After Stroke, a Program of March of Dimes Canada

March of Dimes Canada is a non-profit organization that has provided programs and services to people with physical disabilities since 1941. The organization has been working in collaboration with the Stroke Recovery Association of BC (SRABC) to enhance the lives of stroke survivors across Canada. SRABC became an affiliation of March of Dimes Canada in 2016.

There are approximately 405,000 Canadians living with the effects of stroke in Canada (Heart & Stroke, 2018 Stroke Report). Our After Stroke programs provide stroke survivors with valuable information, resources, and programs to help them transition from the hospital back into their homes and communities. We are committed to maximizing the independence, personal empowerment, and community participation of individuals living with the after effects of stroke.

To learn more please visit afterstroke.marchofdimes.ca

OUR MESSAGE

There is Life After Stroke

There is life after stroke; never give up hope and never stop trying to gain independence and empowerment. We have seen with our own eyes that being determined to get better makes an enormous difference in survivors’ progress in recovery. You may never fully recover, but everyone can keep on improving. Many stroke survivors go on to have successful and enjoyable lives by learning to make the most of the abilities they have.

Support is very important. Family and friends play a huge role in the recovery process. Support from other stroke survivors including their understanding and encouragement is very beneficial as well. Caregivers also need support. You need to set goals; as long as you achieve some of them you are moving in the right direction. If you fail, try breaking your goals in to smaller, simpler steps. Never give up hope, and never stop trying.

We hope you find the information in this booklet useful. If you have further questions after reading, please contact us:

AFTER STROKE
T. 1-888-540-6666
E. afterstroke@marchofdimes.ca
W. afterstroke.marchofdimes.ca
# TABLE OF CONTENTS

RECOVERING FROM A STROKE ........................................... 3
7 STEPS TO STROKE RECOVERY ....................................... 3
WE CAN HELP ................................................................... 4
WHAT IS A STROKE? .......................................................... 4
THE HUMAN BRAIN ........................................................... 5
UNDERSTANDING THE BRAIN ........................................... 5
PREVENTING ANOTHER STROKE ....................................... 7
EFFECTS OF A STROKE ....................................................... 7
EFFECTS OF A STROKE ON A CAREGIVER ....................... 9
THE STRESS OF CAREGIVING ............................................ 9
TIPS FOR CAREGIVERS ..................................................... 9
AFTER STROKE RECOVERY PROGRAMS ........................... 9
FITNESS AND MOBILITY PROGRAMS ................................. 12
ADDITIONAL PROGRAMS AND SERVICES ....................... 13
VISIT OUR WEBSITE ....................................................... 13
SOCIAL MEDIA LINKS ...................................................... 13
PRINTED RESOURCES – GUIDES TO STROKE RECOVERY 14
HOW TO DONATE ........................................................... 15
RECOVERING FROM A STROKE

How well you recover from a stroke depends upon many factors, including how much and which parts of your brain were damaged, as well as the state of your health prior to the stroke. Doctors can provide surgery, medication, and other treatments to mitigate the effects of stroke. The work you do with your stroke rehabilitation team in the hospital, rehabilitation center, and in the community is very important to recovery.

7 STEPS TO STROKE RECOVERY

Step 1 | Exercise and Mobility
Walking, biking, gardening, or even simple household cleaning can all be excellent steps in recovery from stroke. Physical activity can trigger changes in the brain that make up for lost function. Be consistent and turn this physical activity into a habit. It is best to do an activity once a day for a short period rather than a long block of activity once a week. Consistency with physical activity is crucial as it gradually becomes a part of your routine.

Step 2 | Communication and Language
Write down key words, draw pictures, point, and make faces to communicate. Don’t rush or pretend to understand. Be patient with yourself, it will get easier.

Step 3 | Social Interaction
Enjoy family, friends, and favorite activities, take up new interests and reclaim your social life! Connecting with people and passions provides a sense of purpose and self-worth.

Step 4 | Thinking, Memory and Perception
If you have trouble thinking, understanding, and/or remembering, then stick to a routine and keep activities simple. Take notes and use a calendar to jog your memory. Little tactics like these can help you to cope, as well as to improve.

