



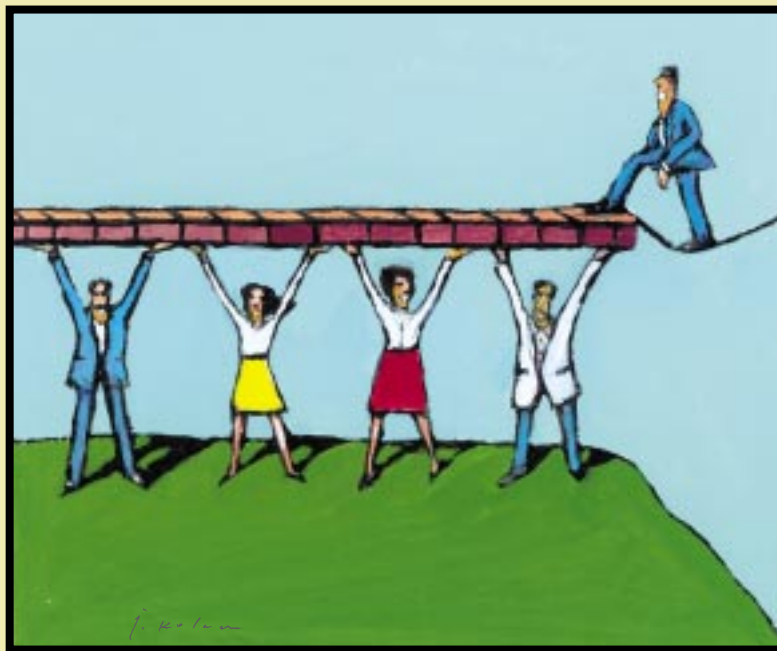
HEART &  
STROKE  
FOUNDATION  
OF ONTARIO

Ontario  
**Stroke**  
System



Stroke Strategy  
Southwestern Ontario

# Tips and Tools for Everyday Living: A Guide for Stroke Caregivers



HEART  
AND STROKE  
FOUNDATION  
OF ONTARIO



ONTARIO ASSOCIATION OF  
NON-PROFIT HOMES AND SERVICES  
FOR SENIORS



Ontario Community  
Support Association  
Association ontarienne  
de soutien communautaire

## Table of Contents

<b>Introduction</b>	2
<b>How to Use this Guide</b>	4
<b>Section 1</b> The Anatomy of Stroke	5
<b>Section 2</b> The Psychosocial Effects	11
<b>Section 3</b> Communication	13
<b>Section 4</b> Leisure Activities	21
<b>Section 5</b> Mobility and Skin Care	23
<b>Section 6</b> Routine Activities of Living	37
<b>Section 7</b> Cognitive and Perceptual Problems	43
<b>Section 8</b> Meal Assistance and Hydration	53
<b>Section 9</b> Specific Behaviours	59
<b>Section 10</b> Managing Continence	63
<b>Section 11</b> Risk Factors for Stroke	67
<b>Section 12</b> Aphasia – Breaking Down Communication Barriers	69
<b>Section 13</b> Quality Improvement and Monitoring	75
<b>Section 14</b> Resources	79

## Note

This publication was prepared with input from a number of health professionals who have reviewed the information to ensure its suitability. However, the information contained herein is for reference only and is intended 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.

The Heart and Stroke Foundation of Ontario (HSFO) and other sponsoring associations assume no responsibility or liability arising from the reader's failure to become informed about the requirements of fulfilling their job. In addition, the HSFO and the other sponsoring associations assume no responsibility or liability arising from any error in or omission from this publication, or from the use of any information or advice contained in this publication.

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## Introduction

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This Guide for stroke caregivers is the joint effort of five organizations: the Ontario Association of Community Care Access Centres, the Ontario Associations of Non-Profit Homes and Services for Seniors, the Ontario Long Term Care Association, the Ontario Community Support Association and the Heart and Stroke Foundation of Ontario. The Ontario Home Health Care Providers Association has not been a formal sponsor to date but has expressed its support for this project and its hope to be more directly involved as we move forward.

The Guide is designed to provide the practical knowledge and skills needed by the people who provide care, day in and day out, to the many thousands of stroke survivors living in Ontario. Many of these caregivers are visiting people in their homes, others are providing care in long-term care facilities and still others are working in day programs and other community settings. All make an enormous difference in the lives of individuals who are struggling to deal with the often devastating impact of a stroke.

This project is part of the Ontario Integrated Stroke Strategy 2000, funded by the Ministry of Health and Long-Term Care<sup>1</sup>. Ministry funding of this project is gratefully acknowledged. It should be noted that the opinions expressed in the Guide are those of the authors and no official endorsement by the Ministry is intended or should be inferred.

2

The Heart and Stroke Foundation of Ontario is pleased to be a partner in the implementation of the Ontario Stroke Strategy. This follows the successful completion of the Foundation-led Coordinated Stroke Strategy (CSS), a three-year demonstration project involving four regional sites, designed to test a model of coordinated stroke care across the full continuum of care. One important component of the CSS was the Stroke Rehabilitation Consensus Panel, which documented rehabilitation issues and presented a vision for the future. To begin implementation of that vision, the Foundation asked the associations identified above to participate in a joint effort to address the issues in long-term care in both the community and in stroke care facilities across the province.

After commissioning some further work in needs assessment and issue identification, the group began work on this Guide and a companion video. It is our hope that these two resources will provide a good starting point for introducing “best practices” for stroke care across the province.

In February 2001, the Ministry of Health and Long-Term Care designated six Regional Stroke Centres. In 2002, three additional Regional Stroke Centres and seven District Stroke Centres were designated. These Centres will be providing leadership in bringing people together at a regional level and across the full continuum of care. Over the next few years as the strategy is implemented, Stroke Centres will be named for the rest of the province. The development of partnerships across the continuum is essential for the delivery of truly client-centred stroke care. Long-term care providers are key players in these regional stroke systems.

<sup>1</sup> For further information, please see *Towards an Integrated Strategy for Ontario: Report of the Joint Stroke Strategy Working Group*. June 2000

A project of this nature depends on the hard work and commitment of many. The members of the Steering Committee are listed and their efforts are gratefully acknowledged. The content of the guide was based on feedback received from front-line staff who work with stroke survivors at a focus group in February 2001. The participants represented the diverse geography of Ontario – rural and urban locations, as well as long-term care and community environments. Sharon Jankowski and her team at St. Joseph’s Health Care London, Parkwood Hospital, deserve special thanks for their content expertise. Lynelle Hamilton assumed much of the responsibility for editing and pulling together the content for the Guide. The material was strengthened by the responses of a number of focus group participants and reviewers:

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The five partnering organizations are committed to continuing to work together, and we look forward to receiving and learning from your feedback. We welcome your comments on this Guide, as well your ideas about how we can make it come alive.

## How to Use this Guide

A stroke can be an overwhelming and life altering condition. In the space of a few moments, a survivor's life can be dramatically (and sometimes permanently) changed. But you already know that. That's why you're reading this Guide.

At first glance, you may find the length of this Guide a little daunting. It does contain a great deal of information. However, it is meant to be used as a resource for specific topics. It is not meant to be read from start to finish, like a novel.

The Guide is organized to help you find the information you need quickly and easily, and to answer your questions about working with stroke survivors:

### Section 1 The Anatomy of Stroke

- What is a stroke?
- Are there different kinds of stroke?
- What happens to the brain, body, mind, and spirit?

### Section 2 The Psychosocial Effects

- How does a stroke affect the family relations, social life, and living environment of a stroke survivor?
- How does this change in the early stages following a stroke, or later on when a stroke survivor is placed in a long-term care facility or returns home?

### Section 3 Communication

- How many different ways can the ability to speak and understand be affected by a stroke?
- What can I do to make communication easier for me and the stroke survivor?

### Section 4 Leisure Activities

- How do I provide more than basic care? How can I help a stroke survivor have more fun and a good quality of life?

### Section 5 Mobility and Skin Care

- How does a stroke affect the person's ability to transfer and get around?
- What can I do to assist a stroke survivor and prevent more problems?

### Section 6 Routine Activities of Living

- What are the easiest ways to assist a stroke survivor with bathing, toileting, and dressing?

### Section 7 Cognitive and Perceptual Problems

- Are there "invisible" problems that cause functional difficulties for a stroke survivor? What are they?

- Are there ways to help that make my job easier and ensure the person is more satisfied with the care I'm providing?

### Section 8 Meal Assistance and Hydration

- How do I make sure a stroke survivor eats well and enjoys meals?

### Section 9 Specific Behaviours

- Why do stroke survivors sometimes say and do things that are frustrating for me?
- What can I do to make the situation better for both of us?

### Section 10 Managing Continence

- Why do some stroke survivors have continence problems?
- Are there ways to help that make things easier for both of us?

### Section 11 Risk Factors for Stroke

- Am I and the people I look after at risk for stroke?
- What can we do about it?

### Section 12 Aphasia – Breaking Down Communication Barriers

- What is aphasia?
- How can I communicate more easily with a person with aphasia?
- How can I help stroke survivors with aphasia communicate better?

### Section 13 Quality Monitoring

- What are best practices of care for stroke survivors, their families, and caregivers?

### Section 14 Resources

- Where can I get more information about stroke?
- How can I find services and equipment to assist a stroke survivor?

Because most topics are inter-related, we've cross-referenced sections when useful information can be found elsewhere in the Guide.

This resource is intended to provide you with a basic understanding of the problems that may be faced by a person who has had a stroke. You'll also find many tips and techniques to make your caregiving more effective and to help the survivor function to the best of his or her ability.

Throughout this Guide, we have used the terms "he" and "she" interchangeably in describing the stroke survivor. This is for convenience only, unless otherwise noted, and is not meant to be gender-specific or show bias.

# Section 1

## The Anatomy of Stroke

Imagine not being able to speak or control one side of your body. Every aspect of your life would be dramatically changed. Stroke is a leading cause of adult disability and death in Canada. Each year, between 40,000 and 50,000 people in Canada will experience a stroke. In this Guide, we'll use the term "stroke survivor" to refer to a person who has had a stroke.

A stroke is a sudden injury to a part of the brain caused by an interruption in its blood supply. A stroke's effects can be long-lasting and can vary widely. The survivor will most likely experience some impairment, even if it is only temporary. Approximately 75% of the people who have a stroke will have some degree of long-term disability. As a result, the survivor's ability to do things she wants to do will be affected. The disability that results from the impairment will vary from person to person and can be extremely frustrating for the survivor.

Survivors are individuals: an activity that is important to one is not necessarily as important to another. Thus, no two survivors will necessarily experience the same degree of disability, even if they have had the same type of impairment.

The experience of having a stroke usually has a sudden and dramatic effect on the survivor. It often causes the survivor to feel fragile and vulnerable. She may feel frustrated, or become extremely sad. This can affect the survivor's quality of life and her recovery.

### You, the Caregiver

In your work, you have an opportunity to make a difference in the lives of those to whom you provide support. Each client is unique, with her own values,

preferences, and needs. By incorporating the approaches suggested in this Guide with the principles of client-centered care (such as respect for individuality, attention to physical comfort, providing emotional support) you can contribute to an enhanced quality of life for the survivors to whom you provide support.

As a caregiver, you will be assisting the survivor in many ways:

- To relearn routine activities of living
- To regain abilities that will allow the survivor to resume her lifestyle
- To support the survivor as she copes with challenges and frustrations
- To provide care and help with activities the survivor cannot (or cannot yet) do independently.

5

The support and help you provide will always be defined by what the survivor needs and by how she prefers to be assisted. As with all the work you do, you will have to adapt your techniques to meet the specific needs and preferences of the survivor.

### What is a Stroke?

A stroke occurs when a blood vessel bringing oxygen and nutrients to a part of the brain bursts (*hemorrhagic stroke* – see Figure 1) or becomes clogged (*ischemic stroke* – see Figure 2). When that happens, the nerve cells in that part of the brain can't function. As a result, the part of the body the affected cells control stops functioning.

Figure 1 – Burst Artery

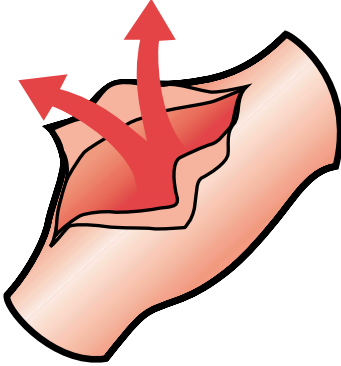
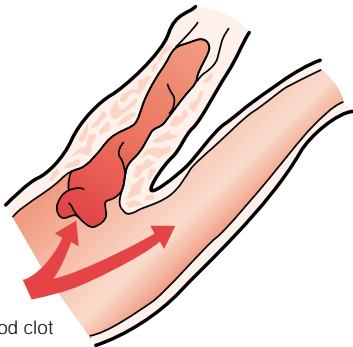


Figure 2 – Blocked Artery



Lodged blood clot blocking the flow of oxygen-rich blood to the brain

## Why Does a Stroke Affect a Person in a Particular Way?

### The Brain's Functions

The brain functions like a computer centre, controlling all of the aspects of who we are and how we function, including our:

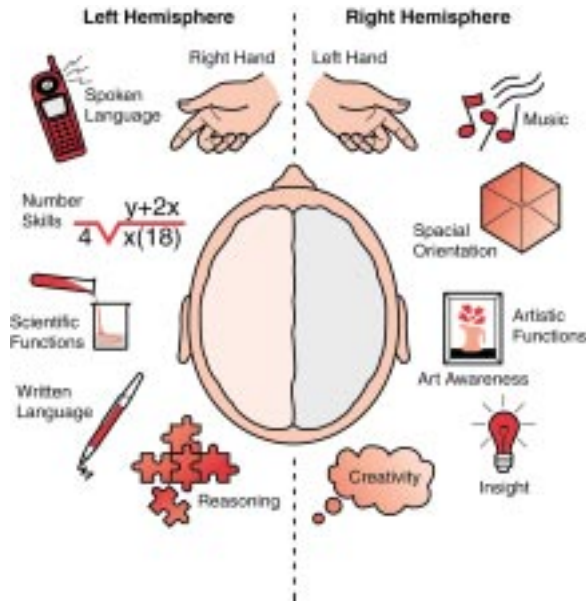
- Personality
- Emotions
- Behaviour
- Ability to move and coordinate movement
- Ability to feel touch, temperature, pain and movement
- Ability to see
- Ability to accurately interpret what we see (perception)
- Ability to think, to remember, understand, plan, reason or problem-solve
- Ability to communicate (speaking and understanding).

The brain is divided into two sides or halves, called hemispheres. Each hemisphere has dominant functions. Figure 3 shows the areas of the brain known to control certain functions.

The left hemisphere of the brain controls the motor and sensory functions of the right side of the body. It is also responsible for scientific functions, understanding written and spoken language, number skills, and reasoning.

If flow is not restored within minutes, brain cells (called neurons) are injured and many will die. Without treatment, neurons will continue to die over the next few hours. The permanently damaged neurons cannot be replaced, repaired or restored.

Figure 3 – Functions Controlled by Areas of the Brain



The right hemisphere of the brain controls the motor and sensory functions of the left side of the body. It controls artistic functions, such as music, art awareness, and insight. It also controls perception, which includes the ability to be aware of the environment, and understanding and interpreting information from the environment.

Within each hemisphere, the brain is also divided into many regions. Each region controls various functions of the body. Damage to a specific region may affect the functions that it controls. Some strokes are so large that they affect more than one region. For example, a large stroke in the left hemisphere of the brain may cause damage to the motor, sensory and language areas. Consequently, a survivor's ability to move, feel and communicate will be affected.

To function, brain cells must have a continuous and sufficient supply of oxygen and nutrients. These are provided by the blood that circulates through the body. Therefore, the blood system supplying the brain is

very important. Each artery supplies a specific area, or territory, of the brain. When the blood supply in a specific artery is interrupted, the area of the brain it supplies will be affected.

Whenever the blood supply is cut off from an area, something remarkable happens. The body attempts to repair the damage. Small neighbouring arteries take over part of the damaged artery's work. Thus, nerve cells temporarily starved of oxygen and nutrients may recover, although other cells still lacking an adequate supply will die. If the blood supply is cut off by a clot, mechanisms in the blood may attempt to dissolve the clot.

Over time and in response to the injury, there is a reorganization of brain tissue. Other areas of brain tissue take over some of the work once done by the damaged cells. As well, areas that first appeared to be damaged may in time recover. As a result, the survivor's ability may eventually improve, or even return to normal.

## How Does a Stroke Affect the Body?

Every stroke is different. Some people suffer a mild stroke, which means that there is very little injury to the brain. A survivor of a mild stroke usually recovers fully or has only a few problems. Another survivor may have had a severe stroke in which a great deal of damage is done. When this happens, it may take a long time for the stroke survivor to regain even partial control of the body functions affected. In fact, even when two people experience the same type of stroke, they may not experience the same degree of disability.

Four factors determine the effect of a particular stroke: location of the damage, severity of damage, how well the body repairs the blood supply system to the brain, and how quickly other areas of brain tissue take over the work of the damaged cells.

Survivors will also recover differently. Many factors determine the recovery process: the survivor's age and general health, personality, coping abilities and emotional state, the support of family and loved ones, and rehabilitation. The most rapid recovery occurs during the first 3 to 4 months. However, recovery may continue over many months or years. While some people are left with significant disability after a stroke, many stroke survivors are able to adjust to their disability and resume activities important to them.

## Common Effects of a Stroke

Although a stroke does not affect any two people in exactly the same way, it often brings similar challenges. Some effects are associated with damage to a particular side of the brain, as each side (hemisphere) of the brain has dominant functions. Strokes that occur in the cerebellum or brain stem can result in dizziness, balance problems, reduced coordination, slurred speech and difficulty swallowing.

Table 1 (page 9) summarizes some of the more common effects, according to the hemisphere involved. Some are common to both sides of the brain, and others are more characteristic of right or left hemisphere damage.

## Stroke Risk

Survivors and their families often ask many questions about risk of another stroke. A person who has had a stroke has a higher risk of having another one. The risk is highest in the first year, at about 15 times the risk among the general population. The risk remains high throughout the first five years. Overall, 30% of those who have had a stroke will go on to have another one at some time.

Risk factors for stroke are discussed in Section 11 of the Guide.

## Early Intervention

A stroke is a medical emergency. It can be as life-threatening as a heart attack. Early recognition and intervention can literally mean the difference between surviving or not, or between mild or significant impairment.

There are five main warning signs of a stroke. They usually occur suddenly, and can be an indication of a full-blown stroke, or a transient ischemic attack (TIA).

### The Five Main Warning Signs of a Stroke

1. Sudden weakness, numbness and/or tingling in the face, arm or leg.
2. Sudden loss of speech or trouble understanding speech.
3. Sudden loss of vision, particularly in one eye, or double vision.
4. Sudden severe and unusual headache, or change in the pattern of headaches.
5. Sudden loss of balance, dizziness, unsteadiness or sudden falls, especially with any of the above signs.

If any of the above symptoms are experienced, you must immediately call for emergency help (911). Quick action improves the person's chances of survival and making a full recovery. Without prompt treatment, brain cells will die. Then, the chances of reducing the neurological damage caused by a stroke are small.

### Transient Ischemic Attacks (TIAs)

A TIA is essentially a mini-stroke caused by a temporarily blocked blood vessel. The symptoms of a TIA usually last only a few minutes. A TIA leaves no permanent brain damage. However, it can be an important warning sign that a person may be about to have a stroke. In about 10% of cases a TIA comes before a stroke.

TIAs should never be ignored. By getting prompt medical attention, people who have had a TIA may be able to reduce the risk of a full-blown stroke.

**Table 1: Common Effects by Hemisphere**

Effect	Right Brain Damage	Left Brain Damage
<b>Swallowing</b>	Dysphagia	Dysphagia
<b>Loss of movement</b>	Usually on left side	Usually on right side
<b>Loss of sensation</b>	Usually on left side	Usually on right side
<b>Fatigue</b>	Usually	Usually
<b>Communication</b>	Usually retain language ability, but may have difficulty producing speech ( <i>dysarthria</i> )	May lose language, ( <i>aphasia</i> ) may also have dysarthria
<b>Difficulty understanding and interpreting</b>	More often have <i>perceptual</i> impairments: left neglect, right vs. left discrimination, judging depth, distance, space, passage of time	Usually normal perception, but may have right neglect
<b>Visual field loss</b>	Left visual field loss	Right visual field loss
<b>Apraxia</b>	Yes	Yes
<b>Memory impairments</b>	Memory impairments (new spatial information – location, time)	Memory impairments (new language information, i.e. names)
<b>Difficulty controlling emotions</b>	Yes	Yes
<b>Difficulty thinking</b>	<p>Impaired judgment or insight into limitations.</p> <p>Tend to <i>overestimate</i> physical ability, underestimate physical disability.</p> <p>May be impulsive, have a short attention span and perseveration.</p> <p>More likely to have difficulty with comprehension or expression of emotions.</p> <p>May be seen as poorly motivated, or exhibiting “bad” behaviour.</p>	<p>Usually judgment is intact, good insight into limitations.</p> <p>Others may think the survivor <i>underestimates</i> physical ability, overestimate physical disability.</p> <p>Normal attention span, reacts slowly and cautiously.</p> <p>Better able to express/comprehend emotions.</p>



## Section 2

### The Psychosocial Effects

A stroke can have a dramatic physical effect on the survivor's ability to move, see and speak. At the same time, a stroke can also have a dramatic effect on the survivor's emotions, on the way he feels about himself and on his relationships.

When someone has a stroke, much of the attention is focussed on the physical side of the stroke. However, survivors who are struggling with the physical effects of a stroke are also dealing with the emotional impact. They may be feeling shock, fear, grief, anger and frustration. The time following a stroke can be an emotional roller coaster with a wide range of feelings: conflict, loss, despair, hope, anger or acceptance.

Family members experience similar feelings. Sometimes these feelings can be very strong, and can affect the family's ability to cope.

