions into short, simple questions**
 - ◆ Rather than “Do you want breakfast and would you like eggs or toast with jam?” ask each question separately and wait for a yes or no before asking the next.
 - ◆ If the answers seem inconsistent, tell them what you understood. Then tell the person you are going to repeat some questions so you can be sure you have understood their wishes.
- **Use pictures and objects**
 - ◆ Use pictures, objects, gestures and drawings to show what you mean.
 - ◆ Use maps, calendars, schedules, and clocks when talking about time and places.
 - ◆ Print key words in large, clear letters as you speak.

- ◆ Urge the person to show you what they mean by gestures, drawing or printing. At first, they may refuse, especially if the stroke affected their writing hand. Tell them you know it is hard to use the other hand, but it may be worth the effort if it helps them communicate.
- ◆ Consider using technology such as electronic tablets for communication.
- ◆ Ask family members for photos or other materials. These can be great starting points for conversations, or to develop a life history book with the person. They can use the book as a memory aid and to get to know new people.
- **Always include the person who has had a stroke**
 - ◆ Never underestimate their ability to understand the conversation around them, especially when it is about them.

Expect communication abilities to vary. Some strategies may work one day, but not the next. Keep trying different approaches.

INCONSISTENT OR INAPPROPRIATE SPEECH

Sometimes, people who have had a stroke may use words they didn't intend to. These words may be related to the word that they wanted to say—like brother instead of sister, or over instead of under, or yes instead of no (and vice versa).

HOW YOU CAN HELP



- Ask your question in a different way.
- If you think you know what they meant to say, print the message and ask if it is right.
- If you are unsure about the message, do not pretend you have understood. Explain that you have not gotten it yet and ask them to repeat themselves.
- Ask if it is all right if you ask questions to help you understand.
- For those who tend to say yes when they mean no, or vice-versa, work with them to develop a non-verbal code—maybe “thumbs up” for yes and “thumbs down” for no. Or have them point to printed yes/no cards. Also, listen closely to their tone of voice. If they are saying yes but sound angry or frustrated, ask if they meant no.

SWEARING AND ANGER

At times, people who have had a stroke may swear and sound very angry when they are frustrated. They are probably not trying to be rude. Swear words are connected to emotion centres in the brain. These connections can still be strong even when other language areas are damaged. This makes it hard to suppress this kind of speech — even though the person might not have used those words in the past.

The person may use swear words and sound angry when feeling any strong emotion, not just frustration. Acknowledge the feeling, and ignore the language.

COGNITIVE COMMUNICATION IMPAIRMENTS

A right hemisphere stroke can cause difficulties in organizing thoughts; concentrating; remembering; interpreting non-verbal communication such as facial expressions; and understanding humour, sarcasm, hints, and jokes. These are called **cognitive communication impairments**.

A very severe stroke, or multiple strokes, can have the same effect.

In these cases, others may overestimate the person's communication abilities, because the person can speak clearly in full sentences, understand direct and concrete communication, tell and laugh at familiar jokes, write some words and sentences, and sometimes read. However, they present several challenges to communication partners, in that they:

- Can speak clearly, but the conversation can jump around or wander off-topic
- Do not always provide information that is relevant to the topic
- Provide too much or too little information
- Make little eye contact, especially with people on their left
- May have problems concentrating
- May have trouble understanding or remembering what they read or heard
- May not see letters and words on their left

HOW YOU CAN HELP



- **Maintain the focus of the conversation**
 - ◆ Request eye contact.
 - ◆ Ask specific questions to get more information.
 - ◆ Remind them of the topic being discussed.
 - ◆ Tell them when you are leaving.
- **Stay on the right**
 - ◆ Always approach from the right.
 - ◆ Get their attention before moving to the left. Stay on the right if necessary.
- **Be direct**
 - ◆ Say exactly what you mean, even if it feels slightly rude at first.
 - ◆ Avoid humour, sarcasm, hints, and other indirect forms of communication.
- **Help the person remember the conversation**
 - ◆ Provide a simple, printed summary of what you discussed.
 - ◆ Use print or pictures if the person can see, understand and remember the material.
 - ◆ Keep printed information short and direct, and use large, clear print.
- **When dealing with what you see as rudeness**
 - ◆ Remember that the person is not being rude on purpose.
 - ◆ Tell them how this behaviour makes you feel and what you would prefer.
 - ◆ Give them suggestions about how they could communicate differently.

GENERAL POST-STROKE PROBLEMS THAT CAN AFFECT COMMUNICATION

Challenge	Potential solutions
Physical impairments stop the person from getting out or talking to others.	<ul style="list-style-type: none"> • Ask where they want to go. • Help them use mobility aids. • Reposition their chair. • Make sure they can reach the telephone or call bell.
The person cannot stand, so it is hard to maintain eye contact.	<ul style="list-style-type: none"> • Squat or sit so you can be at eye level. Do not lean over them. • Find a comfortable distance. Being too far back makes it hard to see or hear you. • Make eye contact before you begin a conversation.
The person needs help to move their wheelchair.	<ul style="list-style-type: none"> • Ask where they want to go and how the chair should be moved. • Tell them what you plan to do before you move the wheelchair.
The person cannot change their facial expression to express emotions.	<ul style="list-style-type: none"> • Ask them to tell you how they feel
The person has impaired hearing.	<ul style="list-style-type: none"> • Talk face-to-face in a quiet room with good lighting on your face. • If they use hearing aids, check that they are working. • If you use amplification devices, keep the microphone close to you so they can hear you above background noise. • Do not talk in a very loud voice. This can distort your speech and overload hearing aids, which can be painful. Also, others may overhear private information. • Ask if they can hear you. Position yourself where you will be heard easily. You may need to try different spots. • Ask questions to determine whether the person is receiving your messages accurately.
The person cannot respond quickly.	<ul style="list-style-type: none"> • Allow extra time — maybe five seconds or so — for the person to start talking, or respond to something you have said. • Create chances for communication. For example, comment on pictures or personal objects. This indicates interest and a willingness to listen. • If you cannot wait for an answer, ask if they mind if you get the information from family members or friends who are there.
The person has impaired vision.	<ul style="list-style-type: none"> • Ask if they can see your face. • Urge them to wear glasses if they need them. • Make sure they are wearing the right type of glasses (distance, reading) for the task. • Make sure the lighting is not too dark or too bright. • If there is visual field loss, move yourself and any materials so they are easily seen in the remaining visual field. • If the person has lost the left half of their vision, place pictures or written materials on their right side, and vice versa. • Ask the occupational therapist for ideas about handling visual field loss, visual spatial inattention and/or body neglect.

For additional tools refer to www.strokebestpractices.ca, Rehabilitation to Improve Communication.

STRATEGIES FOR EFFECTIVE COMMUNICATION

Regardless of the type of communication impairment the person may have, using the following strategies can make the process easier for both of you.

Always remember, when you are developing a communication partnership with a person who has had a stroke, knowing the person as an individual is just as important as knowing the right communication strategies.

Assess: Watch carefully to assess how much the person understands. Under-estimating someone's abilities can cause frustration and anger, while over-estimating can lead you to believe the person is being deliberately uncooperative.

Set the stage: Reduce distractions to help both of you focus on the message. For example, turn off the television or radio.

Get the person's attention: Approach the person who has had a stroke slowly and from the front. If needed, gently touch their hand or arm to get their attention. Introduce yourself. Wear a large, easy-to-read name tag. Know how they like to be addressed (for example, by Mr. or Mrs., their first name, or a nickname).

Make eye contact: Face the person if you can. Keeping eye contact helps them know who is speaking, and it may help them focus on your message.

Deal with private matters privately: Ask for the person's permission before raising a private matter with their family or friends. They may share information with you that they are not ready to share with family. Always include the person in the conversation.

Tell the person that if the information is related to their health and wellbeing, or has an impact on the stroke care team, you will be sharing it with other members of the team as required, so you can all continue to provide the best possible care.

Give one message at a time: Keep the conversation simple. Too many thoughts, ideas and questions at one time can be confusing. Keeping choices limited can stop the person from getting overwhelmed.

Pay attention: The person's facial expressions and body language can help you know if they understood you.

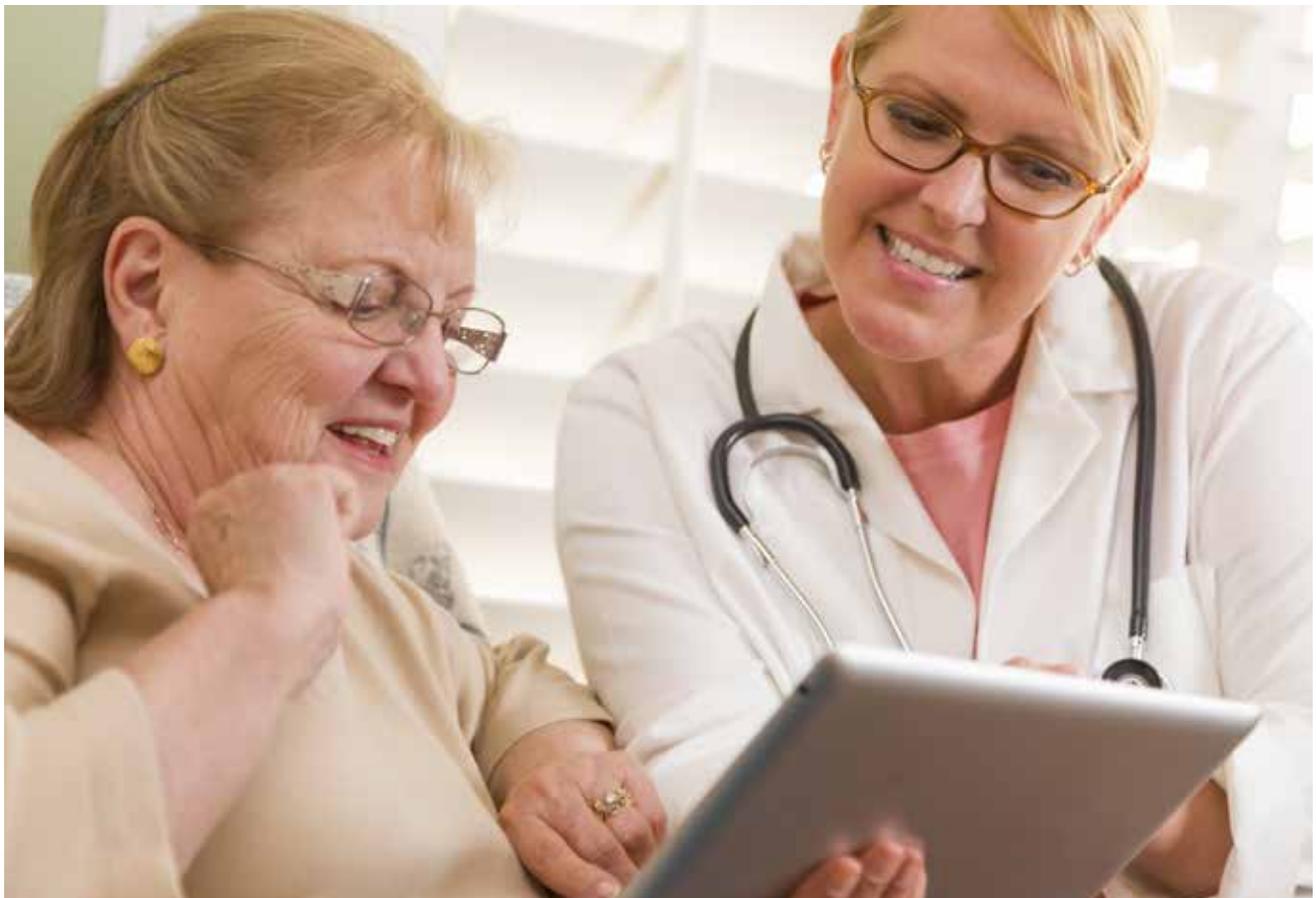
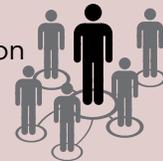
Repeat important information: If you are not sure your message was understood; repeat it using the same words.

