

STROKE IN YOUNG ADULTS

A RESOURCE FOR PATIENTS AND FAMILIES



HEART & STROKE FOUNDATION
**Canadian Partnership
for Stroke Recovery**



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Best Practice Recommendations

The patients and families who shared their stories

About the Heart and Stroke Foundation

Canadian Partnership for Stroke Recovery:

The HSF Canadian Partnership for Stroke Recovery is a joint initiative of the Heart and Stroke Foundation and Canada's leading stroke recovery research centres. Headquartered at the University of Ottawa, the Partnership is restoring lives through research. canadianstroke.ca

About the University of Toronto Stroke Program:

The University of Toronto Stroke Program is a collaboration of academic stroke specialists developing innovative, cutting-edge stroke clinical care, research and education. torontostrokeprogram.com

About the Heart and Stroke Foundation:

The Heart and Stroke Foundation's mission is to prevent disease, save lives and promote recovery. A volunteer-based health charity, we strive to tangibly improve the health of every Canadian family, every day. Healthy lives free of heart disease and stroke. Together we will make it happen. heartandstroke.ca

Medical disclaimer

The information in this guide does not replace your relationship with your doctor. The information is for your general use, so be sure to talk to a qualified health-care professional before making medical decisions or if you have questions about your health.

We do our best to make sure that the information we provide is accurate and reliable but cannot guarantee that it is error-free or complete.

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“ If aphasia is hard on the person, it is also hard on my spouse, kids and family. Communication is a basic necessity. We have 5 senses: see, hear, taste, touch and smell. I would give up one of my senses to have my speech recover. ”

– Scott, who had a stroke at age 43, writes in an email



“ Stroke teaches us to learn our limits and that asking for help isn't a sign of weakness – but wise planning. ”

– Carole, who had strokes at age 42



“ I found practising mindfulness to be a powerful tool in my stroke recovery. You take the time to be compassionate with yourself and to be very honest with the direction you want your life to go. ”

– Andrew, who had a stroke at age 24

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STROKE IN YOUNG ADULTS

Stroke in Young Adults A Resource for Patients and Families

After a stroke, there are so many questions. Why me? Why now? How did it happen? Am I at risk for another stroke? Who will take care of my children? Who will take care of me? How will I pay my bills? Will I be able to work? Why do I feel so different? Will I return to normal?

Aren't I too young for this?

To the last question: Stroke – a blood clot or ruptured blood vessel in the brain – can occur at any age. About four out of every 100 strokes happen in people ages 18 to 45.

To the earlier questions, and many more, this guide is designed to help.

For the purpose of this guide, young adults are defined as those ages 18 to 45, but many of the issues commonly found in younger stroke survivors apply to other age groups as well. In some studies the term “young adult” applies to people as young as age 15, while others include survivors up to age 55.

The causes of stroke are varied. Possible causes in young adults include:

- **an abrupt tear in an arterial wall** in the neck (“dissection”);
- **bulges in weakened blood vessels** (aneurysms) caused by a hereditary condition or acquired disease;
- **abnormal connections** between arteries and veins (arteriovenous malformation or AVM);



“In those early days, the stroke was much harder on my loved-ones than it was on me. But, today, I’m getting better and I’m here. And, with therapy, what I’ve lost is returning.”

– Garima, who had a stroke in her mid-40s

A new stroke happens in about one out of 10,000 young adults each year. Stroke is about four times more common than multiple sclerosis, a neurological disease usually associated with young people.

Every person and every stroke is different and no single resource can meet all needs. This guide is designed specifically for young adults, their families and caregivers and intended to complement existing resources.

Check out these other resources, produced by the Heart and Stroke Foundation, and available at heartandstroke.ca and strokebestpractices.ca:

- Taking Charge of Your Stroke Recovery: A Survivor's Guide to the Canadian Stroke Best Practice Recommendations
- Your Stroke Journey: A guide for people living with stroke
- You've Had a TIA
- Living with Stroke™ series

- **inflammation in blood vessels** (vasculitis) or congenital or acquired blood vessel narrowings (vasculopathies);
- **clotting and bleeding disorders** (coagulopathies) that can happen spontaneously or after an injury;
- **heart problems** like atrial fibrillation, tachycardia, congenital heart disease, and an enlarged heart; and,
- **plaque in small or large blood vessels** from typical vascular risks like diabetes, high blood pressure, smoking, high cholesterol and obesity.

In this guide, you will get answers to questions about physical and mental recovery, as well as resources and services available to you and your family. You should focus on the most relevant material because not every topic will apply to you.

Content includes:

- an introduction to the **hospital stroke team** and how they can help you;
- the **role of family and friends**;
- discussion of **stroke side-effects** that are common in young adults, including fatigue, pain and spasticity, depression and anxiety, communication disorders, vision changes, and issues with memory, thinking and reasoning;
- a look at the benefits of **support groups** and **counselling**;
- the steps to **regaining your drivers' licence**;
- the **transition to work and to school**;
- discussion about **stresses** such as relationships, finances, and retrofitting your home;



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- answers to your questions about regaining your **social life**;
- factors to consider if you want to become **pregnant**; and,
- tips on **stroke prevention** with insight into risk factors more prevalent in younger adults.

The hope is that information in this guide – along with the **voices and concerns of other young stroke survivors** – will help you on your recovery journey.

Keep in mind that you are not alone. Every year, there are 62,000 strokes in Canada and hundreds of thousands of Canadians are living with the effects of stroke. While death rates have declined dramatically in a decade, the number of strokes among younger people has risen, according to a 2014 report by the Heart and Stroke Foundation.

In fact, international studies predict stroke rates among younger adults will double in the next 15 years.

Sometimes called a “brain attack”, stroke happens to people like:

- Pittsburgh Penguins hockey player Kris Letang, 26, who made international headlines in 2014 when he revealed that a minor stroke had briefly sidelined his season.
- Canadian golfer and elite athlete Andrew Parr, who had a stroke at age 24, and works with passion and commitment to compete on the professional tour.

“By making my condition public at this time, I can help other people understand that stroke can strike at any age.”

– Kris Letang,
Pittsburgh Penguins



“Recovering from stroke takes a lot of love from the people around you. Surround yourself with supportive relationships.”

–Andrew, who had a stroke at age 24



- Mother-of-two and office worker Leslie Chipre, who had a stroke at age 31 while shoveling snow. With therapy and personal determination, she moved from a wheelchair to a walker to a cane to playing Lego with her young son. Two years later, her recovery continues. “You have to keep going. I am still making progress.”
- University professor Nikki Martyn-Capobianco, who worked hard for a year to make a full physical recovery after a major stroke at age 34.
- Vimuththan Nantheeswarar, who had a stroke in his mid-20s while in medical school and eventually returned to his studies. He is now a physician.
- Kinesiology student Stephanie Spooner, who had a major stroke on her 21st birthday and went on to complete her undergraduate degree and later earn a Masters before beginning a career in health administration.

Although factors such as heart problems, neck injuries, high blood pressure, diabetes, obesity, smoking, sedentary lifestyle, stress, oral contraceptives, recreational drug use, a history of migraines and genetics play a role, **about one third of the time the cause of stroke among 18- to 45-year-olds is “cryptogenic”, meaning the origin is unknown.**

After a stroke, the deficits and recovery period can look very different for each person, depending on the location of the brain injury, overall health and the intensity and duration of rehabilitation.

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But there is good news:

- Although the most rapid progress occurs in the first three or four months after stroke, **recovery can continue for months and years.**
- The **brain has the ability to learn to compensate** for physical, mental and communication losses.
- There are a number of strategies that have been shown to help, and **resources and tools are available to aid recovery.**
- Research is under way in all parts of Canada to gain new knowledge and find **new approaches to help restore lives** after stroke. Leading these efforts is the Heart and Stroke Foundation Canadian Partnership for Stroke Recovery (www.canadianstroke.ca), the only research organization in the world focused exclusively on stroke recovery.
- Many stroke survivors who invest ongoing effort, determination and commitment to their recovery can progress towards and **meet their goals.**

Read on and we will tell you more.

