



# What About Me?

*A Resource for Caregivers of Stroke Survivors*

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The information in this booklet comes from a variety of sources including Caregivers throughout the region, Stroke Recovery Canada, Northwestern Ontario Regional Stroke Network, and information that was supplied by our presenters at the Caregivers of Survivors of Stroke Conference held in May, 2010.

This publication has a selection of items that will help you in your new or existing role as a family caregiver. It is only a starting point to your journey with links to several resources available to you. Many of their publications are free of charge, you just have to take the first step by contacting them or visiting their websites.

If you are comfortable utilizing the internet, you will have instant access to many helpful resources. Some trusted websites have been included in this publication. If you are not comfortable with accessing the internet (or do not have access) you may want to enlist the help of a family member, friend, neighbour to conduct research with you. Many toll free telephone numbers have also been included for you to call agencies and organizations directly.

*A special thank you goes out to Caregivers across the northwest region for their valuable input into this resource booklet.*

# CAREGIVERS Taking care of yourself

## Caregivers' Needs

A stroke can permanently change the mind and body of a survivor, but also the lives of an entire family. Day to day family life may be changed forever. A stroke means that caregivers must somehow set aside their own shock and fear to support their loved one, whose needs may seem to far outweigh those of the caregiver.

Caregivers, however, must meet the enormous challenge of caring for the physical and emotional needs of their care recipient **without** neglecting their own needs.

## In the event of a stroke, caregivers of a stroke survivor need:

- **Information** about stroke and its impacts, prognosis and the rehabilitation process
- **Education** about the physical and psychological needs of stroke survivors
- **Practical assistance** in enhancing caring and coping skills
- **Increased awareness** of available therapeutic and social service supports
- The **opportunity to share** ideas, information, and coping methods with others dealing with similar issues

## The Work of Care Giving

Care giving is hard, tiring, physical work. Too frequently, little thought is given to a caregiver's ability to deal with the burden of caring.

Physical disability, communication problems, and personality changes in a stroke survivor may cause profound relationship changes. This can place great **stress** on care giving relationships.

After a recent stroke, a survivor might not be able to respond to anyone's needs but his or her own. They may show little appreciation for another's needs or efforts. Spouses and caregivers must often come to terms with what may be permanent changes in their partners such as depression, fatigue, lack of strength, frustration, egocentricity, and thoughtlessness.

The partnership between you and your loved one may also be changed forever. You may now be the shopper, cook, nurse, financier, chauffeur, handyman, and more.

Family caregivers must learn to ask for and accept the help they need to fulfill their role. It is very important to not take on the full responsibility of care giving alone.

***"Caregivers need to look after themselves first. Otherwise, the quality of care that they are capable of giving, their relationship with their care recipient, and their own quality of life can suffer greatly"***

# The Stress of Care Giving

For a stroke survivor, the experience of stroke is terrifying and disorienting. The spouse and family, however, are thrown into a situation that is no less frightening. Often, they must overcome grief, fear, and frustration in order to help the survivor.

Caregivers generally have very demanding expectations of themselves. After the first crisis of a stroke has passed and the caregiver and stroke survivor have settled into a routine, the stress of care giving may emerge. Be on the lookout for any changes in your habits, attitudes and moods.

## Common Sources of Stress for Caregivers

Here are common sources of stress that caregivers may be faced with:

- Trying to live up to the survivors' high expectations and/or their own
- Intensive caring for others at the expense of self-care
- Inability to set appropriate boundaries
- Pushing themselves too hard
- Mental and physical demands
- Heavy workloads
- Time pressures
- Limited resources
- Competing priorities

## Common Physical/Behavioural Reactions:

- Fatigue
- Loss of appetite
- Difficulty falling asleep
- Restlessness
- Headaches
- Changes in sleeping
- Increased blood pressure
- Changes in eating habits
- Increased susceptibility to colds, flus, illnesses, infection

## Common Emotional Reactions:

- Feeling helpless
- Overwhelmed
- Inadequate
- Fragile
- Vulnerable
- Unable to cope or go on
- Increased mood swings
- Decreased motivation
- Feeling burned out
- Crying more frequently and easily
- Isolation
- Changes in communication patterns

## Common Cognitive Reactions:

- Confusion
- Difficulty making decisions
- Difficulty problem solving
- Difficulty concentrating or paying attention
- Memory blanks
- Having ambiguous feelings
- Questioning why this happened in a world that is supposed to be safe

Caregivers are not immune to the above reactions and need to remind themselves that these are normal human responses to stressful circumstances. Although many of the underlying stresses cannot be prevented, you can increase your resistance by taking care of yourself and staying healthy. It is important to pace yourself and know your limits.