#### The Initial Reaction

Typically, shock is the first emotion that most people feel after a stroke. They might be asking themselves questions such as: "Why did this happen to me?" or "How could this have happened?" Survivors who are not able to speak after a stroke can feel extremely isolated and frustrated by their inability to communicate with others.

Additionally, survivors may feel fear, anxiety and worry. They may wonder if they will survive, if they will have another stroke and what their life will now be like.

Similarly, friends and family often experience fear and worry about their loved one. They may also worry about their ability to care for the survivor.

#### As Time Goes On

In general, stroke survivors often feel:

- **Frustrated** about physical limitations, with loss of memory, lack of ability to speak.
- **Tired**, as a result of the stroke and because of the increased effort required to perform routine activities.
- **Disinterested** in social activities and social contact with others. This may be due to feelings of embarrassment about the changes in physical appearance, lack of ability to speak or be understood, etc.
- **Grief-stricken** over loss of abilities, over how they feel about themselves and how they perceive others feel about them.
- **Depressed**. Approximately half of survivors experience some degree of depression. It may be caused by changes in the brain that occur after a stroke, and/or by knowing that they have lost some of their ability to do some things they did before the stroke.
- **Anxious**. Survivors often have many concerns after a stroke. All of these worries can create anxiety – a normal reaction to the changes that occur after a stroke. As the survivor adapts, the anxiety usually lessens.

## What You Can Do to Help

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Stroke survivors have to find new ways to give meaning back to their lives. You can help by:

- Being supportive and offering encouragement
- Allowing the survivor to do as much for herself as possible
- Offering positive feedback, by telling the survivor when she is managing well
- Gently offering information and assistance to the survivor to enable her to become more independent
- Observing for signs of depression or other emotions that negatively affect the survivor.

Concerns about a survivor's mood should be reported to your supervisor.

12

## Psychosocial Issues of the Survivor's Family

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Although the survivor is clearly most affected by a stroke, the survivor's family also experiences many changes and reactions to the stroke. Each family is unique, but in general, family members often feel:

- **Stress from having their household routines disrupted or from having to cope with things at home that they did not have to worry about before the stroke**
- **Worry that their loved one will have a fall or another stroke**
- **Sadness, anger or frustration over loss of a social life and time to themselves**

- **Guilt over their loved one being in hospital or a nursing home while they can live in their own home, or guilt over doing something for themselves instead of always spending time with their loved one**
- **Grief similar to how they would feel if a loved one had died (loss of the person the stroke survivor used to be before the stroke).**

## What You Can Do to Help

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Many of these approaches are similar to those used to support the survivor:

- **Being supportive and offering encouragement.**
- **Offering positive feedback when the family is managing well.** Families need to know that they are seen as doing their best.
- **Gently offering information and assistance to the family.**
- **Observing for signs of stress or other emotions that negatively affect the family.** Concerns about a family member's mood should be reported to the appropriate person.
- **Allowing family members opportunities to participate in the survivor's care.** However, it's also important to encourage them to take time for themselves. Balancing self-care and care for the survivor is important.

## Section 3

### Communication

Imagine, if you can, that everyone around you is speaking in a language you don't understand. When you try to make your needs known, no one around you seems to have any idea what you mean. It would be frustrating, wouldn't it?

Communication challenges are common after a stroke. People communicate constantly, so problems in communication can become extremely upsetting. Stroke survivors often become frustrated with their inability to communicate effectively.

#### What is Communication?

The need to communicate is a basic human need. It's been said that we cannot **not** communicate: everything we do involves sending a message to others.

We usually think of communication as something we do by talking to another. However speech is only one of many ways in which we communicate. Our non-verbal communication – how we stand or move, our facial expression, as well as the tone of our voice – is an important component of communication. A raised eyebrow or a shrug may be all that is needed to be understood. Crossed arms or a frown may radically change the meaning of the words we speak. Recall a time when you understood someone's feelings without that person having to say a word. What did that person do to convey the message?

Non-verbal communication may be more significant than verbal communication, particularly when the non-verbal communication does not seem to “match” the words spoken. For example, consider the following situation: You see a person who is crying and shaking. You decide to ask the person if she is alright. She says

yes. Do you believe her? Probably not. To communicate effectively we need to be able to interpret both the **spoken** and **unspoken** meaning.

In every conversation there are at least two **communication partners**. Each partner has the responsibility to both speak (to send a message) and listen (to receive and understand the message the other has sent). As partners communicate with each other, they learn to read each other's facial expressions and body language. Over time, communication between the partners becomes easier and more successful.

#### Communicating with a Survivor

We are communication partners with those for whom we provide care. Generally speaking, stroke survivors are less able to adjust their communication to the needs of the caregiver. Therefore, the following material is designed to help the caregiver adjust to the needs of the survivor so that they can both understand and be understood.

For true communication to occur, each partner must be able to send a message that is understood by the other partner. This is the hardest part about being a communication partner to a survivor with a communication impairment. It is not enough that the survivor understands what she is told by the caregiver. She must also be able to express her own messages and be understood.

Strokes take away many abilities that are essential to connecting with others. Many impairments after stroke impact communication although they may not necessarily be considered communication deficits.

A conversation cannot occur if the survivor can't physically get to the person she wants to speak to. This is the case for many people with physical disabilities. In nursing homes, residents may have to wait for a caregiver to take them to the person they wish to see. A survivor living alone in an apartment may not be able to get out to talk with others.

As well, people often treat individuals with physical impairments as though they cannot speak or think for themselves. Wheelchair users report that staff in stores and restaurants frequently ignore them and direct all their communication to their physically-able companions, regardless of the communication ability of the wheelchair user. For example, people may ask the companion what the wheelchair user wants to eat in a restaurant, even though there is no reason to believe that the wheelchair user cannot answer directly. These experiences erode the individual's confidence and personal dignity and may result in withdrawal from normal interaction.

Caregivers may be the most frequent and important communication partners in the stroke survivor's life. As such, we are responsible to communicate respect to our survivors, to treat them as adults whose values, interests, concerns, opinions, strengths and weaknesses reflect the experiences of their lives.

## What You Can Do to Help

There are several ways you can demonstrate helpful communication. For example, you might:

- **Ask how the survivor would like to be addressed.**  
Does the survivor prefer being called by his or her first name or as Mr., Mrs. or Ms.?
- **Introduce yourself and your purpose in being there.**  
You may have to introduce yourself many times as the survivor may see many faces in a day. Large easy-to-read name tags can be helpful.
- **Deal with private matters privately.** A survivor's bowel routine is not their room-mate's or friend's business.
- **Use discretion in conversations in the presence of others (friends, family, other health providers) regardless of the survivor's communication impairments.** Avoid talking about the survivor in his presence unless he is part of the conversation.
- **Be calm, direct and positive in all communication.**
- **Help the survivor to have normal interactions by adjusting the environment to compensate for changes resulting from the stroke.**

Table 2 summarizes some of the communications challenges you may encounter with your survivor, and what you can do to help.

## Essential Characteristics of Successful Communication Partners

Successful communication takes effort. In order to communicate successfully, partners must possess specific characteristics:

### At all times:

- **Respect for each other**
- **A clear idea of what message needs to be sent**
- **Respect for the message the other person has to send, and that the message has relevance and importance**
- **A desire to understand the other person's message**
- **Trust that the other person wants to understand the message you are sending**
- **Empathy for each other.**

### When the message is not getting across:

- **A sense of optimism: that the communication will take place**
- **Patience and persistence**
- **Creativity – trying different methods, different words**
- **Honesty when not understanding.**

**Table 2: Post Stroke Problems that Make Communication Harder... and What to Do to Help the Survivor**

<b>Problem</b>	<b>Approach</b>
<b>The survivor is unable to physically get to where she wants to be in order to communicate with others.</b>	<p>Ensure she has the means to contact staff and/or residents/family members (e.g. by encouraging use of mobility aids, positioning chair, call bell, telephone).</p> <p>Ask the survivor where she prefers to be.</p>
<b>The survivor is unable to communicate eye-to-eye, due to inability to stand.</b>	<p>Come around the front of the chair to talk. Begin the conversation by establishing eye contact.</p> <p>Position yourself to be at the survivor's eye level. It's preferable to squat or sit in front of the survivor rather than lean over the wheelchair.</p>
<b>The survivor has impaired hearing.</b>	<p>Communicate face to face in a quiet room with good lighting on your face.</p> <p>Ensure hearing aids (if used) are working and are worn.</p> <p>Ask if he can hear you adequately.</p> <p>Position yourself to be most easily heard (this may require some trial and error to get the right spot).</p> <p>Double check to make sure that messages have been heard accurately.</p>
<b>The survivor is dependent upon others to move their wheelchair.</b>	<p>Before moving the wheelchair, always ask the survivor where she wants to go.</p> <p>Accommodate preferences for how the chair is moved. Tell the survivor what you plan to do before you do it.</p>
<b>The survivor is unable to alter facial expression to reflect emotions.</b>	<p>Ask the survivor how he feels.</p>
<b>The survivor has slowed responses.</b>	<p>Allow time for responses or for the survivor to initiate a message. Five (5) seconds (count them to yourself) can make all the difference.</p> <p>Create opportunities that encourage communication. For example, take a few minutes to comment on pictures or personal objects in the survivor's room or home to indicate your interest and willingness to listen to them.</p> <p>Allow time for the person to answer any question you ask. For example, if you ask a survivor how he is, make certain that you stay to hear the answer.</p>
<b>The survivor has impaired vision.</b>	<p>Ask if she can see (print, pictures, your face) and how well she sees.</p> <p>If the survivor wears glasses, encourage her to wear them. If the survivor has different pairs (e.g., one pair for reading and another for distance) make sure she is using the correct pair.</p> <p>Make sure that lighting is adequate (neither too dark nor too light).</p>
<b>The survivor's ability to manage personal care is limited.</b>	<p>Help the survivor achieve the appearance that she chooses or would have chosen in the past.</p>
<b>The survivor cries or laughs inappropriately and uncontrollably (lability).</b>	<p>Ask if the survivor feels sad or happy. If his expression is not related to his true feeling, reassure him that you understand and that this commonly occurs after stroke. Keep a record of anything that appears to trigger this response and try to reduce the frequency of these triggers.</p>

## Specific Communication Impairments

After stroke, some people have specific communication impairments that result from injury to specific areas of the brain. A survivor may have one or more of these impairments and the problems may be quite mild or very severe, in keeping with the area and extent of the damage. It is important to know the kind of communication problem in order to use appropriate strategies to help.

**Allowing more time for communication is the one strategy that is helpful in all cases.** It can be hard to take those extra few minutes, but those few minutes may save hours in dealing with the errors, frustration, and anger that can result from failed communication.

16

It may be helpful to schedule a **communication time** with the survivor in a quiet place on a regular basis to prevent the build-up of communication frustration. For example, the survivor's knowing that every day she will have 15 minutes of your time just to sit and chat may make all the communication failures in the day a little more bearable.

Communication impairments result from damage to different areas of the brain. Communication impairments include:

- **Motor speech, e.g., dysarthria**
- **Language e.g., aphasia**
- **Cognitive communication.**

## Dysarthria

Dysarthria is an impairment of the ability to make the sounds of speech clearly because of weakness or lack of coordination. Words may sound slurred, the survivor's voice may be very soft, or the survivor may sound as though he is drunk. Dysarthria is a motor skill problem. Survivors with dysarthria have not lost language. They can:

- **Think, plan, decide and reason**
- **Understand spoken language**
- **Read**
- **Write or type**
- **Often use computers or other devices to communicate.**

People unfamiliar with this impairment may underestimate the survivor's abilities to reason and make decisions. People may make assumptions about the survivor's desires and exclude the survivor from making decisions. The survivor's communication impairment may make it very difficult for him to explain that he is quite capable of reasoning and making decisions.

## Area of Injury

There are many different kinds of dysarthria. Each results in weakness or lack of coordination of different muscles of the mouth, throat, and chest. The damage that causes dysarthria is generally deep in the brain (sub-cortical). However dysarthria may be caused by damage on either side of the brain.

## What You Can Do to Help

Using one or more of the following approaches may make it easier to communicate with the survivor with dysarthria:

- **Communicate in a quiet place.**
- **Speak slowly.** This encourages the survivor to speak slowly, which will make his speech easier to understand.
- **Repeat what you have understood and ask for further clarification of anything you have not understood.**
- **Jot down notes as the survivor talks, especially if the problem is very severe.** This makes it easier for both of you to keep track of what has been said.
- **It may be easier for the survivor to write down information.** Provide paper and pen or marker for the survivor to have with him at all times. Sometimes a small portable white board may be useful.
- **Consider use of a computer for word processing and e-mail or a TDY (device for the deaf) for the telephone.** These allow the survivor to type what cannot easily be spoken.
- **A communication picture/word/phrase board may be helpful for quick communication of basic needs.**
- **An alphabet board may be helpful to communicate more complex ideas.** Write the words as the survivor spells them.
- **Communicate about significant issues when the survivor is rested.** Fatigue may make communication more difficult or impossible.

## Aphasia

Aphasia is probably the most often mentioned communication disorder. However, it is often misunderstood. Aphasia is a loss of language itself. It may affect a survivor's ability to talk, read, write or understand. Because many people tend to associate communication skill with mental ability, they may underestimate the abilities of the survivor with aphasia. Because of the communication impairment, the survivor may be excluded from decision-making. It's important to remember that survivors with aphasia:

- **Are able to think, plan, decide, and reason**
- **Usually produce some clear words (the problem is not weakness or lack of coordination)**
- **Understand facial expressions, gestures, and non-verbal aspects of communication. In fact, the survivor with aphasia may be able to "read you like a book."**

## Area of Injury

Aphasia is usually the result of injury to the left hemisphere of the brain. Different kinds of aphasia are produced by injury to different areas of the left hemisphere. This survivor often has weakness or paralysis of the right side of the body.

Table 3 provides some helpful tips on communicating with a survivor who has aphasia.

**Table 3: Communicating When a Survivor Has Aphasia**

Problems	Approaches
<p><b>The survivor has difficulty understanding spoken language.</b></p>	<p>Converse face to face in a quiet room.</p> <p>Speak slowly and give the survivor time to respond.</p> <p>Provide specific choices, e.g., “Would you like an apple or an orange?” or ask yes/no questions such as “Would you like an apple?” or “Would you like an orange?”</p> <p>Introduce a change in topic clearly: “I want to talk to you about your family.”</p> <p>Give information in small amounts at a time.</p> <p>Print key words in large clear print on paper as you talk.</p> <p>Use pictures and objects to show what you mean (even rough drawings can be helpful).</p> <p>Use maps, calendars, schedules and clocks—these are often understood and help when talking about where and when.</p> <p>Never talk <b>about</b> the survivor in his presence unless you are talking <b>to</b> the survivor.</p> <p>Never underestimate the individual's ability to understand non-verbal information, especially when the information is personally relevant.</p>
<p><b>The survivor has difficulty expressing words and sentences.</b></p>	<p>Allow time for responses.</p> <p>Some individuals use swear words unintentionally. Do not dwell on the use of these words.</p> <p>Be patient. After stroke, individuals have good and bad days, even more than most of us.</p> <p>Expect variability in communication from day to day and from time to time within the day.</p> <p>When survivors are struggling for a word, don't jump in too quickly. Supply the word only when it is clear from the survivor's behaviour that the struggle is too frustrating.</p> <p>Allow individuals to express themselves to the best of their ability.</p> <p>Survivors often use words they don't intend (e.g. yes for no). Double check by asking questions in a different way.</p> <p>If you aren't sure what the survivor has said, ask. Don't pretend you have understood.</p> <p>Assure the survivor that you know they know what they want to say.</p> <p>Encourage them to show you, to draw, or to print if they can.</p>

## Cognitive Communication Impairments

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These include a reduced ability to understand and communicate clearly related to the problems with organization of thoughts, concentration, memory and knowledge of non-verbal communication. This is commonly seen in survivors who have had severe or multiple strokes or right hemisphere strokes.

## Right Hemisphere Communication Impairments

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This group of impairments includes difficulties concentrating, scanning the environment, understanding facial expression, non-verbal communication, verbal humour, sarcasm, hints, or jokes. In conversation a survivor with this type of impairment may have difficulty getting to the point, may wander off topic, and give too much or too little information. People who do not know the survivor may overestimate her abilities to communicate and may think she is being rude.

Survivors with right hemisphere communication impairments are able to:

- **Speak clearly in fluent sentences**
- **Understand direct, concrete communication**
- **Tell and laugh at familiar jokes**
- **Sometimes read**
- **Write some words and sentences.**

Table 4 outlines some strategies that will be helpful in communicating with a survivor who has right hemisphere communication impairments.

**Table 4: Communicating When a Survivor Has Cognitive Impairments**

Problems	Strategies
<p><b>The survivor is fluent but sometimes poorly organized or wanders off-topic.</b></p>	<p>Remind the survivor of the topic being discussed.</p>
<p><b>The survivor does not provide all relevant information on a topic.</b></p>	<p>Ask specific questions to get more information.</p>
<p><b>The survivor makes little eye contact (especially with people to his left).</b></p>	<p>Always approach from the right. Get the individual's attention before moving to the left.</p> <p>Request eye contact.</p> <p>Some individuals may not be able to attend to people on the left at all. Sit on their right for all communication.</p> <p>Tell her when you are leaving. If she is not looking at you, she may continue the conversation, unaware that you have left.</p>
<p><b>The survivor may appear rude.</b></p>	<p>Avoid humour, sarcasm, hints, and other indirect ways of conveying meaning.</p> <p>Say exactly what you mean (even if it feels impolite at first).</p> <p>Tell the individual how you feel when he says or does something that appears rude, and tell him what he could do instead. Remember that the survivor is not intentionally rude: he needs your help to correct communication that comes across as rude.</p>
<p><b>The survivor may have difficulty understanding or remembering what she reads because of:</b></p> <ul style="list-style-type: none"> <li>• failure to see the letters or words on the left</li> <li>• difficulty concentrating.</li> </ul>	<p>Use print or pictures to communicate only if you know that she can see, understand and remember this material.</p> <p>When print is used, keep the information short and direct. Keep the print large and clear.</p> <p>To help the survivor remember, it may be helpful to provide a simple printed summary of information you talked about.</p>

## Section 4

### Leisure Activities

People often define themselves by two factors: what they do in their work and what they do for fun. For example, when someone is asked what she did on the weekend, the response is often leisure-related, i.e., walked to the park, read a book, played with grandchildren, or visited with friends, etc.

When someone has had a stroke, the activities that had previously brought pleasure to their lives can be difficult or even impossible to enjoy. Many of the survivors you will see are retired and have engaged in a well-established leisure lifestyle throughout each day prior to their stroke. Many will require support and assistance to return to previous activities or replace those that cannot be regained.

Survivors will encounter a great deal of “free time” – as much as 8-11 hours in each day. That’s a great deal of time to pass! Exploring leisure options is a valuable way to re-establish what has been meaningful prior to the stroke, to structure the day with productive activity, and possibly to maintain function.

The survivor may feel that previous interests are too difficult to resume. However, many leisure interests can be resumed if help and resources are available and the survivor possesses the required cognitive and physical abilities. If the survivor’s primary interest is not possible, seeking alternate interests may be a good option. For example, if a survivor once enjoyed chess (a game which requires complex skills he no longer has), a less complex activity such as checkers may be acceptable.

You have a unique opportunity to assist the survivor to recapture meaningful and productive activity through leisure.

#### What You Can Do to Help

Here are some suggestions to assist with identifying the survivor’s interests:

- **Ask concise questions about the survivor’s leisure interests.** Think about common activities such as cards, reading, games, crafts, etc.
- **Ask the survivor about interests pursued within the community such as church, organizations, shopping, etc.** You may be able to assist him to again take part in these interests.
- **Use communication aids to help determine leisure preferences.** If the survivor is aphasic, try drawing pictures or show him some specific examples of various activities.
- **Record the interests for future reference.** A person may mention a “summer” activity in December. Although not possible at that time, you may want to make note when the season allows.
- **Find out what leisure resources are available for you to access.**

*Once the leisure interests are identified:*

- **Set aside time each day for leisure activity.** Plan for it, much as you would plan for an appointment. It may be helpful to post this information on a calendar.
- **Provide a maximum of two leisure options for each session.** This empowers the survivor by providing opportunity for choice.
- **Try simple, previously pursued interests at first.** Expand the options, as the survivor is able.
- **Choose a quiet, well-lit environment.** This minimizes distraction.
- **Place the activity directly in front or slightly towards the survivor’s unaffected side.**
- **Use assistive devices if it makes the activity easier for the survivor.**

**Assistive Devices**

Assistive devices are specialized equipment developed for individuals with altered abilities such as the use of only one hand, impaired ability to grip or manipulate objects, impaired eyesight or visual field. Assistive devices can make it much easier for the survivor to take part in leisure activities. A survivor who was unable to turn a page while holding a book due as she is able to use only one hand may now be independent in reading with the use of a book holder.

Table 5 lists some commonly-used assistive devices.

**Table 5: Assistive Devices for Leisure Activities**

**Games**

- Card holder to enable one-handed card playing
- Large face cards
- Battery operated card shuffler
- Age-appropriate large-piece jigsaw puzzles

**Reading**

- Book holder
- Talking books/books on tape
- Large print crossword and word search puzzles

**Computer**

- Use of larger size font for text
- Computer magnifier
- Large monitor
- Modified key board

**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, etc.

## Section 5

### Mobility and Skin Care

When mobility is limited, care of the skin becomes extremely important. Lack of mobility often leads to prolonged pressure on the skin, which can result in skin breakdown. Adding to the problem, skin breakdown may go unnoticed because of decreased sensation. This can eventually lead to infection, injury, pain and other serious conditions, further limiting mobility, increasing frustration and putting the survivor at risk. This section of the Guide deals with issues related to mobility and positioning, including caring for the affected arm and hand, and skin care.

