

A Caregiver's Guide to

# Stroke Recovery

Caregiver stories

Spasticity

Physical therapy

Depression

Healthy living

Relationships

Drug coverage



This publication is in partnership with Stroke Recovery Canada,  
a program of March of Dimes Canada





**“In my travels across  
Canada, I have  
met many caregivers  
who amaze  
and inspire me.”**



Published by BioMed Content Group Inc. in partnership with Stroke Recovery Canada, a program of March of Dimes Canada. Special issue to A Patient's Guide to Medical Information.  
*Canadian Publications Mail Sales Agr #40827503. Return undeliverable to 36 Toronto St., Suite 850, Toronto, Ontario M5C 2C5.*

**This publication was made possible by a grant from Allergan Canada ([www.botox.ca](http://www.botox.ca)).**

# Saluting Stroke Caregivers

In my travels across Canada, I have met many caregivers who amaze and inspire me. These are people who are not letting the challenges of caregiving mean an end to their happiness and independence. Instead, they have learned how to take care of themselves while helping their stroke survivors thrive.

Studies have shown that the attitude of the caregiver has a direct impact on the health and well-being of the stroke survivor. In this premiere issue of *A Caregiver's Guide to Stroke Recovery* you will find information and tips on how to be an effective caregiver and how to best motivate your stroke survivor to achieve optimal rehabilitation. At Stroke Recovery Canada, a program of March of Dimes Canada, we are dedicated to helping you and your loved one live as empowered and independently as possible. Contact us to find programs and services in your community. ▣

**Kimberley Dowds**, Associate Director,  
March of Dimes Canada

## Table of Contents

- 4 Caregiver stories
- 7 Your partner for healthy living: exercise & nutrition
- 10 Physical therapy
- 12 Spasticity medical update
- 17 Occupational therapy
- 18 Overcoming depression
- 20 Intimate relationships
- 21 Fight with all you've got: a patient's story
- 23 Set sail for rehabilitation
- 26 A guide to Canadian drug coverage
- 28 Services of Stroke Recovery Canada
- 32 Caregiver's bill of rights

# Life as a Caregiver

## A measured approach

Pat Bonnell had a stroke 26 years ago. At the time, she and her husband Don were deeply immersed in their work, having started a small business five years earlier. After Pat's stroke, Don continued to operate the business, and being self-employed he was able to get away during the day to visit Pat at the hospital.

“Pat had many problems as a result of her stroke,” recalls Don. “She had neurological deficits, became legally blind and developed spasticity (muscle tightness in her left arm and leg).” Because of spasticity, Pat had difficulty walking, her left arm was bent up to her left shoulder, and her left hand could not be opened. Initially, Pat had to be helped with most of her daily tasks. “Her improvement was very slow,” says Don, “but we consciously decided to adopt a positive attitude and to frequently think about the things

we could be thankful for. The support of our families helped tremendously.



**Don and Pat Bonnell**

We persisted in seeking help, and participated in all the rehabilitation programs that were offered. This strategy worked. Over the years, Pat has showed great improvement in function, including spasticity.”

It took several years of physical therapy, exercises and daily efforts to walk to alleviate spasticity in Pat's leg. “My arm was affected even more than my leg,” says Pat. “I could only manage to stretch out my arm with two hours of physical therapy and exercises per day; with anything less, my arm would bend again. Last year, my physical therapist recommended Botox injections (a treatment that relaxes muscles) to make it easier to stretch out the muscles in my arm. This worked. The

improvement in my arm also helped my walking because my posture became straighter.” Don says that treating Pat’s spasticity helped him also. “Pat is able to dress and walk better, and I don’t have to assist her as much.”

Pat’s can-do attitude has made all the difference. She joined Stroke Recovery Canada very early on, getting social support through friendships with other stroke survivor couples. “Optimism is a key requirement,” says Don. “It’s easy to feel sorry for yourself, especially in the initial stages after a stroke, but this never helps. As a caregiver, you must encourage and assist the stroke survivor. The person you love is still the same person after a stroke. Work with them and help them achieve as much independence as will be safe for them. It’s very rewarding to see your loved one rehabilitate and enjoy life again.”

## **Improvement is always possible**

Catherine Eustace was only 14 years old when she had a massive

stroke. Although her parents Micheline and Ed were divorced, they quickly committed to working together to help their daughter. Catherine’s stroke had made them realize that nothing in life can be taken for granted, and they must cherish every moment. Ed, Micheline and Catherine’s older sister Anne-Marie took turns being with Catherine at the hospital, and later at the rehabilitation center and at home. It hasn’t been easy, but nine years later, Catherine has overcome tremendous challenges and is preparing to go to University.