Take time: Give the person time to respond. Do not interrupt them, as this can discourage further communication. Stay patient and calm. Do not expect communication to be fast, even if the topic is simple.

Ask for help: A speech language pathologist can assist with determining a person's communication and speech difficulties and make recommendations for the best methods for you to communicate with that individual.

KEY MESSAGES OF COMMUNICATION

- ❑ **Communication is the exchange of ideas** through speech, language, gestures, or writing. It's a basic human need.
- ❑ **Stroke can cause communication impairments.** The location and severity of the stroke determines the type and the extent of the impairment.
- ❑ Be willing to put in the **time and effort** required to overcome communication problems.
- ❑ **Urge the person** to show you what they mean by gestures, drawing or printing.
- ❑ **Use the strategies** developed by members of the stroke care team to develop effective communication patterns.
- ❑ When you are developing a communication partnership with a person who has had a stroke, **knowing the person as an individual** is just as important as knowing the right communication strategies.



6.2 Positioning



IN THIS SECTION

- Managing the affected shoulder
- Managing the affected hand
- Managing the affected foot
- Positioning

YOUR ROLE AS A HEALTHCARE PROVIDER

Stroke frequently affects a person's ability to move and position their body, especially their affected arm and leg. Proper positioning can help minimize complications such as contracture and pain, and also assists people to be more independent, safe, and comfortable.

MANAGING THE AFFECTED SHOULDER

The shoulder joint is a ball-and-socket joint that can move in many directions. Although the shoulder joint typically allows much movement, it is not as stable as other joints and is therefore at risk of complications such as subluxation or pain due to **impingement** (pinching of soft tissue in the joint). Other joints have strong ligaments to hold the joint in position. However, the shoulder joint is not well supported by ligaments but rather, mainly muscles. Muscles affected by stroke may no longer hold the shoulder joint in alignment (in the correct position). When poor alignment occurs, movement is affected and pain can occur.

A shoulder that is affected by stroke can be injured more easily than the unaffected shoulder. Make sure you know the correct techniques and strategies to handle a shoulder affected by stroke. A physiotherapist or occupational therapist can teach you safe exercises and ways to position and move the affected shoulder and arm.

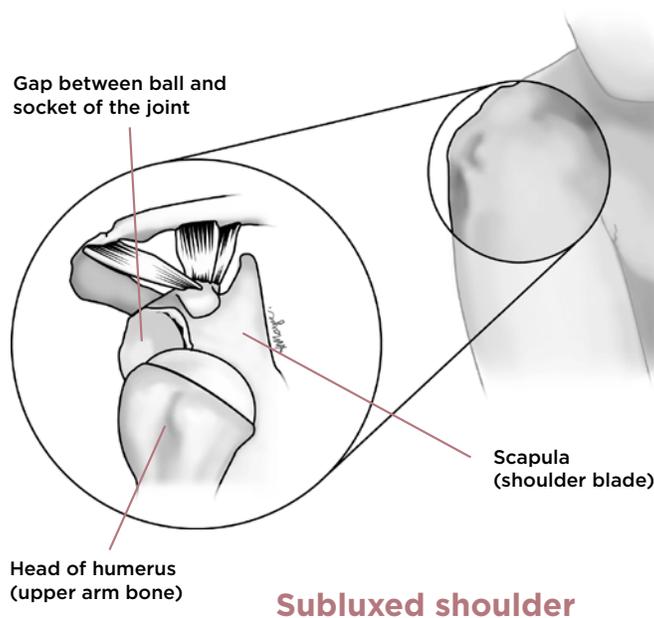
Never perform exercises on an affected shoulder unless they are prescribed by the occupational therapist or physiotherapist. Improper movement may lead to further damage, pain, and loss of function.

THE LOW-TONE SHOULDER

A flaccid or low-tone arm appears heavy and limp. The effects of a stroke can reduce the strength and tone of the muscles supporting the shoulder joint. As a result, gravity can drag the head (top) of the **humerus** (the long bone in the arm that extends from the shoulder to the elbow) down, overstressing the weakened muscles.

This may cause the shoulder to move out of alignment (position). It may even cause a **subluxation** (partial dislocation) of the shoulder. A subluxed shoulder has a noticeable gap between the ball and socket of the joint.

Subluxation can stretch the muscles and ligaments of the shoulder even further. Excessive muscle stretching may cause a constant dull pain, often described as being similar to a toothache. Sometimes severe pain can result from mishandling the affected arm.



ARM SUPPORTS

A **slings** is sometimes prescribed to support the flaccid (low-tone) arm when standing, walking, or transferring. Slings are not to be worn all the time as they can contribute to decreased arm movement, increased spasticity, and pain in the affected arm. Slings can also reduce arm swing during walking and affect balance which can increase the risk of falls. Several different types of slings are available. Ensure you are familiar with the correct way to put on and take off the sling and ensure it is worn according to the care plan.

An **arm trough** is a modified armrest on a wheelchair that can support a flaccid (low-tone) arm. These supports may swivel to let the arm rest in a more natural position. It is important to monitor use of the arm trough. Strapping the arm to the arm trough is not typically recommended due to the possibility of impingement of soft tissues at the shoulder; however, the arm may also be at risk of trauma due to “falling off” the arm trough. Careful observation and communication with the appropriate therapist is important.

A **lap tray** supports the affected arm when the person is in a wheelchair. Also, because it is easy to see the affected arm, the person who has had a stroke can handle and move the affected hand with the unaffected hand. The therapist will ensure that the wheelchair armrests and lap tray are at the correct height.

An **arm wedge** is sometimes used to support an affected arm and reduce swelling. Placing an arm wedge on a lap tray positions the wrist higher than the elbow in a neutral position. If used, ensure the arm wedge is positioned according to the therapist’s instructions.

A **compression glove** can reduce swelling of the affected hand. Compression gloves need to be professionally measured. Compression gloves need to be monitored regularly and worn only according to the care plan. Skin should be monitored frequently.

HOW YOU CAN HELP



- Know the techniques and strategies for movement and positioning that are specified in the person's care plan. They can help prevent injury and further loss of function. If you are unsure, ask the stroke care team to show you the correct way to move or position an affected arm.
- Follow the positioning diagrams in the care plan.
- Always handle the shoulder carefully to prevent painful stretching of muscles and ligaments.
- Support the affected arm and treat it gently.
 - ◆ Use a pillow, lap tray, or wheelchair arm trough when the person is sitting, if this is prescribed in the care plan.
 - ◆ Support the affected arm while moving the person.
 - ◆ Do not pull on the arm when you are moving the person in bed, or helping them transfer, walk or move. Pulling can cause pain and shoulder damage.
 - ◆ Ensure you follow the care plan carefully if slings or other arm support (positioning) devices are recommended to ensure you are using them correctly.

BEST PRACTICE RECOMMENDATIONS

Joint protection strategies should be used during the early or flaccid stage of recovery to prevent or minimize shoulder pain. These include positioning the arm during rest; protecting and supporting the arm during functional mobility; and protecting and supporting the arm during wheelchair use by using a hemi-tray or arm trough. The use of slings remains controversial beyond the flaccid state, as disadvantages outweigh advantages.

THE HIGH-TONE SHOULDER

A spastic or high-tone arm appears stiff or tense. Spasticity can pull the upper arm toward the chest wall. This may make shoulder movement painful and difficult.



HOW YOU CAN HELP



- Support and align the arm properly to reduce muscle imbalance and pain.
- Use pillows or towels to improve arm positioning in bed.
- Support the arm on a pillow or a lap tray or wheelchair arm trough when the person is sitting.
- Report joint or tissue pain to the occupational therapist or physiotherapist for follow up.
- Never perform exercises unless they are approved by the occupational therapist or physiotherapist on your team and they are part of the care plan.

BEST PRACTICE RECOMMENDATION

Spasticity and contractures can be prevented or treated by antispastic pattern positioning, range of motion exercises, and/or stretching.

MANAGING THE AFFECTED HAND

The lack of active movement and potential lack of sensation after stroke can result in a low-tone or flaccid hand prone to swelling and positioning problems, which can cause pain, joint tightness, and skin problems.

Gentle, slow movement is important with a spastic or high-tone (contracted) hand. The hand should never be forced open. Using quick movements to open a tight hand may encourage increased muscle tightness.

A **wrist and hand splint** may be prescribed by an occupational therapist. It is used to position the wrist and hand in a neutral position and prevent excessive wrist and finger flexion.

To relax and open a spastic (contracted) hand (follow instructions from a therapist and never force open a hand):

- Position the person with the shoulder girdle forward.
- Support the hand at the wrist and forearm.
- Gently bend the wrist forward/down before opening the hand.
- Ease the hand open. Sometimes gently straightening the affected thumb helps relax the fingers.
- Avoid pulling on the shoulder.

HOW YOU CAN HELP



- Always be aware of the affected hand. Follow the therapist's instructions to mobilize the hand and treat pain and swelling. Report changes in pain, swelling, or function to the team.
- To reduce swelling, support the arm on pillows, lap tray or arm trough when the person is sitting. Place the arm with the hand in front and fingers opened. Only use a sling when it has been prescribed.
- Use a foam wedge, pillows, or other arm supports to raise the hand and support the wrist, if they have been prescribed.
- Encourage the person to use their unaffected hand to gently open the fingers of the affected hand and place the hand on the supporting surface.
- Use hand splints only as prescribed by the therapist.



MANAGING THE AFFECTED FOOT

Someone who has had a stroke may not have as much movement and sensation in the foot on the affected side. Decreased movement and impaired sensation can cause pain, stiffness, swelling, and possible skin damage.

Reduce swelling by having the person lie down with their legs elevated to chest level with a pillow, rather than raising the footrests on the wheelchair. Circulation in the legs and feet can be impaired by exaggerated hip flexion in sitting. Elevating the legs when in a wheelchair is also not good for the skin due to uneven weight distribution. Use bed positioning instead.



HOW YOU CAN HELP



- Check for problems in the affected limb. Report any concerns to your team.
- Help the person follow the doctor's orders to reduce swelling, such as wearing prescribed pressure stockings.
- When possible, and if prescribed, make standing part of the person's daily routine. For example, have them stand at the kitchen counter or bathroom sink with their weight spread evenly over both legs, with leg joints aligned and heels on the ground, to prevent foot stiffness and deformity.
- If directed to do so, perform prescribed exercises with the foot/ankle. Keep leg joints aligned and heels on the ground.



