



Recovering from a Stroke

A GUIDE FOR STROKE SURVIVORS, FAMILIES, FRIENDS & CAREGIVERS



There is Life After Stroke

After 40 years of helping stroke survivors and their caregivers in BC, we have learned some vital lessons that we want to share with you:

Never give up hope and never stop trying. We have seen with our own eyes that being determined to get better makes a big difference. With effort, you can keep on improving.

There is life after stroke. Many stroke survivors have successful and enjoyable lives.

Support is very important. Family and friends play a huge role. The support of other stroke survivors and their understanding and encouragement really helps. Caregivers also need support.

You need to set goals. As long as you achieve some of them you are moving in the right direction. If it's hard, then break your goals down into smaller steps.

Never give up hope and never stop trying. We can't say that often enough.

Stroke Recovery Association of BC

The Stroke Recovery Association of BC (SRABC) is a non-profit organization. We have been offering information and programs since 1979 for stroke survivors after they leave hospital. We are committed to assisting stroke survivors and their caregivers throughout the province to improve their overall quality of life. Our vision is that every stroke survivor in BC moves through recovery with hope and support to lead a full and rewarding life.

To learn more please visit srabc.ca

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

STROKE RECOVERY ASSOCIATION OF BC

T. 604.688.3603

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RECOVERING FROM A STROKE

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

WE CAN HELP

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

- » Balance: Having a good balance between rest and activity is important. Quality sleep is also important.
- » **Simplify:** Keep activities and information as simple as possible.
- » Repetition: Learning after stroke requires repeating information and practicing skills.
- » **Structure:** A daily and weekly structure and routine are helpful.
- » Consistency: Do things the same way each time.
- » Learn to think differently: You may find you need to adapt and change from past ways of doing things. Trial and error is part of this process.

7 PRIORITIES FOR STROKE RECOVERY

Exercise and Mobility

Walk, bike, garden – even dust. Physical activity can trigger changes in the brain that make up for lost function. Be consistent too so that it turns into a habit. It's better to do an activity once a day for a short period than a long block of activity once a week.

Communication and Language

Write down key words, draw pictures, point, use body language, and use facial expressions to communicate. Don't rush or pretend to understand. Be patient with yourself. It'll get better.

Social Interaction

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

Thinking, Memory and Perception

If you have trouble thinking, understanding and remembering, then stick to a routine and keep activities simple. Also take notes and use a calendar to jog your memory. Little tactics like these can help you cope, as well as improve.

Support

A stroke can cause anxiety, hesitation, even mood changes. So get help from family and friends: ask for what you need and share your frustrations. Don't shut people out. You can also attend stroke support groups and recovery programs. Other survivors can relate to what you're going through; they can provide practical help, validation, and hope.

Healthy Lifestyle

Improve your chances of recovery with healthy habits. Maintain a healthy weight, eat well, cut down on cholesterol, quit smoking and be moderate with alcohol. Limit your caffeine intake too. Little changes go a long way toward recovery.

Navigating the System

Get to know key organizations and resources. Check out facilities and programs that can help as you evolve. Adjust your home. The more you do to make your life easier, the more energy you'll have to work on areas that train the brain.

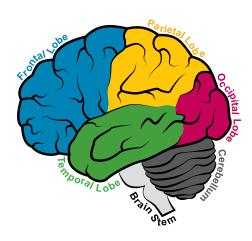
WHAT IS A STROKE?

A stroke is a brain injury caused by:

- » Blood flow to the brain being blocked
- » A blood vessel bursting in the brain

When blood stops getting to your brain, the brain cells don't get the oxygen they need. Bleeding in the brain also damages brain cells.

Blockages and bleeding cause brain cells to stop working properly or to die.



APHASIA-FRIENDLY CONVERSATIONS By Eavan Sinden, SLP.

Aphasia, a language disorder, is a common effect of stroke. It can have a huge impact on a stroke survivor and their quality of life, as well as their family and friends.