If, at any time, you feel overwhelmed and unable to cope, it is important to seek additional assistance. Here are some circumstances which indicate that it is time to get help by speaking to a health professional such as a psychologist, family doctor, psychiatrist, social worker or nurse:

- Feeling extremely helpless
- Having thoughts of hurting yourself or others
- Using alcohol and drugs excessively

### What about me?

- Talk to someone ( a friend or professional) about your feelings
- Journal about your feelings using a notepad or journal book
- Take time to take out your frustrations by being physically active
- Take a break; find some time away from the situation
- Go for a 15 minute walk
- Eat sensibly and avoid excessive use of caffeine and alcohol.
- Be self nurturing and don't forget to laugh
- Remain socially active
- Know and respect your limits
- Spend time with friends
- Before you speak or react to something, count to 10
- Take a few deep breaths

# Taking Time for Myself

## GOALS:

- To do the best to meet your every day needs and other responsibilities
- To do the best to take part in and enjoy recreational and leisure activities



To be a better manager of your life and daily activities, it may be helpful to understand:

- Priorities: the things that you **need** to do and the things that you would **like** to do
- What makes it hard to do them
- What makes it easier to do them
- Solutions and barriers

### Solutions

- Getting assistance when needed: financial, social or physical
- Prioritise.
- Plan ahead.
- Be organised.
- Know your limits.

### Planning your Activities

Be involved in choosing when and how to carry out your activities so that you can choose the best time and way to do it. If you plan your activities on a weekly basis, you may want to use a calendar or day planner. This visual overview can also help you to organize and plan your activities in such a way that your energy level is maintained so that you get the most out of your time!



## Strategies for Good Communication: Problem Solving

Good communication is very important. However, when problems arise and solutions need to be discussed, communicating effectively can be quite stressful. The following may be of help to you when the need arises to discuss and resolve problems.

- Set aside time to talk.
- State the problem while the other person listens but does not speak.
- Then switch - The other person replies and the first person does not speak.
- Finally, spend time coming up with solutions and selecting a solution to work on.
- Word it specifically - who is going to do what, when, where, and how often.
- The **DESC** script is a tool you may use when you want to discuss a problem with somebody. It ensures that you have thought about all aspects of the problem.

**D**escribe the problem.

**E**xplain how it makes you feel.

**D**iscuss possible **S**olutions to the problem.

**D**iscuss **C**onsequences of not adhering to the solution

- Be specific about behaviours you want your partner to increase or decrease. Discuss behaviours you want to change, for e.g. "You put the top on the toothpaste every day. I will stop throwing tea bags in the sink."
- Sometimes words may fail us, but then there may be other ways to get our message across and make the other feel special. An unexpected kiss on the cheek can have a ripple effect that can last throughout the day and even the week! It is also important to think about the manner or how you want your message to be discussed: words, notes, formal letters or actions.
- If the differences between those involved seem too big, you may ask your physician for a referral to a social worker or counsellor.



## Help yourself help your care recipient.

**These tips and suggestions may be helpful to both of you:**

1. Develop patience. Leave the room if you become impatient with their slowness. Try to keep life as normal and active as possible, but recognize that you may have to adjust your living style to allow enough time for their activities. Recognize that their problems are real.
2. Don't be too helpful. They need activity and exercise. Be optimistic and supportive.
3. Don't be overprotective. Encourage independence. Accompany them for medical and other appointments, if possible. This can be a great way to gain information, express your concerns and make treatment suggestions. However, do not speak for them, if he/she is able to communicate his/her own message.
4. Encourage, praise, empathise, but don't exaggerate
5. Find ways to communicate with them and encourage them to communicate his/her needs. Talk with them about your issues, feelings and concerns and how to deal with them.
6. Organize a realistic and flexible schedule for the care recipient, incorporating rest time. Establish household routines and pace yourself.
7. Set specific, realistic goals - this will help boost their confidence and self-esteem.
8. Do something separate from each other. You will have something new to discuss when you get back together. Seek out respite care or assistance so you have some time. Remember to keep time for yourself. Develop or maintain outside interests and hobbies. Then, stick to it!
9. Do not take emotional outbursts personally.
10. Even under the most perfect circumstances things don't always go smoothly. Do the best you can, which is all anyone can do.
11. Plan something to look forward to each day. Plan time together for an activity you both enjoy, like the theatre, a walk, playing a game, watching a movie at home.

12. Ask for help when you need it. Divide responsibilities, if possible. Accept offers of help.
13. Help them stay in touch with the world he or she has known.
14. Maintain your support systems (friends and family). Stay socially active.  
Attending support groups may help to discuss common problems and feelings with others that are in the same circumstances. It is also a good place to meet new friends with similar interests and activities.
15. Involve them in family decision- making whenever possible.
16. Seek help with financial worries. Consider modifications to the home and assistive devices.
17. Consider nursing and housekeeping services.
18. Exercise and be active.
19. Take one day at a time.

**“Caregivers need to look after themselves first. Otherwise, the quality of care that they are capable of giving, their relationship with their care recipient, and their own quality of life can suffer greatly”**

**All relationships worth keeping, need watching, work and care. Your intimate relationships are no exception. They require time, patience, respect, careful thought, and honest communication.**



# Relaxation

## What is relaxation?

Relaxation is the process of becoming aware of tension in your body and learning to let go of that tension. It is a way to reduce the stress in your life or to deal better with the stress.

## What are the benefits of relaxation?

- Decreased tension throughout the entire body
- Decreased pain and stiffness
- Decreased anxiety and mental stress
- Improved sleep
- Improved sense of overall well-being



## Methods of relaxation

Three different relaxation methods you can do on your own are described here. You may find one way that works best for you.

