Timing it Right
Stroke Family Support Program

Oshawa Edition

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TIMING IT RIGHT

STROKE FAMILY SUPPORT PROGRAM

OSHAWA EDITION

Table of Contents

Chapter 1……..……Introduction

Chapter 2……My Family Member Has Had A Stroke

Chapter 3……My Family Member's Condition Has Stabilized

Chapter 4……..Preparing To Go Home

Chapter 5……...The First Few Months at Home

Chapter 6……..……..Getting On With Life In The Community

Chapter 7……...……Notes And Additional Resources

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Chapter #1
TIMING IT RIGHT STROKE FAMILY SUPPORT PROGRAM

The prognosis for stroke survivors' recovery is better than ever before.

Much research has gone into the development of treatments and programs to help patients rehabilitate and reintegrate into society as completely as possible. Studies showing promising statistics, such as a 91% rate of return to work, suggest that the research is working. It has also been shown that the love and care which patients' family caregivers provide is very important in the stroke recovery process. Therefore, it is important for us to enable you, the caregiver, to provide the best support you can.

Much research has been done to study how caregivers, like you, can be better assisted and prepared for this important role in stroke recovery. This guide brings you the best of that research.

One important aspect of this research is that it is not useful for caregivers like you to receive all the informational, emotional, and practical support that you will need throughout this process, all at once. Instead, previous caregivers in your position have found it more helpful to receive information only at the times when they need it. In response to these changing caregiver needs we developed the Timing It Right (TIR) Framework, on which this program was based. The TIR framework is an outline based on research which describes caregivers' needs for assistance, training, emotional, and informational supports at different points of time after the stroke occurred right through to community living. It delivers the right kind of support to caregivers at the time when it is needed most.

Everything in this guide is based on what we have learned from stroke caregivers and health care professionals.

Past caregivers have told us that immediately after the stroke occurred, they were most concerned about:

- Needing to know what had just happened
- Needing to know what this meant for the health of their family member
- Needing to know how this would change their life

You may feel this way too; You are not alone!

We believe there is power in numbers and so we hope that by giving you support based on the feedback of many current and former caregivers, and by connecting you with people in the same situation, you will be helped to support your family member as best you can.

Chapter #1- Introduction

THIS GUIDE

Through our interaction with caregivers in the past, we learned that people in a caregiving position will require more than just information pertaining to stroke; you will need emotional support, and guidance to do the practical things you are required to do (for example, helping your family member with his or her rehabilitation exercises).

We have surveyed stroke caregivers and asked them what kinds of support needs (be it informational, emotional, or practical) are most helpful at the different stages in the recovery process. We have used these results to help design this binder to ensure you receive the kind of support you need, when it will be most useful to you.

How This Guide is Organized:

This guide includes seven chapters. The first chapter, which you are reading now, will introduce the rest of the guide and give a brief overview of what the recovery process entails.

The second, third, fourth, fifth, and sixth chapter of the guide are each devoted to a specific phase of recovery.

The final chapter will provide you with a list of resources you may find helpful.

At the end of each chapter, you will also find 3 blank copies of the Support Needs Management Form for you to use as you manage your support needs outside of this guide.

The following is an overview of each of the following chapters:

Chapter 2: My Family Member Has Had a Stroke

This section corresponds with the stroke event phase – right after the stroke happens. You may find that your greatest need is for educational and emotional support as you try to understand what has happened and who you can talk to about these difficult circumstances. This phase generally lasts for a few days, and can be quite emotionally difficult and stressful. This portion of the guide will outline some educational and emotional resources and who you can go to for help. You may find that you are anxious and concerned about your family member's health – this is normal and you are not alone.

This section will cover:

Informational Support

- Diagnostic Tests
- Types of Stroke
- Current Treatment Options
- Who to Talk to for Help

Chapter #1- Introduction

Emotional Support

- Feelings You May Experience at this Time
- Who to Talk to for Help

Practical Support

- Common Practical Needs for Assistance
- Who to Talk to for Help

Chapter 3: My Family Member's Condition Has Stabilized

Once a stroke survivor's medical condition has stabilized, caregivers generally move into a new, transitional phase. In this phase, the health care professionals in acute care start the recovery process. This phase is relatively short, and you will likely receive answers from your professional health care team regarding the extent of disability resulting from the stroke. Health care professionals will focus on specific markers for patient improvement such as mobility, communication, thinking, memory, and problem-solving. You may find that you will want to begin to learn more about the recovery process, and how you can help your family member who has just had a stroke.

This section will cover:

Informational Support

- What is a Stroke?
- What to Expect after a Stroke
- What is Aphasia?
- Types of Aphasia
- Rehabilitation Treatment Options
- Recovery Process Team Members
- Family Meetings
- Preparing for In-patient Rehabilitation
- Who to Talk to for Help

Emotional Support

- Feelings You May Experience at this Time
- Who to Talk to for Help

Practical Support

- Common Practical Needs for Assistance
- Who to Talk to for Help
- Other Supports

Chapter #1- Introduction

Training Support

- Swallowing and Eating after Stroke
- Communicating with Someone with Aphasia
- Who to Talk to for Help

Chapter 4: Preparing To Go Home

This section focuses on the time just before the stroke survivor returns home from the acute care hospital or rehabilitation facility. You may want to learn about how to assist the stroke survivor in maintaining his or her personal needs. You may also want to learn about how to prepare your home so the stroke survivor can live in a safe environment. Additionally, you may want information about home care services that are available to you.

This section will cover:

Informational Support

- Warning signs of Stroke
- Risk Factors for Stroke
- Secondary prevention
- Medications after Stroke
- Diet after Stroke
- Preparation for Outpatient Rehabilitation
- My Discharge Plan (From Acute Care)
- My Discharge Plan (From Rehabilitation)
- Preparing My Home for Discharge
- Safety Equipment & Assistive Devices
- Completing Successful Transfers
- Who to Talk to for Help

Emotional Support

- Feelings You May Experience at this Time
- Depression in the Stroke Survivor
- Peer Support Groups
- Who to Talk to for Help

Practical Support

- Common Practical Needs for Assistance
- Home Visits & Safety Assessments
- Who to Talk to for Help

Chapter #1- Introduction

Training Support

- Common Training Needs at this Time
- Your Family member's Memory
- Mobility & Exercises after stroke
- Completing Successful Transfers
- Who to talk to For Help

Chapter 5: The First Few Months At Home

After your family member returns home, you may become the primary caregiver, shifting the responsibility out of the hospital environment and away from health care professionals. You are now learning how to adapt to your new lifestyle at home with the stroke survivor, and you are "learning the ropes" while you practice the new skills you learned in the previous phase, though you may have home care and respite supports. You may experience challenges that you did not anticipate, and as such, this section of the guide will provide you with information and resources on how to get support once you are in the home environment.

This section will cover:

Informational Support

- Home Care
- Emergency Contacts
- Who to Talk to for Help

Emotional Support

- Feelings You May Experience at This Time
- Who to Talk to for Help

Practical Support

- Common Practical Needs for Assistance
- Respite Care
- Who to Talk to for Help

Training Support

- Common Training Needs at this Time
- Rehabilitation Exercises
- Pain & Symptom Management
- Who to Talk to for Help

Chapter 6: Getting On with Life in the Community

During this phase, you may find that outpatient rehabilitation programs have finished, and the stroke survivor has adjusted to living in the home. Primary care of the stroke survivor is now dependent upon you, family physicians, and the stroke survivor. You may feel more confident in your abilities, and are now looking for ways to have you and your family member participate in social activities, events, employment, and travel. You may find that you are taking things “one day at a time” and are looking for additional supports in the community to assist you.

This section will cover:

Informational Support

- Intimacy
- Returning to Work
- Who to Talk to for Help

Emotional Support

- Feelings You May Experience at This Time
- Who to Talk to for Help

Practical Support

- Common Practical Needs for Assistance
- Peer Support Groups & Online Resources
- Who to Talk to for Help

Training Support

- Common Training Needs at this Time
- Who to Talk to for Help

Chapter 7: Notes and Resources

The final chapter in our binder, Chapter 7 (Notes and Resources), will provide you with the opportunity to write down any questions or concerns you may have at any point throughout the recovery process. These may be questions, concerns, or ideas you may want to share with health care professionals, the stroke survivor, family, friends, or peers. Open communication will help us to give you the supports you need, when you need them. This section provides you with the opportunity to keep a record of your thoughts throughout the process.

Chapter 7 will also provide you with a calendar and an appointment book. This will provide you with the opportunity to keep track of your important appointments with healthcare professionals, support groups, and other events, so you can spend more quality time focusing on the stroke survivor and yourself

GETTING SUPPORT USING THIS GUIDE

This guide may not answer all of the questions you have, and certain questions may be more specific to your own personal situation. Each section corresponds to a particular phase of your family members' recovery, and provides a list of who to talk to about concerns that pertain to certain themes. By following that list, it is possible to approach the appropriate individual to get the answers you need. The following section may help you self-manage your needs, and gain information not contained in this guide.

Self-Managing Your Support Needs

When you are providing care to a family member who has had a stroke, you may need different types of support including information, someone to talk to about how you are feeling (your emotions), training in caregiving activities, assistance with arranging services, and other types of support.

Not all of your needs will be met by the *Timing it Right Stroke Family Support Program* so we want to provide you with some strategies to help you have as many of your support needs met as possible. We will provide you with some guidance on how to identify your unique support needs, and strategies to use to have these needs met. We will also provide you with some strategies for communicating with health care professionals, the stroke survivor, other family members, friends, neighbours, and other sources of support.

A Seven-Step Approach to Managing Your Support Needs

The following is a series of steps that you can use to identify your needs and the resources to meet these needs. Whenever you need some support, use all of the steps. You can also use the worksheet (3 copies at the end of each chapter of this guide) to work through the seven steps.

Step 1: The first and most important step is to determine what supports you need (informational, emotional, training, or tangible support). You should try to be as specific as you can be. For example, you may need more information about aphasia and communication programs that are available in the community.

Step 2: Once you have specified your support needs, the next step is to list the resources available to help you to meet these needs. You can ask family, friends, and health care professionals to identify additional resources that may be available to you. For example, you may want to ask the speech language pathologist in the rehabilitation centre about any community-based aphasia programs.

Step 3: Once you have identified a few sources of support, decide which resource to try first. Follow through with this resource to see if they can provide the support that you need. For example, contact the community-based aphasia program to determine the types of supports that they provide and whether or not these programs will meet your needs.

Step 4: Next you will need to determine if this resource has met your need. If you feel that your needs are not quite being met you may want to go back to your resource list and try another resource. For example, your own research has helped you identify other community-based aphasia programs that you may want to contact about the programs that they offer.

Steps 5, 6, & 7: The next step will be to try one of these additional resources and again examine whether or not it has fully met your needs. If not, you may have to consider further resources and may want to ask more friends, family, health care professionals, and other individuals to help identify additional resources. You may also have to accept that this need may not be able to be met at this time.

Summary of Support Management Steps

1. Identify the support need (this is often the most difficult and most important step).
2. List resources available to meet this support need.
3. Select one resource to try.
4. Assess the results.
5. Substitute another resource if the first didn't work.
6. Learn about other resources (ask friends, family, professionals for ideas if your solutions didn't work).
7. Accept that these support needs may not be met now.

Support Needs Management Form (Aphasia example)

1. What supports do you need right now?
    - *I need help communicating with my family member*
    - *Inpatient rehabilitation is over and I don't know where to get more support*
    -
    -
    -
2. What resources can you draw upon to get this support?
    - *Outpatient rehabilitation*
    - *Community Aphasia program*
    - *Other??*
    -
    -
3. What resources will I try first?
    - *Community Aphasia program*
    -
    -
    -
    -
4. How did this work out?
    - *OK, we are receiving training in communication strategies*
    - *I could use more support that is directed at my coping and emotional needs*
    -
    -
    -
5. If it didn't work out, what other resources should I try?
    - *I can ask the Community Aphasia program for additional support for my own needs*
    - *Stroke Caregiver Support Groups*
    -
    -
    -
6. Accept that this support need may not be met right now.

GETTING SUPPORT FROM MEDICAL STAFF AND OTHER PROFESSIONALS

Getting Support in an Emergency

- Do not hesitate to call **911** in an emergency.

Improving the Ability to Get Support

- Be sure that questions are phrased clearly
- Learn who on your family members' health care team can answer these questions
- Ask the person directly or have someone else ask for you
- Assign one family member (this may be you) as the spokesperson and primary contact for the healthcare team

It Is Important to Remember…

It is reasonable to assume that medical staff want to help you and would like to give you the assistance you need. Often, certain staff members cannot answer the questions you have because each medical care organization has its own rules about who knows what, and who is allowed to give support to patients and caregivers. When faced with uncertainty about who to talk to, please consult this guide as to how each individual on your health care team is able to assist you. If uncertainty still persists, it is perfectly reasonable to ask a member of the health care team who you can talk to about a particular concern. You are not alone, and resources exist to aid you.

Strategies That May Help When Communicating with Health Care Professionals

- Write down all of the issues that you want to discuss with the doctors or other health care professionals, or you can have someone else write it down for you.
- Place the most important items on the list first.
- Give the health care professionals a copy of that list. It is not necessary to wait for them to ask you if you have any questions or concerns.
- Write down the answers to your questions for future reference.
- If you are afraid that you may not understand or hear everything, you can bring someone with you to the doctor. It may be helpful to bring a relative or close friend.
- If there are concerns about a particular treatment, let the health care team know.
- If problems are persisting, don't wait for the next appointment. Call the doctor right away.
- Ask for an appointment time when the doctor is less likely to be rushed.
- If, for some reason, you find that you will not or cannot follow advice, let the health care team know. Often they can suggest another option. If you do not discuss your concerns, appropriate solutions may not be offered.
- Set a goal for the appointment.

- Keep complete and thorough records of your family member's health history, the onset of conditions and/or disability, surgeries, a list of doctors and their specialties, and a current list of medications.

GETTING COMPANIONSHIP, SUPPORT AND ASSISTANCE FROM FAMILY AND FRIENDS

What to Do…

- List people who can provide companionship and support.
- Do not worry about how far away these people live, how busy they are, how long since you've talked to them, or even how well you know them.
- Telephone calls are often easier to arrange than inviting someone to the home.
- Sometimes you can call on volunteers in the community or church organizations to provide companionship and support.
- Plan how to make visiting pleasant for visitors.
- Don't wait for people to visit – seek them out.
- Let people know what you need, and how they may help.

Tips on Communicating With Family

How a family functions is important to health and coping. Good communication is one of the best ways to have a family that functions well.

Keep the following in mind:

- What is important to you and your family?
- What are your strengths as a family?
- How do you communicate with each other?
- Who in the family is most supportive?

Family functioning is determined by three factors:

- How cohesive or "together" the members of the family feel, and how they support each other.
- How members can express what they feel and think.
- How problems are talked about and solved together.

Good family communication is an important part of good coping.

SUCCEEDING AT CAREGIVING

While using this guide, it will become evident that caregiving involves solving problems. We have been solving problems throughout our lives. The only difference now is that many of the challenges that come with helping stroke survivors may be new. This guide will help you approach these new situations; it will provide information and guidance at times when you need it the most.

The successful caregiver is a team player, working with the stroke survivor, family and friends, and health care professionals to support stroke recovery. The stroke survivor and caregiver are central to the team, requiring participation from both individuals.

Successful caregivers emphasize the positive parts of caregiving. Caregiving can provide a sense of satisfaction and confidence. You may also develop inner strengths that you did not realize you had. It is also possible to find new, rewarding friendships with other caregivers who are going through similar experiences.

It is important to remember that the more you take care of your own needs for rest, food, enjoyment, and relaxation, the better you will be able to help the stroke survivor and yourself. This guide will help you find the resources you need to support yourself and your family member as you embark on your caregiving journey. We have outlined the people to contact if you need assistance or for various questions or concerns. We have also provided the information that previous caregivers found helpful in their journey. It is important to remember that as a family caregiver, you are not alone and resources to help you throughout any phase of recovery do exist. Sometimes you need to become active about finding the answers to certain questions yourself, but this guide will serve as a starting point to acquiring the most appropriate supports for each of your needs.

Chapter #2
MY FAMILY MEMBER HAS HAD A STROKE

As a family member or friend, one of the hardest things to do is watch someone you love experience a serious health event like a stroke. When your family member has a stroke, it may be difficult to cope with the series of events that transpire immediately after the event.

This guide will assist you by providing the answers to some of the questions you may have during this difficult time. Also, this guide will help you determine who can assist you most during this time for various needs.

This Chapter at a Glance:

Informational Support

- Diagnosis: Tests
- Types of Stroke
- Current Treatment Options
- Who to Talk to for Help

Emotional Support

- Feelings You May Experience at this Time
- Who to Talk to for Help

Practical Support

- Common Practical Needs for Assistance
- Who to Talk to for Help

DIAGNOSTIC TESTS

Tests

When someone has shown symptoms of a stroke or a TIA (transient ischemic attack or mini stroke), a doctor will gather information and make a diagnosis. He or she will review the events that have occurred and will:

- Get a medical history
- Do a physical and neurological examination
- Do certain laboratory (blood) tests
- Get a CT scan of the patient's brain
- Study the results of other diagnostic tests that might be needed

The purpose of evaluation is to:

- Check for the cause of the symptoms, such as if the event was caused by a stroke or TIA (also known as a "mini stroke"), low blood sugar (if you have diabetes), or Bell's palsy (a nerve disease).
- If a stroke diagnosis is confirmed, check for the cause of the stroke (was it because of high blood pressure, heart disease, or blood vessel disease?). This information is important to prevent another future stroke.
- Determine whether you need surgery to re-open a blocked artery (carotid endarterectomy).
- Determine whether you need medicines to prevent blood clots.

What are the types of diagnostic tests?

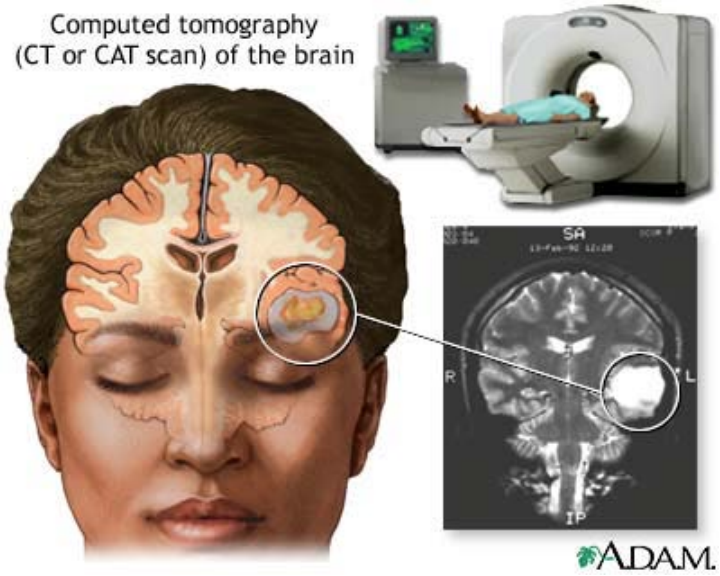
Diagnostic tests examine how the brain looks, works and gets its blood supply. They can outline the injured brain area. They are also used to help identify the cause of the stroke. Most of them are safe and painless.

Diagnostic tests fall into three categories:

- Imaging tests give a picture of the brain similar to X-rays.
- Electrical tests record the electrical impulses of the brain and/or the heart.
- Blood flow tests show any problem that may cause changes in blood flow to the brain.

What are some common imaging tests?

- CT scan (Computed Tomography) or CAT scan is a key imaging test. It uses radiation to create a picture of the brain. It is usually one of the first tests given to patients with a suspected stroke. CT test results give valuable information about the type of stroke and the location and extent of brain injury. CT scans are used to check for bleeding in the brain and to check for evidence of a stroke or other disease, such as a tumour.



- MRI (Magnetic Resonance Imaging) uses a large magnetic field to produce an image of the brain. Like the CT scan, it shows the location and extent of brain injury. The image produced by MRI is sharper and more detailed than a CT scan so it is often used to diagnose small, deep injuries.

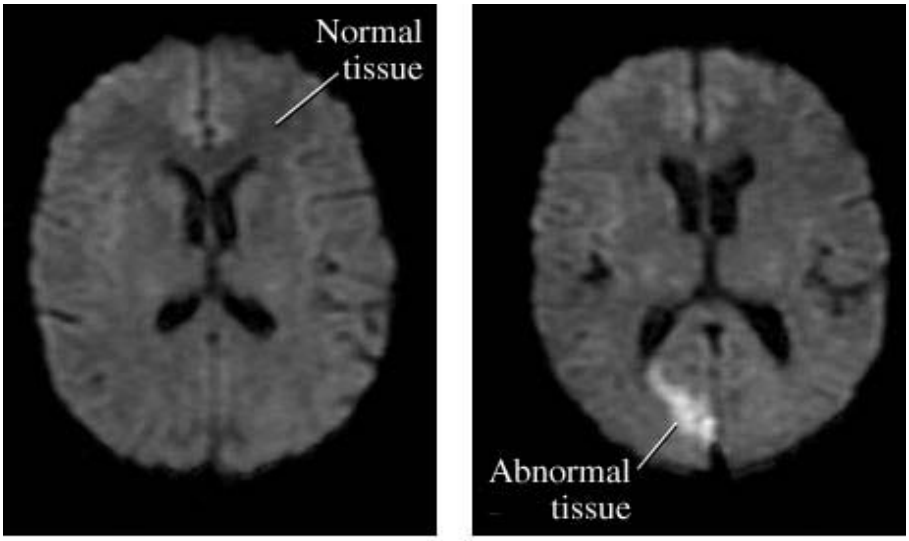


Figure 1 Figure 2

What are some common electrical tests?