When asked what helped the most, Micheline says, “We considered ourselves part of the rehabilitation team, together with the doctors, nurses and therapists. We constantly tried to learn as much as we could about stroke and advocated on our daughter’s behalf, asking medical staff to find solutions for various problems. To receive help, most often we only needed to ask, but sometimes we had to be more persistent. We also

*Continued on next page*

# Life as a caregiver

*Continued from page 5*

sought and accepted support from everyone: our family, hospital, rehabilitation center and Catherine’s school. That way the responsibilities were spread out, and nobody burned out.”

The key lesson Ed learned as a caregiver was never to give up, that improvement is always possible. “For nine years, Catherine had spasticity in her left wrist and ankle, interfering with her ability to use her left hand and walk,” he says. “We didn’t have a treatment for this. Only last year, Catherine’s godmother, a nurse, learned about some of the newer methods to treat spasticity, and we obtained a referral to a spasticity clinic. Now

Catherine can raise her left arm above her head, and her left hand is straighter and stronger. She also walks with less of a limp. It just goes to show you that the rehabilitation techniques are always advancing and Catherine’s quality of life continues to improve.”

A stroke may change what a person can do, but we all have different talents. So, it’s a process of rediscovery. “I had to give up snowboarding,” says Catherine, “but I discovered painting and golf. Immediately after the stroke, I was scared, and then depressed, but when I saw my parents full of hope and fighting for me, I also committed to my recovery. I had to work hard at physical therapy and at restarting my education after a two year delay. At times,

my life felt like constant work. But things are really looking optimistic now. I learned that hard work and commitment can make a big difference.” ▣



Anne-Marie (sister), Micheline, Catherine and Ed Eustace

# Caregiver and Stroke Survivor: Partner for healthy living

## Exercise

Exercise promotes well-being and can improve the quality of life of stroke survivors by strengthening muscles and improving mobility. Each stroke survivor will have an individualized exercise routine depending on his or her disability. You can partner with your stroke survivor for some daily exercise, with each of you doing your own routine. Canada's Physical Activity Guide recommends that adults get 30 to 60 minutes of moderate physical activity per day. You can add it up in periods of at least 10 minutes at a time. Consult a physical therapist or a physician for individualized exercise recommendations. Play some music and make it a fun break for you and your stroke survivor, everyday.

### Exercise suggestions for caregivers

March on the spot for three



to five minutes, and then do the following exercises, 10-15 times each. Start with a few repetitions and build up gradually.

1. Circle your arms slowly to stretch the upper body.
2. Stand at a table and do small knee bends.
3. Sit down and extend your knees. Then, pump your ankles up and down to stretch leg muscles.
4. Sit down, then stand up.
5. From a standing position, go up on your toes, then down.
6. Hold on to a table and do side leg raises.
7. Balance on one leg (make sure you can grab onto something if needed).

*Continued on next page*

## Partner for healthy living

*Continued from page 7*

8. Tap step. Move your right foot forward, to the side, behind you, and back to the starting position. Do the same with the left foot.
9. Walk: in the room, the hallway or anywhere else.

### Take a mental break

Taking regular relaxation breaks can help both caregivers and stroke survivors better cope with the challenges associated with stroke recovery. Furthermore, relaxation can decrease pain and spasticity in stroke survivors.

One of the most basic relaxation techniques is deep breathing. Our bodies react to stress with rapid, shallow breathing. Breathing slowly and deeply will help to ‘turn off’ the stress reaction and ‘turn on’ the relaxation response.

Do the following together with your loved one:

1. Begin by breathing normally, but pay attention to each breath, taking a mental note of how the

air comes in and out of your body.

2. After several breaths, begin to breathe more deeply, with longer inhalations and longer exhalations.
3. Breathe deeply and slowly, focusing all of your attention on each breath. As you exhale, imagine the tension draining from your body and mind. Notice the feeling of calm and relaxation that comes with exhalation. Continue deep breathing for a few minutes.

## 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). The guide has a wealth of information, from age-adjusted portion sizes to tips on meal planning and shopping.

### Healthy eating tips

1. Plan your meals in advance for one or two weeks.
2. Read nutrition labels on packaged food to help you buy items that are low in trans fat, saturated fat and sodium.
3. Try to consume less than 1500 mg of sodium per day.
4. 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).
4. Buy fresh, frozen or canned pre-cut vegetables for quick salads, stir-fries and side dishes.
5. Prepare some foods in

**“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).”**

- advance. Cook double and keep leftovers in the freezer (for example, soups or lasagna).
6. Make gradual improvements to your diet and stick to them.
  7. Work with a registered dietitian to learn other helpful tips. To find a dietitian, ask your doctor or visit [www.dietitians.ca](http://www.dietitians.ca). ▣



# Don't forget **Physical** therapy

**P**hysical therapy can help a stroke survivor regain independence through improving diminished mobility, sensation, coordination, balance, strength and endurance. It also helps alleviate the negative effects of spasticity (stiff muscles).

