TIPS & TOOLS FOR EVERYDAY LIVING

A GUIDE FOR
STROKE CAREGIVERS
The creation of this resource is a perfect example of interprofessional collaboration. The Heart and Stroke Foundation of Ontario would like to acknowledge and thank this dedicated group of professionals from across the province for their time, energy and commitment to this resource and to improving stroke care.

Dr. Stephen D. Bagg
Associate Professor and Head
Dept. of Physical Medicine and Rehabilitation
Queen’s University & St. Mary’s of the Lake Hospital

Leigh G. Barr, BA, MSc Reg CASLPO
Speech-Language Pathologist
Hamilton General Hospital

Jean Benton, RN(EC), BScN, PHCNP, CGN(C), NCA
Primary Health Care Nurse Practitioner
County of Renfrew Municipal Homes for the Aged

Gwen Brown, RN, BA, BEd
Regional Community and Long Term Care Stroke Coordinator
Stroke Strategy of Southeastern Ontario

Ingrid ten Bruggenkate, MSW RSW
Social Worker, Acute Stroke
Kingston General Hospital

Tina Carquese, RPN
Rideaucrest Home

Donna Cheung, OT Reg. (Ont.)
Stroke Rehab & Community Re-engagement Coordinator
South East Toronto Regional Stroke Network

Glenna Churchill, RN, BScN, MSN, GNC(C)
Patient Relations Specialist
Kingston General Hospital

Linda Galanou RN GNC(C) NCA
Registered Nurse/ Care Coordinator
Day Hospital, Providence Care

Sherry Darling, MSc, Reg. CASLPO
Speech-Language Pathologist
Toronto Western Hospital

Rob Fazakerley, RPT
Community Stroke Rehabilitation Program
Parkwood Hospital, St Josephs Health Care, London

Andrea Fisher, RN, MSN, MSc
Advanced Practice Nurse, Stroke
The Ottawa Hospital

Paula Gilmore, MSc, BScOT, OT Reg. (Ont.)
Regional Stroke Community and Long-Term Care Coordinator
SWO Stroke Network

Sylvie Giroux, RN, BSW, RSW, CTA, CFLS
Community and Long Term Care Specialist
Northeastern Ontario Stroke Network

Patrick Hurteau, MPA, OT Reg. (Ont.)
Community & Long Term Care Coordinator
Champlain Regional Stroke Program

Linda Kelloway, RN, MN, CNN(c)
Best Practices Leader
Ontario Stroke Network

Suzanne Khwaja
Social Worker
Parkwood

Kelly Lumley-Leger
Regional Stroke Education Coordinator
Champlain Stroke Region

Karen Mallet, MHSc, MEd SLP (C) Reg. CASLPO
Speech-Language Pathologist
Champlain Regional Stroke Network

Kim Masur, OT Reg. (Ont.)
Occupational Therapist
Closing the Gap Healthcare Group

Jocelyne McKellar, MSW, RSW
Stroke Rehab and Community Re-engagement Coordinator
Toronto West Stroke Network

Sandria Melchiorre, RN, BSc, BScN, MN, CNN(C)
Regional Stroke Advanced Practice Nurse
Stroke Strategy of Southeastern Ontario

Susan J. Oates, RN, BN, MScN, CRN(C)
Clinical Nurse Specialist, Geriatrics
Assistant Clinical Professor, McMaster University St. Mary’s General Hospital

Beverley Powell-Vinden, RN, BNSc, MEd
Manager, Mission Information
Heart and Stroke Foundation of Ontario

Shadab Rana, MD, MPH
Senior Specialist, Mission Information
Heart and Stroke Foundation of Ontario

Sue Saulnier, RN, BNSc, MEd, GNC(C)
Regional Stroke Education Coordinator
Stroke Strategy of Southeastern Ontario

Krystyna Skrabka
Regional Stroke Education Coordinator
South East Toronto Stroke Network

Jodie Sutcliffe, BA, BSc(OT), OT Reg. (Ont.)
Regional Stroke Education Consultant
West GTA Stroke Network

Gina Tomaszewski, RN, MScN
Southwestern Ontario (SWO) Regional Stroke Education Coordinator
SWO Stroke Network

Sharon Trotman, Dip P&OT
Community & Long Term Care Stroke Coordinator
West GTA Stroke Network

Sue Verrilli, BA, RT (R/TRO)
Community and Long Term Care Specialist
Northeastern Ontario Stroke Network

Kim Young, BAH, BHScOT, OT Reg. (Ont.)
Regional Stroke Rehabilitation & Community Coordinator
Central South Regional Stroke Network

Linda LeDuc, RN, BA
Senior Specialist, Professional Education
Heart and Stroke Foundation of Ontario
**TABLE OF CONTENTS**

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Section 1</td>
<td>The brain and stroke.</td>
<td>1.1 – 1.10</td>
</tr>
<tr>
<td>Section 2</td>
<td>The interprofessional care team and you</td>
<td>2.1 – 2.4</td>
</tr>
<tr>
<td>Section 3</td>
<td>Communication</td>
<td>3.1 – 3.10</td>
</tr>
<tr>
<td>Section 4</td>
<td>Post-stroke pain</td>
<td>4.1 – 4.8</td>
</tr>
<tr>
<td>Section 5</td>
<td>Cognition</td>
<td>5.1 – 5.6</td>
</tr>
<tr>
<td>Section 6</td>
<td>Perception</td>
<td>6.1 – 6.6</td>
</tr>
<tr>
<td>Section 7</td>
<td>Stroke and depression</td>
<td>7.1 – 7.6</td>
</tr>
<tr>
<td>Section 8</td>
<td>Stroke and behaviour change</td>
<td>8.1 – 8.6</td>
</tr>
<tr>
<td>Section 9</td>
<td>Mobility, positioning, and transfers.</td>
<td>9.1 – 9.16</td>
</tr>
<tr>
<td>Section 10</td>
<td>Bladder and bowel control (continence)</td>
<td>10.1 – 10.12</td>
</tr>
<tr>
<td>Section 11</td>
<td>Hydration</td>
<td>11.1 – 11.4</td>
</tr>
<tr>
<td>Section 12</td>
<td>Meal assistance and special diets.</td>
<td>12.1 – 12.6</td>
</tr>
<tr>
<td>Section 13</td>
<td>Activities of daily living</td>
<td>13.1 – 13.8</td>
</tr>
<tr>
<td>Section 14</td>
<td>Skin care and hygiene</td>
<td>14.1 – 14.4</td>
</tr>
<tr>
<td>Section 15</td>
<td>Leisure</td>
<td>15.1 – 15.4</td>
</tr>
<tr>
<td>Section 16</td>
<td>Caregiver stress</td>
<td>16.1 – 16.4</td>
</tr>
<tr>
<td>Section 17</td>
<td>Notes</td>
<td>17.1 – 17.4</td>
</tr>
</tbody>
</table>

“Tips and Tools for Everyday Living: A Guide for Stroke Caregivers” 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.

This publication was prepared with input from a number of healthcare professionals who have reviewed the information to ensure its suitability and accuracy at the time of publication. It is intended for reference only and to supplement the learning provided by a recognized educational program that teaches personal support workers and other frontline caregivers. It should not be relied upon exclusively.
How the brain works

To know how stroke affects a person, you need to know how the normal brain works, and how brain functions are organized.

Brain functions

The brain is like a control centre. It manages all of our physical, mental and emotional functions. These functions include:

- **Movement** – motor functions and the coordination of movement
- **Perception** – how we interpret information from our senses
- **Sensation** – such as touch
- **Vision** – how we see
- **Cognition** – thinking, remembering, understanding, planning, reasoning and problem-solving
- **Communication** – speaking and understanding
- **Personality** – including emotions and behaviour
The brain is divided into two parts. These are called the left and right hemispheres. Each hemisphere is divided into regions, which control different functions. The right side of the brain controls some functions, the left others. Some functions are controlled by both sides of the brain.

The left hemisphere of the brain controls:
- Movement (motor functions) and feeling (sensory functions) of the right side of the body
- Scientific functions
- Understanding written and spoken language
- Number skills
- Reasoning

The right hemisphere of the brain controls:
- Motor and sensory functions of the left side of the body
- Artistic functions: music, art awareness, and insight
- Perception: being aware of, and making sense of the surrounding environment

THE TWO SIDES OF THE BRAIN CONTROL DIFFERENT FUNCTIONS.
Oxygen and nutrient requirements

The brain is full of specialized cells called neurons. To work properly – and even to survive – neurons need a constant supply of oxygen and nutrients. A complex network of blood vessels called arteries carries blood to all parts of the brain. Each blood vessel supplies oxygen and nutrients to a specific area of the brain.
Understanding stroke and TIA

A stroke is a sudden injury to part of the brain caused when blood flow in an artery stops. The affected area of the brain is deprived of oxygen and nutrients. This damages the neurons and the functions they control in that area of the brain. If blood flow is not restored within minutes, the damaged neurons start to die. Neurons that die cannot be replaced or restored.

Types of stroke

Stroke can occur in two ways:

1. Rupture of an artery causes a **hemorrhagic stroke** (stroke due to bleeding in the brain tissue).

   ![Burst Artery Diagram]

   Lesions in artery bursts causing blood to leak out of the vessel

2. Blockage of an artery causes an **ischemic stroke** (stroke due to a clot blocking blood flow).

   ![Blocked Artery Diagram]

   Blood clot blocks blood flow

   Excessive cholesterol “build up” in the artery (plaque).

**Transient Ischemic Attack (TIA)**

When an artery has only a temporary blockage, it is called a **transient ischemic attack (TIA)** or warning stroke. The symptoms last only a few minutes to an hour. It is not sure if TIA leaves permanent brain damage, but the symptoms should never be ignored as there is a chance for the person to have another, more damaging stroke. Prompt medical attention can reduce the risk of a further stroke.

**TIA and stroke are medical emergencies**

Stroke quickly damages and kills neurons in the brain. Recognize the signs early and act quickly. Without fast treatment, the chance of reducing stroke damage decreases quickly.
5 warning signs of stroke

Stroke is a medical emergency. Recognizing and responding immediately to the warning signs of stroke by calling 9-1-1 or your local emergency number can significantly improve survival and recovery. If a person is diagnosed with a stroke caused by a blood clot, then doctors can administer a clot-busting drug available only at a hospital, and only within a few crucial hours after symptoms begin.* That’s why it is very important to be able to recognize the 5 warning signs of stroke and immediately call 9-1-1 or your local emergency number.

The five signs

Stroke can be treated. That’s why it is so important to recognize and respond to the warning signs.

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

- **Trouble speaking** – Sudden difficulty speaking or understanding or sudden confusion, even if temporary.

- **Vision problems** – Sudden trouble with vision, even if temporary.

- **Headache** – Sudden severe and unusual headache.

- **Dizziness** – Sudden loss of balance, especially with any of the above signs.

If someone experiences any of these warning signs, immediately call 911 for emergency help.

*Health Canada has approved the clot-busting drug called tPA to be used within 3 hours from the time symptoms begin. However, emerging science is now showing that tPA could be effective up to 4 ½ hours afterward. As a result, the Canadian Stroke Strategy has issued new Canadian Best Practices Recommendations for Stroke Care, which have included this new treatment time. Still, it will be up to the attending emergency doctors to determine when tPA may be administered or if it is appropriate to the situation.
Risk factors for stroke

Who is more likely to have a stroke? What puts them at risk? There are two kinds of risk factors:

* Modifiable risk factors* can be controlled by lifestyle changes, medical treatment, and medications. For instance, irregular heart beat can be treated with a pace-maker. Diabetes can be controlled with medication.

* Non-modifiable risk factors*, such as age, cannot be changed.

<table>
<thead>
<tr>
<th>Type of Risk Factor</th>
<th>Risk Factor</th>
</tr>
</thead>
</table>
| Risk factors you can do something about | Hypertension (high blood pressure)  
Hypercholesterolemia (high blood cholesterol)  
Atrial fibrillation (irregular heart beat)  
Diabetes  
Smoking  
Being overweight or obese  
Physical inactivity  
Excessive alcohol consumption  
Stress (not managing stress) |
| Risk factors you can’t control | Age (while strokes can occur at any age, most occur over age 65)  
Gender (women have a lower risk before menopause than men. But more women than men die of stroke)  
Ethnicity (increased risk for persons of Aboriginal, African or South Asian descent because of higher rates of high blood pressure and diabetes)  
Family history (if a parent or sibling had a stroke before age 65)  
Prior stroke or Transient Ischemic Attack (TIA) |

Stroke risk in stroke survivors

Having a stroke or TIA increases the risk of another stroke. The risk is greatest immediately after the stroke or TIA and stays high for 5 years. Overall, 30% of stroke survivors have a second stroke.
Lowering stroke risk

Stroke survivors can reduce their risk of another stroke by controlling modifiable risk factors. Working to control just one stroke risk factor can reduce the risk of stroke. Setting realistic goals together helps motivate stroke survivors to keep trying.

Effects of stroke

The effects of a stroke depend on many things. Some of these include:

- The region of the brain that was affected
- The size of the area that was damaged by the stroke
- The functions that the area controlled

Strokes that are large enough to affect several areas of the brain affect many functions. For example, a large left hemisphere stroke may damage motor, sensory, and language areas. This may affect the survivor’s ability to move, feel, and communicate.

Common stroke effects

Common effects of stroke include:

- Paralysis or weakness on one side of the body
- Vision problems
- Communication problems
- Fatigue
- Incontinence (loss of bladder control)
- Changes in how a person perceives or interprets the world

Stroke survivors may also experience personality changes. They may have depression or loss of emotional control. Stroke can affect a person’s ability to remember, solve problems, and communicate with others. Some effects can occur with any stroke location. Others are characteristic of left or right hemisphere stroke.

- A survivor of a left hemisphere stroke may:
  - Have trouble reading, talking, thinking, or doing arithmetic
  - Need repeated instructions to finish a task
  - Have trouble grasping general concepts.

- A survivor of a right hemisphere stroke may
  - Have problems understanding maps
  - Have trouble with short-term memory
  - Show poor judgment or impulsive behaviour.
How the survivor feels

A stroke has a sudden and dramatic effect on most survivors. It often causes them to feel fragile and vulnerable, frustrated, or extremely sad. This strong emotional impact can affect the survivor’s quality of life and recovery. Your support can help the survivor and the family deal with their emotions and adjust to the impact of the stroke on their lives.

Stroke recovery

The effect of stroke depends on:

- Where in the brain the damage occurred
- How severe the damage is
- Whether there is any collateral circulation – extra blood vessels in the affected area of the brain that can keep delivering oxygen and nutrients
- Neuroplasticity – how quickly healthy brain areas take over the functions affected by the stroke

For example, a mild stroke causes a small amount of brain injury. The survivor may recover most functions affected by the stroke. A severe stroke that causes a great deal of damage may mean a long recovery. Only parts of the functions affected may be regained.

Stroke survivors also recover differently as individuals, depending on factors such as:

- Age and general health
- Personality, coping abilities, and emotional state
- The support of family and loved ones
- Availability of rehabilitation
- Ability to take part in rehabilitation.

The most rapid recovery occurs during the first 3 to 4 months after stroke. Recovery continues over many months or years.

What is the difference between impairment and disability?

- Impairment is the change in function caused by the stroke.
- Disability is the change in ability to meet daily demands or do things because of an impairment. Disability can be extremely frustrating for the survivor.

Most survivors will have some impairment, even if it is only temporary. About 75% of stroke survivors have some long-term impairment. This will affect their ability to do daily tasks and take part in social and leisure activities. How much it will affect them depends on the person.

Two survivors who have similar strokes and similar impairments may feel different degrees of disability. One survivor might feel they now have a significant disability. Another might adjust to the impairment and resume activities important to them.
What you can do to help

You can help stroke survivors to:

- Relearn routine activities of living
- Regain abilities
- Cope with challenges and frustrations
- Do things they can’t do for themselves yet.

You are also an important support and educator for family members.
You can explain the changes their loved ones are going through because of the stroke.

Upon reflection

Would you be able to recognize the signs of a TIA or stroke?

Would you know what to do?

Are you at risk for a stroke?
What is an interprofessional care team?

The team is made up of the stroke survivor, their family, and their health care providers. The group designs a care plan for each stroke survivor. The team shares information. They also work together to develop care strategies and approaches. They report on how the stroke survivor is doing. They tell each other about changes in the survivor’s care.

The care team helps solve problems and manage issues that affect the stroke survivor. This involves assessment, diagnosis, care planning, implementation, and evaluation.

Assessment: You play an important role in carefully observing the survivor for problem signs and reporting them to the team. Team members can then do a closer assessment.

Diagnosis: The team’s doctor is responsible for identifying medical problems based on the assessment.

Care planning: The team recommends a treatment plan based on the assessment and diagnosis.

Implementation: Your knowledge and close contact with the stroke survivor play a big role in deciding on the best way to implement the plan.

Evaluation: Your observations help the team to judge whether the treatment plan is working well or if there need to be changes.

Team members need to be in touch with one another at all times. Sharing what you know about the stroke survivor with the team will help improve the survivor’s quality of life.

Talk to a team member if you see any problems or changes in the stroke survivor’s condition. You will often need to talk to the nurse or case manager.

The team members

The make-up of the team depends on:

• how severe the stroke was
• the loss of function
• who is there to help (some places do not have all types of health care professionals)

Each team member has knowledge and skills to add. With this team approach, stroke survivors get the best care.
**Doctors**

Doctors are responsible for the overall care of stroke survivors.

The doctors who look after a stroke survivor can include:

- a family doctor
- a neurologist (specialist who deals the nervous system)
- a physiatrist (rehabilitation specialist)
- other specialists, such as a cardiologist (heart specialist)

**Nurses**

Nurses help manage health problems after a person has a stroke. They also help find community services for stroke survivors and their families.

Nurses can include:

- a registered nurse (RN)
- a registered practical nurse (RPN)
- a nurse practitioner (NP)
- an advanced practice nurse (APN)

**Pharmacist**

A pharmacist knows how to manage medications and look for potential drug interactions or side effects.

**Physiotherapist**

The physiotherapist can teach the stroke survivor exercises and strategies to manage mobility, balance, and coordination. The physiotherapist may suggest specific mobility aids to improve the survivor’s independence.

**Occupational therapist**

The occupational therapist can help stroke survivors relearn how to do daily tasks on their own. They help stroke survivors learn new practical skills for everyday life and make the best use of their physical and mental abilities.

**Speech-language pathologist**

The speech-language pathologist works with stroke survivors who have trouble swallowing. They also help those who have trouble speaking, understanding speech and language, reading, or writing. They can help stroke survivors improve their speech and learn other ways to communicate. They can also help prevent problems caused by swallowing difficulties.

**Psychologist**

The psychologist helps stroke survivors who are having problems with thinking, memory skills, or emotional issues.
Social worker
The social worker can help the stroke survivor and family members cope with feelings of anger, sadness, depression, confusion, and anxiety. Social workers can also set up community services such as:

- caregiver support
- respite care
- job and career counselling
- help with moving to long-term care

Recreation therapist
A recreation therapist helps the stroke survivor learn new ways to resume their hobbies and interests. They can also help them choose and plan for new ones.