Check out these terrific resources:

heartandstroke.ca/strokedirectory
heartandstroke.ca/videostories

“You have to become a good problem-solver and your own advocate. There are provincially funded programs through independent living resource centres that can provide you with support to live on your own, but you have to know where to look and how to apply.”

– Stephanie, who had a stroke age 21



Where do I begin?



A tiny clot. A ruptured vessel. These injuries in the brain can affect everything the brain controls all over the body: muscles, joints, movement, eyesight, personality, emotions, confidence, self-esteem, speech, understanding, reading and writing. Because the brain is the control centre of the body, even a small injury can have a major impact – affecting all aspects of daily living.

But the brain is remarkable, resilient and rewireable.

For young adults, uncertainty and unanswered questions in the days, weeks and months that follow a “brain attack” can cause anxiety, worry and stress. And, **young adults face unique challenges, such as those related to career, school, relationships and caring for children and older adults.**

Although stroke is associated with older adults, it can happen at any age, even in babies and children. To learn more about pediatric stroke, check out the following websites:

perinatalstroke.com

strokebestpractices.ca
(patient and family resources)

Who can help me?

There are a number of highly specialized health professionals who can provide you with medical care, recovery therapy, answers to your questions and information about resources and services.

Here's an introduction to some of the people who may be on an inter-professional stroke team (this may differ depending on your needs and location) and how they can help:

- **Stroke neurologists** are physicians with specialized training in diagnosing, treating and managing brain illness, with a focus on stroke. Neurologists perform examinations of the body to see how the nervous system is working. They examine muscle strength and movement, balance and walking ability. They may also test vision, hearing, reflexes, sensation, thinking, memory, speech and language. A neurologist may diagnose the initial stroke, and will look for a cause. He or she will often prescribe treatment, including lifestyle changes, medications and other therapies, as needed, to help treat a stroke, to help deal with symptoms from the stroke and to help reduce the



“Value the people who support you and know that the life ahead of you is very important.”

—Andrew, who had a stroke at age 24



Make sure you know the answers to these questions:

- How and when should I take my medications?
- What equipment or assistive aids do I need at home and how do I use them?
- When do I visit health-care providers?
- Where can I find someone to help me get my groceries, pay the bills and prepare meals?
- What exercises do I need to do at home? And how often?
- Where can I find a stroke survivor support group?
- When can I drive again and how do I get my licence back?
- Can I get an accessible parking permit?
- Do I qualify for Canada Pension Plan-Disability and where do I apply?

risk of future problems. Across Canada, many stroke patients are not seen by stroke neurologists. General neurologists and specialists in internal medicine can fill this role, often with consultation or even telemedicine support from specialists as needed.

- **Stroke nurses** are nurses who specialize in stroke care. They work on the frontline in hospital stroke units, as well as in stroke prevention clinics, stroke rehabilitation and in the community, providing education on risk factor control (blood pressure management, smoking cessation, weight reduction, exercise, etc). Nurses can help in prevention of a recurrent stroke and link you to resources you need to improve recovery.

“It’s okay to ask for help, and it is okay to identify at any point along the spectrum when coping becomes difficult. Often with younger survivors, there is this feeling of embarrassment or failure, or the feeling that you should be able to bounce back quickly. But this is not true and you don’t have to do it all alone.”

– Lisa, a social worker who works with stroke patients

- **Physiatrists** are physicians who specialize in physical medicine and rehabilitation. Physiatrists help restore movement after stroke, diagnose and treat pain and create customized rehabilitation plans. The physiatrist works with other team members, including physiotherapists and occupational therapists, with the goal of maximizing the patient’s function and minimizing

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the disability from stroke. A physiatrist will prescribe a treatment plan that may include drugs and other therapies.

- **Psychiatrists** are physicians with specialized training in diagnosing, treating and managing mental illness. Mood issues are common after stroke and psychiatrists have extensive medical training and understand the complex relationship between emotional health and medical illness. They conduct detailed assessments to examine the biological, psychological and social aspects of a problem. Once a psychiatrist has reached a diagnosis, they will prepare a treatment plan, which may include medication or therapies. In some rural areas, psychiatry services may be accessed via outreach visits or telemedicine.
- **Psychologists** have a doctorate in psychology and extensive training in clinical or counseling psychology. Through therapy, they can help you communicate with your partner more effectively about physical and emotional changes, help you manage your negative emotions, express your needs, deal with pain and make lifestyle changes to reduce stroke risk factors. There are neuro-psychologists who specialize in stroke acquired brain injury who help in understanding the relationship between brain and behavior.
- **Physiotherapists (PT)** help in the assessment, diagnosis and treatment of injury and disability and develop treatment programs. PTs provide exercises to promote faster and more effective recovery. These exercises will help you regain muscle control and strength, reduce spasticity (tight or rigid muscles and joints), reduce tendonitis pain and improve bladder control.

“You must be your own advocate and seek out rehab services and opportunities. It was essential that my family and I did all that we could to educate ourselves so that we could seek out help from the medical community and find support to recover.”

–Mike, a stroke survivor in his mid-40s



“Everyday, I really have to make an effort and really fight to be stronger. It’s easy to say to yourself ‘I can sleep’ and let it destroy you. But you have to want to get up every day and make an effort and want to get better.”

- Emily, who had a stroke at age 32

■ **Speech and Language Pathologists (SLP)** focus on therapies to improve communication after stroke. In hospital, SLPs often focus on swallowing safety to prevent choking (a common cause of pneumonia.) SLPs also assess and treat aphasia (difficulty engaging in conversation due to reduced ability to understand and express language; changes in reading and writing), dysarthria (changes in speech clarity, pitch, quality and breath control that result from changes to muscle tone in the head and neck), apraxia (inability of the brain to plan and coordinate the motor movements needed for accurate speech production) and dysphagia (swallowing difficulties).

“Educate yourself, seek out opportunities in the health-care system to help you recover, fight the frustration, find a reason to keep on fighting and don’t give up on your goals. Nobody is going to do it for you.”

– Sue, whose husband had a stroke



■ **Occupational Therapists (OT)** are healthcare professionals who specialize in adaptation of the physical environment to meet the patient’s needs. They assist with problems related to how you function in your daily activities. They may help attend to your vision, cognition, returning to work or driving and caregiving for your children or your parents. They work with you on how to manage day-to-day activities such as eating, washing, housework and groceries. They also address issues such as the use of assistive devices and resumption of sexual relations.

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“I would recommend two things to the young stroke survivor. Listen to your physician. And stick with your rehab plan. Your chances of recovery are high.”

– Jeffrey, a dad and marathon runner who had a stroke in his 40s

- **Pharmacists** help you manage prescription medications you require to control risk factors, treat complications of stroke and manage pain.
- **Social workers** focus on the psychosocial impact of stroke. They are able to provide you with counseling, link you with required services, provide you with information on community or government programs to help you cover the costs of purchasing equipment to make your home more accessible, provide you with career advice and link you to social support.

Other people on the recovery team may include neurosurgeons (especially when there has been a hemorrhagic stroke), hospitalists, family physicians, dietitians, recreational therapists, kinesiologists, biomechanics, orthotists, dentists and personal support workers.





Important things you can do to get started on your stroke recovery:



- ☐ Set small, realistic and achievable goals and tell people what you want to accomplish. Develop a rehabilitation and recovery plan with the assistance of your health-care team and caregivers.
- ☐ Talk to your health-care team about your progress, your changing needs and update your plan regularly.
- ☐ Keep a therapy journal that includes a list of your health-care providers, therapy programs and questions to ask at your appointments. Review your journal once in a while to remind yourself of the progress you've made.
- ☐ Learn how to safely practice exercises and activities between therapy sessions.
- ☐ Tell your stroke team about any changes in your mood, memory and ability to handle personal affairs. Help is available to you and your family.
- ☐ Know the signs of depression. Depression is common after stroke.
- ☐ Know what changes are needed in your home to make it safe and accessible.
- ☐ Find out the services and resources available in your community and how to access them.
- ☐ Ensure family members and caregivers get the skills training and support they require.
- ☐ Read *Taking Charge of your Stroke Recovery* and *Your Stroke Journey*, two resources developed by the Heart and Stroke Foundation, at www.heartandstroke.ca

Above all, don't be afraid to ask for help when you need it.