“A physical therapist starts by assessing movement and sensory loss, and by asking the stroke survivor and caregiver about their priorities for treatment,” explains Linda Minor, physical therapist at the Glenrose Rehabilitation Hospital in Edmonton. “Try to be as specific as you can when discussing priorities. For example, tell the therapist that you would like to learn how to help your loved one transfer from the bed to the wheelchair or you would like to be able to open his or her hand to wash. The physical therapist will then develop an individualized plan, working towards specific goals that you have agreed upon together. Over time, the program will be reviewed and refined, depending upon the progress and

**Ms. Linda Minor:**  
Physical Therapist,  
Spasticity Clinic,  
The Glenrose  
Rehabilitation  
Hospital, Edmonton



any changes in your and your stroke survivor's needs.”

Physical therapists use a variety of techniques. For example, if the stroke survivor cannot move, the therapist will first ensure that the person is correctly positioned in the bed. The therapist will also recommend changing the position regularly to reduce muscle and joint stiffness. If the survivor suffers from spasticity, the therapist will recommend positions for sitting and lying down in which the spastic muscles are stretched. The therapist will also design a stretching exercise routine, and may employ techniques such as casting (i.e. using a cast to hold the muscles and joints in the correct position). These approaches can prevent the muscles and joints from becoming permanently fixed. If the stroke survivor has weak

limbs, physical therapy will start with small guided movements and practicing simple tasks. As the strength improves, more complex exercises will be initiated to encourage both sides of the body to work together. This will help the healthy parts of the brain to take on some functions previously carried out by the damaged parts of the brain.

Physical therapy is often carried out in combination with medical treatment. For example, “drug therapy may be used to help relax spastic muscles and allow the muscles to be stretched and positioned more effectively,” says Minor.

Physical therapy can begin as soon as the survivor is medically stable. It is best to start right away to prevent deconditioning of the muscles that can occur with prolonged bedrest.

Minor encourages caregivers and stroke survivors to maximize physical therapy and learn techniques they can use outside of therapy sessions. “You can learn

proper techniques to assist your stroke survivor and ensure that neither of you get injured in the process,” says Minor. “Your therapist can also suggest exercises to do at home. For example, stretching exercises should be done daily, especially if spasticity is a problem.”

As a caregiver, you can play a key role in encouraging your stroke survivor to do his or her exercises and engage in other aspects of rehabilitation. Emphasize the importance of active participation, and also try to make it fun. Join your stroke survivor for a daily exercise break. See exercise suggestions for caregivers on page 7. ▣



# Medical Update

**Dr. Christos Boulias:** Psychiatrist,  
Neurorehabilitation services,  
West Park Healthcare Centre, Toronto

**Dr. Farooq Ismail:** Psychiatrist,  
Neurorehabilitation services,  
West Park Healthcare Centre, Toronto



DR. BOULIAS



DR. ISMAIL

## Help for Spasticity

**S**pasticity is defined as uncontrollable muscle tightness, often accompanied by pain and reduced function, such as difficulty walking and using the hands. The restriction of movement can make day-to-day life a struggle for both the stroke survivor and caregiver. Presently, many stroke survivors who suffer from spasticity remain untreated or undertreated, even though effective therapy is available. It is important for caregivers to watch for spasticity in stroke patients and communicate the problem to their doctors in order to receive appropriate care.

Studies show that spasticity affects more than 65% of stroke survivors, usually within three to six months following a stroke. “Spasticity is a natural response of the brain to injury, and is aimed at increasing the tone of flaccid muscles,” says Dr. Christos Boulias, psychiatrist at West Park Healthcare Centre in Toronto. “A certain degree of spasticity is helpful to restore the patient’s ability to use the affected side of the body. However, spasticity often becomes excessive and negatively impacts a stroke survivor’s function. The goal of treatment is to find and maintain the right balance.”

Controlling spasticity can benefit the caregiver’s quality of life as much as the patient’s. “A patient with spasticity may require a great deal of assistance with daily living because his or her abilities are limited. A very spastic patient may even require several people to complete morning and evening routines,” says Dr. Farooq Ismail, physiatrist at West Park Healthcare Centre in Toronto. “In milder cases, spasticity can affect a person’s balance, making it difficult to walk. Spasticity can make it impossible for a stroke survivor to drive, or even unclench an affected hand. If a clenched fist cannot be opened to be washed, a skin infection may result. Spasticity is often overlooked because stroke survivors have many other problems. However, it

**Controlling spasticity  
can benefit  
the caregiver’s  
quality of life  
as much as the patient’s.**

shouldn’t be. The caregiver should alert the medical team to potential spasticity and ask for a referral to a spasticity clinic.”

## **Recognizing spasticity**

The degree of spasticity may vary from mild muscle stiffness to severe, painful and uncontrollable muscle spasms. It may be triggered or aggravated by movement, emotional stress, and physical discomforts such as skin irritation or a full bladder. Watch for a tight fist, bent elbow, arm pressed against the chest, stiff knee or pointed foot in your stroke survivor.