### 1. Breathing Exercises:

- Concentrate on breathing, taking a long slow breath through your nose, hold it for a few seconds and breath out through your mouth
- Keep it slow and easy
- Relaxed breathing promotes relaxation of muscles which may also be beneficial before you begin to exercise

### 2. Guided Imagery:

- Use your imagination to create calm and peaceful thoughts and feelings
- CDs and Tapes are available to create these images, such as Empowered Breathing and Focused Relaxation by Eli Bay. (Available from the The Relaxation Response Institute, tel: 416 932 2784, fax: 416 932 2971, email: [elibay@idirect.com](mailto:elibay@idirect.com)).

### 3. Progressive Relaxation:

- Turn your toes up. Feel the tension in your feet and calves. Hold for a few seconds. Relax. Feel the tension leave and the sensation of warmth and relaxation take over.
- Now tighten your thighs. Hold...Relax
- Tighten your stomach and buttocks. Hold....Relax. Breathe deeply again, letting all the tension leave your body.
- Press your shoulders back. Hold...Relax
- Lift your shoulders up towards your ears; tighten the muscles in your arms and stretch out your fingers. Hold...Relax
- Tighten the muscles in your face (squeeze your eyes closed, press your lips tightly together). Hold...Relax. Let your jaw relax too and your mouth open slightly.
- Now take inventory: Do any parts of your body feel more tense than others?
- Repeat the process in those areas, until your whole body feels limp and heavy.
- Breathe deeply again. Enjoy the relaxed feeling.
- Before getting up and continuing with your day, open your eyes and sit quietly for a minute.

#### How to begin: your relaxation session

- Sit up in a chair or lie in bed.
- Make yourself as comfortable as you can.
- Loosen any tight clothing.
- Do not cross your ankles.
- Use pillows to help support you when necessary. For example, under the knees when lying on your back or under your arms when sitting on a chair.
- Close your eyes and take a slow deep breath. Your stomach should move out as you breathe in and move inwards as you breathe out.
- Each time you breathe out let the tension from your body leave with it.
- Now you can start with your chosen method of relaxation.

Relaxation Internet Resources

Short Online Relaxation Session, Chakra Sound and Colour Relaxation

<http://www.web-lines.com/alignchakras/>

Peer Health Relaxation Programs, Williams College

<http://wso.williams.edu/orgs/peerh/stress/relax.html>

Relaxation Resources, Relaxation.Com

<http://www.relaxation.com/>

## Nutrition

The quality of nutrition has a large impact on both physical and emotional states. “Proper nutrition can speed up stroke recovery and provide caregivers with the energy they need to care for their loved ones,” says Cara Rosenbloom, a registered dietitian.

“An optimal diet is low in salt, saturated fat and trans fat, and includes plenty of vegetables, fruit, whole grains and lean protein choices (like fish),” advises Rosenbloom. “For guidelines on healthy eating, refer to Canada's Food Guide.” The guide is available on the Web, and can be found by simply typing in the name in any search engine. You can also order a copy by calling 1-800-O-Canada (1-800-622-6232). Personalize CFG: “Create My Food Guide”

<http://www.hc-sc.gc.ca>

Click on “Food and Nutrition on the left column. Click on Canada's Food Guide in the right hand column. The guide has a wealth of information, from age-adjusted portion sizes to tips on meal planning and shopping.

### Healthy eating tips

- Plan your meals in advance for one or two weeks.
- Read nutrition labels on packaged food to help you buy items that are low in trans-fat, saturated fat and sodium.
- Try to consume less than 1500 mg of sodium per day. [www.sodium101.ca](http://www.sodium101.ca)
- Consume 2-3 tablespoons of unsaturated oils or soft non-hydrogenated margarine each day. For more information on healthy fats, visit [www.healthyfats.ca](http://www.healthyfats.ca).
- Buy fresh, frozen or canned pre-cut vegetables for quick salads, stir-fries and side dishes.
- Prepare some foods in advance. Cook double and keep leftovers in the freezer (for example, soups or lasagna).
- Make gradual improvements to your diet and stick to them.
- Work with a registered dietitian
- Substitute lower-calorie, lower-fat foods for some of the high-calorie, high-fat items in your diet
- Cut back on or eliminate fried foods
  - Choose low fat milk products
  - Cut back on simple sugars and sweets
  - Choose healthy snacks
  - Choose lower fat choices at restaurants & watch portions

To find a dietitian, ask your doctor or visit [www.dietitians.ca](http://www.dietitians.ca).



