

TAKING ACTION FOR OPTIMAL COMMUNITY AND LONG-TERM STROKE CARE

A Resource for Healthcare Providers

Chapter 1 - The Stroke Care Team

Updated November 2015



HEART & STROKE
FOUNDATION

CANADIAN
Stroke
BEST PRACTICE
RECOMMENDATIONS

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

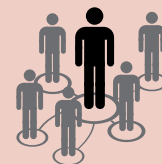
People who have had a stroke receive the best care when their care plan follows the Canadian Stroke Best Practice Recommendations, as these are the most up-to-date and effective ways to treat people who have had a stroke. This resource is based on those recommendations.

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.



JOIN US!

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



Spread the message among your family, friends and community.



Volunteer to help us extend the reach of our activities.



Donate to help fund critical life-saving research.



Lend your voice to our campaigns for healthier government policies.



Be the first to know about our latest research breakthroughs.



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

Learn more at heartandstroke.ca



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