Aphasia is... "a communication impairment that **impacts identity and relationships** because of difficulties speaking, understanding, reading and writing." (*Kagan & Simmons-Mackie*, 2013)

When you have a conversation with anyone, you strike a balance between interaction (the non-verbal communication) and transaction (the information/content). That's why speaking on the phone is so difficult for people with aphasia.

People with aphasia have difficulty with **transaction**, due to limited access to language. **Interaction** remains a strength. By acknowledging interaction as a strength, we are acknowledging the inherent competence of the person with aphasia.

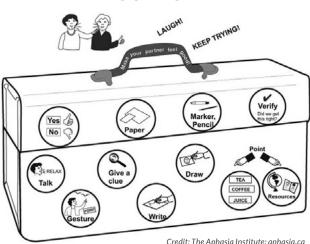
The communication support you can provide (e.g., written keywords, aphasia-friendly resources) facilitates transaction, thus helping the person with aphasia to reveal their competence.

In conversation with a person with aphasia, it is important to recognize that both of you have responsibility for successful communication.

The communication partner should:

- » Use natural adult talk appropriate to the context; use short sentences and everyday language.
- » Be sensitive; make the person with aphasia feel comfortable; handle miscommunication respectfully.
- » Ensure that the person with aphasia understands and has a means of responding.
- » Verify that you have received the intended message (e.g., "Let's see if I understood what you meant"; write or use pictures if it helps).

TOOL BOX



The person with aphasia can:

- » Use appropriate non-verbal skills (e.g., eye contact, body language).
- » Initiate communication.
- » Exchange ideas and opinions.
- » Use communication supports (e.g., writing, gestures, drawing, pointing).

WHAT IS SELF MANAGEMENT?

"From the moment I wake up, I start rehab. And I don't quit rehab until I go to sleep."

- PAT B., Chilliwack Stroke Recovery Program Participant

While not the textbook definition, Pat's attitude and approach to his recovery journey really sums up what we mean by self-management.

It's getting back to life after stroke. It's the actions and choices you make every day to keep on improving.

There are many good resources and toolkits about health and recovery self-management. We recommend the Chronic Conditions Self Management Program through Self-Management British Columbia (https://www.selfmanagementbc.ca/chronicdiseaseprogram). You can attend an in-person workshop, or do the course online.

In the meantime, here are four simple things to get you started in self-managing your recovery.

1. IDENTIFY OR CREATE YOUR NETWORK

Support is a critical part of your recovery. In addition to providing emotional support, encouragement and understanding, people in your network can help you in many practical ways.

Your network is your family, friends and neighbours. Your network also consists of community organizations, and healthcare and service professionals.

You don't have to do it alone.

As you move through the next three steps for self-managing your recovery, it's really important you remember this: setting goals, solving problems and creating action plans can all involve help from others.

If you are feeling alone, we can help. **Call the AFTER STROKE WARMLINE at 1.888.540.6666** to be connected to resources and organizations – and people – in your community.

2. SET A SMART GOAL

Setting a personal goal that is important to you can help you focus and keep track of your progress.

"I will get more exercise" is not a smart goal.

"This month, I will walk for 15 minutes three times a week" is a smart goal.

If you have a goal that doesn't meet one - or some - of these criteria, choose a smaller goal.

A SMART goal is:







RESOURCED (you have what you need to do it)





THERE'S AN APP FOR THAT!



Your smart phone can help you with SMART goals. There are lots of different apps that will allow you to set a goal, remind you to do it and reward you when you're done! With some of them, you can also connect with friends and encourage each other to succeed.

Just type in "goal tracker" to your app store, and shop around. There are many free and free-trial options, so you can download a few to try them out, and choose the one you like the best.

3. MAKE AN ACTION PLAN

Keep it simple. Don't forget your network! If you need support to be successful, think about who can support you and include that in your action plan. It might be as simple as a walking buddy for motivation and conversation, or something more formal, like a visit to your GP to get the go-ahead to start a walking program.