<b>Nutrition Facts</b>	
Serving Size 1 cup (228g)	
Servings per Container 2	
Amount Per Serving	
<b>Calories 280</b>	<b>Calories from Fat 120</b>
	<b>% Daily Value*</b>
<b>Total Fat 13g</b>	20%
<b>Saturated Fat 5g</b>	25%
<b>Trans Fat 2g</b>	
<b>Cholesterol 2mg</b>	10%
<b>Sodium 660mg</b>	28%
<b>Total Carbohydrate 31g</b>	10%
<b>Dietary Fiber 3g</b>	0%
<b>Sugars 5g</b>	
<b>Protein 5g</b>	
<b>Vitamin A 4%</b>	<b>Vitamin C 2%</b>
<b>Calcium 15%</b>	<b>Iron 4%</b>
<small>*Percent Daily Values are based on a diet of other people's secrets. Your daily values may be higher or lower depending on your calorie needs.</small>	
	<b>Calories:</b> 2,000 2,500
<b>Total Fat</b>	Less than 65g 80g
<b>Sat Fat</b>	Less than 20g 25g
<b>Cholesterol</b>	Less than 300mg 300mg
<b>Sodium</b>	Less than 2,400mg 2,400mg
<b>Total Carbohydrate</b>	300g 375g
<b>Fiber</b>	25g 30g
<b>Calories per gram:</b>	
<b>Fat 9</b>	<b>Carbohydrate 4</b> <b>Protein 4</b>

- Compare products more easily
- Determine the nutritional value of foods
- Information in the Nutrition Facts Table is based on a specific amount of food. Compare this to the amount you eat.
- Use % Daily Value to see if a food has a little or a lot of a nutrient.

- Ingredients are listed by weight from most to least
  - Fats: lard, shortening, hydrogenated vegetable oils
  - Sugars: honey, molasses, dextrose, sucrose, fructose, (“ose”), dextrin, syrup
  - Salts: monosodium glutamate (MSG), anything with the word sodium, baking soda, brine

**STEP 1: CHECK SERVING SIZE**

all "facts" apply to this amount

**STEP 2: CHECK CALORIES**

useful to compare similar products

**STEP 3: CHECK TOTAL FAT**

3 g or less= low fat per serving

**STEP 4: CHECK SATURATED FAT**

1 g or less= low saturated fat per serving

**STEP 5: CHECK SODIUM**

140 mg= low per serving

**STEP 6: CHECK TOTAL CARBOHYDRATE**

15 g= 1 carbohydrate choice  
(useful for diabetic meal planning)

<b>Nutrition Facts</b>	
Serving Size ½ cup (114g)	
Servings Per Container 4	
<b>Amount Per Serving</b>	
<b>Calories 90</b>	Calories from Fat 30
<b>% Daily Value*</b>	
<b>Total Fat 3g</b>	<b>5%</b>
<b>Saturated Fat 0g</b>	<b>0%</b>
<b>Cholesterol 0mg</b>	<b>0%</b>
<b>Sodium 300mg</b>	<b>13%</b>
<b>Total Carbohydrate 13g</b>	<b>4%</b>
Dietary Fiber 3g	12%
Sugars 3g	
<b>Protein 3g</b>	

**Look at your labels...**

- FAT?
- CHOLESTEROL?
- SODIUM?

Use the "5, 10, 15 rule"

5% or less: great!

10% or less: ok

>15%: stay away



**Eating Out - Restaurant Menus**

Eating at a restaurant is a nice treat or is necessary when travelling but we have experienced that restaurant foods tend to be low in vegetables, fruit, whole grains and milk and higher in calories, fat and salt. As the consumer, ask your server about healthier menu choices and ask questions about your options. Watch your portion size and ask for leftovers to be packed up (you don't have to eat everything on your plate).

For more tips on making health smart choices when eating out. Contact Eat Right Ontario Call 1-877-510-510-2 or visit [www.eatrightontario.ca](http://www.eatrightontario.ca)

The Heart and Stroke Foundation's Health Check program is also available in many restaurants. Health Check nutrient criteria, developed by the Foundation's Registered Dietitians, include sodium, fat, protein and fibre. More information about healthy eating in restaurants is available online at [www.healthcheck.org](http://www.healthcheck.org)

## Tips for Developing Good Sleep Habits

**With proper sleep habits, it is easier to fall asleep and stay asleep. Some of these good habits include avoiding caffeine and other stimulants late in the day, going to sleep at the same time each night, and sleeping in a comfortable place that is dark, quiet, and neither too warm nor too cold.**

There are many habits you can follow to help you get a good night's sleep. Below is a list of things that typically help people sleep better:

- Try to go to sleep at the same time each night and get up at the same time each morning.
- Try not to take naps during the day, because naps may make you less sleepy at night.
- Avoid caffeine, nicotine, and alcohol late in the day. Caffeine and nicotine are stimulants and can keep you from falling asleep. Alcohol can cause you to wake in the night. It also interferes with sleep quality.
- Get regular exercise. Try not to exercise close to bedtime, because it may stimulate you and make it hard to fall asleep. Experts suggest not exercising for three hours before the time you go to sleep.
- Don't eat a heavy meal late in the day. A light snack before bedtime may help you sleep.
- Make your sleeping place comfortable. Be sure that it is dark, quiet, and not too warm or too cold. If light is a problem, try a sleeping mask. If noise is a problem, try earplugs, a fan, or a "white noise" machine to cover up the sounds.
- Follow a routine to help relax and wind down before sleep, such as reading a book, listening to music, or taking a bath.
- Avoid using your bed for anything other than sleep or sex.
- If you can't fall asleep and don't feel drowsy, get up and read (or do something that is not overly stimulating) until you feel sleepy.
- If you tend to lie awake worrying about things, try making a to-do list before you go to bed. This may help you to "let go" of those worries overnight.
- See your healthcare provider if you think that you have insomnia or another sleep disorder.