- Electrocardiogram (ECG) is a test that is used to check the pattern of electrical activities in the heart. Irregular heartbeat (e.g. atrial fibrillation) can lead to the blood clot formation that can move to the brain and cause a stroke.
- Echocardiogram is a test that uses painless ultrasound waves to monitor the heart and the circulating blood. This test is often used if patients are suspected of having a blood clot in the heart. Blood clots in the heart can travel to the brain and cause a stroke.

- Electroencephalogram (EEG) is also a painless test that measures the brain waves. This test is not used often for stroke diagnosis but it may still be used if doctors think that a patient may have had a seizure.

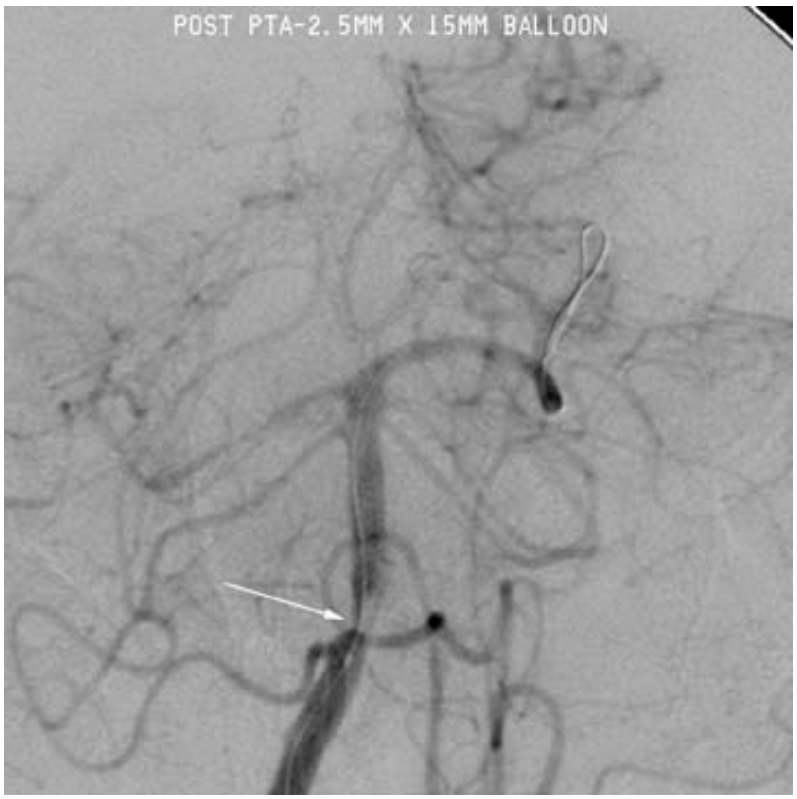
What are some common blood flow tests?

Several blood flow tests exist; most use ultrasound technology. A probe is placed over the suspect artery (usually arteries in the neck or at the base of the skull) and the amount of blood flow is determined.

Examples of blood flow tests are: B-mode imaging, Doppler testing and duplex scanning. These tests give detailed information about the condition of arteries.

Another blood flow test is a medical procedure called angiography (arteriography or arteriogram). In this, special dyes are injected into the blood vessels and an X-ray is taken.

Angiography gives a picture of the blood flow through the vessels. This allows the size and location of blockages to be evaluated. This test can be especially valuable in diagnosing aneurysms and malformed blood vessels and providing information before surgery.



Angiography- In this picture doctors have located the source of a blockage in the artery

TYPES OF STROKE

There are two main types of stroke: strokes caused by blood clots and bleeding stroke.

1. Strokes caused by blood clots (Ischemic Stroke)

As we get older, a waxy plaque can build up along the inside of the arteries that feed the brain. Plaque is like the gunk that builds up in the pipes underneath your sink: the thicker it grows, the less room there is for the blood to flow. Smoking, diabetes, high blood pressure and high cholesterol can cause this buildup. Sometimes, a blood clot can plug an artery narrowed with plaque. This can cut off the flow of blood and cause an *Ischemic Stroke*. Generally speaking, about 80% of strokes are this type.

A blood clot that causes a stroke can form in the artery, where there is a lot of plaque. Or the blood clot may form someplace else in the body. Sometimes a blood clot will form in the heart and travel to the brain.

If your family member has had a stroke caused by a blood clot, here are some terms your doctor may use:

Transient Ischemic Attack or TIA — Some people call a transient ischemic attack (TIA) a mini-stroke, because the symptoms are like those of a stroke but do not last long. A TIA happens when blood flow to part of the brain is blocked or reduced, often by a blood clot. After a short time, blood flows again and the symptoms go away. With a stroke, the blood flow stays blocked, and the brain has permanent damage.

Atherosclerosis — Sometimes called “hardening of the arteries,” occurs when fat (cholesterol) and calcium build up in the inner lining of the arteries, forming a substance called plaque. Over time, the fat and calcium buildup narrows the artery and blocks blood flow through it

Atherothrombosis — when a blood clot forms over a buildup of plaque inside an artery. The blood clot is called a thrombus and the thick, rough, fatty plaque is referred to as atheroma. If the plaque is also present in the arteries in your heart, you may be at risk of having a heart attack.

2. Strokes caused by bleeding (Hemorrhagic Stroke)

Strokes can also be caused by breaks in the blood vessels in the brain.
When the blood vessel bursts, blood rushes into the brain and damages it.
This kind of stroke is called a *hemorrhagic stroke*. High blood pressure can cause this type of bleeding stroke.

If your family member has had a stroke caused by bleeding, here are some terms your doctor may use:

Aneurysm — When the wall of a blood vessel is weak and balloons out.
Aneurysms can be caused by disease or injury to a blood vessel, or you can be born with them. If the aneurysm bursts, it can cause a bleeding stroke.

Intracerebral hemorrhage — A stroke caused when an artery within the brain breaks (ruptures) and blood enters the brain.

Arteriovenous malformations or AVM — In some people, some of the tiny blood vessels within the brain, brainstem or spinal cord are not formed properly (they are malformed). If these tiny blood vessels break or rupture, it can cause a bleeding stroke.

Subarachnoid hemorrhage — a stroke caused by bleeding on the surface of the brain, in the area between the brain and the skull.

3. Other causes of stroke

Most strokes are caused by blood clots or bleeding. In a few people, the flow of blood through an artery can be interrupted by a growth (such as a tumor), infection, or swelling of the brain (edema).

Each stroke is different. How well your family member will recover from a stroke depends upon a number of factors. These factors include how much of your family member's brain was damaged, what parts of his or her brain were damaged, and your family member's health before the stroke.

The work you do with the health care team, the stroke rehabilitation team, as well as the support of family and family members, are crucial to the stroke survivor's recovery.

STROKE TREATMENT PLANS AND OPTIONS

How is Stroke Treated?

Strokes can be treated and often prevented. At the moment, no treatment can cure a stroke, and most people will have some form of residual damage, which will vary from person to person. Residual damage can range from a slight limp, communication difficulties, memory or other cognitive problems, or paralysis on one side of the body. Prevention will be the key to avoid further strokes.

Treatment for Ischemic Stroke

- **t-PA (tissue plasminogen activator)**

  Thrombolytic drugs such as t-PA are often called “clot busters”. t-PA is short for tissue plasminogen activator. They work by breaking up a clot that is blocking a blood vessel in the brain. They are considered a first-line treatment for stroke because of their high rate of effectiveness. However, there is a risk the drug may cause an intracranial hemorrhage (bleeding in the brain). Due to this increased risk for bleeding, doctors have several specific criteria that a patient must meet before thrombolytic therapy can be administered. It can only be given to patients who have a stroke caused by a blood clot (ischemic stroke) and must be given within the first few hours of the onset of symptoms.

- **Aspirin**

  Aspirin is the other important medication used in the treatment of an acute ischemic stroke. Aspirin should not be given within 24 hours of the t-PA. However, it should be given within 48 hours of symptoms. Early aspirin use has been shown to decrease long-term disability and death in stroke patients.

- **Surgery**

  Patients with moderate to large blood clots in their brain who are still awake or conscious may be the best candidates for surgery. Surgical treatment involves removing the large clot from the area. In some cases, surgery may be required to remove plaque from inside the artery in the neck that supplies the brain with blood.

Treatment for Hemorrhagic Stroke

A cerebral haemorrhage (or bleeding in the brain) is associated with higher death rates than ischemic stroke. It can be treated with either surgery or medical intervention and there is currently no medical consensus as to which treatment is best.

- **Surgery**

  In some cases, surgery may be required to repair damage after a stroke or to prevent a stroke from re-occurring. Surgery may be performed to remove blood that has pooled in the brain or to repair broken blood vessels.

- **Medical treatment**

  This involves monitoring blood pressure while providing adequate blood flow to the brain. If increased pressure is suspected, treatment with intravenous mannitol (which reduces pressure on the brain) with or without furosemide (a diuretic that reduces pressure and removes excess water) may be helpful.

Treatment for Subarachnoid Hemorrhage

A subarachnoid hemorrhage can be treated with either surgery or medical treatment. Surgical treatment involves not only finding the site of the bleeding, but also stopping the bleeding in the brain. Currently, surgery for patients in good neurological condition (meaning there are no other complications affecting the nervous system) is the treatment of choice, if the site is surgically easy to get to and there are no other medical complications present.

Medical treatment involves getting blood pressure to normal levels, an initial period of bed rest, pain medication (acetaminophen) to relieve headache and nimodipine (Nimotop), a drug that reduces pressure and decreases brain cell loss). Nimodipine, more commonly used at large hospitals, has been shown to reduce death and hospitalizations.

New Treatment Options

Some people may benefit from treatments that are performed through a thin, flexible tube, called a catheter, into the blood vessels of the brain. Many of these procedures are new and experimental and not all hospitals may be able to do them. Catheter-based procedures are being developed to remove plaque buildup from arteries and to treat aneurysms (weak spots in the wall of a blood vessel that can bulge outward and rupture).

WHO TO TALK TO FOR MORE INFORMATION

For additional informational resources, you may find it helpful to talk to one of the following individuals for various concerns. For instance:

Talk to your Doctor or Neurologist about…

- Your family member's chance of survival
- Your family member's prognosis (i.e. how he or she will do in the long term)
- Information regarding diagnostic tests or scans (e.g. MRI, X-Rays)
- Treatment information (if blood transfusions are required; if ventilators are necessary)
- Referrals to other specialists if required (e.g. counselors, social workers, rehabilitation professionals, case managers)

Previous Caregivers Found…

- Information needs during this time were most often met by health care professionals

If You Require Additional Assistance…

- If you have needs that are not listed in this chapter, please write down any questions you may have in Section 7: Notes and Additional Resources, and approach the appropriate individual on your health care team to ensure that your questions or concerns are addressed.

EMOTIONAL SUPPORT

Feelings You May Be Experiencing At This Time:

There are many different emotions that family members and caregivers can experience. Previous caregivers in your position told us they:

- Had a need for moral support, and knowing others were there for them
- Had a need for encouragement and advice
- Had trouble communicating what was going on with children and others

Please know that these feelings are normal. This is a stressful time and you may feel as if any combination of these emotions has overwhelmed you. Remember you are not alone.

WHO TO TALK TO FOR EMOTIONAL HELP

For additional emotional support, you may find it helpful to talk to one of the following individuals. For instance:

Talk to your Social Worker or a Counselor about:

- How to handle the situation (e.g. how to cope with stress, anxiety, fear, sadness)
- Your emotions – how you are feeling and how the stroke survivor is feeling
- Managing your appointments and getting in contact with others who can help

Talk to your Family or Friends about:

- Needing help at home (e.g. cooking, finances, child/parental care)
- Needing the company of others
- How to handle the situation
- Your emotions – how you are feeling and how they are feeling
- Spending time with you or the stroke survivor
- Making sure your own needs are being met during this difficult time

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in Section 7: Notes and Additional Resources and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

WHO TO TALK TO FOR PRACTICAL HELP

Common Practical Needs for Assistance

Given the events that have occurred, your focus will likely be on your family member and not on the other things that you usually focus on day-to-day. During this phase, it is important to ensure that *your* needs are addressed.

During this phase, previous caregivers appreciated when family, friends, or health care professionals assisted them with more practical matters.

Here are some things you may wish to ask for:

Talk to a Social Worker about…

- Getting assistance with contacting friends and family and notifying them about the situation
- Anything that may assist you or your family member – such as being provided with a blanket, food, or even a place to stay if you live a considerable distance away from the hospital
- Getting assistance with counseling services

Talk to a Doctor or Nurse about…

- Assistance finding and using hospital resources

Talk to your Family or Friends about…

- Having them visit you or your family member at the hospital
- Providing food at home for you or any other family members at home
- Assisting with child or parental care
- Helping with duties around the house

If You Require Additional assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in Section 7: Notes and Additional Resources and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

Support Needs Management Form

1. What supports do you need right now?
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    -
2. What resources can you draw upon to get this support?
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3. What resources will I try first?
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4. How did this work out?
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5. If it didn’t work out, what other resources should I try?
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    -
6. Accept that this support need may not be met right now.

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    -
6. Accept that this support need may not be met right now

Chapter #2- My Family Member has had a Stroke

Chapter #3
MY FAMILY MEMBER'S CONDITION HAS STABILIZED

During this phase, your family member has survived the stroke, and his or her condition has more or less stabilized. You are moving into a new, transitory phase where health care professionals in acute care will begin to develop and implement a treatment plan. This may include developing goals to assist your family member's recovery. Health care professionals will focus on specific markers for your family member's improvement, including mobility, communication, thinking, memory, and problem-solving. You may find that you will want to begin to learn more about the recovery process, and how you can help your family member who has had a stroke. Also, you may wish to start collecting information to plan for additional help including transportation needs, meal assistance, and financial assistance. This section will be your comprehensive guide to assist you through this phase.

This Chapter at a Glance:

Informational Support

- What is a Stroke?
- What to Expect after a Stroke
- What is Aphasia?
- Types of Aphasia
- Rehabilitation Treatment Options
- Recovery Process Team Members
- Family Meetings
- Preparing for In-patient Rehabilitation
- Who to Talk to for Help

Emotional Support

- Feelings You May Experience at this Time
- Who to Talk to for Help

Practical Support

- Common Practical Needs for Assistance
- Who to Talk to for Help
- Other Supports

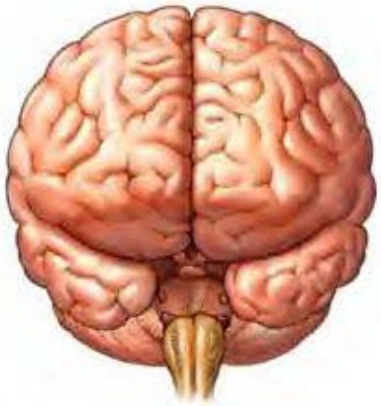
Training Support

- Swallowing and Eating after Stroke
- Communicating with Someone with Aphasia
- Who to Talk to for Help

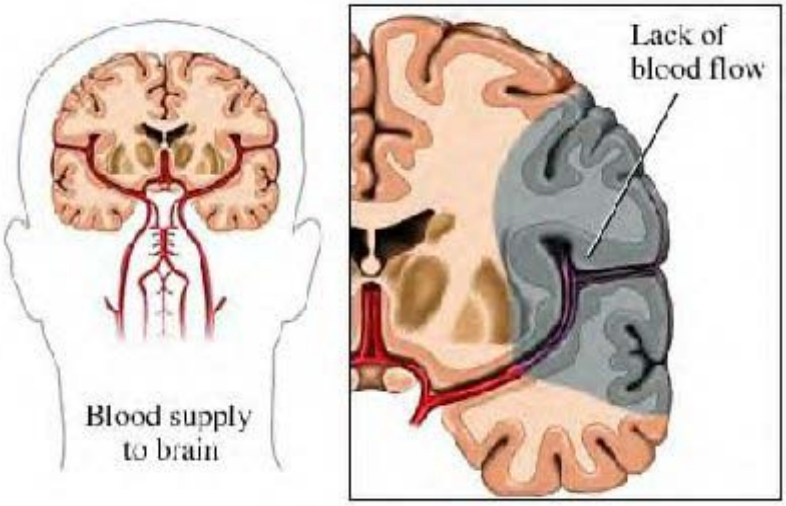
WHAT IS A STROKE?

A stroke happens when something goes wrong with the flow of blood to the brain. Blood vessels called arteries carry blood that is rich in oxygen and nutrients through the body. When an artery to the brain becomes blocked or bursts, the blood supply to a part of the brain is cut off. If the blood flow is cut off for more than a few hours, part of the brain may be permanently damaged.

Different parts of the brain control different body functions. For example, some parts of your brain control your ability to move your arms or legs. Other parts control your ability to talk or to understand speech. When a stroke damages your brain, the injured part of the brain is unable is send messages to the part of the body it used to control.



Normal brain (front view)



WHAT TO EXPECT AFTER A STROKE

Recovery

After a stroke, your family member may experience physical difficulties, particularly in the arm, leg and face on one side of the body, cognitive problems, and speech and language deficits. He or she can expect some degree of "spontaneous recovery" in the days, weeks, and months immediately following the stroke. During this time, physical, cognitive, and communication deficits may decrease on their own as the brain heals. Interventions such as physical therapy, occupational therapy, and speech-language pathology services can enhance this spontaneous recovery or teach the survivor new ways to do things.

The stroke survivor can expect some degree of spontaneous recovery in the first 6 months or so after the stroke, although recovery may continue for over a year. The degree of recovery is highly dependent on the severity and location of the stroke and is very difficult to predict. Many times, improvements in physical abilities occur more rapidly than in communicative ability and cannot be used as a predictor for future speech and language improvements.

Prognosis

The outcome after a stroke is variable, and will depend greatly on the type of stroke that has occurred, as well as the patient’s characteristics. Health care professionals will do the best they can to maximize the stroke survivors recovery. The good news is mortality rates are decreasing, and patients are living longer after stroke than ever before.

Health care professionals may say that there is **“no crystal ball”** when they are discussing your family members’ recovery. Every stroke is different and recovery varies across individuals. Health care professionals can only give you their best estimate of how your family member will recover from their stroke but this may or may not reflect your family members’ actual recovery.

Actively participating in events at the hospital, such as visits with the doctor, nurse, or rehabilitation team will help you, the caregiver, understand your family member’s specific circumstance and prognosis. The better you understand, the more prepared you will be to help your family member, and your family through this difficult time. Do not be afraid to ask questions, or ask someone close to you for help right now.

WHAT IS APHASIA?

Aphasia is an disorder caused by an injury to the brain that affects a person's ability to communicate. It is most often the result of stroke or head injury.

An individual with aphasia may experience difficulty expressing themselves when speaking, difficulty understanding the speech of others, and difficulty reading and writing. Sadly, aphasia can mask a person's intelligence and ability to communicate feelings, thoughts and emotions.

Did You Know...

- Aphasia occurs most commonly following a stroke.
- Aphasia occurs in one third of all stroke survivors.
- Aphasia can be so severe as to make communication with the person almost impossible, or it can be very mild. On occasion, it affects only a single aspect of language use, such as the ability to retrieve names of objects or the ability to read. More commonly, however, multiple aspects of communication are affected.
- In Toronto, it is estimated that there are over 6,600 people living with aphasia. The number rises to over 30,000 in Ontario, 100,000 in Canada and over 1,000,000 in the U.S.
- There are nearly twice as many people with aphasia than there are individuals with Parkinson's Disease and yet the general public knows little or nothing about aphasia.
- The number of people with aphasia is expected to increase significantly as the population ages.
- In a national survey in the U.S., about 70% of those surveyed with communication disorders felt that people avoided contact with them because of communication challenges.

Many people with aphasia and their families have written about living with aphasia and note that maintaining a positive attitude and learning from others' experiences are keys to success in life after stroke. Reading personal accounts, using the Internet for information, and joining support groups are some ways in which you can learn more about living with aphasia.

Aphasia may be a chronic problem. Learning to live with it gracefully is possible and can lead to a fulfilling and satisfying life after stroke.

TYPES OF APHASIA

There are two broad types of aphasia:

Expressive — your family member knows what he or she wants to say, but the words do not come out right.

Receptive — your family member may not understand what people are saying to him or her.

Some stroke survivors may have both forms. Aphasia can also make it difficult to read, write or do math. Aphasia can be very frustrating — both for your family member, as well as for you and your family. The severity of (how serious or debilitating) the aphasia will vary from person to person. In some people, it may be temporary and improves quickly after a stroke. Other stroke survivors may be left with permanent language problems. Speech therapy can help your family member recover his or her use of language, or develop new ways of communicating.

SPECIFIC TYPES OF APHASIA

Wernicke's aphasia: If your family member has this type of aphasia, he or she may speak without hesitation but he or she may use the wrong words and be difficult to understand. Your family member may also have difficulty understanding what is being said to them, and with reading or writing.

Broca's aphasia: In severe cases, your family member may only be able to get out bursts of a few words. His or her vocabulary may be limited and when your family member speaks, he or she may be difficult to understand. But your family member may understand what people are saying to him or her, and may be able to read.

Anomic or nominal aphasia: Your family member may understand what other people are saying and may be able to read, but he or she has trouble naming objects or people, or coming up with nouns. This can make it difficult for people to understand what your family member means.

Global aphasia: There may be total, or near total, loss of the ability to use language. Your family member may not be able to read or write, and it may be hard to understand other people or to express him- or herself. This type of aphasia is often seen immediately after a stroke has occurred. If the damage to the brain is not severe, it may get better over time.

OTHER LANGUAGE-RELATED PROBLEMS

Apraxia

Apraxia (or dyspraxia) is a problem with muscle control, and planning movements. It can affect all or some of the movements your family member needs to make when he or she speaks. If your family member has apraxia, it can limit his or her ability to make hand

gestures, such as waving goodbye, beckoning, or saluting, or pantomiming or pretending movements, such as blowing a kiss or pretending to eat.

Dysarthria
Dysarthria is a speech problem due to weakness, slowness or poor coordination of the muscles used for speaking. If your family member has dysarthria, his or her speech is probably slurred and may be difficult to understand.