Who will take care of me when I get home?

A good hospital discharge plan is critical to ensure you get the help you need when you get home. Make sure your home is safe and accessible so that you don't fall or become injured. Your medical team should advise you on what you need.

For young adult stroke survivors, care often falls to a partner or spouse, a parent, family member or close friends – often at great personal cost to all those involved. For those without a support network, the options range from assisted living (with possible coverage from provincial health-care plans) to long-term care to costly private care.

Talk to a social worker to learn about community and volunteer-managed services available to you – Meals on Wheels, for example – as well as social supports.



“The reality is the transition period from hospital to home is difficult in so many ways...My mom had to retire to take care of me. She is 55 years old. She shouldn't have to retire to take care of her daughter.”

– Emily, who had a stroke at age 32

Who will take care of my children?

“After my stroke, all I wanted was my kids. All I could think was ‘Where are my kids?’”

– Emily, mother of a 15-month-old and four-year-old

For many parents, there is the added worry and responsibility of looking after young children. Often a spouse or partner must take on greater childcare responsibilities in addition to providing support to you. Sometimes a family member or friend moves in for several months until you have gained the strength and mobility to care for your children. Sometimes you need to pay for additional childcare.

Whatever the solution, just as every family is different, there are no simple one-size-fits-all answers, which is why the entire family needs support during the recovery process. It’s important to talk with your physician and social worker about services available to help.

Fighting for my life showed me life is short and I have decided I need to try and enjoy the little moments, especially the ones that impact my son.

I want to ensure he gets enough of me and enough love and knows he is special.

– Nikki, who had a stroke at age 34



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“I was a single parent with small kids. My main goal for stroke recovery was getting back to my kids – just raising them, being able to take them to school. I would say it took about two years to get fully there.”

– Anna, who had a stroke in her 30s

Many people do not know how to explain their situation to their children.

This is a decision that must be made by each family, knowing their children, but it is easy to underestimate their children’s ability to understand, cope and even help. Dr. Rick Swartz, a stroke neurologist specializing in young adults with stroke, encourages parents to be honest with their children, but to follow their lead:

“Answer the questions they ask, but try to avoid going into overwhelming detail – if they want more information, they’ll keep asking. For children, the biggest issue is fear of the unknown. Most children understand that something is different. Even very young children understand “boo-boo’s”, “ouchies” and sickness... in stroke the problem is in the brain not the arm or leg.

“Children need to know that their parent loves them, and that nothing that happened is their fault. If they know that, they’re often very resilient.” **Ask your doctor, social worker, or therapy team if you want help talking to your children about your stroke and its effects.**



“I had to focus all my energies on my recovery at the expense of limited involvement with my children for the first two years after my stroke. No one explained or helped my children or my husband understand my limitations and changes in personality.”

– Carole, who had a series of strokes at age 42

Why do I feel this way?



“I had to gradually build up my stamina and energy again. My advice? Make sure you don't get overtired. Know your limits and when to say you've had enough.”

– Stephanie, who had a stroke at age 21

“I am so tired.”

It is very common to feel extreme fatigue after stroke and to have an overwhelming urge to sleep. Some stroke survivors use a lot of mental energy thinking about their recovery and this can contribute to fatigue. The cause of fatigue may be emotional, physical or mental (or a combination of these). Knowing the cause can help you better manage it.

Accept that you may need several rest periods during the day.

As you work to regain your energy and activity levels, listen to your body, avoid stresses that may impede your recovery and try to get eight hours of quality sleep. Easier said than done?

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Here are some sleep tips:

- Try to go to bed and wake up at the same time to establish a routine
- Avoid alcohol and caffeine within six hours of bedtime
- Keep TV, computers and other technology out of the bedroom
- Sleep in a room that is dark, quiet, and comfortable
- Finish eating at least two to three hours before bedtime
- Get enough exercise during the day to help tire you out at night
- Use a relaxation technique before sleep (muscle relaxation, warm bath, guided sleep meditation to quiet your mind, etc.)

Here are some strategies to deal with fatigue:

- Eat a low-fat, low-sodium diet with lots of fruits and vegetables
- Drink water to stay well-hydrated
- Make a to-do list of tasks and decide which are most important to you
- Plan activities for the time of day when you have the most energy
- Include time for rest in your day

If nothing helps and you still feel constant fatigue, talk to your physician. There could be some underlying medical condition that needs to be treated. For example, fatigue can be the result of **obstructive sleep apnea (OSA)**, a relatively

"It was hard for my small kids to understand my disabilities or my deficits. That was really a struggle. Fatigue was the biggest challenge. Having my child really understand that mummy needs her naps. And if I have headaches that someone else needed to take her to school or the subway."

– Anna, mother of a nine- and 12-year-old

"The social worker needs to explain to the family and other caregivers that, although everything looks fine, there's organic fatigue and the stroke survivor is not lazy or faking it."

– Carole, who had a series of strokes at age 42

You should see your doctor if you notice any of these symptoms:

- ☐ I snore loudly enough to disturb my sleep or others
- ☐ I wake up feeling short of breath
- ☐ I have been observed to choke, gasp, or stop breathing during sleep
- ☐ I wake up feeling unrefreshed
- ☐ I wake up with headaches
- ☐ I feel overly tired during the day

common condition that interrupts your breathing during sleep and may cause you to wake many times in the night.

Sleep apnea affects your wellbeing, mental health and quality of life. It also increases the risk of high blood pressure, heart disease and recurrent stroke. Medical problems like thyroid disorders or anemia can also cause fatigue.

If your physician thinks you have sleep issues, you may be asked to do a sleep study, which takes place during an overnight stay at a sleep lab in a hospital or clinic. If an overnight sleep study is not possible, there are portable monitoring devices to investigate your sleep breathing patterns at home. Ask about them.

There are many effective treatment options for sleep and your treatment will depend on the results of your sleep study. Speak to your specialist.

"I'm in pain."

A stroke can cause people to lose feelings on one side of the body. It can also cause new feelings and these can sometimes be painful. Pain can happen because the connections between the nerves and brain have been changed by the stroke or because the stroke has changed the signals from the brain affecting muscle tone and position.

There are a number of different types of pain after stroke and as many as **three in four stroke survivors face some sort of pain.** In some cases, pain is constant and, in other cases, it comes and goes.

"My headaches still return, sometimes when I over exert myself and sometimes without warning. It feels like a basketball bouncing in my head. I don't know what causes that."

– Garima, who had a stroke in her mid-40s

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Creating better diagnostic tools

Dr. Rick Swartz of the University of Toronto Stroke Program has found that three common conditions can get in the way of his patients recovery from stroke: Depression, Obstructive sleep apnea and Cognitive impairment (DOC). He has developed the DOC screen – a quick five-minute test that identifies these three conditions and looks at how they overlap and interact. With Heart and Stroke Foundation funding, the DOC screen was tested on more than 1,500 patients and compared to the existing gold-standard screening tools. The result? It has been found to be highly effective and able to identify more people with increased

stroke risks. The tool is now being tested in six centres with more than 6,000 patients, thanks to funding from the Ontario Brain Institute and the Canadian Institutes of Health Research, and will link screening to clinical outcomes in stroke patients.

Dr. Swartz and his collaborators think that the DOC screen may help identify people at high risk of long-term poor outcomes. In the short-term, they are developing a user-friendly DOC app to help physicians screen patients, especially young adults, and interpret the results so people with depression, apnea or cognitive problems can more easily be identified and get the help they need.

Musculoskeletal (MSK) injuries: Rotator cuff, frozen shoulder and contralateral pain (pain on the opposite side from the stroke that comes from compensating for the weakened side of the body) can cause severe discomfort.

Neuropathic pain: This is a type of nerve sensitivity that can cause abnormal sensations like burning, muscle aches and painful cramps. One form of neuropathic pain is central post-stroke pain (CPSP), which occurs when the stroke injures the thalamus or parietal lobe in the brain. The result can be coldness or burning, tingling, numbness

New Approaches

Researchers with the HSF Canadian Partnership for Stroke Recovery are testing new approaches to treat spasticity. One study with promising results is looking at the use of BOTOX® to reduce spasticity in combination with different rehabilitation therapies.