<http://sleep.emedtv.com/sleep/good-sleep-habits.html>

### Myths and Facts about Sleep

**Myth 1: Getting just 1 hour less sleep per night won't effect your daytime functioning.** You may not be noticeably sleepy during the day. But even slightly less sleep can affect your ability to think properly and respond quickly, and compromise your cardiovascular health, energy balance, and ability to fight infections.

**Myth 2: Your body adjusts quickly to different sleep schedules.** Most people can reset their biological clock, but only by appropriately timed cues and even then, by 12 hours per day at best. Consequently, it can take more than a week to adjust after traveling across several time zones or switching to the night shift.



**Myth 3: Extra sleep at night can cure you of problems with excessive daytime fatigue.** Not only is the quantity of sleep important but also the *quality* of sleep. Some people sleep 8 or 9 hours a night but don't feel well rested when they wake up because the quality of their sleep is poor.

**Myth 4: You can make up for lost sleep during the week by sleeping more on the weekends.** Although this sleeping pattern will help relieve part of a sleep debt, it will not completely make up for the lack of sleep. Furthermore, sleeping later on the weekends can affect your biological clock so that it is much harder to go to sleep at the right time on Sunday nights and get up early on Monday mornings.

*Adapted from [Your Guide to Healthy Sleep \(PDF\)](#) - The National Institutes of Health - [www.nih.gov](http://www.nih.gov)*

### Signs and symptoms of sleep deprivation and lack of sleep

If you're getting less than eight hours of sleep each night, chances are you're sleep deprived. What's more, you probably have no idea just how much lack of sleep is affecting you.

How is it possible to be sleep deprived without knowing it? Most of the signs of sleep deprivation are much more subtle than falling face first into your dinner plate. Furthermore, if you've made a habit of skimping on sleep, you may not even remember what it feels like to be wide-awake, fully alert, and firing on all cylinders. It feels normal to get sleepy when you're in a boring meeting, struggle through the afternoon slump, or doze off after dinner. But the truth is that it's only "normal" if you're sleep deprived.

### You may be sleep deprived if you...

- Need an alarm clock in order to wake up on time.
- Rely on the snooze button.
- Have a hard time getting out of bed in the morning.
- Feel sluggish in the afternoon.
- Get sleepy in meetings, lectures, or warm rooms.
- Get drowsy after heavy meals or when driving.
- Need to nap to get through the day.
- Fall asleep while watching TV or relaxing in the evening.
- Feel the need to sleep in on weekends.
- Fall asleep within five minutes of going to bed.



While it may seem like losing sleep isn't such a big deal, sleep deprivation has a wide range of negative effects that go way beyond daytime drowsiness.

### The effects of sleep deprivation and chronic lack of sleep

- Fatigue, lethargy, and lack of motivation
  - Moodiness and irritability
  - Reduced creativity and problem-solving skills
  - Inability to cope with stress
  - Reduced immunity; frequent colds and infections
  - Concentration and memory problems
  - Weight gain
  - Impaired motor skills and increased risk of accidents
  - Difficulty making decisions
  - Increased risk of diabetes, heart disease, and other health problems
- [www.helpguide.org](http://www.helpguide.org)

## Where to Seek Help?

Every community has their own and unique programs and services. Information gathering can begin through:

- Municipalities, regional health councils, and libraries
- Distress or crisis centres
- Hospital in your community
- Family service agencies
- Support groups
- Leader of your faith community
- Family and friends you can call to talk things over

The following pages list **just a few** of the organizations that may be able to provide assistance or guide you to other community organizations/services that will best suit your needs. The back page of this booklet has room for you to add your own contact people and organizations. Please feel free to tear it from this booklet and post close to your phone.

***Information in this booklet was up to date as of time of printing this document.  
(March, 2011)***

## ORGANIZATIONS AND SERVICES

### Heart & Stroke Foundation of Ontario

- many free resources to order
- Thunder Bay: (807) 623-1118  
Toll-Free: 1-888-473-4636  
[www.heartandstroke.ca](http://www.heartandstroke.ca)

### Northwestern Ontario Regional Stroke Network: Thunder Bay Regional Health Sciences Centre

(807) 684-6703  
[www.nwostroke.ca](http://www.nwostroke.ca)

### Stroke Prevention Clinics:

- Offers high-risk primary and secondary prevention services. (Physician referral Required).

Fort Frances: (807) 274-3266 x4542  
Kenora: (807) 468-9861 x2528  
Marathon: (807) 229-1740 x289  
Sioux Lookout: (807) 737-2877 x5112  
Thunder Bay: (807) 684-6700

### St. Joseph's Care Group (Rehabilitation Services)

- Physician Referral required
- (807) 343-2431  
[www.sjcg.net](http://www.sjcg.net)

### Stroke Recovery Canada

- Web and print resources for caregivers, peer support groups, “warmline” phone service
- Toll Free: 1-888-540-6666  
[www.marchofdimes.ca](http://www.marchofdimes.ca)