Dietitian
The dietitian helps the survivor and family plan healthy meals. This helps the survivor with their weight, cholesterol levels, dietary needs, or any problems with swallowing or eating.

Health care provider [such as a personal support worker (PSW) or health care aide (HCA)]
You provide hands-on care to the stroke survivor based on your team’s plan and strategies. You can help stroke survivors with activities of daily living, such as personal hygiene, feeding, toileting, positioning and transfers, and taking medication. You may also help with meal preparation, laundry or other tasks. When you do these things, you help improve the survivor’s quality of life.

Follow these principles of client-centred care:

- Respect each person as an individual
- Pay attention to the person’s physical comfort
- Give emotional support

The stroke survivor’s needs and wishes should always help determine how you provide support. Adapt your techniques to meet the needs and preferences of each survivor.

Other members of the health care team
There are other people who can contribute important information to stroke survivors care. Someone who works for housekeeping may inform the team of a survivor’s need to get up; a dietary aid may share that a stroke survivor did not touch a meal.

Stroke survivor
The stroke survivor is both the focus of the team’s efforts and a member of the team. As much as possible, the survivor should have input into the team’s decisions.

Primary caregiver, family, and friends
These people give important emotional support and social contact to the stroke survivor. They can be a great help with rehabilitation exercises. And, they are an important resource for you, because they can provide valuable insights into the survivor that will help you with their care. Because of their closeness to the survivor, they may be able to communicate needs that the survivor cannot express.
What you can do to help

- Know your main contact on the team.
- Provide regular updates about the survivor you care for, especially any changes.
- Ask your team contact for regular updates on recommended care strategies and approaches.

Upon reflection

Who are the members on your team?

How do you communicate with them?
SECTION 3
Communication

Section overview
This section looks at:
• Defining communication and communication partnerships
• How stroke affects communication
• How communication problems affect the stroke survivor
• Developing communication partnerships with stroke survivors
• General post-stroke problems that affect communication
• Specific communication impairments (dysarthria, aphasia, and cognitive communication impairments)

Communication
Communication means exchanging ideas through speech, language, gestures or writing. Communication is a basic, lifelong, human need from birth. By the time they are 3 or 4, children have become good communicators. We get better at communicating as we grow.

Connecting to others is often the basis of a person’s feelings of self-worth and well-being. Communication helps people stay connected to each other. Clear communication is also central to getting needs met.

Nonverbal communication
Recall a time when you understood someone’s feelings without that person saying anything. What did that person do to convey the message?

Everything we do sends a message to others. Even deciding not to speak with someone sends that person a strong message. We need to interpret both spoken (verbal) and unspoken (non verbal) messages.

We usually think of communication as talking with someone. Verbal communication is only one way of communicating.

Nonverbal communication includes:
• Posture
• Movement
• Facial expression
• Tone of voice

Your role as health care provider
You help the stroke survivor stay connected to the world. But communication is not a simple process. You need to understand the communication challenges that a stroke survivor faces. You also need to know strategies and techniques to help the survivor communicate.

Communicating with a stroke survivor calls for:
• Belief that every person can be reached
• Creativity in expressing your feelings and your message
• Understanding the effect of the stroke on communication
• Patience to slow down, listen, watch, and wait for a response
• Skill to convey messages effectively

Heart and Stroke Foundation
When you look at the person speaking, you show that you are interested. When you raise your eyebrow, shrug, cross your arms, or frown, you change the meaning of the words spoken. Nonverbal communication may have even more meaning than speaking.

For example, you see a woman who is crying and shaking. You ask if she is alright and she says yes. Do you believe her? You may not, but to read the meaning of her answer, you may need more information.

She may be saying, “No, I’m not alright, but I don’t want to be a bother.” She might mean, “No, I’m not alright, but I don’t want any help. Leave me alone.”

**Partners in communication**

Every conversation or interaction involves at least 2 equal communication partners. Both partners send and receive messages. Both have to understand the message the other one sends. As partners communicate with each other more often, they learn to read each other’s facial expressions and body language. Over time, their communication becomes easier and more successful.

**Stroke survivors may be less able to take an equal role in a communication partnership than other adults. When communicating with a stroke survivor, you may need to take more responsibility for the conversation than you would with other adults.**

**How stroke affects communication**

Stroke often impairs a person’s ability to communicate and connect with others. Communication problems also make it difficult to determine what the stroke survivor actually understands.

Stroke can cause specific impairments such as slurred speech (dysarthria), loss of language, (aphasia), and cognitive communication impairment (problems understanding and forming thoughts). We discuss these impairments later in this section.

Other stroke impairments can affect communication. Muscle weakness may alter facial expression or prevent the survivor from turning to face the person speaking. The survivor’s voice may be weak and hard to hear. These physical changes make it hard to communicate well.

Physical impairments can stop the survivor from walking down the hall to speak with someone or picking up a phone to call a friend. A survivor who lives alone may be unable to leave home to talk with neighbours and friends. These interactions are very important to the stroke survivor’s sense of connection with the people around them.

**Attitudes of others**

People may assume a survivor is not intelligent because he or she cannot communicate effectively. This can frustrate survivors even more. People often treat individuals with impairments as though they cannot think or speak for themselves. For example, staff in stores and restaurants often ignore people using wheelchairs, speaking instead to their physically able companions. These experiences can offend a stroke survivor. Being ignored can erode confidence. It can make the survivor avoid socializing.
Section 3: Communication

How communication problems affect the stroke survivor

Being unable to communicate frustrates stroke survivors. It can also make them withdraw from social situations. People might think that the stroke survivor cannot or does not want to communicate. When this happens, the stroke survivor may not have a chance to connect to another person – something we all need.

For true communication to occur, the survivor must:

- Understand what the care provider says
- Be able to express thoughts
- Be understood

The stroke survivor deserves respect. This person's values, interests, concerns, opinions, strengths, and weaknesses reflect a lifetime of experience.

Developing a communication partnership with the stroke survivor

As a health care provider, you may be the most important communication partner in the stroke survivor’s life. You may speak to the survivor more often than anyone else does. You can develop a good communication partnership with those in your care by following these tips:

- Provide time and opportunity to communicate. It takes time and effort to overcome communication problems
- Be clear about the message you are sending
- Show that you want to understand the other person’s message
- Respect the message the other person sends
- Trust that the other person wants to understand the message you are sending
- Show your understanding of the other person’s situation

When communication breaks down or is not easy:

- Be hopeful. What needs to be said will eventually be understood
- Be patient and persistent
- Be creative. There is more than one way to get your message across. Try drawing, printing words, or using different words
- Tell the other person that you do not understand something
- Admit you are frustrated
- Address the problem. Ignoring the problem sends a message that you do not respect the other person
- Don’t pretend to understand
- Don’t change the topic to avoid fixing the problem

Useful tips

Assess: Carefully observe the survivor to assess what he actually understands. Under-estimating his abilities can make him frustrated or angry. Over-estimating his abilities can lead you to believe he is being deliberately uncooperative.
**Set the stage:** Communicating is always easier if other things are not happening at the same time. Make sure there are few distractions. This will help both you and the stroke survivor communicate. For example, turn off the TV or radio.

**Get the person’s attention:** Approach the stroke survivor slowly and from the front. If needed, gently touch a hand or arm to help get their attention. Introduce yourself. Wear a large, easy-to-read name tag. The survivor may see many faces in a day. Know how the person likes to be addressed (for example, by Mr. or Mrs., by first name or by nickname).

**Make eye contact:** Face the stroke survivor if you can. Keeping eye contact (if culturally fitting) will help the person know who is speaking and may help them focus on your message.

**Deal with private matters privately:** Get permission before raising a private matter with family or friends. The survivor may share information with you that they are not ready to share with family. Always include the stroke survivor in a conversation.

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

**Pay attention:** The person’s reaction can help you know if you are being understood. Facial expressions and body language can tell you what the person understood.

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

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

### General post-stroke problems that affect communication

<table>
<thead>
<tr>
<th>Challenge</th>
<th>How you can help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical impairments prevent the stroke survivor from getting places or talking to people.</td>
<td>Ask the survivor where they want to go. Urge the person to use mobility aids or reposition the chair. Make sure the person can reach the telephone or call bell to contact family, friends, other residents, or staff.</td>
</tr>
<tr>
<td>The survivor cannot stand, which makes it hard to have eye-to-eye communication.</td>
<td>Move to eye level – squat or sit. Do not lean over the survivor. Do not step back – vision and hearing problems can be an issue. Begin the talk by making eye contact.</td>
</tr>
<tr>
<td>The survivor depends on others to move the wheelchair.</td>
<td>Ask the survivor where they want to go and how the chair should be moved. Tell the survivor what you plan to do before you move the wheelchair. Follow the person’s preference for moving the chair.</td>
</tr>
<tr>
<td>The survivor cannot change their facial expression to show emotions.</td>
<td>Ask the survivor how they feel.</td>
</tr>
<tr>
<td>Challenge</td>
<td>How you can help</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>The survivor has impaired hearing.</td>
<td>Talk face to face in a quiet room with good lighting on your face. If the survivor uses hearing aids, make sure they are working. You can use amplification devices, like Phonic Ear. The microphone needs to be close to you. This way, the survivor can hear you easily above background noise. Do not talk in a very loud voice. This can distort your speech and overload hearing aids, which can be painful. The conversation may be confidential. If you speak loudly, others may hear private information. Ask if the survivor can hear you. Position yourself where you will be heard easily. You may need to try different spots to find the right one. Ask questions. This way, you will know that your messages have been heard accurately.</td>
</tr>
<tr>
<td>Stroke has slowed the survivor’s responses.</td>
<td>Allow 5 seconds for responses or for the survivor to initiate a message. Create chances for communication. Take time to comment on pictures or personal objects. This indicates your interest and willingness to listen to the survivor. Give the person time to answer your questions. Stay long enough to hear the answer. If you cannot wait, ask the survivor if you can get information from family members or friends who are there.</td>
</tr>
<tr>
<td>The survivor has impaired vision.</td>
<td>Ask how well the survivor sees your face or the television. Urge the survivor to wear glasses, if they are needed. Make sure the survivor is wearing the right glasses for the task – distance glasses or reading glasses. Make sure the lighting is not too dark or too bright. If the survivor has a 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 the right side of the table. Ask the occupational therapist for ideas to handle visual field loss. These could include marking the left or right margins of printed materials with coloured lines.</td>
</tr>
<tr>
<td>The survivor cries or laughs at the wrong time and cannot stop (emotional lability).</td>
<td>Ask if the survivor feels sad or happy. Their emotional reaction may differ from how they really feel. Let the person know that you understand. Tell the survivor emotional reactions are common after stroke. Identify and record triggers for these responses. Avoid these triggers.</td>
</tr>
</tbody>
</table>
Specific communication impairments

Stroke injury to certain areas of the brain causes specific communication impairments. The extent of the injury determines the number of impairments and their severity. Communication impairments include:

- **Dysarthria**: Problems making the sounds of speech
- **Aphasia**: Difficulty using language
- **Cognitive communication impairments**: Problems understanding and communicating clearly.

The type of communication impairment determines which strategies can help the stroke survivor communicate.

**Dysarthria**

*Dysarthria* is a motor problem. It is caused by weakness and/or lack of coordination of muscles of the mouth, throat, and chest. Those who have dysarthria have trouble making the sounds of speech clearly. It can be caused by strokes on either side of the brain or in the brainstem. Words may sound slurred, the voice may be very soft, or the survivor may sound drunk. Survivors with dysarthria have not lost language. They can:

- Understand spoken language
- Read and write or type
- Think, plan, decide, and reason
- Use computers or other devices to communicate

Dysarthria makes it hard for the survivor to explain that only speech is affected. People unfamiliar with dysarthria may:

- Misjudge the survivor’s mental abilities
- Make guesses about the survivor’s desires
- Exclude the survivor from decisions

**How you can help**

It is easier to communicate with a person who has dysarthria when you:

- Communicate in a quiet place.
- Ask the survivor to speak *more slowly* and *loudly* than normally. Explain this is the best way to make speech easier to understand.
- Speak *slowly* in a normal voice. This encourages the survivor to speak slowly so that speech is easier to understand. Do not speak loudly or exaggerate your speech. When we speak slowly, we often use a louder voice and exaggerated intonation. This 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** as the survivor speaks, especially if the dysarthria is severe. A written record makes it easier for both communication partners to keep track of the conversation.
- **Provide paper and a pen or a white board and marker.** It may be easier for the survivor to write than talk. The survivor can keep these communication aids near by at all times.
- Consider a **computer** for e-mail or a **teletypewriter** (TTY or TDY). This a device for the deaf, used for the telephone. The survivor can use these devices, to type rather than talk.
- Try a **communication board** with pictures, words or phrases. These boards make it easier to communicate basic needs quickly.
• Use an \textit{alphabet board} to communicate more complex ideas. Write the words as the survivor spells them.
• Communicate about important issues when the \textit{survivor is rested}. Fatigue makes communication harder or impossible.

\textbf{Aphasia}

For most of us, the left side of the brain is the language side. Strokes in the left side of the brain can injure areas of the brain that control understanding and the production of words and sentences. This causes \textit{aphasia}. Aphasia is the \textit{loss of language}, or being unable to use language. Language includes sounds, meanings, and rules for combining words into sentences.

Aphasia may affect a survivor’s ability to talk, read, write or understand language.

Many people link communication skills with mental ability. They may misjudge the mental abilities of the survivor with aphasia. Survivors with aphasia can:

• Think, plan, decide, and reason
• Produce some clear words
• Understand facial expressions, gestures, and nonverbal communication

\textit{Remember} — people with aphasia are able adults who know more than they can say.

\textbf{How you can help}

When you are developing a communication partnership with a stroke survivor, knowing the person is just as important as knowing the communication strategies. Here are some ways you can help the person with aphasia communicate.

\textbf{Set the stage:}

• Talk face to face in a quiet room
• Give information in small amounts at a time
• Assure the survivor you understand that they know what they want to say
• Introduce a change in topic clearly: “I want to talk to you about your family”

\textbf{Be patient:}

• Speak slowly. Give the survivor time to respond
• When a survivor is struggling for a word, don’t jump in too quickly
• Allow survivors to express themselves to the best of their ability
• Supply the word only when the survivor is too frustrated

\textbf{Provide specific choices. Avoid open-ended questions:}

• Ask: “Are you hungry or feeling ill?” Not: “What’s wrong?”
• Ask: “Would you like an apple or an orange?” Not: “What would you like to eat?”

\textbf{Break down longer questions into yes or no questions:}

• Would you like tea? Would you like coffee? Would you like juice?
• Wait for a yes or no answer to each question
• If the answers seem inconsistent, explain what you understood. Then tell the survivor you are going to repeat some questions

**Use pictures and objects:**

• Use pictures and objects to show what you mean. Even drawings can help.
• Use maps, calendars, schedules, and clocks when talking about where and when.
• Print key words in large, clear letters on paper as you speak.
• Urge the survivor to show you, to draw, or to print. At first, the person may refuse to draw or print. The stroke can affect the writing hand. Tell the survivor you know it is very hard to use the other hand, but that they need to try.
• Ask family members to bring in photos or other materials. These give staff starting points for conversations with the survivor. Develop a Life History Book with the survivor, family and friends. The survivor can use this book to get to know new people.

**Always include survivors in any conversations that concern them:**

• Never underestimate the survivor’s ability to understand nonverbal information, especially when it is personally relevant.
• Expect communication ability to vary – survivors have good and bad days, and good and bad times of day. Printed key words might work perfectly one day, but not the next. Keep using strategies that have worked, even if they don’t always work.

**Dealing with inconsistent or inappropriate speech**

Survivors may use words they don’t intend to use. These words may be related to the word that they wanted to say – saying *brother* instead of *sister*, or saying *on* instead of *off*. Ask questions in a different way. This makes sure the survivor communicates what is intended. Print the right word when you determine what the survivor meant.

If you are unsure what the survivor said or meant, explain you have not got the message yet. Ask the survivor to repeat what was said. You can also ask the survivor if it is alright to ask questions to help you understand. Do not pretend to understand.

**Yes or No?**

Survivors may say *yes* when they mean *no*. Work with the survivor to develop a nonverbal *Yes/No* you can use all the time. Try using *thumbs up* for yes and *thumbs down* for no. The survivor can also point to the printed words on Yes/No cards. Listen closely to the intonation. If the person says *Yes* in an angry or frustrated way, ask if they meant *No*.

**Emotional words**

Some survivors may swear and use angry-sounding phrases when frustrated. This does not mean that this person is trying to be rude or is angered easily. Acknowledge the frustration, and ignore the out-of-place language. Swear words and phrases used when angry or surprised are connected to emotion centres in the brain. These connections can still be strong when other language areas in the brain are damaged.
Because these connections are strong, the survivor can find it hard to suppress this kind of speech – even though this person would not have used these words in the past. Sometimes, the survivor will use swear words and strong phrases when feeling any strong emotion.

Fluent aphasias

A survivor may not say many recognizable words. Survivors with fluent aphasias may talk constantly without making much sense. This kind of speech can contain made-up words or phrases with no real content. These survivors are usually unaware of the fact that their speech is incomprehensible. It is important that you still take the time to tell them that you are having trouble understanding them. Focus on nonverbal strategies, like pictures and printed words, when communicating with these survivors.

Cognitive communication impairments

A severe stroke, multiple strokes, or a right hemisphere stroke may cause difficulty with organizing thoughts, concentration, memory, and knowledge of nonverbal communication. These problems cause cognitive communication impairments, a reduced ability to understand and communicate clearly.

A right hemisphere stroke can cause a specific group of communication issues. These include:

- Trouble concentrating
- Problems understanding facial expressions and other nonverbal communication
- Trouble understanding verbal humour, sarcasm, hints, and jokes

This survivor may have trouble getting to the point and wander off topic. They may also give too much or too little information.