### Mobility

Mobility means movement. We move all the time – in bed, rolling, sitting up, standing and walking. The extent to which a stroke affects a person's ability to move can vary greatly. Many factors can affect the survivor's mobility:

- **Motor Loss**
- **Sensation**
- **Fatigue**
- **Muscle Tone**
- **Balance**
- **Posture**
- **Perception**

#### Motor Loss

Motor loss usually occurs on the side of the body opposite to the side of the brain where the stroke occurred. If the stroke occurred in the left side of the brain, the right side of the body may be affected. When a stroke occurs in the brain stem, both sides of the body may be affected.

#### Sensation

Sensation is the ability to feel and recognize touch and temperature, as well as to know what position your body is in space, i.e., up, down, left, right, forward or backward. A survivor's sensation may be reduced or absent. For example, the survivor may not realize that a shoe is too tight, or that her arm is too close to a candle or stove burner.

#### Fatigue

Fatigue is common after a stroke. Brain healing and re-learning the tasks of daily living requires a tremendous amount of mental energy. Stroke survivors usually feel very tired, especially in the initial recovery period. A survivor may become exhausted from completing even simple tasks. This can lead to frustration, sadness and anger, which also use up energy.

#### Muscle Tone

Even when relaxed, normal muscles have slight tension in them to counteract gravity. This is called tone. All normal muscles have tone. In a stroke, two types of tone changes can lead to movement problems: low tone (flaccidity) and high tone (spasticity). A limb with low tone will appear heavy and limp. Careful handling and positioning is important to prevent injury and pain.

Excessive effort can increase spasticity in a limb with high-tone, making movement even more difficult. High tone in a limb for a long period of time can reduce the range of motion in a joint. Careful handling and positioning is important to attain as normal a level of tone as possible and prevent tightening of the muscles (called contractures).

## Balance

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Balance is maintained by reactions that respond automatically to changes in body motion. For it to work effectively, both sensation and motor control must be intact. Because a stroke can affect sensation and motor control, balance can be impaired, resulting in an increased risk of falling.

## Posture

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In a normal standing position, there is parallel alignment of the shoulders, hips and feet. The head and trunk are at midline and symmetrical. With stroke, this normal alignment is often affected. For example, the shoulder girdle and pelvic girdle sometimes rotate backward. In some cases, the survivor may put more weight on the unaffected side.

## Perception

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Visual and auditory neglect, body neglect, apraxia, impaired depth and distance perception, can all impact on a person's ability to move. These are covered in more detail in Section 7 (Cognitive and Perceptual Problems).

## Assisting the Survivor

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One of the primary goals of assistance is to help the survivor's body work as normally as possible. Therefore, any movement you encourage and assist should enhance normal movement as much as possible.

People with spasticity or abnormal control cannot simply learn to use the normal side for everyday activity. Make certain that you know the techniques prescribed for your survivor.

## Guiding Principles for Assisting with Mobility and Motor Function

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- **The goal of assistance is survivor safety and comfort, quality of movement, and as high a level of independence as is possible.**
- **Avoid overtiring the survivor or asking a fatigued survivor to do too much.** Balancing rest and activity is essential to avoid frustration and possible injury.
- **Each person is different and a unique individual.** There is no set recipe that will apply to everyone. Think things through. Does movement look normal? If not, why not and how can you help?
- **Move slowly and gently.** Do not be in a rush! If you are calm, the survivor will be able to participate better. Give the survivor time to think.
- **Talk with the survivor.** Explain and demonstrate, if necessary. Use simple, concise verbal instructions. Make certain the survivor understands what you've said.
- **Encourage the survivor to participate as much as possible.** Provide only the assistance the survivor needs. Coordinate your efforts with the survivor's. Sometimes verbal coaching or guidance may be all that is needed. You need to know what the survivor's abilities and limitations are.
- **Use good body mechanics.** If you are unsure whether you can assist a person alone, ask for a stand-by or another helper (a skilled co-worker or family member). Make sure to coordinate your efforts when you're working with another caregiver.
- **Never pull on the survivor's affected arm or under the survivor's shoulders.** This can cause significant pain and harm to the shoulder joint.

## Handling the Survivor's Affected Shoulder

The shoulder is an area which requires close monitoring and careful handling. It can easily be injured, resulting in a further loss of function.

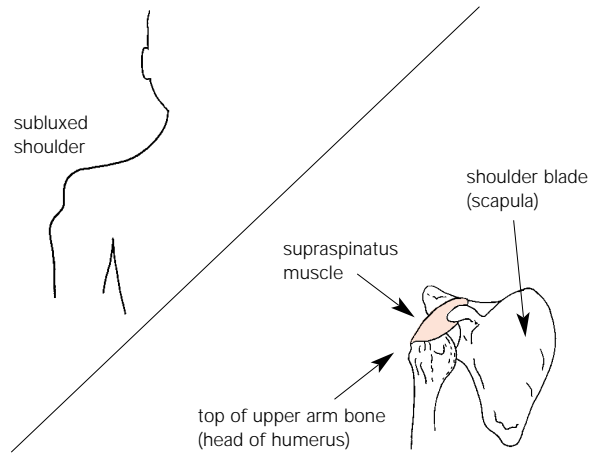
The shoulder is a ball and socket joint that moves in many directions. Unlike other joints where many strong ligaments help to hold the joint in place, the shoulder joint is held together largely by muscles surrounding the joint. After a stroke, the muscles around the shoulder may be affected and no longer hold the joint in place. This results in poor joint alignment and risk of injury.

### Assisting the Survivor Who Has a Low-Tone Shoulder

Muscles often become weak due to insufficient stimulus from the brain. This causes the shoulder joint to become loose and poorly lined up. In some cases, it may even become partially dislocated. This condition is called a *subluxed shoulder* (see Figure 4). You can see a subluxed shoulder: it has a noticeable gap between the ball and socket of the joint (between the head of the upper arm bone – the *humerus* – and the tip of the shoulder). The head of the humerus bone is not properly positioned in its socket because it has been pulled down by gravity.

Subluxation puts the soft tissue around the shoulder joint at risk of developing pain, as the muscles which normally support the shoulder no longer hold the joint in place. This places excessive stretch on those muscles and ligaments. Survivors often report the pain as “toothache type” – that it is constant, dull and diffuse.

Figure 4 – Subluxed Shoulder



### What You Can Do to Help

- **When the survivor is sitting, support the affected arm at all times, using a lap tray or arm trough.** This prevents stretching the soft tissue.
- **Always be careful when handling the limb or repositioning the survivor.** The affected limb should be supported and “un-weighted” prior to repositioning. This will minimize the over-stretching of the soft tissue structures.
- **Seek the advice of a professional if you feel that there is a need.** If you are concerned about the survivor’s limbs, proper positioning, or wheelchair, ask your supervisor to request an assessment by an occupational therapist or physiotherapist.
- **Avoid using passive range of motion exercises on the limb.** The tissues around the joint are very vulnerable to being pinched or injured from poor alignment of the ball in the socket. This pinching can lead to serious pain. As well, a survivor with diminished sensation may not know that this pinching is occurring, resulting in harm.
- **Never pull on a limb during a transfer, when assisting the survivor to move in bed, or to walk.** This can cause pain and damage to the shoulder joint.

## Assisting the Survivor Who Has a High-Tone Shoulder

In some survivors, the balance of muscle tone around the shoulder becomes abnormal with some muscles becoming overactive (*spasticity* or *high tone*). High tone can make movement difficult. This may result in the muscles pulling the humerus in toward the chest wall. Attempts by the survivor or caregiver to move his arm may aggravate pain.

If this reaction is not controlled, it will hinder the survivor's attempt to move. Controlling high tone is the result of a complex learning process. It requires the assessment and guidance of a physiotherapist and the commitment of the survivor. If your survivor has a spastic shoulder, ask for information on how the high tone is best controlled.

26

### What You Can Do to Help

- **Careful attention to supported positioning of the limb in good alignment can help reduce pain and muscle imbalance.** Pain and muscle imbalances related to high tone must be addressed in order to begin to attain normal movement of the arm or strengthening of the muscles. It is hard to promote good alignment of the arm when lying down. Use of pillows or towels can help to improve positioning of the arm in bed, as described in the section on positioning. Support the arm when sitting by using a lap tray or similar device. Seek the advice of a physiotherapist or occupational therapist involved with the survivor (if appropriate).
- **Avoid passive range of motion.** Passive movement of the arm can jam the ball into the socket of the joint and result in sharp severe pain often localized in the front of the joint. It can also damage the tissues around the shoulder and arm, even causing tendonitis.
- **Report joint or tissue pain to the appropriate person for follow-up.**
- **Follow the recommendations of the therapist or other health professional involved.**

## Positioning

The goals of positioning are to:

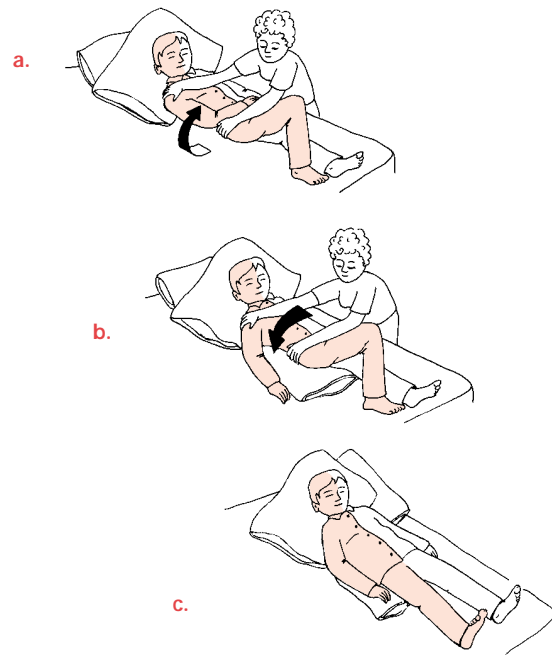
- **Preserve normal body alignment**
- **Alter the abnormal tone patterns that can be associated with hemiplegia**
- **Increase awareness of the affected side.**

You should regularly check on a survivor who is not able to reposition himself. He will have to be repositioned regularly to reduce the risk of pressure sores.

### Lying on the Back

1. Head is in a neutral position (not moved forward or backward).
2. Pillows are used to support the head, the affected arm and affected hip, as shown in Figure 5.

Figure 5 – Positioning – Lying on the Back



## Side-Lying on the Affected Side

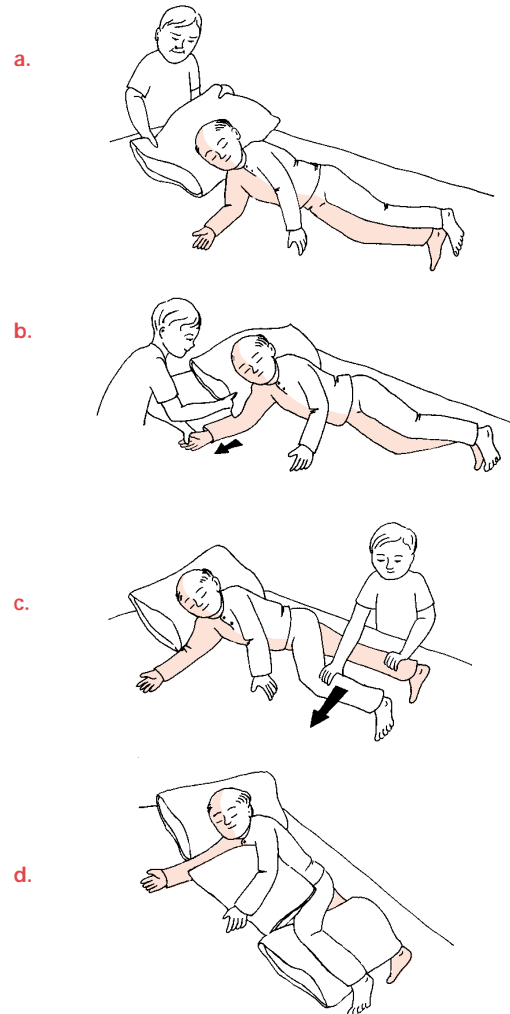
Many survivors are more comfortable lying on their side. One procedure for attaining a comfortable side-lying position is presented below and in Figure 6.

- **Tell the survivor what you are going to do and make sure that he is ready for the procedure.** This will avoid startling the survivor.
- **Turn the survivor onto his affected side.** You may need to use a turning sheet and/or have another person assist you.
- **Place a pillow under the survivor's head.** Make sure the survivor's neck is slightly flexed and in a comfortable position.
- **Position the affected leg straight, and slightly behind the trunk.**
- **Position the affected shoulder slightly forward of the body and straight at the elbow.**
- **Place a pillow under the uppermost arm and in front of the survivor's stomach to prevent him from falling forward.** The unaffected leg is bent (flexed) at the hip and knee. This helps improve positional awareness and reduces the feeling of floating.
- **Place a pillow between the survivor's legs.** This helps to reduce the risk of friction and increases survivor comfort.

## Side-lying on the Unaffected Side

Positioning a survivor on the unaffected side is essentially the same as for sidelying on the affected side. Note that survivors with significant impairment on the affected side may feel trapped in this position and will probably roll onto their back.

Figure 6 – Positioning – Side-Lying



## Rolling Onto the Unaffected Side

- **Encourage the survivor to bend her knees up prior to rolling.** This will make the roll easier.
- **Remind the survivor not to forget her affected arm.** It is not uncommon for the survivor to leave it behind when rolling onto the unaffected side.
- **Encourage the survivor to look to where she is rolling.** Lifting and turning the head to look to the side to which the survivor is rolling makes it easier to do.

## Moving from Lying to Sitting Position

This set of instructions provides one way of assisting a survivor to rise to a sitting position. These are instructions you can give to the survivor. You may have to assist if your survivor is unable to complete all tasks independently.

Ask the survivor to:

- Bend both knees up.
- Lift and turn her head to look in the direction of the roll.
- Roll completely over onto her side, without forgetting the affected arm.
- Bend her hips up (draw knees toward chest).
- Slip both feet over the edge of the bed.
- Push up with her arm(s), looking up as she pushes up.
- Sit up tall.

## Moving from Sitting to Standing

This set of instructions provides one way of assisting a survivor to rise to a standing position. These are instructions you can give to the survivor. You may have to assist if your survivor is unable to complete all tasks independently.

Ask your survivor to:

- Slide his hips forward to the edge of the bed/chair.
- Sit up tall.
- Position his feet about shoulder width apart, with the heels directly below the knees. Be sure that the heels of both feet are touching the floor.

- Bend forward at the hips and look up. Keep his back straight (trunk and neck should remain extended as hips flex). Bring his shoulders forward in line with the knees.
- Push up with both legs. Keep his weight equally distributed over both legs.
- Stand up tall.

## Sitting in a Chair

The following tips and the illustration in Figure 7 can help you help your survivor sit comfortably and safely.

- **Remember the 90° rule.** The survivor is sitting properly when her hips are flexed at 90°, ankles at 90° and elbows at 90°.
- **Regularly remind and/or assist the survivor to reposition hips back in the chair.** Hips often slide forward in a chair, creating a slumped posture. Hips should be back and centred in the chair. Advise your supervisor if the survivor's wheelchair appears to be contributing to improper positioning.
- **Use a lap tray to support the affected arm.**

Figure 7 – Positioning – Sitting



## Transfers (Moving from Bed to Chair)

The ability to safely assist a survivor to transfer depends upon the ability of the caregiver and the ability of the survivor. There is no single technique that will work in all situations. There are three factors to consider when planning a transfer:

- **The survivor's level of control and movement.**  
Poor control over the affected side may cause the survivor to overuse the unaffected side when transferring.
- **Size and weight of the survivor compared to the caregiver.**
- **Time of day and degree of fatigue.** Is the survivor better able to perform in the a.m., but fatigued at night? You will likely have to provide additional assistance when the survivor is tired.

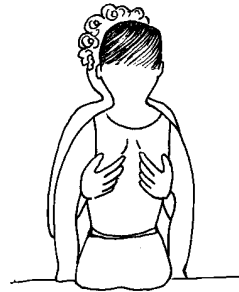
### General Principles of Safe Transfer

Prepare the survivor and yourself for the transfer. Ensure the survivor has appropriate footwear, etc.

- **Make sure that wheelchair brakes are applied, arm rests removed (if applicable) and foot rests are up and swung out of the way.**
- **Assist the survivor into the appropriate starting position by bringing their buttocks closer to the edge of the wheelchair by shifting one side forward at a time.**
- **If the survivor overuses the unaffected side, omit the signal to start the transfer.** This may lessen the survivor's tendency to overuse the unaffected side during the transfer.

- **Position yourself as close to the survivor as possible, without blocking the direction of movement or the survivor's vision of the path of movement.**
- **When assisting the person's upper body, guide and support the movement by placing your hands around their upper back and shoulder blades, as shown in Figure 8.**

Figure 8 – Hand Position for Transfer



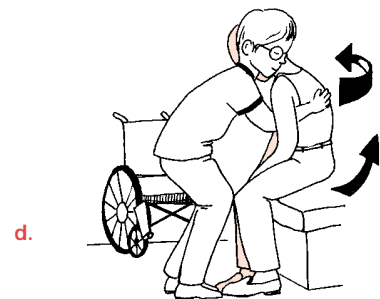
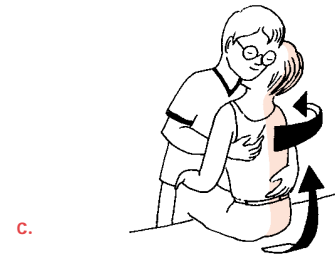
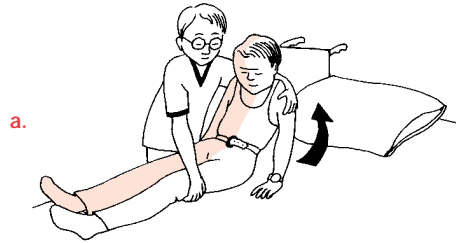
- **Bend your knees when assisting the survivor with the transfer.** Keep your back in normal alignment.
- **Shift weight from front foot to back foot as you assist with the transfer.** This can provide leverage and rotation, making the transfer easier.
- **Avoid pulling the person's affected arm.**
- **Do not lift the survivor by placing your hands under their arms or armpits.** This can cause pain.

## One Person Pivot (Stepping) Transfer

A one-person pivot transfer, as shown in Figure 9, is frequently used with survivors. It can be easily adapted for toilet, car and bed-to-wheelchair transfers. As well, it is used to assist a survivor into a standing position.

- Stand in front of the survivor, supporting the shoulder blades.
- Tell the survivor in which direction the movement will occur.
- Rock the survivor gently forwards and guide them to standing.
- Position your feet on each side of the survivor's affected foot once the survivor has risen to standing. This will allow you to block the hemiplegic leg when the survivor is standing, preventing it from giving way.
- Assist the survivor to transfer weight to the leg closest to the destination and assist the survivor to step/pivot.
- Assist the survivor to bend forward and to place buttocks down and back on the new surface.

Figure 9 – One Person Standing/Stepping Transfer



## Two Person Pivot (Stepping) Transfer

### Application

This transfer is suitable for the survivor who is able to bear weight through the legs but is heavy or unreliable.

### Staffing

The technique requires two caregivers, with the taller of the two positioned behind the survivor (see Figure 10).

### Procedure

- **Lower the bed so that the survivor's feet can rest on the floor.** Lock the bed brakes, if the bed has casters.
- **Adjust or remove the wheelchair's footrests and the armrest on the side closest to the bed.** This allows the chair to be placed close to the bed.
- **Place the wheelchair next to the bed at a slight angle and ensure the brakes are locked.** This allows the rear caregiver to be closer to the survivor.
- **The caregiver in front of the survivor assumes the role of leader and assists the survivor to sit on the edge of the bed with his feet flat on the floor.**
- **The survivor places his arms around the waist of the leader, who, in turn, places, his hands on the survivor's upper back.**
- **The rear caregiver assumes a position behind the survivor with one knee on the bed and supports the survivor at hip level.**
- **If the survivor overuses the unaffected side, omit a verbal signal to start the transfer.** This may lessen overuse during the transfer. Use a non-verbal signal to coordinate the start of the transfer with the other caregiver.

- **Assist the survivor to transfer weight to the leg closest to the destination, to pivot, and to place buttocks down and back on the new surface.** This technique may be performed more effectively with the use of a transfer belt placed low on the pelvis of the survivor. This allows an easier and more comfortable transfer of the survivor without the tendency to lift by using the survivor's clothing. It also allows the second staff member to be of greater assistance during the procedure.
- **Replace the footrests and armrest on the wheelchair.**
- **Reposition the survivor so that he is comfortable.**

Figure 10 – Two Person Standing/Stepping Transfer



## Using a Mechanical Lift

If there is a concern regarding the survivor's/caregiver's ability to perform a transfer, a mechanical lift can be considered. An occupational therapist or physiotherapist should be consulted in determining whether a mechanical lift is appropriate.

## Assistive Devices to Aid Mobility

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### Wheelchair Use

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Most survivors will have some mobility problems, even after rehabilitation. A problem may be as mild as limited exercise tolerance or as significant as total inability to move. A survivor may require a wheelchair for a part or all of his day.

The wheelchair should be appropriately measured and prescribed by a physiotherapist or occupational therapist. If necessary, a pressure relieving cushion and back support may be incorporated into the prescription.

### Propulsion

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Many survivors are taught to self-propel a wheelchair in rehabilitation. However, people change and you should observe your survivor to make sure that she seems to be comfortable and well-positioned in the chair. The following tips will help you to make certain that your survivor's wheelchair is properly used.

- **Pay particular attention to whether the survivor slides forward in the chair when propelling it.**

If sliding occurs, postural tone and control can be affected. This results in the deterioration of transfers, control and an increase in high tone, pain and risk of skin breakdown. A "hemi-height" wheelchair (a chair with a seat that is lower to the ground than a "standard" chair) may be prescribed. This type of chair allows the survivor to reach the floor with her foot without needing to slide forward.