POSITIONING

If the person who has had a stroke cannot turn in bed alone, they will need to be moved often, to reduce the risk of pressure sores. Remember to always follow the care plan and the policies of your place of work.

The goals of positioning are to:

- Preserve normal body and joint alignment (correct positioning)
- Encourage normal muscle tone patterns and discourage abnormal tone patterns associated with **hemiplegia** (paralysis on one side)
- Increase awareness of the affected side
- Encourage optimal functional recovery
- Manage pain
- Reduce **edema** (swelling) if present

LYING ON THE BACK

To position the person who has had a stroke comfortably on their back, follow these steps:

1. Tell the person what you are going to do.
2. Make sure the person's head is in a neutral position, not bent forward or backward.
3. Place a small pillow behind the affected shoulder blade.
4. Place the affected hand on a pillow above heart level.
5. Place a small pillow beneath the affected hip and/or knees.
6. Ask the person if they are comfortable.
7. Support the person's head, affected arm, and affected hip with pillows.



LYING ON THE AFFECTED SIDE

Many people are more comfortable lying on their side.

1. Tell the person what you are going to do, so they are ready and you don't startle them.
2. Turn the person to the affected side. Use a turning sheet/positioning slider if available or have another person help you.
3. Place a pillow under the person's head. Make sure their neck is slightly bent and in a comfortable position.
4. Position the affected leg straight and slightly behind the trunk.
5. Position the affected shoulder slightly forward so the shoulder blade lays flat and the arm appears slightly forward from the trunk. Do not pull on the affected arm, hand, or shoulder.
6. Place a pillow under the upper arm in front of their stomach, so they don't fall forward.
7. Place the unaffected leg forward on one or two pillows with the hip and knee bent.
8. Place a pillow between the legs to reduce friction and increase comfort.
9. Place a pillow behind their back and ensure they are not lying directly on their hip bone.
10. Ask the person if they are comfortable.



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POSITIONING ON THE UNAFFECTED SIDE

Positioning on the unaffected side is the same as positioning on the affected side. People with a lot of impairment on the affected side may feel trapped lying on their side and want to roll onto their back. Ask them to:

1. Bend their knees before rolling to make the roll easier.
2. Be aware of their affected arm. A person who has had a stroke often “leaves the affected side behind” when rolling onto the unaffected side. Position the affected shoulder forward with the arm supported on a pillow.
3. Place a pillow behind their back and ensure they are not lying directly on their hip bone.
4. Look in the direction they want to roll. This is easier when they lift and turn their head in the direction they want to roll.
5. Ask the person if they are comfortable.



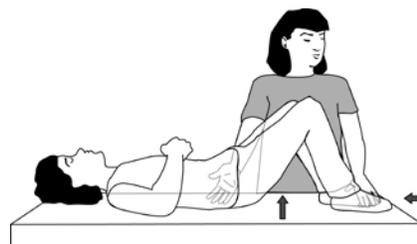
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MOVING ON THE BED

Bilateral bridging is a way to help a person who has had a stroke raise their hips when they are on a bed. This helps with personal care or moving towards the edge of the bed.

Ask the person to:

1. Lie on their back and bend at the hips and knees. The person may need help to bend their affected hip and knee.
2. Place the soles of the feet flat on the bed. You should secure their feet so they don't slip back down.
3. Ask the person to raise their hips, making sure their weight is taken through their feet.
4. Remind them not to push too hard as they change position, so they don't move toward the head of the bed.



SITTING UP

Follow these steps to help someone with impaired mobility sit up from a lying down position.

Ask the person to:

1. Bend their knees.
2. Lift and turn their head and look in the direction of the roll.
3. Roll completely over onto one side. Remember to carefully move the affected arm.
4. Draw both knees toward their chest.
5. Slide both feet over the edge of the bed.
6. Push up with one or both arms, and look up while pushing up.
7. Sit up straight.

MOVING FROM SITTING TO STANDING

Ask the person to:

1. Slide their hips forward to the edge of the bed or chair.
2. Sit up straight.
3. Put their feet shoulder width apart, with their heels slightly behind their knees.
4. Make sure both heels are touching the floor.
5. Bend forward at the hips and look up, keeping their back straight.
6. Bring their shoulders forward in line with their knees. Their trunk and neck should remain extended as the hips bend.
7. Push up with both legs, keeping their weight spread equally over both legs.
8. Stand up straight.

PROPER SITTING POSITION

When a person who has had a stroke is sitting, whether in a chair or a wheelchair, their hips should be back and centered. Hips often slide forward in a chair, creating a slumped posture.

Use the 90 degree rule, where the person sits with their hips, knees, and ankles flexed at 90 degrees. This is more comfortable, promotes sensory and motor recovery, and ensures an even weight distribution under the thighs and buttocks.

HOW YOU CAN HELP



- Regularly remind the person to keep their hips back in the chair. Help them if you need to.
- If you are having trouble seating them in the wheelchair in the right position, let the team know. The wheelchair, cushion, or backrest (if used) may need to be re-evaluated.
- Support the affected arm on a lap tray, if recommended. If a lap tray isn't available, try using a pillow.
- Adjust the wheelchair footrests to make sure the affected foot is supported, while ensuring the hip, knee, and ankle joints are all at about 90 degrees for even weight distribution.

KEY MESSAGES OF POSITIONING

- Stroke frequently affects a **person's ability to move** and position their body, especially their affected arm and leg.
- **Proper positioning** can help minimize complications such as contracture and pain and also assists people to be more independent, safe, and comfortable.
- **Know the techniques and strategies** for movement and positioning that are specified in the person's care plan. They can help prevent injury and further loss of function.



6.3 Transfers



IN THIS SECTION

- Wheelchair use
- Safe transfer guidelines
- Assisting with mobility (transfers, repositioning)

YOUR ROLE AS A HEALTHCARE PROVIDER

Stroke frequently affects a person's ability to move parts of their body, and to move easily and safely from one position to another. This can be frustrating and confining and may contribute to feeling socially isolated. There are many techniques to help a person with stroke improve their ability to move on their own and increase safety. By using proper wheelchair positioning and recommended equipment you can help the person be safer, more comfortable and independent. In addition, using correct and safe techniques for transfers and repositioning, recommended mobility methods, and appropriate equipment to help a person who has had a stroke transfer and change position will increase their safety, confidence, and independence.

WHEELCHAIR USE

Most people who have had a stroke have some problems with movement, and some will require a wheelchair for part or all of the day. The occupational therapist or physiotherapist will decide what type of wheelchair is needed, and whether a specialized back support, pressure-redistribution cushion, or additional accessories are necessary.

Most people who have had a stroke will learn to use their wheelchair while in an acute care or a rehabilitation hospital. You may need to remind them how best to use their wheelchair. Some of the problems they may experience include:

- Sliding forward in their seat resulting in a poor sitting posture
- Bumping into obstacles on their right or left side if they have a visual field impairment, visual spatial inattention and/or body neglect*
- Leaving the affected arm hanging over the side of the wheelchair because they are not aware of the arm's existence or cannot see or feel how the arm is positioned
- Leaning excessively to one side
- Complaining of discomfort while seated in the chair
- Forgetting to put on the brakes before getting up or sitting down
- Having difficulty or being unable to correctly position the wheelchair when transferring to another surface such as the bed or toilet (may be too far away or angled incorrectly)
- Sliding forward in the seat to make it easier to propel the chair with the unaffected leg(s)



* Refer to 4.1 and 4.2 for additional information.

Any of these issues should be discussed with the team, and the occupational therapist may need to re-assess wheelchair and/or seating needs. A **hemi-height wheelchair** may be recommended. It has a lower seat than a standard wheelchair and allows someone to reach the floor with their feet without sliding forward.

ASSISTING WITH MOBILITY (INCLUDES TRANSFERS, REPOSITIONING)

Safety guidelines: Safe techniques, guidelines, and work expectations for moving people may vary from one site to another and from an institution to the community. Be aware of your employer's safe work practices and transfer techniques and apply these at all times. Attend education sessions that may be offered and participate in refreshers to make sure you are up to date with any changes that should be implemented. In addition, be sure to use equipment that has been recommended. Be safety conscious at all times.

A **transfer** is when someone moves from place to place (i.e., from bed to chair, wheelchair to toilet, or into a car). **Repositioning** includes activities such as helping someone move in bed, or adjusting a person's position in a wheelchair.

If you are ever unsure of a person's ability to transfer or reposition themselves, consult your team members. An occupational therapist or physiotherapist can help. Unsafe transfers and repositioning can result in injury and pain to you or to the person being moved.

When you are transferring or repositioning someone, remember to:

- **Know the care plan** and use all recommended techniques and equipment as developed by the team for each person.
- **Use good body mechanics** throughout the task by:
 - ◆ Maintaining good standing posture.
 - ◆ Engaging your core muscles (trunk) to protect your back.
 - ◆ Standing with a sturdy base of support so you will be in better control and can stay balanced.
 - ◆ Bend at the knees and avoid excessive forward bending from the back.
 - ◆ Shifting your weight to use your legs for most of the work.
 - ◆ Reducing the distance between you and the person you are transferring. When you are close to them, you won't have to reach and the forces on you will be lighter.
- **Communicate clearly with the person**, so they know what to expect.
 - ◆ You could use "1-2-3 go" or "Ready, Steady, Stand".
 - ◆ Give short, clear and simple instructions.
 - ◆ Communicate in a non-rushed and respectful manner.
- **Prepare the environment** so nothing is in the way and you are ready for the transfer.
 - ◆ Move a bedside table or any clutter.
 - ◆ Position the wheelchair for the specific transfer.
 - ◆ Put on the wheelchair brakes (and/or the bed brakes if applicable).
 - ◆ Swing away or remove the wheelchair footrests.
 - ◆ If applicable, keep a walking aid close by.
 - ◆ If applicable, lower the bed rails.
- **Use recommended equipment.**
 - ◆ Use a transfer belt only when recommended.
 - ◆ Never lift a person using their clothing or their arm.

- **Never pull on or grab the affected arm or under the shoulders.** This can cause shoulder pain, injury, and long-lasting complications.
 - ◆ Use an arm sling for a transfer if recommended.

TRANSFERS

A person's ability to transfer and reposition themselves varies a great deal and depends on the severity of the stroke and amount of recovery made. As a result, different methods and equipment may be recommended for different people. Always follow the care plan.