People who do not know the survivor may overestimate their communication abilities and think the survivor is being rude. Survivors with right hemisphere communication impairments can:

- Speak clearly in full sentences
- Understand direct, concrete communication
- Tell familiar jokes and laugh at these jokes
- Write some words and sentences
- Read (sometimes)

A survivor with right hemisphere communication impairments presents several challenges to communication partners. The survivor:

- Can talk well, but the conversation can jump around or wander off-topic
- Does not provide all relevant information on a topic
- Makes little eye contact, especially with people on their left (left neglect)
- May appear rude
- May have problems concentrating
- May have trouble understanding or remembering what they read
- May not see letters and words on the left

How you can help

You can communicate well with a survivor who has right hemisphere issues using these strategies:
Maintain the **focus** of the conversation:

- Request eye contact
- Ask specific questions to get more information
- Remind the survivor of the topic being discussed
- Tell the survivor when you are leaving

**Stay on the right:**

- Always approach the survivor from the **right**
- Get their attention before moving to the left
- If you need to, stay on the right

**Communicate directly:**

- Say exactly what you mean, even if it feels rude at first
- Avoid humour, sarcasm, hints, and other indirect ways of communicating

**Help the survivor remember the conversation:**

- Provide a simple, printed summary of what you discussed
- Use print or pictures if the survivor can see, understand and remember this material
- Keep print information short and direct. Use large, clear print

**Deal with what you see as rudeness:**

- Remember that the survivor is not being rude on purpose
- Tell the survivor how you feel about this behaviour
- Tell the survivor what would work better
- Help the survivor change communication that appears rude

---

**Upon reflection**

*Have you ever communicated with a stroke survivor with aphasia?*

*What were some strategies that worked? How did you feel?*
Section overview

This section looks at:

• Defining pain
• Facts about post-stroke pain
• Types of pain in stroke survivors
• Identifying pain in stroke survivors
• Pain assessment and pain scales

Your role as health care provider

You spend time with stroke survivors. This means you may be the first person to see signs of pain. Tell the members of the care team if the stroke survivor has pain. Then the survivor can get that pain assessed and treated quickly and properly. This can make a big difference to the stroke survivor’s quality of life. You can also reduce the survivor’s pain by using the care strategies and approaches recommended by the interprofessional care team.

Defining pain

Pain is a sensation in your body that causes acute discomfort or suffering. Everyone experiences pain at some point – a sore back, a broken leg, or a cut finger.

Pain can be described by:

• How long it has been present (duration) or
• What causes it (source)

Duration of pain

Pain is either acute or chronic.

Acute pain is usually short lived. It comes from an event, such as surgery or trauma. If it is not treated properly, it may lead to chronic pain.

Chronic pain usually lasts more than 3 to 6 months. It lasts longer than the time it takes a wound to heal. Chronic pain may cause anxiety, fear, depression, and sleeplessness. People with chronic pain may become cut off from others.

Sources of pain

Tissue damage leads to a pain that can be sharp, dull, or aching. This pain may start from the source of damage.

Nerve damage can be in either the:

• Central nervous system (the brain and spinal cord) or
• Peripheral nervous system (the nerves outside the central nervous system)

People who have nerve damage describe the pain in many ways: sharp, burning, or shooting, like a sudden shock, aching, tingling, pricking, cutting, piercing, stabbing, or numbness. For some, even a light touch may cause severe pain.

Identifying the type of pain is important. Knowing what type it is helps you find the right treatment.

Pain is very common in stroke survivors.
Important facts about pain in stroke survivors:

- Pain may be present in parts of the body with impaired mobility
- People with dementia or cognitive impairment experience pain
- Pain may be present even if the individual is not conscious
- Pain affects quality of life
- Among survivors who live in long-term care homes and those who are elderly, studies show:
  - 1 in 2 have ongoing and frequent pain
  - 1 in 4 have pain daily
  - 7 in 10 have untreated pain

If not treated properly, pain:

- Causes anxiety, sleep disturbances, memory problems, depression, impaired posture, and reduced appetite
- Interferes with daily activities like going to the bathroom, dressing, and grooming
- Reduces the ability to move around, talk to other people and participate in recreational activities
- Increases irritability and causes people to refuse care

Central post-stroke pain

Less than 10% of survivors have central post-stroke pain. This pain is caused by damage to the brain or spinal cord from a stroke.

The survivor may be in constant pain or might find that their pain comes and goes. It feels like burning, tingling, stabbing, or like acid under the skin. Physical activity, a light touch, stress, cold temperature, or a change in the weather can worsen the pain. The survivor may complain of pain:

- Where there is no visible tissue damage
- From a light touch, such as bedding touching the legs
- When pain is unusually severe – for example, when a person feels extreme pain after bumping their elbow

Managing central post-stroke pain

This type of pain is very difficult to treat. It may only partially respond to intervention. Some survivors manage pain through:

- Nerve blocks
- Local anaesthetic drugs
- Pain medications
- Antidepressants
- Anticonvulsants

By identifying central post-stroke pain before it becomes chronic, survivors can get help early. This can have a positive effect on long-term management of their pain.

How you can help

- Watch for symptoms that may indicate the stroke survivor is in pain.
- Acknowledge the survivor’s pain.
- Report the pain to the appropriate person, so that a specialized consultation can take place.
Hemiplegic shoulder pain

*Hemiplegia* is paralysis of one-half of the body. Hemiplegic shoulder pain – shoulder pain on the side affected by stroke – is very common. The pain may begin within a few weeks of the stroke or 2 to 3 months later.

The shoulder joint can move in many directions. Other joints have strong ligaments to hold the joint in position. However, the shoulder has only muscles for support. Muscle tone, the slight tension always present in normal muscle, counteracts the downward pull of gravity and holds the shoulder joint in position.

Muscles affected by stroke may no longer hold the joint correctly aligned, causing pain and movement problems such as:

- Partial dislocation or shoulder *subluxation*
- Having a muscle that is stiff and contracted (*spasticity*) or overstretched and limp (*flaccidity*)
- Shoulder or hand syndrome: shoulder pain followed by a stiff, swollen and painful hand and wrist

Identifying and treating shoulder pain early is important. Treatment is difficult and may be even more difficult after the pain is established.

Shoulder subluxation

Shoulder *subluxation* (partial dislocation) results from low muscle tone. A low-tone limb appears limp and heavy. Low-tone muscles around the shoulder allow the joint capsule to stretch and the shoulder joint to separate. Gravity then pulls the arm further down. The survivor may be unaware of the arm position. Subluxation is not always painful.

Failing to support the shoulder joint or pulling on the affected arm during transfers can cause the shoulder to partially dislocate.
How you can help
Careful handling and positioning can prevent injury and pain. Early supportive positioning and handling of the arm by staff and family members can help prevent subluxation.

- Always handle the shoulder carefully. This can help prevent painful stretching of shoulder muscles and ligaments.
- Support the shoulder joint appropriately when the survivor is walking, standing or sitting.
- If you are not sure about the care strategies, talk to members of the health care team. They include a physiotherapist, occupational therapist, or physiatrist.

Spasticity (High Tone)
Muscle spasticity involves abnormally high muscle tone. Spasticity shortens the muscles and reduces the shoulder joint space. Spasticity also prevents normal arm movement and results in stiff and painful joints. The pain of spasticity is like a muscle cramp.

A doctor and physiotherapist are often involved in managing spasticity. Injections of botulinum toxin (also known as Botox™) can reduce spasticity. Muscle relaxant medication may be helpful.

The physiotherapist may recommend approaches to assist with a spastic hand.

How you can help
You can help prevent spasticity from getting worse by handling and positioning a high tone limb carefully.

Treat the high-tone arm gently. This means:

- Not forcing the arm to move
- Applying prescribed splints properly for the correct length of time
- Using proper positioning

If you are not sure about the care strategies, talk to members of the health care team. These include a physiotherapist, occupational therapist, or physiatrist.

Shoulder or hand syndrome
Shoulder or hand syndrome may begin with shoulder pain. The person can develop a stiff, swollen, and painful hand and wrist. They may also have a decreased range of motion in both the shoulder and hand. A pain management specialist may recommend nerve blocks, specialized pain medications, electrical stimulation, motor imagery, exercises and other approaches to manage the pain.

How you can help

- Use recommended positioning to protect the affected arm and hand
- Use the prescribed exercises
- If you are not sure about the care strategies, talk to members of the team, especially the physiotherapist, occupational therapist, or physiatrist
Other shoulder and arm conditions

Other conditions affecting the arm or shoulder may cause stroke survivors pain. These conditions can be present before the stroke. They can also develop because of injury after the stroke. Common conditions include:

**Rotator cuff tear:** The *rotator cuff* is the name for the group of muscles holding the shoulder in place. A tear may have been present before the stroke.

**Tendonitis:** A *tendon* is a tough fibre that connects a muscle to a bone. Tendonitis is inflammation of a tendon. Tendonitis affecting the shoulder most often results from inflammation of the long head of biceps, due to overuse or injury.

**Shoulder bursitis:** A *bursa* is a small, fluid-filled sac that reduces friction and allows tendons around the joint to glide more easily. Bursitis is inflammation of a bursa. Shoulder bursitis is caused by *impingement* (pinching) of the shoulder bursa.

**Upper arm fracture:** Fractures of the upper arm bone are common shoulder injuries. These fractures are often due to osteoporosis and are common in older individuals.
Identifying pain in stroke survivors

Lack of consciousness does not always mean lack of pain.

Stroke survivors may not say they are in pain – but they may express pain in the following ways:

**Verbally**
- Using pain words: burning, itching, throbbing
- Making sounds: moans, groans, grunts, cries, gasps, sighs
- Exclamations and cursing: That hurts! Ouch! Stop that!

**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
- Impairment of bowel and bladder function

**Through facial expressions**
- Frowning
- Grimacing
- Wincing

**Through behaviour changes**
- A usually restless survivor is quiet
- A usually quiet survivor is restless
- Change in appetite

Those with impaired communication may need a family member to explain how the survivor shows pain.

You can use a translation list to ask about pain, if the survivor speaks a language that you do not know.

**Pain assessment**

Pain assessment is completely subjective. There is only one person who knows how severe the pain is – the person feeling it.

Pain is hard to assess. Older people may not report pain because they may:
- Believe pain is part of aging
- Not want to be a burden
- Have impairments that make it hard to communicate
Pain scales

Using a pain scale regularly helps track an individual's pain severity and pattern. You can use it to assess pain at different times, before and after treatment. Pain assessment scales are simple to use. The survivor simply points to the number on the scale that represents the amount of pain they feel. On this scale, 0 is no pain and 10 is the worst pain possible. Ask your team what scale is used where you work.

Numeric rating scale

Aphasia rating scale

Be observant and recognize pain in the stroke survivors you care for. Up to 70% (7 out of 10) survivors in long-term care homes have untreated pain.
Pain is inevitable — suffering is optional.

**How you can help**

Your knowledge of the individual survivor is an important tool in identifying pain. Ask survivors who report pain for more information:

- Ask yes or no questions
- Use simple words to help survivors identify the problem
- Point to areas that may be painful when asking questions
- Ask about pain during or after movement
- Be patient and take time. Stroke survivors may need more time to explain what they feel
- Use a pain assessment scale regularly to track a survivor’s pain. Survivors whose pain is being treated may still experience pain
- Discuss the survivor’s pain and pain management with the team. Ensure that pain management strategies and medication are adequate

**Upon reflection**

Can you recall caring for a person in pain? How did you provide support?

Some strokes affect how survivors communicate. Describe some ways they may indicate they have pain.

If you find that someone you are caring for is in pain, what should you do? Who would you report it to?

What strategies would you use to help someone with pain?
Section overview
This section looks at:

- Explaining cognition
- Some of the possible cognitive problems after stroke
- Strategies for helping stroke survivors with cognitive problems

Your role as health care provider
When you understand how a stroke affects the survivor’s cognitive abilities, you can provide better care and support. You play an important role helping the stroke survivor stay safe. You can also help the survivor learn to be more independent.

Cognition
Cognition refers to how we know things and how we think. Cognition involves:

- **Attention**: Being able to concentrate on one thing for a period of time.
- **Orientation**: Being aware of time, place, and who we are.
- **Memory**: Being able to retain and recall personal experiences, information, and skills.
- **Insight**: Knowing and understanding our abilities and limitations.
- **Judgment**: Making good choices and decisions while being aware of our own capabilities.
- **Sequencing**: Being able to arrange things or perform actions in the right order.
- **Problem solving**: Knowing how to recognize a problem and find a good solution.

Cognitive problems
Cognitive problems are *invisible barriers*. They are not as easily seen as physical problems. A survivor with cognitive problems may not appear to have any impairment. Yet, cognitive problems can have a major impact on a survivor’s function and level of independence.

Family and friends can sometimes overestimate the survivor’s abilities. They may become frustrated and angry with the survivor who has cognitive problems. They may believe that the survivor is acting this way on purpose, is unmotivated or being stubborn. However, we might be expecting too much.

Do not confuse cognitive problems related to stroke with dementia. Although some stroke survivors may also have dementia, you need to know the difference to provide the survivor with the right care.

After someone has a stroke, their cognitive abilities may be affected. A stroke survivor can improve some of these skills over time. However, some problems may persist and adaptive strategies need to be considered. In this section, we go through some of the cognitive problems and adaptive strategies that can help.

Identify problems and find strategies to help the survivor with cognitive problems. Doing so can help the survivor perform tasks. It also reduces frustration among family, friends, or care givers.
Attention

Attention means being able to focus on one thing. Survivors may have a short attention span. They may be easily distracted. This limits their ability to focus on a task. The survivor may need more time to finish a task because of distractions.

How you can help

- Get rid of any distractions – including television, radio, and other conversations
- Give short, simple, step-by-step instructions. Make sure the survivor understands the instructions before you continue. Help the survivor focus on one thing at a time
- Make direct eye contact – this helps the survivor focus on what you are saying and follow your instructions
- Give the survivor more time to think
- Slow down so the survivor doesn’t feel pressured

Orientation

Orientation is the awareness of time, place and person. After a stroke, the survivor may lose some awareness in any or all of these areas. For instance, the survivor may think the year is 1975, or the season is fall instead of summer. The survivor may think that they are in school instead of a long-term care home. Or, they may not know their correct date of birth or age.

How you can help

- Give gentle reminders and the correct information. Do not make the survivor feel foolish
- Include the date when greeting the survivor. For example: Good morning, Mrs. Smith
  Today is Wednesday, October 15th
- Post a calendar to help the survivor keep track of the day and date
- Use a bulletin board to list personal information and post family pictures
- Limit changes to the survivor’s schedule to keep them from getting confused

Memory

Memory means being able to retain and recall personal experiences, information, and skills. Attention is the basis for most types of memory. A survivor who cannot pay attention to new information cannot store it in memory. Memory problems can affect the stroke survivor’s ability to learn new information and carry it over to everyday tasks. Stroke can affect different types of memory:

- Short-term memory: The name of a person you just met.
- Recent memory: What you ate for breakfast.
- Long-term memory: Memories from childhood.

How you can help

- Encourage the survivor to use memory aids. These may include a daily planner, calendar, and sticky notes
- Repeat information to help the survivor remember it
- Store items in the same place. Label drawers and cupboards with the contents
- Provide simple, clear information. Provide only the key information. This helps the survivor focus on what is important
• Present new information one step at a time. This allows the survivor to concentrate on one piece of information before moving to the next step
• Use signs or pictures as memory cues. You may want to place a sign on the survivor’s door and family pictures on the bulletin board

Case example:
Mrs. Wright has experienced some memory problems as a result of her stroke. She often becomes upset when she cannot remember where familiar items are stored or what she did the day before.

Fiona (her support worker) helps Mrs. Wright by jotting down the day’s activities in a journal. When Mrs. Wright is uncertain about an event, she can look it up. As a result of these “reminders”, Mrs. Wright often can recall the event. In order to help Mrs. Wright find stored items, Fiona takes care to return each item to the same place. Labels on the outside of Mrs. Wright’s cupboard help her to locate items more easily.

Insight
Insight means recognizing and understanding your abilities and limitations. A lack of insight may lead a survivor to perform unsafe actions. For example, a survivor may not recognize that a weak leg makes it unsafe to walk alone.

How you can help
• Make the environment as safe as possible
• Have walking aids and other assistive devices close at hand for survivors with impaired mobility
• Gently remind the survivor about the stroke and the resulting limitations
• Provide the necessary amount of supervision to ensure the survivor’s safety

Case example:
Mr. D’Angelo had a stroke three years ago. He thinks he can transfer to and from the toilet independently but in reality requires assistance due to his poor balance. As a result, Mr. D’Angelo is at high risk for falling.

When he was first assigned to assist Mr. D’Angelo, John (his support worker) discussed this issue with Mr. D’Angelo’s wife and his occupational therapist. Together, they developed strategies to reinforce with Mr. D’Angelo the need to call for assistance during toilet transfers.

Judgment
Judgment means making the right choices and decisions while being aware of one’s own capabilities. With impaired judgment, the survivor may make choices that are not safe, for example, not wearing the right clothing in extreme weather.
How you can help

- Discuss your concerns about the survivor’s safety with the team
- With your team members, develop strategies to optimize safety and functioning
- Do not place the survivor in difficult or challenging situations. The survivor may be unable to decide what actions are safe
- Maximize the safety of the environment. If the survivor uses a wheelchair, make sure the wheelchair seatbelt is fastened. If the person uses a walker, keep it within reach

**Impulsivity**

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

How you can help

- Encourage the survivor to slow down
- Give clear and specific instructions
- Divide tasks into small steps. This lets the survivor focus on one part of the task at a time
  Make sure that the survivor performs one task before moving on to the next. For example, “Swallow that mouthful of food first. Then you can take another bite.”
- Make the environment as safe as possible. Make sure that walking aids and assistive devices are close by

**Sequencing**

*Sequencing* means being able to arrange things or perform actions in the right order. A survivor with sequencing difficulties may be unable to start a task because the survivor doesn’t know where to begin. The survivor may do things in the wrong order. For example, the survivor 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 survivor understand the task
- Help the survivor plan the task. Encourage the survivor to think through the task. Explain the next step to the survivor if needed
- Give the survivor time to practice the task, even though it takes a while or is difficult
- Repeat the task the same way each time

**Sample Sequencing**

*To put on a sweater, the survivor is instructed to:*

a) Put the affected arm into its sleeve first
b) Put the unaffected arm into its sleeve
c) Pull sweater over head
d) Pull sweater down in back

This sequence is repeated in the same order each day.
Problem-solving

*Problem solving* is being able to recognize a problem and find a good solution. Problems with insight, sequencing, and memory can affect the survivor’s problem-solving ability. For example, the survivor may be unable to get toothpaste out of the tube, not realizing that the cap has to come off the tube.

How you can help

- Break tasks into small steps. Focus on one step at a time. This helps the survivor focus on one part of the problem before moving to the next.
- Give verbal cues. This helps the survivor develop the solution to a problem.
- Help the survivor identify different ways of solving the problem. Talk about the different ways the problem could be approached.

Upon reflection

Think of an everyday task, like brushing your teeth. What challenges might you have if you had problems with memory? What about sequencing? What about attention?

What 3 strategies would you use to support a stroke survivor who has problems with orientation?
Perception

Perception refers to the way we understand our environment. Perception is how we process and interpret information from our senses: vision, hearing, touch, taste, and smell.

Practice and repeating activities can improve perceptual abilities.

Stroke may cause different perceptual problems, including:

- **Time awareness**: How we see time passing
- **Spatial relations**: How objects relate to each other and how we relate to objects in the environment
- **Visual neglect**: Less awareness of the body and environment on the side of the body affected by the stroke
- **Unilateral body neglect**: Less awareness or failure to attend to the affected side of the body
- **Apraxia**: Difficulty making purposeful movements even though the survivor has the physical ability and the understanding to perform the task
- **Perseveration**: Repeating a word, phrase, or action and not being able to stop
- **Vision problems**: Double vision, partial loss of vision in one or both eyes, and visual field loss

Like cognition problems, perceptual problems are *invisible barriers*. They are not as easily seen as physical problems. A survivor with perceptual problems may not appear to have any impairment. Perceptual problems change how the survivor interprets what they see and how they make sense of the world.