Step 5 | Support
A stroke may cause depression, anxiety, feelings of loneliness, and mood changes. Do not be afraid to ask your family and friends for help in times of need. You can also attend stroke support groups and recovery programs, where you are able to connect with other survivors who can relate to what you are going through. They can provide you with practical help, validation, and hope.

Step 6 | Healthy Lifestyle
Improve your chances of recovery with healthy habits. Lose weight, cut down on cholesterol, quit smoking, and reduce your alcohol and caffeine intake. Little changes like these can go a long way towards recovery.
Step 7 | Navigating the System

Get to know key organizations and resources in your local area. Visit facilities and programs that can help you as you recover. Join a support group to become more involved in your community. Learn how to use public transportation. Make adjustments to your home and vehicle to allow you to retain independence in your personal life.

WE CAN HELP

Here are a few useful guidelines to help you get the most out of your rehabilitation:

» **Rest:** Tiredness and fatigue are common after a stroke.

» **Simplify:** Keep activities and information as simple as possible.

» **Repetition:** Learning after stroke requires repetition of information and practice of skills.

» **Structure:** A daily and weekly structure and routine are helpful.

» **Consistency:** Do things the same way each time.

» **Learn to Compensate:** You have to adapt and change from past ways of doing things. For example use a day-timer or calendar to help you to remember things.

WHAT IS A STROKE?

A stroke is a brain injury caused by:

» Blood flow to the brain being blocked

» A blood vessel bursting in the brain

THE HUMAN BRAIN

The brain is the most complicated organ in your body. It is a network of special cells that are constantly sending signals and messages from one part of your brain to another. It controls everything that you do. It is responsible for your movements and helps you to walk and maintain balance. It makes sure that you know where you are going, and that you don’t get lost. It controls memory and awareness. It helps you to recognize and remember things, like who the members of your family are. It controls your senses so that you can hear and understand what others are saying to you. It helps you to see what is around you and to understand what you see. It controls your personality and how you behave. All of your thoughts, feelings and emotions come from your brain. It helps you to make decisions. It governs communication including your speech, reading, and writing. It even controls life support systems, like breathing and eating.

Your brain is divided into two halves called the right and left hemispheres and four different areas called lobes. Each of these parts are in charge of a different aspect of your functioning. The affects that you may feel post stroke all depend on:

» The part of your brain that is damaged

» How serious the damage is
UNDERSTANDING THE BRAIN

Understanding how the brain works is important in beginning to understand your stroke and learning how to cope with the new mental and physical changes.

Frontal lobes
Located at the front of your brain, the frontal lobe is responsible for reasoning and communication. This area receives information from all over the brain and is ultimately in charge of your planning, organization, decision making, judgment, impulse control, language and memory. It can simply be described as your emotional control center.

Parietal lobes
Situated in the middle of your brain, the parietal lobe is divided into two functional regions; left and right. The left side of the lobe is responsible for your speech and language skills, giving you the ability to move your tongue, lips, and throat muscles while simultaneously recalling the words you want to say and the meaning of these words. The left and right side of the lobe are both responsible for your motor functions. The left side of the lobe controls the movement on the right side of your body, and the right side of the lobe is responsible for the movement on the left side of your body. Your spatial reasoning is also found in the right side of the parietal lobe which allows you to find your way around a building, navigate while driving, and complete simple tasks such as getting your arm through a sleeve. Additionally, the right side is in charge of your creative side and how musically and artistically inclined you are. The parietal lobe and the frontal lobe are in constant communication: the parietal lobe receives directions from the frontal lobe.

Limbic System
Located at the bottom of the brain, these regions are responsible for your appetite control, thirst, and portrayal of basic emotions (tears, red face, and increased pulse).

Brain Injury
In the case of a brain injury such as a stroke the area of the brain affected can help predict the survival and functional outcome of the patient. Damages to areas in the frontal lobe lead to problems such as paralysis, inability to focus on a task, changes in social behaviour and personality, difficulty with problem solving, and inability to communicate effectively. Damages to the parietal lobes results in functional problem such as lack of awareness and coordination, visions loss, and difficulty reading and writing. Strokes occurring and affecting the limbic system can lead to the loss of basic human drives and natural inhibition. These distinct functionality losses make treatment and rehabilitation unique for each survivor.