Dysphagia
Dysphagia (or aphagia) is difficulty swallowing. It may be caused by weakness or a lack of sensation in the mouth. Dysphagia involves many of the same muscles involved in speech. It is usually diagnosed and treated by your speech-language pathologist and dietician. Dysphagia can make it difficult to eat.

THE RECOVERY PROCESS:
REHABILITATION TREATMENT OPTIONS

The goal of stroke rehabilitation is to restore as much independence as possible by improving physical, mental, and emotional functions. This must be done in a way that preserves the dignity of the stroke survivor, and allows the stroke survivor to re-learn basic skills that the stroke may have affected, such as eating, dressing, and walking.

Rehabilitation should start in the hospital, as soon as possible after the stroke. Rehabilitation may begin as soon as the patient is medically stable, and should be continued after release from the hospital, if needed.

Stroke rehabilitation options may include:

- Rehabilitation in the same hospital
- Rehabilitation facility – in-patient care at a rehab facility
- Out-patient care at a rehabilitation facility (or Day Hospital)
- Home therapy
- Community-based programs

Available options will depend on several factors including available beds, the stroke survivors' stamina or activity tolerance for therapy, and your geographical area.

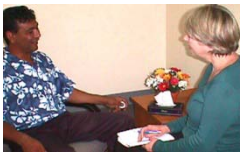
THE RECOVERY PROCESS: TEAM MEMBERS

Rehabilitation Health Care Team

Throughout the recovery process, you and your family member will work with a team of health care professionals. It is important that you get to know your health care team and feel comfortable discussing with them any issues that arise. This section will teach you what each different health care professional does, so you will know who to go to with specific questions or concerns.

A doctor is a licensed medical practitioner. Your doctor may be a neurologist (a doctor who specializes in the brain or nervous system), neurosurgeon, internal medicine specialist, rehabilitation specialist (physiatrist), geriatrician, or family physician. Doctors provide supervision and care for medical problems related to the stroke.

Nurses work closely with your family member, family, and the health care team during the initial stages following a stroke. Until the stroke survivor can do more for him or herself, nurses will help with daily care such as giving medications, bathing, dressing, and toileting.



Psychologists and social workers also aid caregivers and stroke survivors with emotional and adjustment issues by providing counseling and support services. Social workers may help families and caregivers determine the best possible options to meet rehabilitation and recovery needs.

Occupational therapists help stroke survivors re-learn the skills needed for everyday living including eating, toileting, dressing, and taking care of themselves. They also address changes in your family member's cognitive and perceptual status (ie. thinking, memory, and visual skills).

Physiotherapists help restore physical function including movement, muscle strength, coordination, and balance on the side of the body affected by the stroke. They will also help the stroke survivor re-learn mobility skills such as getting out of bed and walking.

Speech-language pathologists (SLPs) are trained to work with stroke survivors who may have developed problems communicating, or swallowing as a result of a stroke. Speech language and swallowing therapy will involve techniques to reduce and compensate for these impairments.

Recreational therapists help your family member plan new hobbies and interests, or learn new or different ways to resume old ones.

Pharmacists fill your family member's prescriptions and can answer questions you might have about medications.

Dieticians help you and the stroke survivor plan healthy meals to help with weight control, cholesterol levels, dietary needs, or any problems the stroke survivor might have with eating. The dietician also works closely with the speech-language pathologist for dysphagia screening and treatment.

Occupational Therapy Assistants/ Physical Therapy Assistants may help the stroke survivor with their therapy sessions. These trained individuals can help restore physical functioning and cognitive skills the same way an Occupational Therapist or Physiotherapist would.

The stroke survivor is an integral part of the recovery team. Your family member may face many challenges throughout the recovery process. A crucial component of the recovery process is the dynamic between the stroke survivor and you, the caregiver. Communication between you and the stroke survivor is important; as this will help you both achieve your goals. It will also help you both realize each of your needs, and how to overcome any challenges and obstacles together.

Your family and friends are an important part of the recovery team, as each individual can provide you with additional supports that you may need. You may find that your family can offer you emotional support, comfort, understanding, and reassurance during the often challenging recovery process. Family members might also assist you by helping with caregiving activities, or by providing support around the house with chores and cooking meals. It is important that you feel comfortable enough to ask your family and friends for help when you need it. This program will help you learn how to ask for assistance when you need it, and who you can turn to for different supports.

Peers who have gone through similar situations as yours are an important part of the recovery team as they can teach you strategies that helped them to face different challenges. Peers can also provide you with emotional support and community resources that will help you realize that you are not alone, and that help *is* available to you. Information on support groups and where to find them will be discussed in our ***Resources*** section (Chapter #7).

FAMILY MEETINGS

During a **family meeting** your whole family can meet with the health care team and receive information on the diagnosis, prognosis, and future directions to take in your family member's care.

Previous caregivers have found family meetings to be extremely helpful.

What are family meetings?

A family meeting is when all the health care providers who look after your family member (including the doctor, nurse, physiotherapist, occupational therapist, recreational therapist, speech therapist, social worker, and even dietician) meet to let you know how your family member is doing. They will tell you their role in your family member's care and the goals each of them have set for his/her recovery.

Family meetings can take place at three different points in your family member's recovery process: 1) during acute care, following the stroke, 2) during in-patient rehabilitation, further into treatment and recovery, and 3) once during out-patient rehabilitation, to discuss progress made towards your family member's goals. In many cases, there is only one family meeting that takes place closer to discharge.

Many of your questions can be answered at this time.

The health care team uses this opportunity to bring you and your family up to speed on everything that is going on with your family member post stroke at that time. Therefore, this is a valuable opportunity for the family to learn about your family member's situation.

How can you arrange a family meeting?

Unfortunately, family meetings are not standard practice (particularly during acute care), and thus, not all patients and families will have the opportunity to take part in a family meeting. As a result, the caregiver may have to request a family meeting.

If you would like to request a family meeting, the best person to speak to is your family member's social worker. A social worker can organize such a meeting. The social worker is also responsible for getting the entire health care team together for the meeting.

What happens at a family meeting?

In acute care, family meetings can be described as an information-sharing event. The medical doctors typically begin the family meeting with an overall medical review of the patient. Often times, in family meetings taking place in acute care, the medical doctors will even show X-rays or CT scans, taken of the patient, to the family. Afterwards, family members and the patient can ask the doctors any questions they may have.

Once the medical doctors have given an overview of your family member's stay in the hospital, the rehabilitation team will discuss what aspects of your family member's care they are looking after. They might discuss the following:

- Goals that they are working on with your family member to help them recover
- Specifics as to how the stroke has affected your family member's ability to function
- Treatments they are providing to help your family member achieve these goals
- Any special or concerning issues they are dealing with (for example, if your family member's mood is interfering with his/her therapy)
- Plans for the next step in your family member's recovery process (for example, if your family member needs to go to a rehabilitation facility for further therapy, or if your family member has to go to a long-term care facility because he/she may not meet the criteria for entry into a rehabilitation program).

Any questions you may have for the rehabilitation team can be asked at this time. You may find it helpful to write down the answers to these questions for future reference.

Family meetings taking place during in-patient or out-patient rehabilitation will be structured and function the same way as family meetings in acute care. You may find however, that family meetings in a rehabilitation setting will focus on longer-term outcomes and long-term goals.

When can I arrange a family meeting?

Family meetings can be arranged once the patient is deemed medically stable. Often, this is when the patient has been discharged from the emergency department into a stroke unit or general hospital ward.

Often times, previous caregivers felt like no one was willing to answer their questions. This can be a frustrating experience.

Family meetings provide an appropriate opportunity to ask these questions, and finally get straight answers.

PREPARING FOR INPATIENT REHABILITATION

Who goes to In-patient Rehabilitation?

Not every stroke survivor goes to an in-patient rehabilitation facility. An obvious consideration is the severity of your family member's stroke. In addition to this, for a stroke survivor to be able to go to inpatient rehabilitation, he/she must:

1. Be able to participate in a rehabilitation therapy session that lasts at least 30 minutes (may be less for lower intensity programs).
2. Be able to tolerate sitting upright, with or without support.
3. Be able to demonstrate carry-over of learning (can retain information learned from the last session, and build on this information in the next session).
4. Be able to consistently follow instructions to participate in therapy sessions.

What is Inpatient Rehabilitation?

Inpatient Rehabilitation helps stroke survivors who are medically stable, but still need intensive therapy before they are ready to return home.

Stroke survivors are referred to a rehabilitation or restorative care facility by their health care team while they are in the acute care hospital. Once their medical condition has stabilized and a spot opens for them at the rehabilitation or restorative care facility, they are transferred directly from the acute care hospital.

Each rehabilitation or restorative care facility is staffed by a highly experienced, multidisciplinary team, which includes specially trained nurses, physiatrists, neuropsychologists, physiotherapists, occupational therapists, dietitians, social workers, and recreation therapists.

Family members are also considered to be an important part of the rehabilitation team and therefore, **you are highly encouraged to participate** in therapy sessions.

You may notice that there are several other stroke survivors in inpatient rehabilitation. This may be a great opportunity to meet other caregivers in your position who are also caring for a recovering stroke survivor.

How long is In-patient Rehabilitation?

The length of stay in inpatient rehabilitation varies depending on the type of program the stroke survivor is enrolled in. There are two types of programs within Lakeridge Health.

Active Rehabilitation

Stroke survivors receive intensive therapy 5 days a week. They generally stay for 5 weeks at the rehabilitation facility. The stroke survivor can sometimes go home on the weekends. This can be arranged with the rehabilitation team.

Low Intensity Rehabilitation

Stroke survivors also receive therapy, although sessions may be less frequent and last shorter durations compared to an active rehabilitation program. Therapists will adjust treatment sessions based on what your loved is able to tolerate. The length of stay is generally 8 weeks.

Which program your loved one will go to will depend on the severity of his or her stroke, his or her rate of recovery, and their tolerance for therapeutic activities. The health care team in acute care will recommend to you the best program that meets your loved one's needs.

Need More Information?

Many in-patient rehabilitation hospitals will be able to provide you with more information on what to expect in rehabilitation, and who to talk to in order to get your questions answered.

WHO TO TALK TO FOR MORE INFORMATION

As your family member's condition stabilizes, your information needs may change. Caregivers generally found that at this time, their focus began to shift from the immediacy of the event, to how to assist their family member's progress after the stroke.

For additional informational resources, you may find it helpful to talk to one of the following individuals for various concerns. For instance:

Talk to your Doctor about:

- Your family member's status and progress (how your family member's condition has improved)
- Your family member's treatment plan (dietary changes, new medications, options for rehabilitation if your family member qualifies)
- Information about stroke
- Hospital transfer information (if your family member needs to be transferred to another hospital that is better suited to his or her needs, your doctor will discuss this with you)
- Clarification on the roles of your Health Care Team (who they are and how they can help you)
- Other resources as required (e.g. referrals to social workers, counselors, other professionals)

Talk to your Social Worker about:

- Discharge information (for example, date of discharge, whether your family member will be returning home or beginning rehabilitation sessions at an in-patient facility)
- Resources for financial assistance
- Other resources you may need at this time (such as long-term care information, home care information)

Talk to your Physiotherapist about:

- Your family member's physical progress
- The amount of assistance your family member needs to get out of bed and/or walk
- Exercises you can do with your family member

Talk to your Occupational Therapist about:

- Your family member's progress with their thinking, memory, or visual skills
- The amount of assistance your family member needs for their self-care
- How you can help your family member re-learn skills needed for everyday living

Talk to your Speech-Language Pathologist about:

- Information pertaining to Aphasia (problems your family member may experience with communicating)
- Dysphagia (problems your family member may experience with swallowing)

Talk to your Dietician about:

- Dietary Changes
- Challenges your family member may be having with eating, utensils, or food choices
- Dysphagia (problems your family member may experience with swallowing)

Previous Caregivers Found…

- Informational needs during this time were most often met by health care professionals – especially through doctors and rehabilitation therapists
- Social workers were helpful in assisting with financial information and transportation resources

EMOTIONAL SUPPORT

Feelings You May Be Experiencing At This Time:

There are many different emotions that family members and caregivers experience during this phase. Previous caregivers in your position told us they:

- Had a need for moral support, and knowing others were there for them
- Had a need for encouragement and advice
- Had trouble communicating what was going on with children and others

Previous caregivers also told us they did not know with whom they could discuss their emotional needs. If you need emotional support or someone to talk to, please speak with your social worker. Social workers are trained to provide you with counseling and can also help you secure the supports you need.

Please know that these feelings are normal. This is a stressful time. Remember you are not alone.

WHO TO TALK TO FOR EMOTIONAL HELP

During this time, you may find that you may require additional emotional support as your family member's condition stabilizes. You may begin to wonder how to cope with the upcoming challenges, when your family member may return home, or who you can go to in order to develop a strong support network for yourself during this time. It is important to remember that you are not alone, and help is available when you need it.

For additional emotional support, you may find it helpful to talk to one of the following individuals. For instance:

Talk to your Social Worker or a Counselor about:

- How to handle the situation (e.g. how to cope with stress, anxiety, fear, sadness)
- How to ask family and friends for assistance
- How to ensure your own needs are being met during a time that tends to be very focused on the stroke survivor
- Your feelings overall – how to make sense of them, how to gain support, how to be understood

Talk to your Family or Friends about:

- Your feelings overall – how to make sense of them, how to gain their support if you need it, and how to be understood
- Ensuring your own needs are met – support at home, help with chores, assistance with meals if you don't have enough time or energy to prepare them
- Needing someone to stay with you at home, or someone to stay with the stroke survivor at the hospital for a sense of comfort and to not feel alone

Previous Caregivers Found…

- Emotional needs (someone to talk to) were best met by social workers, counselors, family, and friends
- Support at home was often offered and provided by family and friends, and when this was not possible, talking on the phone also proved helpful

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in Section 7: Notes and Additional Resources and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

PRACTICAL SUPPORT

Common Practical Needs for Assistance

During this phase, you may wish to receive some assistance from the people around you. Given the events that have happened, your focus will still likely be on your family member and not on the other things that you usually focus on day-to-day. During this phase, it is important to ensure that your needs are addressed, and it is important to talk to the members of your health care team (including your family and friends as well) so they can assist you.

Previous caregivers in your position found that their needs included:

- Having someone visit your family member
- Having someone visit you
- Assistance with household chores
- Financial assistance
- Finding a place to stay near the hospital
- Having someone assist with meals, transportation, and accommodation.

WHO TO TALK TO FOR PRACTICAL HELP

During this phase, previous caregivers appreciated when family, friends, or health care professionals provided hands on assistance with a variety of activities.

Here are some things you may wish to ask for:

Talk to a Doctor or Nurse about…

- Ensuring your family member's needs are being met at the hospital – that regular routines are being met, and that they are mindful about accessibility (for instance, if your family member cannot reach the cord that allows them to call for assistance, ensure that the health care professional moves it for easy access)
- Follow-up appointments (scheduling them, what they are for, what dates they will take place)
- Any pain or symptom management issues that are bothering you or the stroke survivor.

Talk to a Social Worker or a Counselor about…

- Financial assistance
- Follow-up appointments (for yourself or your family member concerning various matters pertaining to discharge or counseling)
- Needing a place to stay near the hospital
- Transportation assistance

Talk to Family or Friends about…

- Assisting you at home with household chores
- Providing food for you or your family (in case you or your family don't have time or energy to prepare meals).

OTHER SUPPORTS

If your friends or family are unable to help you with **meal preparation**, you may want to visit www.mealcall.org/canada/. This website will direct you to the appropriate number for you to call for assistance with meals.

If you have difficulty arranging **transportation** to and from the hospital and cannot find friends or family to assist you, please consider the following options:

Durham Region Specialized Transit Services
www.durhamregiontransit.com
1-866-247-0055

Go Transit
www.gotransit.com

There are more resources and number you may wish to call for assistance located in the **'Additional Resources'** section, at the back of this guide.

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in Section 7: Notes and Additional Resources and approach the appropriate individual on your health care team to ensure that your concerns are addressed.
- Consult Section 7: Notes and Additional Resources for resources in your community pertaining to a wide range of supports.

TRAINING SUPPORT

Swallowing and Eating

A stroke can affect the muscles of the mouth, tongue and throat. As a result, your family member may have trouble swallowing. This is known as dysphagia (or aphagia). Dysphagia may be temporary or permanent. Because it involves many of the same muscles used in speaking, dysphagia is usually diagnosed and treated by a speech-language pathologist. If not treated, swallowing problems can lead to serious health problems, such as choking or inhaling food (aspiration) that can lead to pneumonia, malnutrition, dehydration, and choking or inhaling food (aspiration) which can lead to pneumonia.

During the early stages of the stroke survivor's recovery, your family member's speech language pathologist or dietitian may order meals that are easy for him or her to eat. For example, soft foods such as applesauce or porridge may be easier for your family member to swallow than thin liquids such as water or juice.

Your family member may also be given:

- Liquids thickened to the consistency of pudding or liquid honey
- Food that is softer or smoother (such as mashed potatoes)
- Food that has been chopped or minced into smaller pieces
- Food that has been pureed or put in a blender

As swallowing improves, many stroke survivors can go back to eating regular food.

What You Can Do

Here are some tips if your family member is having difficulty swallowing or eating:

- Always follow the guidelines recommended by the speech language pathologist for food and liquid textures.
- When eating, have your family member sit up straight in a bed or chair.
- Have your family member take small bites. Try using a teaspoon rather than a tablespoon.
- Ensure your family member chews on the stronger side of his or her mouth.
- Your family member should chew each mouthful thoroughly before swallowing.
- Your family member should clear his or her throat and mouth of food after each bite.
- He or she should not talk while chewing.
- If drooling on the weakened side of your family member's mouth is a problem, have him or her wipe his or her face frequently with a napkin or cloth.
- Avoid distractions while eating. Turn off the TV or radio. Avoid busy restaurants and dining rooms if your family member is easily distracted while eating.
- After eating, your family member can remove food trapped in his or her cheek with his or her finger. He or she can use a small mirror to see where food is trapped. Your family member should brush his or her teeth and rinse after each meal.

- If your family member suffers heartburn or acid reflux after eating, try to avoid highly spiced or seasoned foods; citrus fruits and juices and other acidic foods (e.g. tomatoes); drinks with caffeine, such as coffee, tea, chocolate and cola; peppermint or spearmint; or high fat, fried foods.

Special Devices to Assist with Eating

Special devices are available to make eating easier if your family member is using only one hand. Your family member's occupational therapist or dietician can tell you what types of devices may help your family member and where to get them.

Devices include:

- Plates with big rims to hold food in
- Dishes with gripper pads on the bottom to keep them from slipping
- Cup or container holders
- Modified utensils with buildup or bent handles
- Cutting utensils made for one-handed use, such as a rocker knife, cheese knife or pizza cutter
- Modified cups with a cut-out or partial lid

Additional Things You Can Do

If your family member requires help to eat, ask the nurse, dietician, speech-language pathologist or other member of the stroke rehabilitation team to show you how to do it. **Because of the danger of choking, do not try to feed your family member unless you are trained how to do it.**

Ask the speech language pathologist or dietician to explain any special food and liquid textures your family member might find easier to eat. The dietician or occupational therapist can help you learn how to prepare foods that are safe for the stroke survivor to eat.

Small, frequent meals may be easier to eat and digest. Work with your dietitian to ensure meals are balanced and healthy. Good oral hygiene is important. Take your family member to regular dental check-ups. If necessary, assist the survivor in brushing and flossing.

Most people need to drink at least 6 – 8 cups of non-caffeinated fluids a day (drinks without caffeine). Non-caffeinated drinks include water, fruit juices, milk and some soft drinks. Sometimes, stroke survivors may not drink enough fluids and can become dehydrated. This is not healthy, and in severe cases can be dangerous.

Signs of Dehydration Include:

- Decreased urine output (urinates less)
- Dark, concentrated and/or strong-smelling urine
- Frequent urinary tract or bladder infections
- Thick stringy saliva
- Constipation
- Dizziness when sitting up or standing
- Confusion or a change in mental status
- Weight loss of 3.5 pounds (1.5 kg) or more 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", this may be a sign of dehydration.

COMMUNICATING WITH SOMEONE WITH APHASIA

If your family member has aphasia, here is some information you can use, as well as information you can share with your family and friends. It may help them understand how to better communicate with your family member.

- Do not leave the stroke survivor out of social gatherings or conversations.
- Try to help the stroke survivor so he or she does not feel lonely and cut off from people.
- Phrase questions so they can be answered with a "yes" or "no" or a nod or shake of the head. Remember that sometimes, stroke survivors may get these responses confused. Try using pieces of paper with "Yes", "No" and "I don't know" written on them. Ask the survivor to point to the correct response.
- Speak in a natural voice. Do not shout or talk too fast. Pauses and speaking at a moderate pace may help the survivor understand you.
- When talking with a stroke survivor, turn off distractions such as the TV or radio. Keep conversations clear and direct.
- Have only one person speak at a time.
- During the early stages of recovery, when giving the stroke survivor choices, limit the number of choices to two. For example, ask the stroke survivor, "Would you like coffee or tea?" Try writing down the choices. If the person with aphasia is having difficulty reading, use a drawing beside the written word. If this is still difficult, try asking a question that can be answered with a 'yes', or a 'no'.
- In time, as the person recovers, you can try adding more choices.
- Short, concrete, common words may be easier to understand. For example, say "leg" instead of "limb", "bread" instead of "nutrition" or "house" instead of "residence."
- Do not rush a person with aphasia. Be patient and give him or her time to come up with the right word.
- The single most important thing you and your family can do is to remember that aphasia means that your family member has difficulty with language, not with thinking.
- In many respects, your family member is still the same person inside. Having aphasia does not mean that your family member is not intelligent or does not understand things.

