

Enabling self-management following stroke: *A checklist for patients, families, and caregivers*

Introduction:

Heart & Stroke is committed to supporting people who have experienced a heart condition, stroke, and vascular cognitive impairment. People with these conditions, their family members, and caregivers, demonstrate incredible resilience as they find ways to adapt and manage living with these conditions. Teaching self-management skills and providing timely information and education are key components of success for people with lived experience across the full continuum of care.

This checklist is designed to support those who are transitioning home after a stay in hospital by offering guidance to people recovering from stroke and their families and caregivers.

It provides **tips to help guide recovery** after stroke while aligning to Canadian Stroke Best Practice Recommendations. People are encouraged to use this list to discuss different aspects of recovery with their stroke care team.

Recovery is a process that can last months and even years after a stroke. It is important to challenge your body every day, but to do so **safely** and remember that everyone's recovery is different. The tips listed here are a starting point to support your journey. It is important to also **check back regularly with your therapists** for additional support as needed.

For more information and strategies to support your recovery, please visit the [Stroke Best Practice Patient Resources page](#), the [Rehabilitation and Recovery Infographic](#), the [Transitions and Community Participation Infographic](#), as well as the [Heart and Stroke.ca/stroke](http://HeartandStroke.ca/stroke) webpages. For more information regarding the Canadian Stroke Best Practice Recommendations, please click [here](#).

You are in charge of your recovery!

Enabling self-management: A checklist for patients, families, and caregivers, was created as a resource to support people living with stroke and as a summary of information shared during a Heart and Stroke webinar: "Picking up the pieces: skills for managing transitions to home and self-care during COVID-19". Please see webinar [here](#).

This publication, Enabling self-management: A checklist for patients, families, and caregivers, is for informational purposes only and is not intended to be considered or relied upon as medical advice or a substitute for medical advice, a medical diagnosis or treatment from a physician or qualified healthcare professional. You are responsible for obtaining appropriate medical advice from a physician or other qualified healthcare professional prior to acting upon any information available through this publication.

Enabling self-management: A checklist for patients, families, and caregivers, was developed on behalf of the Heart and Stroke Foundation in collaboration with the Winnipeg Regional Health Authority's (WRHA) Community Stroke Care Service, and their rehabilitation therapy team, including Brenda Semenko, Occupational Therapist; Candice Tremblay, Physiotherapist; Alanna Friedman, Speech-Language Pathologist. It was edited by Rebecca McGuff, Occupational Therapist and Stroke Best Practices program lead, Heart and Stroke.

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Move More, Sit Less

- Regular activity is an important part of healthy living, stroke prevention, and a great way to maintain/improve your independence and function.
 - Canadian stroke best practices encourage people to reduce sedentary behaviours and work towards activity goals as tolerated (aiming for activity 4-7 days per week, accumulating to at least 150 minutes per week, in episodes of 10 minutes or more **in addition to** regular activities of daily living).
- Mobilize (walk, move) using the equipment and techniques suggested by your therapist (e.g., walk with a walker/cane or propel a wheelchair).
- Participate in activities that challenge your balance and coordination, and work on strengthening your weakest muscles.
- Complete your home exercise program, as prescribed.
- Over time, you will likely be able to participate in activities and hold positions for longer periods of time, complete more repetitions of each exercise, and/or vary the speed of the task.
 - With any physical activity, it is normal for your breathing and heart rate to increase, to feel a little tired, warm and/or sweaty. Exercises and stretches should not be painful. Do not exercise if you feel dizzy, extremely fatigued, short of breath, are having extreme pain, or any other adverse symptoms. Listen to your body and take rest breaks as needed.
- For more information, visit the Heart and Stroke [Rehabilitation and Recovery Infographic](#)
- Important:** *A stroke, heart attack, or cardiac arrest is an emergency that requires immediate medical attention. Call 9-1-1 if you or someone with you experiences [signs](#) of a heart attack, stroke or cardiac arrest.*

Move Safely

- Use equipment and adapted and/or modified techniques, as recommended, to help you move safely (e.g., walking aid, braces/orthotics).
- Decrease your risk of falls; minimize clutter, increase lighting, and remove tripping hazards such as throw rugs. Wear appropriate footwear and clothing that fits.
- Hold handrails and use adapted and/or modified techniques, as needed, to help you manage stairs.
- For more information, visit the Heart and Stroke [Rehabilitation and Recovery Infographic](#)

Transfer Safely

- Move from one surface to another (transfer) using the equipment and techniques suggested by your therapist. Remember: proper set up can help make transfers easier and safer.

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- Your strength will increase with each transfer you make, so take care to use proper techniques as shown by your therapist.

Skin Health

- Check skin carefully every day for any redness or breakdown, especially if sensation is impaired.
- If primarily sitting and/or laying throughout the day, shift positions frequently to help maintain circulation and prevent skin breakdown.
- Report any increases in pain, swelling, spasticity or pressure areas on your skin to your therapist or physician.