Equipment used for transfers and repositioning includes:

- Transfer belts
- Sliders
- Bed rails
- Trapeze bars
- Wheelchairs
- Arm slings
- Wall grab bars or floor-to-ceiling poles
- Mechanical floor lifts
- Sit-stand lifts
- Overhead lift systems



Types of transfers include:

- One-person assist transfer
- Two-person assist transfer
- Mechanical lift: one or two person assist

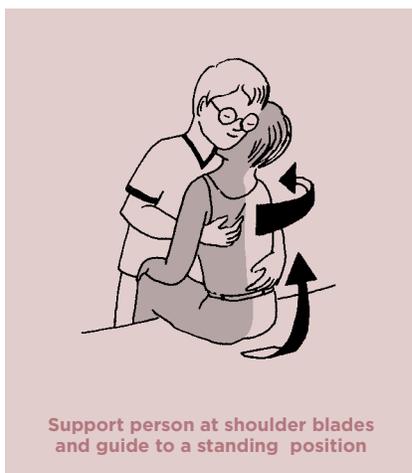
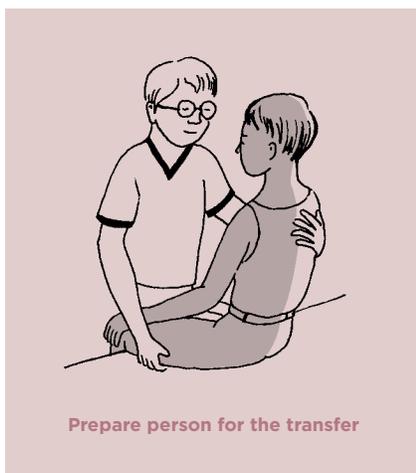
The occupational therapist and/or physiotherapist will assess each person and determine the most suitable technique and equipment requirements. Here are some of the factors that will be taken into consideration during the assessment and in making the decision.

- The person's ability to move
- Balance
- Weakness on one or both sides
- Visual inattention and/or neglect
- Cognitive abilities (Is the person impulsive?)
- Pain
- Fatigue
- Other medical conditions
- Confidence or fear
- Client behaviour
- Client's ability to follow instructions, one or two step commands
- Client's weight and height
- Functional abilities
- Automatic use of affected side
- Equipment available
- Whether the environment is spacious or cluttered
- Whether the floor surface is hard or has thick carpet
- Support available from family, caregivers, or staff

If you are not sure you can do a transfer safely, ask for help.

METHOD FOR ONE-PERSON ASSIST TRANSFER (FOR EXAMPLE, BED TO WHEELCHAIR)

1. The person must be able to bear weight through their arms and legs.
2. The person must be assessed for contraindications to using a transfer belt.
3. Make sure the person is wearing appropriate footwear that offers good support and grip.
4. Position the wheelchair close to the bed (parallel to or at a slight angle to the bed) with the brakes on and footrests swung away or removed. Check the care plan to find out whether the person should be transferring towards their right or left side). There should be enough space to stand between the bed and the chair.
5. Put on the transfer belt if recommended, just above the hip bones and at the small of the waist.
6. Help the person get into the starting position: shift their hips forward so their feet are flat on the floor and their knees are over their toes.
7. If the person is in a chair, stand at their side.
8. If the person is in bed, stand facing them but off to the side slightly. Position yourself in a walking stance facing forward. Bend your knees so that you are at a height closer to that of the person you are assisting.
9. Stand with your feet in a wide stance, with one foot pointing slightly towards the direction that you are assisting the client to move toward.
10. a) If the person is wearing a transfer belt, use your hand closest to the person to reach behind and grasp the far loop of the transfer belt. Use your other arm to support the person's forearm. Do not place your hands inside the loops.
b) If the person is not wearing a transfer belt, support them with one hand on their lower back. Use your other hand to support their weak arm or their upper or lower back.
11. The person should place their hands on the surface they are sitting on (e.g., the bed, armrests) to help push up.
12. Instruct them to lean forward over their knees.
13. On the count of three, help the person stand by shifting your body weight from your back foot to your front foot.
14. Once the person is standing, straighten your hips and knees but remain in a wide base of support.



15. Make sure the person stands briefly to adjust their balance.
16. The person may now use their walker or cane if applicable.
17. The person should take small steps toward the surface they are transferring to.
18. Ensure the person can feel the surface (bed, chair, and commode) at the back of their legs.
19. Stand in walking (wide) stance facing the person and shift your weight from your front leg to your back leg as you assist the person to sit.
20. Replace footrest on the wheelchair and remove the transfer belt.
21. If the person cannot complete the transfer with minimal assist, sit the person back down and get help to perform a two-person transfer, or use a mechanical lift.
22. A re-assessment by an occupational therapist or physiotherapist may be indicated.

TWO-PERSON ASSIST TRANSFER

NOTE: Some organizations do not allow two-person assist transfers. If this is the case where you work, a mechanical lift may be the best option for those who require more help than one-person minimal assist. Find out your employer's policy on this and follow it.

The two-person assist transfer is used, for example, when the person has unpredictable physical ability or behaviour, needs support from both sides to maintain balance, has difficulty following directions, and/or needs additional support to move from sit to stand or reverse.

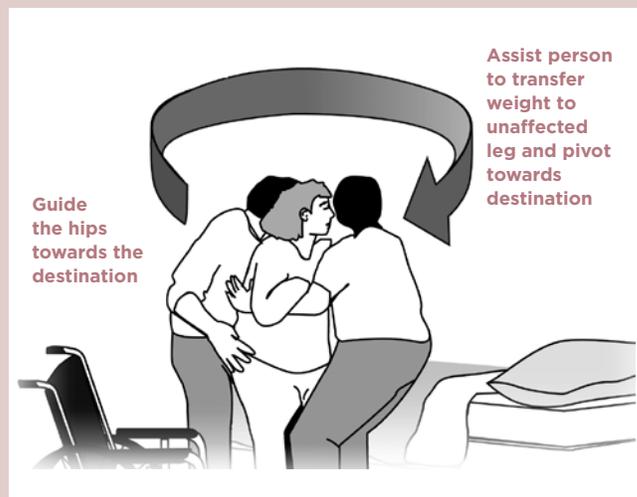
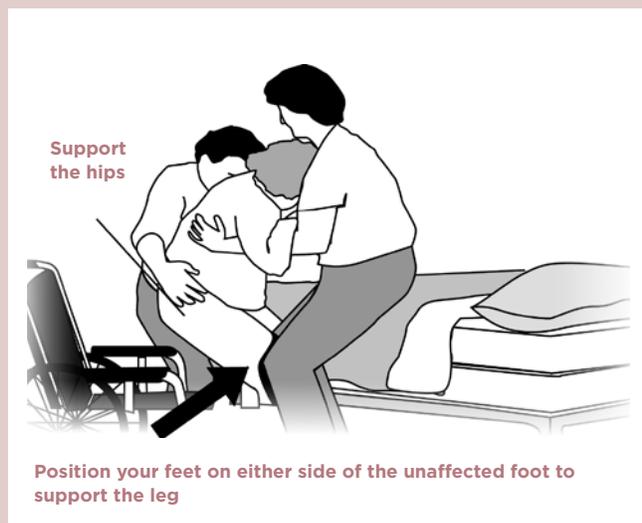
Two people (usually two healthcare workers) are needed for this transfer. Workers should stand on each side of the person being transferred.

METHOD FOR TWO-PERSON ASSIST TRANSFER (FOR EXAMPLE, BED TO WHEELCHAIR)

1. Lower the bed so the person's feet rest on the floor.
2. Lock the bed brakes, if the bed has brakes.
3. Place the wheelchair parallel to the bed or at a slight angle, leaving space for one worker to stand by the person's side.
4. Ensure wheelchair brakes are locked.
5. Swing away or remove the wheelchair footrests and the armrest on the side closest to the bed.
6. Help the person move toward the edge of the bed with their feet flat on the floor, with knees over toes.
7. Put on the transfer belt if recommended, placing the belt just above the hip bones into the small of the waist.
8. You and the other worker stand at each side of the person, facing the person's side.
9. Bend your knees so you are more at the level of the person who is still seated.
10. Contract your abdominal muscles to support and protect your back.
11. Stand in a wide stance with one foot pointing towards the direction you are moving to.
12. Grasp the loops of the transfer belt but never place your hands inside the loops.

13. Ask the person to lean forward and on the count of three, have the person push up from the bed with both arms and through both of their legs as much as possible. Support the affected arm with an arm sling if needed and recommended.
14. As you assist the person to stand, shift your weight from the leg closest to the bed to the leg farthest from the bed.
15. Move into a tall standing position as the person moves up, maintaining your wide base of support.
16. Make sure the person's feet are in a good position.
17. Allow the person to stand briefly and adjust their balance.
18. The person may now use a walker or cane if recommended. Place the mobility aid within their reach.
19. Have the person take small steps to turn around and back up towards the wheelchair.
20. Ensure the person has backed up far enough so the back of their legs touch the seat of the wheelchair.
21. Have the person reach back and place their hand(s) onto the armrests if possible.
22. As you continue standing beside the person with a wide base of support, instruct them to push their buttocks out toward the chair and on the count of three, gently lower to the seat.
23. Once the transfer is complete, replace the wheelchair footrests and armrest.
24. Remove transfer belt and arm sling if used.
25. Make sure person is comfortable and seated safely.

This is one method of transferring. In all cases, follow the guidelines taught in your facility or community program. Always talk to someone from the team if difficulties are encountered for either you or the person who has had a stroke, for your safety and that of the person being transferred.



REPOSITIONING

Follow your employer's guidelines and the care plan for repositioning someone in bed, in a wheelchair, or on another surface. This task can be very specific to each person. Repositioning may require equipment such as friction-reducing sliders or a mechanical lift, and may require one, two, or more staff to complete.

Again, always follow the care plan and talk to someone from the team if difficulties are encountered for either you or the person you are repositioning.

BEST PRACTICE RECOMMENDATION

The patient, family and caregiver should receive skills training to enable them to safely transfer and mobilize the patient. This should include what to do if a fall occurs, and how to get up from a fall.

KEY MESSAGES OF TRANSFERS

- ❑ Stroke frequently affects a **person's ability to move** parts of their body, to move easily and safely from one position to another.
- ❑ **Staying in the same place** for too long puts pressure on their skin and increases the risk of complications.
- ❑ **Using correct and safe techniques** for transfers and repositioning, recommended mobility methods, and appropriate equipment to help a person who has had a stroke transfer and change position will increase their safety, confidence, and independence.
- ❑ **Know the care plan** and use all recommended techniques and equipment as developed by the team for each person.



6.4 Mobility



IN THIS SECTION

- Walking
- Assistive devices and walking (gait) aids
- Stairs
- Movement and exercises

YOUR ROLE AS A HEALTHCARE PROVIDER

A stroke can affect a person's ability to maintain their balance, use their affected leg, and/or walk very far. They may require assistance and walking aids to walk even short distances. The challenges will be even greater if they have cognitive impairments such as poor judgment, are impulsive, or have visual perceptual impairments such as visual neglect. Always refer to the care plan, as it will identify if the person is able to walk, and what assistance and assistive devices are needed for safety

WALKING

Learning to walk safely is usually very important for most people after stroke. To avoid falls and injury, stress the importance of safety — they need to slow down and be aware of their foot placement. If they have neglect or vision problems, remind them to turn their head to that side so they do not bump into things.

In addition to being able to walk safely, it is equally important to think about the quality of walking. As the brain “re-programs”, the amount and type of practice becomes critical to the quality of movement and extent of functional recovery.

A physiotherapist can provide special instructions on how to help someone walk. In all cases, remember the following general principles.