WHO TO TALK TO FOR MORE TRAINING HELP

Talk to a Rehabilitation Therapist about…

- Learning various exercises and techniques to help your family member regain some level of independence or mobility
- Learning how to assist with every day activities

Talk to your Speech-Language Pathologist about…

- Communication strategies to assist your family member if he or she has Aphasia (your speech-language pathologist may invite you to sit in on your family member's rehabilitation sessions to learn various strategies to assist him or her)

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in Section 7: Notes and Additional Resources, and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

Support Needs Management Form

1. What supports do you need right now?
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    -
2. What resources can you draw upon to get this support?
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3. What resources will I try first?
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4. How did this work out?
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5. If it didn’t work out, what other resources should I try?
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6. Accept that this support need may not be met right now.

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    -
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Chapter #3- My Family Member’s Condition has Stabilized

Chapter #4
PREPARING TO GO HOME

During this phase, your family member is getting ready to leave acute care or rehabilitation, and you are about to begin to support your family member in the home. We have found that caregivers are vulnerable to feelings of confusion or being under prepared at this stage, so this section of the guide is designed to assist you in developing accurate expectations and preparing yourself, your family member, and your home environment for the return from hospital.

Because this phase of recovery focuses on preparing for discharge, we will give you information concerning when your family member will return home, how to prepare your home for discharge; any special equipment that will be needed; as well as how to ask your family and friends for assistance.

This Chapter at a Glance:

Informational Support

- Warning Signs of Stroke
- Risk Factors for Stroke
- Secondary Prevention
- Medications after Stroke
- Diet after Stroke
- Preparation for Outpatient Rehabilitation
- My Discharge Plan (From Acute Care)
- My Discharge Plan (From Rehabilitation)
- Preparing My Home for Discharge
- Safety Equipment & Assistive Devices
- Completing Successful Transfers
- Who to Talk to for Help

Emotional Support

- Feelings You May Experience at this Time
- Depression in the Stroke Survivor
- Peer Support Groups
- Who to Talk to for Help

Practical Support

- Common Practical Needs for Assistance
- Home Visits & Safety Assessments
- Who to Talk to for Help

Chapter #4 – Preparing to go Home

Training Support

- Common Training Needs at this Time
- Your Family Member's Memory
- Mobility Exercises after Stroke
- Completing Successful Transfers
- Who to Talk to for Help

WARNING SIGNS OF STROKE

What are the warning signs of stroke?

The warning signs of stroke are the brain's way of telling you that it is under attack. The warning signs will depend upon what part of your brain is in trouble. Not everyone will have every warning sign.

Warning Signs of Stroke

Weakness
Sudden weakness, numbness, or tingling in the face, arm or leg.

Trouble speaking
Sudden temporary loss of speech or trouble understanding speech.

Vision problems
Sudden loss of vision, particularly in one eye, or double vision.

Headache
Sudden, severe and unusual headache.

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

If you or someone you know is having any of these signs
CALL 9-1-1 or your local emergency number immediately.

STROKE RISK FACTORS

Evaluating the risk for stroke is based on heredity, natural processes, and lifestyle. Many risk factors for stroke can be changed or managed, while others that relate to hereditary or natural processes cannot be changed.

Risk factors for stroke that can be changed, treated, or medically managed:

- **High blood pressure**
  The most important controllable risk factor for brain stroke is controlling high blood pressure.

- **Heart disease**
  Heart disease is the second most important risk factor for stroke, and the major cause of death among survivors of stroke.

- **Cigarette smoking**
  The use of oral contraceptives, especially when combined with cigarette smoking, greatly increases stroke risk.

- **History of transient ischemic attacks (TIAs)**
  A person who has had one (or more) TIA is almost 10 times more likely to have a stroke than someone of the same age and sex who has not had a TIA.

- **High red blood cell count**
  A moderate increase in the number of red blood cells thickens the blood and makes clots more likely, thus increasing the risk for stroke.

- **High blood cholesterol and lipids**
  High blood cholesterol and lipids increase the risk for stroke.

- **Lack of exercise, physical inactivity**
  Lack of exercise and physical inactivity increases the risk for stroke.

- **Obesity**
  Excess weight increases the risk for stroke.

- **Excessive alcohol use**
  Drinking more than 2 standard drinks per day for women or 4 standard drinks per day for men raises blood pressure, and binge drinking can lead to stroke.

- **Drug abuse (certain kinds)**
  Intravenous drug abuse carries a high risk of stroke from cerebral embolisms (blood clots). Cocaine use has been closely related to strokes, heart attacks, and a variety of other cardiovascular complications. Some of them, even among first-time cocaine users, have been fatal.

Risk factors for stroke that cannot be changed:

- **Age**
  For each decade of life after age 55, the chance of having a stroke more than doubles.

- **Diabetes**
  Diabetes is strongly linked with high blood pressure and, therefore, it increases a person's risk of stroke. Although there is no cure for diabetes, good management of diabetes can decrease a person’s risk of stroke.

- **History of prior stroke**
  The risk of stroke for someone who has already had one is many times that of a person who has not had a stroke.

- **Heredity/genetics**
  The chance of stroke is greater in people who have a family history of stroke.

Other risk factors of stroke to consider:

- **Temperature, season, and climate**
  Stroke deaths occur more often during periods of extreme temperatures.

SECONDARY PREVENTION

Always Say Never Again

In medicine, secondary prevention activities are aimed at early disease detection. Knowing the warning signs of stroke, and reviewing the causes or risk factors for stroke, will help you prevent or act quickly in the case of a second stroke.

Preventing Another Stroke

There are about 40,000 to 50,000 new strokes in Canada in a given year. Stroke is the fourth leading cause of death, and a leading cause of disability in Canada. There are 300,000 Canadians living with stroke. A stroke survivor has a 20% chance of having another stroke within 2 years.

Your family member's health care team can introduce several ways to help your family member prevent another stroke.

Overview of Prevention Guidelines

You and your family member have control over many stroke risk factors. In the United States, the National Stroke Association and its panel of stroke experts have developed ten simple guidelines to help you and your family member reduce risks for stroke.

- Know your family member's blood pressure. If it is elevated, work with their doctor to keep it under control. A normal blood pressure reading is considered less than 130/80.
- Find out if your family member has atrial fibrillation, which is an irregular heartbeat rhythm (also called AF). If your family member has AF, work with your doctor to manage it.
- If your family member smokes, help them to stop.
- If your family member drinks alcohol, they should do so in moderation.
- Know your family member's cholesterol number. Speak to a doctor if it is high.
- If your family member is diabetic, follow their doctor's recommendations carefully to control their diabetes.
- Include exercise in the activities your family member enjoys in his or her daily routine.
- Encourage your family member to eat a lower sodium (salt), lower fat diet, and abide by dietary instructions provided by the Canadian Food Guide.
- Ask your doctor if your family member has circulation problems that increase their risk for stroke. If so, work with their doctor to control them.
- If your family member has any stroke symptoms, seek immediate medical attention.

MEDICATIONS AFTER A STROKE

If your family member has had a stroke or Transient Ischemic Attack (TIA – a mini stroke), he or she has a greater chance of having a second stroke or TIA. There are several things you and your family member can do to lower the chance of having another stroke including reducing blood pressure and cholesterol, quitting smoking, exercising regularly, eating healthy foods and taking the right medications as directed.

Medication to Prevent Stroke

Medication may help reduce stroke risk by controlling high blood pressure or high cholesterol, treating heart disease, or by interfering with the blood's tendency to form potential stroke-causing blood clots. There are many different medications your doctor may prescribe to reduce your family member's risk of having another stroke or TIA. It is important that you understand:

- What medication(s) your family member is taking
- Why he or she is taking them
- How and when your family member should take them (e.g. are they to be taken with food?)
- Any side effects of your family member's medication
- What happens if your family member suddenly stops taking his or her medication

Blood Pressure Lowering Medications

High blood pressure is one of the most important and easily controllable stroke risk factors. Often it can be controlled through diet and exercise, but medication may also be necessary. Medications to reduce blood pressure are called 'antihypertensives' (anti = against + hypertensive = high blood pressure). Several different kinds of medications are available to treat high blood pressure including the most common groups of drugs called calcium channel blockers and ACE-inhibitors. It is important to remember that your family member and his or her doctor may have to try several different drugs before your family member find the one that works best. This is common, so try not to be discouraged if it happens. Once your family member finds a drug that works, be sure that he or she takes it exactly as prescribed.

Blood Thinners

After a stroke occurs, there are several clot prevention medications available to help reduce the risk of a second stroke. Blood thinners help to reduce the risk of formation of blood clots forming that can lead to a stroke. There are two types of blood thinners:

1. **Antiplatelet medication** (Platelet Aggregation Inhibitors). This group of medications keeps tiny cells (platelets) in the blood from sticking together and forming blood clots. There are three common types of antiplatelet medication including Aspirin, a combination of Aspirin and Dipyridamole, and Clopidogrel. Aspirin is the least expensive and longest standing clot prevention medication. A newer, more effective option is a combination of aspirin and

extended-release dipyridamole, called Aggrenox®. Clopidogrel (Plavix®) and ticlopidine (Ticlid®) are other options your family member's doctor might consider. Different medications may be prescribed depending on which ones your family member can tolerate.

2. **Anticoagulant medication** also stops blood from forming clots, however this medication uses a different chemical process. Common examples include Heparin and Warfarin (Coumadin®). Patients taking Warfarin should be carefully monitored by a physician to see if he or she has the right level of medication in his or her blood. They should also be aware of foods rich in vitamin K such as green leafy vegetables, alfalfa, egg yolks, soy bean oil and fish liver, which may counteract the drug's effects. Your family member should try to maintain a consistent level of vitamin K in his or her diet. If your family member alters his or her intake of vitamin K drastically from one day to the next, be sure to tell his or her doctor.

Anticoagulant medication may also be prescribed for people who have atrial fibrillation (irregular heartbeat) or those with particular heart conditions (e.g. A prosthetic heart valve).

Your family member may bleed more easily when taking these medications. It is important you try to prevent accidental injuries (e.g. falling over) or that you or your family member tell his or her health professional before undergoing other medical treatment (e.g. surgery).

Your doctor will help you to decide which medication is the most effective for your family member's condition.

Cholesterol-Lowering Medications

High levels of cholesterol may also increase stroke risk by not allowing blood to move freely through the arteries. Cholesterol build-up can break off, causing a stroke to occur. Several drugs, including a new class of drugs called statins, may help lower cholesterol levels. Some statins have also been proven effective in reducing the risk of stroke or TIA in patients who have had a heart attack, even if they have average or only slightly elevated cholesterol levels.

Remembering to Take Medication

If your doctor prescribes medication, it is important that your family member continues to take it unless the doctor tells him or her to stop. If your family member has difficulty remembering to take their medications then you can try:

- Giving your family member his or her medications at the same time every day. It is important to get your family member in a routine.
- Using a pillbox or dispenser that notes day and times. You can organize this with your local pharmacist.
- Using a medication diary or daily chart to keep track of your family member's medications.

Your doctor will help you and your family member to work out the right medication, dosage and timing for his or her lifestyle. Your family member should never stop taking his or her medication or change how much is taken without talking to his or her doctor. In some cases, suddenly stopping medication can be dangerous.

Understanding and Reporting Side Effects

Medications can occasionally produce side effects. It is important to remember and report any side effects experienced by your family member to your doctor, no matter how big or small. In order to report the side effects to your doctor, you must first understand the particular side effects the medications can produce. Pharmacists commonly provide a list of possible side effects when they dispense the medications. The doctor may be able to make changes that reduce or remove the side effects that may be experienced, however they can only do that if you report them.

Other Medications

Your family member may be taking a number of medications for different medical reasons. For example he or she may use injections or tablets to control diabetes or he or she may take tablets for arthritis. You should speak to the doctor or pharmacist about how your family member's medications interact and ask questions you have regarding any medication being taken.

DIET AFTER A STROKE

Many people can return to their usual diet after stroke. Some stroke survivors will be encouraged to change their diet to decrease the chance of another stroke from occurring. However some stroke survivors may experience short or long-term difficulties with eating or drinking. After a stroke, there is a greater risk of poor nutrition, poor fluid intake and weight loss. This is often due to:

- Swallowing problems (called dysphagia)
- Problems with movement (eg. using a knife and fork)
- Problems with thinking (eg. forgetting to eat)
- Loss of appetite

Who Provides Advice On Nutritional Needs?

- **A Dietitian can assess your family member's diet** and provide ways to help you meet the nutritional needs of your family member and you, and prevent poor nutrition from slowing down your family member's recovery. Dietitians often work with the Speech Pathologist who looks at the consistency of foods and fluids that your family member can swallow safely.

- **Dietitians can provide nutritional assessment and advice to decrease your family member's risk of having another stroke.** These risk factors include high cholesterol, high blood pressure, being overweight, poor fruit and vegetable intake and diabetes.

- While your family member is recovering in hospital, **nursing staff and/or your dietitian** should weigh your family member once a week and monitor how much he or she is eating and drinking. If your family member is at home, you may like to do this yourself.

Eating To Reduce Risk of a Stroke

Healthy eating can reduce the risk of stroke or having another stroke by reducing risk factors such as high cholesterol, high blood pressure, being overweight and diabetes. The following information should be used as a guide only and may not be appropriate for people who are underweight or with swallowing problems. Ask a Dietitian for an eating plan to suit you and your family member.

Eat Plenty Of:

1. Fruit and Vegetables – You and your family member should aim to eat at least 7 servings of vegetables or fruit everyday. Some days you may eat more vegetables and other days more fruit to reach the total of 7 servings per day. Fruit and vegetables reduce the risk of stroke as they contain:

- *Antioxidants* which can help reduce damage to blood vessels
- *Potassium* which can help control blood pressure
- *Fibre* which can lower cholesterol
- *Folate* which may reduce risk of stroke

2. Wholegrain Breads and Cereals – These include wholemeal or wholegrain breads, brown rice, wholemeal pasta, and breakfast cereals such as Bran Flakes and porridge. Wholegrain breads and cereals contain fibre, potassium, folate and other vitamins and have been associated with a reduced risk of stroke.

3. Fluids - Aim to drink 8 cups of fluid per day unless your family member is on a fluid restriction. Water is the best choice. Getting the right amount of fluid is particularly important if your family member has a swallowing problem and is only drinking thickened fluids.

Eat In Moderation:

- *Meat, Chicken, Fish* - Red meat and chicken can be a part of a healthy diet. Be sure to choose lean cuts of meat, watch your portion size, trim off any visible fat and take the skin off chicken. Fish has been associated with a lower risk of certain types of stroke. Try to have fish at least 2-3 times a week. This can be fresh, frozen or tinned/canned, but not the deep-fried battered types.
- *Low Fat Dairy* - The calcium and potassium in low fat dairy can help control blood pressure and may contribute to lowering the risk of stroke. Low fat dairy foods include low fat milk, yogurt, low fat cheese and low fat custard. Milk and yogurt containing less than 2% milk fat (e.g. skim milk, 1%milk) are your best dairy food choices. It is recommended to consume them daily.

Eat In Small Amounts:

- *Healthy Fats* - These include polyunsaturated and monounsaturated fats like olive oil, canola, margarine (if low in trans fat), avocado and nuts. Too much of these fats may lead to weight gain, however small amounts can help control cholesterol and reduce the risk of stroke.

Limit:

- *Unhealthy Fats* - These include saturated and trans fats. These can be found in butter, lard, fatty meats, full-cream dairy, pastries, chips and other snack foods (including fatty fast-foods). Saturated and trans fats can raise cholesterol and increase the risk of stroke. The less trans and saturated fat you eat the better.

- *Salt intake* - Too much salt in your family member's diet can raise blood pressure and increase risk of stroke. Choose no added salt or reduced salt products. Limit foods like salty snacks (e.g. pretzels), foods in brine, processed meats and convenience meals & sauces that are high in salt. Try not to add salt to foods. (You might want to try supplementing salt with spices or herbs for flavor). People should limit their sodium intake to less than 2300mg per day.
- *Alcohol* - If you or your family member drink alcohol regularly, a safe level of intake for women is no more than 1 standard drinks per day, and for men no more than 2 standard drinks per day. Everyone should have at least 1 or 2 alcohol free days every week. A standard drink is a small glass of beer, a can of mid strength beer, 100mls of wine or a nip of spirits. It is a good idea to discuss alcohol intake with your doctor as alcohol may interact with some of your family member's medications or make it harder to control blood pressure.

Canada's food guide is a useful resource for healthy eating. For more information, please see:
http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index_e.html

PREPARATION FOR OUTPATIENT REHABILITAION

After stroke rehabilitation during acute care or in-patient rehabilitation, follow up care is often required. Outpatient rehabilitation programs meet the needs of patients requiring physical, occupational and/or speech therapies. The goal is to integrate services to improve the functional level of each patient. Outpatient rehabilitation services focus on developing a patient's optimal level of function and community integration.

Out-patient services are available for patients who require help from at least two different therapy professionals (Example: Help from a Physiotherapist, and help from a Speech Language Pathologist).

Make sure you, as the caregiver, attend these therapy sessions as frequently as possible. This is a chance for you to comment on the things you have noticed in the stroke survivor's recovery, and mention areas the patient still needs help with. These sessions are also a valuable opportunity for you to learn how to help the stroke survivor, to learn new skills that may make your job easier, and to make sure your family member is continuing to practice at home the skills that he or she has learned in therapy.

DISCHARGE PLANNING

What is Discharge Planning?

Sometimes it seems as though discharge from the acute care hospital and/or the rehabilitation hospital happens all at once, and very quickly. But discharge planning is a process, not a single event. Medicare defines discharge planning as: “A process used to decide what a patient needs for a smooth move from one level of care to another.” As a result of that process, the discharge plan may be to send your family member to his or her home or someone else’s home, a rehabilitation facility, a nursing home, or some other place outside the hospital where they are currently receiving care. Discharge from a hospital does not mean that your family member has completely regained function, but it does mean that the health care team has determined that a facility other than the present hospital is now best able to continue the recovery process. If your family member receives in-patient rehabilitation after acute care they will experience the discharge planning process more than once, as they prepare to return home.

Who Does It?

Only a physician can ultimately authorize a hospital discharge, but many people are involved in working out the details of the discharge plan. As the patient’s family caregiver, you are one of the most important members of this team. You alone have essential information about and understanding of the patient’s home situation, as well as about your own caregiving capabilities. Make sure you are involved from the outset.

There are many professionals involved in your family member’s discharge, including a social worker, a CCAC representative, and other members of the health care team. Your main contact is usually the social worker. It is important for you to know who this person is and to understand how they can help you, so you can save yourself the stress of navigating unfamiliar territory on your own. If the social worker does not come to see you and your family member early in the hospital stay, find out who is in charge of your family member’s discharge and ask for an appointment.

You can be assured that your family member will be going to a place that does not present immediate dangers to his or her health and well-being, and that realistic plans have been made for appropriate follow-up care. Discharge planning is a short-term plan to get your family member out of the hospital. It is not a blueprint for the future. Your family member’s condition may improve or worsen over time. You may or may not be able to sustain the level of caregiving that is required at the outset. Even though no one can predict what the needs will be four weeks, or four months, from discharge, it is important for you to think about the long-term needs of your family member as much as possible. You may be able to build into the immediate plan services that will be important in the long run (e.g., respite care).

When Should it Happen?

Many health care providers say that discharge planning should begin early so that everyone has as much time as possible to prepare. As such, we suggest that you start thinking about it – and connecting with your social worker– as soon as you are ready to. This will help you to find the best way possible to balance the many considerations that have to be made in coming to a decision. These considerations often include the time at which your family member wants to return home, the professional judgment of the hospital staff, and your own needs.

What Should I be Doing While my Family Member is in the Hospital?

It is normal and expected that your mind will be mostly occupied with questions about your family member's condition and a desire to ensure that he or she is receiving the best care possible. However, if you can, it is helpful to start thinking about the larger implications of this life change.

Social workers are trained to help you work through this thought process, but you can also speak to a nurse, doctor, patient advocate, or chaplain. They will guide you in considering things such as whether you are able to take time off from work, how much care you can provide at home, how your own health situation will affect matters, and what your other family responsibilities are.

Thinking through issues like these is important because health care providers may assume that since you have been such a faithful and loving companion in the hospital, you will be available full time for future care. If that is not the case, you need to say so – firmly and consistently. A discharge plan that is based on faulty assumptions or incomplete information is not going to work.

One concrete way to determine your ability to help is to make a list of all the tasks that will have to be done when your family member leaves the hospital. A social worker or counselor can help you with this. Then look at the list and determine what you can and cannot do. For the tasks which you will not be able to do yourself, ask the social worker to guide you to people and services that can provide the care.

You can also begin to learn some of the techniques that are important for your family member's care. Sometimes hospital staff are able to train you formally but you can also learn by watching and asking questions. Even if you are not going to provide all the care yourself, it is important that you understand how it should be done so that you can instruct or supervise others.

Don't be afraid to say that you are not able or do not want to do certain tasks, such as personal hygiene or wound care. Remember that you are a family member, not a professional. You should not have to do anything that interferes with maintaining your special relationship with your family member, or that may place your own health at risk (e.g. injuring yourself during transfers).

What are my Choices?

Ideally, a discharge plan is based on a careful review of all the options. These may include sending the patient home with in-home rehabilitation therapy and some assistance with personal care, or in-patient rehabilitation where they can begin to re-learn how to perform every day activities.

Whatever is ultimately recommended, it is important that you are comfortable, but keep an open mind about what has been recommended as most appropriate. For example, if the discharge plan calls for a rehabilitation facility that is too far away or one that you do not believe provides excellent care, you should feel free to explore other possibilities. You may wish to research other possibilities on your own; you can ask your family and friends to work with you in this process. It is important to remember however, that in some situations other possibilities may not be possible.

Take Care of Yourself

While you are busy making all the arrangements for a smooth discharge process for your family member, don't forget that you need to take care of yourself as well. You probably have been spending a lot of time at the hospital. You may not have been sleeping well or eating regular meals. Maybe you are worrying about all the things that you have not had time to do at home or at your job. All this takes a toll on your own health and well-being, and can end up making a difficult time even harder.