Nutrition

- Drink plenty of water or other fluids. Signs and symptoms of dehydration can include decreased urine output, decreased skin elasticity, dry mouth, constipation, urinary tract infection, dizziness and/or confusion.
- Ensure you are eating a balanced diet to give you energy, keep your skin healthy, help heal wounds and fight against infection.
- Speak to a Dietitian and refer to the Canada Food Guide for information about a balanced diet.

Feeding and Swallowing

- Follow therapist recommendations for texture and fluid modifications. **DO NOT** change textures without consulting your Speech-Language Pathologist and/or Dietician. Following therapist recommendations reduces the risk of food going into your lungs and causing infection (aspiration pneumonia).
- Self-feeding is encouraged when possible.
- Ensure you reduce distractions and provide a quiet space for meals.
- Sit upright for all eating/drinking and remain upright (90 degrees) for at least 30- 45 minutes after a meal.
- Clear food residue from the mouth after the meal is finished and complete oral care (brush your teeth) after eating to ensure good oral hygiene.
- For more information, visit the Heart and Stroke [Rehabilitation and Recovery Infographic](#)

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Activities of Daily Living

- Try to be as independent as possible with daily tasks such as brushing your teeth, getting dressed and using your computer.
- Use suggested equipment to improve safety and maximize independence wherever possible (e.g., bars/seat for shower, raised seat/bars for toilet, walking aid, if required).
- Try to participate in household tasks or portions of tasks as much as possible including meal preparation tasks, writing out a grocery list, folding the laundry, using the phone.

Leisure

- Continue to make time for leisure activities – do something that you enjoy every day.
- Consider completing leisure activities with others to increase motivation (e.g., online yoga classes, taking short walks with a friend, playing cards).
- Break down leisure activities into smaller component parts and practice those first (e.g., if returning to golfing, practice holding and using a putter before a heavier/longer club).

Arm and Leg Use

- Move and use your affected arm and leg many times every day to help your brain make new connections and to promote motor recovery; follow strengthening exercises and activities prescribed by your therapist.
- Use your affected arm and hand every day for as many tasks or portions of tasks that you safely can (e.g., hold cutlery to eat, help fold laundry, hold phone, turn on TV, use computer). Many repetitions are required every day.
- Complete hand coordination tasks as able, e.g., sort coins, pick up small objects, fasten buttons, flip cards.
- Consider other ways to work on your arm and leg at home including visualization of movements (mental imagery) and mirror box therapy. See the Stroke Engine and Heart and Stroke websites for additional information on these and other interventions.
 - Heart and Stroke: Stroke Recovery and Support, physical changes – [Arms and Legs](#)
 - Stroke Engine: Mirror Therapy – [Lower Extremity](#) and [Upper Extremity](#)
 - Stroke Engine: [Motor Imagery/Mental Practice](#)
- For more information, visit the Heart and Stroke [Rehabilitation and Recovery Infographic](#)

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Arm and Leg Care

- To maintain full movement in all of your joints, complete the stretches suggested by your therapist for your arm and leg every day. This is especially important if spasticity (muscle tightness from stroke) is present.
- Support the affected arm (if it has limited movement) when transferring and mobilizing, and during daily tasks such as getting washed and dressed; talk to your therapist about appropriate ways to support your arm.
- NEVER pull on the affected arm** (this includes while transferring, moving in bed, mobilizing, or receiving assistance with care).
- Only use an arm sling if suggested by your therapist.
- If you have shoulder pain review your shoulder stretches and exercises with your therapist.
- Check for edema (swelling) of the affected hand; support hand on pillows or on a supportive surface such as an arm-board in front of your body when sitting.
- Discuss other edema management strategies with your therapist if required.

Sensation

- Follow the therapist's instructions to help manage and address sensory loss.
- General Strategies may include:*
 - Explore different textures and shapes with your affected hand if experiencing sensory loss. To do this, close your eyes and concentrate on the differences between various textures and shapes of household objects and compare how this feels with your unaffected hand.
 - If experiencing sensory changes throughout your body, using different pressures, materials, vibrations, etc. to help with sensory return or desensitization may be considered.
 - If having difficulty knowing where your arm/leg is in space, practice activities that encourage both arms/legs to do the same task at the same time, e.g., clap your hands together at different heights, match the position of your arm/leg with your other arm/leg, tap both feet using the same rhythm and amplitude. Look frequently at your arm/leg initially to ensure the desired position is being maintained.

Speech

- Practice exercises provided by your therapist, that are specific to the type of speech deficit; follow the exercises as outlined.
- General Strategies:*

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- Speak slowly, exaggerate your mouth movements and pause when needed. Remind family members to be patient and only provide cues following your attempts to express yourself independently.
- ❑ **Word-Finding Strategies:**
 - Use antonyms (words with opposite meaning) or synonyms (words with same/similar meaning), try to describe the target (shape, use, colour, etc.), use gestures, or pantomime.
 - Augmentative and alternative communication strategies may be used if speech is unintelligible. This may include low tech options (pictures, words) or high-tech options (communication device, iPad with app, etc.). Connect with your therapist to determine which option may be best for you.