Brain Function
Robert P. Lehr Jr., Ph.D.
Professor Emeritus, Department of Anatomy, School of Medicine,
Southern Illinois University

-Verna Amell, Ph.D, Psychologist, GF Strong Rehabilitation Centre (1987)
PREVENTING ANOTHER STROKE

People who have had a stroke have a greater chance of having another one, especially during the first year following the initial stroke. There are several things you have some control over that can help you to avoid another stroke, including:

» Reducing cholesterol
» Losing weight
» Getting regular exercise that increases your breathing and heartbeat
» Limiting your intake of caffeine, animal fats, sugars, and processed foods
» Eating plenty of fruits, vegetables, and high-fiber foods
» Quitting the use of tobacco products
» Limiting your alcohol consumption
» Reducing your stress level
» Avoiding use of narcotic drugs
» Healthy sleep patterns

EFFECTS OF A STROKE

Effects of a stroke can include, but are not limited to those listed below. Remember that every stroke and every person is different.
EFFECTS OF A STROKE ON A CAREGIVER

Caregiving can be physically, emotionally, and financially straining. Too frequently, little thought is given to a caregiver’s ability to provide care. Caregivers, their family, and friends must consider:

» Financial status
» Ability to prepare the home – i.e. bath rails, shower chair, non-skid mats
» Age and health of the caregiver and stroke survivor

PHYSICAL EFFECTS
» Part or all of one side of the body is paralyzed
» Loss of feeling or numbness in part or all of one side of the body
» Loss of awareness of part or all of one side of the body
» Problems with movement, which can affect walking, sitting, bathing, using the toilet, dressing etc.
» Pain
» Fatigue
» Loss of vision

EMOTIONAL EFFECTS
» Loss of emotional control (e.g. crying easily – sometimes for no apparent reason)
» Depression
» Anxiety
» Anger
» Frustration
» Loss of self esteem

COGNITIVE EFFECTS
These effects involve things like thinking, understanding and learning:

» Loss of ability to recognize familiar objects or understand their use
» Difficulty judging distances, shapes
» Slow, cautious behavior
» Problems planning, organizing and starting tasks
» Problems recognizing current abilities and limitations
» Problems with body image

COMMUNICATION EFFECTS
» Inability to use or understand words (aphasia)
» Loss of writing abilities
» Slurred speech
» Difficulty in absorbing information

PERSONAL AND SOCIAL EFFECTS
» Awkwardness
» Inappropriate behavior
» Isolation
» Family breakdowns
» Loss of privacy
» Change in roles
» Challenges with relationships
» Work and career issues
» Financial concerns
THE STRESS OF CAREGIVERING

For a stroke survivor, the experience of stroke may be terrifying and disorienting. The spouse and family, however, are thrown into a situation that is no less frightening. Often, the caregiver’s feelings become secondary to the stroke survivors.

Caregivers generally have very demanding expectations of themselves. After the initial shock has passed and the caregiver and stroke survivor have settled into a new routine, the stress of caregiving may emerge and the caregiver may exhibit irritability, anxiety, numbness, or fatigue. They may also feel that they just can’t manage. Caregivers may become distant and detached, or experience health problems of their own.

The expression of these feelings is natural and normal. The caregiver should not feel guilt or embarrassment by these feelings.

TIPS FOR CAREGIVERS

» Organize a realistic and flexible schedule for the stroke survivor
» Incorporate downtime for yourself and your loved one
» Prioritize physical activity for yourself and your loved one
» Do not be hesitant to ask others for help

COGNITIVE EFFECTS
These effects involve things like thinking, understanding and learning:

» Loss of ability to recognize familiar objects or understand their use
» Difficulty judging distances, shapes and new information
» Slow, cautious behavior
» Problems planning, organizing and starting tasks
» Problems recognizing current abilities and limitations
» Problems with body image

COMMUNICATION EFFECTS

» Inability to use or understand words (aphasia)
» Loss of writing abilities
» Slurred speech
» Difficulty in absorbing information