Try to find a little time to unwind. Even a few hours doing something you enjoy or talking to a trusted friend or family member will help. Ask the discharge planner or social worker about resources in the community you can turn to when the hospital stay is over. If your employer has an Employee Assistance Program, call to get referrals. There are support groups of many kinds, counselors familiar with caregivers' stresses, and many different kinds of practical, emotional, and even financial help.

PUTTING IT ALL TOGETHER FOR DISCHARGE PLANNING

Discussion

At the very outset of discharge planning, health care professionals, family caregivers, and the patient (if appropriate) should discuss the following:

- The patient's condition, and any changes that may have occurred as a result of treatment at the facility
- Any likely symptoms, problems, or changes that may occur when the patient is at home, and what to do about them
- The patient's care plan, the caregiver's needs, and any adjustments that must be made to meet these needs
- The potential impact of caregiving on the caregiver
- Warning signs of stress; techniques for reducing stress.

Planning

Prior to discharge, health care professionals should work with family caregivers – with patient consent, if appropriate – to:

- Arrange for an in-hospital assessment to determine OHIP eligibility for home care services, such as visiting nurses and home care aides
- Set up home care services for which the patient is eligible and other services for which the patient/family can pay
- Get the home ready by arranging for equipment rental and home modification
- Provide a 24-hour phone number the caregiver can call to speak with a health care professional (such as Telehealth Ontario at 1-866-797-0000) should problems arise
- Organize transportation home for the patient
- Schedule a follow-up appointment with the doctor

MY DISCHARGE PLAN
(DISCHARGE FROM ACUTE CARE HOSPITAL)

My discharge planner is _____, and can be reached at
(name)

the following phone number: _____.

My family member _____ will be discharged on the
(name)

following date _____.
(MM/DD/YYYY)

Optional:

My family member will continue care at _____
(Rehabilitation or Care Centre Name)

located at _____ .
(Address)

Phone number:_____.
(Phone number of facility)

In case of assistance, I have been asked to call _____.
(Phone Number of Emergency Care)

Other Notes:

_____

_____

_____

MY DISCHARGE PLAN
(DISCHARGE FROM REHABILITATION HOSPITAL)

My discharge planner is _____, and can be reached at
(name)

the following phone number: _____.

My family member _____ will be discharged on the
(name)

following date _____.
(MM/DD/YYYY)

Optional:

My family member will continue care at _____
(Out-Patient Rehabilitation or Care Centre Name)

located at _____ .
(Address)

Phone number:_____.
(Phone number of facility)

In case of assistance, I have been asked to call _____.
(Phone Number of Emergency Care)

Other Notes:

_____

_____

_____

PREPARING MY HOME FOR DISCHARGE

After your family member has had a stroke, changes in your home or the home of your family member may make it easier and safer for the stroke survivor to move around and perform everyday activities. These changes can be as simple as moving furniture and appliances, or as complex as purchasing special devices and building ramps.

Your occupational therapist can help you decide what changes you should make in the home. Many adaptations are easy and inexpensive to make. If your family member needs special devices, or modifications have to be made, your social worker may be able to help you find funding. Your family member may be eligible for full or partial funding for special devices or home modifications from your provincial ministry of health or social services, or your private health insurance. Organizations such as the March of Dimes (www.marchofdimes.ca), the Canadian Red Cross (www.redcross.ca) or other groups in your community may also be able to help you.

Depending upon your family member's needs, you may find it helpful to:

- Move thermostats, plugs and switches to make reaching them easier
- Rearrange furniture that blocks the path where your family member walks
- Raise the height of chairs using wooden platforms
- Remove loose mats, area rugs or older style shag rugs that your family member could trip over

Where to Find Assistive Aids?

Here are a few rehabilitation equipment vendors who may carry the assistive devices you need. Please remember to speak with an occupational therapist or physiotherapist regarding what equipment is best for your family member. An occupational therapist will also be able to supply you with a complete vendor list, if needed.

CIMS Drug Mart Home Health Care
1355 Kingston Rd (Unit 106), Pickering
905-839-0364

Shoppers Home Health Care
Ajax- 905-427-4171
Whitby- 905-579-5300

Durham Medical
www.durhammedical.ca
905-728-1112
1-888-479-4687

SETTING UP YOUR HOME: SAFETY EQUIPMENT AND TIPS FOR CAREGIVERS

Using the Toilet

Many challenges a stroke survivor may face are related to using the toilet. Therefore, the use of handrails, or grab bars can help an individual to stabilize when sitting on and getting up from the toilet. In addition, the floor surrounding the toilet should be non-slip. If bath rugs are in front of a toilet, they should have some sort of backing to prevent sliding, such as non-skid tape.

Changing the height of the toilet may make using the toilet less difficult. A raised toilet seat or a toilet seat riser reduces the distance from a standing to sitting position so a person does not have to squat or bend down as far to reach the seat. Risers are usually made of plastic and can be placed on top of the toilet seat or between the seat and toilet rim. Raise the toilet seat by loosening the bolts and placing a “shim” underneath the regular seat, or purchase a raised toilet seat. Raised toilet seats may also be purchased with arm rests to further assist users in getting on and off the toilet (ex. a versa frame, as pictured above).

Because accidents are often unavoidable, it is a good idea to keep a pair of clean clothes in all bathrooms. Stroke survivors may also feel more comfortable if they wear disposable under-garments.

It is important to remember if purchasing disposable briefs to insure proper fit for the stroke survivor. This will avoid the garment from slipping while walking, while decreasing the chances of impaired mobility or falls.

Grooming

Using the Bathroom Sink

Faucets are often easier to use when the handles are lever handles, which allow a person to turn water on and off with a fist or arm movement.

Someone who uses only one hand will find it difficult to use items such as nail brushes and soap bottles. Suction pads can be used to hold tools in place on a counter top. Non-slip pads or sheets may also be useful. Your Occupational therapist can advise about these.

Brushing teeth can be made easier by increasing the size of the toothbrush handle and using a flip-top for dispensing toothpaste. A toothpaste squeezer may also be helpful for people with limited grasping ability.

When shaving, an electric razor may be easier to handle and safer than a regular razor.

If your family member finds it hard to safely get in and out of the bathtub, consider using a tub bench and a hand-held, flexible shower hose. Because there are so many different options available, it is important to speak to your family member's occupational therapist to find out which one will be best suited to your family member's needs.

A stroke survivor who uses only one arm/hand may want to try using soap-on-a-rope in the shower. A bath mitt and long-handled brush can also make bathing easier.

Dressing

The National Stroke Association suggests to "avoid tight-fitting sleeves, armholes, pant legs and waistlines; as well as clothes which must be put on over the head." Clothes should have fastens in the front. To make fastening clothes easier, Velcro fasteners or elastic can replace buttons, zippers and shoe laces. Assistive aids such as reachers, sock aids, dressing sticks, and shoe horns can also make dressing easier for the stroke survivor. For individuals with less mobility in one arm/hand, remember it is always easier to dress the weaker side first and then proceed to the stronger side.

Sleeping

To avoid accidents in the night due to being unable to get to the bathroom soon enough, a stroke survivor may want to keep a commode chair near the bed. A three in one commode chair has three features: a raised seat, grab bars on both sides of the chair, and a removable bucket. During the day or when it is not needed, the commode chair can be kept in a nearby closet.

Stroke survivors must also understand that accidents are often unavoidable. To make accidents easier to clean up, pads can be placed underneath sheets on the bed which are washable and reusable, with a cloth and waterproof side to prevent staining on furniture. These pads are often washable and reusable.

You may also find it helpful to use a low bed (removing the box springs is an easy way to reduce the height) to make getting in and out easier. A night-light can also be helpful in the bedroom at night.

Grab bars or side rails can also be added to beds to assist in making bed mobility easier.

Storing and Accessing Food

A person with impaired vision may be unable to read some of the labels on food and spice containers. Labeling containers with black bold letters in all caps on a white background may help to make identifying foods easier. Plenty of spacing between bottles makes for easy identification and removal from the shelf or rack. Switching some foods or spices to containers with larger-sized lids may help to make the containers easier to open.

Cutting food can be dangerous if the stroke survivor has trouble using their hands. Purchasing pre-sliced foods may be the safest solution to this problem. Weighted handles or built up handles make utensils and cooking tools easier to handle. A spiked cutting board or a non-skid surface holding the cutting board can also decrease the chance of the stroke survivor accidentally cutting themselves.

The Kitchen

You may wish to purchase and install faucets that can be turned on and off with the wrists

Try storing dishes and pot lids on vertical plate holders. Placing kitchen items on low shelves or in places where they are easily reached can help your family member. Purchasing a revolving shelf (or “Lazy Susan”) can make items easier to reach. Also, long-handled reachers or tongs can help your family member reach items on high shelves

Install casters or wheels on utility carts so your family member can use them to carry items to the stove or refrigerator.

To keep plates from sliding, put wet washcloths or paper towels under them to keep them in place

Cleaning

After a stroke, when the survivor has less energy and endurance, everyday cleaning tasks such as sweeping, mopping, washing counters, walls and other surfaces, garbage disposal, and general tidying may need to be done while seated. Working in small areas and taking frequent breaks can make these tasks more manageable. Products are available to simplify steps in cleaning processes, such as disposable wipes presoaked in cleaning solutions or multipurpose solutions for cleaning multiple objects. Long handled mops, sponges, and dust pads can also prevent having to bend over to complete tasks. Items such as vacuums can also be purchased in lightweight models to avoid using excess energy.

Doorways

Entryways and hallways should have a 32-inch clearance to accommodate people in wheelchairs. When doors do not open as wide as hinges were designed, application of a lubricant allows the hinges to work as they were designed. This extra space can allow a person using a wheelchair or walker to fit through the doorway. The edges of a swelled door may need to be shaved to allow for extra space, in some cases the door may need to be removed completely.

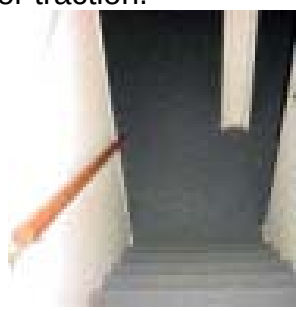
Stroke survivors who are unable to grasp with their fingers or twist their wrists to open doors can use a downward movement of their fist to open lever door handles more easily than regular doorknobs. The location of the knob may need to be moved as well.

Uneven thresholds should be fixed or changed to prevent tripping and allow easier wheelchair access. A portable ramp is often an affordable solution.

Flooring and Stairways

In addition to avoiding slippery surfaces whenever possible, wearing non-skid shoes can prevent slipping. Secure carpets or runners in hallways or stairwells for traction.

Handrails provide support while going up and down stairs. They may be attached to reinforced walls or the floor or ground. Outdoor handrails need to withstand weather conditions. A ramp may need to be added as well.



If the house requires going up and down a lot of stairs, consider a chair-lift, elevator, or build a ramp where there are four stairs or fewer.

Bright tape can also be applied to the edges of each step to provide greater visual contrast for distinguishing the steps.
Rugs should be taped down with non-skid tape or removed.
Thick carpet should be replaced when it makes movement in a wheelchair difficult.
Pathways should be clear of clutter and electrical cords.
Extension cords can be used to reroute cords along walls, and

cords should be secured to the floor or walls when possible. Cords with frayed ends should be discarded and replaced.

Other Suggestions

Individuals who do not require a wheelchair but find it difficult to move from place to place on their own may need to use a cane, walker, or scooter. A physiotherapist can recommend the most suitable walking aid for your family member. In addition, they may feel more comfortable if handrails or grab bars are mounted to the walls of the home. An occupational therapist can make recommendations for grab bars.

Phones should be easily accessible for the stroke survivor in every room of the house. A cordless phone or a wearable call button may be necessary and would prevent tripping on a phone cord. Emergency phone numbers should be posted in a highly visible area.

A large button phone is easier to read and use for patients with limited movement or vision problems. High contrast such as dark on light or light on dark also helps people with vision problems to read the numbers and words on phones. A picture phone reduces the need to remember phone numbers or to press several buttons to make a call. The phone can be programmed to fit a person's individual needs. A symbol, drawing, or photograph corresponds to emergency numbers and numbers of family or friends.

WHO TO TALK TO FOR MORE INFORMATION

As your family member's condition has improved throughout acute care and rehabilitation, he or she is now ready to return home. You are now transitioning into a phase where you become the primary caregiver – responsible for more of your family member's needs than you were when they were in the hospital. This may include medication management, home exercises, and helping your family member regain independence. This can be overwhelming for one person to face, so in addition to giving you information we want to help you connect with others who can share the load. Here are some of the things which the different members of your team can help you with:

Talk to your Social Worker or Health Care team about…

- Discharge planning (discuss the date of discharge, the options available to you and your family member in terms of care or respite services)
- Financial assistance (home modifications may be costly – discuss financial options with your social worker, and acquire resources to help you)

Talk to your Community Care Worker or Case Manager about…

- Home-safety assessments (find out information about assessing your home to determine what changes need to be made to ensure your home is a safe environment to which your loved one will return)
- Home care assistance (resources for accessing home care if necessary)

Talk to a Rehabilitation Professional about…

- Ongoing care at home (learn which exercises to continue at home)
- Home-safety assessments (find out information about assessing your home to determine what changes need to be made to ensure your home is a safe environment to which your family member will return)

Talk to a Doctor, Nurse, or Rehabilitation Professional about…

- Hospital transfers – when and where they are occurring (if applicable)
- Information pertaining to long-term care, home care, or how to alternate caregiving activities with family members
- How to prevent a stroke
- How to manage stroke and other medical conditions (such as diabetes, high cholesterol, etc.)

Talk to your Peers about…

- How to handle upcoming challenges
- How to find time for yourself to relax

Previous Caregivers Found…

- Informational needs during this time were met by health care professionals, rehabilitation professionals, community case workers, social workers, and peers.

EMOTIONAL SUPPORT

Feelings You May Be Experiencing At This Time:

There are many different emotions that family members and caregivers can experience. Previous caregivers in your position told us they:

- Felt more relaxed, and optimistic during this phase.
- Felt comfortable and able to share their feelings and emotions with their friends, family, and peers now.
- Felt support came from the social worker and rehabilitation team as opposed to the primary care doctors now.
- Wished for a greater sense of empathy from the health care professionals.
- Wished to interact more with peers.

If you feel as though the rehabilitation team or doctors are unaware of your needs, do not hesitate to discuss this with them. A social worker can also be a valuable source of support and guidance at this time.

This is a stressful time and you may feel as if any combination of these emotions has overwhelmed you. Please remember these feelings are normal. You are not alone.

DEPRESSION AFTER STROKE: THE STROKE SURVIVOR

Grief, extreme sadness and depression are very common among people who have had a stroke. Depression can affect anyone at any time.

Research shows that:

- Around half of all stroke survivors will experience depression
- Family members of stroke survivors often experience depression as well
- Depression is more common in the first year after stroke, but can happen at any time

What is Depression?

- Depression is common and affects about 1.3-1.7 million Canadians each year.
- Depression is not just a low mood or feeling sad, it's an illness that requires attention.
- Depression is often associated with an imbalance of certain chemicals in the brain.
- People with depression generally feel sad, down or miserable most of the time. They find it hard to function every day.
- Depression may be influenced by major life-changing events such as stroke, but can also be influenced by personal factors, such as bad experiences in the past or certain personality traits.

How to Tell if a Person is Depressed and Not Just Sad

A person may be depressed, if for more than two weeks they have:

1. **Felt sad, down or miserable** most of the time, OR
2. **Lost interest or pleasure** in most of their usual activities AND experienced symptoms in at least three of the following four categories:

1) Behaviour

- Stopped going out
- Not completing tasks
- Withdrawing from close family members and friends
- Relying on alcohol and sedatives
- No longer doing things they once enjoyed
- Unable to concentrate

2) Thoughts

- ‘I’m a failure’
- ‘It’s all my fault’
- ’Nothing good ever happens to me’
- ‘I’m worthless’
- ’Life is not worth living’

3) Feelings

- Overwhelmed
- Guilty
- Frustrated, angry or irritable
- No confidence
- Unhappy
- Indecisive
- Disappointed
- Miserable or sad

4) Physical

- Tired all the time
- Sick and run down
- Headaches and muscle pains
- Churning gut
- Sleep problems
- Poor appetite/weight loss

While some of the symptoms above may be related directly to the stroke, they are also signs of depression. Typically, depression will go on for weeks or months if left untreated.

Treatments for Depression

Research to date has not identified the best treatments for depression in people with stroke. Depression may be mild, moderate or severe and there is a range of effective treatments available for adults with depression.

A doctor may recommend physical exercise for preventing and treating mild depression, or psychological treatments and/or drug treatments for moderate or severe depression. Treatment can be recommended by your family member’s doctor, or he/she may be referred to a psychiatrist (a doctor who specializes in mood disorders).

Depression is treatable and with proper treatment, your family member can get back to everyday life and focus on his or her recovery from the stroke.

Psychological Treatments

Psychological treatments are sometimes called Talking Therapies:

- **Cognitive Behaviour Therapy** (CBT) helps to correct negative thought patterns. CBT is a structured program which recognizes that the way people think affects the way they feel. CBT teaches people to think rationally about common difficulties.

- **Interpersonal Therapy** (IPT) is a structured program with a specific focus on improving relationships. People with depression may sometimes be easily upset by other people's comments. They may feel criticized when no criticism was intended. IPT helps people find new ways to get along with others.

- **Grief counseling.** Grief is a normal reaction to loss. Grief counseling involves talking about the situation to help the person come to terms with loss and life changes.

Psychological Treatments Can Help To:

- Change negative thoughts and feelings
- Encourage the person to get involved in activities
- Speed the person's recovery
- Prevent depression from recurring
- Identify ways to manage depression and stay well.

Medications

If a person is only mildly or moderately depressed, psychological treatment alone may be effective. However, if depression is severe, medication is often necessary as well.

Medical research indicates that depression is often associated with an imbalance of certain chemicals in the brain. Antidepressants help rebalance these chemicals. Antidepressants take several weeks to have their full effect and should never be stopped unless a doctor is consulted.

How to Help Someone with Depression

People with depression do not usually get better by themselves. They need the help and support of their families and friends. Often it is a family member or caregiver who notices that the stroke survivor may have depression.

You Can Help a Stroke Survivor by:

- Encouraging the person to talk about the things causing distress
- Suggesting the person talks to a doctor or another health professional
- Assisting the person to make an appointment
- Going with the person to see a doctor or other health professional
- Following up after the appointment
- Encouraging or helping the person to become involved in social activities

It Would be Unhelpful to:

- Put pressure on the person by telling them to ‘snap out of it’ and ‘get their act together’
- Stay away or avoid the person
- Tell the person to stay busy or get out more
- Pressure the person to mask how they’re feeling with drugs and/or alcohol.

If you or someone you know needs help, talk to your doctor or another health professional about getting the right help.

PEER SUPPORT GROUPS: RESOURCES

Stroke Recovery Canada
Peer support groups and social programs geared to help stroke survivors survive and thrive after stroke. The Toronto Pathfinders are a peer support group and programs for those under the age of 50.
www.strokerecoverycanada.com or 416-425-4209

Ontario March of Dimes
March of Dimes screens and matches volunteers with people, who want the chance to socialize, take part in group activities, attend an event, or just chat over coffee.
Out trips & social clubs, one day events & excursions providing opportunities for people with disabilities to socialize in community settings.
Warmline- The Warmline is a confidential, peer support toll-free line for those affected by stroke (stroke survivor or family member/caregiver).
www.dimes.on.ca or 416-425-3463 or 1-888-540-6666

Generation S: Young Stroke Survivors
An informal, interactive information zone for younger stroke survivors.
www.orgsites.com/pa/generation-s

Self Help Resource Centre

The self help resource centre has a directory that can link you to over 500 self-help/mutual aid groups in the Greater Toronto Area
www.selfhelp.on.ca or 416-487-4355
http://www.selfhelp.on.ca/stroke/resources.htm

WHO TO TALK TO FOR MORE EMOTIONAL HELP

During this time, you may find that you may require additional emotional support as you prepare to welcome your family member home. You may begin to wonder how to cope with the upcoming challenges ahead, and you may wish to establish a strong support network for yourself during this time.

For additional emotional support, you may find it helpful to talk to one of the following individuals. For instance:

Talk to your Social Worker or a Counselor about…

- How to handle the situation (e.g. how to cope with stress, anxiety, fear, sadness)
- How to ask family and friends for assistance
- How to locate peer social networks for caregiving support
- How to ensure your own needs are being met during this time
- Your feelings overall – how to make sense of them, how to gain support, how to be understood

Talk to your Peers about…

- How they felt during this time – talking to those who have gone through a similar situation may help you handle some of the challenges you may face

Talk to your Doctor about…

- How to ensure your own needs are being met during this time

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in **Section 7: Notes and Additional Resources** and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

PRACTICAL SUPPORT

Common Practical Support Needs for Assistance

During this phase, you may wish to get support from the people around you. Given that you are now preparing to welcome your family member home, your focus will likely be on preparing your family member, yourself, and your home for discharge. During this phase, it is important to ensure that your needs are addressed, and it is important to talk to the members of your health care team (which includes your family and friends) so they can assist you.

Some of your needs may include:

- Setting up a home-safety assessment (ensuring your home is safe and well-prepared for the return of your family member)
- New safety equipment to help your family member
- Discharge planning – having someone enrol you in home care or long-term care (if required)
- Assistance with financial matters
- Transportation assistance

HOME SAFETY ASSESSMENTS & WEEKEND PASSES

In some circumstances, your **occupational therapist** may assess your home prior to your family member's discharge to provide recommendations for safety and independence (i.e. shower chair and ramps). You can ask the occupational therapist about this service if it is not offered to you.