Family and friends may sometimes expect too much of the survivor. They may become frustrated and angry, believing the survivor is acting this way on purpose or is not motivated enough.

We need to see perceptual problems as effects of the stroke. You can help by identifying the problems and using strategies to help the survivor function. This may also reduce frustration among family, friends, and caregivers.
Time awareness

*Time awareness* is the recognition of time passing. After stroke, the survivor’s understanding of how time passes may change. For example, the survivor may want dinner soon after finishing lunch, not realizing that only 20 minutes have passed.

**How you can help**

- Link events to other events, not to specific times. For example, *Bingo will start after lunch*, rather than *Bingo is in an hour*.
- Review the daily schedule with the survivor.
- Maintain a consistent schedule to limit confusion.
- Reassure the survivor who is anxious about an appointment or meeting. Tell them you know about the appointment and will let them know at the right time.
- Listen to the survivor, but let the person know the reality: *I know it seems like I left you for hours, but I have only been gone for 15 minutes*.
- Use a digital clock or talking clock.

### Case example:

Mr. Barton asks his support worker to find out if it is time to go for lunch. The support worker explains to him that it is only 10:00 a.m. and that lunch isn’t until 12:00 noon. He then positions Mr. Barton’s digital clock so that he can see it.

Spatial relations

*Spatial relations* refer to how objects relate to each other and how we relate to objects in the environment. Problems with spatial relations can include:

- Misjudging the height of steps
- Pushing towards the affected side during transfers
- Knocking items over
- Missing the chair when sitting down
- Tripping over rugs, steps, and uneven pavement

**How you can help**

- Talk with your team about the best strategy or assistive devices to use. Some examples are: a non-spill cup, fluorescent tape at the edge of steps and on the lip of the bathtub.
- Encourage the survivor to practise and repeat actions. This may help the survivor become familiar with the activity and retrain the brain.
- Make the environment as safe as possible. For example, get rid of clutter to prevent the risk of falling.

Visual neglect

*Visual neglect* causes decreased awareness of the body and environment on the side affected by the stroke. The survivor may pay attention to only part of an object or part of a view. They may bump into things on the affected side. They may not see food in front of them on the affected side.
How you can help

- Arrange the environment to provide stimulation on the stroke-affected side. This helps the survivor become more aware of the whole environment.
- Approach the survivor from the unaffected side to avoid startling them. Then, move to the affected side to speak. This provides stimulation on the affected side.
- Use visual cues to assist the survivor. For example, place a line of red tape at the edge of a table on the affected side.
- Encourage the survivor to scan the environment. One strategy is called the *Lighthouse Strategy*: Ask the survivor to imagine their eyes as beams of light sweeping from side to side. Remind the survivor to use the Lighthouse Strategy during activities.

Case example:

Mr. Wong has left neglect. When a support worker approaches him, she goes to his right side first. Once he is aware that the support worker is there, she crosses over to his left side to provide stimulation on that side. In this way, she encourages Mr. Wong to attend to that side of the environment.

Unilateral body neglect

*Unilateral body neglect* is a decreased awareness or failure to attend to the affected side of the body. The survivor of a right brain stroke may ignore the left half of their body. The survivor may forget to dress the affected side or may leave the affected arm hanging over the side of the wheelchair.

How you can help

- Talk with the team about using the affected arm or leg in daily activities
- Position the affected arm so the survivor can see it
- Gently rub the affected arm to stimulate sensation and awareness
- Encourage the survivor to help position the affected limb
- Use cues to draw attention to the affected side. For instance, ask the survivor “Where is your arm?”

Case example:

Mrs. Brown initially had a problem with leaving her affected left arm hanging over the side of her wheelchair. She was provided with a lap tray. Support workers reinforced the importance of positioning her left arm on the lap tray so that it would not get injured. Over time, Mrs. Brown became better able to place her affected arm on the tray without cueing.

Apraxia

Apraxia is difficulty in making purposeful movements, even though the survivor has the physical ability and understanding to perform the task. This happens because messages from the brain to the muscles are not being processed properly.

Apraxia can affect how the movement is planned for both sides of the body, not just the affected side. For example, the survivor may still have trouble performing simple, everyday tasks like hair brushing or getting dressed. Apraxia can also affect the survivor’s ability to speak.

How you can help

- Talk with the team about the best strategy or assistive devices to use. These may include physical cues, verbal cues, and demonstration
- Use short and simple instructions to limit confusion
- Break the task into simple steps. Use these steps every time the task is performed
- Encourage repetition and practice of activities
- Provide hand-over-hand guidance if necessary. Guide the survivor but do not perform the task

Case example:

Initially, Mr. Black would try to use his toothbrush to comb his hair. Each day, support workers guided Mr. Black’s hand as he used his toothbrush to brush his teeth. A few weeks later, Mr. Black was able to pick up his toothbrush and use it correctly without assistance.

Perseveration

Perseveration is the uncontrollable repetition of a word, phrase, or action. When this happens, the person cannot move on to the next activity or thought. The survivor may seem to get “stuck”. For example, they may keep washing their face over and over, or keep repeating the same word.

How you can help

- Plan the task with the survivor. This will help the survivor understand the steps involved.
- Provide clear, step-by-step instructions. Give the survivor time to practise the sequences.
- Help the survivor stop if they get “stuck” and assist them to start the next step.
- Provide hand-over-hand and visual cues. For example, showing the survivor a cup during teeth brushing to cue the person to stop brushing and begin rinsing.

Vision problems

Problems with vision are fairly common after a stroke. Problems include:

- double vision
- partial loss of vision in one or both eyes
- blurred vision
- visual field loss
Sometimes, vision problems improve in the weeks after a stroke. However, many survivors must learn to adapt to their vision problems using techniques taught to them by their therapists.

**How you can help**

Talk with the team about the best strategies for dealing with a specific vision problem – for example, from which side to approach the survivor.

Encourage the survivor to use the techniques the team recommends to deal with vision problems during activities. These techniques might include:

- The *Lighthouse Strategy* (imagining the eyes as beams of light sweeping from side to side)
- Visual cues such as a sign on the door saying “bathroom” to help the survivor find the way
- Reference points or anchors – for example, red tape on the edge of a table

For visual field loss:

- Encourage the survivor to turn their head to the affected side
- Place items on the affected side to increase the survivor’s awareness of that visual space
- Encourage the use of an eye patch or prism glasses, if prescribed

**Upon reflection**

*What are three strategies you can use for someone who has unilateral body neglect?*

*Think of someone you have cared for who had problems with spatial relations. How did you help that person stay safe?*
The impact of stroke on the survivor’s feelings and social life

Stroke can affect the survivor's emotions and self-image. It can also affect relationships with family, friends, and others. Many people who survive a stroke feel fear, anxiety, frustration, anger, sadness, and grief for their physical and cognitive losses. These feelings are a natural response to the effects of a stroke. Survivors may feel they are on an emotional roller coaster. They may feel angry one minute and sad the next.

Some emotional disturbances and personality changes are also caused by the physical effects of brain damage. These feelings may or may not be depression. It is important for a doctor to decide if the person is depressed or just having a normal reaction to the effects of a stroke.

First reactions

Shock is the first emotion most people feel after stroke. They might ask, Why did this happen to me? How could this have happened?

Survivors who cannot speak can feel very isolated and frustrated by their inability to communicate.

Survivors may wonder if they will survive. They may worry about having another stroke. They may be unsure what life will be like.

They may be concerned how their family will cope. They might wonder if they will work again. Anxiety is a normal reaction to the changes that occur after a stroke. It usually decreases as the survivor adapts.

Later reactions

As time passes the stroke survivor may have these feelings:

Frustration about:

• Physical limits
• Memory loss
• Trouble speaking

Fatigue from:

• Effects of stroke
• Increased effort needed to do routine tasks
Not seeming to care (lethargy) about social contact:

- Being embarrassed about physical changes
- Having trouble speaking or being understood

Sadness about:

- Loss of abilities
- How they feel about themselves
- How they believe others feel about them

How you can help

You can help stroke survivors find value in their lives.

- Be supportive and encourage the survivor.
- Find out how the survivor is feeling. Look for signs of depression or other emotions that affect the survivor in a negative way.
- Share your findings with the interprofessional team.
- Allow the survivor to do what they can. Provide support if the task becomes too hard, frustrating or tiring.
- Offer positive feedback. When a survivor is managing well, say so.
- Gently offer information that helps the survivor be independent

Post-stroke depression

It is normal to feel sadness and a sense of loss after a stroke. But sometimes a stroke survivor can develop a true clinical depression.

Depression is a sense of hopelessness. It disrupts a person’s ability to function. It is common among stroke patients. But depression can be treated. And the faster it is treated, the better.

About one-third to one-half of survivors suffer from depression during the year after a stroke. Post-stroke depression can occur right after stroke. Most often, it develops within 3 months. Depression can also occur up to 2 years after stroke.

Depression gets in the way of physical and mental recovery. It can decrease energy, so the survivor participates less in rehabilitation. It can reduce the survivor’s ability to care for themselves. Depression in a stroke survivor can also affect the health of caregivers at home.

Less than half of survivors with post-stroke depression are identified. Learn to recognize the signs of depression and get help fast. If a survivor is thinking about death, dying, or ending their life, report this information to your supervisor immediately.

Is it “the blues” or clinical depression?

Only a doctor can diagnose clinical depression. However, recognizing how stroke survivors are feeling, and sharing that information with the team, can help identify depressed individuals. To do that, you need to know the difference between feeling sad and being clinically depressed.
Section 7: Stroke and depression

7.3 Signs of post-stroke depression

**Physical signs**
- Trouble sleeping
- Weight loss
- Decreased energy
- Easily fatigued

**Attitudes**
- Not caring about anything
- Loss of interest in things that were previously enjoyed
- Negativity: everything is gloomy
- Self-focus: me, myself and I
- Difficulty connecting to others

**Emotions**
- Feelings of hopelessness and worthlessness
- Sadness and anxiety or nervousness
- Thoughts of death and suicide
- Difficulty coping, easily overwhelmed

**Mental function**
- Difficulty concentrating
- Problems making decisions
- Confused, feeling of living in a fog
- Short-term memory problems

It is not always easy to see depression. People do not always know when they are depressed. They may be ashamed of being depressed. They may think that depression is a normal reaction to loss. The survivor may not want to admit to being depressed. They may think that treatment will change their personality or have side effects.
Health care professionals may not know that the stroke survivor is depressed. They may mistake the signs and symptoms of depression for the effects of the stroke or aging. It is also difficult to assess a survivor with communication or cognitive problems.

**How you can help**

You are the team member who is the closest to the survivor. You can help identify depression through what you see and your conversations with the survivor.

**Know the survivor:**
- Get to know the survivors you look after. It can help you identify mood changes
- Take the time to listen
- Talk to family and friends. Find out what they were like before the stroke
- Have team discussions. Learn about the survivors you look after from other staff

**Communicate with the survivor:**
- Depression is a medical illness. Always communicate with caring and hope. Be accepting – not judgmental
- Learn how to communicate with survivors who have communication problems
- Ask survivors how they are feeling. If they are feeling pain, make sure they get treatment to relieve the pain

**Observe the survivor. Look for:**
- New symptoms
- Sudden changes in behaviour or personality
- Signs of depression lasting more than 2 weeks
- Sleeping or napping more than usual
- No longer attending favourite social activities.

**Support the survivor:**
- Find out what resources are available
- Let survivors know about activities and assistance
- Help them plan and structure the day. Routine can help people adjust

**Encourage survivors to do things:**
- Help them get to activities they enjoy
- Spend time with them in activities such as playing cards or board games
- Find activities that make them feel better, such as listening to music, watching videos, or reading

**Encourage emotional expression:**
- Allow stroke survivors to express their grief and sadness about what they have lost
- Always give them hope that things can improve
- Share what you learn with the rest of the team
Test yourself: What have you learned about depression?

<table>
<thead>
<tr>
<th>Are these statements true or false?</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Post-stroke depression is often not identified.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Depressed people can just “snap out of it”.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Asking a depressed person about suicidal thoughts is dangerous.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. A person who has had a stroke is at higher risk for depression.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. A stroke survivor who is depressed may experience physical, emotional, and cognitive changes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. “The blues” and clinical depression are the same thing.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Depression is a treatable medical illness.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I can help identify depression in a survivor by really listening to and knowing them.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. When I see the signs and symptoms of depression in a survivor I should keep it to myself.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The impact of stroke on behaviour

Some stroke survivors may have little or no change in behaviour. Others, however, may go through major behaviour changes. Behaviour changes depend on:

- Where the stroke was in the brain
- How severe the stroke was
- How long ago the stroke occurred
- The survivor’s personality, cognitive abilities, and behaviour before the stroke

Some behaviours result from cognitive or perceptual problems. Other behaviour changes have to do with changes in the survivor’s ability to communicate.

You may not see consistent behaviour changes. A survivor may have good days and bad days, or good and bad times during the course of a day.

It is important to remember that the behaviour changes are due to the stroke. The survivor is struggling to cope with the effects of the stroke – that takes time. Treat the survivor as you would like to be treated. Show respect and kindness. Exercise patience.

Personality changes

Damage to the brain can decrease a survivor’s emotional control. It can also change the way the survivor behaves and relates to others. Here are some of the effects:

- The behaviour may not match the survivor’s feelings at the time. For example, the survivor may laugh at a sad story.
- Survivors may not realize how their behaviour affects others. For example, the survivor may not realize that they have said things that hurt or upset a family member.
- Survivors may have extreme mood swings, such as being upset one minute and laughing the next.
- They may lose interest in things around them. For example, a survivor who used to read regularly may no longer pick up a book.
- They may appear stubborn, selfish, or demanding.
What you can do to help

Whatever the behaviour, it is best to use patience, common sense, and a problem-solving approach. Here are some strategies to deal with specific behaviours, based on their causes.

**Emotional lability**

*Emotional lability* is a lack of emotional control. You may observe:

- Emotional responses that appear excessive. For example, the survivor may sob uncontrollably at a touching story.
- Emotional responses that do not match the emotions being experienced. For example, the survivor may laugh on hearing bad news.

Emotional lability can be upsetting to the people around the stroke survivor. Communication difficulties may result when people misinterpret a survivor’s emotional responses.

**What you can do to help**

- Ask the survivor if the feelings they are showing on the outside match how they are feeling on the inside.
- The survivor may be embarrassed after losing control of emotions. Try distracting the survivor to help them regain control and get on with an activity. For example, call the survivor’s name. Or, ask an unrelated question in a matter-of-fact way. Encourage the survivor to slow down and take some deep breaths.
- Explain to the survivor and family members that loss of emotional control is common after stroke.

**Case example:**

Since his stroke, Mr. Tomas has had difficulty with emotional control. He cannot watch the evening news without crying uncontrollably. This reaction upsets him. His support worker finds it effective to distract Mr. Tomas. She asks him if he would like a snack or if his favourite show is on next. This sometimes helps Mr. Tomas stop crying.

**Social isolation**

Survivors may have trouble coping with their *self image* (how they look). A poor self image can cause low *self esteem* (how they feel about themselves). They can lose confidence. Survivors may feel sadness or despair, or that life no longer has meaning. They may also feel helpless, with little control over their lives.

These feelings can cause stroke survivors to stop doing things that used to be important to them. They can be discouraged by the physical and emotional challenges. They may isolate themselves and avoid social activities, family, and friends.

A survivor may regain the ability to perform many activities of daily living. However, he or she may seem to have lost interest in living. As one survivor put it, “There’s more to life than relearning how to pull on your pants.”
What you can do to help

Helping the survivor to participate in life again is one of the most important things you can do.

Interests:

• Try to learn what matters to the survivor and what their interests are. What activities are most important? What brings enjoyment?
• Help the survivor to return to favourite activities. Get help from the team if you need it.

Personal care:

• Encourage survivors to participate in their own care as much as possible
• Include the survivor in discussions and decisions about care
• Rearrange personal items in a way that gives the survivor more independence

Social activities:

• Encourage the survivor to attend activities. Just showing up is the first step in starting to take part again
• Give the survivor the chance to talk about life experiences and memories
• Support the survivor in contacting and participating in their faith community

Case example:

Judith Rosen had a stroke 18 months ago. She has some weakness on the right side. The right side of her face droops. She feels very self-conscious and is reluctant to go out. Her support worker encourages Mrs. Rosen to go out, first to quiet, familiar places. Little by little, Mrs. Rosen is becoming less self-conscious and more interested in going out.

Anger and aggression

Everyone, including stroke survivors, has angry outbursts from time to time. But some survivors may even be physically aggressive towards family or support staff. This is uncommon, however.

Survivors may refuse to comply with directions. They may have a hard time getting over their anger. This makes it difficult to reason with them. It is important to identify the causes of angry outbursts. Events like these may cause angry outbursts:

• Inability to communicate or to perform a task, leaving the survivor feeling frustrated
• A toileting accident that embarrasses the survivor
• Pain in the affected side that makes the survivor feel helpless and frustrated

What you can do to help

Look for causes:

• Identify the cause of the anger and try to find solutions
• Identify pain so that it can be treated
Tips and Tools for Everyday Living: A guide for stroke caregivers

Prevent outbursts:
- Learn the survivor’s preferences in daily routines. Follow them whenever possible
- Do not alarm the survivor by approaching from the affected side. Instead, approach the survivor from the unaffected side
- Explain what you are planning to do, so the survivor is prepared
- Help the survivor feel successful by alternating between easy and more difficult tasks
- Offer support or assistance as needed during activities that cause frustration

During an outburst:
- Remove the survivor from the situation or activity that triggered the outburst
- Redirect the survivor’s attention to something positive, such as a favourite activity

Lethargy (lack of interest)
Survivors with damage to the right side of the brain may seem to lack interest in daily activities or leisure activities. If a survivor tries to do something and fails, they may refuse to try again, or be unwilling to try at all.

What you can do to help
Learn what interests them:
- Make it as easy as possible to participate. Attendance is the first step in participation
- Reinforce and support any interest the survivor shows. Use praise and encouragement
- Encourage the survivor to try again if an initial attempt to do something fails
- Do not embarrass or force a survivor who refuses. Instead, try later

Case example:
Harry Johnston had a stroke almost a year ago. He experienced very little loss of mobility. However, he seemed to lose all interest in previous pastimes. His support worker has helped 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. She is encouraging him to play Hearts, an easier card game.

Social judgment

Social judgment is saying and doing the right thing in a situation. Personality changes due to stroke may cause poor social judgment, which leads to other problems. Problems with cognition can contribute.