HOW YOU CAN HELP



- Before you start, make sure the person is wearing appropriate footwear with good support and grip. Slippers provide minimal support and can lead to a fall and injury.
- Use any devices and aids that have been recommended and that are part of the care plan such as a transfer belt, assistive device such as a brace, and walking aids.
- As a rule, stand on the person's affected side. However, there are exceptions. The therapist will tell you if you should position yourself somewhere else when you are helping the person walk.
- If the person starts to lose their balance while walking, have them stop and regain it before continuing.
- Remind the person about the importance of posture. Have them stand upright and tall, with eyes looking forward, resisting the temptation is to look at their feet.

- If necessary, cue the person verbally and/or manually by placing your hand on their chest or shoulder and applying light pressure to help them stand tall.
- Have them keep the hip, knee, and ankle of the affected leg lined up, to help the leg take their weight smoothly and safely with each step.
- Remind them to share the weight equally between the right and left feet. Sometimes rocking side to side, as if slow dancing, will help with this.
- Make sure the person is balanced before they start to move.

To step forward with the affected leg

- If they have a walking aid, have the person put it at the appropriate distance, and ask them to step forward. If they are having difficulty swinging the leg forward, as if it is stuck to the ground, make sure they are shifting their weight to the standing leg.
- As they step forward with the swinging leg, remind them to strike with the heel first as they put the foot down in front. This helps the foot clear the ground and encourages better hip, knee, ankle flexion.
- As much as possible, discourage them from:
 - ◆ Sliding the affected foot through
 - ◆ Landing on a flat foot (encourage heel strike)
 - ◆ Landing with feet close together (this creates a narrow base of support)
 - ◆ Hip hiking
 - ◆ Swinging the leg wide to the side
 - ◆ Looking at their feet
 - ◆ Slumping in the spine, better to stand up tall

To step forward with the unaffected leg

The challenge is that the affected (weaker) leg has to take all of the body's weight while the unaffected (stronger) leg swings forward. This is often difficult because of problems with strength and balance in both the leg and trunk.

Encourage the person to:

- Focus on the strength in the affected leg — “Stand strong on that leg!”
- Take it slow, don't rush
- Work towards equalizing the stance time between affected and unaffected leg (even the pace between steps)
- Avoid leaning too much on the walking aid

People who have had a stroke often start to use just their strengths to do an activity. This is called “compensating” for the weaker side or muscles. However, using only the stronger movements and muscle groups will not help re-develop the correct movements affected by the stroke. You might want to remind the person that “the only way to get stronger is to get rid of weaknesses.”

This process is tiring, frustrating, and can take a tremendous amount of work, but it is necessary to re-establish normal efficient movement. It takes much longer to undo a bad pattern of movement than to learn a good one, so your role as facilitator is vital. Work closely with the physiotherapist to learn how to best help a person who has had a stroke stand, walk, and transfer from one position to another.

ASSISTIVE DEVICES

Assistive devices may be recommended and prescribed by a physiotherapist to help a person who has had a stroke be more independent and safe during mobility. Talk to the physiotherapist or another member of the team if you have questions about how to use any recommended assistive device.

Commonly used assistive devices include:

- **AFO (ankle-foot orthosis)** fits in the shoe under the sole of the foot. It runs up the back of the calf and fastens with a Velcro™ strap below the knee. This device holds the ankle straight and reduces foot drop. An ankle-foot orthotic is often custom made to get the best fit for a client.
- **Foot-up brace** is a device that helps a person with foot drop. It attaches on any lace-up shoe and helps the person raise the front of their foot, to clear the ground when walking and reduce the risk of tripping.
- **Ankle brace** helps support a weak ankle and maintains the joint in a good position while weight bearing or walking.



Check regularly for:

- Signs of redness, skin irritation, or breakdown from the device
- A change in leg, foot, or ankle swelling
- Reports of discomfort as a result of the device

Report any of these changes to the appropriate member of the team as soon as possible. The brace may need to be modified or replaced, particularly if there are changes in the person's muscle size, if the person has lost or gained weight, or if there is swelling.

Putting on and removing these devices can present an additional challenge for someone who has had a stroke. The occupational therapist may recommend ways to make this task easier.

The physiotherapist will choose the right walking aid and make sure it is the right height.

Walking (gait) aids might include:

- Different types of canes: e.g., a straight or single point cane, quad cane
- Two- or four-wheeled walkers
- A rollator walker

BEST PRACTICE RECOMMENDATIONS

Task and goal-oriented training that is progressively adapted should be used to improve performance of selected lower-extremity tasks such as walking distance and speed, and sit to stand. Treadmill-based gait training (with or without body weight support) can be used to enhance walking speed and distance walked when over-ground training is not available or appropriate.

STAIRS

Stairs can be difficult for people who have had a stroke. Never take someone on stairs until they have been properly assessed, usually by a physiotherapist, and always follow the instructions in the care plan. Before you help someone use stairs, make sure they only need minimal help.

Always talk with the physiotherapist if you are uncomfortable helping someone on stairs or are uncertain about someone's ability to manage the stairs. Do not continue if you feel it is unsafe for you or the person who has had a stroke.

HOW YOU CAN HELP



It is common for people to rush, put only part of their foot on the stair, or continue even when they are off balance. Preparing the person before you start will improve safety for both of you.

- As with all exercises, but particularly with stairs, remind the person before you begin that using stairs should be done slowly and thoughtfully.
- Ask the person to put their full foot on the stair, and do not allow them to proceed until this is done properly.
- Stop, stand, and rest where needed, so the person can catch their breath and “reset.”

Typically, people who have had a stroke are told to lead with the unaffected (strong) leg when going up the stairs, and with the affected (weaker) leg when going down. There are exceptions, however, so always check the care plan to determine the best way for each person to manage stairs.

Ascending stairs

- Assist from behind, using a transfer belt if recommended.
- Instruct the person to use the handrail where possible. A gait aid may also be recommended.
- Ask the person to lead with the unaffected (strong) leg to step up to the stair first.
- Then ask them to step up to the same stair with the affected (weaker) leg. This stepping pattern is often called “marking time.”



- When it is safe for the person to do so, the therapist may recommend that the person use a pattern of one foot per stair, also known as “reciprocal stepping.”

Descending stairs

- Assist from in front, using a transfer belt if recommended.
- Use the handrail, where possible.
- Ask the person to lead with the affected leg while stepping down to the stair below.
- Have them follow with the unaffected leg on the same stair (marking time) or to the next stair (reciprocal stepping) as instructed by the therapist.



BEST PRACTICE RECOMMENDATION

The patient, family and caregiver should receive education regarding suitable gait aids, footwear, transfers, wheelchair use (e.g., direction of transfer, transfer belt use, seatbelt use, arm support devices, foot rests and brakes), considering the healthcare and community environment.

MOVEMENT AND EXERCISES

A physiotherapist or occupational therapist may recommend that a person who has had a stroke do specific activities and exercises to promote greater independence, movement, strength, and overall recovery. You may be asked to assist the person in these activities and exercises. If so, follow the plan provided and ask for clarification whenever needed. In addition, report any problems with the tasks to the appropriate person on the team.

Consider the following when helping someone complete their rehabilitation program:

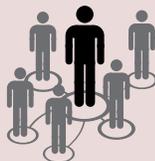
- **Balance rest and activity** to avoid frustration and prevent injury. Do not overtire the person or ask them to do too much.
- **Adjust your approach** to each individual and respect differences between people. Some people will make more gains than others.
- **Think things through, using short, simple steps.** Ask yourself if a movement looks normal. If it doesn't, try to determine why not. Talk to your team about concerns you have.
- **Stay calm and do not rush.** Moving slowly and gently will help the person participate better and give them time to think.
- **Explain what you are doing and make sure the person understands before you do it.** Use simple concise instructions and demonstrate what you mean, if necessary.
- **Encourage the person to participate** as much as possible. Give them the time they need and only provide as much assistance as is necessary.
- **Match your efforts to theirs.** This is easier when you know their abilities and limits and allow them to pace themselves by doing short bursts of simple activities. Coach or guide them as needed.
- **Use good body mechanics.**
- **Always ask for help if you need it.**

BEST PRACTICE RECOMMENDATIONS

Management strategies for post-stroke fatigue can vary, and are not mutually exclusive, due to the potential multifactorial nature of post-stroke fatigue. In addition to education of both patient and caregivers about post-stroke fatigue, strategies can include optimizing daily functioning for high priority activities (e.g., daily routines and modified tasks that anticipate energy needs and provide a balance of activity/rest); engaging in planned exercise schedules with increasing physical demands appropriate to tolerance level to improve deconditioning and physical tolerance; and communicating energy status and rest needs to family members, caregivers, employers and social groups.

KEY MESSAGES OF MOBILITY

- ❑ To avoid falls and injury after a stroke, **stress the importance of safety** — they need to slow down and be aware of their limitations.
- ❑ **Use any devices and aids** that have been recommended and that are part of the care plan such as a transfer belt, assistive device such as a brace, and walking aids.
- ❑ Remind the person about the **importance of posture**. Have them stand upright and tall, with eyes looking forward, resisting the temptation is to look at their feet.
- ❑ **Follow exercise plan** for the person with stroke and monitor or assist with exercises as needed.
- ❑ **Report changes** in mobility to the stroke care team.



6.5 Activities of Daily Living



IN THIS SECTION

- Activities of daily living (ADL): Seven steps to success
- Toileting
- Bathing
- Grooming
- Dressing
- Instrumental activities of daily living (IADL)

YOUR ROLE AS A HEALTHCARE PROVIDER

Being able to complete routine and meaningful activities independently builds self-esteem and a sense of accomplishment. A key part of your role is to help a person who has had a stroke perform routine daily activities such as toileting, bathing, grooming, and dressing as independently and safely as possible. This improves their physical, cognitive, visual and perceptual abilities and can improve mood. Gaining independence, safety and confidence are important to resuming self-care, work, and social and leisure activities.

ACTIVITIES OF DAILY LIVING

Activities of daily living, such as having a bath, brushing our teeth, getting dressed, or shaving are things most of us do without thinking or much effort. A stroke can change that significantly.

There are many factors that can affect a person's ability to complete activities of daily living, including:

- Loss of movement on one side
- Impaired ability to grasp and fine motor control to reach for and hold items
- Lack of sensation on the affected side
- Neglect or decreased awareness of one side
- Difficulty planning and sequencing tasks
- Short attention span or other cognitive impairments
- Decreased vision
- Decreased motor planning (apraxia)

No matter what task the person is attempting, always let them do it as independently as their abilities will allow, even if it takes them extra time. Your challenge is to make sure the task is not too hard, tiring, or frustrating, and to always keep safety in mind. The following seven steps can help you meet that challenge.

SEVEN STEPS TO SUCCESS

1. Set the stage

The first step to success is to make sure the person is ready for the activity. Review the steps and expectations together and agree on them. Before you begin, tell the person what is expected of them and how you will assist. Limit noise and distractions. Allow adequate time to promote independence. Be aware of how much they can do and let them lead.

2. Prepare the tools

Being ready ahead of time allows you to position the person safely and complete the task in a timely manner. Gather the tools and supplies you will need in advance. Put items in a convenient place within the person's reach.

Arrange the items in the order they will be needed. For example, lay clothes out in the order they will be put on. For someone with neglect, you can:

- Arrange items on the affected side to increase awareness.
- Point out the items on the affected side if necessary. However, if severe neglect makes this approach too frustrating, place items on the unaffected side.