### Stroke Recovery Canada - Thunder Bay Peer Support Group

(807) 345-6595 ext 105  
Toll Free: 1-800-335-0715

### VON Thunder Bay and District

- Nursing and Professional Programs/Services
  - Personal Support/ Respite
  - Care/Homemaking/Home Support Services
  - First Nations Services
- Phone: (807) 344-0012  
[www.von.ca](http://www.von.ca)

## MENTAL HEALTH SERVICES

### Canadian Mental Health Association

Dryden; Ignace: (807) 223-8841  
Fort Frances: (807) 274-9400  
Rainy River: (888) 813-6503  
Sioux Lookout: (807) 737-4996  
Thunder Bay: (807) 345-5564  
[www.cmha.ca](http://www.cmha.ca)

## MEDICAL EQUIPMENT ASSISTANCE

Canadian Red Cross Thunder Bay & District Branch

Home Equipment Loan Program  
(future expansion into region)  
(807) 684-9693 or 1-888-890-1997  
[www.redcross.ca](http://www.redcross.ca)

### Ontario March of Dimes

- Assistive Device Funding Supplement  
(807) 345-6595 or 1-800-335-0715  
[www.marchofdimes.ca](http://www.marchofdimes.ca)

### Ministry of Health & Long-Term Care: Assistive Devices Program

- Financial assistance with purchases of assistive devices  
1-800-268-6021  
[www.health.gov.on.ca](http://www.health.gov.on.ca)

## “211 ONTARIO NORTH” SERVICE

211 Ontario North provides up-to-date, accessible, comprehensive access to information about social, community, health and government services in the City of Thunder Bay and District. 24 hours a day, call 211 (also available at 1-807-624-1729), toll-free 1-866-624-1729, or TTY 1-888-622-4651. Information is also available online at: [www.211ontarionorth.ca](http://www.211ontarionorth.ca) or via email: [211@lspc.ca](mailto:211@lspc.ca)

## REHABILITATION, RESPITE, HOME CARE SERVICES

### Community Care Access Centre (CCAC)

- Assists individuals to plan and make informed choices about managing their health care needs or the needs of someone they care for
- Coordinates information about other services available within the community and links individuals with these services when appropriate
- Determines access to health care services provided in the home

[www.ccac-ont.ca](http://www.ccac-ont.ca)

### Northwest CCAC Head Office

Thunder Bay (807) 345-7339 or 1-800-626-5406

### Northwest CCAC Branch Offices

Atikokan (807) 597-2159 or 1-877-661-6621

Dryden (807) 223-5948 or 1-877-661-6621

Fort Frances (807) 274-8561 or 1-877-661-6621

Geraldton (807) 854-2292 or 1-866-449-2424

Kenora (807) 467-4757 or 1-877-661-6621

Marathon (807) 229-8627 or 1-866-449-3313

Rainy River (807) 852-3955 or 1-877-661-6621

Red Lake/

Ear Falls (807) 727-3455 or 1-877-661-6621

Sioux Lookout (807) 737-2349 or 1-877-661-6621

### Bayshore Home Health

Thunder Bay and District

(807) 345-0367 or 1-866-227-3894

[www.bayshore.ca](http://www.bayshore.ca)

### Comcare Health Services

(807) 346-0633 or 1-866-346-0633

[www.comecarehealth.ca](http://www.comecarehealth.ca)

### Rainy River District Home Support Program

Fort Frances: (807) 274-3261

Atikokan: (807) 597-5516

### Saint Elizabeth Health Care

Thunder Bay and surrounding area

(807) 344-2002

[www.saintelizabeth.com](http://www.saintelizabeth.com)

### Wesway Respite Services

- Family Directed Respite Funding (Districts of Thunder Bay, Kenora and Rainy River)

(807) 623-2353 or 1-888-623-2353

[www.wesway.com](http://www.wesway.com)

## ABORIGINAL SERVICES

### Anishnawbe-Mushkiki Community Health Centre

Administration: (807) 343-4843

Clinic: (807) 343-4819

[www.anishnawbe-mushkiki.org](http://www.anishnawbe-mushkiki.org)

### Dilico Anishinabek Family Care

(807) 623-8511 or 1-800-465-3985

[www.dilico.com](http://www.dilico.com)

### Gizhewaadiziwin Health Access Centre

Fort Frances, ON

(807) 274-3131

[www.gizhac.com](http://www.gizhac.com)

### Health Canada First Nations and Inuit Health Branch

- Non-Insured Health; Benefits Program
- Medical Supplies & Equipment; Medical Transportation
- Health Care Services

(807) 343-5307 or 1-800-640-0642

[www.hc-sc.gc.ca/fniah-spnia/index-eng.php](http://www.hc-sc.gc.ca/fniah-spnia/index-eng.php)

### Meno Ya Win Health Centre

Sioux Lookout, ON

(807) 737-1275 or 1-877-737-1275

[www.slmhc.on.ca](http://www.slmhc.on.ca)

### Metis Nation of Ontario

- Respite - Transportation - Advocacy

(807) 624-5018 or 1-800-265-2595

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

### Nishnawbe-Aski Nation

(807) 623-8228 or 1-800-465-9952

[www.nan.on.ca](http://www.nan.on.ca)

### Wassay-Gezhig Na-Nahn-Dah-We-Igamig

Keewatin, ON

(807) 543-1065

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

### First Nation Communities in Ontario

[www.communities.knet.ca](http://www.communities.knet.ca)