Here's a basic template, with a sample plan filled in:

SMART GOAL:

S

SPECIFIC



MEASURABLE



ACHIEVABLE



RESOURCED



TIMELINED

This month I will walk for 15 minutes three times a week.



THINGS I NEED FOR SUCCESS:

- ✓ Get it in my schedule; plan regular days and a set time
- ✓ Motivation / a walking buddy
- ✓ A plan 'b' in case it is raining
- ✓ Walking shoes

ACTION ITEM 1:

Find out the days / times that will work for my buddy and me in January, and make a schedule for the month. Put reminders in my calendar (on the wall and in my phone).

ACTION ITEM 2:

Think about a couple of routes – need to have a place to sit around the half-way point. Visit the mall and the rec centre to make a plan for rainy days. Also, test out my shoes and if I need better ones, buy them at the mall!

ACTION ITEM 3:

Walk! Start slow and steady. It's okay to go for a shorter time if needed.

4. BE A PROBLEM SOLVER

Solve the problems that come between your recovery goals and life after stroke.

There are four steps to problem solving:

FIRST: Determine the problem and cause of the problem.

Let's say you set the goal to walk for 15 minutes, 3 times a week, but you weren't successful: "I tried for a couple of weeks, but I only went walking once or twice. I found it kind of boring."

The problem: I didn't go walking.

The cause: It was boring.

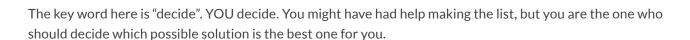
NEXT: Come up with some possible solutions.

You can do this on your own, or you might find it helpful to brainstorm with someone.

Examples of ideas to solve the problem (but these are just examples. You should identify your own!):

- » Find something to listen to, e.g., music, a podcast, a Ted Talk, or an audio book.
- » Try mindful walking (walking meditation) being aware of each step and breath while walking.
- » Keep your eye on the prize. Maybe getting more physically fit is the first step towards a bigger goal, e.g., going back to work, or dancing at a grandchild's wedding.
- » Check out your local gym; you might be able to watch TV while you're on the treadmill.
- » Make your 15-minute walk a part of your day, e.g. get off the bus a couple of stops early.





FINALLY: Try it out and see if it works.

Give it a couple of weeks. If the idea you chose doesn't solve the problem, you have options! You can:

- » Go back to the list and choose another idea.
- » Go back to the cause and make sure it's the true cause of the problem. Are you sure you stopped walking because it was boring? Or did you stop for another reason?
- » Go back to your goal and make sure it's the right goal. Why does it have to be walking? If your ultimate goal is to get more exercise, there are lots of other things you can do to achieve that.



PREVENTING ANOTHER STROKE

People who have had a stroke have a greater chance of having another one, especially during the first year following the first stroke. This creates added stress.

According to the World Stroke Organization 2019 Global Fact Sheet, negative behavioural factors (poor diet, smoking, lack of exercise, etc) account for 66% of the "stroke burden". High blood pressure is the single greatest risk factor, followed by dietary risk factors, high BMI (i.e. body fat), smoking, high fasting glucose (i.e. pre-diabetic), and alcohol consumption.

The best available, global, scientific data tells us that simply changing your behaviour (improving your diet, living a healthy lifestyle, getting exercise) decreases your risk of stroke, including a second stroke.



WSO 2019 GLOBAL FACT SHEET: STROKE RISK FACTORS



Metabolic risks
(high systolic blood pressure (SBP),
high body-mass index (BMI),
high fasting plasma glucose (FPG),
high total cholesterol, and low
glomerular filtration rate) account

72.1% (66.4–77.3) of stroke burden



Behavioural factors (smoking, poor diet, and low physical activity) account for

> 66.3% (59.3 to 73.1)

and
environmental risks
(air pollution and lead exposure)

of stroke burden.