(Learn more about recovery research at canadianstroke.ca)



Loss of Pain

While pain is debilitating, loss of pain sensation in a limb after stroke can lead to injury. For example, one stroke survivor described how she opened a door on her foot and ripped off a toenail but didn't feel anything. She was unaware of the injury until she noticed a trail of blood. **"You need to be aware of where your body is at all times,"** she says.

or itching and shooting pain. This pain usually occurs on the side of the body affected by stroke and may begin right after the stroke or, more often, several months later.

Spasticity: As many as 4 out of every 10 people who have a stroke experience a condition called spasticity – tightness or stiffness in an arm, shoulder, hand or leg – within the first year. The severity of the condition can range from mild to severe – from being a nuisance to something that gets in the way of basic activities like walking, bathing, answering the phone, opening the door or cutting fingernails.

Headaches: Stress, depression, lack of sleep, certain medications and changes in fluid levels in the skull can cause headaches. **(If you experience a sudden very severe headache, call 9-1-1 immediately.)**

Swollen hand: Paralysis in a hand may cause it to swell and become very painful because it is immobile. This happens because the fluid in the tissue in your hand cannot circulate properly.

The type of pain that each person experiences after stroke varies and it's difficult to predict how long it will last. Treatments differ for each cause of pain. But it's clear that it can interfere with recovery and have an impact on your quality of life.

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So, who can help you manage your pain? Your physician, physiotherapist and psychologist will consider approaches such as **medications, relaxation techniques, exercise, cognitive-behavioural therapies, acupuncture and massage for pain relief.**

Hospitals in most communities in Canada have pain-management clinics. Ask your health-care provider for more information.



***"I feel sad. I feel afraid.
I feel anxious. I feel angry."***

Anxiety, sadness, grief, anger, guilt, blame, frustration and fear are normal emotions after stroke for both survivors and their family members. These powerful feelings can affect how you and your family look at life and how you cope with recovery. Many people will find that these emotions improve as they recover and adjust to their 'new normal.' However, some people feel upset almost all the time, with no improvement. Other people may have felt positive and motivated early after their stroke, but then feel very down in the long-run.

If your feelings of sadness and upset last most of the time, feel overwhelming, lead you to feel worthless or hopeless or if they interfere with your function or motivation, then you may be experiencing depression.

Depression is more than an emotional reaction.

Depression is a medical illness that can be treated.

One of every three people with stroke will develop depression.

"My senses are very heightened since my stroke. I will take my daughter to the Science Centre and see all the geometric colours and blocks. With so many people around, I get intense headaches very quickly."

–Jeffrey, who had a stroke in his 40s

Depression Symptom Checklist:

- ☐ I feel sad, down or depressed most of the day, for two weeks or more
- ☐ I no longer enjoy and have no interest in activities or hobbies that I can still do
- ☐ I feel worthless, excessively guilty or hopeless
- ☐ I feel tired or low energy
- ☐ I have difficulty concentrating or making simple decisions
- ☐ My sleep is disturbed – I am unable to sleep or oversleeping
- ☐ My appetite has changed; I'm losing or gaining weight without trying
- ☐ I often feel restless or irritable
- ☐ I feel very slowed down
- ☐ I have had thoughts of death, suicide or of harming myself

****If you are having thoughts of harming or killing yourself, call 911 or go to your nearest emergency department for assistance.***

How does depression happen? Post-stroke depression may involve a psychological reaction to this life-changing and life-threatening event. It also results from biological and structural changes to the brain that disrupt the flow of healthy brain chemicals, known as neurotransmitters. Other things like genetics, medical issues and stress can also be related to depression.

Depression negatively impacts physical and cognitive recovery and impacts quality of life. Many stroke survivors do not get the treatment they need for depression because it may be seen as an understandable reaction to their situation.

Talk to your physician, or a professional on your rehab team, if you think you may be depressed.

Many stroke neurologists or family physicians can help with depression. They may refer you to a psychiatrist for specialized assessment, diagnosis and a treatment plan. A psychologist or other therapist may be contacted to provide psychotherapy.

Depression can occur any time after stroke. It occurs most often in the first six months and is still common within two years after stroke.

Depression can be treated. Though treatment cannot take away the real-life problems caused by your stroke, it can improve your mood, energy, motivation and other related symptoms. Treating depression can help your recovery. Studies have linked untreated depression to slower stroke recovery and to increased mortality.

STROKE IN YOUNG ADULTS

Treatment may include medications. There are many antidepressant options available and several have been studied in post-stroke depression. Your physician can tell you more about how these medications can help. She or he can also talk with you about any concerns you may have, including potential side effects and how to manage them.

Treatment may include psychotherapy, or counseling, which involves talking during regularly scheduled appointments. Medication and psychotherapy can be used together. Therapy can be a source of support and may target specific problems, emotional reactions, negative thought patterns, grief, transitions or relationships. Psychotherapy can be provided by psychiatrists, psychologists, social workers and some family doctors, as well as other professionals with specialized training.

Anxiety is also common after stroke. While it is very understandable to worry after a stroke, sometimes worries and fears can become overwhelming and continue over a long time. If so, it may become an Anxiety Disorder. Anxiety often happens with depression too.

“I have never been a nervous person – but now I get anxious. At first, I thought every car ride would result in death, and while I am not so terrified anymore, I still get anxious.”

– Garima, who had a stroke in her mid-40s

“The biggest problem I have is everyone looks at me and says ‘you look great, you look wonderful.’ But you aren’t. You are not wonderful.”

– Jeffrey, stroke survivor in his mid-40s





Signs of Anxiety Disorder

- ☐ Uncontrollable worry most of the day, for several weeks or months
- ☐ Feeling restlessness or like you can't relax
- ☐ Staying up most nights worrying
- ☐ Irritability
- ☐ Low energy and feeling tired
- ☐ Trouble concentrating because of your worries
- ☐ Muscle tension related to the anxiety and tension

Anxiety can also take the form of a panic attack, which is sudden, intense fear, with several physical sensations, like a racing heart, dizziness, shortness of breath, sweating, and trembling, which happen all at once. It can feel terrifying and usually peaks within 5-10 minutes.

Anxiety can be treated. Many of the treatments that are effective for depression are also used for treating and relieving anxiety. Mindfulness-related techniques, relaxation strategies, gentle yoga and physical exercise can be helpful for managing anxiety as well.

After stroke, you may experience **changes in personality and emotions** as a result of damage in the brain. Sometimes family members may notice this even more than you do. Though these things are less common than depression or anxiety, they can be stressful.

"I really believe yoga helps with recovery. You can incorporate and integrate a lot of the healing required on physical and emotional levels."

—Andrew, who had a stroke at age 24. He recommends joining a yoga studio or buying a yoga video

STROKE IN YOUNG ADULTS

Changes include:

- Exaggerated or unpredictable emotions, with bursts of laughing or crying for no reason
There are different names for this, including emotional lability and pseudobulbar affect
- Irritability, anger or aggression
- Impulsive behaviour – acting without recognizing the consequences
- Apathy, which appears as lack of motivation, care and interaction

It is important to talk to your health team about these changes. They may be mistaken for depression, but are actually a direct result of the brain injury. Some of these changes can improve with time and medication may play a role. Behavioural techniques are often useful, including strategies that family members can learn.

“Everyone in our family is under incredible stress.”

Stroke doesn’t only impact one person. It affects the whole family. Relationships and responsibilities may change after stroke. These changing family roles may be quite stressful. Stroke survivors may need to rely on family members for support:

- Spouses may take on caregiving responsibilities, assume the role of patient advocate, shoulder more of the financial burden
- Children may take on more responsibility in the home, and may become fearful of the future and filled with anxiety

“Depression is not something that’s spoken about too much. It’s important people get emotional support as well as financial and physical.”

– Chris, whose fiancé Julie had a stroke at age 28





“From a caregiver standpoint, you need to take some time for yourself. With the cooking, cleaning, going to work, caregiving, you need to take time to unwind. Go to the gym. Do something for yourself.”

—Chris, whose fiancé Julie had a stroke at age 28

- ▣ Siblings may need to take time away from school or work to provide care and transportation
- ▣ Parents may become caregivers of their adult children

Stroke may change the way family members communicate with one another.