- **Always observe a survivor's activity and ask "Does it look normal?"** If not, ask "Why not?". Then consider "What can I do to change it?" Watch for increasing levels of tone as an indicator of the survivor using excessive effort. If this is happening, re-evaluate the activity, as excessive effort only reinforces and perpetuates abnormal movement patterns.
- **Remember the "too much too soon" rule.** Trying to do too much too soon will negatively affect the survivor's ability in the long term, as overuse can result in deterioration and increases the need for assistance. Always balance the benefits of 'quicker' independence and overuse of the unaffected side with the increased risk of overuse and deterioration.

## Walking

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### General Principles

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- **Pay attention to the survivor's balance.** Make certain that she is balancing and distributing weight evenly over both legs before setting out to walk. If balance wavers as the survivor walks, she should stop and regain balance before going on.
- **The hip, knee and ankle should be lined up so that the affected leg accepts the survivor's weight smoothly and safely.**
- **Encourage the survivor to look up, not at the floor.** The trunk should be erect. This encourages better posture.
- **Look for good placement of the affected foot after swinging it forward.** Weight should be distributed throughout the foot so that the foot does not roll to the outside.
- **Look for good placement of the walking aid (e.g., cane, rollator or walker if used).**
- **Encourage the survivor to pay attention to safety, slowing down when necessary.**
- **Observe for attention to the affected side.** Is the survivor aware of her body and space, e.g., not bumping into objects on the affected side?
- **Always stand on the survivor's affected side.**
- **Only provide assistance where necessary.** If steady-  
ing is required place one hand on the survivor's back and one hand in front.
- **Do not hold the survivor under her affected arm.**

### Walking Aids

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Encouraging weight bearing through the affected leg helps to stimulate more normal movement. When a person leans on a cane, she automatically bears less weight through the affected leg. Leaning too heavily on a cane will result in abnormal gait.

### What You Can Do to Help

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- **Observe the survivor for signs that the aid is not appropriate or is being used incorrectly.** An aid that is too tall or too short will cause the survivor to assume a poor position. Consult the appropriate person if you feel that there is a problem.
- **Assist walking by providing stability and cueing.**
- **Avoid lifting or pulling.**
- **Follow any instructions prescribed by the survivor's physiotherapist.**

## Stairs

Stairs can be challenging. The following tips can help you assist your survivor safely.

- **Assist your survivor to use stairs only if he requires no more than minimal guiding assistance.**
- **If the survivor can climb the stairs reciprocally (by using one foot per step), he should use the hand rail (if present).** Assist from behind going upstairs and in front going downstairs, if required.
- **If the survivor cannot ascend the stairs reciprocally, recommend that he use one step at a time.** Usually the survivor is taught to lead with the strongest leg going upstairs and the weakest leg going downstairs. However, if the survivor has high tone that results in his affected leg crossing midline, he may have been taught to lead with the strong leg going downstairs and upstairs. Check to see what the survivor has been taught.

34

## Caring for the Survivor's Hand

After a stroke, the hand is prone to swelling and positioning problems due to lack of sensation or movement. A hand with low tone often swells, as fluid pools. Swelling and disuse may result in pain and skin problems.

### What You Can Do to Help

- **Always be considerate of the affected hand.** When sitting, the survivor must always have her arm supported on a lap tray or arm trough, with the hand positioned in front, fingers opened and wrist supported.
- **Use foam wedges or arm supports placed on the tray to elevate the hand and reduce swelling.**

- **Encourage the survivor to use her unaffected hand to gently bend and open the fingers of the affected hand, and to place the hand on the supporting surface.**
- **Never force the hand open.** If it is extremely spastic, make sure that the shoulder girdle is in the forward position as shown in Figure 11. Then, supporting the hand at the wrist, gently stroke the back of the hand (the extensor) and wrist. This should help the fingers start to open. This promotes good positioning and makes cleaning of the palm and between the fingers easier.

Figure 11 – Arm Support to Elevate Hand



- **Contrary to popular belief, squeezing soft balls should be discouraged as it promotes closure of the hand and tightness of the fingers.**
- **Follow any instructions prescribed by a therapist to mobilize the hand, and treat pain and swelling.**
- **Report any changes in pain, swelling or function to the appropriate person.**

## Foot Care

The affected foot can experience many of the same complications as the hand, i.e., problems of swelling, pain and stiffness.

### What You Can Do to Help

- **If sensation is impaired, regularly check the skin for redness, blisters, or breakdown.** The survivor may not be aware of a developing problem.
- **Encourage the survivor to follow a physician's instructions to reduce swelling.** Assist the survivor to wear any prescribed pressure stockings and to follow instructions for elevation or rest. Lying down for short periods with the legs at or above the level of the chest is more effective when dealing with swelling. Elevating leg rests on wheelchairs do not have much benefit as the leg is only partially elevated and the hip is flexed, impairing blood flow. Additionally, having the legs elevated tends to promote a slumped posture in the chair.
- **Whenever possible, incorporate standing into the survivor's daily routine.** One way of doing this is to promote standing at the kitchen counter or bathroom sink with weight evenly distributed through both legs, the leg joints well lined up and the heels on the ground.
- **Be aware of the potential for ankle instability while standing with assistance.** Prevention of ankle and foot stiffness and deformity is important. Report any concerns to the appropriate person.

## Skin Care

### Skin Breakdown

The skin is the largest organ of the body. It provides a defense against infection. Skin breakdown can be prevented by frequent changes of position and by being mobile. Damage to the skin can pose a major threat to well-being and comfort.

A survivor is at risk for skin breakdown for several reasons:

- **Loss of the ability to move**
- **Loss of sensation**
- **Increased moisture due to incontinence or perspiration**
- **Dry skin**
- **Decreased activity**
- **Poor nutrition**
- **Dehydration**
- **Lack of ability to communicate pain and discomfort**
- **Friction and shear from improper positioning.**

### What You Can Do to Help

- **Thoroughly inspect the survivor's skin each day.** Pay particular attention to bony prominences such as heels, hip bones, and elbows. Look for redness and signs of abrasion. Any concerns should be immediately reported to the appropriate person for follow-up.
- **Regularly wash skin with mild cleansing agents.** Do not scrub skin. Make sure to rinse off all soap residue. This protects the skin's 'natural barrier' and removes harmful irritants. Clean soiled skin promptly.

- **Treat dry skin with moisturizers.** Dry, flaky or scaling skin areas are at greater risk of development of pressure ulcers, infection and irritation because of the loss of the skin's natural barrier.
- **Do NOT massage over bony prominences or red-dened areas.** Massaging these areas results in reduced skin blood flow and a significant decrease in skin temperature. Decreased temperature causes slower healing.
- **Minimize skin exposure to moisture from incontinence, perspiration or wound drainage.** Use an approved barrier to protect the skin, such as an incontinence product, wound dressing or barrier cream. Moisture makes skin more likely to break down. Urine, stool, perspiration or wound drainage may contain other factors that irritate the skin.
- **Use proper positioning, transfer and turning techniques to minimize skin injury due to friction and shear forces.** Shear injury happens when the skin remains stationary and the underlying tissue shifts, resulting in diminished blood supply to the skin. Keep the head of the bed at the lowest level possible (less than 30°). Limit the amount of time the head of the bed is elevated as it causes shear force.
- **Use proper techniques to reduce friction injuries.** Friction injury occurs when the skin moves over a coarse surface. Voluntary or involuntary movements by the survivor can lead to friction injury, especially the heels and elbows. Use dressings and padding to protect areas at risk. Use linens to lift (rather than drag) the survivor when repositioning.
- **Prevent prolonged sitting or lying in one position.** Remaining in one position increases the risk of collapsed blood capillaries, resulting in inadequate blood circulation to skin areas. Survivors who are unable to independently move or reposition themselves are more likely to develop ulcers and skin problems. There are several things you can do to reduce prolonged sitting or lying in one position.
- **Maintain or improve current activity level, mobility and range of motion.** You may want to seek the advice of the survivor's physiotherapist.
- **Establish a written repositioning schedule to ensure that the survivor is not left in one position for too long a time.** Reposition the survivor at least once every 2 hours.
- **When repositioning a survivor in bed, a side-lying position of 30° is preferred, rather than turning the survivor completely onto his side.** Avoid positioning the survivor directly on the hip, as this increases the risk of a pressure ulcer. Use devices such as foam wedges or pillows to support the survivor in the proper position. Use pillows between knees, ankles, etc. to keep bony prominences apart.
- **Use of a water pillow, thick foam or specialty boot may be needed to relieve pressure to heels.**
- **Avoid positioning the survivor on a pressure ulcer.** If this is not possible, minimize the time in this position.
- **Provide nutritional support.** There is a link between poor nutritional intake and the development of skin problems and poor healing. Encourage and/or assist the survivor to eat meals as well as appropriate snacks. Adequate fluid intake (6 to 8 cups a day) is also very important.
- **Use proper wedges and padding.** Do not use donut-type devices as they decrease blood flow to the area and increase tissue breakdown.
- **Be aware of the many appliances that may reduce the risk of skin breakdown.** Special pressure-reduction mattresses, alternating air mattresses, elbow pads, pressure reduction seat cushions for wheelchairs, as well as an appropriately-sized wheelchair are but some of the devices available. These would be recommended by the nurse or therapist, based on the survivor's needs.
- **Report any unusual observations to the most appropriate person.** Depending upon the situation, this may be a nurse, case manager, physician or family member.

*Reference: Clinical Practice Standards-Pressure Ulcers developed by the Nursing Skin Care Committee, Parkwood Hospital, London, Ontario*

## Section 6

### Routine Activities of Living

Being able to do everyday activities as independently as possible is important to most stroke survivors. The ability to perform routine activities of living (such as bathing, dressing, and grooming) can help to improve the survivor's self-esteem. Performing these activities can help improve physical, cognitive and perceptual abilities. They're also essential in preparing for other activities, such as work, recreation and social outings.

### Assisting the Survivor

As a caregiver, you have limited time to assist the survivor with routine activities of living. Often, you are balancing these activities with household tasks, or with the needs of other clients or residents. We hope that the following suggestions will make it easier for you to assist survivors with routine activities and to promote their independence.

There are six general facets to assisting:

- **Set up of the required supplies**
- **Proper positioning**
- **Encouraging use of the affected side**
- **Cueing and guiding**
- **Use of assistive devices**
- **Recognition and encouragement.**

Many assistive devices are available to make it easier and safer for survivors to perform their self-care activities. Many devices can pose risk if not used properly. Be sure that you and the survivor know how to use any device properly. If in doubt, seek the advice of a knowledgeable person.

### Grooming

Grooming activities include washing one's face, brushing teeth or cleaning dentures, shaving, putting on make-up and combing hair. Survivors should be encouraged to be as independent as possible with grooming tasks without it becoming too energy consuming for themselves or time-consuming for the caregiver. For example, some survivors can be set up to complete their grooming tasks while the caregiver is doing something else.

Several factors can affect the survivor's ability to independently complete routine activities of living. These include: neglect on the affected side, loss of movement on one side, difficulty planning and sequencing tasks, lack of sensation, impaired fine motor control, impaired attention span and/or impaired grasp.

#### What You Can Do to Help

##### Setting Up Grooming Items

- **When setting up grooming items, consider whether the survivor has neglect on his affected side.** Items can be arranged on the survivor's affected side to increase awareness of that side.
- **Depending on the severity of the neglect, you may have to give verbal instructions by pointing out the items on the survivor's affected side.** If the survivor's neglect is very severe, you may have to put the items on his unaffected side to reduce frustration and enhance independence.

##### Provide Hand-Over-Hand Guidance

- **The survivor may require hand-over-hand guidance or physical assistance to complete the task.** Because of motor planning problems, a survivor may have difficulty performing purposeful activities such as brushing teeth or hair. Over time, the amount of assistance often can be reduced as the survivor becomes more able to do things for himself.

### Encourage Use of the Affected Limb

- **Encourage survivors to use their affected hand to assist with the performance of grooming tasks.** The amount of assistance required to encourage this activity will depend on how much movement and feeling they have in their affected arm. The involvement of the affected arm helps to improve awareness of it and provides stimulation to the brain.
- **Proper positioning at the sink reduces strain and fatigue.** The survivor should be positioned so that he is touching the counter or sink. If the survivor uses a wheelchair, ensure that it is properly placed and wheels locked. If the survivor does not use a wheelchair, position a chair in front of the sink so that the survivor can rest as required. If possible, his feet should be positioned flat on the floor.
- **Properly support and position the affected arm.** If possible, place the affected arm on the counter but ensure that it is well-supported. It is important not to raise the affected arm above shoulder height since this can cause shoulder pain.

### Provide Cueing

- **If the survivor has neglect, he may require verbal or physical instructions to complete tasks on the affected side.** For example, a survivor may require cueing to brush his teeth or wash his face on the affected side.

### Recognize & Encourage

- **Encourage survivors who are able to complete some or all of their grooming tasks.** Give positive feedback after each step is completed rather than just at the end of the task.

## Assistive Devices

Assistive devices that may be useful for survivors include: a denture brush with suction cups on the back, built-up handles on tooth brush or comb handle or an electric toothbrush.

## Bathing

Difficulty getting into and out of the tub, maintaining balance and fear of losing balance can turn the once-enjoyed experience of bathing into a dreaded one. The bathroom can be a hazardous place. Floors and fixtures can be slippery when wet. There's often little room to move about easily. A fall in the bathroom can cause injury. Positioning, moving about as well as getting into and out of the tub can be dangerous. Have patience, and acknowledge the survivor's concerns as you assist him or her.

## Assistive Devices

Many assistive devices are available. These devices can enhance a survivor's function and/or safety. Table 6 lists some of the more common ones. If the survivor is living in an apartment or private home, it is strongly recommended that the survivor consult with an occupational therapist regarding which equipment is most suitable for the survivor. Advice about purchasing the correct equipment can avoid difficulties and injuries.

**Table 6: Assistive Devices for Bathing**

- Tub transfer bench
- Hand-held shower head
- Bath seats
- Non-skid bath mat or decals
- Bath boards
- Long-handled bath brush
- Wall grab bars
- Wash mitt
- Clamp on grab bars
- Soap on a rope
- Hydraulic lift (whirlpool tub)

## Assisting the Survivor to Bathe

The amount of assistance and equipment that a survivor will require to bathe will depend on her physical abilities. If the survivor is living in her own home or apartment, it is strongly recommended that she be assessed by an occupational therapist to determine the safest way to bathe and what equipment is needed. A survivor should be independent if she is going to sit in the bottom of the tub (i.e., not use a bath bench). Unless a survivor is able to sit in the tub without assistance, the use of a tub transfer bench is recommended.

### Assisting a Survivor Who Uses a Tub Transfer Bench

#### Equipment

##### Set-Up

- Suggest the use of a non-skid bath mat or decals to reduce the slipperiness of the tub surface.
- The survivor may also benefit from the use of wall grab bars. Consult a therapist for advice as to the specific aid and the location where it should be installed.
- Avoid bath mats or rugs on the bathroom floor, as they can slide and cause a person to fall.
- Ensure that the water is at an appropriate temperature.
- A commode-style tub bench allows easier cleansing of the survivor's buttocks.

#### Procedure

- Transfer the survivor onto the part of the bench that sits over the side of the tub. Refer to the Mobility section for how to do a transfer.
- Assist the survivor to move her buttocks back onto the bench.
- Assist the survivor to turn and get her legs over the side of the tub.
- Ensure that the survivor is well-positioned on the tub transfer bench.
- Encourage the survivor to do as much of her washing as she can. Assistive devices such as a hand-held shower head, a bath mitt and soap on a rope can enable the survivor to do more for herself.
- To get off the transfer bench, assist the survivor to lift her legs out of the tub.
- Position the survivor so that she is sitting on the edge of the bench.
- Dry the survivor off as much as possible. Ensure that the floor is dry before transferring the survivor back to the wheelchair.

## Dressing

### What You Can Do to Help

#### Positioning

- **The survivor should be sitting in a chair with a back support.** His feet should be positioned flat on the floor. The survivor should not be sitting on the edge of the bed.

#### Set Up

- **Whenever possible, provide the survivor the opportunity to select clothing and accessories.** What we wear is an expression of who we are. Clothing choices are personal. If the survivor has difficulty with judgment or decision-making, offer choices that are appropriate. For example, you might offer a choice of the blue shirt or the brown shirt if a survivor has difficulty selecting appropriate clothing. No matter which the survivor chooses, it is appropriate.

#### Cueing & Guiding

- **Once clothing is selected, arrange the items on a chair in the order that the survivor is going to put them on.**
- **If the survivor is encouraged to participate in dressing, watch to see how much effort is involved.** For example, if the survivor tries to put a sock on and the affected arm tightens up, check to see if the arm relaxes when the task is completed. If the tone remains high, it is an indication of too much effort which can have a negative effect on the recovery of the affected side. Assist the survivor to put on his socks in this situation.
- **If the survivor can participate in dressing, it may be necessary to provide verbal guidance to (cue) the survivor to put on each item as required.**
- **Limit distractions and provide clear and concise instructions.** Break the task down into simple steps. Demonstration may be used to explain how to do something like putting on a shirt. Figure 12 illustrates one method of putting on a shirt. Figure 13 illustrates a procedure for putting on a sock. Figure 14 illustrates one method of putting on trousers.

Figure 12 – Putting on a Shirt

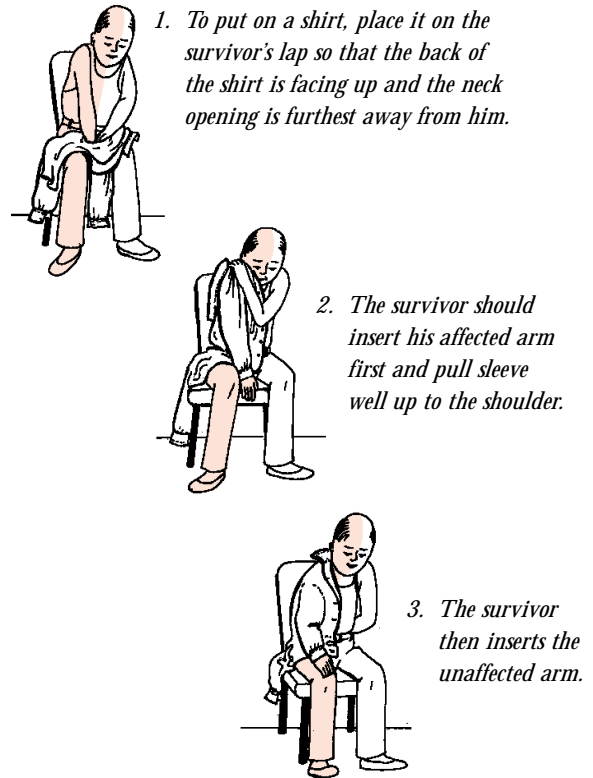


Figure 13 – Putting on Socks

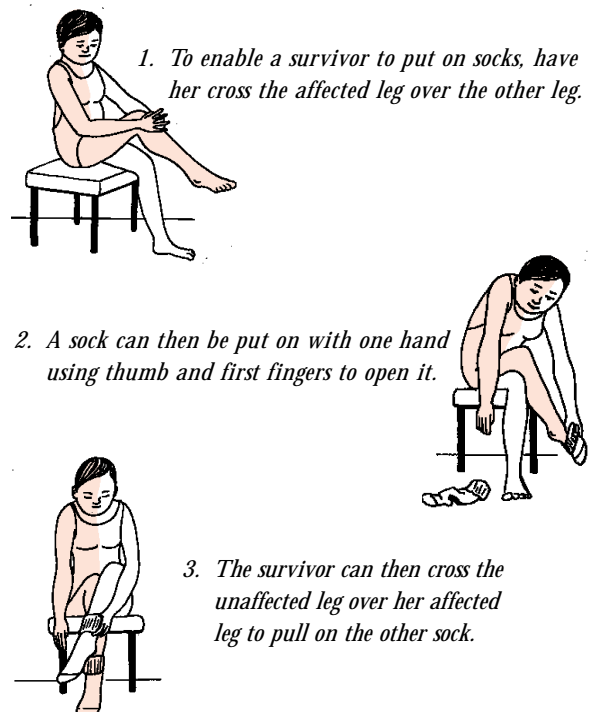
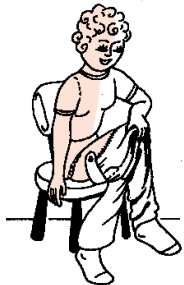


Figure 14 – Putting on Trousers

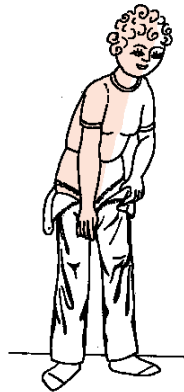


1. *Have the survivor cross her affected leg over the unaffected leg and pull her trouser leg up as far as possible.*



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.*



## When Assisting the Survivor to Dress

### What You Can Do to Help

- **Tell the survivor what you are going to do.**  
Explain in clear, simple phrases as you perform the various tasks.
- **Assist with dressing the affected arm or leg first.**  
You may find it easier to slide your arm through the garment from the opening (e.g, the wrist end of the sleeve or the ankle end of the pant leg). Gently grasp the survivor's arm or leg and draw the garment up into proper position.
- **When assisting the survivor to undress, undress the unaffected arm or leg first.**

## Adaptive Devices & Clothing

Looser fitting clothing will be easier to put on. Adapted clothing may enable a survivor to do more for themselves. Some common adaptations include shoes with velcro fastening or elastic laces, front fastening brassieres, pre-tied or clip on ties, as well as elasticized waist bands on pants, shorts or skirts.

Adaptive devices can be used to enhance the survivor's ability. Examples include a reacher, a long-handled shoehorn and a footstool.

## Toileting

Toileting is an extremely personal activity. Many survivors who require assistance with toileting find the need for help and the invasion of privacy distressing.