Often times, your family member will also be able to go home for one or more weekends during acute care and/or inpatient rehabilitation. This is often referred to as a weekend pass. On a weekend pass you will be able to take your family member home with you for one or both days to begin "learning the ropes", and adjusting back into life at home. No health care professional will supervise you or assist you through this weekend. Please talk to your healthcare team members for more information about day and weekend passes. Generally, weekend passes are not allowed during the first weekend of your admission to the rehabilitation hospital, but may be available for the remaining weekends your family member is in in-patient rehabilitation.

WHO TO TALK TO FOR MORE PRACTICAL SUPPORT HELP

During this phase, caregivers appreciate when social workers, rehabilitation professionals, health care professionals, peers, and family assist them with practical things that need to be done (e.g., forms, arranging services, things around the home).

Here are some things you may wish to ask for:

Talk to a Rehabilitation Professional or Community Care Professional about…

- Follow-up (appointments to be made to monitor how you and your family member are doing)
- Weekend or weekday passes (what they are, how to make arrangements)
- Home-safety assessments (setting them up; assistance with what to do next)
- New equipment (what they are, where to get them)

Talk to your Family about…

- Providing assistance with household chores
- Visiting you and your family member at home
- Spending the night with you if required
- Assisting with meals for you and your family

Talk to your Social Worker about…

- Discharge planning
- Enrolling your family member in the appropriate long-term care or supportive living facility (if required)
- Financial assistance (Long-term disability; Canada Pension disability, etc.)
- Transportation assistance
- Home Care options

Talk to a Doctor or Nurse about…

- Home care assistance
- Allowing your family member to stay in the desired facility for an extended period if required
- Follow-up (appointments to be made regarding how you and your family member are doing)

Talk to Peers about…

- How to handle upcoming challenges (gain perspectives on some of their experiences, and receive any tips or support they may have to offer you)

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in **Section 7: Notes and Additional Resources** and approach the appropriate individual on your health care team to ensure that your concerns are addressed.
- Consult **Section 7: Notes and Additional Resources** for resources in your community pertaining to a wide range of supports.

TRAINING SUPPORTS

Common Training Needs

During this phase, you may wish to learn to help your family member with various tasks pertaining to symptom management, rehabilitation, and personal hygiene.

Some needs you may wish to address include:

- How to help your family member with memory problems
- How to help with your family member's mobility
- How to complete successful transfers
- How to help your family member maintain an adequate level of personal hygiene
- How to assist in the rehabilitation process once you return home
- How to take care of your family member
- How to assist with dietary or lifestyle changes

The following section outlines who to contact for these needs.

WHAT YOU CAN DO ABOUT YOUR FAMILY MEMBER'S MEMORY

Check with your family member's doctor or psychologist. In some cases, the memory problems can be treated medically. Remember that the brain works better if the whole body is as healthy as possible. This means your family member should be as physically active as possible, eat a healthy diet and drink plenty of non-alcoholic fluids. Make sure your family member gets enough rest, as simply being tired can cause poor memory.

- **Be organized**. Have a place for things that are easily misplaced (e.g. a key rack near the door or an eyeglass holder beside their chair). As soon as your family member is finished using an item, he or she can immediately return it to its place. A routine of doing things in the same way, at the same time can also help your family member remember.

- **Use short simple instructions** when asking the stroke survivor to do something to maintain attention and avoid feeling overwhelmed.

- **Use calendars or day planners** to make notes of things your family member needs to remember. He or she is more likely to remember things if they are written down.

- **Write down grocery lists or errands that need to be done**. After your family member picks up an item or finishes a job, he or she can cross it off. Place a list of the most important things to remember (such as emergency phone numbers, when medications should be taken, etc.) in several places, such as the fridge, the car, the bedroom, beside the phones, and the bathroom.

- **Use a small tape recorder** to have your family member record directions to the place where he or she is going. The tape recorder can also be used to record the steps to complete a task or project. Have your family member replay the tape as he or she goes, stopping it after each step of the project or segment of the journey.

- **An alarm clock, a watch or a stove timer** can help your family member remember things such as taking medications or returning phone calls.

- **Double-check important directions or instructions**. Say them out loud to help your family member remember. Keep repeating them at regular intervals.

- **Find triggers that jog your family member's memory**. For example, a picture of a toothbrush in the bathroom may remind him or her to brush his or her teeth.

- **The more your family member listens and pays attention to what's being said, the more likely he or she is to remember**. The key is to have your family member relax and to reduce background noise and distractions. Have your family member turn off the television or radio when talking to someone so he or she can concentrate on what is being said. When learning something new, he or she can go to a quiet place where there are no distractions. Your family member should pace him- or herself and try to learn only what he or she can manage at one time.

- **Even if your family member forgets people's names, if he or she recognizes their faces, he or she can still greet them**. If your family member is expecting to see people he or she hasn't seen for a while, look at some photographs of them together. The photos will help your family member to remember what they look like.

- **Watching the news on television or reading a newspaper** will help your family member to remain aware of his or her surroundings and what is happening. It can also help him or her to practice attention skills.

- **Every day, your family member should try to do exercises to sharpen his or her senses**. For example, he or she can try to memorize the phone numbers of the people who have phoned during the day. He or she can also try to recall a picture, a taste or a sound soon after your family member experiences it; then he or she can try again after a few hours or even a few days. At a restaurant, your family member can try to remember the items on the menu or the tastes of the foods he or she tries.

MOBILITY AND EXERCISES AFTER A STROKE

A common problem after a stroke is paralysis or weakness on one side of the body, such as in an arm and/or leg. It is important to understand that the stroke affects the brain and that the problem is not primarily in the muscle themselves. Although most improvement usually occurs in the first three months after a stroke, further recovery may continue for several years.

Role of the Physiotherapist After Stroke

Physiotherapists are specially trained to identify movement problems that may be caused by a stroke and can help to improve your family member's activities such as walking, keeping balanced and using his or her arm.

Common Problems

The problems which physiotherapists can help the stroke survivor with include:

- Weakness (paralysis) in leg and/or arm muscles.
- Loss of sensation or feeling. Sometimes there can be a loss of feeling in the skin or the joints themselves.
- Poor coordination or balance often as a result of weakness or loss of feeling.
- Muscle or joint stiffness. Muscles and joints easily become stiff if not used normally. Spasticity (muscles are continuously contracted or flexed) may also be present limiting movement.
- Shoulder pain or subluxation (bones move out of normal position) caused by weak shoulder muscles allowing the shoulder bones to move out of joint.
- Lack of energy (fatigue). If your family member has difficulty moving, he or she normally uses more effort and energy to move, which can lead to increased fatigue. However, fatigue can also be common when recovering from a stroke.

Therapy for Movement Problems

Your family member's therapist will be able to work with you and your family member to decide the best exercises and other therapy for your family member. Therapy may involve:

- Practicing tasks/activities that your family member has difficulty doing. This may include rolling over in bed, sitting up, standing up, walking and using his or her hand and arm.
- Often your family member will need to practice parts of the movement first. Eventually he or she will practice the whole movement, all with the guidance of his or her therapist.
- Exercises to improve your family member's strength, sensation (ability to sense or feel things), coordination, balance and/or fitness. Often this can be done as he or she practices normal activities such as standing up or walking.

- Exercises that use electrical stimulation and other equipment (eg. treadmills) may also be used as part of your family member's therapy to help improve his or her ability to move.
- Having your family member join a fitness centre or club in the community to keep him or herself fit. Often after a stroke, fitness levels drop, so it is important that your family member keep as active as possible in the long-term. Talk to your family member's therapist about whether this is right for them.
- Stretching or supporting your family member's muscles to reduce their stiffness or pain. Often when muscles are not being used normally they get stiff and can also become painful. It is important to keep the muscles flexible.
- Teaching your family member how to safely walk which may include the help of certain aids like a walker or cane. Never use a cane or walker without getting advice from your family member's physiotherapist first. Some people are better avoiding the use of these supports early after a stroke as it changes the way muscles learn to move again and limits recovery. Your family member's therapist will help determine if he or she needs them.
- Limiting the use of your family member's good arm to encourage use of the affected arm. Research has found that by forcing your family member to use his or her affected arm, he or she can improve the extent of recovery. It is important to seek the advice of your family member's therapist first.

What Can I Do?

Research has found that the more your family member does, the better he or she gets. The physiotherapist can give you advice on what is best for your family member to do by him or herself or with your assistance. Your family member should then practice throughout the day what he or she has learned. You may also need to check with a doctor in case there are other medical conditions (e.g. heart condition), which may limit the amount of activity which is safe to do.

Ongoing exercise will help maintain the movement your family member regains after a stroke to keep him or her as healthy as possible. You may consider having them join a local gym or finding an exercise group (e.g. walking group) if he or she would like to participate. Remember exercising helps with your family member's movement as well as reducing his or her risk of further strokes such as reducing blood pressure. Exercising is also known to help your family member feel more positive and improve his or her energy levels.

COMPLETING SUCCESSFUL TRANSFERS

Safe lifting and transferring is dependent on good technique, proper equipment and selecting the method that best suits the stroke survivor. An appropriate lift or transfer should be safe for the patient, allow the patient to assist as able, and provide the least work for the caregiver by making use of good body mechanics and/or equipment. Caregivers should obtain training for transfers from a health care professional like a physiotherapist, an occupational therapist, or a nurse.

By placing less physical demand on the caregiver, there is less risk of back or shoulder injury.

When performing any lift or transfer, it is important to pay attention to posture to eliminate twisting, reaching or stooping. Patient handling and assistive devices are designed to make the job easier. With proper body mechanics and when used correctly, the devices outlined below can greatly reduce the risk of injury to the caregiver.

Transfer Belt

The belt allows you to control the movement of your family member during the transfer. It can be used for one-person pivot/knee block transfers, two-person side-by-side transfers, and patients who need walking support. The belt is worn at the waist by the patient, and provides a handhold and secure grip.

The stroke survivor should be flexible enough to be able to stand; able to cooperate and follow directions; capable of gripping a handle with at least one hand and sitting unassisted on the edge of a bed or chair; and able to partially bear weight on one or both legs.

Sliding Device

If a stroke survivor is unable stand up to transfer from bed to wheel chair, a sliding device such as a slide board can be used. The board is rigid and strong enough to fill gaps between two surfaces. Some models have moving sliding sections. The board allows the patient to assist with the transfer.

Roller Sheets

Durable, tubular sliding sheets are designed with materials that alleviate resistance during movements. They are used to move a patient who is laying or seated up or down in the bed, turn a patient, and reposition or pivot a patient in bed.

If the patient does not fit properly on the sheet, or is too large for the width of a large sheet, he or she is probably too large to move without a mechanical device.

Mechanical Lift

A mechanical lift can be used for transferring from bed to chair, bed to stretcher, bed to commode and floor to bed. These lifts are used to move stroke survivors who are unable to help themselves during a transfer, if a stroke survivor is unable to bear weight, or is particularly heavy. Two types of mechanical lifts are detailed below.

Ceiling Lift - Does not require floor space and can be used by one caregiver. The ceiling lift is battery powered, and can be used for all types of lifts/transfers: fallen patients, bathing, toileting, bed to chair, etc. They are used for totally dependent patients, and those who require special medical considerations due skin integrity and broken bones, for example. There are special slings for toileting, bathing and orthopedic needs.

Hoyer Lift - To use this type of lift, the bed must be 4-6 inches off the ground, so the base of the lift can fit under it. A sling that provides adequate head and neck support is used with this type of lift. Hoyer lifts are not to be used for bathing as they cannot be positioned close enough to the tub.

Standing/Bent Pivot

Standing/bent pivot transfer devices are used for those who have trouble standing and/or transferring on their own.

With this device, the user is bent over a chest pad and kneepad, via a strap underneath the legs, which is connected to a rotation lever. They are available in manual and powered versions. Stroke survivors must be able to bear weight through one or both legs, and have some upper body strength and control.

Sit-to-Stand Device

Used to transfer patients between two seated postures, the sit-to-stand device is designed to support only the upper body.

These devices have a wide adjustable base, sling materials that are extremely strong, and most have an electrical motorized lifting mechanism. The newer devices can transfer patients up to 300 lbs. The stroke survivor should be able to bear weight through one leg and hold the frame with at least one hand.

WHO TO TALK TO FOR MORE TRAINING HELP

Talk to a Nurse about…

- How to help your family member with his or her personal needs (how to assist with hygiene, toileting, changing a catheter)
- How to perform successful transfers with your family member (i.e. getting them out of bed and onto a chair, or vice versa)

Talk to a Rehabilitation Therapist about…

- How to perform successful transfers with your family member (i.e. getting them out of bed and onto a chair, or vice versa)
- How to help your family member with his or her personal needs (how to assist with hygiene, toileting, changing a catheter)
- Talk to the Occupational therapist specifically about your family member's cognitive and perceptual deficits, and strategies for management.
- Speak with a physiotherapist about assisting your family member's mobility and exercises.
- Talk to the speech language pathologist about strategies for communicating with your family member if aphasia is a concern.

Talk to a Doctor or Dietician about…

- How to assist with recommended dietary or lifestyle changes as outlined by this individual (how to make sure your family member's dietary needs and medication schedules are met and adhered to)

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in **Section 7: Notes and Additional Resources**, and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

Support Needs Management Form

1. What supports do you need right now?
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2. What resources can you draw upon to get this support?
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3. What resources will I try first?
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4. How did this work out?
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5. If it didn’t work out, what other resources should I try?
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6. Accept that this support need may not be met right now.

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    -
6. Accept that this support need may not be met right now

Chapter #5
THE FIRST FEW MONTHS AT HOME

Now that your family member has returned home, you may notice that responsibility has been shifted out of the hospital or rehabilitation environment, and away from health care professionals, towards you, the primary caregiver. You are now learning to adapt to your new lifestyle at home with your family member. You are “learning the ropes” while you practice the skills you learned while preparing for your family member’s return. You may find that you wish to have more time for yourself, and respite services as well as home care may be options you may wish to consider. You also may find that you are faced with some unexpected challenges. As such, you will now receive the information and resources on how to get the supports you need, now that you and your family member are back home.

This Chapter at a Glance:

Informational Support

- Home Care
- Emergency Contacts
- Who to Talk to for Help

Emotional Support

- Feelings You May Experience at this Time
- Who to Talk to for Help

Practical Support

- Common Practical Needs for Assistance
- Respite Care
- Who to Talk to for Help

Training Support

- Common Training Needs at this Time
- Rehabilitation Exercises
- Pain & Symptom Management
- Who to Talk to for Help

HOME CARE

Home care is a group of services that allows people with health problems to live as well and as independently as possible, in their own homes and communities.

The care provided at home can come from a number of sources — family members, friends, neighbours, community volunteers, health professionals, paid care workers, government-run and volunteer-run community health, social services agencies and private care agencies. A new and growing source of home care is tele-home care or telehealth, which uses information and communication technologies to deliver patient care at home.

Most home care services are publicly funded but a growing proportion is paid for by private insurance plans, charitable organizations and by individuals out of their own pockets. Patients and families also bear the indirect costs of lost employment opportunities, lost wages, unpaid family labour as well as the psychological, social, physical and economic burdens.

TYPES OF HOME CARE SERVICES

Professional Nursing and Therapeutic Services

Clinical care provided by registered health care professionals

- Nursing
- Physiotherapy
- Occupational therapy
- Speech therapy
- Social work
- Personal support workers
- Nutrition counseling

Medical Services

- Intravenous antibiotic therapy
- Dialysis
- Life support systems
- Ventilator assistance
- Tube feeding

Personal Care Services

One-on-one care provided by family members, home care workers, community volunteers

- Assistance with activities of daily living
- Assistance with personal hygiene (e.g., bathing)

Support Services

A wide range of homemaking and personal support services provided by family members, friends, neighbours, government agencies, community agencies and organizations, private agencies and individuals.

- Homemaking
- Companionship services
- Volunteer visiting
- Transportation
- Meal programs delivered to the home
- Community dining
- Home maintenance
- Respite care
- In-home respite — including overnight care
- Adult day programs — care away from home during working hours
- Institutional respite — the ill person stays for a weekend, a week or longer
- Palliative care: home care for someone with a progressive, life-threatening illness

EMERGENCY CONTACTS

If you or the stroke survivor experience an emergency situation please **call 911 immediately**. Even if you are unsure if the situation warrants a 911 call, please call just to be sure. A representative from the emergency hotline can guide you through the situation and assist you until medical personnel arrive.

Once you have called 911, or if the situation is not a medical emergency you may want to call a friend, family member, or neighbor for support.

Telehealth Ontario is another great source for medical help. Telehealth Ontario is a free, confidential telephone service you can call to get health advice or general health information from a Registered Nurse. The number for telehealth is **1-866-797-0000**

For advice on emotional, psychological, or medical non-emergencies, feel free to contact your local family doctor. You may have written this number down in the My Appointments Calendar, the My Notes section, or the My Rehabilitation Team: Contact Information section of this binder.

Also, feel free to contact your local **Community Care Access Centre (CCAC)** for help or advice**.** CCACs are local organizations that can help you access government-funded home care services and long-term care homes. They also help people to navigate the array of community support and health agencies in local communities.

Please visit: **http://www.ccac-ont.ca/**

WHO TO TALK TO FOR MORE INFORMATIONAL HELP

As you have now taken on the role of being the primary caregiver, you may face unanticipated challenges in the home environment. You are now responsible for a majority of the treatment plan, and as such, you need to be well-equipped with the resources and supports to assist you throughout this phase.

For additional informational resources, you may find it helpful to talk to one of the following individuals for various concerns. For instance:

Talk to your Rehabilitation Professionals about…

- Care processes at home (what to do next, how to handle upcoming challenges, how to adapt according to your family member's new lifestyle)
- Resources pertaining to home care, respite services, or long-term care options if required
- Your family member's level of independence (what he or she can do unsupervised versus what should be supervised or requires assistance)
- Aphasia information (how to cope with communication challenges; tips and recommendations to assist you in communicating with your family member)

Talk to your Peers about…

- Care processes at home (what to do next, how to handle upcoming challenges, how to adapt according to your family member's new lifestyle)

Talk to a Case Manager or Social Worker about…

- Resources pertaining to stroke or aphasia support, peer support groups, other networks or resources you may need

Previous Caregivers Found…

- Informational needs during this time were met by health care professionals, rehabilitation professionals, community case workers, peers, and community resources.

EMOTIONAL SUPPORT

Feelings You May Be Experiencing At This Time:

There are many different emotions that family members and caregivers can experience. Previous caregivers in your position told us they:

- Felt compassion from others around them
- Felt others understood their situation better now
- Wondered if they were doing everything right
- Felt a connection with peers in their position
- Felt peers were a good source of support, and that peers could reassure the feeling that caregiving was often done by “trial and error”
- Felt a need for health care professionals to be more interested in how they were doing

Please know that these feelings are normal. This is a stressful time and you may feel as if any combination of these emotions has overwhelmed you. Remember you are not alone.

If you feel as though the rehabilitation team or doctors are unaware of your needs, do not hesitate to discuss this with them. A social worker can also be a valuable source of support and guidance at this time.

WHO TO TALK TO FOR MORE EMOTIONAL HELP

During this time, you may feel quite alone and that you require additional emotional support as you adjust to having your family member back into the home environment. You may be wondering how to cope with the day-to-day challenges you face.

For additional emotional support, you may find it helpful to talk to one of the following individuals. For instance:

Talk to your Social Worker/Case Manager about…

- How to handle the situation (e.g. how to cope with stress, anxiety, fear, sadness, uncertainty)
- How to ask family and friends for assistance
- How to connect with peers for caregiving support
- How to ensure your own needs are being met during this time
- Your feelings overall – how to make sense of them, how to gain support, how to be understood

Talk to your Peers about…

- Visiting you or your family member
- Connecting and sharing your experiences through a support group
- Sharing your experiences and learn how other caregivers handle the day-to-day challenges
- Needing reassurance that life does get better over time
- Gaining a sense of encouragement – that everything will be alright

Talk to your Health Care Professional about…

- Ensuring your own needs are being met during this time
- Your feelings overall – how to make sense of them, how to gain support, how to be understood

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in **Section 7: Notes and Additional Resources** and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

PRACTICAL SUPPORT

Common Practical Needs for Assistance

During this phase, you may wish to be provided with some assistance from the people around you. Given that you have now had some experience being a primary caregiver, your focus is on how to cope with upcoming challenges, and how to ensure that you are living a life that is beneficial for your family member as well as yourself. You may find that you need to ask other people for support for various matters.

Some of your needs may include:

- Needing home care
- Needing time to run errands outside of the home
- Needing time for yourself
- Requiring someone to assist you to get things done at home or outside of the home
- Having someone alternate caregiving activities with you occasionally
- Being linked with community resources
- Being provided with the opportunity for follow-up
- Being linked with resources pertaining to home care, respite services, long-term care

RESPITE CARE

Caregiver Respite

There are various services offered to help you, the caregiver, to have a break or do some things for yourself. These services are called respite care services, and there are three ways that they can be provided: In-home respite, Adult day programs, and short-stay respite.

In-home Respite

This service brings someone to your own home to provide help with care (e.g. personal care) and to allow a regular family caregiver to take a break.

If you are eligible for services coordinated by the CCAC, in-home respite is paid for by the Ministry of Health and Long-Term Care. Otherwise, these services may be available from various providers, in which case you will likely have to pay a fee for these services.

Adult Day Programs

These programs provide social and other therapeutic activities at a location outside your home. Programs usually include planned recreation and physical activities, meals, transportation to the program and some personal care. There can be a consumer fee for this service to cover the meals and transportation costs (approximately $15 to $50 per day). Subsidies may be available.

Short-Stay Respite

The temporary care provided in a long-term care home under "caregiver respite" is considered a "short stay" and is subject to an accommodation rate which is different from the regular (i.e. long-stay) home accommodation rate. There is a consumer fee for this service. For more information on "short stay" costs, see http://www.health.gov.on.ca/english/public/program/ltc/15_facilities.html

If you need a slightly longer break from your Care-giving duties (e.g., to take a vacation or visit family), you can call your local CCAC and arrange for your loved one to stay in a long-term care facility temporarily.