## **Spasticity treatments**

The treatment of spasticity aims to address specific goals. “We assess the negative impacts of excessive spasticity as reported by the caregiver and patient, and make treatment decisions based on what the caregiver and patient want to achieve,” explains Dr. Boulias.

*Continued on next page*

# Help for spasticity

*Continued from page 13*

“For example, the goal could be to achieve the right amount of tension in the fingers of the affected hand to enable the patient to wash or cook, or it could be to make the affected arm or hand move in a way that the patient can drive a manual car.”

The treatment of spasticity involves physical therapy and medical management. The choice of treatment depends on whether the goal is to combat focal or generalized spasticity. Focal spasticity affects a smaller part of the body, such as a hand or an extremity, whereas generalized spasticity affects larger areas of the body or the whole body.

“Since the treatment is designed to reach specific goals in terms of a patient’s function, botulinum toxin A (Botox) injections are used

**Focal spasticity** affects a smaller part of the body, such as a hand.

**Generalized spasticity** affects greater areas of the body or the whole body.

as a first line treatment for focal spasticity,” says Dr. Ismail. “These injections are a simple, effective treatment with virtually no side effects. When Botox is injected into specific muscles, it promotes muscular relaxation, thereby reducing spasticity and helping the patient function more normally. To enable a patient to hold a spoon, these injections may have to be administered in varying amounts for different fingers. The effects are reversible after about three months, allowing the spasticity balance to be modified to the desired level. Botox injections are usually followed by intensive physical therapy, which involves determining ‘anti-spastic’ body positions (in which the spastic muscles are stretched) and doing stretching and range of motion exercises.”

“For generalized spasticity, we may use oral medications (dantrolene, baclofen, tizanidine or diazepam) or a baclofen pump,” says Dr. Boulias. “Oral medications are effective but often cause side effects such as sedation and muscle weakness, especially on

the healthy side of the body. Liver dysfunction is also a concern. Often, we use a low dose of an oral medication to reduce the overall level of generalized spasticity, and subsequently use Botox to reach specific goals.”

Another, although rarely used, option for generalized spasticity is the baclofen pump — a round metal disc about one inch thick and three inches in diameter — that is surgically placed under the abdominal skin. The pump delivers the medication directly to the spinal cord through a catheter (a small, flexible tube). Problems associated with the infusion pump include overdosage and sudden withdrawal of baclofen. The decision to use this treatment depends on its availability and whether the benefits outweigh the side effects in a patient.



**Dr. Boulias (left), Dr. Ismail (right) with patient Garth Rutledge and his wife Mary**

## Talking to a doctor

If you suspect that your loved one has excessive spasticity, talk to his or her doctor and ask for a referral to a spasticity clinic. Describe the symptoms you have observed and how they interfere with daily activities. Try to be very specific. Avoid general statements such as “I would like my stroke survivor to be able to move.” Instead, use specific observations such as “his nails are digging into his palm” or “her elbow is twisted, and she has difficulty dressing herself.” Describing specific concerns will help your doctor understand the impact of spasticity

*Continued on next page*

## Help for spasticity

*Continued from page 15*

on your and the stroke survivor's lives, and will enable your stroke survivor to receive an appropriate assessment.

### Message to caregivers

“Spasticity is a common, debilitating condition that can be effectively treated. However, to be treated, it must first be recognized,” says Dr. Ismail. “After a stroke, patients face many difficulties and may not be able to recognize the reasons for their restricted function. Patients may also be told that their disabilities cannot be treated because brain damage cannot be reversed. However, physicians who specialize in muscle analysis and movement can often find many solutions for day-to-day problems, and can improve the quality of life for both the patient and caregiver.” Treatment can also help prevent further complications. “If left untreated, the spastic

**Many effects of stroke can be rehabilitated.**

**Talk to your stroke survivor's doctor.**

**You have the right to receive relief from the problem of spasticity.**

muscles can freeze permanently into abnormal, often painful, positions,” adds Dr. Boulias. “Also, if a patient keeps walking on a foot that is turned in, it can damage the joint. If the hand cannot be opened to be washed, a skin infection may develop, requiring treatment with antibiotics.” Today, many effects of stroke can be rehabilitated. Take the initiative and talk to your stroke survivor's doctor. You have the right to ask for the best services and treatments, and to receive relief from the problem of spasticity. ▣

## Occupational Therapy Highlights



Occupational therapists help stroke survivors improve their functional status and find practical solutions to everyday living. This involves designing new ways

of carrying out activities important for stroke survivors' independence, lessening the burden for the caregivers. For example, occupational therapists can teach stroke survivors to get in and out of bed, dress, use the restroom, make meals and eat.

Occupational therapists also help stroke survivors return to their leisure activities or take up new ones, relearn skills they might need to return to work, or overcome problems with memory and concentration.