### What you Can Do to Help

- **Be certain that you know whether a survivor may be left unattended on the toilet.** This determination is often made by a therapist and will depend upon the survivor's balance, judgment and physical tolerance.
- **Provide for dignity and privacy when assisting a survivor with toileting.** For example, a survivor may not want the bathroom door open when she is in the bathroom, even if no one other than you is present.
- **The amount of assistance and type of equipment that a survivor will need to toilet will depend on her physical abilities and the layout of the facilities.** If the survivor is living in her own home or apartment, an assessment by an occupational therapist is useful to determine what equipment is needed. There are various types of raised toilet seats, wall grab bars and versa frames available.
- **If the survivor does not have the necessary trunk control to sit up, she may have to be toileted in bed.**
- **To transfer onto the toilet, a one or two-person pivot transfer can be used.** Pages 30 and 31 provide the procedures for a pivot transfer.
- **The survivor may benefit from having a wall grab bar to hold onto once she is standing.** This provides stability while you manage her personal care and clothing. Avoid having the survivor pull on the wall grab bar to get up to standing, however. This pulling action can cause the muscles of the survivor's affected leg to tighten and make it more difficult to stand.
- **If the survivor cannot be safely transferred by two people onto a toilet, consider using a commode chair.** A pivot transfer may be used if appropriate. Another method requires the assistance of two caregivers and is dependent on the survivor's standing ability. The procedure is presented below.

### Using Two Caregivers to Assist a Survivor to Use a Commode

- **Position one caregiver in front of the survivor.**  
This caregiver assists the survivor to stand up from the wheelchair.
- **The second caregiver removes the wheelchair and places the commode behind the survivor.**
- **The second caregiver pulls down the survivor's pants/underwear.**
- **Both caregivers then assist the survivor to sit onto the commode.**
- **Once toileting is completed, the caregiver in front helps the survivor to stand.**
- **The second caregiver does the personal care and pulls up the pants.**
- **While the first caregiver steadies the survivor, the second caregiver switches the commode with the wheelchair.**
- **The two caregivers then assist the survivor to sit in the wheelchair.**

### Assistive Devices

There are many assistive devices that can make toileting safer and easier. Suggest that the survivor get the recommendation of the appropriate professional when selecting equipment. Table 7 lists some common assistive devices.

**Table 7: Assistive Devices for Toileting**

- |                       |                  |
|-----------------------|------------------|
| • Raised toilet seats | • Commode chairs |
| • Wall grab bars      | • Urinals        |
| • Versa frame         |                  |

Hygiene products such as wipes may enable survivors to do their own personal care after toileting.

## Section 7

### Cognitive & Perceptual Problems

Cognitive and perceptual problems have been described as *invisible barriers*. They are not as easy to see as physical problems. You would not know there was anything wrong with the survivor if you met them on the street. Yet, these problems alter how survivors interpret what they see and how they make sense of the world. They can have a great impact on the survivor's ability to relearn skills and abilities.

Because the problems aren't readily seen, family and friends can overestimate the survivor's abilities. When too much is expected, the survivor cannot meet these expectations. Families, friends and caregivers can become frustrated and angry with the survivor, believing that the behaviour is intentional or that the survivor is not motivated or uncooperative. It is important to recognize these problems as effects of the stroke. Identifying and using strategies to help the survivor with cognitive and perceptual problems will help the survivor be more successful with performing tasks and may reduce the frustration among family, friends or care providers.

#### Cognition

The term *cognition* refers to the act or process of knowing information. It involves several mental abilities, e.g., attention, orientation, memory, abstract thinking, problem-solving and judgment. A survivor may have impairment in one or more of these areas.

This type of impairment should *not* be confused with a diagnosis of dementia. Some individuals who have had a stroke (usually many strokes) do have dementia. These individuals have multiple cognitive problems, including memory problems.

After an individual has had a stroke, these mental abilities may or may not be affected. A survivor may experience improvement of his mental abilities over time. However, some of the problems may persist and adaptive strategies may need to be considered.

This section discusses the most common changes: impaired attention span, memory impairment, impulsivity and lack of insight and judgment.

#### Impaired Attention Span, Concentration and Ability to Focus

Stroke survivors often have a short attention span and limited ability to focus on tasks at hand. This means that they can only remember a few bits of given instruction or only focus on one simple task at a time. For example, a survivor may be given a list of three instructions and only be able to attend to the first one before she is distracted by someone or something in the room. It is important to keep in mind that if a survivor isn't able to attend to information, then she won't be able to remember it or follow instructions. As well, the survivor may need more time to process her thoughts.

#### What You Can Do to Help

- **Eliminate distractions.** When giving a survivor instructions, ensure that the environment is quiet. For example, turn off TV or radio, pull the curtain around the bed.
- **Provide short and simple instructions.** Make certain that the survivor understands what you have said before you continue.

- **Try to make direct eye contact with the survivor.** **This helps the survivor to follow your instructions.** It will also help the survivor to 'read' your facial expression, which may help you get the meaning across.
- **Give the survivor more time to think.** Adapt your pace so that the survivor doesn't feel pressured.

## Memory Impairment

Memory is the mental ability to input, store and retrieve information. There are two types of memory: short-term and long-term. Short-term memory has to do with immediate recall of information presented. Long-term memory is information that has been stored for a long period of time. Stroke survivors may have difficulty remembering information obtained after the stroke, yet may be able to clearly describe events that happened years ago, before the stroke.

Memory problems can affect stroke survivors' ability to learn new information and carry it over into day-to-day tasks. Even a mild stroke can affect learning and memory abilities.

When you initially talk to a stroke survivor, you may not immediately know that he has a memory impairment. The survivor may come up with convincing stories to compensate for his memory impairment.

### What You Can Do to Help

Some simple techniques can help the survivor to deal with memory impairment. For example, you might:

- **Encourage the survivor to use memory aids like a day planner or calendar to record appointments.** Some survivors benefit from using a memory book, or journal in which they (and others) write down information that is important to the survivor.

- **Maintain a consistent routine and environment from day to day.** This consistency helps the survivor to remember daily routine events. It also promotes a sense of predictability.
- **Store items in the same place.** Use labels to identify contents of drawers and cupboards. If appropriate (and available) use clear plastic boxes that allow the survivor to easily see what is inside.
- **Provide short and simple instructions.**
- **Present new information one step at a time.** Allow the survivor to finish one step before going on to the next.
- **Use signs or pictures, or other familiar items to assist the survivor to locate their room.**

*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.*

## Impulsivity

Impulsivity occurs when a survivor acts too quickly and without thinking. As a result, the survivor can do something unsafe and hurt herself. For example:

- **A survivor stands up quickly from his wheelchair without putting on his brakes. The wheelchair moves suddenly, causing the survivor to fall.**

- **A survivor puts spoonfuls of food in her mouth so rapidly that she does not have time to chew and swallow each mouthful. With too much food in her mouth, she begins to choke.**

### What You Can Do to Help

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- **Encourage the survivor to slow down.**
- **Encourage the survivor to think about the task and break it down into small steps.**
- **You may have to tell the survivor to stop and perform a specific task.** Be clear and specific with your directions. For example, “Put your wheelchair brakes on” or “Swallow that mouthful of food before taking the next one.”

### Lack of Insight and Judgment

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The survivor may be a poor judge of his own abilities and safety, sometimes causing him to do things that pose greater risk. The survivor may not realize that he has this problem or may deny that he does. Sometimes, lack of insight and judgment may cause the survivor to respond inappropriately in social situations. This impairment is more typical of a right hemisphere stroke, but can be seen in strokes affecting either hemisphere.

### What You Can Do to Help

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- **Watch to see what the survivor can safely do rather than take his word for it.** Be aware of hazards and take steps to avoid accidents. Be prepared to assist the survivor if a hazardous situation arises. The survivor’s family, physiotherapist or occupational therapist can often provide useful information about the survivor’s ability.
- **Avoid placing the survivor in situations that are too difficult for him.** Encourage a more realistic view of abilities and problems in a calm and supportive manner.

- **Take steps to make the environment safe for the survivor.** Provide the necessary amount of supervision, remove or relocate hazards, etc. If the survivor uses them, make sure that lap trays and seat belts are properly attached and monitored.
- **Consistency is very important.** Reinforce with the survivor the need to call for assistance.

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.

### Impaired Abstract Thinking Skills

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The survivor may have difficulty understanding indirect or implied messages. “Come sit here for supper” may have more meaning than “Supper is ready.” A direct message is clear about what you want the person to do.

The survivor may also have difficulty generalizing – applying what is learned in one setting to another setting. For example, the survivor may find it very difficult to do a safe transfer in a new environment, even though she is well able to do the same task in a familiar setting.

## What You Can Do to Help

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- **Provide clear step-by-step instructions when helping a survivor perform a task, focusing on one thing at a time.**
- **Give direct messages**, i.e., “Put your brakes on before you stand up from your wheelchair” rather than “Do you think the brakes should be on?”
- **Do not take blunt or direct comments personally if they seem rude.** The survivor may be communicating in the only way she now understands. She may say “Take me to my room” rather than the indirect and more socially polite, “Would you have time to take me to my room?”
- **Help the survivor to problem solve. Provide information to help the survivor resolve the issue by using gentle reminders.** For example, if the survivor is having difficulty opening a jar, you might remind her that the mechanical jar opener worked well the last time. Avoid quizzing the survivor. The point is to provide information, not to focus on what she hasn’t been able to do on her own.
- **Avoid putting the survivor in situations that require generalizing or problem-solving beyond what she can do.**
- **When changes in routine are necessary, discuss them in advance and help the survivor to be mentally prepared.**
- **When there is a change in routine or environment be prepared to assist the survivor to relearn the task at hand.** Many survivors may not do as well when the routine or environment changes.
- **Train in settings where the behaviour will be performed.** For example, train and practice transfers in the setting where they will be done.

## Perseveration, Inability to Sequence, and Problem-Solve

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Stroke survivors often have difficulty with sequencing activities, and moving on from one idea to the next. They may complain of “getting stuck” on one thing (*perseveration*). This may affect their ability to learn, plan, and problem-solve both routine and more complex tasks and activities.

### Difficulty in Planning or Starting a Task

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This impairment can make it difficult for a survivor to plan, to set goals or to identify the steps involved in attaining the goal. Some people have difficulty in starting a task.

## What You Can Do to Help

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- **Remember that difficulty starting a task is not a sign of laziness.**
- **Provide clear step-by-step instruction in a form the survivor can understand.** Use words or pictures if necessary to get the information across.
- **Help the survivor to plan out the task.** Provide the next step if the survivor is unable to do so.
- **Give the survivor time to practice the sequences.** Avoid doing the task for the survivor because he is slow or has difficulty.

### Sample Sequencing

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

- Put the affected arm into its sleeve first
- Put the unaffected arm into its sleeve
- Pull sweater over head
- Pull sweater down in back

**This sequence is repeated in the same order each day.**

## Perception

Perception involves a survivor's ability to organize, understand and interpret sensory information from within her body and from the external environment. The sensory information comes from the different senses such as sight, hearing and touch.

It is easy to overestimate the abilities of a survivor with right brain damage because the cognitive and perceptual problems are not as easy to see as the physical problems. However, these problems can have a greater impact on the survivor's ability to relearn to care for themselves.

This section discusses five types of perceptual problems:

- **Time awareness**
- **Neglect**
- **Body neglect**
- **Apraxia**
- **Impaired depth and distance perception.**

### Time Awareness

This impairment causes the survivor's sense of time to be distorted. It is a change in how the survivor perceives that the time has passed. To a survivor with this impairment, minutes can seem like hours. For this reason, digital clocks, "talking" clocks (clocks that announce the time) and timers are useful in helping the survivor to cope with this impairment.

### What You Can Do to Help

- **Link events to other events, not to time.** For example, it's usually more helpful to say that the survivor's daughter is coming to visit after lunch, instead of "in an hour or so."
- **Review the survivor's daily schedule.** Keeping a journal may help to adjust to the passage of time.
- **Reassure a survivor who is anxious about an appointment.** Tell the survivor that you are aware of any appointment and will remind or come to get him.
- **Acknowledge the survivor's perception, but also present the reality.** For example, you might say, "I know that it seems like I left you for hours, but it has only been 15 minutes."
- **Maintain a consistent schedule.**
- **A digital clock or talking clock may be easier for a survivor to understand than a clock with hands.** Determine if the survivor can read the digital clock. If not, a talking clock may be more useful.

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.

## Visual and Auditory Neglect

Visual or auditory neglect results in a decreased awareness of the environment or of items on the affected side. As a result, the survivor may bump into things on his affected side or he may not hear someone speaking to him from that side.

Visual or auditory neglect tends to be more common among survivors of a right hemisphere stroke but can also happen with left hemisphere stroke.

### What You Can Do to Help

- **Arrange the environment so that there is some activity or stimulation on the affected side.** This helps the survivor to become more aware of the environment on the affected side. However, if the impairment is severe, this may not work. If so, attempt to arrange the survivor's surroundings so that activity and stimulation is at midline or on the unaffected side to maximize function and safety. If possible, discuss this with the survivor's occupational therapist.
- **Approach the survivor from the unaffected side.** Then, cross over to the other side when speaking with him. This will avoid startling the survivor and will also provide stimulation on the affected side.
- **Use a positive approach.** Point out important objects and items of interest on the affected side in a calm manner.
- **Use visual cues to assist the survivor.** For example, a red line along the margin of a page of a book can help the survivor to "see" the entire line of type.

**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.**

## Body Neglect

Body neglect results in a decreased awareness of the affected side of the body. This can cause the survivor to "neglect" the affected side. For example, some stroke survivors may talk about their arm belonging to someone else. Some survivors with body neglect may forget to dress the affected side or may leave the affected arm in an unsafe position at the side of their wheelchair.

### What You Can Do to Help

1. **Position the affected arm so it is within the survivor's view.** If the survivor uses a lap tray, position the affected arm on the tray.
2. **Gently stroke the affected arm, but make sure this action does not cause increased tightness of the arm.** Tactile stimulation may help the survivor to more easily recognize the limb.
3. **Provide cues to the survivor, as required.** For example, if the survivor is able to shave himself, he may need cueing to shave his affected side.

**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 the inability to perform purposeful movements even though the survivor has the physical ability and understanding of the task. This is because messages from the brain to the muscles are not being properly processed. Note that apraxia can affect how the movement is planned for either side of the body, not just the affected side.

The survivor may have difficulty planning movements, following commands or using a familiar object. For example, the survivor may not be able to use a familiar object such as a comb or toothbrush correctly, even when holding it in the unaffected hand. A survivor is asked to wave good-bye to someone but doesn't do it. Later, she does it spontaneously as someone is passing.

Apraxia can interfere with a survivor's ability to speak or write. A survivor with dressing apraxia may put clothes on backwards, upside down or inside out.

### What You Can Do to Help

- **Use physical cues, such as putting a label on the back of a shirt to help the survivor identify the correct way to put it on.**
- **Use short and simple instructions.**
- **Use verbal cues and instructions instead of demonstration.** A survivor with perceptual problems can more easily understand verbal information.
- **Break the task down into several simple steps.** Use the same sequence of steps daily.
- **Maintain a consistent routine.**
- **Provide supportive and encouraging feedback after each step.**
- **The survivor may require hand-over-hand guidance at first to use a familiar object, e.g., shaver, deodorant.** When you do this, take care to guide the survivor, not do the task for him.

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.

## Impaired Depth and Distance Perception

People with impaired depth or distance perception have difficulty judging distances. For example, a survivor may have difficulty judging the distance when sitting down, climbing stairs or reaching for a cup.

### What You Can Do to Help:

- **Use assistive strategies and devices.** Put yellow fluorescent tape along the edges of the steps to highlight the point where the depth changes. Use a weighted cup with an enlarged handle to make it easier for the survivor to grasp while being more resistant to tipping.
- **Repeat an activity and provide opportunities for practice.** This can help the survivor become familiar with the distances involved and helps to 'retrain' the brain.

Mrs. Hernandez had difficulty judging the distance from her bed to her chair. As a result, she nearly fell. Support workers have helped Mrs. Hernandez practice moving between her bed and her chair. As a result, she is now able to safely get to her chair before trying to sit down.

## Vision Problems

Problems with vision are fairly common after a stroke. A survivor may lose part of the vision in one or both eyes, a condition known as a visual field deficit (see Figure 15). Double vision (diplopia) can occur after a brain stem stroke. Sometimes vision problems improve in the weeks following a stroke. Most stroke survivors learn to make up for visual problems by following specific techniques, provided that the vision problem is not complicated by neglect.

### What You Can Do to Help

- Learn what specific techniques the survivor uses. Where possible, help her to use these techniques.
- Encourage the survivor to use recommended techniques.
- For a visual field deficit – have the survivor turn her head to her affected side to compensate for a visual field loss on that side.
- Encourage the survivor to wear an eye patch or prism glasses, if prescribed. Some survivors use these appliances to counteract the effects of double vision.

**Julie Doucet has a double vision (diplopia). As a result, she often has difficulty seeing clearly enough to complete many tasks. This has been frustrating for her, so her physician recommended an eye patch. Wearing the patch eliminates the double vision and allows Ms. Doucet to see clearly enough to prepare meals, watch television and do other things she enjoys.**

Figure 15 -Example of a visual field deficit



## Sensory Deprivation

As a result of not receiving all of the sensory information from the environment, stroke survivors may develop signs and symptoms of sensory deprivation. Sensory deprivation is more likely to result from a right hemisphere stroke. The symptoms of sensory deprivation include confusion, irritability, delusions or hallucinations. Stroke survivors are usually older, with reduced hearing, vision and sense of touch, and therefore are at greater risk of sensory deprivation.

Night-time and early morning are often hard for people more susceptible to sensory deprivation, as there is less stimulation. Sounds and sights may be misinterpreted. The survivor may “hear” his daughter’s voice in the hall and be angry at her for not coming in to visit. The survivor may “see” some type of animal or object in the room when glancing at a pile of clothes. The survivor also may become confused about where he is, thinking that he is in another setting.

## What You Can Do to Help

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Many of the effects of sensory deprivation can be minimized by taking the right steps:

- **Enrich night-time environment with a radio playing softly, or the television on with little or no sound, or by leaving the night light on.**
- **Adapt the environment to encourage and support the survivor's involvement in and interaction with it.** Provide clear stimulation. Consider (with the survivor's permission) rearranging items so that they may be more easily recognized.
- **Present information clearly.** Have a large, easy to read illuminated clock or timepiece. When writing, use large letters. Avoid cluttered designs.
- **Remove unnecessary distractions.** Too much stimulation will simply discourage the person from attempting to relate to the environment. For example, noise, clutter, even music in the background may make it impossible for the survivor to focus on sensory information that is important to him.
- **Encourage and assist the survivor to use techniques that enhance perception.** Assist the survivor to practice any techniques recommended by an occupational or physiotherapist. Avoid doing things for the survivor when it is better that the survivor learn to do for himself.
- **Reorient the survivor to his location, the date and time etc. frequently throughout the day.**

- **Explain or clarify any misperceptions he is experiencing in a clear and calm manner.** Remember that the misperception is quite real to the survivor. For example, if the survivor can hear people talking outside his room, he may believe that they are talking about him. Reassure him that this is not true. Explain that the people are talking about something else.
- **If the survivor continues to be confused about what happened, attempt to change the topic and discuss something else, e.g., "Is that a picture of your family?"**
- **Minimize the effect that existing sensory losses may have.** Encourage the survivor to wear his glasses and hearing aids, if prescribed.

Mr. Jonas shares a room with three other residents. At times, he has difficulty understanding what is going on around him, particularly in the morning, when there is a great deal of activity. When staff discussed the problem with Mr. Jonas, they decided to wake him a bit earlier than his roommates. This allows Mr. Jonas time to adjust to his surroundings when the setting is less noisy and busy.



## Section 8

### Meal Assistance and Hydration

Eating and drinking provide pleasure in themselves. As well, eating and drinking are often associated with normal social interaction, and are integral parts of many religious and cultural observances and traditions.

Poor nutrition and unsafe swallowing can endanger the survivor's health and quality of life. In the early stages of recovery, if swallowing is inadequate, some survivors may require placement of a tube directly into their stomach or intestine to provide them with adequate nourishment. Survivors' chewing and swallowing abilities should be closely monitored by health care professionals. As swallowing ability improves over time, survivors are usually able to return to a regular or modified oral diet, as assessed by a registered dietitian (see sidebar on page 56 regarding common special diets).

#### Feeding & Swallowing

Feeding means the movement of food from plate to mouth which facilitates the individual preparing the mouth and throat for the swallow. Normally, this is under voluntary control. The survivor who is fed loses this control and is at greater risk for aspiration.

Swallowing means the movement of food from the mouth through the throat (pharynx) and the esophagus to the stomach. This movement of food is involuntary in everyone.

#### Feeding and Swallowing Problems After A Stroke

There are four significant consequences of feeding and swallowing problems: dehydration, malnutrition, aspiration, and diminished quality of life.

*Dehydration* is the lack of sufficient hydration. It can lead to several problems: dry mouth, constipation, urinary tract infections, confusion or even severe illness or death. The section on dehydration discusses these issues in greater detail.

*Malnutrition* is the lack of sufficient nutrition. It can lead to weight loss, reduced vitality, skin breakdown and impaired wound healing, as well as a reduced resistance to infection.

*Aspiration* is the inhaling of bacteria in saliva, food, fluid, or refluxed material in the airway. It can lead to choking (airway obstruction), upper respiratory problems or pneumonia. Anyone can choke or aspirate, but alert, aware individuals who are in control of their own eating protect themselves by controlling the food in their mouths.

Because eating is often a social function, problems can cause the survivor to withdraw from previously-enjoyed activities. This has a direct effect upon the survivor's quality of life.

Survivors and their families are best able to judge the impact of changes in diet and manner of eating. Survivors and their families must be informed and involved in decisions around change in diet or meal assistance.