The above services can all be arranged by your local CCAC (http://www.ccac-ont.ca/), or for more information you can contact The Ministry of Health and Long-Term care at **INFOline** at 1-866-532-3161 (Toll-free in Ontario only)

Informal Respite Care

Informal respite care can also be provided by family members, friends, or neighbors. Having a friend watch over the stroke survivor while you run errands, or take a much needed break will help you maintain good health, while keeping the stroke survivor safe.

WHO TO TALK TO FOR MORE PRACTICAL SUPPORT HELP

During this phase, previous caregivers appreciated when peers, case workers, family, friends, and rehabilitation professionals assisted them with other matters that are not quite informational or emotional supports.

Here are some things you may wish to ask for:

Talk to a Case Manager about…

- Home care options (home care visits, long-term care options, respite services)
- New equipment to assist you at home
- Linking you with community resources (support groups, financial services, other services)

Talk to a Rehabilitation Professional about…

- Home care options (home care visits, long-term care options, respite services)
- New equipment to assist you at home
- Follow-up appointments regarding your family member's improvements over the long term
- Getting physiotherapy treatments at home if required

Talk to your Family or Friends about…

- Alternating caregiving activities (ensuring you have more time to run your own errands or have time for yourself; taking your family member to rehabilitation sessions if required)
- Visiting you and your family member
- Providing meal assistance at home if required

Previous Caregivers Found that…

- Relaxation sessions gave the caregiver a chance to get away and reduce some tensions
- Transportation services were needed during this time- please see the Notes and Additional Resources Section for more information.
- Having time to run errands outside of the home or having time to oneself was regarded as very beneficial.

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in **The Notes and Additional Resources section** and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

Consult The Notes and Additional Resources section **for resources pertaining to a wide range of supports.**

TRAINING SUPPORT

Common Training Needs

During this phase, you may wish to learn new strategies to help your family member with various tasks pertaining to rehabilitation, and personal hygiene. Moreover, you may wish to receive feedback that the strategies you are using are being done properly, and are benefiting your family member.

Some needs you may wish to address include:

- How to help your family member to exercise at home
- How to help your family member manage their pain
- How to help your family member be more independent
- How to continue physiotherapy at home
- How to assist your family member who has aphasia with communication strategies

The following page outlines who to contact for these needs.

EXERCISES TO CONTINUE AT HOME

The ability to move around is basic to the level of independence your family member can achieve and maintain after a stroke. Walking, bending and stretching are forms of exercise that can help strengthen your family member's body and keep it flexible.

Exercising is an important way to help your family member regain previous functioning. Exercising body parts affected by the stroke may be difficult however, therefore it is strongly encouraged that you speak to your physiotherapist, occupational therapist, recreational therapist, or health care professional before beginning any exercise routine.

Type of Exercise

Mild exercise, which should be undertaken every day, can take the form of a short walk or a simple activity like sweeping the floor. Stretching exercises, such as extending the arms or bending the torso, should be done regularly. Moving weakened or paralyzed parts can be done while seated or lying down. Swimming is another beneficial exercise if the pool is accessible and a helper is available.

A physical or occupational therapist can help with such problems as muscle tightness, low endurance or the inability to sit up from a lying position. The exercise program should be written down, with illustrations and guidelines for a helper as necessary.

Fatigue

Fatigue while exercising is to be expected. Like everyone else, your family member will have "good" and "bad" days. Your family member can modify these programs to accommodate for fatigue or other conditions. Avoid overexertion and pain. However, it may be necessary that your family member tolerate some discomfort to make progress.

Walking Aids

A physiotherapist should make recommendations for the appropriate device and the progression to less supportive equipment.

- Training in safety procedures and proper technique for use is essential.
- The walker, which provides the most support, requires the use of two hands. It can be fitted with wheels if it is too difficult to lift between steps.
- The hemi-walker, less supportive than the walker, is used with one hand on the unaffected side of the body. It has a strong base of support and is quite stable, but requires a large, open walking space for maneuvering around objects.
- The quad cane, a four-footed device, provides a broad base of support, although less than either the walker or the hemi-walker. It is recommended for individuals with fairly good balance and weight-shifting ability who require additional stability.
- The standard cane provides minimal support for the person who needs only occasional assistance with balance, or while walking on uneven terrain, or when fatigued.

PAIN AND SYMPTOM MANAGEMENT

After a stroke, your family member may have trouble with movement because of paralysis or muscle weakness. If they are not used, muscles and limbs may stiffen and tighten. This can cause painful joint stiffness.

Another problem your family member may experience is spasticity or muscle stiffness in his or her affected limb. A spastic limb is difficult to move and it may hurt when being moved. These difficulties may interfere with everyday activities or with your family member's physical therapy.

If one arm is weak and hanging down, it can pull on the other shoulder muscles. This can contribute to a painful shoulder (sometimes commonly referred to as a "frozen shoulder"). The paralyzed arm should be supported when your family member is standing or sitting up to keep the blood circulating.

How Can You Lessen the Pain?

Usually, muscles are not completely paralyzed by a stroke. It is important to work with your family member's therapist to regain as much movement and control as possible. Pain can be caused by the stress on the muscles and joints because of muscle weakness and stiffness. Keeping your body and joints properly positioned and supported can go a long way to preventing pain.

Your family member should never be lifted by his or her affected arm or shoulder. This could cause serious damage to his or her arm or shoulder. Your physiotherapist can help your family member to regain mobility and manage any pain he or she might have. This may involve special exercises or functional activities to retrain the weak muscle, or to help control posture and movement. You, your family, or friends may be able to assist your family member with these. Your physiotherapist can give you some ideas.

What to Do if the Pain Gets Worse?

Tell the doctor or therapist about your family member's pain, especially if it comes on suddenly. Follow his or her advice about looking after the affected part of your family member's body. Do not let his or her joints get too tight or stiff. Appropriate activity can help to reduce the pain, even if he or she does not regain all of his or her normal movements.

Care of your Family Member's Affected Hand

A stroke can cause lack of sensation or movement in the hand. Because the hand is not being used, fluids may pool in it. This causes swelling and may result in pain and skin problems. To reduce hand problems:

- When sitting, make sure your family member's affected arm is supported on a lap tray or arm trough. The hand should be positioned in front, with the fingers opened and the wrist supported.
- Use foam wedges or arm supports placed on the tray to elevate the hand and reduce swelling.
- Try having your family member use his or her other hand to gently bend and open the fingers of his or her affected hand, and to place the hand on the supporting surface.
- If the hand is extremely contracted, tight or spastic, do not force it open.
- Gently stroke the back of the hand and wrist. This should help the fingers start to open.
- Do not squeeze soft balls. Squeezing a ball encourages the hand to close and the fingers to tighten.
- To ensure optimal positioning of the hand and arm, talk to your family member's occupational therapist about splinting or other positioning devices.

Care of your Family Member's Feet

Changes in the way a person walks are common after a stroke. These changes can eventually lead to problems with the feet. However, most of these problems can be avoided by taking a few very simple steps:

- Have you or your family member check your family member's feet every day for cracks, blisters, sores, swelling or any changes in skin colour. This is especially important if your family member has diabetes, or circulation problems or reduced sensation in the feet. Any sign of infection such as redness, swelling, or discharge should be seen by your family member's family doctor or chiropodist (foot specialist) immediately.
- Your family member should always wear socks. Socks made of natural fibres (e.g. cotton or wool) will help to absorb sweat and keep the feet cool and dry.
- Poorly fitting shoes can cause foot problems. When buying shoes make sure the shoes are wide and deep enough, but fit snugly at the heel. Shop for shoes at the end of the day, when your family member's feet are naturally swollen and have both feet measured.
- Ideal shoes for a stroke survivor have low heels, shock absorbing soles, laces or Velcro®, deep, rounded toe boxes, and leather or canvas uppers.

Many stroke survivors require special footwear to give support and to accommodate braces or orthotics (devices that provide additional support and straightening of the foot within the shoe). Footwear advice, modifications and orthotics can be prescribed by a chiropodist or in consultation with the physiotherapist.

Skin Care

The skin is the body's largest organ. It provides a defense against infection. It is important to keep your family member's skin healthy. A number of factors can increase a stroke survivor's risk of skin damage such as: loss of sensation or the ability to move, dry skin, poor nutrition, dehydration, or friction on the skin because of improper positioning. Moisture from perspiration or incontinence can also irritate the skin.

What can be done to prevent skin damage:

- Check the stroke survivor's skin each day.
- Pay particular attention to bony areas such as heels, hip bones and elbows.
- Look for redness and signs of abrasion, scraping or bruising.
- Regularly wash with mild cleansing agents. Clean soiled skin promptly.
- Do not scrub the skin. Be sure to rinse off all soap residue, which can irritate the skin.
- Treat dry skin with moisturizers.
- Minimize your family member's skin exposure to moisture from incontinence, perspiration or wound drainage. Ask a nurse about ways to protect the skin, such as using incontinence products, wound dressings or barrier creams.
- Use proper positioning, mobility, transfer and turning techniques to minimize skin injury due to friction. Your family member's nurse or physical therapist can help you learn proper positioning and mobility techniques.
- Ensure that your family member does not sit or lie in one position for long periods of time.
- If your family member is confined to his or her bed for long periods of time, a water pillow, thick foam or specialty boot can be used to relieve pressure on the heels.
- Make sure your family member is eating a healthy diet and drinking enough fluids. Ask your dietitian for help.
- If the problem persists, talk with the stroke rehabilitation team about special devices that could help, such as pressure-reduction mattresses, alternating air mattresses, elbow pads or pressure reduction seat cushions for wheelchairs.

Fatigue

Caring for a family member with stroke and having to learn new ways to do things can be tiring. If fatigue (feeling tired) is a problem for you and/or your family member, here are some helpful tips:

- Ensure you, and your family member eat a healthy balanced diet that follows *Canada's Food Guide to Healthy Eating*.
- Drink plenty of fluids.
- Plan your family member's day to take advantage of the times when you have the most energy.
- Every day, make a 'to do' list and decide which jobs are the most important to you and your family member. On days when you and your family member feel tired, do only the things you must. On high energy days, you can both work your way a little further down the list.

- If necessary, take short rest breaks when you become tired.
- Ensure you and your family member do something you enjoy every day.
- Know when to ask for help. Don't think you or your family member have to do everything yourselves.

Memory and Problem Solving

Even a mild stroke can affect your family member's ability to learn and to remember. He or she may have trouble:

- ***Learning and remembering new information*.** Your family member may be able to remember events that happened before the stroke, but have trouble learning and remembering new information. For example, someone with this problem might remember how to play a card game they played in the past, but be unable to learn new games.
- ***Applying information to a new setting (therapists call this "generalizing" the information)*.** For example, your family member may learn how to move from a wheelchair to a bed while in the hospital, but is unable to do the same task at home.
- ***Doing something without being reminded or prompted (therapists refer to this as "initiating actions").***
- ***Becoming confused or lost in what should be a familiar place or losing track of the time or date.***

The first thing you or your family member should do is to talk with his or her doctor. It is important to know what is causing the memory problem. Memory problems can be caused by many things. Some of these can be treated. For example, being depressed or eating an unhealthy diet can affect your family member's memory. In these cases, depression treatment for your family member or changing his or her diet can help his or her memory improve.

Problem solving is a complex activity that involves both memory and planning.
If a stroke has affected your family member's memory or his or her ability to make decisions, it may be hard for your family member to organize his or her thoughts.

Some stroke survivors have limited attention spans. Attention span refers to how many pieces of information he or she can remember, use, or act upon.

Having difficulty remembering things or solving everyday problems can be upsetting. It can affect many parts of your family member's life, such as:

- ***Your Family member's Emotions*:** Having trouble remembering or solving problems can make your family member feel that he or she is losing his or her independence. Your family member's self-esteem may suffer. He or she may feel anxious or depressed.

- ***Your Family member's Behaviour*:** Stroke can change a person's behaviour. If certain parts of the brain are damaged from a stroke, your family member may become slow and cautious or he or she may show poor judgment (for example, say or do inappropriate things). He or she may also become more irritable (for example, losing their temper easily).
- ***Your Family member's Social Life*:** Your family member's social life may suffer if he or she keeps forgetting appointments and social engagements. If people stop visiting or inviting your family member to events, he or she may begin to feel lonely and isolated.
- ***Your Family member's Hobbies*:** Even activities and hobbies that were once enjoyable may seem overwhelming if your family member has a memory problem.
- ***Stroke Survivor's Self-Care*:** Some people with memory problems have difficulty remembering to dress appropriately or to brush his or her hair or teeth.
- ***Your Family member's Safety*:** Sometimes, if your family member is forgetful, it can be more than a nuisance — it can be dangerous. Things to watch out for your family member include:
    - Leaving on heating devices such as irons, electric blankets and heating pads
    - Being accidentally burned by hot water faucets that are not clearly marked as "hot" or water heaters that are set too high
    - Confusing food items with toxic substances such as cleansers and disinfectants
    - Getting your family member's medications confused (e.g. taking too many pills or taking the wrong pills at the wrong time)
    - Forgetting to chew food thoroughly, which can lead to choking
    - Some stroke survivors experience memory problems and disorientation that cause them to wander away from the home
- ***Your Family member's Ability to Drive*:** Every stroke survivor should get a doctor's permission before he or she goes back to driving a car. In some provinces, a re-test or Driver Rehabilitation course may be required. A stroke can cause physical, perceptual or judgment problems that can make driving dangerous.

WHO TO TALK TO FOR MORE TRAINING HELP

Talk to a Rehabilitation Professional about…

- How to help your family member's level of independence (how to assist with mobility, how to perform various exercises, how to improve your family member cognitive functioning, or helping your family member walk).
- How to continue therapy at home (either with a professional or by yourself)
- How to communicate with your family member with aphasia (you may also wish to visit The Aphasia Institute at www.aphasia.ca)
- How to complete successful transfers (i.e. getting him or her out of bed and onto a chair, or vice versa)

Talk to a Speech-Language Pathologist about…

- How to communicate with your family member with aphasia

Talk to an Occupational Therapist about…

- Your family member's cognitive and perceptual function and strategies for dealing with these challenges

Previous Caregivers Found it Helpful to…

- Talk to rehabilitation professionals about specific training techniques
- Talk to peers allowed for the sharing of techniques and exercises
- Talk to peers and rehabilitation professionals to obtain feedback on your caregiving activities

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in **The Notes and Additional Resources section**, and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

Support Needs Management Form

1. What supports do you need right now?
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5. If it didn’t work out, what other resources should I try?
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6. Accept that this support need may not be met right now.

Support Needs Management Form

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Chapter #6
GETTING ON WITH LIFE IN THE COMMUNITY

During this phase, most caregivers have adapted to providing care in the home and stroke survivors' have adjusted to living back at home. Hopefully you are also feeling more confident in your caregiving abilities, and are now looking for ways to have you and your family member participate in social activities, events, employment, and travel. You may find that you are taking things "one day at a time" and are looking for additional supports in the community to assist you.

This Chapter at a Glance:

Informational Support

- Intimacy
- Returning to Work
- Who to Talk to for Help

Emotional Support

- Feelings You May Experience at This Time
- Who to Talk to for Help

Practical Support

- Common Practical Needs for Assistance
- Peer Support Groups & Online Resources
- Who to Talk to for Help

Training Support

- Common Training Needs at this Time
- Who to Talk to for Help

INTIMACY

Sexual desire is a natural human drive, and it is understandable that you and your family member would be interested in fulfilling this together, especially if you were sexually active before the stroke. However, physical changes can interfere with intimate relations with others. Your family member may not have feelings on one side of his or her body, or he or she may have problems speaking. Some men have difficulty getting an erection or discharging semen. Women may have less feeling in the vagina and more dryness. Medications such as tranquilizers, high blood pressure medicine and sleeping pills may also reduce your family member's sexual ability and desire.

Feeling Nervous About Resuming Intimacy?

Being anxious about intimacy is normal. Sexuality is closely linked with the way you see yourself. If the stroke has changed your family member's appearance, they may wonder if you are still attracted to them. As well, either of you may be depressed and not interested in giving or receiving attention. All these things can lead to anxiety and may cause you both to avoid intimate relations. However, delaying intimacy only increases anxiety.

Returning to a satisfying sex life may require some changes. Both you and your partner will need to adjust to the physical changes in your family member's body. Accepting these changes may take time, effort and honest communication. If you feel uncomfortable discussing your sexual feelings with each other, ask your doctor to refer you to an appropriate professional. Your social worker or mental health professional may also be able to help.

Don't feel that you must have sexual intercourse to show love for your partner. Hugging, kissing, caressing, massaging and touching all show love and affection. Find out different ways to please each other. Affection for each other is important.

- Stay as attractive as you both can through good grooming and personal hygiene.
- Plan in advance for intimacy. Choose times when you are both rested and will have no interruptions. Also, set aside plenty of time. That way, if you or your family member has slowed sexual responses, you can allow yourselves enough time for lovemaking.
- Don't worry about your partner having another stroke during intercourse. Sexual activity raises your blood pressure, but no more than walking up a short flight of stairs.
- Try relaxing together before you begin. For example, give a massage, listen to music or soak in a bath.
- Some couples enjoy sharing intimate books or movies. Talk with your partner to see if this would be helpful.
- Experiment with new ways of having sexual relations if your family member has paralysis or loss of sensation. These adjustments are not always easy. But it's important to make your sexual activity as easy and comfortable as possible.
- Use a water-soluble lubricant such as K-Y Jelly, if you or your partner has vaginal dryness.
- Do not use petroleum jelly — it doesn't dissolve in water and can cause vaginal infection.

- Try to empty your bladders before sexual activity. Limiting fluids like water, coffee and juices two hours before sexual activity can decrease the amount of urine in the bladder.
- Some of drugs prescribed to stroke survivors, such as blood pressure lowering medications or antidepressants, can affect the urge or ability to have sex.
- Avoid using alternative herbal remedies in an attempt to restore sexual function or interest. Many herbs interact with the medications commonly used by stroke survivors.

RETURNING TO WORK

If you or your family member were employed when your family member had the stroke, you may be worried about whether either of you will be able to return to work. This is especially true if your family member is a younger stroke survivor. As you think through this issue, here are some factors to consider:

- The kind of job you had
- The effects of the stroke on your family member
- Your family member's general state of health
- Your age

Ready to Retire?

If you are close to, or over, retirement age, you or your family member may not want to return to work. You both may feel that you would rather spend more time with your family, pursuing hobbies or interests you enjoy, or volunteer work. In this case, it is quite possible that a retirement pension, employment insurance, or disability pension can help you financially. To help you find out what benefits your family member is eligible for, talk with:

- Your family member's social worker
- Your family member's former employer's human resources department
- If your family member is a member of a union, his or her union representative
- Your local Employment Insurance office

Going Back to Work

If your family member wants to go back to work, talk with members of the stroke rehabilitation team. The occupational therapist, psychologist or social worker can help determine if your family member can go back to his or her old job. Maybe your family member will have to change the way he or she works. For example, this may include learning to do things with one hand. Some stroke survivors will also choose to find another job that may be more suitable to their new needs.

Employers have a responsibility to make reasonable accommodations in the workplace or in job descriptions for employees who become disabled. These accommodations can range from very simple things, such as creating a handicapped parking space near the door, or more complex changes, such as allowing your family member to work a flexible schedule, or providing special equipment so your family member can do his or her job. If your family member wants to return to his or her job begin by talking to any of the following members of the stroke rehabilitation team:

- your family member's social worker
- psychologist
- occupational therapist
- vocational rehabilitation therapist

- You will also want to talk with your family member's employer's human resources department and, if applicable, your family member's union representative.
- The Web site www.enablelink.org also has information on employment law.

Changing Careers

After a stroke, your family member may consider changing careers. Maybe he or she feels he or she cannot return to his or her previous type of work. Or maybe your family member feels that he or she has been given a chance to try something new.

Choosing a new career can be exciting. Spend some time exploring new ideas.
Be realistic about disabilities or problems created by your family member's stroke, but focus on the positive. Starting a new career demands that you and your family member be patient, positive, proactive and persistent. Don't expect overnight success. But don't give up without giving it your best. You can support your family member in making a change. You might also want to call upon members of the stroke rehabilitation team such as the social worker, occupation therapist, or vocational rehabilitation therapist.

If you or your family member thinks that retraining would help, contact your local Human Resources Development Canada office. Some offices provide aptitude testing and résumé writing workshops, as well as retraining programs.

Aptitude testing, career counselling and résumé-writing services are also provided through many community colleges and Boards of Education continuing adult education programs. There are also private agencies that can provide similar services.

Contact your local office of the March of Dimes (www.marchofdimes.ca) for information about their programs for people with disabilities. The organization offers job training, as well as financial assistance for needed assistive devices.

WHO TO TALK TO FOR MORE INFORMATIONAL HELP

Now that you have adapted to being the primary caregiver, you probably are accustomed to dealing with many different challenges. You are now well on your way to becoming a very successful caregiver, as you have had months of experience behind you. Even so, there may still be new or unexpected needs which you encounter, and so we want to provide you with some suggestions regarding who you can talk to regarding these concerns:

Talk to your Rehabilitation Professionals about…

- Challenges the stroke survivor may still be facing, and possible solutions to them.
- Resources pertaining to home care, respite services, or long-term care options if required

Talk to your Peers about…

- Care processes at home (what to do next, how to handle upcoming challenges, how to adapt according to your family member's new lifestyle)

Talk to a Case Manager about…

- Resources pertaining to stroke or aphasia support, peer support groups, other networks or resources you may need

Previous Caregivers Found…

- Informational needs during this time were met less by health care professionals, and more by rehabilitation professionals, community case workers, peers, and community resources.