Similar to physical therapists, occupational therapists use an individualized approach and begin by assessing the physical, sensory, perceptual, cognitive, and psychosocial abilities of a stroke survivor. The therapist will then discuss treatment priorities with the stroke survivor and caregiver, and will design a program to achieve specific goals. This may involve exercises to build muscle strength and adaptations, such as handrails, bath seats, and mobility devices. When complex activities are too challenging, the occupational therapist may explain how to break them into parts and then how to link the parts.

To find resources on occupational therapy or to locate an occupational therapist in your community, visit [www.otworks.ca](http://www.otworks.ca). ▣

# Overcoming depression

Dealing with the effects of stroke is challenging enough for survivors, but also may adversely impact caregivers — often more than they are willing to admit. While some feelings of frustration and unhappiness are normal, they should be distinguished from depression, which is marked by insistent feelings of hopelessness and despair. It is not uncommon for depression to affect both the survivor and caregiver, especially as they begin to realize that stroke-related disability is a reality. For the stroke survivor, depression may also be caused by biochemical changes in the brain.

Motivation is key after a stroke, with the caregiver and stroke survivor working as a team towards successful rehabilitation. However, a depressed stroke survivor will lose determination needed to work towards rehabilitation, and a depressed caregiver will be unable to function as an effective member of the rehabilitation team. For these

## The symptoms of depression:

- a sad mood
- lethargy
- fatigue
- loss of interest in usual activities
- feelings of hopelessness
- self-loathing
- difficulty concentrating
- social withdrawal
- irritability
- decreased appetite
- sleep disturbances
- suicidal thoughts

reasons, it is extremely important to recognize and treat depression.

In some depressed individuals, a sad mood may not always be evident but other symptoms can be suggestive of depression. It may also be difficult to recognize depression in some stroke survivors, particularly if the stroke has caused dramatic changes in behaviour, function and the ability to communicate. “Depression in stroke survivors could be directly related to the damage to the brain, or could be a reactive depression related to the various ‘losses’, such as loss of function, independence,

relationships and/or ability to support the family,” says Dr. Saty Sharma, physiatrist at Baycrest and Sunnybrook Health Sciences Centre in Toronto. “Also, some prescription and over-the-counter medications may cause depression and related symptoms, and the possibility of drug-related adverse effects or drug interactions must be ruled out.”

Consult a physician if you or your stroke survivor has been experiencing two or more symptoms of depression for more than two weeks. The earlier depression is recognized and treated, the better will be the outcome. The management of depression may involve psychological counselling and antidepressant medications. Treatment will improve the mood and contribute to the stroke survivor’s recovery.

Caregivers can help themselves and stroke survivors prevent or manage depression. Some tips:

- Set attainable rehabilitation goals. If the goals are beyond reach, frustration will result.
- Stroke survivors may feel

isolated. Involve them in daily activities and routines. Encourage them to be independent while recognizing their limitations.

- Maintain social contacts. Find a support group. A support group can help provide emotional support, as well as useful tips for managing disabilities.
- Exercise regularly. Aerobic and strengthening exercises are beneficial for stroke survivors.
- Seek relief from physical discomforts, such as pain, muscle spasms and constipation, that may contribute to depression.
- If possible, become a volunteer. Helping others will help you feel better about yourself. ▣

**Consult a physician if you or your stroke survivor has been experiencing two or more symptoms of depression for more than two weeks.**

# Intimate Relationships

Given all the issues facing a stroke survivor, sexually-related matters may not seem important in the initial stages of recovery. However, as recovery progresses and survivors and their spouses begin to have sexual feelings again, sexual activity can once again be an important source of pleasure, relaxation and intimacy. There is rarely a medical reason why a stroke survivor should not become sexually active again, but barriers to sexual activity may include depression in either partner, spasticity, fatigue, incontinence, muscle weakness or a lack of balance. The stroke survivor may be afraid of having another stroke or may have medication-related loss of libido, while the caregiver may lose sexual interest because of the spouse's altered appearance and manner. A caregiver may also have difficulty shifting from providing physical care to being a lover.

To successfully restart sexual activity, stroke survivors and their spouses must learn to openly

discuss the effects of stroke on their sexual relationships. For example, to compensate for loss of sensation, it may be necessary to experiment with new ways of touching. One-sided weakness may call for being propped up with a pillow. Spasticity in the legs may require time for massage and relaxation, and may be helped by treatment. Incontinence may be overcome by emptying the bowels or the bladder before sexual activity. Remember that it will take time to rediscover what works best for you as a couple. Create an environment in which both of you feel comfortable. To begin with, re-introduce familiar activities, such as kissing, touching and hugging. Use lots of caressing and massage. Allow plenty of time and keep an open mind!