*Adapted from the Riverdale Mealtime Assistance Handbook, The Riverdale Hospital, Toronto, Ont. (Corporate Communication, 2000)*

## How a Stroke Can Affect Swallowing

A stroke can affect the function of muscles involved in feeding, swallowing and breathing as well as the alertness and attention to eating that protect us all from choking. Some effects are easy to see, such as facial weakness and drooling. However, some are invisible to the caregiver and unrecognized by the survivor. For example, the survivor who has lost the normal reflexive cough cannot cough when choking and may silently aspirate food or fluid.

## What You Can Do to Help

### In General:

- **Safe feeding practices should be used with all stroke survivors.**
- **Observe for signs and symptoms of swallowing problems to help prevent the development of serious health problems.** All individuals who show signs or symptoms of a swallowing problem should be referred to a speech language pathologist or registered dietitian for an assessment.

### Set-up

- **Set up the environment to minimize distractions.** A calm environment will help the survivor focus on chewing and swallowing. Avoid busy restaurants and dining rooms for a survivor who is very easily distracted.
- **Proper positioning is essential** (as shown in Figure 16). The survivor should be sitting upright in a wheelchair or a straight back chair. If he is unable to get out of bed, ensure that he is sitting at a 60 to 90 degree angle with his head forward and in midline. Stabilize with pillows.
- **Table 8 provides tips for addressing common problems.** Always discuss concerns with the appropriate person.

**Figure 16 – Proper Positioning when Assisting a Client with Meals**

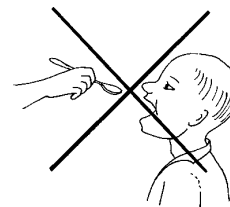
### 1. Positioning in bed for feeding.



### 2. Positioning in chair for feeding.



### 3. DON'T feed from above the mouth.



## Assistive Devices

A range of assistive devices is available to make meal-times easier. Examples include: rimmed plates, a gripper pad to prevent dishes from slipping, cup or container holders, modified utensils (built-up or bent handle), cutting utensils for one-handed use (rocker knife, cheese knife, pizza cutter), and modified cups with a cut-out or partial lid. An occupational therapist can offer valuable information as to the most suitable devices.

**Table 8: Common Problems & Approaches**

<b>Problems in the Mouth</b>	<b>Approaches</b>
<ul style="list-style-type: none"> <li>• Coughing/choking during meals</li> <li>• Drooling/poor lip closure/loss of food from mouth</li> <li>• Spitting out of food</li> <li>• Pocketing of food in cheeks</li> <li>• Slow, effortful eating</li> <li>• Difficulty swallowing pills</li> <li>• Rapid, uncontrolled rate of eating</li> <li>• Poor intake of solids/fluids</li> <li>• Avoidance of specific foods/fluids</li> <li>• Survivor throws head back to swallow</li> <li>• Weight loss</li> </ul>	<p><b>Optimal positioning (applies to all stages of swallowing):</b></p> <ul style="list-style-type: none"> <li>• Upright at 60 - 90° angle</li> <li>• Head flexed forward</li> <li>• Head in midline</li> <li>• Stabilize with pillows</li> <li>• Monitor/cue rate and amount of feeding (small amounts of 1/2 to 1 tsp.)</li> <li>• Teach survivor to monitor self feeding with a mirror, to remove pocketed food with tongue and be aware of drooling</li> <li>• Remain upright at least 30 minutes after meal</li> <li>• Complete mouth and dental care after meal</li> <li>• Check for a complete swallow (laryngeal elevation)</li> <li>• Encourage use of napkin/cloth if drooling present</li> <li>• Provide only 1 to 2 pills at a time which may be crushed in applesauce, thick drink or given whole in thick drink or applesauce</li> <li>• If survivor is easily distracted, present only one food item at a time</li> </ul>
<p><b>Problems in the Throat</b></p> <ul style="list-style-type: none"> <li>• Coughing/choking during meals</li> <li>• Altered voice quality, i.e., wet or gurgly voice especially after eating or drinking</li> <li>• History of chest infections</li> <li>• Poor air intake/weak cough</li> <li>• Survivor reports “tight throat” or food sticking in throat</li> </ul>	<p><b>Approaches</b></p> <ul style="list-style-type: none"> <li>• Provide small amounts (1/2 to 1 teaspoon) of food/fluid</li> <li>• Encourage to swallow twice</li> <li>• Encourage to cough to clear throat</li> </ul>
<p><b>Problems in the Esophagus</b></p> <ul style="list-style-type: none"> <li>• Survivor reports food sticking in throat/lump in throat</li> <li>• Survivor reports most difficulty swallowing solids</li> <li>• Survivor reports reflux/heartburn</li> <li>• Survivor reports fullness after eating very little</li> </ul>	<p><b>Approaches</b></p> <ul style="list-style-type: none"> <li>• Provide small, frequent meals</li> <li>• Avoid lying down within 2 hours of eating</li> <li>• Elevate head of bed 30° to prevent reflux</li> <li>• Wear clothes that fit loosely</li> <li>• Avoid tight belts</li> </ul>

**Important Note:** The strategies outlined are general recommendations for survivors with dysphagia; individualized assessment by a Speech/Language Pathologist, Occupational Therapist and Registered Dietitian are highly recommended.

## Common Special Diets

### Pureed Foods

This would include:

- Mashed/blenderized foods
  - Dense, smooth foods of pudding consistency
- Some survivors requiring pureed foods are able to manage more advanced textures, such as scrambled eggs (this should be based on individual assessment).

### Minced/Moist Minced Foods

This would include:

- Most foods the texture of ground beef / finely chopped
- Small, soft food particles approximately the size of macaroni noodles
- Very soft, very moist foods such as casseroles and pastas with sauces and gravies often safe and appropriate as long as foods are finely chopped.

### No Dry Particulates

This would exclude:

- Any foods that are dry, crumbly and stringy
- Raw fruit and vegetables, e.g., carrots, celery, lettuce, broccoli, cauliflower, apples, grapes
- Corn, peas, lima beans, mixed vegetables, baked beans, bean salad, coleslaw
- Rice, noodles, taco shells
- Cookies, crackers, fruit crumbles, pastries, bagels, dry cakes or muffins, crusts
- Dry cereal such as bran, grape nuts, shredded wheat
- Snack foods such as popcorn, chips, pretzels
- Coconut, raisins, nuts, seeds
- Peanut butter, dry crumbly cheeses.

### No Bread Products

This would exclude:

- Gummy, doughy foods such as bread, especially when very fresh
- Muffins, English muffins, pancakes, waffles, cookies, cakes, pastries, tea biscuits, buns/rolls, croissants, toast/french toast, sandwiches, squares, bagels.

### No Mixed Consistencies

This would exclude:

- Foods that combine liquids and solids together, i.e., canned fruit that has not had the syrup drained
- Cereal with milk, unless the milk has completely soaked into the cereal.

### No Thin Fluids

The following fluids/items are considered THIN and should be avoided if the survivor requires thickened fluids:

- Water, all juices, milk, tea/coffee, broth/cream/strained soups, soft drinks, commercial supplements as Boost™, Ensure™
- Ice cream/sherbet, milkshakes/ice cubes/ice chips/gelatin – these are considered thin fluids because they will melt at room temperature if left at bedside and melt in survivor's mouth prior to swallowing.

### Thickened Fluids

Thickened fluids are any fluid or beverage that has been thickened to the consistency of pudding or liquid honey. Recommendations for the safe thickness of fluids are individualized for each survivor. Thickeners are available to thicken both cold and hot beverages.

### Foods Which May Cause Reflux

- Highly spicy, seasoned foods
- Citrus foods and other acidic foods such as tomato products, onions, green pepper, radish, garlic
- Peppermint/spearmint
- Coffee, tea, chocolate and cola
- High fat, fried foods.

**Important** – Diet texture modifications related to dysphagia may result in dietary deficiencies. A registered dietitian should assess the survivor to ensure that modifications result in an appropriate, balanced diet.

## The Importance of Dental Hygiene

Think of how your mouth feels first thing in the morning, before you've brushed your teeth. A clean mouth and teeth are essential to good health and comfort. Recent studies have even suggested a possible link between gum disease and other conditions, including heart disease, pneumonia and stroke, as bacteria from diseased gums may travel through the bloodstream.<sup>1</sup> Proper dental hygiene is important whether the survivor takes food orally or by tube. Bacteria and food particles in the mouth can be particularly dangerous to the lungs.

### What You Can Do to Help

- **Assist your survivor to brush his teeth with a soft toothbrush and fluoridated toothpaste, and if possible, to floss using a floss wand.** Toothettes and other oral swabs are not sufficient to clean the mouth properly.
- **Properly clean dentures when required, not just at bedtime.** As well as sticking to tooth surfaces, food particles can build up under the denture and cause irritation.
- **Encourage the survivor to maintain regular oral check-ups.**

## Dehydration

Most people do not think of water as a nutrient, but it is! In fact, water is the most essential of all nutrients. The average adult body can live for weeks without food, but for only days without water. Survivors who have difficulty swallowing may fear choking and avoid fluids.

Dehydration can be life threatening. It may result in diminished functional abilities – both physical and mental/cognitive. It can also put the survivor at increased risk for infections and falls. As well it can lead to constipation and fecal impaction.

A survivor may be at risk for becoming dehydrated if he:

- **Has dysphagia (swallowing difficulties), especially with thin fluids**
- **Refuses fluids at meals/snacks**
- **Needs help with eating and drinking**
- **Lacks the feeling of being thirsty (common among older adults)**
- **Is not able to communicate or tell someone that he is thirsty**
- **Has memory problems, or is forgetful**
- **Has an illness that increases fluid loss from the body, e.g., vomiting, diarrhea, and fever with sweating**
- **Has fluid losses (from urine, diarrhea, vomiting, sweating, drooling) that are greater than fluid intake**
- **Keeps his fluid intake low on purpose, for fear of incontinence.**

A survivor may be dehydrated if she has:

- **Decreased urine output**
- **Dark, concentrated and/or strong-smelling urine**
- **Frequent urinary tract infections (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. You can test for this by gently pinching the skin on the survivor's arm. If it does not spring back into place but remains "pinched up" when released, suspect dehydration.**

<sup>1</sup> Scannapieco, FA. Periodontal Disease as a Potential Risk Factor for Systemic Diseases. J Periodontol 1998; 69: 841-850

## Fluid Needs for Health

Most people need at least 8 cups of non-caffeinated fluids daily. Drinks that contain caffeine, such as coffee, tea and cola soft drinks actually cause the body to lose fluids: these should be taken in moderation (only 2-3 per day maximum) and should not be counted as part of the daily fluid requirement.

The best way to ensure that the survivor consumes at least 8 cups of fluids daily is to make available and encourage intake of water, juices, milk and other non-caffeinated beverages. Take the time to find out what non-caffeinated beverages the survivor prefers. Bear in mind that frozen liquids are also fluids. A popsicle or frozen juice bar may supply needed liquids, if there is no other reason for the survivor to not eat them. Use the following conversions to gauge the survivor's intake:

8 cups = 2 liters = 2000 milliliters

1 cup = 250 ml, 1/2 cup = 125 ml

Some foods, such as gelatin (Jello®), pudding, ice cream, soup and canned fruit contain, or are made with so much water that they can contribute to a survivor's fluid needs. Table 9 provides the fluid content of some common foods.

**Table 9: Fluid Provided by Common Foods:**

Food	Serving Size	Fluid Provided
Gelatin (Jello®)	1/2 cup	120 ml
Pudding	1/2 cup	100 ml
Ice Cream/Sherbet	1/2 cup	60 ml
Popsicle	1 popsicle	90 ml
Yoghurt	1/2 cup	90 ml
Canned Fruit	1/2 cup	100 ml
Soup	1 1/2 cups	165 ml

## Swallowing Problems with Thin/Regular Fluids

As the result of their stroke, some survivors may not be able to drink thin liquids (regular liquids) safely. A speech language pathologist who specializes in swallowing problems must assess a survivor and determine whether or not it is safe for her to drink regular fluids. This assessment may have been performed when the survivor was in the hospital after her stroke.

If the survivor has been advised to avoid thin/regular fluids, the following fluids and food items should be avoided:

- Water
- All juices
- Milk
- Tea/coffee
- Broth and cream soups
- Soft drinks
- Commercial supplements/meal replacements, such as Ensure™ and Boost™
- Ice cream, sherbet, milkshakes, gelatin
- Ice cubes, ice chips.

Ice cream, sherbet, milkshakes, gelatin, ice cubes and ice chips may not seem like thin fluids, but if they are left sitting out or held in the mouth before swallowing, they will melt and become thin. Therefore they also must be avoided.

## Thickened Fluids

If the survivor has been advised to follow a diet with thickened fluids, that means that all of the survivor's fluids must be thickened to a specific recommended consistency. Commercially available thickeners are available through pharmacies, and can be used with hot and cold beverages. The appropriate consistency is determined for each survivor. Never use a thickener unless you have been taught by the appropriate person how to mix it to attain the correct consistency.

## Section 9

### Specific Behaviours

Survivors act differently, depending upon what part of their brain has been injured, the severity and type of injury, how recently the stroke occurred, and their previous personality and behaviour. Some survivors have no change in personality or behaviour, while others experience significant changes in one or both.

Some areas of the survivor's brain may function normally while other areas won't. A survivor may seem as capable as ever when doing one task but be totally unable to do another task of seemingly equal difficulty.

Sometimes the pattern of behaviour and thinking is inconsistent; there may be good days and bad days, or good hours and bad hours. Despite these inconsistencies, stroke survivors have identifiable patterns of behaviour.

Stroke can affect behaviour in a number of ways. Each survivor is unique, as is the effect of the stroke on her behaviour. The underlying cause of various behaviours can be a result of cognitive or perceptual problems as discussed in the previous section. **The strategies you use to deal with a behaviour will depend upon the underlying cause.** While the strategies presented in this section may help to deal with some of the more common behaviours, patience, common sense and the ability to problem-solve may be the best strategies of all.

#### Changes in Personality

Damage to the brain can cause survivors to have less control over their positive or negative emotions. This loss of control can change the way survivors behave or interact with others. For example, some survivors may appear to have wild mood swings, become irritated

with little provocation, or be stubborn, selfish or demanding. They can become indifferent or disinterested in things around them. These changes can be upsetting to family and friends.

It's essential to remember that these changes are due to a stroke and may not express the survivor's true feelings. A survivor may have little idea of the effect she is having on those around her. She is struggling to cope with a major threat to her sense of who she is. Learning to adapt and live with changes resulting from a stroke takes time.

The frustration, reduced self-esteem, anger, fear, helplessness, pain, confusion and grief experienced by a stroke survivor would have a profound impact on anyone's behaviour. The common sense approach suggests that we should treat the people we assist as we ourselves would like to be treated – with kindness, patience and respect.

### Behaviours Common to Many Strokes

#### Loss of Emotional Control (Emotional Lability)

Not only can a stroke survivor experience a loss of ability to move the affected arm or leg, but he can also experience a loss of control of emotions. This loss of emotional control is called emotional lability. Although people who have had a stroke have good reason to feel angry or depressed, excessive crying (or laughing) is often due to brain injury and isn't directly connected with perceived losses. Survivors' feelings and their outward show of emotion aren't always linked.

Many people will also have less ability to control their emotions. They may sob when they hear a touching story, or when they hear very good news.

### What You Can Do to Help

- **Double check with the survivor to find out whether he is indeed feeling the emotion being expressed, or whether it is unrelated to how he feels.**
- **Redirect or distract the survivor if incidents of loss of control are embarrassing to the survivor or interfering with an activity.** Calling the survivor's name, asking an unrelated question etc., in a matter-of-fact way can help, as can encouraging the survivor to close his mouth and take some deep breaths.
- **Explain that it is common to lose control of emotions after a stroke.**

60

Mr. Tomas has experienced a loss of emotional control after his stroke. He now finds it difficult to watch the nightly news, as the stories make him cry uncontrollably. His support worker helps him by distracting him when his sadness distresses him. He will ask him if he wants to have a snack, or if his favourite show is on next. This makes it easier for Mr. Tomas to stop crying,

### Social Isolation or Withdrawal

Many survivors experience diminished self-image, self-esteem and confidence. They may be dealing with feelings of depression or despair as they come to realize their losses. Survivors may feel a lack of meaning or purpose. They may also feel helpless, and have a sense of little control over their environment, and life in general.

These challenges can be daunting. A survivor may regain ability to perform many of her routine activities of living, yet 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." Assisting the survivor to again take part in life (as she chooses) is one of the most important things you can do.

### What You Can Do to Help

- **If at all possible, find out your survivor's interests.** Learn what matters to the survivor. What activities are most important? What brings her enjoyment? Assist the survivor to regain pursuits and activities of interest.
- **Promote the survivor's active participation in all aspects of her care, and to the best of her abilities.**
- **Encourage involvement in discussions and decisions.**
- **Modify the environment to encourage and support independence.**
- **Encourage and support involvement in social activities.** Recognize that attendance can be the first step in participation.
- **Provide opportunities for discussion of positive life experiences and memories.**
- **Support contact with the survivor's faith community, if the survivor is a member.**

Judith Rosen had a stroke 18 months ago. She has some right side weakness that has caused the muscles on one side of her face to droop. As a result, she feels very self-conscious and has been reluctant to go out.

Her support worker encourages Mrs. Rosen to go out, first to quiet, familiar places. Little by little, Mrs. Rosen has become less self-conscious and has taken a greater interest in going out.

## Angry Outbursts or Aggressive Behaviour

Like everyone, stroke survivors may have angry outbursts on occasion. Although not common, some survivors may be physically aggressive towards family or support staff. Survivors may refuse to comply with directions and/or have a difficult time getting over anger. During these times it may be difficult to reason with the survivor, as it is with any angry person.

With the help of the survivor, it may be possible to identify triggers for these outbursts. Triggers come from many sources:

- Frustration over tasks which the survivor is unable to do
- Embarrassment caused by a toileting accident
- Pain the survivor is experiencing in his affected arm or leg
- Frustration with problems in communicating.

### What You Can Do to Help

- Identify triggers and attempt to resolve them.
- Learn the survivor's preferences for routine and how things are done. Follow these preferences whenever possible.
- Remove survivor from the situation or activity that triggered the outburst.
- Redirect the survivor's attention towards something more positive for him.
- Alternate easy and more difficult tasks to give the survivor an opportunity for success and a sense of accomplishment.
- Approach the survivor from his unaffected side to reduce the risk of alarm or surprise.
- Explain to the survivor what you are planning to do so he is prepared and aware of what is happening.

- Offer support or assistance as needed during activities that cause frustration.
- Identify any pain issues which need to be addressed.

## Lack of Interest & Motivation (Lethargy)

Many survivors with right hemisphere damage can appear to have lost interest in performing daily and leisure activities. When an attempt is unsuccessful, survivors may seem to easily give up. They may seem to resist encouragement to try, or to try again.

### What You Can Do to Help

- Learn what interests the survivor. Wherever possible, adapt the activities as necessary to encourage interest and participation.
- Provide praise for expressed interest in activities.
- Support any involvement in activities, even simple attendance at an event. Recognize that attendance is the first step in participation.
- If the first attempt at a task was unsuccessful, encourage the survivor to try again. Do not force the survivor, or embarrass a survivor who refuses. Instead, try later.

Harry Johnston had a stroke almost a year ago. Although he experienced very little loss of mobility, 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. She is careful to encourage him to participate in activities that he can easily do, so as to reduce the risk of frustration.

## Frustration Due to Communication Difficulty

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Imagine not being able to communicate. Frustration is a common and natural consequence of communication difficulty.

### What You Can Do to Help

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- **Make an effort not to overestimate or underestimate communication and comprehension skills.** Observe the survivor to assess what she actually can do and understand. Underestimation can lead to frustration or anger, overestimation may lead you to believe the survivor is being deliberately uncooperative.
- **Provide time and opportunity to communicate.** Communication problems may become impossible to overcome if there is too little time or opportunity.
- **Use short simple messages, supported communication techniques, and pantomime if helpful.** Yes/No cards, word lists and picture cards may be helpful.

Section 3 on Communication provides additional information you might find useful.

## Social Judgment

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Social judgment refers to the survivor's ability to guide and check his own behaviour. This means doing the right thing at the right time. Examples of impaired social judgment can include:

- **Saying the wrong thing at the wrong time**
- **Changes in personality. A shy survivor may become immodest or a talkative survivor quiet. A survivor may become more rigid in their behaviour and personality. A survivor who once was neat now may care little about personal appearance.**

Many of these difficulties result from problems with memory and other cognitive problems.

## What You Can Do to Help

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- **Don't put the survivor in situations that require him to make social judgments that exceed his capabilities.** It's important not to make the situation worse by failing to recognize the survivor's problems.
- **Provide the survivor feedback and cues to learn behaviours appropriate to situations.** Feedback helps the survivor recognize inappropriate behaviour and learn a better way of conducting himself.
- **When the survivor acts appropriately be sure to let him know.** Always praise appropriate or desired behaviours. Make sure that your praise is specific and adult in tone.
- **Identify inappropriate behaviour in a matter-of-fact, non-punitive way.** Offer options for alternate behaviour.

## Confused or Uncooperative Behaviour

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This may be related to sensory deprivation. See the strategies discussed in the section on sensory deprivation (page 50).

## Rudeness

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See strategies discussed in Table 4 (page 20).

## Section 10

### Managing Continence

Incontinence is an embarrassing condition. A change in bladder function is a distressing, disabling problem with major implications for the quality of life after a stroke. Incontinence can cause survivors to limit travel, activity or even family events. Understandably, survivors are often devastated by the loss of control.

Continence is a major factor in determining whether a survivor can be cared for at home. It's one of the leading reasons given when an application is made to a long-term care facility.

It's important to recognize that incontinence resulting from any condition, including stroke, may be resolved, improved or better managed. The ability to improve bladder function depends on the size and location of the brain damage, the degree of physical limitation, age, and the presence of other health problems such as diabetes. This section describes methods that you can use to assist the stroke survivor to manage the condition.