28.1% (25.3 to 30.9)





Globally, high systolic blood pressure

is the largest single risk for stroke (57.3% [49.8-64.4])

followed by dietary risk factors (51.1% [40.7-61.2]), high BMI (23.6% [15.1-33.3]), smoking (23.4% [20.2-26.6]),

high fasting glucose (17.3% [11.6-24.7]), alcohol use (11.9% [9.4-14.6]), high LDL cholesterol (10.0% [5.9-16.7]), impaired kidney function (8.6% [7.1-10.2]), and low physical activity (4.5% [0.8-8.6]).



All risk factors combined

88.8% (86.5-90.9)

of the global stroke burden

Source: World Stroke Organization

EFFECTS OF A STROKE

Effects of a stroke can include the following. Remember that every stroke and every person is different.

PHYSICAL EFFECTS

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

COGNITIVE EFFECTS

These effects involve things like thinking, understanding and learning:

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

EMOTIONAL EFFECTS

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

COMMUNICATION EFFECTS

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

PERSONAL AND SOCIAL EFFECTS

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

FOCUSING ON THE 7 PRIORITIES FOR STROKE RECOVERY - OUTLINED ON PAGE 3 - CAN HELP YOU IMPROVE IN EACH OF THESE AREAS.

The 7 priorities are derived from Canadian Stroke Best Practices, the principles of chronic disease self-management, and what we know about neuroplasticity – the brain's ability to adapt and learn.

The 7 priorities focus on regaining function, maintaining health, and self-management of one's recovery. They form a framework for empowerment of stroke survivors to set and achieve goals for living active and connected lives.

The 7 priorities also form the foundation for our community programs, which are designed to support stroke survivors in reaching their personal goals for recovery and community reintegration. In other words, getting back to "life after stroke". There's more information on these programs on pages 10 and 11.

STROKE RECOVERY PROGRAMS

SRABC offers a range of programs designed to support stroke survivors in the community after they leave hospital.

STROKE RECOVERY PROGRAMS

SRABC has around 30 local Stroke Recovery Programs across the province. There is a list of our Programs on pages 14-15 of this booklet. Programs provide a friendly and motivational place where stroke survivors, families, friends, and caregivers can get encouragement, support, information, and resources for recovery. Programs range in size from approximately 5 to 35 participants. The programs on offer vary depending on the resources available. Most include:

- 1. Physical exercises
- 2. Communication and memory exercises
- 3. Social interaction and recreation
- **4.** Support from fellow stroke survivors
- 5. Caregiver support
- 6. Stroke recovery education
- 7. Help finding other health and community resources

OTHER PROGRAMS AND SERVICES

- » Next Steps mall walking (see page 15 for locations).
- » Talk, Adapt, Learn, Knowledge (TALK) a support group that discusses the hidden effects of stroke, led by a counsellor - meets bi-monthly in Vancouver.
- » Centre of Excellence monthly workshops on stroke recovery held in Surrey.
- » Conversation Groups for people with aphasia.
- Young Stroke Survivors of BC includes a moderated Facebook group, monthly discussion groups, and webinars on demand.
- » PERK Activities for Stroke Survivors a holistic program comprised of 14 diverse activity domains that provide stimulating, thought-provoking activities to help survivors to connect with themselves and others.
- » Graded Repetitive Arm Supplementary Program (GRASP) a 10-week community-based program for people who want to improve hand and arm function after stroke. Includes weekly group sessions supervised by a GRASP instructor and daily home exercises.

Please note, not all programs/services are available at all locations.

To get the latest information on program dates and locations, please contact the Provincial Office:

T. 604.688.3603 **TF.** 1.888.313.3377

F. 604.688.3660 **E.** office@strokerecoverybc.ca

srabc.ca



OTHER INFORMATION & RESOURCES

GF STRONG REHABILITATION CENTRE

Offers regular community education sessions throughout BC, called Understanding Stroke and Building Community Connections. If you can't attend one, they can send you the information by email, fax or through the mail.