PERSONAL AND SOCIAL EFFECTS

» Awkwardness
» Inappropriate behavior
» Isolation
» Family breakdowns
» Loss of privacy
» Change in roles
» Challenges with relationships
» Work and career issues
» Financial concerns
AFTER STROKE RECOVERY PROGRAMS

We offer a range of programs, services, and information designed to support stroke survivors, their family, and caregivers in the community after they leave the hospital. Services that promote stroke recovery are listed below:

Hospital Visitation Programs

Our hospital visitation programs, Peers Fostering Hope and Linking Survivors with Survivors, help people living with stroke, their family, friends, and caregivers. The goals of the programs are to enhance quality of life, alleviate feelings of isolation, and help new stroke survivors re-engage in their community post-stroke. This is achieved through efforts of trained Peer Volunteers who visit stroke survivors in acute care, inpatient, and outpatient rehabilitation units in local hospitals.

Peer Volunteers are persons who have had a stroke and possess experiential knowledge and optimism gained from their own recovery journey. The programs operate in collaboration with local hospitals with peers jointly trained by March of Dimes Canada and the hospital’s volunteer service department.

If you or someone you know is in the hospital due to a stroke, arrange a visit with one of our Peer Volunteers. For more information call our toll-free line at 1-888-540-6666 or email afterstroke@marchofdimes.ca


Linking Survivors with Survivors (LSWS) runs in Waterloo-Wellington, Ontario and is funded through the Waterloo-Wellington Local Health Integration Network.

Conductive Education (CE™)

Conductive Education™ is an innovative physical and neuro-motor rehabilitative program that uses individualized learning strategies to preform daily functions. The program is a holistic approach to recovery and breaks down activities into doable tasks that focus on routine and positive reinforcement.

Services currently operate in Alberta, Halifax, and Ontario. It is also being developed in British Columbia.

Aphasia and Communication Disabilities Program (ACDP)

ACDP, funded by the Ontario Ministry of Health, is an adult day program for people with communication disorders led by a group of seasoned Speech Language Pathologists (S-LP), Communicative Disorders Assistants (CDA), and volunteers. The program focuses on helping clients to become active participants in their community. The aphasia day program provides services to people in Ontario, mostly residing in York and Simcoe, Durham, Peterborough, and the Greater Toronto Area.
**Aphasia Camps**

Aphasia Camp brings together people with aphasia, their families, health care professionals, and volunteers to explore meaningful approaches to aphasia management. Activities are both recreational and therapeutic in nature and campers have the opportunity to participate in diverse activities. Camps currently run in Alberta, British Columbia, Manitoba, Ontario, and Nova Scotia.

**Stroke Wellness Retreats**

The Health and Wellness Retreats are overnight recreational getaways for people living with the effects of stroke and their loved ones. The retreats provide opportunities for guests to connect with people with similar lived experiences and build a community of peer-to-peer support. The retreats include leisure and recreational activities.

**Living with Stroke™**

Living with Stroke is a 6-8 week community-based support and education program, based off the Heart and Stroke curriculum, designed for stroke survivors and their caregivers. The program helps you cope with the changes as a result of stroke and provides a social and supportive environment for participants. Sessions currently operate across Canada through various partnerships and service collaborations. Meetings are led by trained facilitators and are highly interactive; focused on skill-building, sharing experiences, and learning from one another.

**Stroke Support Groups**

The After Stroke program has and is establishing support groups across Canada. Support groups provide a friendly place for stroke survivors, families, friends, and caregivers to receive encouragement, assistance, resources, and support. The programs offer, or will help you find, the following services and programs in your community:

- Physical activity and exercise programs
- Communication and memory exercises
- Social interaction and recreation
- Support from fellow stroke survivors
- Caregiver support
- Stroke recovery education
- Help finding other health and community resources

**FITNESS AND MOBILITY PROGRAMS**

**Together in Movement and Exercise (TIME™)**

TIME™ is a group exercise class that is run through the Toronto Rehabilitation Institute. It is a circuit-based exercise routine that helps participants strengthen muscles, increase...
cardiovascular health, and become more confident in their abilities

**Fitness and Mobility Exercise (FAME) – is this trademarked?**
FAME is an exercise program focused on stretching and strengthening muscles, improving balance, and increasing cardiovascular health. The program operates within a group setting which provides motivation along with social activity to keep participants engaged within their communities. The overall goal of the program is to improve the participants’ independence by improving fitness and mobility. Service currently operates British Columbia

**Next Steps Walking Program**
The Next Steps Walking Program is a group-based walking program that focuses on having fun, setting goals, and staying motivated. The program operates in local indoor malls with easy access to washrooms and seating. Most participants are slower walkers and typically require a walking aid. Members are encouraged to walk at their own pace and distance while building friendships and integrating themselves within the community. Programs currently operate in British Columbia and Ontario.