### Continence Problems

Stroke survivors may:

- Often experience urgency to void but have difficulty or be unable to control the urgency
- Have diminished ability to feel bladder fullness and have bladder control
- Experience physical complications such as infection and skin breakdown
- Experience significant changes in their lifestyle as they attempt to cope with the urgency.

The physical complications may cause serious illness, decrease a survivor's tolerance for activity, or even prevent participation in some activities. Skin breakdown may require expensive dressing, cause more pain and risk of infection, as well as be time-consuming for the caregiver.

### Psychosocial Reaction to Incontinence

The effects of incontinence go beyond the physical. Incontinence can have a dramatic and long-lasting effect on the survivor's sense of self and lifestyle. Activities are interrupted by frequent toileting. The survivor may be confined to places close to toileting facilities because of bladder urgency. The survivor may limit socialization and participation in activities because of the fear of accidents. Sexual activity may decrease.

Family relationships may be strained when management of voiding requires assistance. Stressed family members may limit their visits or reduce the number of outings made with the survivor.

## Normal Bladder Function

Normal bladder function is a highly coordinated activity involving the lower urinary tract (bladder, urethra, and internal and external sphincter) and the peripheral and central nervous systems. It is dependent upon four groups of functions:

- **Neurologic Function** – the message getting to and from the brain
- **Urologic Function** – the ability to produce urine and store it in the bladder
- **Psychologic Function** – cognition, perception, ability to interpret the message
- **Mobility** – the physical ability to get to and use appropriate facilities.

Normal bladder emptying occurs from 3 to 6 times during the daytime and possibly once during the night. Sensation is first felt at about half capacity but a person with normal bladder function is able to discourage or stop the sensation for as long as 1 to 2 hours until full capacity.

## Age-Related Changes that Affect Continence

There are age-related changes in the urinary system that may affect continence. These changes include:

- **Thinning of the bladder wall.** The bladder spontaneously empties at smaller volumes, resulting in more frequent, less controlled voiding.
- **Diminished bladder capacity.** The bladder may hold only 250-300cc of urine instead of the 500-600cc in the normal adult. Therefore the older adult will void more frequently.
- **Inability to empty the bladder completely.** This results in urinary retention. The bladder becomes like an over-stretched balloon, unable to regain its original shape because of loss of elasticity.

## Symptoms of Bladder Dysfunction

Many symptoms can signal bladder dysfunction:

- **Loss of small amounts of urine with coughing, sneezing, or other physical exertion**
- **Difficulty or inability to stop urine stream**
- **Dribbling between voids**
- **Loss of large amounts of urine following a sudden urge**
- **Unsuccessful rushes to the bathroom**
- **Voiding more than eight times during the day or twice per night**
- **Loss of urine with or without movement**
- **Weak or interrupted urine stream**
- **Sensation of bladder fullness, even after voiding**
- **Frequent bladder infections (urinary tract infections)**
- **Awareness of the need to void seconds before the bladder empties.**

Sometimes because of the bladder's decreased ability to empty completely it may appear that the survivor is voiding normally. However, the survivor actually retains large urine volumes. This creates an increased risk of urinary tract infections as well as causing urine to back up into the kidneys.

## What You Can Do to Help

In order to help the survivor, you'll need to identify the source of the problem. This section offers a variety of ways you might respond to different factors causing incontinence. Some methods may be useful in many situations.

- **Allow for privacy.** Always remember that voiding is a very personal and private act.
- **A commode or toilet is preferred to a bedpan as it encourages better and more complete bladder emptying.** Sitting on a commode or toilet proves a more natural position, allowing for gravity as well as increased abdominal pressure to work in the survivor's favour.
- **If a bedpan must be used make sure the head of the bed is raised as upright as possible.** This allows for more normal positioning.
- **Make sure the survivor has some way of calling for assistance, if necessary.**
- **If the survivor uses a urinal, keep it within easy reach and where he can see it.** A small light may need to be left on at night.
- **A fixed schedule to void instead of waiting for the urge can be useful.** If a survivor is consistently incontinent at a certain time of the day then adjust the schedule to toilet the survivor before that time.
- **Once a routine is established, encourage the survivor to attempt to void, whether or not he feels the urge to do so.**
- **If the survivor has a communication impairment, he may demonstrate increased agitation because of the need to void and the inability to express this need.** Also, the survivor may become more agitated when wet or as a result of the fear of being incontinent.
- **A survivor with periodic agitation, what seems like constant requests for toileting, or experiencing a change from his normal urinary pattern needs your attention.** There may be an infection.

## Bladder Retraining

In many cases, it is possible to gradually increase the intervals between toileting. By doing so, it is possible to "retrain" the bladder to increase the intervals between voids. This protocol would usually be established by a nurse. This is more successful with a cognitively intact survivor who is experiencing urge. The goal is to correct the habit of frequent voiding, to increase bladder capacity and to improve the survivor's ability to suppress the feeling of urgency. This technique has several steps.

**Step One** The survivor uses a mandatory voiding schedule.

**Step Two** Gradually, the intervals between voids are increased.

**Step Three** The survivor is taught to void according to schedule and to resist the urge to attempt to void in response to sensation. This is attained through the use of relaxation or distraction techniques.

**Step Four** The interval between voids is periodically increased by 15 minutes (you may have to start with less) with a goal of the interval to be every 3 to 4 hours.

Write the schedule down so the survivor and other caregivers can keep track and know when to toilet. Encourage the survivor and provide positive reinforcement. It's also important to monitor the survivor for signs and symptoms of urinary tract infection.

## Incontinence Due to Cognitive, Language and Mobility Problems

Assisting the survivor who is incontinent because of cognitive, language and mobility problems requires creativity and sound problem-solving skills. Socially appropriate voiding requires the correct interpretation of the message to void, understanding the implications of the message to void, and the performance of the necessary steps to void under socially acceptable conditions.

Survivors whose attention, concentration, judgment and decision making problems alter their ability to correctly identify and respond to the need to void may benefit from a schedule with regular reminders or physical assistance to void.

A survivor who cannot move freely or who has decreased physical ability will likely require more time or assistance to get to the toilet as well as to remove the necessary clothing.

Reduced ability to communicate can make it very difficult to ask for and obtain assistance, particularly when the need is urgent.

### Symptoms of a Urinary Tract Infection

A number of symptoms can signal a possible urinary tract infection. If any of the following are present, infection should be suspected. The survivor should be referred to her physician for diagnosis and treatment.

#### Common symptoms include:

- Increase in frequency of voiding or incontinent episodes
- Changes in behaviour, especially increased agitation when unable to communicate symptoms
- Burning or pain when voiding
- Cloudy, strong smelling urine.

Fever is less common with urinary tract infections.

## Reducing the Risk of Urinary Tract Infections

The following techniques will help to reduce the risk of urinary tract infections:

- **Ensure adequate fluid intake of 6 to 8 glasses a day.** Often older adults will cut back on the amount of fluids taken to decrease the number of times they need to toilet. This actually can have the opposite effect, as the urine then becomes more concentrated and irritates the bladder wall. This irritation causes increased sensation and stimulation to void. There is often a burning sensation when voiding.
- **Encourage an increase in fluids when the survivor experiences burning during urination.** Inadequate fluid intake creates a vicious circle: because of burning when urinating the survivor decreases fluid intake. This causes greater urine concentration and burning. Increasing fluid intake flushes the bladder and decreases the burning sensation.
- **Restrict caffeine intake to 2 cups per day or less.** Caffeine is found in coffee, tea, most soft drinks and chocolate.
- **If excessive night voiding is a problem, adjust the timing of the fluid intake (not the amount per day) so more is taken earlier in the day and only 1 cup is taken after 7 p.m.**
- **Report any change in bladder function to allow for further investigation.**

# Section 11

## Risk Factors for Stroke

Risk factors are conditions that put a person at greater risk of a stroke. Having one or more of the risk factors does not mean that a person will automatically have a stroke, just that the person has a greater chance of having one. The more risk factors a person has, the greater her chance of having a stroke.

Risk factors can be divided into modifiable and non-modifiable, as shown in Table 10. **Modifiable** means that they can be eliminated or controlled through changes in lifestyle and medical management. **Non-modifiable** means they are beyond an individual's

control. It is important to have a support plan that deals with the specific risk factors for the survivor and helps them change their behavior to minimize the risks as much as possible. The Ontario Stroke Strategy places an emphasis on prevention. Regional Stroke Centres will have Secondary Prevention Clinics that can provide a diagnosis and risk factor management plan. The Heart and Stroke Foundation of Ontario and the Ontario College of Family Physicians are working on strategies to support risk factor management. Be aware of the risk factor management plan and encourage the survivor to follow her plan.

Table 10: Modifiable Risk Factors		Non-Modifiable Risk Factors
Lifestyle	Disease	
High fat, high salt diet	High blood pressure ( <i>Hypertension</i> )	Age
Smoking	Diabetes	Gender
Obesity	Heart disease	Race
Sedentary lifestyle	<ul style="list-style-type: none"> <li>• Heart attack (<i>MI</i>)</li> <li>• Atrial fibrillation</li> </ul>	Family history
Excessive alcohol intake	<ul style="list-style-type: none"> <li>• Congestive heart failure</li> <li>• Valve disease</li> <li>• Coronary artery disease</li> </ul>	
	TIAs	
	Previous stroke	



## Section 12

### Aphasia – Breaking Down Communication Barriers

Imagine yourself living in a foreign country where you do not speak the language. You would continue to have thoughts, possess all your former knowledge, and have the same ability to make decisions. But you would be unable to speak to the residents of the country. You could not rely on their spoken or written words to help you understand. This is similar to living with aphasia.

Communication requires at least two components: speech and language. Speech refers to the muscles you use to produce sounds. The muscles of your lips, tongue, throat, and lungs are all used to produce sounds that make up words. Language refers to the “dictionary” of words, word meanings, and rules for combining words into sentences. This “dictionary” is located in your brain. Aphasia is a language difficulty that occurs when a stroke has affected the part of the brain that holds the language “dictionary.”

#### Your Role as Caregiver

People with aphasia are competent adults who know more than they can say. As a caregiver, you will be an important person in the life of the person for whom you are caring. In many situations you may be one of the few people the person with aphasia has an opportunity to communicate with. This section is intended to provide you, the caregiver, with some tools to help you communicate with people with aphasia.

As with any new skill, it will take time to become comfortable with some of the strategies. Some will be more effective with certain people with aphasia but will not work for others. It is important to remember that every person with aphasia is different and has different abilities. Keep trying!

#### Communicating With a Person With Aphasia

On the following pages, you will find tools and suggestions to help you improve communication between you and a stroke survivor with aphasia. These tools are divided into two components:

- General Strategies for Communication
- Pictographic Topic Pages

The pictographic pages, adapted from the Aphasia Institute of Toronto, are designed for you, the communication partner, to use when facilitating a discussion with a person with aphasia. The pictographs will help you get your message across by providing visual clues to the topic of the conversation. As well, pictographs will help the person with aphasia get his/her message across by providing choices and something to point to (see page 72-73 for examples\*). Please note that the pictographs are not meant to be used as a “communication board.”

The resources are based on Supported Conversation for Adults with Aphasia™ (SCA™) and have been developed by the Aphasia Institute.

*\* You may want to enlarge each pictograph so that you and the stroke survivor both have copies.*

## Strategies to Help You Get Your Message Across

Here are some solid strategies that might help:

- Look at the person with aphasia when speaking. Your facial expression can help the person with aphasia understand you.
- Speak in a tone of voice appropriate for communicating with an adult. Do not sound condescending. Do not sound like you are speaking to a child.
- Communicate one idea at a time.

~~*“I will help you get up, showered and dressed and then I am going to take you to the dining room for you to have breakfast but first you have to take your pill.”*~~

*“Here is your pill to take.”* Pause and give pill.

*“First I am going to help you take a shower.”* Pause.

*“Then I will help you get dressed.”* Pause.

*“After all that, I will take you for breakfast.”*

- Write down key words. Use a thick black marker and printed letters.
- Use gestures and facial expressions.
- Use objects from the environment to help get your message across.
- Use YES/NO questions.
- Draw simple pictures.
- Acknowledge that the person with aphasia is a competent, knowledgeable person who can make decisions. Acknowledge that the person with aphasia knows what they want to say but cannot say it.

Table 11 provides a scenario between a caregiver and a resident in a long-term care facility that helps to illustrate the above strategies.

**Table 11: Communication Scenario Between Caregiver and Person with Aphasia**

Conversation	Strategies Used by the Caregiver
<i>“Mrs. Jones, I want to tell you about an event we have coming up. I think you will be interested.”</i>	Comes prepared with a calendar, scrap paper, and a black marker.
<i>“This is today.”</i>	Points to the date on the calendar.
<i>“On Tuesday,</i>	Points to the date on the calendar and then writes down (TUESDAY OCT 6).
<i>“The John Higgins Band is coming to play.”</i>	Writes down (JOHN HIGGINS BAND).
<i>“They are coming here.”</i>	Uses hand gesture to indicate the location.
<i>“Do you want to go?”</i>	Writes down (DO YOU WANT TO GO?) and points to the resident. Writes down (YES/NO/I DON'T KNOW) and waits for the resident to point to the response.

## Strategies to Help the Person with Aphasia Get Their Message Across

- Encourage the person with aphasia to write down a word or draw if they can.
- Encourage the person with aphasia to point to something.
- Attempt to identify the general topic first and then move onto understanding the details.  
*“Are you talking about your family?”*  
*“Are you talking about your daughter?”*  
*“Are you wondering if she is coming to visit today?”*
- Ask YES/NO questions.
- Use a written YES/NO if needed.
- If you do not have the time to communicate explain this and give a time when you will return to finish your conversation. Make sure you do return.
- Encourage the person with aphasia to use some of the words you have written down to communicate.

*“I have heard you are a big fan of music?”*

YES • NO • I DON’T KNOW

*“What kind of music do you like?”*

OPERA • CLASSICAL • BLUES • OTHER

## Where to Get Extra Help

**The Aphasia Institute** is a community-based, volunteer-driven organization that offers long-term support and education for adults with aphasia, their families, health professionals, and the community. Internationally respected, the Toronto-based Institute provides information, referral services, and client assessments to meet the needs of clients and their families. It is also committed to raising public awareness about aphasia through education, research, and outreach activities.



The Aphasia Institute offers a 12-week Introductory Program for clients with aphasia and their family members. It provides an opportunity to learn how to bridge communications gaps, and as a result, regain self-confidence and a brighter outlook for the future.

The Community Aphasia Program enables clients who have completed the Introductory Program to continue progressing within the Institute’s internal community, while preparing to re-enter and participate in their own external communities. Conversation groups, peer support groups, exercise classes, crafts, music therapy, painting, and a Toast Master International group help build skills in a friendly and supportive environment.

For more information, please call 416-226-3636.

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Pictographic Topic Pages – Health and Nutrition

**HEALTH**





**PAIN?**



yes                      no


**HEALTH**

Do you have a problem with...

 Bowel and/or Bladder	 Headache
 Vision	 Lungs Breathing
Something Else	

**HEALTH**


Do you want to see a Doctor?






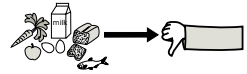


yes                      no

**NUTRITION**

I don't want to Eat because...


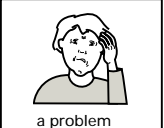







 No Appetite	 Nausea	 Heartburn
 Swallowing Problems	 Depression	
 Don't Like the Food	Other	





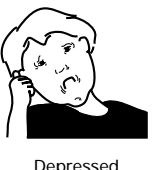

Pictographic Topic  
Pages – Feelings

**FEELINGS**


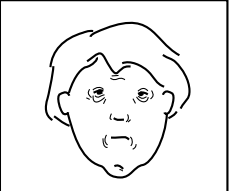
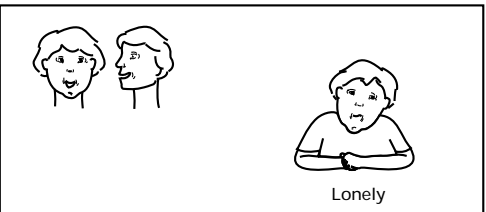
I want to Talk about...

 my family	 a problem	 my health
 food / diet	 money	 my medication
 my hobbies	place name and picture of your setting here	Something Else

**FEELINGS**

 Happy	 Sad
 Angry	 Worried
 Depressed	 Frustrated

**FEELINGS**

 Bored / Don't Care	 Tired
 Lonely	
OTHER	



## Section 13

### Quality Improvement and Monitoring

*Tips and Tools* incorporates current best practices in caring for stroke survivors in a long-term care facility or through a community based program. Quality monitoring will help ensure that the content in this Guide supports you in the best possible way – making your job easier and the person you care for more satisfied with the care you provide.

As you introduce each section of *Tips and Tools* into your organization and care planning process, decide on ways to maintain what works to ensure quality, and to adapt or improve if necessary.

In this section, we outline the principles and process for developing a quality monitoring program within your own care setting.

#### Goals

The two goals of quality monitoring are to meet and exceed the expectations of stroke survivors, their families, and caregivers, and to establish and maintain best practices in caregiving.

#### Features

A good quality monitoring process:

- Measures what you are doing and compares it to best practices
- Promotes health and wellness, with a focus on quality of life

- Is customer focused
- Is consistent with CCHSA standards
- Uses an interdisciplinary team approach
- Works from the guiding principles of continuous improvement.

#### Measurement

Your organization will already have a number of measurement tools on hand to help you gather information. There is no need to reinvent the wheel. Examples of these include:

- Reports such as risk management
- Compliance reports by the Ministry of Health and Long-Term Care
- Accreditation
- Strategic goals and strategies for your organization
- Resident, client, and family satisfaction surveys
- Employee satisfaction surveys
- Care planning goals and strategies
- Content of the *Tips and Tools* “Facilitators Guide” and the *Tips and Tools* “Manual”
- Attendance at inservice
- Suggestion boxes
- Quizzes.

Develop new satisfaction surveys, audits, and so on only if there is no other way to access the information you need.

## Quality of Life

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- *Tips and Tools* promotes independence, relearning, regaining, and coping and supporting functional abilities of the stroke survivor and all those involved with care. You can monitor optimal quality of life through interviews, observation, and/or satisfaction surveys related to each of these areas.
- You may wish to establish a stroke group with a focus on support, exercise, or learning. Obtain feedback from the group on how satisfied they are with strategies used from *Tips and Tools* and what they would like to change.

## Customer Focus

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- Ensure goals and strategies are resident or client-focused. Evaluate and revise as needed.
- Check frequently, both formally and informally, that the survivor, family, and caregivers are satisfied with the various aspects of care. Use the relevant section of *Tips and Tools*, along with the care plan, as the basis for your review. Ask specific questions related to satisfaction with care provided based on the sections of the Guide.
- Ask about and observe the relevant functions of those under your care – for example, mobility, communication, and behaviour.
- Look for trends, triggers, lingering dissatisfaction.
- Involve all associated with the care in problem solving to reduce, modify, or eliminate the root of the problem.

## Team Approach

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- As part of the care planning process, set resident or client-focused goals and strategies, referring to the “What You Can Do to Help” subsections in the relevant sections of *Tips and Tools*.
- Identify a *Tips and Tools* coach (described in the Facilitator’s Guide) to support and assist the team.

- Check that all team members have the resources, knowledge, and skills to fulfill their role. Ensure learning is continuous.
- Monitor and review strategies that have been implemented on an ongoing basis.
- Have the goals been met? If so, celebrate success! If not, identify what the “real problem” is before deciding on a solution. Problem-solve together, remembering that the stroke survivor and family are members of the team.
- Try possible solutions and find out what works the best.
- Discuss and share lessons learned.

## Continuous Improvement

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- Use indicators (discussed in more detail below) to check how you are doing when applying the knowledge and skills gained from *Tips and Tools*.
- Figure out what is working and what isn’t. Problem-solve with all involved.
- Try a new or different approach, and then find out if it’s working.
- Continue to implement changes as needed.
- Identify what lessons were learned from the experience. Share that information with your colleagues.

## Indicators

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Indicators can be used to assess how you are doing with implementing the material covered in *Tips and Tools* – to help you identify in a general way the parts of the Guide you are using well and those you might want to use more effectively.

Table 12 provides some examples of indicators corresponding to each of the sections in *Tips and Tools*. These should be used as examples only. Your examples will be specific to what you need to find out and will change over time. Information for these indicators is usually available in your facility or through a survey or audit.

<b><i>Tips and Tools</i> Section</b>	<b>Indicator</b>
<b>Section 1 The Anatomy of Stroke</b>	The number of staff who attended <i>Tips and Tools</i> inservice, relative to the total number of staff in the organization.
<b>Section 2 The Psychosocial Effects</b>	The number of stroke survivors coping with stroke-related feelings (anxiety, depression, grief, etc.), relative to the total number of stroke survivors being cared for by the organization.
<b>Section 3 Communication</b>	The number of stroke survivors with supports in place to facilitate communication, relative to the total number of stroke survivors with decreased communication.
<b>Section 4 Leisure Activities</b>	The number of stroke survivors participating in leisure activities of their choice, relative to the total number of stroke survivors in the organization.
<b>Section 5 Mobility and Skin Care</b>	The number of stroke survivors being cared for using one or more suggestions in the "What You Can Do to Help" subsection, relative to the total number of stroke survivors in the organization.
<b>Section 6 Routine Activities of Living</b>	The number of stroke survivors who are more independent because of assistive devices, cueing, or positioning, relative to the total number of stroke survivors in the organization.
<b>Section 7 Cognitive and Perceptual Problems</b>	The number of stroke survivors using one or more suggestions in the "What You Can Do to Help" subsection, relative to the total number of stroke survivors in the organization.
<b>Section 8 Meal Assistance and Hydration</b>	The number of stroke survivors with swallowing difficulties using approaches outlined in this section, relative to the number of stroke survivors with swallowing problems.
<b>Section 9 Specific Behaviours</b>	The number of stroke survivors with one or more specific behaviours caused by the stroke that are being addressed through suggestions in the "What You Can Do to Help" subsection, relative to the total number of stroke survivors with specific stroke-related behaviours.
<b>Section 10 Managing Continence</b>	The number of stroke survivors with stroke-related bladder dysfunction on a bladder retraining schedule, relative to the number of stroke survivors with stroke-related bladder dysfunction.
<b>Section 11 Risk Factors for Stroke</b>	The number of stroke survivors with a plan to modify risk factors (smoking, activity level, diet, weight, etc.), relative to the number of stroke survivors.
<b>Section 12 Aphasia</b>	The number of stroke survivors with aphasia who can communicate because the caregiver uses communication strategies, relative to the number of stroke survivors.