T. 604.737.6221

RESOURCES FROM HEART & STROKE FOUNDATION

Heart and Stroke Foundation provides online information to survivors and family members/care partners. www.heartandstroke.ca/stroke

FAMILY CAREGIVERS OF BRITISH COLUMBIA - FAMILY CAREGIVER SUPPORT LINE

People who are caring for a loved one who had a stroke need to take care of themselves too. Family Caregivers of BC provides resources, peer support groups, and a support line.

T. 1.877.520.3267

www.familycaregiversbc.ca

BC 211

bc211 is a Vancouver-based nonprofit organization that specializes in providing information and referral regarding community, government and social services across BC.

Online searchable community resources: http://www.bc211.ca/

Online chat service http://chat.bc211.ca/

Call: 211

VISIT OUR WEBSITE

Learn how to recover from stroke and take back your life. Find expert advice, guides, videos, community group programs designed for stroke survivors in BC. SRABC's website is at srabc.ca

SNIPPETS AFTER STROKE

Subscribe to our monthly newsletter: strokerecoverybc.ca/newsletter

AFTER STROKE WARMLINE

If you are a stroke survivor or caregiver looking for information about stroke recovery programs and services thoughout BC, call our Warmline.

T. 1.888.540.6666

SOCIAL MEDIA LINKS

We post useful information on stroke recovery here. Please take a look at the links, 'like' us, 'follow' us and let us know your ideas.

🌎 / StrokeRecoveryBC 💟 @ StrokeRecovBC 🔘 @ StrokeRecovBC 🔼 StrokeRecoveryAssociationofBC

PRINTED RESOURCES

SRABC GUIDES TO RECOVERING FROM A STROKE:

Most titles are available in English, Chinese, Punjabi and Hindi. It is noted when they are not. Please email office@strokerecoverybc.ca or visit our website for copies. The titles are:

Daily Living

Helps to answer questions about how to successfully return home and resume daily living after stroke.

Adjusting the Home after Stroke

Answers two questions:

What can be done to make the home safe? How can the home be set up to help recovery?

Self-Advocacy

Answers questions about how to get what you need after a stroke, whether you are a caregiver or a stroke survivor.

Getting Back into the Community

Helps with how to get back into the community after a stroke.

7 Priorities for Stroke Recovery

This guide describes the brain's ability to adapt to your new needs (neuroplasticity), then follows up with priorities to meet your goals. Each priority includes options to suit your stage of recovery. (English Only)

Understanding Aphasia

Answers questions about speech and language problems after a stroke.

(English and Chinese Only)

Exercise & Mobility

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



"Practice makes perfect? ... maybe ... but practice DEFINITELY makes progress, and that is guaranteed!"

- CHRIS F., Stroke Survivor (since January, 2017)

FREQUENTLY ASKED QUESTIONS

ARE STROKE RECOVERY ASSOCIATION OF BC AND THE HEART AND STROKE FOUNDATION THE SAME THING?

NO, we work together but are two different organizations. We do different things.

The Stroke Recovery Association of BC works with stroke survivors and their families and caregivers in local communities to improve the survivors' overall quality of life as they recover from a stroke.

WHAT DOES IT COST TO JOIN?

Most of our programs are free; in some cases there's a small participant fee to help cover costs like rent, instructors, and coffee. When the fee is a barrier to participation, it can be waived.

WHAT IF THERE IS NO STROKE RECOVERY ASSOCIATION PROGRAM IN MY COMMUNITY?

There may still be programs and services available. Talk to your doctor, rehabilitation therapist or social worker for information, or contact us. We are here for you to you identify your needs and goals for recovery and work with you to find available resources that support these goals.

WHAT IS THE RELATIONSHIP OF SRABC AND MARCH OF DIMES CANADA?

