

Transitions and Community Participation

Your guide to taking charge of your stroke recovery

By the numbers



More than 400,000
Canadians are **living with**
the effects of stroke



Almost **twice** as many
women as men go to
long-term care after stroke.

How have you been affected by stroke?



For more information on this topic and to check out similar infographics on other stroke best practices, visit www.strokebestpractices.ca/resources/patient-resources

Definition

Transitions refers to the movement of people across various healthcare locations, settings, and providers. **Community** is defined as the physical and social environment where individuals may live after a stroke, including any non-hospital setting, where one would reside and resume life roles and activities, such as a family home, assisted living facility, long-term care, or other residential settings.

Goal

The goal of transition management is to facilitate and support seamless movement across the continuum of care, and to achieve and maintain optimal treatment, outcomes, adaptation, and quality of life for you, your family and caregivers. Community participation involves returning to your desired and meaningful activities of daily living, community interests and life roles following stroke. This includes returning to active community living and contributing to your social groups and family life.

Support

Stroke is a sudden and life-altering event that may require an extended recovery period. It may result in new challenges in management of day to day limitations. Stroke can also have an impact on those close to you as your family and caregivers often take on additional roles. The healthcare team should be aware of this and ensure the proper support is available and that your needs are met.

After your stroke, you should be screened for level of coping, risk for depression, and other physical and psychological issues at each transition point. If issues are identified and the healthcare team receives your consent, you should be referred to appropriate services to address the issues and promote optimal outcomes.

Support is essential after stroke. You should be provided with information about peer support groups in the community where available and a list of community resources, including how to access these services, that will support your self-management at each care setting.

Tips for a successful recovery:

Share your concerns. Your healthcare team should work with you to answer all your questions, help you identify and address your physical, emotional, mental and cognitive needs and provide education. This should happen at any stage or setting in your journey.

Write about it. Keep a journal so you can monitor your achievements and progress, record information about your medications or therapy, keep track of medical appointments, and write down questions to ask at your appointments.

Use a checklist. It can help you start a conversation about important issues you may be experiencing. Fill out a new one before every medical appointment. It gives you an ongoing record of your progress and makes it easier for your doctor, nurses or others on your healthcare team to understand how you are doing and work with you to get additional help if you need it. Add items that are unique to your recovery. Check out our post-stroke check at strokebestpractices.ca/resources/patient-resources.

It's a team effort. Transitions of care requires the participation of you, your family and caregivers, health professionals and the broader community. It should involve collaborative goal setting, shared decision making and an individual recovery plan that is developed together and regularly reviewed and updated as you progress.

The power of community. If you have experienced stroke or heart condition, or are caring for someone who has, connecting with other people who know what you are going through can help the recovery journey. These communities share experiences, quality information and tips, while offering social and emotional support in a safe, inclusive and respectful community. Learn more at heartandstroke.ca/connect.

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Education

Education is an essential component of care for you, your family and caregivers and should be addressed by the healthcare team through recovery in all settings.

- ✓ **Action:** The healthcare team should discuss your learning needs with you and develop an individual recovery plan that includes educational needs. This plan should incorporate hands on training, skills development and education for family and caregivers. Make sure you ask questions, such as what type of stroke you had and what you can do to prevent another stroke. Ask if your family and caregivers can join therapy sessions to help them learn proper skills to support your self-management.



Interprofessional Care Planning & Communication

After a stroke, care can be complex and require ongoing monitoring and management. Clear communication in a timely manner is essential to ensure continuity of care, safety and to reduce risk of complications resulting from the confusion that can arise during transition points.

- ✓ **Action:** You, your family and caregivers should be actively engaged in development of an up-to-date individualized recovery plan that is regularly reviewed and updated as you progress. This plan should represent your goals, values, and individualized care needs, such as identifying potential issues or needs that could delay transition to the next stage of care.

Specific transition planning activities might include:

- Before you transition home, a member of the healthcare team may visit your home to make the necessary modifications for accessibility and safety.
- Caregiver training so they can be supportive to your ongoing needs.
- Goal-oriented visits to the next stage of care to identify potential barriers, assess readiness for transition and to inform therapy and transition planning activities.
- Booking of appointments prior to leaving the current setting.

You should receive written discharge instructions that address your functional ability, risks and safety considerations, action plans for recovery, medications at discharge and instructions for adjustment, follow-up care, provider contact information and information for one point of contact.



Community Participation Following Stroke

As you begin to create a new routine of daily life after your stroke, you may need to make some small adjustments or big changes to help you find a “new normal.” The return to home is consistently reported as a stressful and challenging time as you adjust to new roles and potentially altered functional and cognitive abilities. Participation in life roles and meaningful activity positively contributes to overall sense of wellbeing and purpose.

- ✓ **Action:** If you are living in the community after your stroke, you should have access to regular and ongoing medical follow-up appropriate to your individual needs. If you experience a decline in physical abilities while living in the community, you should receive targeted interventions regardless of how long ago the stroke occurred.
- ✓ **Action:** After a stroke, you usually must wait before driving again. You may need vision tests, occupational therapy, or other assessments before driving. Discuss your goals for driving with your healthcare team.
- ✓ **Action:** Following your stroke, you may receive assessments for vocational interests (i.e., work, school, volunteering) and your potential to return to them. Ask your healthcare team about this.
- ✓ **Action:** Ask your doctor about education sessions or guidance about any expected changes in intimacy and sexuality that you may experience and about strategies to maximize sexual function.



Transition to Long-Term Care Following a Stroke

In long term-care, the care should be supportive and provided by knowledgeable staff who are able to meet your specific stroke needs. You should be assessed by the long-term care staff on arrival to the facility to inform your individualized recovery plan. This plan should be updated regularly to reflect your ongoing needs.

- ✓ **Action:** Keep active and participate in leisure activities while in long-term care. Ask for support to be able to engage in personally valued activities. Involve your family and caregivers in these activities



End of Life

Having a stroke raises difficult life issues. After a severe stroke, some people may not be able to recovery and the care may be focused on palliation and comfort measures. There may be unique needs for end of life care, including physical, spiritual, cultural, psychological, ethical, and social needs. This might involve updating or developing an advanced care plan and/or assigning a substitute decision-maker.

- ✓ **Action:** You, your family members and caregivers should talk to your healthcare team about advanced care planning and should be provided with disability supports and services as required. This includes referral and liaison with community-based hospice or palliative care services and should be coordinated as appropriate based on the goals of care and condition.