**Stroke Warmline | ® 1-888-540-6666**
A post-stroke community navigation line that assists survivors and their loved ones to access services at the right place and the right time. It’s a toll-free line that operates Monday to Friday 9:30am to 4:00pm EST. A staff will return your call within 48 hours.

T. 1-888-540-6666
E. afterstroke@marchofdimes.ca
W. afterstroke.marchofdimes.ca

**ADDITIONAL PROGRAMS AND SERVICES**
For more information on a variety of programs and services, resources, and guides that promote quality of life for survivors please contact us.
Some of these programs include but are not limited to: Assistive Devices Program, DesignAbility, Home and Vehicle Modification Program, Independent Living, Recreation and Integration Services.

**VISIT OUR WEBSITE**
Learn how to recover from stroke and take back your life. Find expert advice, guides, videos, community group programs designed for stroke survivor, and best of all – hope. Visit our After Stroke website at afterstroke.marchofdimes.ca
SOCIAL MEDIA LINKS

We post useful information on stroke recovery here. Please take a look at the links, ‘like’ us, ‘follow’ us, and let us know your ideas.
Facebook: /MarchofDimesCanada Twitter: @modcanada

PRINTED RESOURCES – GUIDES TO STROKE RECOVERY

Please email afterstroke@marchofdimes.ca or visit afterstroke.marchofdimes.ca to access a guide:

**Daily Living**

This guide will help to answer questions about how to successfully return home and resume daily living after stroke.

**Adjusting the Home after Stroke**

This guide will help to answer two questions: What can be done to make the home safe? How can the home be set up to help recovery?

**Self-Advocacy**

This guide will help to answer questions about how to get what you need after a stroke, whether you are a caregiver or a stroke survivor.

**Getting Back into the Community**

This guide will help to answer questions about how to get back into the community after a stroke.

**Understanding Aphasia**

This guide will help to answer questions about speech and language problems after a stroke.

**7 Steps to Stroke Recovery**

This guide describes the brain’s ability to adapt to your new needs (neuroplasticity). The guide follows up with steps to meet your goals. Each step includes options to suit your stage of recovery.

**Exercise & Mobility**

Can you exercise after a stroke? Yes! This guide helps you get started with exercise and improve your mobility after a stroke. It covers goal setting, injury prevention and making choices that are right for you.


This handbook talks about the problems and rewards that come from caring for an adult with a chronic illness or disability. The aim is to give caregivers information and ideas about how to cope. It is available in English and French. There are copies available at afterstroke.marchofdimes.ca or call in to get a guide mailed to you at 1-888-540-6666
HOW TO DONATE

Stroke is the leading cause of disability in Canada and the third leading cause of mortality. Hospitals do a great job of treating those who suffer from a stroke, but sooner or later those survivors go back home. What then?

Please help to bring stroke survivors in Canada back to life. Support these survivors in leading a happy and fulfilling life independently and within their communities by making a donation today. When you decide to donate to After Stroke at March of Dimes Canada, you help build a world where every stroke survivor has respect, inclusion, and support in their community.

To Donate

Visit afterstroke.marchofdimes.ca and click on Donate at the top of the page.
Sincere thanks to the Stroke Recovery Association of British Columbia, an affiliate of After Stroke, a program of March of Dimes Canada, for creating this resource - your experience and support have added incredible value.

March of Dimes Canada
10 Overlea Blvd.,
Toronto, ON M4H 1A4

Toll-free: 1-800-263-3463
Tel: 416-425-3463

www.marchofdimes.ca
March of Dimes Canada Charitable Registration No. 10788 3928 RR0001