## FINANCIAL AND VOCATIONAL RESOURCES

### Canada Mortgage & Housing Corporation Residential Rehabilitation Assistance

- Program for Persons with Disabilities  
1-800-668-2642  
[www.cmhc-schl.gc.ca](http://www.cmhc-schl.gc.ca)

### Veterans Affairs Canada

1-800-522-2122  
[www.vac-acc.gc.ca](http://www.vac-acc.gc.ca)

### Government of Canada

- Canada Pension Plan (CPP)
- Old Age Security (OAS)
- Canada Pension Plan Disability Benefits  
1-800-277-9914  
[www.hrsdc.gc.ca](http://www.hrsdc.gc.ca)

### Service Canada

- Employment Insurance  
1-800-206-7218  
[www.servicecanada.gc.ca](http://www.servicecanada.gc.ca)

### Ministry of Community & Social Services Ontario Disability Support Program

(807) 473-3130 or 1-800-465-5561  
[www.mcscs.gov.on.ca](http://www.mcscs.gov.on.ca)

### Ontario Works

(807) 766-2111 or 1-877-281-2958  
[www.mcscs.gov.on.ca](http://www.mcscs.gov.on.ca)

### Ministry of Health & Long-Term Care Trillium Drug Program

- Assistance with medication fees  
1-800-575-5386  
[www.health.gov.on.ca](http://www.health.gov.on.ca)



## ADDITIONAL AGENCIES

### Alzheimer Society of Thunder Bay

(807) 345-9556 or 1-888-887-5140  
[www.alzheimerthunderbay.ca](http://www.alzheimerthunderbay.ca)

### Aphasia Institute

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

### Brain Injury Services of Northern Ontario

Thunder Bay, ON  
(807) 623-1188 or 1-866-796-1188  
Kenora/Rainy River Office  
(807) 547-2501 or 1-888-547-2501  
[www.bisno.org](http://www.bisno.org)

### Canadian Centre on Substance Abuse

(613) 235-4048  
[www.ccsa.ca](http://www.ccsa.ca)

### Canadian Diabetes Association

(807) 577-4232 or 1-800-226-8464  
[www.diabetes.ca](http://www.diabetes.ca)

### Canadian Council for Tobacco Control

1-800-267-5234  
[www.cctc.ca](http://www.cctc.ca)

### Centre for Addiction & Mental Health

(807) 626-8111 or 1-888-751-5231  
[www.camh.net](http://www.camh.net)

### Diabetes Health Thunder Bay

(807) 344-3505 or 1-800-489-3422  
[www.sjcg.net](http://www.sjcg.net)

### Dietitians of Canada

(416) 596-0857  
[www.dietitians.ca](http://www.dietitians.ca)

### Northern Diabetes Health Network (NDHN)

(807) 626-9788 or 1-800-565-3470  
[www.ndhn.com](http://www.ndhn.com)

### Telehealth Ontario

1-866-797-0000

### Thunder Bay District Health Unit

(807) 625-5900 or 1-888-294-6630  
[www.tbdhu.com](http://www.tbdhu.com)

## Caregiver's Bill of Rights

- Ask for the best treatment and services for my stroke survivor and be persistent in finding solutions to problems.
- Take pride in what my loved one and I have accomplished and celebrate our successes.
- Take care of myself and maintain parts of my own life that do not include the person I care for.
- Ask for help from others. Recognize the limits of my endurance and strength.
- To be angry, get depressed, and express difficult feelings; seek help if these feelings interfere with my life.
- Receive acknowledgment, affection or forgiveness from my stroke survivor for my efforts.

## My Notes

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## INTERNET RESOURCES FOR FAMILY CARE GIVERS

Aphasia and Stroke Caregivers Guide  
[www.squidoo.com/strokecaregiver](http://www.squidoo.com/strokecaregiver)

Canadian Best Practice Recommendations for Stroke Care  
[www.strokebestpractices.ca](http://www.strokebestpractices.ca)

Care for the Caregiver A workshop manual Veterans Affairs Canada  
[www.vac-acc.gc.ca/providers/sub.cfm?source=caregivrmanual](http://www.vac-acc.gc.ca/providers/sub.cfm?source=caregivrmanual)

Caregivers Corner  
[www.orgsites.com/pa/generation-s/\\_pgg5.php3](http://www.orgsites.com/pa/generation-s/_pgg5.php3)

Canadian Caregiver Coalition  
[www.ccc-ccan.ca](http://www.ccc-ccan.ca)

Caregiver Connect  
[www.caregiver-connect.ca](http://www.caregiver-connect.ca)

Caring Web  
[caringweb.utoledo.edu](http://caringweb.utoledo.edu)

Stroke Recovery  
[www.strokensw.org.au](http://www.strokensw.org.au)

Family Caregiver Alliance  
[www.caregiver.org](http://www.caregiver.org)

Icommunicate your online speech therapy resource  
[www.icommunicatetherapy.com/](http://www.icommunicatetherapy.com/)

Ontario Stroke Network  
[www.ontariostrokenetwork.ca](http://www.ontariostrokenetwork.ca)