If intercourse is too difficult, consider other forms of lovemaking, such as touching, hugging, massage, oral sex and self-touching. Couples may also want to consider sexual counselling. ▣

# Fight with all you've got

Vancouver residents John and Carolyn Carter are a testimony to strength, teamwork — and the bonds of love. Seven years ago, at age 52, Carolyn suffered a debilitating stroke. Engaged to be married at the time, she had been visiting her family in England, preparing for the wedding that was to take place in her homeland. Caught up in the planning, Carolyn ignored some of the classic warning signs of stroke, including weakness on one side of the body, sudden dizziness, and severe headache with no known cause. It was while she was on the phone to John in Vancouver that she realized something was seriously wrong: her left arm was more than just weak, she couldn't move it at all. Hanging up with John, Carolyn quickly called an ambulance. She was rushed to a hospital, where John joined her the next day. He spent the following eight months by Carolyn's side, unwavering in his determination that they work through this challenge together. For Carolyn,

an active young woman, she felt as if she had been catapulted into old



**John and Carolyn Carter**

age. “The previous day, I was independent, capable and attractive,” she recalls. “And then, I became immobilized, invisible and incapable. I really wished I could die, but my children loved me and cared for me every day. What’s more, John insisted that we go ahead with the wedding!”

“Initially, nobody could give us any definitive answers about what to expect in terms of recovery,” says John, recalling the time. “Carolyn had suffered a massive stroke and was paralyzed on her left side. We had little choice but to take one day at a time. Together, we did everything possible to obtain rehabilitation services. Carolyn’s determination to try

*Continued on next page*

## Fight with all you've got

*Continued from page 21*

every treatment really helped. She made an amazing comeback in her function and independence.”

John and Carolyn resolved to learn everything they could about stroke and spasticity. “One book was really helpful to us: *My Year Off*’ by Robert McCrum,” says John. “It allowed us to look at the stroke as a phenomenon, to better understand what we felt, and it encouraged us to believe that rehabilitation was possible.”

Two years later, Carolyn enrolled in a “Chronic Disease Self-Management Program” and learned how to set weekly goals and work towards them. “The course was empowering,” shares Carolyn. “It encouraged me to become a volunteer leader, which gave me confidence and a sense of purpose. It is extremely empowering to be helping others who are in a similar situation.”

A key aspect of stroke recovery is to set goals and fight with all

you've got to achieve them. “The Chronic Disease Self-Management Program taught me to set specific goals for my rehabilitation and to seek treatments to achieve them,” says Carolyn.

Stroke recovery is a journey that can take years, but teamwork, a positive attitude and active pursuit of rehabilitation made all the difference for John and Carolyn. “To keep being positive while you are working towards your goals, it helps to step back and enjoy the moment. Often, our daily lives are so rushed that we miss many simple pleasures. A stroke forces both the survivor and caregiver to slow down — and surprisingly we found it to be an amazing experience! You start noticing and appreciating things that you had simply missed before.” ▣

Carolyn Carter has founded a peer support group “Vancouver Younger Stroke Survivors.” The group meets monthly for social networking, hosts a website and publishes a newsletter. For information, visit [www.peernetbc.com/groups/VYSS](http://www.peernetbc.com/groups/VYSS)

# Set sail for rehabilitation

Each year, between 40,000 and 50,000 Canadians have a stroke, and close to 80% of these people survive and require rehabilitation. The goals of rehabilitation are to help survivors reclaim as much of their lives and independence as possible. Although rehabilitation does not reverse the brain damage caused by a stroke, it can help survivors achieve the best possible long-term outcomes.

“Every survivor, even if he or she has had a stroke for the second or third time, should be assessed for rehabilitation potential,” says Dr. Saty Sharma, physiatrist and director, Spasticity Clinic, ATC/Elkie Adler MS Clinic at Baycrest and Sunnybrook Health Sciences Centre in Toronto. Rehabilitation helps stroke survivors regain lost skills and adapt their lives to deal with any residual disabilities. According to experts, the most important elements in any rehabilitation program are active participation of the stroke survivor, dedicated



DR. SHARMA



DR. SATKUNAM

**Dr. Saty Sharma:** Physiatrist, Spasticity Clinic, ATC/Elkie Adler MS Clinic at Baycrest and Sunnybrook Health Sciences Centre, Toronto

**Dr. Lalith Satkunam:** Physiatrist, Spasticity Clinic, The Glenrose Rehabilitation Hospital, Edmonton

support of the caregiver, and appropriate management by a multidisciplinary team of medical experts.

“Depression is not uncommon in both stroke survivors and caregivers, and can substantially reduce the effectiveness of rehabilitation efforts,” says Dr. Sharma. “All survivors and caregivers should seek counselling to learn how to deal with life after a stroke. If needed, treatment strategies can be used to help manage the emotional challenges

*Continued on next page*

## Set sail for rehabilitation

*Continued from page 23*

that may occur, including depression.”

There are many rehabilitation centers across Canada, offering a range of services. Caregivers and stroke survivors should have frank discussions with their physicians about the problems which they encounter on a daily basis. Stroke survivors can then be referred to the centers where their disabilities can be best managed.