There may be financial stress as families deal with paying their bills, as well as covering new expenses such as therapy, household renovations, assistive devices, additional childcare and transportation. There is often a loss of sexual intimacy as stroke survivors and their partners cope with disability, pain, fear and low self-esteem.

It’s common to feel isolated. Perhaps you’ve had to take time away from your job. You may be in a care setting surrounded by people much older than you. You may need a lot of help with day-to-day activities. Alternatively, you may be okay physically, but have profound fatigue, thinking and memory problems or emotional changes.

Whatever the challenge, **you and your family do not need to handle these emotional and psychological changes alone.**

It is important you reach out right away because your physician and care team can help. There are effective treatments, including medication, psychotherapy for you or as a couple or family, which can have a really positive impact.

STROKE IN YOUNG ADULTS

I had to put my infant daughter in daycare because I couldn't look after her. My older daughter has been talking about death since I had my stroke. My mom is fed up. My husband is fed up. In the first months after my stroke, we exhausted our extended health-care benefits. One of the biggest arguments we have now is the money... I wish I could snap my fingers and be normal."

– Emily, 32, a young mother and stroke survivor

Therapy can help you communicate with your partner more effectively; manage your negative emotions and express your needs; and create a positive dialogue between you and your partner about both physical and emotional changes you may be experiencing.

RESOURCES:

Depression and Anxiety:

The Ontario College of Psychologists can connect you with a psychologist without referral from your family physician. cpo.on.ca

The Canadian Mental Health Association's website offers useful information on depression, anxiety and other mental health issues. cmha.ca





Support:

Stroke Recovery Canada provides an extensive list of provincial and regional support groups on its website. Search “Stroke Recovery Canada” on the web.

Warmline for Stroke Recovery Canada is a non-crisis information and support line, including connection to community services and peer support groups: **marchofdimes.ca: 1-888-540-6666.**

Stroke Recovery Association of Calgary – Young Survivors Support Group. **sracalgary.com/young_survivors.** Provides peer support to young stroke survivors, including an online forum (StrokeTalk) and informal get-togethers.

Stroke Survivors Association of Ottawa. **Strokesurvivors.ca**

Family & Caregivers:

Stroke Engine is an excellent website for people with stroke and their families. It offers good information on depression, among other things. **StrokeEngine.ca**

Tips and Tools for Everyday Living: A Guide for Stroke Caregivers is a resource published by the Heart and Stroke Foundation that provides practical advice for family caregivers. **heartandstroke.ca/tipsandtools**

thefamilycaregiver.com: Provides useful articles and links to resources on home care and family caregiving issues.

Alberta Health Services has a ‘Family Caregiver Centre’, which provides articles and links to resources for family caregivers. Search “Alberta Health Services Family Caregiver Centre” on the web.

STROKE IN YOUNG ADULTS

Information on managing relationships.

See if any of these articles resonate with you.

psychologytoday.com/blog/professor-cromer-learns-read/201201/after-brain-injury-learning-love-stranger

mskctc.org/tbi/factsheets/relationships-after-traumatic-brain-injury

brainline.org/landing_pages/Family.html

Excellent general information:

ontariostrokenetwork.ca has terrific resources under “Programs and Resources”

Stroke Recovery Association of British Columbia
strokerecoverybc.ca

The BC Brain Injury Association’s website offers useful resources for people living with stroke: brainstreams.ca

Brainline.org is an excellent website for information about brain injury, recovery, relationships and support for families too.

“I have been more irritable at home than I ever was. I don’t even know I’m doing it but I can actually bite my wife’s head off.”

– Jeffrey, stroke survivor in his 40s



For my family, the stroke was – to put it mildly – terrifying. I just wanted to close my eyes, turn off the lights, mute the chatter, and escape the intense pain.

– Garima, mother of two teens, who had a stroke in her mid-40s



The images used in this section are examples of pictographic images that can be used to exchange ideas, often without words.

"We can't communicate."

More than a third of people who have a stroke develop an invisible disability called aphasia which occurs when there is damage to the language and communication centres in the brain.



While aphasia doesn't affect intelligence, it can knock out the ability to speak, understand, write and read.

The most frequently used treatment is speech therapy.

While you may be the person with aphasia, communication is not just your problem. Your medical team, family, friends and community should know how to best help you communicate.



Some tips to help in communication include:



Take your time.
Don't try to speak quickly and ask others to slow down if you need it



Let your communication partners (the people you're speaking to) know that you need time to think.
Let your partners know they should not interrupt you



Use gestures



Use pencil and pads to write messages



Point to pictures/letters

STROKE IN YOUNG ADULTS



Finding a way to get communication going is goal #1 because it is so essential to all your relationships, your life roles and most of your activities.

Even if speaking, understanding, reading and writing are 'knocked out', if others know how to provide support and use specialized pictographic material (like the ones shown here), you can still talk.



Your speech-language pathologist will determine which rehabilitation strategies are most suitable for you.

It is really important to find support groups and other resources for you and for your family. You can learn about ongoing research projects and clinical trials by searching online or contacting your local university.



*Use devices
that will speak
for you*



*Structure
your day so that
communication-
intensive tasks
are done when
you have the
most energy*



*Advocate for
yourself so that
others understand
what you are
dealing with*



*Be patient
and kind with
yourself*



Ask if there are local aphasia groups or centres in your area or contact the Aphasia Institute for information about programs, resources and training for you and for your family. aphasia.ca

They can also familiarize you with online tools that may help improve communication after stroke, including online support groups.



Check out aphasia apps (for example: tactustherapy.com) to help you to communicate or to practise your talking. Computers with adaptive software and hardware, devices with artificial voice output or picture and word displays are also among available solutions.

"The biggest challenge for both of us has been frustration. There is nothing more frustrating than knowing what you want to say but being unable to say it. ...It is horrible to try to guess what your husband is trying to say, only to guess it wrong and, in the process of trying to help him, make things worse."

– Sue, whose husband had a stroke



STROKE IN YOUNG ADULTS

Additional helpful links include:

Visit **StrokeEngine.ca** and also search Aphasia Recovery Connection on Facebook to learn more.



“Julie’s aphasia is a big issue. She can’t communicate. She always has a pen and paper on hand,” says her fiancé Chris. Rather than buy apps to help Julie practice her speech, Chris downloaded images from the Internet and arranged them in categories – from animals to automobiles to sports and movies – “and we go through the pictures and practice what they are...You have to be patient. It’s frustrating for both people sometimes and you have to take a breath.”

Reactivating the Brain

A unique collaboration among scientists at the University of Toronto, the University of Ottawa and Baycrest Health Sciences Centre, funded by the HSF Canadian Partnership for Stroke Recovery, is using three different kinds of imaging technologies to study how the brain can be reactivated and reordered with aphasia therapy.



“Something’s happened to my eyesight.”

You may experience vision loss, including blind spots, double vision, blurred vision and reduced blinking rates, depending on where the stroke occurs in the brain.

It is also common to experience changes to visual perception after stroke – the ability of the brain to take in information from the eye, interpret it, and create a visual image to recognize, organize, remember and use.

The most common visual perception issues after stroke are **spatial neglect**, which is the inability to report, respond, or orient to stimuli on one side of the visual field, and **inattention**, which is the inability to pay attention to stimuli.

The signs and symptoms of a visual perception problem vary from case to case and can include complaints of bumping into things, eyestrain, losing your place while reading, slow reading, difficulty seeing motion and difficulties recognizing shapes as well as copying them. This can be one of the biggest barriers to getting driving again after stroke. First, the vision has to be good enough to drive, and the brain has to be able to pay attention to things happening on both sides of the road to be safe behind the wheel.

Therapies, which include eye exercises, compensatory strategies and specialized activities, are available to help improve vision and perception. **Talk to your physician about what could work for you.**

STROKE IN YOUNG ADULTS

"My mind is fuzzy."

It is not uncommon to experience problems with cognition (thinking, reasoning, memory, processing emotions) after stroke – leading to some important safety-related issues. Sometimes people can be at risk to wander off or get lost, or could burn food when cooking. If memory or thinking issues are a concern for you or your family, talk with an occupational therapist and/or see your physician for an assessment. There are many supports, strategies, therapies and medications that may help.