Family and friends may draw the wrong conclusions when they see behaviour that is out of character for their loved one. Some examples:
• A shy person may suddenly want to be the centre of attention
• A talkative individual may become quiet
• An easygoing person may now show a rigid personality
• A previously neat and fastidious person may become sloppy about personal grooming and appearance

What you can do to help

Recognize the survivor’s limits:
• Avoid situations that require the survivor to make decisions beyond their capabilities

Give feedback and cues:
• Your feedback can help the survivor recognize inappropriate behaviour
• Inform the survivor of inappropriate behaviours in a straightforward way
• Offer appropriate alternatives
• Do not criticize

Reinforce appropriate actions:
• Always react in a positive way to reinforce appropriate behaviour

Upon reflection

What types of behaviour changes can survivors experience after stroke?

As a care provider, what strategies can you use to deal with negative behaviour changes in a survivor?”
Tips and Tools for Everyday Living: A guide for stroke caregivers

Heart and Stroke Foundation
Every healthcare organization has a minimum manual lift policy to reduce manual lifting. These policies differ between organizations. Minimum manual lift policies are designed to ensure a safe working environment. They reduce the risk of injury to you and your patient. You need to be familiar with your organization’s policy. You also need to know about available mechanical lifts and assistive devices, such as transfer discs and transfer poles.

The techniques for positioning, transfer, and mobility of stroke survivors described here follow stroke best practice. If you are unsure of the survivor’s ability to transfer, consult members of the interprofessional team such as the physiotherapist, occupational therapist, or the mobility expert.

Moving after a stroke

We move all the time – in bed, rolling, sitting up, standing, and walking. Stroke can affect a survivor’s mobility, depending on several factors.

Fatigue

Healing the brain and relearning the tasks of daily living takes a great deal of energy. Stroke survivors often feel very tired, especially during their initial recovery. Even simple tasks may be exhausting. Fatigue can produce frustration, sadness, and anger.

Loss of sensation

Sensation means being able to:

- Feel
- Be aware of touch and temperature
- Know where the body is in space

A stroke survivor may have less or no sensation in the affected part of the body after the stroke. For example, a survivor may not realize a shoe is too tight, or an arm is too close to a candle.

Loss of motor function

A stroke survivor can lose the ability to move body parts (loss of motor function). The loss usually occurs on the side of the body opposite the side of the stroke. For example, a left brain stroke can affect motor function on the right side of the body. Brain stem stroke, however, can affect motor function on both sides of the body.
Muscle tone
Muscle tone is the slight tension always present in normal muscle, even when the muscle is at rest. Normal muscle tone counteracts the downward pull of gravity. Stroke can alter muscle tone, causing high tone (spasticity) or low tone (flaccidity). Changes in muscle tone can cause mobility problems.

- **Flaccidity:** A limb with low tone appears heavy and limp. Handle the affected limb carefully. This can prevent injury and pain.
- **Spasticity:** A limb with high tone may appear stiff or tense. Careful and gentle handling and positioning can help prevent spasticity from worsening. Increased spasticity can cause muscle contractures (shortening). Constant high tone will reduce the range of motion in a joint.

Balance
To keep your balance, you need motor control and sensation. The body adjusts to make up for changes in position and movement. This helps us maintain balance. Problems with sensation or motor control after stroke can impair balance, increasing the risk of falls.

Posture
When you stand, your shoulders, hips, and feet are parallel, and your head is upright in the middle. Stroke may cause the survivor to put more weight on the unaffected side. The affected shoulder (shoulder girdle) and hip (pelvic girdle) may rotate backward.

Perception
Changes in perception caused by stroke may affect mobility. These changes include:

- Visual and auditory neglect (less awareness of the environment on the side of the body affected by stroke)
- Body neglect (less awareness of the body on the side affected by stroke)
- Apraxia (difficulty making purposeful movements, even though the survivor has the ability and understanding to perform the task)
- Impaired depth and distance perception (such as double vision, partial loss of vision in one or both eyes, and visual field loss)

By using the right techniques, you can prevent pain or injury to the survivor, yourself, or another health care provider helping you.
Assisting with mobility

Helping a stroke survivor means helping the survivor be safe, comfortable, and independent. It is also critical that you make the most of the quality of movement. This means assisting and encouraging the survivor’s body to work as normally as possible. Here are some things to keep in mind when you assist stroke survivors:

Know the plan, techniques, and strategies the team has developed for the survivors in your care.

Balance rest and activity to avoid frustration and prevent injury. Do not overtire the survivor or ask a tired survivor to do too much.

Respect differences between people and adjust to the individual.

Think things through. Ask yourself:
- Does a movement look normal?
- If not, why not?
- How can you help?

Do not rush. Staying calm lets the survivor participate better.
- Move slowly and gently
- Give the survivor time to think

Explain what you are doing. Make sure the survivor understands.
- Use simple and concise instructions
- Demonstrate what you mean, if needed

Encourage the survivor to participate as much as they can. Provide only the assistance the survivor needs.

Match your efforts with the survivor’s.
- Know the survivor’s abilities and limits
- Use verbal coaching or guidance when needed

Use good body mechanics:
- Ask for help if you need it
- Coordinate your efforts when working with another care provider
- Never pull on the affected arm or under the shoulders. Pulling can cause the survivor a lot of pain and harm the shoulder joint

Managing the affected shoulder

The shoulder joint is a ball-and-socket joint that can move in many directions. Other joints have strong ligaments to hold the joint in position. However, only muscles support the shoulder joint. Muscles affected by stroke may no longer hold the joint in alignment.

The affected shoulder can be injured more easily than the unaffected shoulder. If you have any concerns, talk to members of the team about the right techniques and strategies. A physiotherapist or occupational therapist can teach you safe exercises and ways to position and move the affected shoulder.

Never perform exercises on an affected shoulder, unless specifically prescribed by the physiotherapist. Improper movement may lead to further tissue damage and loss of function.
The low-tone shoulder

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 of the humerus down, overstretching the weakened muscles. This may cause the shoulder to move out of alignment. It may even cause a partial dislocation (subluxation), of the shoulder. A subluxed shoulder has a noticeable gap between the ball and socket of the joint.

Subluxation allows the muscles and ligaments of the shoulder to stretch further. Excessive muscle stretching may cause a constant dull pain. Survivors often describe this as toothache-type pain.

What you can do to help

Learn the techniques and strategies in the care plan of each stroke survivor. These techniques can help prevent injury and further loss of function in the low-tone shoulder. Members of the team can show you the correct way to move or position a survivor’s arm.

Watch the shoulder closely. Always handle it carefully. This can prevent painful stretching of muscles and ligaments.

Support the affected arm and treat it gently:

- Use a lap tray or arm trough when the survivor is sitting
- Support the affected limb before moving the survivor
- Do not pull on the arm when you are moving a survivor or helping them walk or move in bed. Pulling the arm may cause pain and shoulder damage

The high-tone shoulder

Spasticity, or high muscle tone, can pull the upper arm toward the chest wall. This makes movement painful and difficult.

What you can do to help

- Support and position the limb in good alignment. This will reduce muscle imbalance and survivor pain
- Use pillows or towels to improve arm positioning in bed. Support the arm on a lap tray when the survivor is sitting
- Get advice from the survivor’s physiotherapist or occupational therapist
- Report joint or tissue pain to the right person for follow-up
- Never perform exercises unless approved by the mobility expert on your team
Managing the affected hand

Flaccidity: Lack of sensation and mobility after stroke can make a low-tone hand prone to positioning problems and swelling. Swelling and disuse may cause pain and skin problems.

Spasticity: Gentleness is important with a spastic hand. It should never be forced open. Ask the survivor not to squeeze a ball to exercise the hand. This kind of activity will only worsen spasticity.

Relaxing a spastic hand

To relax and open a spastic hand, position the survivor with the shoulder girdle forward.

Support the hand at the wrist, and gently stroke the back (extensor surface) of the hand and wrist. Gently position the hand properly when the fingers are open. The hand can now be cleaned.

What you can do to help

Always be aware of the affected hand. Follow the therapist’s instructions to mobilize the hand and treat pain and swelling.

Report any changes in pain, swelling, or function to the right person.

To reduce swelling, support the arm on a lap tray or trough when the survivor is sitting. Use a foam wedge or arm support to raise the hand and support the wrist. Place the arm with the hand in front and fingers opened.

Encourage the survivor to use their unaffected hand to gently open the fingers of the affected hand and place the hand on the supporting surface.

Managing the affected foot

The survivor may have less movement and sensation in the foot on the affected side. They may have pain, stiffness, swelling, and possible skin damage because of impaired sensation.

Reduce swelling by having the survivor lie down from time to time. Elevate the legs to chest level with a pillow.

If possible, get the person to stand. This will increase weight-bearing and prevent foot stiffness and deformity. You may need to help the survivor, if their ankle is weak or unstable.

- **Note:** Raising the leg rests on wheelchairs is not helpful. That is because circulation in the legs and feet is impaired by exaggerated hip flexion. Use bed positioning instead.
What you can do to help

Check the survivor for any problems in the affected limb. Report any concerns to the right person.

Regularly check any skin that has impaired sensation for redness, blisters, or breakdown.

Encourage the survivor to follow the doctor’s orders to reduce swelling. This might include helping the survivor to wear prescribed pressure stockings.

When possible, make standing part of the survivor’s daily routine. For example, have the survivor 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.

Positioning

Survivors who cannot turn themselves in bed need to be moved often. This will reduce the risk of pressure sores. The goals of positioning are to:

- Preserve normal body alignment
- Change abnormal muscle tone patterns associated with hemiplegia (one-sided paralysis)
- Increase awareness of the affected side

Lying on the back

To place the survivor in a comfortable position on their back, follow these steps:

1. Tell the survivor what you are going to do.
2. Make sure the survivor’s head is in a neutral position. It should not be bent forward or backward.
3. Support the survivor’s head, affected arm, and affected hip with pillows.
Lying on the affected side

Many survivors are more comfortable lying on their sides. Following these steps:

1. Tell the survivor what you are going to do.
2. Make sure the survivor is ready. Do not startle the survivor.
3. Turn the survivor onto the affected side. Use a turning sheet or have another person help you.
4. Place a pillow under the survivor’s head. Make sure the neck is slightly bent and in a comfortable position.
5. Move the affected leg straight and slightly behind the trunk.
6. Move the affected shoulder slightly forward of the body and straight at the elbow.
7. Place a pillow under the upper arm in front of the survivor’s stomach. This stops the person from falling forward.
8. Bend the unaffected leg at the hip and knee. This reduces the feeling of floating.
9. Place a pillow between the survivor’s legs to reduce friction and increase comfort.

Positioning a survivor on their unaffected side

Positioning a survivor on the unaffected side is the same as positioning that person on the affected side. Survivors with a lot of impairment on the affected side may feel trapped in this position. They often roll onto their backs. Try to get the survivor to:

- Bend the knees before rolling to make the roll easier
- Be aware of the affected arm. Survivors often leave the affected side behind when rolling onto the unaffected side
- Look in the direction they are rolling. This is easier to do if the survivor lifts and turns the head to look in the direction they want to roll
Moving on the bed: bilateral bridging

*Bilateral bridging* can help the survivor raise the hips. This helps with personal care or moving towards the edge of the bed.

Here are some ways to help the survivor raise their hips:

- Help the survivor bend at the hips and knees, placing the soles of the feet flat on the bed.
- Get the survivor to raise their hips off the bed. Make sure that weight is taken through the feet.
- Try to stop the survivor from pushing too firmly. Pushing too much can make the survivor move towards the head of the bed.

Sitting up

You can teach the survivor techniques for moving safely. You may need to help the survivor rise to a sitting position.

Ask the survivor to follow these steps:

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

You may need to help the survivor rise to a standing position. Not all survivors can perform all the actions independently.

Ask the survivor to follow these steps:

1. Slide their hips forward to the edge of the bed or chair.
2. Sit up straight. Position the survivor's feet shoulder width apart with their heels directly below the knees. Make sure both heels are touching the floor.
3. Bend forward at the hips and look up.
4. Keep a straight back. Bring their shoulders forward in line with the knees. Their trunk and neck should remain extended as the hips bend.
5. Push up with both legs. Keep their weight spread equally over both legs.
6. Stand up straight.

Sitting in a chair or wheelchair

When the survivor is sitting, the hips should be back and centred in the chair. Hips often slide forward in a chair, creating a slumped posture.

The 90° rule: The survivor should sit with hips, knees and ankles flexed at 90°

Remember the 90° rule. This will help the survivor to sit comfortably and safely.

- Regularly remind or help the survivor to move their hips back in the chair
- If you are having trouble seating the person in the wheelchair in the right position, let the team know. The chair could be part of the problem
- Support the affected arm on a lap tray
- Adjust the foot rests to make sure the affected foot is supported
Transfers

Moving from bed to chair or chair to toilet

Safely helping a survivor to move depends on the abilities of both the health care provider and the survivor. No single technique works in all situations. Consider the following factors when planning a transfer:

- The survivor’s level of control and movement: Poor control of the affected side may cause overuse of the unaffected side during transfers
- Size and weight of the survivor compared with the health care provider
- Time of day and how tired the survivor is (a fatigued survivor needs more help). Is the survivor better able to perform in the morning but fatigued at night?
- Your level of comfort in safely moving the survivor. If you are not sure you can do this safely, ask for help

Rules for safe transfers

Follow these steps when helping a stroke survivor to move:

1. Make sure the survivor is wearing safe shoes.
2. Apply wheelchair brakes.
3. Move any arm rests and swing foot rests out of the way. Support the affected arm with a sling if needed.
4. Help the survivor get into the right starting position. The persons unaffected side should be closest to the chair. Shift the person’s buttocks closer to the edge of the wheelchair, one side at a time.
5. Position yourself as close to the survivor as possible. Do not block the direction of movement or the survivor’s view of the path of movement.
6. Guide and support the survivor’s upper body. Place your hands around the upper back and shoulder blades.
7. Bend your knees and keep your back straight. **Note:** Do not lift the survivor by placing your hands under the arms or armpits. This can cause pain. Do not pull the affected arm.
8. Shift your weight from the front to the back foot. Doing this makes the transfer easier.
One-person pivot (stepping) transfer

A one-person pivot (stepping) transfer is often used for assisting a survivor to stand. It is also used for toilet, car, and bed-to-wheelchair transfers.

Follow these steps:

1. Stand in front of the survivor, supporting the shoulder blades.
2. Tell the survivor which way they are being moved.
3. Rock the survivor gently forward and guide the person to a standing position.
4. Position your feet on either side of the affected foot to support the leg and prevent it from collapsing.
5. Assist survivor to step and transfer weight to the leg closest to the destination.
6. Pivot.
7. Help the survivor bend forward and place the buttocks down and back on the new surface.
Two-person pivot (stepping) transfer

The two-person pivot (stepping) transfer is used on the survivor who can bear weight on the legs but is heavy, likely to make sudden movements, or unable to follow direction. You need 2 health care providers for this transfer. The taller care provider stands behind the survivor. The care provider at the front leads the transfer. The rear care provider guides the hips.

Step 1: Getting ready for the transfer

Both caregivers:
- Lower the bed so the survivor’s feet rest on the floor
- Lock the bed brakes, if the bed has casters
- Adjust or remove the wheelchair foot rests and the arm rest on the side closest to the bed
- Place the wheelchair beside the bed at a slight angle
- Lock the wheelchair brakes to allow the rear care provider to be closer to the survivor

If you are standing in front:
- Assist the survivor to sit on the edge of the bed with feet flat on the floor
- Have the survivor place the unaffected arm around your waist
- Place your hands on the survivor’s upper back
- Position your feet on either side of the affected foot to support the leg and prevent it from collapsing

If you are standing behind:
- Stand behind the survivor with one knee on the bed

Step 2: The transfer

If you are standing in front:
- Use a no-verbal signal (like a head nod to the second caregiver) to start the transfer if the survivor overuses their unaffected side
- Assist the survivor to transfer weight to the leg closest to the destination
- Turn, and place the buttocks down and back on the new surface

Note: A transfer belt placed low on the survivor’s pelvis can simplify this step. It can also make it more comfortable for the survivor, and allow the care provider at the back to help more.

If you are standing behind:
- Support the survivor at hip level and guide (do not lift) the hips
Both caregivers:

- Do not lift using the survivor’s clothing
- Replace the wheelchair foot rests and arm rest
- Position the survivor comfortably

A low-pivot transfer may be more effective if the stroke survivor can help by coming into a half-standing position, but not a full standing position. Follow the steps above.

Wheelchair use

Even after treatment, most survivors have some problems moving. These problems range from someone who is easily fatigued to being unable to move. A survivor may require a wheelchair for part or all of the day. The physiotherapist or occupational therapist can decide what wheelchair is needed. They will know whether or not the survivor will also need a pressure-relieving cushion and back support. Many survivors learn to move their wheelchair during rehabilitation. You may need to remind them how best to use their wheelchair.

Survivors may slide forward in a wheelchair so that their feet can reach the floor. Sliding forward in a wheelchair can:

- Affect postural tone and control
- Cause problems with transfers and control
- Increase high tone (spasticity), pain, and the risk of skin breakdown

The physiotherapist or occupational therapist may prescribe a hemi-height wheelchair. This chair has a lower seat than a standard chair. It allows the survivor to reach the floor with their feet without sliding forward.

What you can do to help

Watch the survivor moving the wheelchair so you can spot any problems. Ask yourself these questions:

- Does the movement look normal? If not, why not?
- What can I do to change it?
- Do I need to have a member of the team assess the survivor?

Watch for increasing muscle tone (stiffness). This tells you that the survivor is using too much effort. Check with the healthcare team if you are concerned. Excessive effort reinforces abnormal movements. Make sure the survivor is not doing too much too soon.

The too much, too soon rule

Doing too much, too soon has a long-term, negative effect on the survivor’s ability. Overuse can cause wear and tear on the unaffected side and increase the need for help. Always balance the benefits of faster independence with the risk of overuse and deterioration.
Walking

The survivor may need to learn to walk again – safely. They may have to cope with balance problems, using the affected leg, and using a walking aid. The following principles can help the survivor walk safely.

Balance and posture

- Good balance prevents falls. The survivor should be balanced before starting
- Body weight should be spread evenly over both legs
- If the survivor starts losing balance while walking, have them stop and regain balance before continuing
- The survivor should stay erect and look ahead, not at the floor

Weight bearing

- The hip, knee, and ankle of the affected leg should be lined up. This position helps the leg take the survivor’s weight smoothly and safely with each step
- After the survivor swings the affected leg forward, body weight should be spread over the whole foot to stop it from rolling onto the outside edge
- If needed, help the survivor walk by standing on their affected side. Place one hand on the survivor’s back and one hand in front if they need support

Walking aids

- Putting weight on the affected leg can help the survivor to move more normally. Walking aids include canes, walkers, and rollators
- However, leaning on a walking aid puts less weight on the affected leg. Leaning too heavily on a walking aid causes abnormal gait. The physiotherapist can choose the right walking aid and can make sure the aid is the right height

Safety

The survivor must pay attention to safety and slow down when necessary. Some survivors may not always be aware of where their body is in space. Some have limited sight on the affected side. This means they may be less aware of objects on that side. Remind these survivors to turn their head to that side so they do not bump into objects.