“At Baycrest Spasticity Clinic we treat the excessive muscle tightness, called spasticity, which often develops after a stroke,” explains Dr. Sharma. “A referral by a physician is required to get an appointment with us, but this may be initiated by a stroke survivor, a caregiver, or a therapist who has identified a problem. A referral from the survivor’s family doctor is preferred because the family doctor can provide important information about associated medical problems, the treatment

history, and the response to medications.”

The Baycrest Spasticity Clinic has a number of trained specialists. These include a physiatrist, two nurses, a kinesiologist (movement therapist) and occupational therapists. “We start with a thorough assessment of the patient’s function, which is restricted by spasticity, and recommend a treatment strategy which usually includes medical management (e.g. Botox injections or oral medications), muscle stretching with the kinesiologist and educational sessions with a nurse,” says Dr. Sharma. “We also work with other clinics to obtain additional services when needed. For example, a consultation with a neurologist is available if there is a concern about recurring strokes. Appointments can also be arranged at the Brace Clinic or on-site Seating Clinic.”

In Edmonton, the Glenrose Rehabilitation Hospital is a state-of-the-art stroke rehabilitation center with both in-patient and out-patient units. “At our rehabilitation centre, all patients

are assessed and treated by physicians, nurses, physical therapists, occupational therapists, social workers and recreation therapists,” says Dr. Lalith Satkunam, a physiatrist at the centre. “As necessary, patients are referred to various departments, such as psychology, speech and audiology, pharmacy, nutrition and pastoral care. Teams of experts are also available to help with feeding and swallowing, orthotics, assistive devices, driving assessment, dental and sexual health. All patients and caregivers are encouraged to attend the stroke education series.” In addition, a Caregiver College is available for caregivers and family members who would like to learn how to meet the needs of their stroke survivors.

“Last year, we also opened a Spasticity Clinic. Spasticity is very common after a stroke, and today it can be treated much better than several years ago,” continues Dr. Satkunam. “In addition to oral medications,

we now have Botox injections which are very effective in reducing the tightness in specific muscles. Caregivers need to recognize the impact that spasticity can have on day-to-day activities of stroke patients. Treating spasticity can greatly improve the lives of both stroke survivors and their caregivers.”

Caregivers should seek help if spasticity interferes with day-to-day functioning and caring for their stroke survivors. “Referrals to physiatrists or neurologists dealing with spasticity are warranted in such cases,” says Dr. Satkunam. “All stroke patients with spasticity deserve an assessment to determine potential treatment options that can improve their quality of life.” ▣



**Dr. Satkunam with a patient**

# A guide to Canada's drug coverage

Living with the effects of stroke can impose a large economic burden on stroke survivors and their families. Apart from the direct costs associated with medical care, there are also considerable indirect costs due to loss of productivity. Reducing the financial burden of stroke is crucial to facilitating successful rehabilitation. And, the more independent a stroke survivor can become, the less need there will be for costly healthcare services.

Most Canadians get some reimbursements through private insurance plans, provincial or territorial drug benefit programs, or federal programs for certain groups. Some treatments may be covered under Special Authorization, a process where a drug plan or drug benefit program makes a prescriber request coverage for a specific drug before approval can be granted. The

website [www.drugcoverage.ca](http://www.drugcoverage.ca) has a wealth of information on Canadian drug coverage, provided by province and by program. Some frequently asked questions are featured below.

## **How do I find out what drug insurance coverage is available to my stroke survivor?**

Visit [www.drugcoverage.ca](http://www.drugcoverage.ca), click on the “Guide To Drug Coverage” button on the sidebar, and pick a province. The Guide will help you identify what plans/programs your loved one may be eligible for. You can also visit a local pharmacy and ask the pharmacist.

## **Can an individual be covered by more than one benefit plan?**

Yes. For example, a retired person may be covered by a provincial drug benefit as well as private pension benefit plan. An



individual may also be covered by both his/her own and spousal benefits.

[www.drugcoverage.ca](http://www.drugcoverage.ca) for more suggestions.

### **What if the insurance company does not cover a drug?**

Call the insurance provider to make sure it is not covering the medication and ask for the reason. Let the employer's Human Resources Manager know that the physician has recommended the medication and what the insurance company says. Have the manager contact the insurance company. If your employer has a drug plan that does not cover the prescribed medication, they can consider making an exception. Visit the Rejected Claims button on

### **What if the insurance company does not cover the full cost?**

The out-of-pocket portion may be applied to a second drug plan, such as a spousal drug plan or a provincial/territorial drug program for which an individual may be eligible.