Having a second stroke can lead to further problems with thinking and memory. **The best way to reduce the risk of cognitive issues is to reduce the risk of stroke.** Ensuring that you are prescribed and taking appropriate medications and making any lifestyle changes suggested by your physician and team will help prevent problems.

To improve cognition, research at the HSF Canadian Partnership for Stroke Recovery (CPSR) shows that **exercise can be an effective treatment.** Physical exercise boosts blood flow to the brain, primes the brain for repair and can improve mental functioning. A study of patients who participated in a cardiac rehab program found that fitness was associated with maintaining the size of the brain's most important memory centre.

"I am just one face of stroke. A face of stroke that is invisible. I have no obvious physical signs and people don't understand. The cognitive impacts of stroke are hard to describe or convey."

– Garima, who had a stroke in her mid-40s





Games, puzzles and activities that challenge your brain may also help stimulate mental functioning.

These include Sudoku puzzles, word searches, crosswords, and jigsaw puzzles. Attending a concert (music has been shown to be therapeutic) and staying connected socially could have further benefits for the brain.

After a stroke it can be hard to socialize like before – maybe from language or thinking issues, maybe from mood problems or maybe from just feeling different or shy. It is important to stay connected with people who support you. If you are feeling withdrawn and not able to be with people, talk to your physician and rehabilitation team to make sure that medical, fatigue or mood problems aren't getting in your way.



“Cognitively, stroke survivors can easily get overwhelmed and not cope with day-to-day stresses as well as before. There may be personality changes and the stroke survivor may seem distant or detached but this is likely because they are so preoccupied with survival and physical recovery there isn't much left to give.”

– Carole, who had a series of strokes at age 42

STROKE IN YOUNG ADULTS

***“How long will I need to use a cane?
It’s embarrassing.”***

It’s common for young stroke survivors to feel self-conscious about physical changes in their bodies caused by stroke. This can be even more upsetting if assistive devices are required, such as a wheelchair, walker, cane or AFO (ankle foot orthotic).

When this is the situation, stroke survivor Carole Laurin says it helps to work at changing the way you see yourself. Choose a stylish cane to make a fashion statement and “try to see assistive devices as helpers with style instead of hindrances. This helps improve low self-image.”

Many stroke survivors are required to wear an AFO to prevent injuries because the ankle may be too weak or have too much spasticity to walk safely without it. Some stroke survivors manage to strengthen their ankle through physical therapy exercises and eventually the spasticity reduces with time.

Patience, determination, perseverance, hard work and time can help you improve or overcome weakness and spasticity. Rebuilding the muscles and activating the muscle memory through therapy exercises regularly done at home can be rewarding regardless of how long it takes.

Julie, 28, has to wear a helmet to prevent injury because she had part of her skull removed to reduce swelling after her stroke. Until a scheduled surgery to replace the skull, Julie is self-conscious about going out of the house with her helmet. “People are always staring and it upsets her,” says her fiancé Chris, 31.





**“When will
I get my life
back?”**

***“I need to talk to someone.
I feel so alone.”***

***“People shouldn’t
have to go through
this alone. It is the
hardest thing I have
had to face in my life.
It’s not about dying.
It’s not about being
disabled. It’s about
who I am as a person.
I am a different person
now. I have to be
okay with that.”***

–Emily, 32

Feeling connected is important during stroke recovery.

Peer volunteers at hospitals and community centres, family, friends and caregivers provide much needed emotional support.

Seek out other stroke survivors in your area or online who will relate to you about your feelings and challenges.

There are also vital networks of stroke recovery support groups to link stroke survivors and family members.

These groups – some of which are under the March of Dimes’ Stroke Recovery Canada umbrella, and some of which are independent – can help increase social activity, encourage personal growth and reduce isolation.

To subscribe to Stroke Recovery Canada’s The Phoenix newsletter, contact src@marchofdimes.ca.

STROKE IN YOUNG ADULTS

Or call the Warmline of March of Dimes Canada, a confidential peer support toll-free line for those affected by stroke and their carers: **1-888-540-6666**.

Heart and Stroke Foundation has some terrific online resources for individuals and families dealing with stroke. A list of some of these resources, available at no cost by visiting www.heartandstroke.com or www.strokebest-practices.ca, appears on page 4. The HSF Canadian Partnership for Stroke Recovery supports the valuable StrokeEngine.ca website. Stroke Engine has the latest evidence on the role of different therapies in supporting recovery.

“I have been working in peer support for almost two years. Patients are so happy to speak to someone who has been through a similar experience. Some people want to talk about the practical. What happens in rehab? Am I going to be able to do gardening after this? ... Some people just want to talk.”

– Anna, 43

“I want my driver’s licence back.”

For most young adults, there is a strong desire to regain their driver’s licence after a stroke – but there’s no question it can be a long and frustrating process, involving many steps. These steps differ from province to province. If you have been told not to drive, you will need to be reassessed before considering driving again. In some



While returning to driving is very important to you, don’t rush! Give yourself time to recover. It’s also important that you consider the costs. Depending on the province in which you live, you may be required to pay for the detailed driving assessment out of your own pocket, and the test can be expensive so it is important that you give yourself the best chance to pass. Don’t take the test before you are ready; your physician and occupational therapist can help you decide when the time is right for you.

Adaptations that will assist with your driving difficulties may include special mirrors, push/pull acceleration/brake hand controls, an extended signal lever for right-hand use because the left hand is not functional, a steering wheel ball (to control the steering with one hand), a left foot accelerator, easy release hand brake, Infrared controls on the steering wheel, a rooftop wheelchair storage device and a swivel seat. Provincial governments provide funding for some basic vehicle modifications after stroke. Learn more here: marchofdimes.ca/EN/programs/hvmp/pages/homeandvehicle.aspx

situations, this can be just a physician's assessment, while in other places you may require detailed testing to assure your safety and that of others on the road. Each province has different rules, and each stroke is different. Be sure to discuss this with your physician. In many places, people are reassessed one to four months after their stroke. Issues that may be evaluated to ensure that you will be safe on the road include:

- You have no major physical, thinking, visual or perceptual problems
- There is no obvious risk that you will have a sudden recurrence
- The cause of your stroke is being treated/ you are on treatment for preventing more strokes
- You have not had a seizure after your stroke

If further testing is required, you may be referred by your physician for detailed driving assessment.

The purpose of this complete driving assessment is to see if your specific problems make it difficult for you to drive. You may require certain adaptations on your car, to learn new ways of driving, and you may require restrictions to your licence, such as no night driving.

“Regaining his ability to drive was integral to my husband’s recovery in other areas. His ability to be independent was important for his self-esteem, his language recovery and further fueled his resolve to work hard towards achieving his other recovery goals.”

– Sue, wife of stroke survivor



STROKE IN YOUNG ADULTS

In order to regain your driving abilities after your stroke you may benefit from or be required to get rehabilitative training with a stroke driving instructor, who is a specialized type of occupational therapist.

Elements of these training programs can include:

- Simulator training programs, involving the use of appropriate adaptive driving equipment
- Exercises and activities to improve physical abilities
- Solutions for driving anxiety
- Identification of adaptive driving needs and prescriptions for vehicle conversions

“Without a driver's licence it was like being a kid again and having to ask my Mom to drive me places. Getting back my driver's licence was good for my spirit and quality of life.”

–Stephanie, who had a stroke at age 21

“I want to go back to work.”

Returning to work will depend on a large number of factors: the severity of your stroke, your recovery, what kind of job you do, other needs and demands in your life, what kind of support is available and your insurance coverage. Your family physician or occupational therapist can help you decide if you are ready to return to work.

While not everyone can or wants to return to work, for those who do there is no timetable to follow. Sometimes the process can be fast, and sometimes it is a gradual process that takes years of rebuilding confidence and adapting to new needs. Even if you are unable to return to work right away, it doesn't mean you never will. You must allow yourself whatever time you need.

The Southwestern Ontario Stroke Network has developed a useful return-to-work assessment that you can complete on your own or with input from your family, physicians or employer. swostroke.ca/return_to_work_questionnaire.