Stairs

Stairs can be challenging. Survivors who can climb stairs using the opposite foot on the next step, should use the hand rail. Survivors who cannot manage stairs this way need to place first one foot and then the other on the same step, before moving to the next step (see drawing on next page.)

Survivors usually learn to lead with the stronger leg when going up stairs. They lead with the weaker leg when going down stairs. The survivor may have been taught to lead with the stronger leg going up and down stairs. If you are not sure which strategy to use, ask the physiotherapist.

Before you help someone use stairs, make sure they need only a small amount of help. If the person needs help, assist from behind going up stairs and from in front going down stairs.
Assistive devices

Assistive devices can help a stroke survivor with mobility problems to function. If you think one of the following devices might help a stroke survivor in your care, talk to a member of your interprofessional team.

Ankle supports

A brace can support an unstable ankle that turns when the person stands. A brace may also be useful if ankle weakness prevents the survivor from raising a foot enough to clear the floor when walking (foot drop). Ankle braces can prevent injury and increase walking safety.

Ankle-foot brace (orthosis)

An ankle-foot brace 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 type of support holds the ankle straight and reduces foot drop. Ankle-foot braces may need to be custom-made if the survivor has high-tone leg muscles (ankle spasticity).

Ankle last

An ankle last is a strong elastic strap that attaches to the outside of the shoe. It wraps around the ankle. This type of brace supports a low-tone ankle that turns in during walking and standing.

Air cast ankle stirrup

An air cast ankle stirrup has 2 plastic supports filled with air. They fit on either side of the ankle, stabilize it, and prevent it from turning in.
Arm supports

These support the arm and protect it from harm.

Sling

A sling can support a low-tone arm during transfers or while standing. Slings should not be used all of the time. They prevent arm swing during walking. They may contribute to the elbow stiffening in the bent position.

Arm trough

Arm troughs are modified arm rests on wheelchairs that may support the low-tone arm. These supports may swivel. This lets the arm rest in a more natural position.

Lap tray

Lap trays can support the affected arm when the survivor is seated in a wheelchair. By placing the affected arm where they can see it, the survivor can handle and move that hand with the unaffected hand.

Arm wedge

Placing an arm wedge on a lap tray positions the wrist higher than the elbow in neutral position. An arm wedge can support the affected arm and reduce swelling.

Compression glove and wrist splint

A compression glove can reduce swelling of the affected hand and needs to be professionally measured. A wrist splint can be used to position the wrist in a neutral position and prevent excessive wrist flexion.

Upon reflection

Think of a transfer that was very challenging for you.

• How was it challenging?
• What did you do to make it safe?
• Can you improve that person’s positioning or transfers?
• How would you do this?

Who can tell you about proper exercises for the stroke survivors you care for?

What transfer aids might help the stroke survivors you care for?

What affects a stroke survivor’s ability to transfer? Do those things apply to survivors in your care? How could you address them?

What resources does your facility have to help you decide which transfer technique is best for the stroke survivors in your care? (such as books or training)
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 1 or 2 hours, until the bladder is full. Most people urinate 3 to 6 times during the day and possibly once or twice during the night.

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 internal and external 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.

The diagrams on the next page show the anatomy of the male and female pelvis.

Aging of the bladder and urethra

As a person ages, the bladder shrinks. An aging bladder holds only 250 to 300 mLs of urine – about half of what a younger bladder holds. Older people need to empty smaller amounts from their bladders more frequently.

Also as people age, the bladder wall becomes thinner and muscle tone decreases. The urine stream is weaker and the bladder does not empty completely.
Tips and Tools for Everyday Living: A guide for stroke caregivers

**MALE ANATOMY**

- Bladder
- Pelvic bone
- Urethra
- Testicle
- Tail bone
- Rectum
- Prostate
- Anus

**FEMALE ANATOMY**

- Ovary
- Uterus
- Bladder
- Urethra
- Pelvic floor muscles
- Anus
- Vaginal opening
- Tail bone
- Rectum
Men may have even more trouble emptying their bladder if they have an enlarged prostate. The prostate surrounds the urethra.

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, which is called **stress incontinence**.

Some older people have involuntary bladder wall contractions that give them the feeling they need to urinate. This is called **urge incontinence**.

Almost half of stroke survivors who have problems with incontinence had the same problems before the stroke. It is important to identify all the factors that affect the stroke survivor’s bladder control. With lifestyle changes and your support, about 80% of incontinence problems can be resolved.

**Stroke and loss of bladder control**

**Urinary incontinence**

The stroke survivor may have lost the ability to identify and respond to the need to urinate. Many stroke survivors lose bladder control right after a stroke but get it back within 8 weeks. Or, the incontinence may come and go or be permanent.

**Urinary retention**

Stroke may interrupt nerve pathways that control bladder emptying. If this happens, the survivor does not feel an urge to urinate. The bladder fills, but the person is unable to empty it. Urinary retention causes urine to back up. This can increase the risk of urinary tract infection and damage the kidneys. The stroke survivor may need to have the urine removed with a catheter (a tube inserted into the urethra, which empties the urine into a bag).

**Urge incontinence**

Stroke may cause involuntary bladder contractions. This causes the stroke survivor to feel a strong urge to urinate and lose control before reaching a toilet.
**Complicating factors**

Various factors can complicate bladder problems due to stroke:

**Vision problems:** The survivor may be unable to find the bathroom or use the toilet independently.

**Decreased mobility:** The survivor may be unable to get to the bathroom independently or quickly enough.

**Lack of motor coordination:** The survivor may have difficulty managing clothing, adult diapers, transfers, or the toilet.

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

**Normal bowel function**

The bowels absorb nutrients and fluid from a person’s diet. They also remove solid waste (stool) from the body.

There are 2 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 5 or 6 feet long. It begins at the end of the small bowel and ends at the rectum.

A healthy bowel depends on:

- How the muscles and nerves work together
- Eating a high-fibre diet
- Drinking 6 to 8 cups of non-caffeinated fluids each day

Usually, bowel movements occur anywhere from 3 times a day to 3 times a week.
Stroke and bowel function

Constipation

Constipation happens when the bowels don’t move often enough and the body passes a hard, dry stool after a long time. It is the most common bowel management problem among stroke survivors. Stroke can weaken the muscles that expel the stool. This can cause constipation or make it worse.

Constipation reduces the stroke survivor’s quality of life, comfort, functional ability, and social life.

A person with constipation will have had 2 or more of these symptoms in the past 12 months:

- Less than 3 bowel movements per week
- Straining*
- Hardened stools*
- Feeling of incomplete stool evacuation*
- Feeling of blockage or obstruction*
- Need for manual stool evacuation*

* A person with constipation has these problems for more than one-quarter of their bowel movements.

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 megacolon (enlarged colon). The person may need enemas and laxatives to clear the bowel. Laxatives should not be used for long periods. After their 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 the last part of the bowel slips or falls out of place.

Urinary incontinence: Constipation can increase pressure on the bladder and get in the way of a stroke survivor’s ability 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. Note: People can mistake fecal incontinence for diarrhea, when in fact the survivor has severe constipation. It is critical to identify and treat constipation early.

The physical and emotional impact of bladder and fecal incontinence

Physical problems

- Skin breakdown and infection
- Urinary tract infection
Tips and Tools for Everyday Living: A guide for stroke caregivers

- Pain
- Falls and injuries: A survivor with poor mobility or coordination may fall while hurrying to the toilet
- Dehydration: A stroke survivor may restrict fluid intake in an attempt to manage incontinence

Incontinence is a major reason for transfer to a long-term care facility, rather than returning home.

Emotional problems
The stroke survivor and family members are often devastated by the loss of bladder or bowel control. Incontinence dramatically affects the stroke survivor’s feelings of self-worth and well-being, as well as their lifestyle. They may feel the need to stay close to a toilet. Activities are interrupted by frequent bathroom visits. The survivor may socialize less and stop taking part in activities or travel because of the fear of accidents. Sexual activity may decrease. Depression, a common complication of stroke, can make the survivor less able to manage incontinence.

Having to help a stroke survivor go to the bathroom can strain family relationships. It might even limit family visits and reduce outings with the survivor. Strategies for managing incontinence play a big role in determining whether the survivor can remain at home.

Factors that increase the risk of constipation and urinary incontinence

Environmental
- Poor access to a toilet, such as long distances to the bathroom
- Limited room for a wheelchair in the bathroom
- Lack of equipment such as bedside commodes
- 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 or avoiding fluids to prevent urinary incontinence
- Not eating enough, or enough foods with fibre
- Not getting enough activity or exercise
- Ignoring the urge to go to the bathroom

Identifying urinary incontinence
Because bladder problems can have such serious health and emotional consequences, they need to be regularly assessed. Watch for these signs and symptoms of incontinence and notify the nurse as soon as possible if you see:
• Any change in the survivor’s normal pattern of going to the bathroom
• Loss of small amounts of urine (dribbling). This might happen when the survivor does something physical, such as lifting, coughing, or sneezing (stress incontinence). Or it might happen 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 survivor might become aware of the need to urinate only seconds before the bladder empties. They might find it difficult or impossible to stop the urine stream.
• Urinating more than 8 times per day or twice per night
• A weak or interrupted urine stream
• The survivor’s bladder still feels full, even after urinating (a sign of urinary retention)
• Frequent urinary tract infections

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 onset of constipation
• Sudden change in bowel pattern or stool
• Abdominal pain
• Rectal bleeding
• Liquid stools
• Constant straining with bowel movements
• No bowel movements in at least 3 days
• Fever
• Weight loss

Managing bladder and bowel problems
Managing bladder and bowel problems is critical to the stroke survivor and the family caregiver. Avoiding even one episode of incontinence a day can greatly increase the stroke survivor’s self-esteem and quality of life. Reducing incontinence saves you time as a health care provider. It cuts down on the use of continence products such as pads or diapers. Most importantly, it can prevent complications, such as urinary tract infection, skin breakdown, pain and falls caused by rushing for the bathroom.

The role of the interprofessional team
The interprofessional team’s process for managing bladder and bowel problems includes assessment, diagnosis, care planning, implementation, and evaluation.

Assessment
Your careful and accurate observation provides much of the information needed for assessment. You can keep a voiding diary to organize the information for the team. The diary usually includes details about:
• Urination
• Bowel habits, stool colour, and consistency
• Straining and discomfort with bowel movements
• Diet and fluid intake
• Mobility, activity or exercise
• Any signs of skin breakdown around the anus, scrotum, and vulva (perineal skin), such as swelling, redness, oozing or crusting
• How the survivor transfers from the bed to the commode chair
• Problems the survivor has with undressing and dressing
• The survivor’s behaviour and response to care
• Impact of the problem on the family

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

**Report the following urgent information as soon as you can:**

- The survivor has been unable to pass urine for the past 4 hours
- The survivor is unable to have a bowel movement
- The survivor has a fever
- The survivor reports pain in the lower abdomen or back
- You notice perineal skin breakdown or the survivor complains or shows signs of discomfort

**Diagnosis**

The team’s doctor diagnoses the urinary incontinence and bowel problems and their causes. A urologist might be added to the team to address urinary incontinence. The team’s nurse will inform you about the treatment plan.

**Care planning**

Based on the diagnosis, the team recommends a treatment plan. The things you have observed about the survivor play a big role in deciding on the best way to implement the plan. You may also be able to suggest ways to tailor care for the individual.

The team’s plan might include:

- Reviewing the survivor’s medications and laxative use
- Increasing the stroke survivor’s activity levels
- Habit training – drawing up a routine toileting schedule
- Setting up best positioning on the toilet
- Increasing fluid intake or changing the diet

The team’s dietitian can create a diet that helps with constipation – for example, by increasing fibre and fluid intake. **Note:** Those who cannot move or do not get enough fluids should not receive fibre supplements.

The team can also apply proper bladder and bowel care programs. These include:

- Habit training – a process where a regular routine of toileting is established with the goals of having regular bowel movements
- Prompting the survivor about scheduled trips to the bathroom
• **Redirection**, particularly for stroke survivors with cognitive impairment. Redirecting might mean, for example, distracting the survivor with a TV program they like, so that they can control their need to go the bathroom a little longer and stay on their schedule.

If any part of the plan is unclear, be sure to ask the nurse for an explanation.

**Implementation – What you can do to help**

- **Be alert** to any behaviour that may communicate the need to urinate.
- **Observe and record** bowel and bladder habits.
- **Report** any changes or new problems with the survivor’s mobility to the nurse.
- **Identify and move** any furniture or other obstacles to getting to the toilet.
- **Place a night light** near the bed to orient the survivor to the room at night.
- **Allow the survivor privacy** but ensure they can call for assistance.
- **Encourage** the survivor 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. Encourage the stroke survivor to sit leaning forward during urination, with the feet flat on the floor or on a stool, to help bladder emptying.

**Urinal:** If the stroke survivor uses a urinal, keep it where it can be easily seen and reached. It may help to place one urinal on each side of the bed.

**Bedpan:** Make sure the head of the bed is raised as upright as possible to allow the survivor to sit as normally as possible when using a bedpan.

**Evaluation**

You have an important role in observing the survivor’s response to the plan of care and reporting it to the team. Take note of the survivor’s expressed concerns, as well as nonverbal reactions. For example, during a wheelchair-to-toilet transfer, you may observe the stroke survivor grimace and become agitated. Report this observation to the team. This report may lead to an assessment. The assessment may result in a diagnosis of pain and effective pain treatment.
Strategies for managing urinary incontinence

Prompted voiding

*Prompted voiding* can help treat urinary incontinence and constipation. This strategy has three parts:

1. **Monitoring**
   - At regular intervals, ask if the survivor would like to use the toilet. Survivors 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.
   - Watch for behaviour that shows a need to urinate or move their bowels. A survivor with an impaired ability to communicate may show increased agitation because of a fear of incontinence. The survivor may also become more agitated when wet.
   - Take note of the usual times a survivor needs to urinate or have a bowel movement. Take them to the toilet on that schedule, whether or not they have an urge to go to the bathroom. Maintain a voiding diary.

2. **Prompting and redirecting**
   - At regular intervals, prompt the survivor to use the toilet
   - Between those times, encourage bladder control by redirecting or distracting the survivor with activities, such as watching television or listening to the radio
   - Work with the nurse to adjust the schedule as needed to reduce the chance of incontinent episodes

3. **Positive feedback**
   - React in a positive way when the survivor stays dry and uses the toilet when needed. Manage incontinent episodes without comment.

Bladder retraining

*Bladder retraining* gradually increases the times between going to the bathroom. This helps the survivor to:

- Correct the habit of frequent voiding
- Increase bladder capacity
- 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 (the muscles that control urination and bowel movements).

The protocol also includes a schedule for urinating such as this:

- Periodically increase the interval between voids by 15 minutes (or less if needed)
- Continue increasing the intervals until the time between voids is 3 to 4 hours

What you can do to help

- Remind and encourage the survivor to practice pelvic floor exercises, if they are part of the care plan
- Write down the toilet schedule to help the survivor and other care providers keep track
• Encourage the survivor to keep to the schedule and resist the urge to go in between toilet visits. You can distract the survivor with activities, such as reading or listening to music. The survivor can also use relaxation techniques.
• Encourage and praise the stroke survivor for staying on schedule.

**Urinary catheters**

A urinary catheter or another external device may be needed on a temporary or permanent basis. A urinary catheter increases the risk of urinary tract infection. Appropriate catheter care can reduce this risk.

**Catheter care**

• Ensure the stroke survivor drinks 6 to 8 cups of fluid daily (1,500 - 2,000 mLs). Adequate fluid intake keeps the catheter draining well and free of sediment.
• Ensure the drainage bag is positioned below the level of the bladder. This prevents urine from backing up into the bladder.
• Position the catheter tubing so that it does not kink or pull on the catheter.
• Secure tubing to leg with tape to prevent accidents.
• Empty urine every 8 hours.
• Prevent tubing contamination. Follow your organization’s procedures for disconnecting and connecting tubing.

**Patient monitoring**

Report the following to the nurse:

**Urine output:**

• Any change in output over a 4-hour period
• Decreased output, with the survivor reporting 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

**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 problems. Watch for these signs and symptoms. Report them to the nurse as soon as possible.
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

What you can do to help
- Report any signs and symptoms of a urinary tract infection to the nurse.
- Ensure an adequate fluid intake – 6 to 8 cups per day.
- Encourage the survivor to drink more fluids if they have a burning feeling during urination.
- Limit intake of caffeinated drinks to 2 cups per day.
- Encourage the survivor to drink cranberry juice or take cranberry pills. Cranberry juice attacks common bacteria that cause urinary tract infections.

Upon reflection

Can you remember a person you cared for who was incontinent?

How did it affect the person emotionally? How did it affect their social life?

You are called to a resident’s room. The resident says, “I need to go to the bathroom right away. Can you help me get to the bathroom?” You are caring for another resident at that moment, but you want to help.

How should you respond? What would be the right action to take?
Daily fluid requirements

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

People need at least 6 to 8 cups of non-caffeinated fluids daily to stay hydrated. This chart shows equivalent amounts in ounces, litres (L), and millilitres (mLs):

<table>
<thead>
<tr>
<th>Measure</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cups</td>
<td>6</td>
</tr>
<tr>
<td>Ounces</td>
<td>48</td>
</tr>
<tr>
<td>Litres</td>
<td>1.5</td>
</tr>
<tr>
<td>Millilitres</td>
<td>1500</td>
</tr>
</tbody>
</table>

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:

<table>
<thead>
<tr>
<th>Food</th>
<th>Serving Size</th>
<th>Fluid Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jellied dessert</td>
<td>½ cup</td>
<td>120 mL</td>
</tr>
<tr>
<td>Pudding</td>
<td>½ cup</td>
<td>100 mL</td>
</tr>
<tr>
<td>Ice cream or sherbet</td>
<td>½ cup</td>
<td>60 mL</td>
</tr>
<tr>
<td>Popsicle</td>
<td>1 popsicle</td>
<td>90 mL</td>
</tr>
<tr>
<td>Yogurt</td>
<td>½ cup</td>
<td>90 mL</td>
</tr>
<tr>
<td>Canned Fruit</td>
<td>½ cup</td>
<td>100 mL</td>
</tr>
<tr>
<td>Soup</td>
<td>1½ cups</td>
<td>165 mL</td>
</tr>
</tbody>
</table>

Simple conversion for daily fluid requirement

$1 \text{ cup} = 250 \text{ mL}$  
$½ \text{ cup} = 125 \text{ mL}$

Limit caffeinated drinks to 2 to 3 per day. These include coffee, tea, and cola. Caffeine is a diuretic. It promotes urination and fluid loss. Caffeinated drinks should not be counted as part of the daily fluid intake.