EMOTIONAL SUPPORT

Feelings You May Be Experiencing At This Time:

There are many different emotions that family members and caregivers can experience. Previous caregivers in your position told us they:

- Were doing things for themselves better now, not just for the stroke survivor
- Benefited from caregiver specific groups, not just stroke survivor groups
- Needed more attention from health care professionals about their own needs
- Needed someone to speak to socially, not just about caregiving activities

Please know that these feelings are normal. This can still be a stressful time. Remember you are not alone.

If you feel your needs are not being met do not hesitate to speak to the social worker or your doctor about getting the resources you need.

WHO TO TALK TO FOR MORE EMOTIONAL HELP

During this time, you may be wondering how to cope with the day-to-day challenges you face.

For additional emotional support, you may find it helpful to talk to one of the following individuals. For instance:

Talk to your Social Worker about…

- How to cope with added stress, sadness, or feeling overwhelmed
- How to ask family and friends for assistance
- How to connect with peers for caregiving support
- How to ensure your own needs are being met during this time
- Community programs, reintegration services, or volunteer agencies that can help.
- Intimacy issues

Talk to your Peers about…

- Visiting you or your family member
- Connecting and sharing your experiences through a support group
- Sharing your experiences and learn how other caregivers handle the day-to-day challenges
- Needing reassurance that life does get better over time
- Gaining a sense of encouragement – that everything will be alright

Talk to your Health Care Professional about…

- Ensuring your own needs are being met during this time
- Your feelings overall – how to make sense of them, how to gain support, how to be understood

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in **Section 7: Notes and Additional Resources** and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

PRACTICAL SUPPORT

Common Practical Support Needs for Assistance

During this phase, you may wish to receive some level of care by the people around you. Even though you have now had experience being a primary caregiver for several months, there are still ways that others can practically help you and your family member to live the best life possible.

Some of your needs may include:

- Needing home care
- Needing time to run errands outside of the home
- Needing time for yourself
- Requiring someone to assist you get things done at home or outside of the home
- Having someone alternate caregiving activities with you occasionally
- Being linked with community resources
- Being provided with the opportunity for follow-up
- Being linked with resources pertaining to home care, respite services, long-term care
- Financial assistance
- Transportation assistance
- Referrals for various organizations or programs

The following page provides a guideline for who to talk to in order to ensure that you are being cared for at this time.

PEER SUPPORT GROUPS & ONLINE RESOURCES

The following is a list of online resources you may find helpful. Through these websites you will find information on online support groups, or events happening in your community.

- Stroke Recovery Canada www.strokerecoverycanada.com
- Caregiving Online http://www.caregiving.com/
- The Stroke Network http://www.strokenetwork.org/
- March of Dimes www.marchofdimes.ca
- Self Help Connection www.selfhelpconnection.ca
- Generation S Young Stroke Survivors www.orgsites.com/pa/generation-s
- The Internet Stroke Centre http://www.strokecenter.org/pat/support.htm

There are a number of other sites online that you may find helpful. Your acute, rehabilitation, or community hospital may also have a website that offers information on support groups or upcoming events. Please feel free to check out your specific hospital's webpage.

WHO TO TALK TO FOR MORE PRACTICAL SUPPORT HELP

During this phase, caregivers appreciate when peers, case workers, family, friends, and rehabilitation professionals assist them with a variety of issues.

Here are some things you may wish to ask for:

Talk to a Rehabilitation Professional about…

- Home care options (home care visits, long-term care options, respite services)
- Additional follow-up appointments regarding your family member's improvements over time
- Getting physiotherapy, occupational therapy, or speech language pathology treatments at home or in the community, if they are required

Talk to a Case Manager about…

- Linking you with community resources (support groups, financial services, other services)
- Home care options (home care visits, long-term care options, respite services)

Talk to your Family or Friends about…

- Alternating caregiving activities (ensuring you have more time to run your own errands or have time for yourself; taking your family member to rehabilitation sessions if required)
- Visiting you and your family member
- Joining a community involvement organization with you, or taking up a hobby with you
- Providing meal assistance at home if you require help

Previous Caregivers Found that…

- Relaxation sessions that were provided offered the ability for the caregiver to get away and reduce some tensions
- Transportation services were needed during this time – please see **Section 7: Notes and Additional Resources** for more information
- Having time to run errands outside of the home or having time to oneself was regarded as very beneficial

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in **Section 7: Notes and Additional Resources** and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

TRAINING SUPPORT

Common Training Needs

During this phase, you may wish to learn new strategies to help your family member with various tasks pertaining to symptom management, rehabilitation, and personal hygiene. Moreover, you may wish to receive feedback that the techniques you are using are being performed properly, and are benefiting your family member.

Some needs you may wish to address include:

- How to perform exercises with your family member
- How to facilitate your family member's level of independence
- How to assist your family member who has aphasia with communication strategies

The following page outlines who to contact for these needs.

WHO TO TALK TO FOR MORE TRAINING HELP

Talk to a Rehabilitation Professional about…

- How to help your family member's level of independence (how to assist with mobility, how to improve cognitive skills, speaking or eating skills, how to perform various exercises, or helping your family member walk)
- How to continue physiotherapy/Occupational therapy/speech language pathology at home (either with a professional or by yourself)
- Receiving feedback pertaining to the exercises you are using (are they being done properly? Are they benefiting your family member?)
- Making sure you are completing transfers appropriately (i.e. are you lifting and assisting in the correct way as to not hurt yourself?)

Talk to a Speech-Language Pathologist about…

- How to communicate with your family member with aphasia
- Referrals to support networks such as the Aphasia Society

Talk to a Health Care Professional about…

- How to perform injections as part of the ongoing medication routine (if necessary)

Previous Caregivers Found…

- Talking to rehabilitation professionals about specific training techniques was mostly useful
- Trial-and-error is often a useful way of discovering what works and what does not
- Talking to peers allowed for the sharing of techniques and exercises
- Peers and rehabilitation professionals also found that providing feedback for caregivers was regarded as beneficial as it helped the caregivers' confidence levels, as they knew what to do and how to do it

If You Require Additional Assistance…

- If your needs are not listed in this chapter, please write down any questions you may have in **Section 7: Notes and Additional Resources**, and approach the appropriate individual on your health care team to ensure that your concerns are addressed.

Support Needs Management Form

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3. What resources will I try first?
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4. How did this work out?
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5. If it didn’t work out, what other resources should I try?
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6. Accept that this support need may not be met right now.

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Chapter #7
NOTES AND ADDITIONAL RESOURCES

My Notes

This section is for you to make notes about any questions, comments, concerns, or thoughts you may have throughout the recovery process. This is a useful section to make a list of questions you wish to ask appropriate members of your health care team.

Please be sure to consult the section entitled “The Recovery Process: Team Members” in the Introduction section. This will assist you in determining who to approach for various questions or concerns.

My Appointment Calendar

This section is for you to plan and schedule your family member’s follow-up appointments by day, week, and month so you can stay on track of all appointments.

Remember to consult your calendar each day so you do not miss any important appointments or deadlines.

Additional Resources

This is a comprehensive list of resources available in the Oshawa region surrounding the following supports:

- Stroke Support
- Aphasia Support
- Counseling Support
- Rehabilitation Support and Facilities
- Long-Term Care Facilities
- Community Care Access Centres
- Home Care Services
- Respite Services
- Government Assistance
- Financial Assistance
- Transportation Assistance
- Caregiver Peer Support Groups
- Stroke Survivor Peer Support Groups
- Courses Offered

Please consult this list whenever you need assistance or information concerning any of these matters.

MY NOTES

Date: _____

Question/Concern/Thought: _____

_____

_____

_____

_____

Who to talk to: _____

Spoke with: _____

Discussed with appropriate individual: ☐ Yes ☐ No

Date Discussed: _____

Date: _____

Question/Concern/Thought: _____

_____

_____

_____

_____

Who to talk to: _____

Spoke with: _____

Discussed with appropriate individual: ☐ Yes ☐ No

Date Discussed: _____

Chapter #7 – Notes & Additional Resources

Date: _____

Question/Concern/Thought: _____

_____

_____

_____

_____

Who to talk to: _____

Spoke with: _____

Discussed with appropriate individual: ☐ Yes ☐ No

Date Discussed: _____

Date: _____

Question/Concern/Thought: _____

_____

_____

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_____

Who to talk to: _____

Spoke with: _____

Discussed with appropriate individual: ☐ Yes ☐ No

Date Discussed: _____

Chapter #7 – Notes & Additional Resources

Date: _____

Question/Concern/Thought: _____

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_____

Who to talk to: _____

Spoke with: _____

Discussed with appropriate individual: ☐ Yes ☐ No

Date Discussed: _____

Date: _____

Question/Concern/Thought: _____

_____

_____

_____

_____

Who to talk to: _____

Spoke with: _____

Discussed with appropriate individual: ☐ Yes ☐ No

Date Discussed: _____

Chapter #7 – Notes & Additional Resources

Date: _____

Question/Concern/Thought: _____

_____

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_____

Who to talk to: _____

Spoke with: _____

Discussed with appropriate individual: ☐ Yes ☐ No

Date Discussed: _____

Date: _____

Question/Concern/Thought: _____

_____

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_____

Who to talk to: _____

Spoke with: _____

Discussed with appropriate individual: ☐ Yes ☐ No

Date Discussed: _____

Chapter #7 – Notes & Additional Resources

Date: _____

Question/Concern/Thought: _____

_____

_____

_____

_____

Who to talk to: _____

Spoke with: _____

Discussed with appropriate individual: ☐ Yes ☐ No

Date Discussed: _____

Date: _____

Question/Concern/Thought: _____

_____

_____

_____

_____

Who to talk to: _____

Spoke with: _____

Discussed with appropriate individual: ☐ Yes ☐ No

Date Discussed: _____

ADDITIONAL NOTES

ADDITIONAL NOTES

ADDITIONAL NOTES

MY REHABILITATION TEAM: CONTACT INFORMATION

Primary Doctor

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Neurologist

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Physiatrist

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Primary Nurse

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Psychologist

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Social Worker

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Case Manager

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Physical Therapist

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Occupational Therapist

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Speech-Language Pathologist

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Recreational Therapist

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Family Physician

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Dietician

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Other Contacts

Role:

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Role:

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

Role:

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Location: _____

MY FAMILY, FRIENDS, AND PEERS

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Relationship: _____

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Relationship: _____

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Relationship: _____

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Relationship: _____

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Relationship: _____

Chapter #7 – Notes & Additional Resources

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Relationship: _____

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Relationship: _____

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Relationship: _____

Name: _____

Phone: _____

Fax: _____

E-mail: _____

Relationship: _____

MY APPOINTMENT CALENDAR

Please use the following calendar to help organize your upcoming appointments. List who the appointment is with under name, and the office number under the number section.

Week of _____

Monday			Tuesday	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		
		3		
		4		
		5		
Wednesday			**Thursday**	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		
		3		
		4		
		5		
Friday			**Saturday/Sunday**	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		

		1		
		2		
		3		
		4		
		5		

Week of _____

Monday			Tuesday	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		
		3		
		4		
		5		
Wednesday			**Thursday**	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		
		3		
		4		
		5		
Friday			**Saturday/Sunday**	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		

		3		
		4		
		5		

Week of _____

Monday			Tuesday	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		
		3		
		4		
		5		
Wednesday			**Thursday**	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		
		3		
		4		
		5		
Friday			**Saturday/Sunday**	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		
		3		
		4		

		5		

Week of _____

Monday			Tuesday	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		
		3		
		4		
		5		
Wednesday			**Thursday**	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		
		3		
		4		
		5		
Friday			**Saturday/Sunday**	
Number	**Name**		**Name**	**Number**
		8		
		9		
		10		
		11		
		12		
		1		
		2		
		3		
		4		
		5		

ADDITIONAL RESOURCES

Stroke Support

Canadian Stroke Network
Room 3105 – 451 Smyth Road
Ottawa, Ontario
K1H 8M5
Tel: 613-562-5800 x8593
Fax: 613-562-5631

Heart and Stroke Foundation of Canada
Durham Regional Offices
UNIT 2-105 Consumers Dr
Whitby, On
L1N 1C4
905-666-3777

Ontario Prevention Clearinghouse
Prevent Stroke Program
180 Dundas Street West, Suite 1900
Toronto, Ontario M5G 1Z8
Email: info@preventstroke.ca

Head Injury Association of Durham Region (HIAD)
20-850 King St W
Oshawa ON L1J 8N6
905-723-2732

Aphasia Support

The Aphasia Institute
73 Scarsdale Road
Toronto, ON M3B 2R2
Canada
Tel: 416-226-3636
Fax: 416-226-3706
E-mail: aphasia@aphasia.ca

Canadian Association of
Speech-Language Pathologists & Audiologists
130 Albert Street Suite 2006
Ottawa, Ontario
KIP 5G4
Tel: 1-800-259-8519

York-Durham Aphasia Centre
Westminster United Church
1850 Rossland Rd
Whitby, On
Tel: 905-642-2053 or 1-866-580-9322
Email: ydac@ydac.on.ca
www.ydac.on.ca

Counselling Support

Canadian Association of Social Workers
383 Parkdale Avenue Suite 402
Ottawa, Ontario
K1Y 4R4
Tel: 613-729-6668

Rehabilitation Support and Facilities

Canadian Council on Rehabilitation and Work
20 King St. West, 6th Floor
Toronto, Ontario
M5H 1C4
Tel: 416-974-7600
TTY 416-974-2636

Canadian Occupational Therapy Foundation
55 Eglinton Ave East, Suite 308
Toronto, Ontario
M4P 1GS
Tel: 416-487-5438

Canadian Physiotherapy Association
890 Yonge Street 9th floor
Toronto, Ontario
M4W 3P4
Tel: 416-924-5312

Equipment/Supplies Rental and Purchase New Equipment

Shoppers Home Health Care
Ajax – 905-427-4171
Whitby – 905-579-5300

Durham Medical
www.durhammedical.ca
905-728-1112
1-888-479-4687

C.I.M.S. Home Health Care
1355 Kingston Rd (UNIT 106)
Pickering, On
905-839-0364

Personal Medical Alert System

Lifeline
Main Office
Tel: 1-800-543-3546

Long-Term Care Facilities

Community Care Access Centres
Central East CCAC
Head Office
920 Champlain Crt
Whitby, On
L1N 6K9
905-430-3308
www.310ccac.ca
- allows you to search for specific services available for your area of need

Community Nursing Home
15941 Simcoe Street
Port Perry ON L9L 1N5
905-985-32-5
www.cnhportperry.ca

Extendicare-Oshawa
82 Park Road North
Oshawa ON L1J 4L1
905-579-0011
www.extendicare.ca

Fairview Lodge
632 Dundas Street West
Whitby ON L1N 5S3
905-668-5851
www.durham.ca

Fosterbrooke LTC Facility
330 King Street West
Newcastle ON L1B 1G9
905-987-4702
www.retirementresidencesreit.com

Hillsdale Estates
590 Oshawa Boulevard North
Oshawa ON L1G 5T9
905-579-1777
www.durham.ca

Hillsdale Terraces
600 Oshawa Boulevard North
Oshawa ON L1G 5T9
905-579-3313
www.durham.ca

Marnwood Lifecare Centre
26 Elgin Street
Bowmanville ON L1C 3C8
905-623-5731
www.ourhomeyourhomecanada.ca

Strathaven Lifecare Centre
264 King Street East
Bowmanville ON L1C 1P9
905-623-2553
www.ourhomeyourhomecanada.ca

Sunnycrest Nursing Home
1635 Dundas Street East
Whitby ON L1N 2K9
905-576-0111
www.sunnycrest.ca

The Village of Taunton Mills
3800 Brock Street North
Whitby ON L1R 3A5
905-666-3156
www.oakwoodretirement.com

The Wynfield
451 Woodmount Drive
Oshawa ON L1G 8E3
905-571-0065
www.chartwellreit.ca

Thornton View
186 Thornton Road South
Oshawa ON L1J 5Y2
905-576-5181
www.retirementresidencesreit.com

Home Care Services

Canadian Red Cross
585 Wentworth St.E
Unit 40
Oshawa, On
L1H 3V8
905-723-2933
1-866-723-2933
Durham_region@redcross.ca

DHS Health Care Services
88 Centre St. N Ste 1
Oshawa, ON, L1G 4B6
905-571-1511
1-800-461-6756

Paramed Home Health Care
201-1143 Wentworth St W
Oshawa, On
L1J 8P7
905-433-7600

Home Instead Senior Care
595 Wentworth St. E
Unit 51
Oshawa, On
L1H 3V8
905-723-1800
www.homeinstead.com

Bayshore Home Health
Area Director: Diane Moore
1 Mary St N
Unit C
Oshawa, Ont
L1G 7W8
905-433-4002
1-877-433-4003
www.bayshore.ca

Note that some of these Home care services MAY NOT be covered by OHIP

* For additional resources, please see Community Care Access Centres or visit www.310ccac.ca

Respite Services

Durham Association for Family Respite Services
20 - 850 King Street West
Oshawa, Ontario
L1J 8N5
info@dafrs.com

Some Long Term Care facilities and Retirement Homes in Durham provide short stay respite services, see below:

Extendicare-Oshawa
82 Park Road North
Oshawa ON L1J 4L1
905-579-0011
www.extendicare.ca

Bon Air Nursing Home
131 Laidlaw St S.
Cannington, On
705-432-2385
www.chartwellreit.ca

Community Nursing Home
1955 Valley Farm Road
Pickering, ON
905-831-2522
www.cnhpickering.ca

Fosterbrooke Long Term Care Facility
330 King St W
Newcastle, ON
www.retirementresidencesreit.com

Lakeview Manor
133 Main St W
Beaverton, ON
705-426-7388
www.durham.ca

Sunnycrest Nursing Home
1635 Dundas Street East
Whitby ON L1N 2K9
905-576-0111
www.sunnycrest.ca

Winbourne Park LTC Centre
1020 Westney Road
Ajax, ON
905-426-6296
www.retirementresidencesreit.com

Government Assistance

Assistive Devices Program
5700 Yonge Street 7th Floor
Toronto, Ontario M2M 4K5
Tel: 1-800-268-6021

Canadian Medic Alert Foundation Inc.
PO Box 9800, Don Mills Postal Station
Toronto, Ontario M3C 3T9
Tel: 1-800-668-1507

Client Services Unit - Ministry of Health and Long-Term Care
Suite M1-57, Macdonald Block
900 Bay Street
Toronto ON M7A 1R3
Toll free : 1-800-268-1154
In Toronto : 416-314-5518
FAX : 416-314-8721

Disease Prevention Division
Systems for Health Directorate, Health Promotion
Jeanne Mance Building, 6th Floor
Tunney's Pasture
Ottawa, Ontario K1A 1B4
Tel: 613-954-8651

Ontario Long Term Care Association
345 Renfrew Drive, Suite 102-202-301
Markham, ON L3R 9S9
Tel: 905-470-8995
Fax: 905-470-9595

Financial Assistance

CPP Disability Benefits
www.hrsdc.gc.ca
Tel: 1-800-277-9914

Ontario Disability Support Program (ODSP)
www.cfcs.gov.on.ca/cfcs/en/programs/IES/Ontario DisabilitySupportProgram/default.htm
Tel: 1-888-789-4199

Transportation Assistance

Durham Region Specialized Transit Services
www.durhamregiontransit.com
Ajax Pickering: 905-683-4114
Oshawa Whitby Clarington: 905-725-4000
Brock/Scugog/Uxbridge 1-800-263-1916

Blue Line (accessible Vans)
Oshawa/Clarington – 905-440-2000

Community Care Durham Volunteer Transportation
www.communitycaredurham.on.ca

Caregiver Peer Support Groups

Stroke Recovery Canada
10 Overlea Boulevard
Toronto, ON M4H 1A4
Tel: 1-888-540-6666
Fax: 416-425-1920
Email: info@strokerecoverycanada.com

Stroke Survivor Peer Support Groups

Stroke Recovery Canada (March of Dimes)
Peer Support Department
10 Overlea Boulevard
Toronto, On
M4H 1A4
Tel: 1-800-2633463
www.strokerevoverycanada.com
Email: peersupport@marchofdimes.ca

Courses Offered

The Aphasia Institute
73 Scarsdale Road
Toronto, ON M3B 2R2
Canada
Tel: 416-226-3636
Fax: 416-226-3706
E-mail: aphasia@aphasia.ca

Toronto Rehab
550 University Ave.
Toronto, ON
M5G 2A2
Tel: 416-597-3422 ext. 3000
Fax: 416-597-1977

Meals on Wheels

Oshawa Senior Citizens Centres
43 John Street W
Oshawa, ON L1H 1W8
905-576-6712

Grocery Gateway (Home Grocery Delivery)
www.grocerygateway.com
Tel: 905-564-8778

Recreational/Day Programs

Oshawa Senior Citizens Centres
905-576-6712
info@oscc.ca
www.oscc.ca

Durham Warm Water Aquatics
Ontario Shores
(Durham Warm Water Program)
700 Gordon Street
Whitby, ON L1N 5S9
905-430-1665
http://www.dwwap.com/
email: registrar@dwwap.com
REQUIRES DOCTOR REFERRAL

Community Care Durham
Clarington
2440 Hwy.2 Unit #1
G.B. Rickard Complex
Bowmanville, ON L1C 0K6
Home Support: 905-623-2261
COPE: 905-623-4123
Respite: 1-888-255-6680 x 251

Oshawa
20 Sunray Street, Unit #6
Whitby ON L1N 8Y3
Home Support: 905-430-5613
COPE: 905-666-0689
Respite: 1-888-255-6680 x 251

Whitby
20 Sunray Stree, Unit#5
Whitby ON L1N 8Y3
Home Support: 905-668-6223
COPE: 905-668-6223 x 227
Respite: 1-888-255-6680 x 251

Interpreter Services

Access Alliance Multicultural Community
Health Centre (Over 60 languages available)
340 College Street, suite 500
Tel: 416-324-867