The self-assessment considers where you're at with your job expectations and provides you with questions to ask your employer. The tool is free for anyone to use.

“Be open-minded and take your time. Don’t expect that you are going to continue in your career exactly in the same way. Chances are that you are going to be better at something else now that your circumstances have changed.”

– Anna, stroke survivor age 43



Help from an occupational therapist, vocational therapist, physician and people at your workplace are most likely to make a return to work successful.

There are several factors that need to be considered when returning to work including: physical/functional disability, memory/cognitive problems, aphasia and fatigue.

The ability to ease into the job will depend on the amount of rehabilitation you’ve had, employer attitudes, physical work environment and the employer's ability to provide assistance (in the form of devices, for example).

It is important to discuss your options with your employer.

Your employer may be able to provide modifications to your job so that you can continue working or may help you transfer to another position. Many people return to part-time or full-time work after stroke. In many cases, returning to work may be necessary, as employment provides supplementary health insurance.

I probably recovered too quickly. I never took the signs to slow down. I tried to go back to work and by 2 o’clock in the afternoon on the first day I had my head on the desk. I couldn’t get through the day. It wasn’t possible. I went home and I didn’t go back to work for another 12 weeks. I tried to do too much too quickly. The advice I would give someone else is to listen to your health-care team.”

– Jeffrey, stroke survivor in his 40s

STROKE IN YOUNG ADULTS

RESOURCES:

Return-to-work resources are available in communities across Canada. Ask your stroke team for local contacts. Here are a few examples of programs that may be able to help:

- **Ontario Disability Support Program (ODSP)** – Employment Supports helps people with disabilities find a job. ontario.ca/socialassistance - check the website for the office nearest you.
- **Job Opportunity Information Network (JOIN):** joininfo.ca
- **Opportunities Fund for Persons with Disabilities** helps people with disabilities prepare for, obtain and maintain employment or self-employment – in particular those who are not eligible for **Employment Insurance (EI)** benefits. hrsdc.gc.ca/eng/funding_programs/ofpd/index.shtml – check the website for the Service Canada Centre nearest you.
- **Canadian Council on Rehabilitation and Work** promotes and supports meaningful and equitable employment of persons with disabilities. ccrw.org or 1-800-664-0925
- **March of Dimes Employment Services** provides job training and helps people with disabilities find employment. marchofdimes.ca/EN/programs/employment/Pages/default.aspx or call 416-425-3463 or 1-800-263-3463
- **Career Edge** is a national internship program for graduates with disabilities. careeredge.ca

“I just got my CPP disability. It took eight months. I’ve had four social workers since I started this process. Without their help, I wouldn’t have known where to turn.”

–Emily, who had a stroke at age 32

"I want to go back to school."

After experiencing a stroke, it may be necessary to take some time off from school for recovery and rehabilitation. You should work with your physician and occupational therapist and education specialist to figure out what you are able to do and how you may need to modify your schedule or workload after stroke. **Returning to school can be fast or very slow. Take the time you need and reach out for help and support.**

"My school was very understanding... I really did not think I would be able to finish my medical degree – but I got more confident, and received more support, and I was able to go back and finish. I'm glad that I did that."

– Vimuththan, who had a stroke in his 20s while in medical school

Financial aid, learning adaptations, special equipment and professional support may be available to you.

Educational institutions provide:

- Accessibility advisers and learning support staff to help you get comfortable in an academic environment by linking you with counseling, learning skills, assistive devices, peer mentoring and note-taking services, special arrangements for classes and exams and alternate formats for course material
- Accessibility services that can help you manage mobility and functional issues
- A social worker or education specialist to help plan your transition back to school and link you to both the social and financial support you need to ease the transition

Universities and colleges have contact information on their websites.

STROKE IN YOUNG ADULTS

"I am worried about money."

Finances can be stressful at any time. After a stroke, this can be an added concern for patients and families. **Ask your social worker about provincial and federal programs you may qualify for to cover the cost of home renovations, assistive devices and other expenses associated with your recovery.**

Check with your employer to see if you have disability coverage. This often acts as a bridge before some provincial programs kick in. Your social worker or therapist can also connect you with opportunities for benefits and programs to assist you financially.

There are several important questions to ask your employer:

- What disability benefits do I have?
- What rehabilitation benefits are available from the Long Term Disability (LTD) Benefits carrier?
- What coverage do I have for extended health?
- Will my LTD coverage continue once I get CPP-Disability from the federal government?

Other important questions to ask your employer can be found at swostroke.ca.

"Mike is unable to return to work, which has turned us into a one-income family. This is financially challenging and difficult for both of us."

–Sue, wife of stroke survivor

The family and friends of Julie Poulin, who had a stroke at age 28, established a crowd-funding account with GoFundMe.com to help pay for her rehabilitation treatments. A community fundraiser and silent auction were also organized to cover some of the costs. While studies show patients can improve for months and years after stroke, there is a cap on the number of funded treatments they receive.

RESOURCES:

- **Employment Insurance (EI)** provides temporary financial assistance to unemployed Canadians who have lost their job through no fault of their own, while they look for work or upgrade their skills. servicecanada.gc.ca/eng/sc/ei/index.shtml – check the website for the Service Canada Centre nearest you.
- **Disability Tax Credit** is a non-refundable tax credit that a person with a qualifying impairment can claim. cra-arc.gc.ca/disability
- **Registered Disability Savings Plans (RDSP):** This is a savings plan for people who are eligible for the disability tax credit. cra-arc.gc.ca/disability
- **Canadian Red Cross- Health Equipment Loan Program (HELP)** loans medical equipment on a short-term basis. redcross.ca/what-we-do/community-health-services-in-canada/health-equipment-loan-program



Once the outpatient therapy runs out, you're on your own. We were lucky to find a program for people with Acquired Brain Injury. It is funded by our city. There are two six-hour classes a week at a recreation centre. All of the participants are between ages 18 and late 40s. They get aqua therapy, cooking lessons, speech therapy, physio. There are 12 people in the class and four or five staff. People should look for municipal programs for people with Acquired Brain Injury."

- Chris, whose fiancé Julie had a stroke at age 28

STROKE IN YOUNG ADULTS

***"I want to feel connected.
I want a social life."***

For many people, stroke leads to loss of self-confidence. One way to rebuild confidence, to feel productive and to socialize is through leisure activities and volunteer opportunities.

"Whether it's walking, hiking, writing or whatever, start doing something that you like. It may not be easy but you can relearn very quickly."

- Andrew, who had a stroke at age 24

Consider taking a painting class. Join a book club (audiobooks and e-books are available free from most public libraries and can be delivered to the nearest branch.) Join or create a free meditation group. Or start a club of common interest with other stroke survivors you met in the hospital or through your local stroke survivor association. There may be adaptive or assistive devices to help you continue your favourite leisure activity.

Organize a movie night at home with some friends or other stroke survivors.

Volunteering locally can help you build self-confidence and possibly make new connections. Depending on where you live, there are agencies that can help you find volunteer jobs suited to your abilities and skills.



"Socially, it has been tougher to meet new friends and the dating scene is kind of rough. It's difficult when you can't do a lot of the activities and sports other people can do. I can't drink because of the medication I take. I can't be out all night partying. I would recommend that before you delve into dating, make sure you're feeling good about yourself."

- Stephanie, who had a stroke at age 21



“I want to have a baby.”

Overall for healthy young adults, the risk of stroke is about 1 in 10,000. Pregnancy is a higher risk time with strokes occurring in roughly 1 in 4,000 known pregnancies. If you’ve already had a stroke, your risk may be higher. However, **the majority of pregnancies in women with a history of stroke make it to term with good maternal and neonatal outcomes** – so a history of stroke doesn’t necessarily have to stop you from having a baby.

Talk to your obstetrician or maternal fetal specialist or stroke specialist about questions you may have related to pregnancy after stroke. Treatment will vary, depending on the type of stroke you experienced.

In general, it’s important to address lifestyle issues before considering pregnancy. Ensure you manage your blood pressure, control your weight, eat a healthy diet, stop smoking, engage in regular physical activity and regulate blood sugar levels.