Written Expression

- ❑ Follow the therapist's instructions and therapy plan to target written expression.
- ❑ Practice copying personal information and automatics (alphabet, numbers, days of the week, months of the year).
- ❑ Use a built-up or larger pen if needed, to facilitate holding the pen in your hand.

Auditory Comprehension (Understanding what is said)

- ❑ Follow the therapist's instructions and therapy plan to target auditory comprehension. Offering visual cues such as pictures or words can be very helpful.
- ❑ Communication partners: use basic instructions, speak slowly, do not provide too much information at one time and allow lots of time for the individual to respond.

Reading Comprehension (Understanding what is written)

- ❑ Follow the therapist's instructions and therapy plan to target reading comprehension.
- ❑ **General strategies for Reading Comprehension:**
 - Read out loud and read through the information two to three times to ensure all the information is understood. Try spelling out the words. Provide a summary about the information. Begin with single words and move on to sentences and paragraphs as you improve. Use a ruler or bookmark to go line by line when reading sentences and paragraphs.

Vision

- ❑ Get vision checked if any changes are noted; ensure glasses are worn as prescribed.

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- Scanning strategies:**
 - Encourage family to sit/stand on the side you have difficulty looking toward and practice looking at them during conversation. Practice scanning tasks that encourage your eyes to move from left to right, e.g., word searches, crosswords, reading aloud. When moving around, remember to scan the environment around you.
- Reading strategies:**
 - Use a straight edge when reading to help guide your eyes. Consider using a colored strip along the left side of the page to help your eyes find the start of the line, if needed. Try increasing the font size on your computer, if needed.
- Visual attention strategies:**
 - Read aloud whenever possible; have a discussion with someone about the content of what you have read or write down five key points.
- For more information, visit the Heart and Stroke [Rehabilitation and Recovery Infographic](#)

Attention and Memory

- Minimize distractions when trying to focus your attention (e.g., turn off TV and radio, turn down bright lights).
- Use a calendar, journal or app on your phone to record information (including amount of sleep, comments on mood, amount of exercise done, etc.).
- Practice cognitively challenging tasks such as games requiring mental math (e.g., cards, cribbage), follow a simple recipe, make 'change' as if you were shopping.

Body Awareness

- Don't forget about your affected side when moving in bed, transferring, walking, and/or using a wheelchair! Know where your arm and foot are at all times to keep yourself safe and prevent injury.
- Dress your weaker side first and undress it last.
- When sitting, remember good posture. Good posture and alignment help improve breath support for speech and your ability to move more effectively and efficiently. Holding good posture can be tiring if you are not used to it. Speak with your therapist about ways to improve your endurance (e.g., try sitting with good posture for 30 seconds every hour or every time you sit down).

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Spatial Awareness

- Practice perceptually challenging tasks such as puzzles, word searches and crossword puzzles.
- Choose tasks that encourage following a pattern (e.g., putting together Lego or a simple craft/sewing project).
- Follow a simple map or think through/talk about directions to a new location. Plan your route.

Time Awareness

- Practice thinking and talking about the time (e.g., what time it is, how much time has passed since breakfast, etc.).
- Use a calendar or schedule to help record important information; pick a consistent time every day to update and review your schedule.

Conserve Your Energy

- Establish daily routines and habits that make sense for you.
- Plan to do the things you need to do each day for the times when you have the most energy.
- Pace your activities – take breaks before you get tired (this helps save your energy for things you want and need to do later).
- Position your body comfortably for the task (e.g., sit if possible to do meal preparation tasks such as chopping vegetables).
- Prioritize/set goals for tasks that need to be done that day or week. Write them down.
- Reflect: If you are especially tired one day, think about what you did the day before. Was it more than normal? You may have to adapt your expectations of what you can accomplish daily but remember that as your strength and energy levels increase, you can make new adjustments to your day.

Stay Healthy

- Take medications as prescribed by your physician; have someone assist with this as required.
- Monitor your blood pressure and blood sugars, as prescribed by your physician.
- Plan regular follow-up appointments with your physician.

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Sleep Hygiene

- Stick to a routine; try to get up and go to bed at the same time every day.
- Do something relaxing before bed if that helps you fall asleep.
- Try to avoid stimulating activities prior to bed. Use of technology prior to bed may make it more challenging to fall asleep.

Wellbeing

- Surround yourself with supportive people (those who encourage you to do things for yourself).
- Monitor your mood. Get help if you need it. Speak to your family physician for assistance with medical management.
- Practice relaxation techniques such as meditation and deep breathing.
- Connect with your therapist or physician if you experience changes in your mood or have difficulty sleeping.
- Consider online stroke recovery groups and other online support groups, such as the Heart and Stroke Community of Survivors.
- Consider joining one of the Heart and Stroke Online Communities:
 - [Community of Survivors](#)
 - Caregiver online support group: [Care Supporters' community](#)
- For additional information, visit the Heart and Stroke [Transitions and Community Participation Infographic](#)