TAKING ACTION FOR
OPTIMAL COMMUNITY AND LONG-TERM STROKE CARE

A Resource for Healthcare Providers

Chapter 5 - Body Function (Mental and Emotional)

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.

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

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.

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* 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.

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* 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.

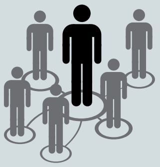
BEST PRACTICE RECOMMENDATION

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

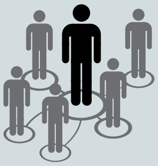
- **Gently encourage the person to be as independent as possible. Help them only if the task they are trying to do becomes too hard or tiring.**
- **Always be alert for signs of depression.**
- **Be positive. When you notice improvements or that the person is doing better, say so. Track their successes 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

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.

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.

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.

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