Some medications can affect the baby, but others may be just fine. If possible, talk to your physician before planning a pregnancy. If you discover you are pregnant while taking medicines, do not stop on your own. Rather, talk to your physician as soon as possible to determine if any changes are needed.

“What can I do to prevent another stroke?”

“I want to know if younger adults have different risks.”

Risk factors for stroke can be divided into two categories: things we can change and things that we can't. **Risk factors you can change include:**

- ▣ high blood pressure
- ▣ diabetes management
- ▣ atrial fibrillation
- ▣ high cholesterol
- ▣ tobacco use
- ▣ drug use
- ▣ alcohol use
- ▣ inactivity
- ▣ obesity
- ▣ stress

Risk factors you can't change include:

- ▣ age
- ▣ gender
- ▣ history of stroke
- ▣ clotting disorders
- ▣ genetic heart defects
- ▣ infection in the heart

These risk factors apply to all age groups. You can assess your risk by visiting the Heart and Stroke Foundation's Risk Factor Assessment Tool on their website at heartandstroke.ca/risk.

However, there are some risk factors that are more prevalent in younger adults and require attention.

Modifiable:

Recreational drug use is more common in young adults and greatly increases the risk of both ischemic and hemorrhagic stroke. Recreational drugs like marijuana, hashish, ecstasy or MDMA, cocaine, heroine, LSD and PCP significantly increase stroke risk because they alter the blood vessels in the brain. Misuse of cough medicines as a recreational drug carries a similar risk and even over-the-counter cough medicines used appropriately can trigger blood vessel changes. With drug use, blood vessels are constricted, blood pressure increases and there is damage to heart valves. It's not just the drugs themselves that are dangerous. Other compounds mixed into the drugs can have very harmful effects.

Use of oral contraceptives can increase stroke risk, especially if you smoke, you are obese or you have a history of migraines. There are many other forms of birth control. Talk to your physician about alternatives that could work for you.

Vascular risk factors (high blood pressure, cholesterol, diabetes, obesity, inactivity etc) are becoming more common in young adults, and even children. These risk factors may not be present in all young people with stroke, but if found, they should be controlled.



STROKE IN YOUNG ADULTS

Uncontrollable:

Arterial dissection is an abrupt tear in an arterial wall caused by a neck injury, forceful neck movements, extreme neck extension or whiplash. This is the most common single identifiable cause of stroke in young adults.

New or existing problems in the heart – like infections of the heart valve (endocarditis), other valve problems, clots or benign growths in the heart (e.g. atrial myxoma) can cause blood clots that can move with the blood up to the brain and cause a stroke. Blood thinners, surgeries and medications to improve heart function may be needed. If issues are found on tests of the heart, many young patients will also be referred to heart specialists for further assessment and treatment.



"I don't know why I need to exercise."

Stroke reaches well beyond the brain. It damages muscles, weakens memory, impedes thinking, causes bone loss and increases the risk of fractures.

The good news is that **exercise is a single proven treatment that benefits many risk factors while also helping promote stroke recovery.**

Exercise has been found to improve brain health and cognition (thinking, decision-making, memory), lower blood pressure, improve cholesterol levels, control blood sugar and reduce sleep apnea in people post-stroke and it has been shown to improve mobility.

Research under way in Canada shows the benefits of exercise post-stroke. You may be eligible to participate in a clinical trial. **Learn more at canadianstroke.ca.** Consult your health-care team about when it is safe to start exercising and what level of exertion is safe.



Exercise also improves bone health, which is a big issue for people living with stroke. A year after stroke, most people experience a significant decrease in bone density (especially on the affected side of the body) because they are not only walking less and standing less, but using their non-affected limbs to support most of their body weight.

A recent study, funded by the HSF Canadian Partnership for Stroke Recovery, revealed stroke patients who participate in a cardiac rehabilitation program for six months make rapid gains in how far and how fast they can walk, the use of weakened limbs and the ability to sit and stand – even years after their strokes.



"I can't lose weight."

Anyone who has ever been on a diet can tell you that losing weight is difficult. Food not only sustains us, it also provides comfort, especially during stressful times. But during stroke recovery it is important to eat healthy foods – low in sugar, sodium and fat – to promote recovery and reduce the risk of another stroke. Ask your physician for a **referral to a dietitian** to help modify your diet to include more fresh fruits and vegetables and lean protein.

As well, your **occupational therapist can help you learn to prepare meals, organize your daily routines and go grocery shopping.**

STROKE IN YOUNG ADULTS

"I've tried and failed to quit smoking."

The process of quitting smoking is different for everyone and your family physician can provide some advice. Strategies include using self-help resources, counseling, using nicotine replacement therapy, or prescription medications. If one method doesn't work for you, don't give up. While quitting "cold turkey" can work for a few people, the odds of success are higher with support, therapies and medications. If one approach doesn't work, stay motivated – try another or use a combination of strategies. It is true that many people need more than one attempt to quit successfully. Don't be discouraged!



Other things that might help include:

The One-Step-at-a-Time series created by the Canadian Cancer Society. Do a web search for "Canadian Cancer Society one step at a time".

This series includes resources for smokers who don't want to quit; smokers who want to quit; and tools for family/partners/friends to help a smoker quit.

“Remind me of the stroke signs.”

It is very important that you know what stroke looks like and that you are aware of the warning signs for future events. Research has shown that young people are less likely to think their symptoms are a problem, less likely to go to hospital and, when they do, they do not use ambulance services to get there. Be on the lookout for the following signs and symptoms and visit the Heart and Stroke Foundation website (www.heartandstroke.ca) for more information:

FACE is it drooping?
ARM can you raise both?
SPEECH is it slurred or jumbled?
TIME to call 9-1-1 right away.

ACT **F A S T** BECAUSE THE QUICKER YOU ACT,
THE MORE OF THE PERSON YOU SAVE.



STROKE IN YOUNG ADULTS

Some final words

“People come out of a near-death experience in many ways. Some become more spiritual. Or they become religious. What changed for me is it probably helped me to see things clearer. In almost three dimensions...I’ll walk downstairs in the morning and make a cup of coffee and I’ll actually smell coffee now. People say in life ‘stop and smell the roses’. It’s so true. I’ll actually stop now, and my sense of smell and sight are clearer. I guess it’s more defined. That’s what I’ve found. I’ll give my little girl and my wife a hug that is that much tighter”

– Jeffrey, who had a stroke in his 40s

“I was having trouble until I came across a program that taught “mindfulness” at my local hospital. Honestly, that program changed my entire way of thinking. It taught me how to deal with my pain and to make a better and faster recovery. There are different types of meditation they introduced to us and I figured out one that suited my needs, which I now practice daily. I also learned to notice triggers of my pain and to try to avoid those triggers – like stress, even family stress.”

– Vimuththan, who had a stroke in his 20s. To get started, search “mindfulness” on Google. There are websites, books and videos easily accessible that provide a starting point.





“Choose to see the word “plateau” as your body’s way of telling you that you might need a rest period and to focus on another body part or to reassess your therapy plan and make the necessary changes to move forward. Plateaus require patience and continued planning to see you through to the next phase of your recovery.”

– Carole, who had strokes at age 42

“I don’t want you to think it’s all negative. There are some things that have not changed. I am still as optimistic as ever, I have a wonderful support network and I do feel truly blessed to be making the recovery that I am.”

– Garima, who had a stroke in her mid-40s

“After a stroke, your whole life seemingly shatters before your eyes. But your life is not over. It is a time to reassess your life and to be honest with yourself. You end up at a starting point again. You can decide which direction you want to take. It’s not about being the same. It’s about creating a new life which can be more fulfilling and more in line with what you really want.”

– Andrew, who had a stroke at age 24

STROKE IN YOUNG ADULTS

“The stroke was both the worst experience and one of the best experiences of my life. The stroke gave me the opportunity to re-evaluate my life and my career and think about what I want and what makes me happy and fulfilled.”

– Nikki, who had a stroke at age 34

Links:

canadianstroke.ca

heartandstroke.ca

StrokeEngine.ca

strokebestpractices.ca

torontostrokeprogram.com

ontariostrokenetwork.ca

strokestrategy.ab.ca





www.canadianstroke.ca