3. Position yourself properly

Make sure you and the person are properly positioned, according to the care plan, and incorporate safe handling methods at all times to prevent injuries for you and the person you are helping.

Where possible, work from the person's affected side to increase their awareness of that side, be in a good position to support an affected limb, and help if the person loses their balance. Review the care plan as there may be situations where it specifies a different way to position yourself.

Support the affected arm as instructed and recommended in the care plan. Encourage the person to help with this, to build their awareness of the affected side.

4. Encourage use of the affected limb

Using the affected limb improves sensory awareness, and promotes motor recovery and functional use of the affected limb, leading to greater independence. Assist only as much as necessary.

The amount of movement and feeling a person has in an affected arm will determine how much the person is able to assist in their daily activities versus how much you will have to assist. If there is very limited mobility of the affected arm, it may be used to help stabilize items during a task.

5. Cue and guide

A short attention span or an inability to plan or remember how to do a task can make it challenging for the person who has had a stroke to accomplish daily tasks. You may need to provide assistance and support by giving instructions and cues. Hand-over-hand guidance may be recommended for some types of impairment such as apraxia. A therapist can advise if this method is appropriate.

You can also follow the same process that you might use to address other impairments:

- Break the task into small steps.
- Give clear, simple instructions.
- Talk them through the steps.
- If there are communication issues, demonstrate the task for them.
- Always approach the task the same way and use the same cues to help the person master the skill.
- Encourage them to participate at every stage of the activity, and help them succeed by doing for them only the parts of the task that they cannot do alone.

6. Use assistive devices

Assistive devices (e.g., glasses, hearing aids, long-handled reachers or other prescribed devices), make it easier and safer for people who have had a stroke to do more for themselves. An occupational therapist or another member of the team can advise on the best equipment and assistive devices, based on each person's abilities and environment.

If you don't know how to use a particular device or piece of equipment, ask to be shown.

7. Recognize and encourage

Relearning everyday tasks can be challenging and frustrating. When you recognize each success, you help build self-esteem and motivate the person to keep trying. For instance, when bathing, reaching for the grab bar during a transfer is an important success. So is washing their face or drying their upper body.

Make sure the type of encouragement you give respects the person and maintains their dignity. Do not treat them like a child.

TOILETING

Toileting is a personal and private activity. Those who need assistance with toileting may find the need for help and the invasion of privacy distressing. After assessing the person's balance, judgment, and physical ability, an occupational therapist decides if they can be left unattended on the toilet.

Always respect the person's dignity and privacy when helping with toileting. For example, accept that someone may want the bathroom door closed (as long as it is safe to do so — check the care plan), even if you are the only one present.

Plan ahead

Before you begin, refer to the care plan to check if the person can be left unattended on the toilet.

Ensure that needed equipment is in place before transferring someone onto the toilet or commode. Place toilet paper or wipes within reach.

Position properly

Follow the care plan when transferring and positioning the person on the toilet:

- Use the transfer method recommended in the care plan to help someone onto the toilet.
- Support their affected arm with a sling if recommended.
- Position their feet flat on the floor. This helps them maintain their balance and feel more secure.

If the person cannot be safely transferred onto the toilet, they may be able to use a commode (portable toilet). Commodes can be used when a toilet is not accessible, or to help someone get into the bathroom if it has wheels. It can also be used at the bedside if it is too far to get to the toilet. Make sure brakes are applied when transferring on and off the commode.

Follow positioning, mobility, and transfer guidelines recommended in your work environment; most facilities and communities have safe patient handling guidelines and training sessions to ensure you and the patient remain safe. Follow safe work practices and attend education sessions on a regular basis.

Someone with severe impairments and limited function after stroke may need to be toileted in bed. This should be a last resort. To toilet someone in bed, help them roll onto their affected side and then position the bed pan. Be sure to protect the affected arm.



Assistive Devices

Wall grab bars and **floor to ceiling poles** help the person rise and maintain their balance while you complete or assist with personal hygiene and clothing. Have the person get up from or sit down on the wheelchair or commode by pushing on the armrests rather than pulling on the grab bars or pole.

Raised toilet seats make rising and sitting back down easier and safer.

Commodes can be stationary, or have wheels, which make it easier to move the commode short distances such as in the bathroom and over the toilet.

Toilet frames (over arm toilet bars, also called versa frames) provide arm support and a solid surface to push up from when rising and support when lowering during transfers.

Toilet paper holders should be positioned within easy reach. Remind the person never to use the toilet paper holder as a substitute for a grab bar.

Hygiene products such as personal wipes make it easier to perform personal care after toileting.

BATHING

Stroke can change bathing from a private and pleasurable activity into an unpleasant experience. Fear of injury and invasion of privacy can affect a person's sense of dignity and add to their sense of loss. Be aware of these feelings and concerns and be patient and compassionate when helping someone bathe.

An occupational therapist can determine the safest transfer method and recommend equipment to promote independence and safety. A tub transfer bench or bath seat/chair along with grab bars may be recommended if someone is unable to safely sit in the tub or stand in the shower without help.

Safety first! The risk of falls in the bathroom is very high, especially when undertaking activities such as trying to stay balanced when getting in and out of the tub, standing on wet surfaces, moving around without footwear, and moving in tight areas. The hard surfaces in a bathroom can result in serious injuries from a fall. Hazards to watch out for include wet and slippery floors and fixtures, and scatter mats and rugs that slide easily.



Prepare the tools

- Remove floor mats or rugs from the bathroom unless they have non-slip and secure backing.
- Check that the water temperature isn't too hot or too cold.
- Put soap, cloths, towels, and lotions within reach. Use rubber (non-skid) tub bathmats (or a suitable alternative) to increase secure foot grip when stepping in and out of the tub.
- Prepare and place recommended equipment in the tub before assisting a person to transfer.

Position properly

Follow these steps when using a tub transfer bench:

1. Transfer the person onto the part of the bench over the side of the tub.
2. Support them as they move their buttocks back onto the bench, turn, and lift their legs over the side of the tub.
3. Ensure they are well positioned on the bench.
4. Help them wash as needed.
5. Help them slide towards the edge of the tub bench and lift their legs out of the tub.
6. Have them stay sitting on the edge of the bench, making sure their feet are well supported on the floor.
7. Help them dry off as needed.
8. Make sure the floor is dry before the person stands or transfers to the wheelchair.

Assistive Devices

A **tub transfer bench** is a bench that has two legs in the tub and two legs out of the tub. It allows the person to sit down without having to step over the side of the tub. It may have a cutout like a commode that makes it easier to clean the buttocks.

Bath seats and **bath boards** allow those with low activity tolerance or reduced balance to sit and rest when needed.

Grab bars (wall and clamp-on) increase independence and safety. An occupational therapist can recommend the type of bar, where to install it, and how to use it safely. Bars can be used for getting into the tub, or to stand even briefly while in the shower.

Hand-held shower heads and **bathing tools** such as a long-handled bath brush, a wash mitt, or soap on a rope promote independence.

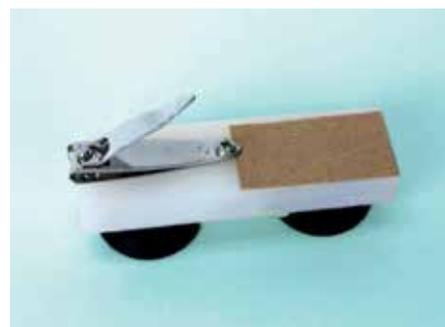
Non-skid bath mats or **decals** reduce the risk of falls from a slippery tub or shower floor.

Hydraulic lifts can lower a person into the tub further than being on a tub bench/bath seat, and lift the person back up to ease transfer out of the tub.

GROOMING

Grooming includes:

- Face washing
- Brushing teeth or cleaning dentures
- Shaving
- Putting on makeup
- Combing hair
- Nail care



Position properly

If the person will need help with any of these tasks, position them on a stable chair or wheelchair with their feet flat on the floor. If the person's wheelchair is very low, consider using a different chair in the bathroom. A wheeled commode may also be a good option but it should not be used to transport a person from one room to another.

If the person will be standing and balance is limited, a nearby grab bar and chair could be used for safety and support.

Support the affected arm/hand on the counter. Do not raise the arm above shoulder height unless you have been instructed in the correct method by a therapist as this may cause shoulder pain. If indicated in the care plan, help the person place the affected arm in a sling if standing or on the wheelchair arm tray/trough before starting the task.

Assistive devices that make daily tasks easier for people with limited hand function (such as weak grip or poor dexterity) include:

- A suction cup denture brush or toothbrush
- A toothbrush or comb with a built-up handle
- An electric toothbrush
- Liquid soap in a pump container
- A nail clipper board, which is a standard sized nail clipper securely attached to base with suction cup feet (check with healthcare team before use)

DRESSING

Loose-fitting and relaxed fit clothing is easier to put on. Adapted clothing allows the person to dress with greater independence. Common clothing adaptations include:

- Shoes with Velcro™ fasteners or elastic laces
- Front-closing brassieres
- Pants, shorts, and skirts with elasticized waist bands

Assistive devices that make it easier for a person who has had a stroke to dress include:

- A long-handled reacher
- A dressing stick
- A button hook or zipper pull
- A footstool
- A sock aid and long-handled shoe horn

Prepare the tools

Clothing choices express our personality. Whenever possible, let the person select their own clothing and accessories. Offer appropriate choices if they have difficulty with judgment or decision making.

Arrange clothes in the order they are to be put on if the person has trouble with sequencing.

Position properly

Position the person in a sitting position in a chair with a back support, with the feet flat on the floor. Do not have them sit on the edge of the bed to dress as this is an unstable surface and easy to slide off.

Encourage use of affected limb

Dress the affected arm or leg first. Undress the unaffected arm or leg first. You may find it easier to slide your arm through the garment from the wrist or ankle end, gently grasp the person's arm or leg, and draw the garment up the limb.

Here are some strategies that people who had a stroke can use to dress more independently.

Putting on a shirt

1. Place the shirt on the person's lap so the back of the shirt is facing up and the neck opening is furthest away. If the person is doing these themselves, tell them to use the tags as cues to know how to position the shirt.
2. Ask the person to insert the affected arm first and pull the sleeve well up to the shoulder. This prevents the shirt from sliding back down, and reduces the amount of energy needed to lift the arm up. Be careful never to lift the affected arm too high as this may cause pain and injury at the shoulder.
3. Bend the head forward through the neck opening.
4. Insert the unaffected arm.



Putting on socks

1. Cross the affected leg over the other leg. If this is too difficult, try putting one leg on a low stool, and let the toes hang over the edge.
2. Put the sock on with one hand using thumb and first fingers to open it.
3. Cross the unaffected leg over the affected leg to pull on the other sock.

Putting on pants

A sturdy table or counter to help with balance when putting on pants may be helpful.

1. Cross the affected leg over the unaffected leg and pull the pant leg up as far as possible.
2. Uncross legs and insert the other leg in the pants.
3. Partially stand up and pull the pants to the waist.

INSTRUMENTAL ACTIVITIES OF DAILY LIVING

Instrumental activities of daily living (IADLs) are the more complex daily tasks such as domestic chores, household management, meal preparation, shopping, financial management, and transportation.