Help the survivor stay hydrated. Find out the survivor’s favourite non-caffeinated drinks. Make them available and encourage the survivor to drink during the day.
Dehydration and stroke

Dehydration is a health risk that rapidly becomes life-threatening. When people are dehydrated they may lose physical, mental, and cognitive function. They have an increased risk of:

- Infection
- Falls
- Constipation and fecal impaction
- Urinary tract infection

Increased risks for stroke survivors

Survivors with swallowing problems may fear choking and avoid drinking fluids. Survivors who fear incontinence may decrease their fluid intake in an attempt to prevent accidents.

In addition, the risk of dehydration is increased if survivors:

- Are on a thickened fluid diet and do not take all the fluids provided
- Refuse fluids at meals or snacks
- Need help with eating and drinking
- Lack the feeling of being 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
- Have fluid losses greater than their fluid intake

Signs of dehydration

Watch carefully for these signs of dehydration:

- 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 7 days
- Fever
- Decreased skin elasticity (Gently pinch the skin on the survivor’s arm. If the skin remains pinched up when you release it, suspect dehydration)

Report any of these signs to the nurse.

Dehydration is potentially life-threatening. It is vital to encourage survivors to consume enough fluids.
Hydration and urinary incontinence

Stroke survivors with urinary incontinence may believe that drinking less will decrease their need to urinate. The reverse is actually true.

Low fluid intake decreases urine production. This results in concentrated dark urine. This strong urine irritates the bladder lining. As a result, the survivor needs to void small amounts of urine 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 urinary tract infection.

Hydration and constipation

Normal, healthy bowel function depends on adequate fluid intake. The normal frequency of bowel movements is anywhere between 3 times a day and 3 times a week. Low fluid consumption can result in hard stools that are difficult to pass.

What you can do to help

Encourage the survivor to drink enough fluids – 6 to 8 cups (or another amount, if prescribed) daily. Encourage the survivor to develop these good habits:

- Sip fluids during the day, rather than drinking large amounts at once
- Drink water, the preferred liquid. Consider providing the required amount of water in a container
- Limit caffeine intake to 2 to 3 cups or less per day

You may need to provide the survivor with gentle reminders to drink. Try to give them liquids at the temperature they prefer. For instance, some survivors prefer room-temperature water, and others prefer ice-cold water. Offer a variety of liquids such as popsicles and puddings.

Upon reflection

What are three things you can do to help a stroke survivor stay hydrated?
Eating, swallowing and stroke

Eating and drinking are a necessary and pleasurable part of life. Stroke can change that. A stroke can leave survivors unable to feed themselves or to swallow food or liquid safely.

**Eating:** The effects of a stroke can interfere with moving food from the plate to the mouth in two ways. Arm and hand movement may be affected. or, the cognitive abilities that help a person know how to eat may be affected. This can make meal time challenging and frustrating.

**Swallowing:** Swallowing requires the coordinated activity of many muscles to move food from the mouth to the stomach. These muscles move food and liquid through the pharynx (throat) and down the esophagus to the stomach. Stroke can affect these muscles and their action.

Weakness in facial muscles and drooling are easy to see. But other effects of stroke may be invisible to observers and unrecognized by the survivor. Effects of a stroke that may make meals challenging include:

- Difficulty getting the food or drink to the mouth
- Difficulty chewing and moving food in the mouth
- Loss of the normal cough reflex: This leaves the survivor unable to cough when choking. They may silently aspirate (inhale) solid or liquid food into their lungs.
- Decreased alertness and attention. A normal level of alertness and attention to eating protects against choking. Stroke survivors may be vulnerable to choking.
- Swallowing problems may prevent survivors from safely taking in enough nourishment, especially during early recovery

Consequences of eating and swallowing problems

Eating and swallowing problems can cause:

**Dehydration:** Not consuming enough liquids can result in dehydration. Dehydration can cause dry mouth, constipation, urinary tract infection, confusion, and even severe illness or death.

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

**Aspiration:** Is the entry of saliva, solid or liquid food, or *refluxed* stomach contents (stomach contents coming back up) into the airway. This can cause choking, airway obstruction, respiratory problems, and pneumonia.
Quality of life: Eating is often a social activity. Swallowing and eating problems can make the survivor reluctant to take part in group meals. This can increase social isolation and decrease quality of life.

Observing signs and symptoms of swallowing problems

Here are some general guidelines for managing dysphagia or swallowing problems. Each survivor will need to have their own assessment by members of the team such as the speech-language pathologist, occupational therapist, and registered dietitian.

### Common Swallowing Problems

<table>
<thead>
<tr>
<th>Common Swallowing Problems</th>
<th>Management Approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coughing or choking during or after meals</td>
<td>Always use the best positioning (see pictures below):</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>• Trunk (upper body) upright at 60–90°, stabilized with pillows</td>
</tr>
<tr>
<td>No swallow reflex</td>
<td>• Head in midline and flexed forward</td>
</tr>
<tr>
<td>Drooling</td>
<td>Monitor feeding rate and amount:</td>
</tr>
<tr>
<td>Poor lip closure, loss of food from mouth</td>
<td>• Provide small, frequent meals</td>
</tr>
<tr>
<td>Altered voice quality: wet or gurgling voice</td>
<td>• Small amounts: ½ –1 teaspoon at a time (do not use a tablespoon)</td>
</tr>
<tr>
<td>Associated Problems</td>
<td>• Medications: crush 1–2 pills at a time in food</td>
</tr>
<tr>
<td>Spikes in temperature shortly after meals</td>
<td>• Present one food item at a time if the survivor is easily distracted</td>
</tr>
<tr>
<td>Watery eyes when eating or drinking</td>
<td>Check for complete swallow: laryngeal elevation that is the movement of the Adam’s</td>
</tr>
<tr>
<td>Runny nose when eating or drinking</td>
<td>apple up and down</td>
</tr>
<tr>
<td>Spitting food out</td>
<td>Encourage swallowing twice</td>
</tr>
<tr>
<td>Pocketing of food in cheeks, under tongue, side of</td>
<td>Encourage napkin use if drooling</td>
</tr>
<tr>
<td>mouth</td>
<td>Teach survivor to:</td>
</tr>
<tr>
<td>Slow, effortful chewing</td>
<td>• Monitor self-feeding with a mirror</td>
</tr>
<tr>
<td>Difficulty swallowing pills</td>
<td>• Remove pocketed food with tongue</td>
</tr>
<tr>
<td>Rapid, uncontrolled eating</td>
<td>• Be aware of drooling</td>
</tr>
<tr>
<td>Low intake of solids or fluids</td>
<td>• Remain upright at least 30 minutes after meal</td>
</tr>
<tr>
<td>Avoiding specific foods or fluids</td>
<td>Perform mouth care after meals</td>
</tr>
<tr>
<td>Throwing head back to swallow</td>
<td>Brush teeth, gums, and tongue with a toothbrush</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>Encourage coughing to clear the throat</td>
</tr>
<tr>
<td>Poor oral care or hygiene</td>
<td>Elevate head of bed 30° to prevent reflux</td>
</tr>
<tr>
<td>Dental problems, such as loose or decayed teeth</td>
<td>Encourage survivor to wear loosely fitting clothes and to avoid tight belts</td>
</tr>
<tr>
<td>Poorly fitting dentures</td>
<td>Ask the survivor how they feel</td>
</tr>
<tr>
<td>Weight loss</td>
<td></td>
</tr>
<tr>
<td>History of chest infections</td>
<td></td>
</tr>
<tr>
<td>Poor air intake or weak cough</td>
<td></td>
</tr>
<tr>
<td>Survivor reports:</td>
<td></td>
</tr>
<tr>
<td>• Tight throat</td>
<td></td>
</tr>
<tr>
<td>• Food sticking in throat</td>
<td></td>
</tr>
<tr>
<td>• Difficulty swallowing solids</td>
<td></td>
</tr>
<tr>
<td>• Reflux or heartburn</td>
<td></td>
</tr>
<tr>
<td>• Fullness after eating very little</td>
<td></td>
</tr>
</tbody>
</table>
Assessing and monitoring swallowing ability
Several health care professionals assess and monitor a survivor’s nutritional status and ability to chew and swallow safely. These assessments may be performed during hospitalization. Since changing diet texture for swallowing problems may cause dietary deficiencies, only trained professionals should make these changes.

- A trained healthcare professional screens survivors for swallowing problems
- A speech-language pathologist assesses swallowing ability and recommends safe diet textures and strategies for safe feeding and swallowing
- A registered dietitian ensures that the recommended diet texture or tube feed meets the survivor’s nutrition and hydration needs
- An occupational therapist recommends positioning strategies and adaptive equipment for feeding

Management of swallowing problems
To eat safely, stroke survivors with swallowing problems often need their food textures adapted. The type of swallowing problem determines the food textures a survivor can swallow safely. For example, a survivor who cannot safely swallow thin fluids may be able to manage thickened fluids. A stroke survivor who cannot manage adapted food textures may need to be fed through a tube. Tube feeding can provide the calories and nutrients needed. If swallowing ability improves, survivors can often return to a soft or regular diet.

This table shows common special diets for survivors with swallowing problems:

<table>
<thead>
<tr>
<th>Type of Diet</th>
<th>Allowed Foods (✓) and Foods to Avoid (✗)</th>
</tr>
</thead>
</table>
| Pureed foods         | **Allowed foods**
|                      | ✓ Mashed and blenderized foods                                                                         |
|                      | ✓ Dense, smooth foods of pudding consistency                                                            |
| Minced or moist minced foods | **Allowed foods**
|                      | ✓ Most foods the texture of ground beef                                                                |
|                      | ✓ Finely chopped foods                                                                                  |
| Thickened fluids     | A diet with thickened fluid means that all fluids must be thickened to the consistency recommended by a speech-language pathologist. Commercial and pre-mixed thickeners can be used with hot or cold beverages. These thickeners are available through pharmacies and some hospitals. Instructions for thickening hot and cold beverages appear on the side of the can or box. It is helpful if a speech-language pathologist or registered dietitian demonstrates the thickening process and the desired fluid thickness for each person. Pudding is the thickest consistency. Liquid honey is not as thick as pudding. Nectar is not as thick as liquid honey. **Allowed foods**
<p>|                      | ✓ All fluids thickened to consistency recommended by speech-language pathologist. Recommendations are individualized for each survivor. |</p>
<table>
<thead>
<tr>
<th>Type of Diet</th>
<th>Allowed Foods (✓) and Foods to Avoid (x)</th>
</tr>
</thead>
</table>
| No dry particulates             | Foods to avoid  
  ✓ Dry and crumbly foods, breads, muffins, cookies  
  ✓ Peanut butter, dry crumbly cheeses                                                                                     |
| No bread products               | Foods to avoid  
  ✓ All breads, cakes, pastries, sandwiches, and other meals prepared with bread                                                                                       |
| Other problematic foods         | Foods to avoid  
  ✓ Rice, stringy foods, dry cereal, snack foods, raisins, nuts, seeds                                                                                                       |
| No mixed consistencies          | Foods to avoid  
  ✓ Foods combining liquids and solids                                                                                            |
| No thin fluids                  | Foods to avoid  
  ✓ Water, beverages, soups, commercial supplements  
  ✓ Ice cream, ice, cold jellied products                                                                                   |
| No foods that may cause reflux  | Foods to avoid  
  ✓ Spicy, seasoned foods  
  ✓ Citrus products and other acidic foods  
  ✓ Peppermint and spearmint  
  ✓ Coffee, tea, chocolate, cola  
  ✓ High-fat and fried foods                                                                                               |

**Assistive devices for meals**

The occupational therapist can recommend the best devices for an individual survivor. Assistive devices 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

**What you can do to help**

- Observe stroke survivors for signs and symptoms of swallowing problems.
- Contact the speech-language pathologist when you see these signs
- Set up the environment to minimize distractions. A calm environment helps the survivor focus on chewing and swallowing. Avoid busy dining rooms for a survivor who is very easily distracted.
- Use proper positioning (see next page). Seat the survivor upright in a wheelchair or a straight-backed chair. Position a survivor who is unable to get out of bed at 60° to 90° with the head forward and in the midline. Stabilize the survivor with pillows.
- Use safe feeding practices with all stroke survivors
- Discuss concerns with the appropriate person on your team
Proper positioning when providing meal assistance to a stroke survivor

Positioning in bed for feeding

Positioning in chair for feeding.

DON’T feed from above the mouth.

Oral hygiene

A clean mouth and clean 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. A clean mouth and teeth are important whether the survivor takes food orally or by tube.

Performing oral care and assessment

1. Remove dentures, if the survivor wears them, as food particles can collect and cause irritation. This should be done after each meal.
2. Check the mouth for food debris. This should also be done after each meal.
3. The oral cavity and tongue should be pink and moist. Examination of the oral cavity and tongue should be done at least once a day. Report these problems:
   - The mouth should not be dry with patchy white areas
   - The tongue should not be white and coated
What you can do to help

- Help the survivor to brush 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 they require it, not just at bedtime.
- Encourage or help the survivor to perform mouth care before and after meals, if possible.
- Encourage the survivor to have regular dental check-ups.

Upon reflection

Think about a stroke survivor who had difficulty eating.

What did you do that helped?
Stroke and daily routines

Having a bath, brushing your teeth, getting dressed, or shaving are things most of us do without thinking. A stroke can change that. These factors affect a survivor’s ability to complete these activities of daily living:

• Loss of movement on one side
• Impaired ability to grasp
• Impaired fine motor control
• Lack of sensation on the affected side
• **Neglect** (loss of awareness of the affected side)
• Difficulty planning and sequencing tasks
• Short attention span

Helping a stroke survivor with the activities of daily living means letting the survivor be as independent as their abilities will allow. Your challenge is to make sure the task is not too hard, tiring, or frustrating. All the while, you must keep safety in mind. The following 7 strategies can help you meet those challenges with any daily activity.

1. Set the stage

The first step to success is making sure that the survivor is ready for the activity. Let the survivor know what you would like to do. Limit distractions.

2. Prepare the tools

Being ready ahead of time allows you to position the survivor safely and complete the task in a timely manner.

Consider the tools and supplies needed. Put them in a convenient place within the survivor’s reach. This increases independence and helps make up for weakness and poor balance.

Arrange the items in the order they will be needed. For example, lay clothes out in the order they will be put on.

For a survivor with neglect:

• Arrange items on the affected side to increase awareness
• Point out the items on the affected side if necessary
• If severe neglect makes this approach too frustrating, place grooming items on the unaffected side to enhance independence
3. Position properly
Making sure you and the survivor are both properly positioned prevents injuries. It also helps the survivor’s ability to do the task more independently.

Make sure the affected arm is properly supported. Encourage the survivor to take part in this, so that they become more aware of the affected side.

4. Encourage use of the affected limb
Using the affected limb improves awareness, stimulates the brain, provides exercise, and builds survivor independence.

The amount of movement and feeling in the affected arm determines how much help the survivor needs to perform an activity. Assist only as much as necessary.

Watch to see how much effort the survivor uses for a specific task. For example, if the affected arm tightens up when the survivor puts on a sock, check to see if the arm relaxes when the task is completed. High muscle tone after completing a task indicates too much effort. This can delay recovery of the affected side. In this situation, assist the survivor to do the task.

5. Cue and guide
Stroke survivors may have problems like a short attention span or an inability to plan or remember how to do a task. You may need to help the survivor by giving instructions and cues. You may need to use “hand-over-hand” guidance.

Tips:
- Break the task into small steps
- Give clear, simple instructions
- Talk the survivor through the steps
- If the stroke survivor has problems with communication, demonstrate the task
- Use consistent steps or cues to help the survivor master the skill
- Help them succeed by doing for them only the parts of the task that they cannot do themselves

6. Use assistive devices
Assistive devices, like glasses, hearing aids and any special prescribed equipment, can make it easier and safer for survivors to do more for themselves.

An occupational therapist or another member of the healthcare team can advise on the best equipment for the individual’s abilities and environment.

Make sure you know how to use a particular device. If you don’t know, ask someone to demonstrate.

7. Recognize and encourage
Relearning everyday tasks you have done for years can be challenging and frustrating for a survivor. Recognizing each success is the key to maintaining self-esteem. That will motivate the survivor to keep relearning tasks.
Recognize success. For instance, when bathing, reaching for the grab bar during a transfer is an important success. So is washing the face and hair.

Be careful of the type of encouragement you give – always make sure it respects the survivor and maintains the person’s dignity and self-esteem.

Encourage participation in every stage of the activity.

**Toileting**

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

> Always consider the survivor’s dignity and privacy when helping with toileting. For example, respect the survivor’s wishes if they do not want the bathroom door open, even if you are the only one present.

**Prepare the tools**

Before you begin, make sure you know whether the survivor can be left unattended on the toilet.

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

**Position properly**

**Using a toilet**

- Use a 1-person or 2-person pivot to transfer the survivor onto the toilet
- Support the affected limb with an armrest or sling
- Position the survivor with feet flat on the floor. This position improves balance and gives the survivor more control. Most toileting equipment now has height-adjustable legs.

**Using a commode**

If a survivor cannot be safely transferred onto the toilet, they may be able to use a commode. Use a pivot transfer if appropriate.

Follow these steps for a 2-person transfer if the survivor can stand:

1. Front care provider: Help the survivor to stand up from the wheelchair.
2. Rear care provider: Remove the wheelchair.
3. Rear care provider: Place the commode behind the survivor.
4. Rear care provider: Pull down the survivor’s pants and underwear.
5. Both care providers: Help the survivor to sit on the commode.
6. Front care provider: Once toileting is completed, help the survivor up and support in a standing position.
7. Rear care provider: Help the survivor with personal care as much as needed and pull up the underwear and pants.

8. Rear care provider: Switch the commode for the wheelchair.

9. Both care providers: Help the survivor to sit in the wheelchair.

10. Help the survivor with handwashing.

Toileting in bed

A survivor without the trunk control to sit up may need to be toileted in bed.

Toileting in bed is a last resort. Whenever possible, promote the survivor’s independence and dignity by trying a tilting commode instead of a bedban. However if the survivor must be toileted in bed, help them roll onto their affected side to position the bed pan. Be sure to protect their affected arm.

Using assistive devices

Wall grab bars: A grab bar helps the survivor to remain standing while you manage personal care and clothing. Advise the survivor not to pull on the grab bar to stand. This can tighten the muscles of the affected leg, making it harder to stand. Instead, tell the survivor to push off from the arm rests of the wheelchair or commode.

Raised toilet seats: A raised seat can make transfers easier and safer.

Commode chairs: Freestanding and over-toilet commode chairs are both available.

Toilet frames: These devices provide arm support and a solid surface to push against during transfers.

Toilet paper holders: Position the toilet paper holder so the survivor can reach the paper.

Hygiene products: Wipes make it easier for survivors to perform personal care after toileting.

Ensure all assistive devices are secure before using them.

Bathing

Stroke can change bathing from a private pleasure into an unpleasant experience. Fear of injury and invasion of the survivor’s privacy may change the survivor’s view of bathing. It is important to recognize the survivor’s fears and concerns and to use patience when helping with bathing.