### **How can Special Authorization be obtained?**

To receive Special Authorization, a letter from a physician has to be submitted, detailing the patient's condition, with specific clinical information, and indicating why the treatment is necessary. In some cases, specific criteria must be met before approval is granted. When discussing treatment options with your physician, ask what treatments might be covered under Special Authorization. ▣

#### **For information on reimbursement for prescription medications:**

talk to your pharmacist,  
visit [www.drugcoverage.ca](http://www.drugcoverage.ca), or  
call Stroke Recovery Canada's Warmline at 1-888-540-6666

# Services offered by Stroke Recovery Canada



*A program of March of Dimes Canada, a nationally registered charitable organization providing support services to people with disabilities, their families and caregivers across Canada.*

## Caregiver Support



### Caregivers must also care for themselves

Stroke is more likely to permanently alter the mind and body of a person and, with them, the life of an entire family, than any other single type of disability. Day-to-day family life may be changed forever.

Stroke requires that caregivers must somehow set aside their own shock and fear to support the survivors, whose needs may seem to far outweigh their own. However, caregivers need to look after their own needs first. Otherwise, the quality of care that they are capable of giving, their relationship with the stroke survivor and their own quality of life can suffer greatly.

### Stroke Recovery Canada is a one stop resource for

- emotional support and the opportunity to speak with other caregivers who are dealing with similar issues
- practical help in enhancing caring and coping skills
- increased awareness of available therapeutic and social service supports
- education about the physical and psychological needs of stroke survivors
- information about stroke rehabilitation options

**“I didn’t have a stroke, my entire family had a stroke,”  
said Lloyd MacDonald, a Stroke Recovery Member from Regina,  
Saskatchewan. “This national program helps to connect  
everyone affected by a stroke with the support they need.”**

## Other Key Services

### **Stroke survivors are not alone**

Stroke Recovery Canada can link you with peer support groups. These groups help survivors cope with what is often a long process of recovery and rehabilitation. A peer support group can be a tremendous source of strength, optimism and support for its members.



### **Education and Information**

Stroke Recovery Canada provides free and easy access to information on medical treatments, rehabilitation options and support resources. In addition to distributing information to members, Stroke Recovery Canada offers additional services on its website and through seminars, conferences and its newsletter “The Phoenix.”

### **Warmline 1-888-540-6666**

The Warmline is a confidential, peer support toll-free line for those affected by stroke. A non-medical and non-crisis resource, the Warmline offers information and support to stroke survivors, family members and caregivers. The volunteer at the other end of the line is typically a stroke survivor, a family member of a survivor, or another member of the community who is familiar with the stroke experience.

# MEMBERSHIP FORM

*Please print clearly*

**Yes,** I would like to join  
**Stroke Recovery Canada™.**

**Please complete the following information.**

**I am a:**

- caregiver to a stroke survivor
- family/friend of a stroke survivor
- stroke survivor
- health care professional
- other: \_\_\_\_\_

**For stroke survivors:**

**Year of your stroke:** \_\_\_\_\_ **Year of birth:** \_\_\_\_\_

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

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

**City:** \_\_\_\_\_ **Province:** \_\_\_\_\_ **Postal Code:** \_\_\_\_\_

**Day telephone:** \_\_\_\_\_ **Evening telephone:** \_\_\_\_\_

**E-mail:** \_\_\_\_\_

*Including your e-mail address helps us save postage and mailing costs, providing us with more resources for this program. We comply with Canada's Personal Information Protection and Electronic Documents Act.*

Please return completed form to:  
**Stroke Recovery Canada™**  
**c/o March of Dimes Canada**  
**10 Overlea Blvd.**  
**Toronto, ON M4H 1A4**  
**Fax: 416-425-1920**

**Register online**  
**[strokerecoverycanada.com](http://strokerecoverycanada.com)**

PLEASE CUT ALONG THE DOTTED LINE

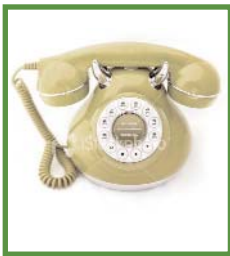


When a stroke happens to someone you love, it feels like your world is in pieces. Even after a hospital stay and rehabilitation, there are often many questions and concerns. “How can I help my stroke survivor reclaim his or her life and be as active and independent as possible? How can I manage to have a life while caring for my loved one after stroke?”



## Stroke Recovery Canada™ is reconnecting lives

Stroke Recovery Canada is a national service offering post-recovery support, education and programs for stroke survivors and their families through its work with local peer support groups across the country. Stroke Recovery Canada provides Canadians with the resources needed to reconnect their lives.



**Contact Stroke Recovery Canada's  
Warmline 1-888-540-6666  
[www.strokerecoverycanada.com](http://www.strokerecoverycanada.com)**

Join a support group. Seek services and treatments.

**You are not alone**

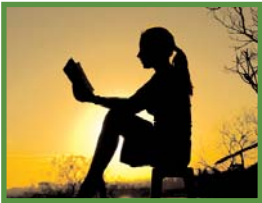


# Caregiver's Bill of Rights



**As a caregiver to a stroke survivor,  
I have the right to:**

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



**A CAREGIVER'S GUIDE TO STROKE RECOVERY**



CUT OUT AND KEEP ON YOUR FRIDGE AS A REMINDER