For someone who has had a stroke, their ability to participate in these activities may be affected. They may be receiving assistance from family members or healthcare providers. If a person who has had a stroke is participating in any of these tasks, the same factors that impact their ability to complete ADLs should be considered, as listed above.

If you are providing assistance in these areas, keep the seven steps to success in mind to enable independence and keep the person safe. An occupational therapist or other member of the healthcare team may provide guidance and recommendations to promote safety and independence for these tasks.

HOW YOU CAN HELP



- Maintain a balance between knowing when to help and when to allow someone to do a task independently.
- Be patient. Allow adequate time for each step.
- Recognize small successes and contributions to each task.

KEY MESSAGES OF ACTIVITIES OF DAILY LIVING AND INSTRUMENTAL ACTIVITIES OF DAILY LIVING

- ❑ Being able to **complete routine and meaningful activities independently** builds self-esteem and a sense of accomplishment and is an important part of recovery.
- ❑ **Encourage the person** who has had a stroke to be as independent as possible and actively participate in daily activities.
- ❑ **Ensure the environment** is safe for the person with stroke to participate.
- ❑ **Assistive devices** (e.g., glasses, hearing aids, long-handled shoe horn or other prescribed equipment), make it easier and safer for people who have had a stroke to do more for themselves. Use only the devices agreed upon by members of the stroke care team.



6.6 Leisure and Social Activities



IN THIS SECTION

- The importance of leisure activities
- Meaningful leisure activities after stroke
- Identifying and planning leisure activities
- Assistive devices

BEST PRACTICE RECOMMENDATIONS

Patients should be given the opportunity to discuss pre-stroke leisure pursuits and be assessed for rehabilitation need to resume these activities. Participation in leisure activities should be encouraged. Patients who experience difficulty engaging in leisure activities should receive targeted therapeutic interventions.

YOUR ROLE AS A HEALTHCARE PROVIDER

Leisure and social activities add pleasure and satisfaction to life. You can help the person who has had a stroke return to activities they used to enjoy, or try new activities that fit their interests and abilities. Provide encouragement and support so they feel confident enough to try new things or change their approach so they can continue to participate in the things they used to do. You can work together with the person who has had a stroke and the team to explore community programs and resources or find assistive devices.

THE IMPORTANCE OF LEISURE AND SOCIAL ACTIVITIES

Leisure and social activities such as exercise, sports, reading, spending time with children, grandchildren or friends, a hobby, and so on, refresh the body, mind, and spirit. Meaningful leisure gives people a positive sense of self, reaffirms their pleasure in living, and enhances their quality of life.

Meaningful leisure activities play an important role in helping someone who has had a stroke occupy their time, structure their day, and maintain function. They can meet the person's need for social contact, competition, fitness, feelings of accomplishment and control, intellectual stimulation, creative expression, and stress relief. To do so, the activities must be meaningful rather than just "time-fillers."

Without pleasant activities, hobbies, and pastimes, the days can feel long, empty, and meaningless.

MEANINGFUL LEISURE ACTIVITIES AFTER STROKE

Often, someone who has had a stroke resume the activities they used to do with some modifications or by using assistive devices. For instance, a person who enjoyed fishing but now only has the use of one arm may need specialized equipment to hold the rod so he/she can use their unaffected hand to operate the reel.

Someone who loved to read but who now has a short attention span could listen to audiobooks. Someone who liked to play chess may find cognitive impairments make it too difficult, but they could play checkers instead.

Some leisure activities that might suit the interests and abilities of someone who is recovering from a stroke include:

- Physical activities: Tai Chi, walking, yoga, swimming, bowling, curling
- Outdoor pursuits: Gardening, fishing, bird watching
- Solitary pleasures: Computers, reading, crosswords
- Entertainment: Movies, concerts, theatre, shopping
- Community outings: Group excursions, such as with a seniors' club
- Social: Dinner parties, dining out
- Mechanical tinkering: Fixing cars, building models
- Artistic and creative pastimes: Painting, sewing, needlework, ceramics
- Service groups: Faith community activities, volunteer organizations
- Cultural groups or clubs

IDENTIFYING AND PLANNING LEISURE ACTIVITIES

Getting to know the person can help a great deal in planning leisure activities. Find out about them by asking:

- What are your favourite activities?
- What do you enjoy about them?
- Who do you enjoy doing things with?
- Where do you like to do your favourite activities?
- When do you prefer to do these activities?

HOW YOU CAN HELP



- If there are communication difficulties, you could show them a picture collage of a variety of appropriate leisure activities and ask them to point to what they might enjoy. Share what you learn with other members of the team, such as a recreation or occupational therapist, who may be able to suggest activities, figure out how to modify an activity, or recommend assistive devices. If you are unsure whether an activity is safe or appropriate, talk to the team.
- Look for community resources. Community organizations offer many activities, including theatre, festivals, fairs, senior centres, or faith-based functions, to name a few. Check the community newspaper or local television or radio stations to see what may be coming up. Many communities also publish newsletters for seniors, guides to leisure facilities, and recreation centre brochures that can help identify options.

ASSISTIVE DEVICES

There are many assistive devices to help people with impairments (such as vision loss, decreased mobility, and/or the use of only one hand) take part in leisure activities.

Games

- Card holder for one-handed playing
- Large-face cards
- Battery-operated card shuffler
- Large-piece jigsaw puzzles
- Pool cue holder
- Electronic games



Reading

- Book holder
- Talking books, audiobooks, books on CD
- Large print crosswords, Sudoku, word search puzzles
- Page magnifier or magnifying glass
- Computer programs that scan and read information aloud

Computer

- Larger size text
- Computer magnifier
- Large monitor
- Modified key board
- Speech recognition software
- Electronic tablets such as iPads™ with games and activities

Crafts

- Needle threader
- Clamp and holder to enable one-handed embroidery, knitting, crocheting
- Other adaptations to stabilize projects if working one-handed or with reduced hand function on one side
- Enlarged grips for pens, pencils, paint brushes, and other tools

Outdoor activities

- Three-wheeled bicycle
- Fishing rod holder
- Adapted gardening tools and table

Sports

- Aqua/water therapy
- Swimming pool noodles and life jackets
- Wheelchair-based sports (e.g., curling seated in a wheelchair and using a deliver stick to “throw” the rock)
- Bowling ball ramp or a bowling ball pusher
- Specialized golf equipment such as a modified golf cart so the person can swing the club while seated, a modified glove to assist with gripping, or a device to insert the tee into the ground, position the ball on the tee, and retrieve it from the ground

KEY MESSAGES OF LEISURE ACTIVITIES

- ❑ **Leisure and social activities** add pleasure and satisfaction to life.
- ❑ Meaningful leisure gives people a **positive sense of self**, reaffirms their pleasure in living, and enhances their quality of life.
- ❑ People who have had a stroke **may need modifications** to help continue participating in leisure activities, or may need to try new activities.
- ❑ **Many assistive devices** are available to help overcome challenges in participating in leisure activities.
- ❑ **Encourage persons** who have had a stroke to actively participate, and show patience and understanding.



6.7 Caregivers, Family, and Friends



IN THIS SECTION

- The impact of stroke on the family
- Stresses on the caregivers

YOUR ROLE AS A HEALTHCARE PROVIDER

The first step in supporting the caregivers and family of someone who has had a stroke is to recognize the effect the stroke is having on them. You can help them adapt and cope. Often, the skills and strategies you will need — patience, understanding, and knowledge — are similar to those you use with the person who had a stroke.

THE IMPACT OF STROKE ON THE FAMILY

A stroke affects the whole family. The person who has had a stroke will experience losses and need time to adjust to the changes a stroke can bring. Family members experience these changes and losses as well, and may experience many emotions when dealing with them. Each family is unique and family members may react differently, depending on their relationship with the person who has had a stroke and their own personalities.

Areas of impact and examples of the specific difficulties may include:

Financial

- Loss of income: The stroke survivor may have been the primary breadwinner and can no longer work.
- Money and benefits: The caregiver may not understand or is overwhelmed by managing the survivor's finances on their behalf; or applying for benefits on their behalf.
- A caregiver may feel guilty for working and leaving their loved one at home.

Roles and responsibilities

- Older children in the family may need to take on responsibilities for younger children in the home if their parent had a stroke and is unable to parent how they used to.
- The stroke survivor did all of the household chores before their stroke and are now unable; their caregiver may need to learn these tasks in order to take them over.
- A friend may be appointed power of attorney, and now needs to pay all of the stroke survivor's bills.

Routines (examples)

- The stroke survivor always picked their children up from school prior to their stroke; the children now need to take the bus every day.
- A stroke survivor now lives in a long-term care facility; their loved ones need to alter their daily routines so that they have time to visit on a daily basis.

- A married couple may not be able to continue going on their annual overseas vacation due to the stroke survivor's limited mobility.

Physical Health and Wellness (examples)

- A caregiver may lose sleep at night because they need to wake up every few hours to help the stroke survivor to the toilet, resulting in the caregiver feeling fatigued and run down.
- Having to physically assist the stroke survivor with bathing, toileting, and mobility may cause physical strain to the caregiver (particularly if they themselves are frail or injured).

Mental Health and Wellness (examples)

- Family members may become anxious and stressed regarding the stroke survivor's health needs; for example, worrying that the stroke survivor is eating the right diet, is taking their medications properly, is safe when walking and not going to fall, etc.
- Caregivers may feel guilty taking time for themselves, wishing it were over, or feeling like the care they provide "isn't good enough".

Family members and caregivers may go through the same emotions that the stroke survivor experiences: grief, depression, anger, fear about the future, financial concerns, or worry about good care. Just like the person who had a stroke, they too may feel like they are on an emotional roller coaster. For some, the grief can be very intense, almost as if the person has died.

HOW YOU CAN HELP



- Ask how they are being affected by the changes that have happened.
- Offer information and assistance.
- Give encouragement and positive feedback. Family members need to know that others notice and appreciate their efforts, and recognize that they are doing their best.
- With the survivor and/or family's permission, encourage those who wish to help with care to get involved. Provide information and support so they feel confident in their ability to help.
- Encourage family members to take time for themselves. They need to balance care for themselves and care for the survivor.
- Watch for signs of undue stress or other negative emotions. If you are concerned about a family member's mood, tell someone on your team.



STRESSES ON THE CAREGIVERS

Caregivers may be family members, friends, neighbours, or others. There is usually one primary caregiver who has the main responsibility for looking after the stroke survivor. This person could be the spouse, an adult child, a sibling, a close friend, or a neighbour.

Caring for someone with stroke can be difficult, stressful, and time-consuming, particularly if the caregiver has little or no training or support. Listed below are some of the common emotions that caregivers feel.

Anxiety

- Longevity of caregiving: How long they will be able to keep caring for the person who has had a stroke. This is especially true if the caregiver has health problems or is older.
- Responsibility: Some caregivers feel it is their duty as spouse, child, or family member to care for the person single-handedly. This is stressful, but failing to provide care would be an even greater source of stress.

Worry

- Financial stress: Whether they will be able to provide financially for the family.
- Quality of care: Whether they are providing the best possible care.