Bathing safety

An occupational therapist’s assessment can determine the safest way for the survivor to bathe and the most appropriate equipment. A survivor who cannot sit in the tub without help should use a tub transfer or bath bench.

The danger points for survivors involve maintaining balance while:

- Getting in and out of the tub
- Moving around the bathroom
- Being positioned and transferred
Bathroom hazards include:

• Wet or slippery floors and fixtures
• Small bathrooms that make it hard to move safely
• Hard surfaces that can cause serious injuries during falls
• Bathtubs that challenge survivors with limited mobility
• Bath mats and rugs that slide and cause falls

Prepare the tools

• Remove bath mats or rugs from the bathroom
• Check the water temperature to make sure it is not too hot or cold
• Put cleansers, cloths, towels, and lotions within reach
• Put assistive devices, such as tub benches, in place

Position properly

When using a tub transfer bench, follow these steps:

1. Transfer the survivor onto the part of the bench over the side of the tub.
2. Help the survivor while they move their buttocks backwards onto the bench, turn, and lift their legs over the side of the tub. Ensure the survivor is well positioned on the tub bench.
3. Help the survivor wash as needed.
4. Help the survivor lift legs out of the tub.
5. Position the survivor sitting on the edge of the bench.
6. Help the survivor to dry off as needed.
7. Make sure that the floor is dry before transferring the survivor back to the wheelchair.

Use assistive devices

Tub transfer bench: A commode-style tub bench makes it easier to clean the survivor’s buttocks.

Grab bars: Wall and clamp-on grab bars can increase a survivor’s independence. An occupational therapist can recommend the type of bar, where to install it, and how to use it safely.

Hand-held shower head: This allows survivors to do more for themselves.

Bath seats and bath boards: These devices allow survivors with low activity tolerance or reduced balance to sit and rest when needed.

Non-skid bath mats or decals: These can reduce the slipperiness of the tub surface.

Bathing tools: A long-handled bath brush, a wash mitt, and soap on a rope can enable survivors to do more for themselves.

Hydraulic lift: A lift allows survivors to transfer to and from the bottom of a soaking tub or a whirlpool tub.
Grooming

Grooming includes:

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

Position properly

If the survivor will need help with any of these tasks, position them on a stable chair or wheelchair with their feet flat on the floor. The survivor should be touching the sink or counter, so that they can rest when they need to.

If the survivor will be standing, use a grab bar for safety and support.

Place the survivor’s affected arm on the counter and ensure it is well supported. Do not raise the arm above shoulder height. This may cause shoulder pain. If necessary, help the survivor to place the affected arm in a tray or sling before beginning the grooming task.

Use assistive devices

Many devices make daily tasks easier for people with decreased grip or dexterity. They include:

- A denture brush with suction cups on the back
- A tooth brush or comb with a built-up handle
- An electric toothbrush
- Liquid soap in a pump container
- Nail clipper mounted on a board (check with health care professional before use)

Dressing

Prepare the tools

Clothing choices express our personality. Whenever possible, let the survivor select clothing and accessories. If the survivor has difficulty with judgment or decision-making, offer appropriate choices.

Arrange clothes in the order they are to be put on for survivors who have difficulty with sequencing.

Position properly

Position the survivor in a sitting position in a chair with a back support, with the feet flat on the floor. Do not position the survivor sitting on the edge of the bed as this is a soft and unstable area.
Encourage use of the affected limb

Help with dressing and undressing the affected 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 survivor’s arm or leg, and draw the garment up the limb.

Here are some strategies that survivors can use to dress more independently:

**One method of putting on a shirt**

1. To put on a shirt, place it on the survivor’s lap so that the back of the shirt is facing up and the neck opening is furthest away from him.
2. The survivor should insert his affected arm first and pull sleeve well up to the shoulder.
3. The survivor then inserts the unaffected arm.

**One method for putting on socks**

1. To enable a survivor to put on socks, have her cross the affected leg over the other leg.
2. Sock can then be put on with one hand using thumb and first fingers to open it.
3. The survivor can then cross the unaffected leg over her affected leg to pull on the other sock.
One method for putting on trousers

1. Have the survivor cross her affected leg over the unaffected leg and pull her trouser leg up as far as possible.
2. Uncross legs and insert the other leg in the trouser.
3. Partially stand up and pull the trousers to the waist.
4. The survivor may use a table to help with balance when putting on trousers.

What you can do to help

Loose-fitting clothing is easier to put on. Adapted clothing allows the survivor to do more. Common clothing adaptations include:

- Shoes with Velcro fasteners or elastic laces
- Front-closing brassieres
- Pre-tied or clip-on ties
- Pants, shorts, and skirts with an elasticized waist band.

Adaptive devices that make it easier for survivors to dress include:

- a long-handled reacher or shoe-horn
- a button hook
- a footstool
- a sock-aid.

Upon reflection

Think of a time when you adapted your approach to a routine activity to suit a survivor’s abilities. What was the stroke survivor’s experience when you took the time? How did they feel? How did the family feel? How was it worth the time?

Were you able to meet their need to do things independently without getting overwhelmed? How?
How stroke affects skin

Skin breakdown and ulceration (sores) can cause serious infection. Stroke survivors face skin breakdown because of:

- Decreased activity and mobility
- Decreased or absent sensation
- Increased moisture from incontinence or perspiration
- Poor nutrition, dehydration, and dry skin
- Inability to communicate pain and discomfort
- Improper positioning, causing friction

Effective skin care

Correct skin care is very important for survivors who have trouble moving. You play a key role in maintaining the health of the survivor’s skin.

Inspect and report

Check the survivor’s skin carefully every day. Pay special attention to bony prominences – heels, hip bones, and elbows. Search for redness and cuts. Report concerns or signs of skin irritation to the right person – the nurse, case manager, physician, or family member.

Clean

Gently wash (do not scrub) skin regularly, using mild cleansers. Rinse thoroughly. Cleanse soiled skin promptly. This removes irritants and maintains the skin’s natural barrier.

Moisturize

Treat dry skin with moisturizers. Dry, flaky or scaling skin can bring about pressure ulcers, infection and irritation. Do not massage bony prominences or reddened areas. Massage in these areas reduces blood flow and skin temperature and slows healing.

Protect from too much moisture

Sources of moisture on the skin that can cause it to break down include:

- Urine or stool from incontinence
- Perspiration
- Fluids from a draining wound

Your role as health care provider

The skin is the largest organ in the body. Intact skin keeps us safe from infection. Skin maintains body temperature and hydration. You can help keep the stroke survivor’s skin healthy. Your care also reduces the risk of skin problems by making sure the survivor is correctly positioned and moved often.
These fluids all contain chemical irritants that damage the skin. Protect skin from contact with moisture. Use an incontinence product, wound dressing or barrier cream as needed. If you are not sure how to protect the skin, talk to a member of the interprofessional team such as the nurse or case manager.

**Protect bony and compromised areas**

Position the survivor in bed in a 30° side-lying position. Do not position the survivor completely on their side. Laying the survivor directly on the hip increases the risk of a pressure ulcer.

To help support the survivor in the proper position:

- Use foam wedges or pillows
- Use pillows between knees and ankles to separate bony prominences
- Use a water pillow, thick foam, or specialty boot to relieve pressure on the heels
- Use wedges and padding. Do not use donut devices. They decrease blood flow and increase tissue breakdown

Avoid positioning the survivor on a pressure ulcer. If you have to lay someone on a pressure ulcer, keep them there for as little time as you can.

**Reduce friction forces**

Friction injury occurs when the skin moves over a coarse surface. A friction injury can happen when you move the survivor in bed or they move themselves. These injuries happen often on the heels and elbows. Dressings and padding can protect delicate areas. Prevent damaging friction by using linens to lift the survivor when you move them. Do not pull or drag the survivor.

**Reduce shear forces**

When the body moves without the skin moving, the person can get shear injury. For example, raising the head allows the survivor’s body to slide down, while the skin remains pressed against the sheets. Shear injuries lead to less blood supply to the skin. Prevent shear by lifting the head of the bed no more than 30° and limiting the amount of time in this position.

**Move often**

Having a person sit or lay in the same position for a long time reduces circulation to their skin. This increases the risk of skin damage and ulcers. Risk of damage is greatest among survivors who cannot move themselves without help. Write up a plan for moving the survivor at least once every 2 hours and follow it.
If the survivor can move themselves, maintain or improve their current activity level, mobility, and range of motion, then the risk of skin breakdown is reduced. The physiotherapist can give you advice on the right activity levels for each person.

**Provide nutritional support**

Poor nutrition is linked to skin problems and poor healing. Help the survivor eat meals and snacks and drink enough.

**Use pressure-reduction devices**

Devices that help to prevent skin breakdown include:

- pressure-reducing mattresses
- alternating air mattresses
- elbow pads
- pressure-reducing seat cushions for wheelchairs

The nurse or therapist may recommend one of these devices, based on the survivor’s needs.

**Cleaning the contracted hand**

Survivors with spasticity may have a contracted hand with a closed fist. This hand often sweats. Poor air circulation may cause skin damage, resulting in odour and infection.

Good hygiene can prevent skin damage in these cases. Gently open the hand and fingers to clean and trim the nails. This also provides essential sensory input.

Those who have a painful hand may want to clean it themselves.

**Hygiene and incontinence**

Stroke survivors, especially those with urinary incontinence, have an increased risk of developing perineal skin problems (problems on the skin of their genitals) and urinary tract infections.
Use the right hygiene and skin care to 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. Remember to wear gloves for peri-care. Remove the gloves and wash your hands, as well as the hands of the stroke survivor, after peri-care
- Do not use deodorant sprays, powder, or perfumes on perineal skin

**Continence products**

Use the right continence products. Do not use menstrual products. Continence products draw urine away from the surface of the pad and promote healthy skin. Follow the directions on the package.

Watch for leaking, tightness, skin irritation, or rash. Report redness, irritation, or skin breakdown to the nurse.

---

**Upon reflection**

*Did you learn anything new about skin care today? What did you learn?*

*How will it change the way that you provide care?*

*Think of a stroke client you have cared for who had skin breakdown. Why do you think this breakdown occurred?*

*How might it have been prevented?*
Everyone has different interests and abilities. Your role is to help each survivor identify activities that are of interest. You also help them take part in those activities.

The importance of leisure activities

Leisure is free time. Many people define themselves by what they do in their leisure time – exercise, reading, grandchildren, friends, a serious hobby, and so on.

Leisure activities refresh the body, mind, and spirit. Meaningful leisure gives people a positive sense of self. It reaffirms their pleasure in living.

Taking part in leisure activities can:
- Improve social life
- Reduce depression
- Relieve stress
- Structure time
- Improve self-confidence
- Increase independence
- Improve life satisfaction
- Enhance quality of life

Leisure after stroke

Because stroke affects physical and cognitive abilities, it can change the activities the survivor can take part in. For instance, if a tennis player has a stroke that affects one side of the body, they may have to look for another activity. A person who enjoys fishing may need adjustments to their rod and reel in order to fish again. A stroke survivor who loves to read, but now has a short attention span, may have to switch from reading books to listening to audiobooks.

Many people have already retired from full-time work before they have a stroke. They would already have established a pleasant leisure lifestyle. Impairments from the stroke can make it difficult or impossible for a stroke survivor to keep that lifestyle. Without pleasant activities, hobbies, and pastimes, days can feel long, empty, and meaningless.

Support, adaptations, assistive devices, and varying amounts of assistance can help survivors resume favourite activities or find new ones. Survivors can often find alternative leisure activities that interest them. For example, a survivor with cognitive impairments who once enjoyed chess may like playing checkers as an alternative.
Meaningful leisure activities

Leisure activities help the survivor occupy their time, structure the day, and maintain function. To do so, the activities must be meaningful – not just ways to fill the time. Survivors may be drawn to specific activities to meet their needs for:

- Social contact
- Competition
- Fitness or physical activity
- A feeling of accomplishment
- Intellectual stimulation
- Creative expression
- A sense of control
- Stress relief

Leisure activities that might suit the interests and abilities of stroke survivors include:

- **Physical activities**: Walking, yoga, swimming
- **Outdoor pursuits**: Gardening, fishing, bird watching
- **Solitary pleasures**: Computers, reading, crosswords
- **Entertainment**: Movies, concerts, live theatre, shopping
- **Community outings**: Group excursions, such as with a seniors’ club
- **Social life**: Parties, dinner parties, dining out
- **Mechanical tinkering**: Fixing cars, building models
- **Artistic and creative pastimes**: Painting, sewing, needlework, ceramics
- **Service groups**: Activities of faith groups, volunteer organizations
- **Cultural groups**: Ethnic clubs, folk dancing from various cultures

What you can do to help

Identify leisure activities

If a survivor is unsure of what leisure activities are available, ask these questions:

- What do you like to do?
- Where do you like to do your favourite activities?
- When do you prefer to do these activities?
- Who do you enjoy doing things with?
- Why do you enjoy these activities?
- How can you participate in the activities?

Share this information with other members of the team, such as a recreation or occupational therapist, who can help find something meaningful for the survivor. If you are not sure what activity might be appropriate, talk to the team.
Community resources and information

Community organizations offer many activities. Share what you know with the stroke survivor about church functions, live theatre, festivals, fairs, older adult centres, and any other activities or events.

Direct the stroke survivor (or a family member) to information about community resources or local events in the community newspaper, on the local cable television station, and on local radio stations. Look for newsletters published for seniors in the area, community guides to leisure facilities, and recreation centre brochures.

Assistive devices

Assistive devices are specialized tools for people with altered abilities, such as:

- Use of only one hand
- Impaired ability to grip or manipulate objects
- Impaired eyesight or visual field loss
- Decreased mobility

Assistive devices help a survivor to take part in leisure activities. If you are unsure how a device is used, ask a member of your team. Here is an overview of the assistive devices available:

Games

- Card holder for one-handed playing
- Large-face cards
- Battery-operated card shuffler
- Age-appropriate large-piece jigsaw puzzles
- Pool cue holder

Reading

- Book holder
- Talking books, books on CD
- Large print crosswords, Sudoku, and 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
- Voice recognition program (Dragon Naturally Speaking)

Crafts

- Needle threader
- One-handed embroidery hoop and clamp
- One-handed crochet and knitting clamp
- C-clamp to stabilize projects
- Enlarged grips for pens, pencils, paint brushes, and other tools

Outdoor Activities

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

Physical Activities

- Aqua/water therapy
- Modified rules for games and sports
- Oversized badminton racquets and birdies
- Modified golf balls
- Accessible golf cart
- Swimming pool noodles and life jackets
- Bowling ramps

**Upon reflection**

Can you think of a stroke survivor you have cared for who has found a way to continue a leisure activity?

Who would you contact on your team to get help with leisure activities?
The impact of stroke on the survivor’s family

A stroke affects the whole family. Family members may have strong feelings and go through many changes. They may feel they are on an emotional roller coaster, making it hard to cope.

Each family member will react differently, depending on the relationship they have with the stroke survivor and their own personality. One family member may be afraid for the future of a loved one. Another might worry about how they will care for the survivor. While each family is unique, their reactions could include:

**Stress from:**
- The disruption of household routines
- The need to cope with new issues or problems

**Worry that:**
- Their loved one will fall
- Their loved one will have another stroke or die

**Sadness, anger, or frustration about:**
- The loss of their social life or time at work
- The loss of time for themselves

**Guilt about:**
- Living in their own home while their loved one is in a hospital or long-term care home
- Taking time for themselves instead of spending all their time with their loved one

**Grief:**
- Intense sadness, just as if the survivor had died
- Feeling they have lost the person the stroke survivor used to be

What you can do to help

Here are some ways you can help the stroke survivor’s family:

- Ask family members how they are being affected by the stroke
- Be supportive. Offer information and assistance
• Give encouragement and positive feedback when the family is managing well. The family often needs to know that others appreciate their efforts. Show them that you know they are doing their best.
• Encourage family members who wish to help with the survivor’s care to get involved.
• Encourage family members to make time for themselves. They need to balance care for themselves and care for the survivor.

Watch family members for signs of stress or other negative emotions. Report your concerns about a family member’s mood to someone on your team who can help.

Stresses on the informal caregiver

The informal caregiver is the person 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 a stroke survivor can be difficult, stressful, and time-consuming. The caregiver may have some of these feelings:

Anxiety about:
• How they will be able to keep caring for the survivor. This is especially true if the caregiver has health problems or is older.
• Their role. Depending on the culture they grew up in, caregivers may feel it is their duty as spouse, child, or family member to care for the survivor single-handedly. This is stressful, but failing to care for the survivor would be an even greater source of stress.

Worry about:
• Money – being able to keep providing financially for the survivor

Fear of:
• Social isolation: Initial offers of help and support from friends and relatives often decrease over time
• Others judging the quality of care the survivor is getting

Guilt about:
• Being unable to care for the survivor
• Placing the survivor in a long-term care home

Frustration at:
• Seeing the survivor struggle to cope
• Seeing no improvement, or less improvement than hoped

Anger about the stroke:
• How it affected both of their lives
• How it affected their plans – “This isn’t the retirement we planned”

Exhaustion from:
• Caring for the survivor. Extreme fatigue may make the caregiver seem apathetic towards everything else
Exhausted caregivers may appear uncaring or cold
Care giving often consumes all their energy and emotion

Confusion about:
- A role reversal in a relationship. The main caregiver, usually the wife, may now be cared for by her husband, or a parent may now be cared for by a child
- The role reversal may increase the stress felt by both the survivor and the caregiver

What you can do to help
You can play an important role in identifying caregiver stress. You can also encourage and support the informal caregiver. Here are some ways to help:

Listen to the caregiver.
Caregivers may need to share their worries. Suggest a tea or coffee break and listen to the caregiver. They may need to talk repeatedly about their fears for the survivor. However, they may be uncomfortable discussing the stress and fatigue of care giving, due to fears of being judged or criticized.

Observe the caregiver.
Weeping, anger, poor eye contact, and withdrawal from others are signs of stress. Share these observations with your team.

Learn about the caregiver’s support system.
This may include family members, friends, neighbours, the family doctor, and members of the caregiver’s faith group. Encourage the caregiver to seek help from their support system.

Reassure them about the survivor’s care.
Demonstrate your ability to meet the survivor’s needs for care.

Communicate clearly and consistently with caregivers.
Ask them directly what can be done to decrease demands placed on them. Do not lecture them about what they should or should not be doing.

Encourage the caregiver
Help the caregiver to have a realistic sense of hope about the future. Encourage them to believe that they will be able to adjust to the new reality.

Refer the caregiver to helpful resources.
A very helpful resource is “Let’s Talk about Stroke: An Information Guide for Stroke Survivors and their Families”, published by the Heart and Stroke Foundation.

Report your concerns
If you feel that a caregiver is not doing well and needs more support, report your concerns to your case manager.
Upon reflection

What are some signs of caregiver stress or burnout?

Think about an informal caregiver you have met while caring for a stroke survivor.

What kind of stress were they feeling?

What did you do to support the caregiver? Can you think of anything else you could have done?