March of Dimes Canada  
[www.marchofdimes.ca](http://www.marchofdimes.ca)

Northwestern Ontario Regional Stroke Network  
[www.nwestroke.ca](http://www.nwestroke.ca)

Ontario Patient Self-Management Network  
[www.ontpsm.net/](http://www.ontpsm.net/)

Prevent Stroke Ontario  
[www.preventstroke.ca](http://www.preventstroke.ca)

Safe Stroke  
[www.safestroke.org/](http://www.safestroke.org/)



Sleep Connections - Sleep and Stroke  
[www.sleepandyou.com/sleep-connections-stroke.htm](http://www.sleepandyou.com/sleep-connections-stroke.htm)

Stroke Camp  
[www.strokecamp.org/?resourcesCAR](http://www.strokecamp.org/?resourcesCAR)

Stroke Caregivers Handbook  
[www.strokesafe.org](http://www.strokesafe.org)

Stroke Engine  
[www.strokenengine.ca/](http://www.strokenengine.ca/)

Stroke Family Caregiver  
[www.whcenter.org/19303.cfm](http://www.whcenter.org/19303.cfm)

Stroke Recovery Canada  
[www.strokerecoverycanada.com](http://www.strokerecoverycanada.com)

Stroke Sense  
[www.strokesense.org/SurvivorsCaregivers\\_Main.htm](http://www.strokesense.org/SurvivorsCaregivers_Main.htm)

Stroke Survivor Caregiver  
[www.strokesurvivor.com/caregiver\\_expert.html](http://www.strokesurvivor.com/caregiver_expert.html)

Stroke Survivor and Caregiver Resource guide  
[www.americanheart.org/downloadable/heart/1208185807185STROKE%20GUIDE%204-12-08.pdf](http://www.americanheart.org/downloadable/heart/1208185807185STROKE%20GUIDE%204-12-08.pdf)

The Family Caregiver Forums  
[www.nfcacares.org](http://www.nfcacares.org)

Your Health Care Options  
[www.health.gov.on.ca](http://www.health.gov.on.ca)



## Sources and References

### Caregiver's Guide to Stroke Recovery

Published by BioMed Content Group Inc. in partnership with Stroke Recovery Canada, a program of March of Dimes Canada.

### Help for Caregivers

Resources available through Stroke Recovery Canada

### Caregiver's Handbook

PDF Version - Courtesy of Senior Magazine Online [www.seniormag.com](http://www.seniormag.com)

### Being a Caregiver - A checklist to healthy caregiving

Geriatrics interprofessional interorganizational collaboration  
[HTTP://rgps.on.ca/giic/index.en.html](http://rgps.on.ca/giic/index.en.html)



**Responding to Stressful Events: Self Care for Caregivers**

Public Health Agency of Canada  
[www.phac-aspc.gc.ca](http://www.phac-aspc.gc.ca)

**Let's Talk About Stroke**, (An Information Guide for Survivors and Their Families)

The Heart and Stroke Foundation of Canada  
[www.heartandstroke.com](http://www.heartandstroke.com)

**Canadian Stroke Network**

[www.canadianstrokenetwork.ca](http://www.canadianstrokenetwork.ca)

**HealthyOntario.com**

[www.healthyontario.com](http://www.healthyontario.com)

**American Stroke Association**

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

**The Caregiver's Handbook, from the American Association of Retired Persons**

<http://www.acsu.buffalo.edu/~drstall/hndbk0.html>

**How much sleep do you need?**

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

**Your Guide to Healthy Sleep** (Adapted)

The National Institutes of Health  
[www.nih.gov](http://www.nih.gov)

***Presentations from the Presenters at "Caregiver's of Survivors of Stroke Conference", May 2010***

**Let's Talk: Hey! Enough about you... what about me?**

Dr. Scott Sellick, Director of Supportive Care; Thunder Bay Regional Health Sciences Centre (TBRHSC)

**Meals Made Easy: Healthy Eating**

Cayla Mantis, Dietitian; TBRHSC

**Tools & Tips to a Better Night Sleep**

Dr. Paul Johnston, Clinical Psychologist; TBRHSC

**Taking time for yourself: prioritising leisure and maintaining your own fitness**

Denise Taylor - Physiotherapist, St. Joseph's Care Group

Fiona MacLean - Physiotherapist, TBRHSC

Laura Swancar & Deanne Lee - Occupational Therapists, TBRHSC

**Ask Us: Open Question Panel with Health Care Providers**

Sharon Jaspers, Nurse Practitioner; TBRHSC

Elaine Edwards, Clinical Stroke Nurse; TBRHSC

**Patient Family Centred Care**

Mary Jane Kurm, Manager 2A Medicine; TBRHSC

## Acknowledgments

*Funding for this initiative provided by:*



*Project administered by:*



a program of March of Dimes Canada

## MY EXTENDED FAMILY, FRIENDS AND NEIGHBOURS

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## OUR IMPORTANT CONTACTS

### Family Doctor

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

### Social Worker

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

### Case Manager

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

### Physical Therapist

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

### Occupational Therapist

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

### Speech-Language Pathologist

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

### Recreational Therapist

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

### Dietitian

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

### Other Contacts

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