Fear

- Social isolation: May occur as initial offers of help and support from friends and relatives decrease over time.
- Meeting expectations: Fearing that others are judging the quality of care they are providing or the decisions they are making as a substitute decision maker.
- Things getting worse: Concern about another health crisis causing the person's care needs to become harder to manage.

Guilt

- Not being able to meet the needs of the person who has had a stroke and worrying about what the person will think of them.
- Having to make decisions as a substitute decision maker, such as having to decide to place the person in a long-term care home or agreeing to services (such as in-home respite) that the person does not want or feel they need.

Frustration

- Watching the person struggle, and having to allow them the freedom to fail in order to learn through their rehabilitation process.
- Seeing the person struggle to cope emotionally through multiple changes.
- Managing expectations of recovery: Seeing no improvement, or not as much improvement as they hoped.

Anger

- Feeling resentful about how the stroke has affected their lives, thinking “This isn't the retirement we planned.”

- Lack of recognition as a caregiver: from the stroke survivor, other family/loved ones, workplace, government, etc.

Exhaustion

- **Physical:** Providing physical care as well as taking on other caregiving tasks (cooking, cleaning, errands, etc.) can be exhausting. This can be made worse if the caregiver is not sleeping well at night — perhaps they are up during the night to help the person who had a stroke go to the toilet.
- **Mental and emotional:** Watching the person struggle with physical, cognitive, perceptual, and emotional difficulties can take an emotional toll. It can also be emotionally exhausting when the person who had a stroke has behavioural or personality changes that the caregiver has to manage and cope with.
- **Extreme fatigue** may make the caregiver seem apathetic or uncaring and make it difficult for them to make decisions and think clearly about their situation.

Confusion

- **Role reversals:** Caregivers sometimes have to take on roles that the person who has had a stroke used to do. This often requires the caregiver to learn and adjust quickly (e.g., a child may take on caregiving for their parent, including helping with self-care; a wife may need to take on the role of financial manager in the household if her husband previously paid all the bills and can no longer do so). Role reversal can increase the stress felt by both the person who had a stroke and the caregiver.
- **Faith/spiritual confusion:** The caregiver may wonder why this happened to them or to the person who has had a stroke, or what message they should take from caregiving.

HOW YOU CAN HELP



You can play an important role in identifying caregiver stress, and supporting them in what may be a new and unfamiliar role.

- **Listen to the caregiver.** Caregivers may need to share their worries. Suggest that they might want to call someone who can help them cope with stress, such as a social worker or someone in their faith community. Be aware that they may be uncomfortable discussing the stress and fatigue of caregiving, as they may worry that you will judge or criticize them. Always communicate with understanding and empathy. Be caring and accepting and never judgmental.
- **Observe the caregiver.** Weeping, anger, poor eye contact, and withdrawal from others are signs of stress. If you feel it is serious, share these observations with your team.
- **Learn about the caregiver's support system.** Support systems can include family members, friends, neighbours, a doctor or other healthcare professional, and/or social or faith groups. Encourage the caregiver to seek help from their support system.
- **Reassure them about the care that is being provided.** Demonstrate your ability to meet the person's needs.

- **Communicate clearly and consistently with the caregiver.** Ask what can be done to decrease the demands placed on them. Avoid lecturing about what they should or should not be doing.
- **Encourage the caregiver.** Try to give them a realistic sense of hope about the future, and encourage them to believe that they will be able to adjust to the new reality. Remind them that most people who have had a stroke continue to improve for months or years.
- **Refer the caregiver to other resources.** Be aware of helpful resources. Your Stroke Journey and Taking Charge of Your Stroke Recovery are available from the Heart and Stroke Foundation of Canada. You could also suggest they attend a Living with Stroke support and education group, or another relevant support group. These provide valuable information about life after stroke and help them see that they are not alone in their struggles.
- **Report your concerns.** If you feel a caregiver is not doing well and needs more support, talk to your case manager or suggest that the caregiver call the case manager or social worker to discuss options.

BEST PRACTICE RECOMMENDATIONS

Patients, families and caregivers should be screened at each transition of care stage for their level of coping, risk for depression, and other psychosocial and physical issues (such as residual physical deficits, including aphasia), stroke severity, family functioning, screening for caregiver/family distress as appropriate to the individual.

KEY MESSAGES OF CAREGIVERS, FAMILY, AND FRIENDS

- ❑ **A stroke affects the whole family.** The person who has had a stroke will experience losses and need time to adjust to the changes a stroke can bring.
- ❑ **Family members experience** these changes and losses as well, and may experience many emotions when dealing with them.
- ❑ Caring for someone with stroke **can be difficult**, stressful, and time-consuming, particularly if the caregiver has little or no training or support.
- ❑ **Listen to family and caregivers**, and provide understanding and encouragement to them.
- ❑ **Communicate issues** with caregivers to the stroke care team.



APPENDIX A

Managing Stroke Risk Factors



The information in this table is based on the Canadian Stroke Best Practice Recommendations. It lists the most common risk factors for stroke and the recommendations to address them.

Family physicians or other medical specialists on the team should discuss the relevant risk factors and best practice recommendations with the person who has had a stroke and their family members, where appropriate, to ensure they know how to decrease the risk of another stroke or of other medical problems.

Risk factor for stroke	Best practice recommendations to manage risk factors
High blood pressure	<ul style="list-style-type: none"> ● High blood pressure or hypertension is the single most important modifiable risk factor for stroke. ● Patients should be informed about things that increase blood pressure (e.g., high sodium in the diet) and ways to lower blood pressure (e.g., exercise, medication, reducing stress). ● Patients should be told their target blood pressure levels and given counseling and medication to meet them, if necessary. ● Targets for anyone who has had a stroke or transient ischemic attack is to keep blood pressure consistently lower than 140 systolic (top number) and 90 diastolic (bottom number). These targets may be lower for people with diabetes, kidney disease, or other health problems. ● Patient blood pressure levels should be regularly monitored and medication adjusted if necessary.
High cholesterol	<ul style="list-style-type: none"> ● Cholesterol is a form of fat in blood. There are two types of cholesterol: high-density lipoproteins (HDL) or “good” cholesterol, and low-density lipoproteins (LDL) or “bad” cholesterol. ● High cholesterol can be inherited, caused by too many saturated fats in the diet, or both. ● Higher levels of LDL mean a higher risk of stroke and heart attack. ● For most people, the target is to keep LDL less than 2.0 mmol/litre. ● People who have already had a stroke or transient ischemic attack may benefit from cholesterol-lowering medications (usually a statin drug). ● Healthcare providers should give patients information about how to decrease dietary fat.
Diabetes	<ul style="list-style-type: none"> ● Diabetes is a risk factor for stroke and heart disease. People with diabetes have twice the risk of stroke compared to someone without diabetes. ● Diabetes can affect blood vessels. It can lead to high blood pressure and increase the risk of clots forming in the arteries and travelling to the brain, possibly causing a stroke. ● Healthcare providers should give patients information about how to manage diabetes.

Atrial fibrillation	<ul style="list-style-type: none"> ● Atrial fibrillation is an irregular heart rhythm, known as an arrhythmia. ● Atrial fibrillation increases the risk of stroke by three to five times. It increases the risk of clots forming in the arteries and travelling to the brain, possibly causing a stroke. ● Healthcare providers should give patients information about treatment options, based on symptoms, age, and medical issues. ● Medication such as acetylsalicylic acid (ASA) or a stronger blood thinner may be prescribed. ● If a blood thinner called warfarin is prescribed, blood levels may need to be checked regularly. ● Healthcare providers should give patients information about how to manage atrial fibrillation.
Unhealthy weight	<ul style="list-style-type: none"> ● Increased weight can lead to high blood pressure, high cholesterol, diabetes, and sleep apnea, all of which are risk factors for stroke. ● Ideally, women should have a waist circumference of less than 88 centimetres and men less than 102 centimetres. This may be different for some ethnic groups (e.g., people of Asian descent may have lower target values). ● Healthcare providers should work with patients to determine a healthy weight based on height, build, age, and health status.
Unhealthy diet and high sodium	<p>Healthier diets include:</p> <ul style="list-style-type: none"> ● Lots of fresh fruit, vegetables, whole grains (e.g., no white bread), and fibre. ● Limited amounts of saturated fats (aim for less than 200 mg per day). ● The recommended daily sodium intake from all sources is known as the Adequate Intake. Adequate intake levels are: <ul style="list-style-type: none"> ◆ 1500 mg/day for people aged 9 to 50 years ◆ 1300 mg/day for people aged 51 to 70 years ◆ 1200 mg/day for people over 70 years <p>No one should exceed 2300 mg per day.</p>
Lack of exercise	<ul style="list-style-type: none"> ● Participate in moderate exercise such as walking (ideally brisk walking), jogging, cycling, swimming or other dynamic exercise four to seven days each week, in addition to routine activities of daily living. ● People who have had a stroke should get at least 150 minutes of moderate to vigorous activity per week, in episodes of ten minutes or more. ● Stroke survivors who are at risk of falls or who have other health conditions (such as cardiac disease) that put them at risk of complications should be supervised by a healthcare professional (physical therapist or cardiac rehab) when starting an exercise program.

Smoking	<ul style="list-style-type: none"> ● Smoking is a major cause of stroke and heart disease. ● Smoking adds to the build up of plaque in blood vessels, which may cause clots to form and travel to the brain. ● Nicotine raises blood pressure. ● Carbon monoxide can reduce the amount of oxygen carried to the brain. ● Smoking cessation treatment that includes counseling and medication has the best success rate for helping people quit smoking and stay smoke-free. ● Health risks decrease significantly within three years of quitting smoking.
Heavy alcohol intake	<ul style="list-style-type: none"> ● Heavy drinking and binge drinking are risk factors for high blood pressure and stroke. ● Alcohol can change the effects of some medication. ● Based on the 2013 Canadian Low Risk Alcohol Consumption Guidelines, alcohol consumption should be limited to: <ul style="list-style-type: none"> ◆ For women who are not pregnant: Maximum two drinks per day and no more than ten drinks a week. ◆ For men: Maximum three drinks per day and no more than 15 drinks a week.
Sleep apnea	<ul style="list-style-type: none"> ● Sleep apnea is a condition where breathing repeatedly stops and starts during sleep. It is often associated with snoring and fatigue. It causes less oxygen to reach the brain, and can lead to high blood pressure. ● People with sleep apnea are at a higher risk for stroke. ● People who have had a stroke are more likely to develop sleep problems, including sleep apnea, after their stroke. ● If symptoms of sleep apnea are present, patients may be referred to a sleep specialist for assessment, diagnosis, and possible treatment.
Stress	<ul style="list-style-type: none"> ● Having a stroke is stressful physically and emotionally. ● Stress can cause the heart to work harder, increase blood pressure, and increase sugar and fat levels in the blood. This can increase the risk of clots forming and travelling to the brain. ● An assessment or counseling by a mental health specialist may be required.
Birth control and hormone replacement therapy	<ul style="list-style-type: none"> ● Women of childbearing age or in menopause who are taking estrogen-containing hormones are at increased risk of stroke, transient ischemic attack, and heart attack.



Family history can double your risk of heart disease and stroke. Don't be blindsided. Know your risks — and what to do about them.



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