SRABC is an affiliate of March of Dimes Canada's 'After Stroke' program. The two organizations signed a collaboration and affiliation agreement in 2016 to work together collaboratively to support stroke survivors and their caregivers with the transition from hospital to home, and home to community.

afterstroke.ca

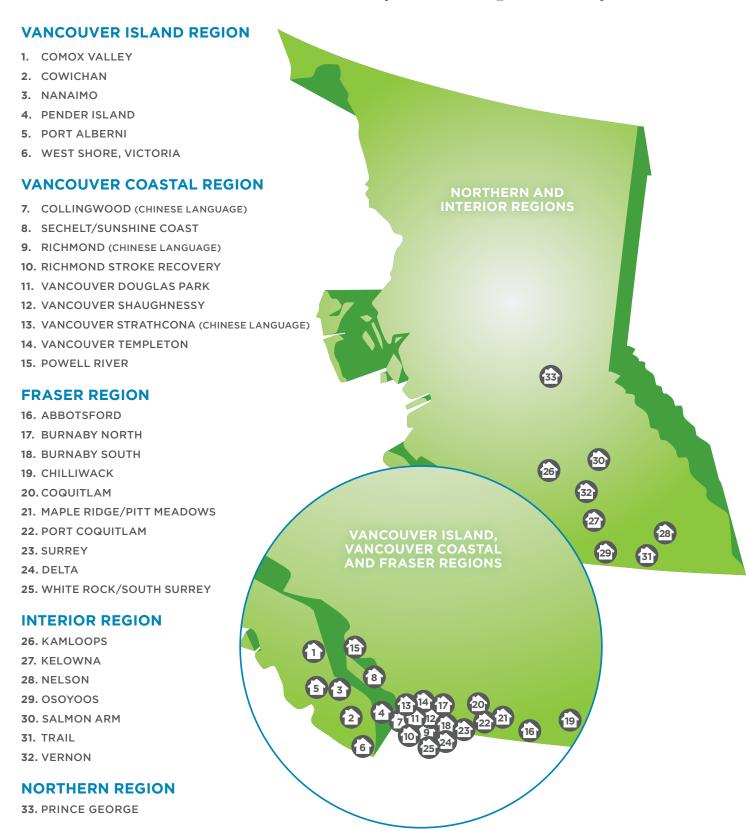




STROKE RECOVERY PROGRAMS

Please see our website for the most up to date list of programs and contact information.

- » srabc.ca
- » Contact the Provincial Office at 604.688.3603 or by Email at office@strokerecoverybc.ca



NEXT STEPS MALL WALKING PROGRAMS

Next Steps is a fun, friendly walking group for stroke survivors that helps you set goals and stay motivated during recovery.



ABBOTSFORD RECREATION CENTRE

ABBOTSFORD

CAPILANO MALL

NORTH VANCOUVER

KINGSGATE MALL

VANCOUVER

OAKRIDGE CENTRE

VANCOUVER

SURREY CENTRAL CITY MALL

SURREY

TSAWWASSEN MILLS

DELTA

HOW TO DONATE

Having a stroke is devastating. One minute you are a fully functioning person, the next, you can't think, can't speak, can't feel and can hardly move. There are 8,100 strokes in BC every year.

Hospitals do a great job of saving people who survive a stroke but sooner or later those survivors go back home. What then?

When you decide to donate to Stroke Recovery Association of BC, you help build a world where every stroke survivor has respect, inclusion, and support in their home community. Please help to bring stroke survivors in BC back to life by making a donation today.

There are 2 ways to DONATE

- 1. **By Cheque:** Cheques payable to Stroke Recovery Association of BC can be mailed to us at: 301-1212 West Broadway Vancouver, BC V6H 3V1
- 2. Online via PayPal at srabc.ca

If you have any questions about donating to SRABC, please contact us.





AFTER STROKE WARMLINE

If you are a stroke survivor or caregiver looking for information about stroke recovery programs and services throughout BC, call our

WARMLINE: 1.888.540.6666

For general inquiries about the Stroke Recovery Association of BC, call **1.888.313.3377**



The Stroke Recovery Association of BC gratefully acknowledges the support of our partners:

Province of British Columbia Provincial Health Services Authority



We acknowledge the financial support