## Section 14

### Resources

#### General Resources

##### Resources From Heart and Stroke Foundation of Ontario (HSFO)

Healthline Catalogue

Blood Pressure Wallet Card

Children's Stroke Storybook: Jack's Story

Coping With Stress

The Emotional Journey: Understanding Emotional Issues After Stroke

Five Main Warning Signs of Stroke

A Guide to Understanding Strokes

How Stroke Affects Behaviour

Know Your Blood Pressure

Let's Talk About Stroke – Guide for Stroke Survivors and Families (*This resource can be downloaded at [www.heartandstroke.ca](http://www.heartandstroke.ca)*)

Memory Loss After Stroke (*This resource can be downloaded at [www.heartandstroke.ca](http://www.heartandstroke.ca)*)

The Stress Test

Stroke Warning Signs Poster and Wallet Card

Stroke: A Guide for the Family

Stroke: Medical Test and Treatments Booklet

Strokeline Newsletter (Current Issue) (*This resource can be downloaded at [www.heartandstroke.ca](http://www.heartandstroke.ca)*)

Take Control – Action to Reduce Your Risk

To order HSFO Resources, call 1-888-473-4636 (HSF-INFO) or your HSFO Regional Hospital Specialist. To locate your HSFO Regional Hospital Specialist, contact Julie Fiorini at 416-489-7111, 335 or [jfiorini@hsf.on.ca](mailto:jfiorini@hsf.on.ca)

#### General Web Sites

##### American Stroke Association

[www.strokeassociation.org](http://www.strokeassociation.org) or 1-888-478-7653

##### Caregiver Network

[www.caregiver.on.ca](http://www.caregiver.on.ca) or 416-323-1090

##### Heart and Stroke Foundation of Canada

[www.heartandstroke.ca](http://www.heartandstroke.ca) or 1-888-473-4636 (HSF-INFO)

##### Heart and Stroke Foundation Professional

**Education** [www.heartandstroke.ca/profed](http://www.heartandstroke.ca/profed) or 416-489-7111, 456

##### National Stroke Association

[www.stroke.org](http://www.stroke.org) or 1-800-787-6537

##### Ontario Association of Community Care

**Access Centres** [www.oaccac.on.ca](http://www.oaccac.on.ca) or 416-750-1720

##### Self-Help Resource Centre

[www.selfhelp.on.ca](http://www.selfhelp.on.ca) or 1-888-283-8806

##### The Stroke Information Directory

[www.stroke-info.com/fact\\_sheets.htm](http://www.stroke-info.com/fact_sheets.htm)

##### Stroke Recovery Association

[www.strokerecovery.org](http://www.strokerecovery.org) or 1-888-540-6666

##### Stroke Survivors International

[www.strokesurvivors.org](http://www.strokesurvivors.org)

 The red maple leaf identifies a Canadian web site.

## Resources Consulted in the Development of This Guide

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Heart and Stroke Foundation of Canada & National Stroke Association. *A Guide to Understanding Strokes*. Ottawa: Author; 1996.

Nursing Skin Care Committee, St. Joseph's Health Care-Parkwood Hospital. *Clinical Practice Standards – Pressure Ulcers*. London: Author; nd.

Evans D. *Stroke Education and Counselling Resource Guide*. Province-Wide Nursing Project, London-Woodstock Participating Joint Agency Committee.

Stroke Rehabilitation Program, St. Joseph's Health Care-Parkwood Hospital. *Family Support and Education Group Series Handouts*. London: Author; nd.

Hinds PM. *After Stroke*. New York: HarperCollins; 2001.

Loesche WJ, Abrams J, Terpenning MS, Bretz WA, Dominguez BL, Grossman NS, Hildebrandt GH, Langmore SE, Lopatin DE. Dental findings in geriatric populations with diverse medical backgrounds. *Oral Surg Oral Med Oral Pathol Oral Radiol Endol* 1995 Jul; 80:43-54.

Longmore S. Predictors of aspiration pneumonia: how important is dysphagia. *Dysphagia* 1998; 13: 63-81.

Lynch M & Grisogono V. *Strokes and Head Injuries: A Guide for Patients, Families, Friends and Carers*. London UK: John Murray; 1991.

Pedretti L. *Occupational Therapy: Practice Skills for Physical Dysfunction* (2nd Ed.). Toronto: C.V. Mosby; 1985.

American Heart Association. *Recovering from a Stroke*. Dallas: Author; 1994.

The Riverdale Hospital. *Riverdale Mealtime Assistance Handbook*. Toronto: Corporate Communication; 2000.

Siev E, Freishtat B, & Zoltan B. *Perceptual and Cognitive Dysfunction in the Adult Stroke Patient*. Thorofare NJ: Slack Incorporated; 1986.

## Section 1 – The Anatomy of Stroke

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### General Information

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*A Guide to Understanding Strokes* is a picture book explaining different types of stroke and warning signs. (See Resources From HSFO)

### Web Sites

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#### The Brain Matters

[www.thebrainmatters.org/stroke.htm](http://www.thebrainmatters.org/stroke.htm)

**Centre for Neuro Skills** [www.neuroskills.com](http://www.neuroskills.com)  
(Go to Brain Map, under Resources)

🍁 **Heart and Stroke Foundation of Canada**  
[www.heartandstroke.ca](http://www.heartandstroke.ca) or 1-888-473-4636  
(HSF-INFO)

🍁 **Heart and Stroke Foundation Professional Education** [www.heartandstroke.ca/profed](http://www.heartandstroke.ca/profed) or  
416-489-7111, 456

**Internet Stroke Center** [www.strokecenter.org](http://www.strokecenter.org)

#### The Whole Brain Atlas

[www.med.harvard.edu/AANLIB/home.html](http://www.med.harvard.edu/AANLIB/home.html)

## Section 2 – The Psychosocial Effects

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### General Information

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Videotapes that describe how stroke survivors cope with anxiety, depression, and anger may be borrowed or rented from local pharmacies, libraries, or colleges/universities.

Check the Yellow Pages under “Social and Human Services” for stroke recovery groups.

Contact your local Community Care Access Centres (CCAC) for information about emotional and psychological assessment, support, and financial assistance.

Check with local religious groups regarding supportive counselling or contact Psychologists Referral Service at 416-961-0069.

*Children's Stroke Storybook: Jack's Story* helps children understand some of the emotional difficulties that affect families and stroke survivors. (See Resources From HSFO)

*Coping With Stress* (See Resources From HSFO)

*The Emotional Journey: Understanding Emotional Issues After Stroke* (See Resources From HSFO)

*The Stress Test* (See Resources From HSFO)

### Web Sites

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#### Depression and Stroke

[www.nimh.nih.gov/publicat/stroke.cfm](http://www.nimh.nih.gov/publicat/stroke.cfm)

#### Ontario Psychological Association

[www.psych.on.ca](http://www.psych.on.ca) or 416-961-5552

#### Stroke Recovery Association

[www.strokerecovery.org](http://www.strokerecovery.org) or 1-888-540-6666

#### StrokeHelp.com

[www.strokehelp.com](http://www.strokehelp.com) or 1-888-665-6556

## Section 3 – Communication

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### General Information

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Your local hospital or CCAC may be able to provide information about regional speech programs or resources.

Check university departments of medicine, rehabilitation, or speech-language pathology for information on communication.

For aphasia, see Section 12 Resources.

### Web Sites

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#### Canadian Hard of Hearing Association

[www.chha.ca](http://www.chha.ca) or 1-800-263-8068

#### Canadian Hearing Society

[www.chs.ca](http://www.chs.ca) or 416-928-2500

#### Canadian National Institute for the Blind

[www.cnib.ca](http://www.cnib.ca) or 416-486-2500

#### Dysarthria

[www.asha.org/speech/disabilities/dysarthria.cfm](http://www.asha.org/speech/disabilities/dysarthria.cfm)

#### Ontario Association of Speech-Language Pathologists & Audiologists

[www.osla.on.ca](http://www.osla.on.ca) or 416-920-3676

## Section 4 – Leisure Activities

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### General Information

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Contact community day programs, community centres, and stroke support groups in your area.

### Web Sites

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**Abledata** [www.abledata.com](http://www.abledata.com) or 1-800-227-0216

🍁 **Canadian Abilities Foundation**  
[www.enablelink.org](http://www.enablelink.org) or 416-923-1885

🍁 **Canadian Therapeutic Recreation Association**  
[www.canadian-tr.org](http://www.canadian-tr.org)

🍁 **Ability Online**  
[www.ablelink.org](http://www.ablelink.org) or 416-650-5411

🍁 **Active Living Alliance for Canadians With a Disability** [www.ala.ca](http://www.ala.ca) or 1-800-771-0663

🍁 **Active Living Magazine**  
[www.activelivingmagazine.com](http://www.activelivingmagazine.com) or 905-957-6016

**American Therapeutic Recreation Association**  
[www.atra-tr.org](http://www.atra-tr.org) or 1-703-683-9420

**Therapeutic Recreation Directory**  
[www.recreationtherapy.com](http://www.recreationtherapy.com)

🍁 **Toronto Therapeutic Recreation Association**  
[www.toronto-therapeutic-recreation-com.com](http://www.toronto-therapeutic-recreation-com.com)

## Section 5 – Mobility and Skin Care

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### General Information

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Contact your local CCAC for seating assessments (by an occupational therapist) or mobility assessments (by a physiotherapist).

Contact local rehabilitation centres for professional services and to request lift/transfer videos.

Your local medical supply companies may help to locate professionals and provide information on mobility equipment, supplies, and pressure relief products. (See Product Sources)

**Assistive Devices Program** [www.gov.on.ca/health](http://www.gov.on.ca/health)  
Provides partial coverage of costs for certain products for patients who qualify (see below).  
Contact: 416-327-8804 (Toronto);  
Toll Free: 1-800-268-6021 or 1-800-387-5559;  
TDD/TTY: 416-327-4282.

The Ontario Ministry of Health and Long-Term Care covers the following assistive devices:

- Wheelchairs, Positioning and Ambulation Aids
- Communication Devices
- Diabetic Supplies
- Enteral Feeding Equipment Supplies
- Hearing Aids
- Pressure Modification Devices
- Orthotic Devices
- Ostomy Supplies

### Web Sites

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🍁 **Abilities Magazine** [www.abilities.ca](http://www.abilities.ca)

🍁 **Canadian Association of Occupational Therapists**  
[www.caot.ca](http://www.caot.ca) or 1-800-434- 2268

🍁 **Directory for Accessibility**  
[www.accessibilitydirectory.ca](http://www.accessibilitydirectory.ca) or 1-800-263-3463

**Mobility and the Aged** The importance of adjustability and consistent reassessment when treating mobility-impaired elderly clients  
[www.rehabinternationalpub.com/issues/fall2001/7.asp](http://www.rehabinternationalpub.com/issues/fall2001/7.asp)

🍁 **Ontario Physiotherapy Association**  
[www.opa.on.ca](http://www.opa.on.ca) or 416-322-6866

🍁 **Registered Nurses Association of Ontario**  
[www.rnao.org](http://www.rnao.org) or 1-800-268-7199

🍁 **Terry Fox Mobile Clinic**  
[www.rehab.on.ca/mobile](http://www.rehab.on.ca/mobile) or 613-737-7350, 5308

## Section 6 – Routine Activities of Living

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### General Information

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Contact your local CCAC for seating assessments (by an occupational therapist) or mobility assessments (by a physiotherapist).

Contact local rehabilitation centres for professional services.

Your local medical supply companies may be able to help locate professionals and provide information on activity of daily living (ADL) equipment and supplies. (See Product Sources)

## Section 7 – Cognitive and Perceptual Problems

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### General Information

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Contact your local CCAC or rehabilitation centre for cognitive and perceptual assessments and follow up suggestions and protocols.

*Memory Loss After Stroke* provides practical tips for survivors and caregivers. (See Resources From HSFO)

## Section 8 – Meal Assistance and Hydration

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### General Information

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Assessment by a team consisting of a dietitian, speech-language pathologist, occupational therapist, and registered nurse can provide helpful information for survivors who have swallowing problems. Check to see if some or all of these resources are available locally by contacting the CCAC or local hospital.

Contact local rehabilitation centres for professional services.

Check with associations, hospitals, and rehabilitation centres for videos on feeding. Some catalogues may have these as well.

Consult ADL catalogues for equipment and aids. (See Product Sources)

### Web Sites

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🍁 **Ontario Society of Occupational Therapists**  
[www.osot.on.ca](http://www.osot.on.ca) or 416-322-3011

🍁 **Ontario Association of Speech-Language Pathologists & Audiologists**  
[www.osla.on.ca](http://www.osla.on.ca) or 416-920-3676

🍁 **Dietitians of Canada**  
[www.dietitians.ca](http://www.dietitians.ca) or 416-596-0857

**Dysphagiaonline.com**  
[www.dysphagiaonline.com](http://www.dysphagiaonline.com)

## Section 9 – Specific Behaviours

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### General Information

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Contact your local CCAC or rehabilitation centre for professional services. Consider asking for a psychologist or behavior management specialist. Note: Neuropsychological evaluation can be useful to determine which cognitive functions are intact and which are impaired.

Check to see if there is a psychogeriatric service associated with a local or neighbouring hospital.

*How Stroke Affects Behaviour*

(See Resources From HSFO)

*Children's Stroke Storybook: Jack's Story*

(See Resources From HSFO)

### Web Sites

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#### **StrokeHelp.com**

www.strokehelp.com or 1-888-665-6556

#### **Articles for Survivors and Families**

www.brain-train.com/articles.htm

## Section 10 – Managing Continence

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### General Information

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Contact your local CCAC or rehabilitation centre for assessment and treatment services for incontinence.

Local medical supply companies dealing in incontinence products often carry name brand products with tear-off Kegel Exercise instruction sheets.

### Web Sites

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#### **Canadian Continence Foundation**

www.continence-fdn.ca or 1-800-265-9575

#### **Foundation for Medical Practice Education**

www.fmpe.org/en/services/modules.html or  
1-800-661-3249

#### **National Association for Continence**

www.nafc.org or 1-800-252-3337

#### **Urology Resource Centre**

www.urologyresourcecentre.org/incont.html  
or 905-681-9300

#### **VON** www.von.ca or 613-233-5694

## Section 11 – Risk Factors for Stroke

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### General Information

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*Blood Pressure Wallet Card*

(See Resources From HSFO)

*Five Main Warning Signs of Stroke*

(See Resources From HSFO)

*Know Your Blood Pressure*

(See Resources From HSFO)

*Stroke Warning Signs Poster and Wallet Card*

(See Resources From HSFO)

*Stroke: A Guide for the Family*

(See Resources From HSFO)

*Take Control – Action to Reduce Your Risk*

(See Resources From HSFO)

### Web Sites

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See General Web Sites

#### **Foundation for Medical Practice Education**

www.fmpe.org/en/services/modules.html or  
1-800-661-3249

#### **Stroke-TIA.org** www.stroke-tia.org

## Section 12 – Aphasia

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### Web Sites

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🍁 **The Aphasia Institute**

[www.aphasia.on.ca](http://www.aphasia.on.ca) or 416-226-3636

🍁 **York Durham Aphasia Centre**

[www.ydac.com](http://www.ydac.com) or 905-642-2053

🍁 **Stroke Recovery Association**

[www.strokerecovery.org](http://www.strokerecovery.org) or 1-888-540-6666

### Product Sources

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**Velcro** can be ordered from catalogues or local sewing supplies stores. Buying in bulk is less expensive.

**Foam** can be purchased from fabric/upholstery companies uncut and in bulk, and then cut with an electric bread knife. Foam can also be purchased from department stores.

**Pressure Modification Devices, Prosthetic Devices, Respiratory Supplies/Equipment, Visual Aids, Wheelchairs, Positioning and Ambulation Aids Devices** may be supplied by the following companies:

**Adaptive Engineering Lab** [www.aelseating.com](http://www.aelseating.com) or 1-800-327-6080. Seating and positioning equipment for people in wheelchairs.

**Broda Seating** [www.brodaseating.com](http://www.brodaseating.com) or 1-800-668-0637, 23. Seating products for use in hospitals, nursing homes, assisted living facilities, and residences.

**Bruno Independent Living Aids** [www.bruno.com](http://www.bruno.com) or 1-800-882-8183. Mobility products including power chairs, scooters, vehicle lifts, and stairway elevators.

**Columbia Medical** [www.columbiamedical.com](http://www.columbiamedical.com) or 1-800-454-6612. Products for children and adults with disabilities.

**Convoid** [www.convoid.com](http://www.convoid.com) or 1-888-266-8243.

Lightweight, compact, folding pediatric, adult, and geriatric wheelchairs.

**Dana Douglas**

[www.danadouglas.com](http://www.danadouglas.com) or 1-800-267-3552.

Bathroom safety and mobility products.

**Disabledshopper.com**

[www.disabledshopper.com](http://www.disabledshopper.com) or 1-678-382-3701. Specially designed products for disabled and elderly people.

🍁 **Dolomite Home Care Products**

[www.dolomitehcp.com](http://www.dolomitehcp.com) or 1-888-687-2390.

Home health care products including walkers, Aquatec bath products, and e-Motion power assist.

**Dynamic Living** [www.dynamic-living.com](http://www.dynamic-living.com) or

1-888-940-0605. Kitchen products, bathroom helpers, and other daily living products.

**Family Senior Store** [www.familyseniorstore.com](http://www.familyseniorstore.com) or

1-888-717-1006. Extensive catalogue of aids for daily living.

🍁 **HealthCraft Products**

[www.healthcraftproducts.com](http://www.healthcraftproducts.com) or 613-744-3001.

Home medical equipment.

**Home Health Aides**

[members.shaw.ca/bcseniors/Home\\_Health\\_Aides.html](http://members.shaw.ca/bcseniors/Home_Health_Aides.html)

Extensive list of web sites that offer ADL aids.

🍁 **HPU Rehab** [www.hpurehab.com](http://www.hpurehab.com) or

1-888-634-5808. Various types of medical equipment, including pressure relieving cushions and mattresses, bariatric wheelchairs, and scooters.

**Invacare Corporation** [www.invacare.com](http://www.invacare.com) or

1-800-597-2117. Wide variety of medical equipment.

🍁 **Kino Mobility** [www.kinomobility.com](http://www.kinomobility.com) or

1-888-495-4455. Supplier of accessible vehicle mobility products.

🍁 **Obus Forme** [www.obusforme.com](http://www.obusforme.com) or

1-888-225-7378. Therapeutic products for pain prevention and relief.

**Otto Bock** [www.ottobock.com](http://www.ottobock.com) or 1-888-858-4422.

Prosthetic and orthotic components, rehabilitation products, mobility and seating aids.

🍁 **Parsons ADL**

[www.parsonsadl.com](http://www.parsonsadl.com) or 1-800-323-5547.

Accessories for daily living.

🍁 **PDG Product Design Group**

[www.prodgroup.com](http://www.prodgroup.com) or 1-604-323-9220.

Products for clients with special needs such as wheelchairs for heavier than average users, extra wide cushions, and laptop tray systems.

**Products for Seniors**

[www.productsforseniors.com](http://www.productsforseniors.com) or 1-800-566-6561.

**Reactivate** [www.reactivate.com](http://www.reactivate.com) or 1-604-885-2322.

**Sammons Preston Roylan**

[www.sammonspreston.com](http://www.sammonspreston.com) or 1-800-323-5547.

Special needs clothing catalogues.

🍁 **Silverts Clothing** [www.silverts.com](http://www.silverts.com) or

1-800-387-7088; 905-738-4545.

🍁 **SOS Rehabilitation**

[www.sosrehab.com](http://www.sosrehab.com) or 1-800-667-3422.

Wide variety of aids for daily living.

**Stannah Stairlifts** [www.stannah.com](http://www.stannah.com) or

1-800-877-8247. Manufacturer of stairlifts.

**Sunrise Medical** [www.sunrisemedical.com](http://www.sunrisemedical.com) or

1-888-703-9021. Homecare, rehabilitation, and respiratory products.

**Tranquility Products** [www.tranquilityproducts.com](http://www.tranquilityproducts.com)

or 1-800-467-3224. Incontinence products.

**TiLite** [www.tisport.net](http://www.tisport.net) or 1-800-545-2266.

Custom titanium wheelchairs.

**The Wright Stuff** [www.thewright-stuff.com](http://www.thewright-stuff.com) or

1-877-750-0376. Tools, appliances, and equipment for people with varying physical needs.

The web site and product information in the Resources section is provided for educational purposes only and is not meant to be inclusive. The Heart and Stroke Foundation of Ontario is not responsible for individual web site content and does not endorse any specific organization, program, or product.

## Related Resources

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The following resources, produced by the Heart and Stroke Foundation of Ontario, are available by calling 416-489-7111 ext. 456.

**Building a Coordinated Stroke System:  
An Evaluation of the Coordinated Stroke Strategy**

**A Guide for Establishing a Regional  
Coordinated Stroke Strategy**

**A Guide to Developing Stroke Prevention Clinics**

**A Guide to Organizing Acute Stroke Care**

**Moving Towards a Regional Stroke Rehabilitation System**

**Organized Stroke Care: Managing Change**

**Organized Stroke Care: Resources**

**Organized Stroke Care in Ontario: The Time is Now!**

The Heart and Stroke Foundation has also produced **Let's Talk About Stroke**, a resource for stroke patients.