

My Guide for Stroke Recovery

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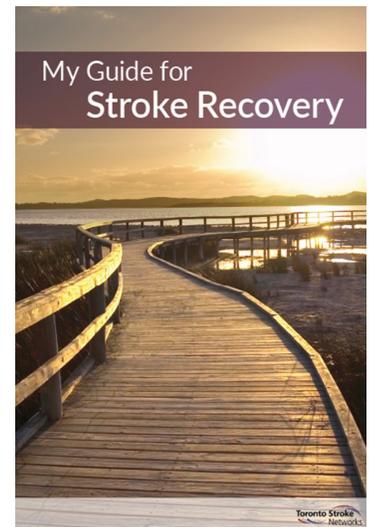
Communiqué

My Guide for Stroke Recovery (MGSR), previously known as *My Stroke Passport*, was refined to:

- ◇ serve as a patient-mediated education tool
- ◇ empower persons with stroke and their family/caregivers to learn about stroke and what it means for them
- ◇ allow persons with stroke and/or caregivers to take an active role in their care and recovery.

By introducing and supporting the use of MGSR, health care providers are delivering patient-centred care while enabling persons with stroke to learn to manage their own care. The goal is for MGSR to become a standard resource used by all providers caring for individuals with stroke in Toronto.

“Extremely informative. Prior to my stroke I had little knowledge... sections on information about me, setting goals, going home and life after stroke are very important and informative.” (Person with Stroke)



**My Guide for Stroke
Recovery**

How My Guide for Stroke Recovery supports quality care

MGSR supports the implementation of best practice for transitions as outlined in:

- ◆ The 2015 [Quality Based Procedures Clinical Handbook for Stroke](#)
- ◆ [Canadian Stroke Strategy Best Practice Recommendations on Transitions](#). In the 2013 update it is noted that as a stroke system, we should:

“equip each individual with tools and information to manage their recovery or the recovery of a loved one after stroke and optimize participation and fulfillment of life roles; tailored to unique needs, coping mechanisms, strengths, challenges and living situation.”

(CSS BPR, Transitions 2013)

MGSR is literature based:

- ◆ Patient-mediated interventions have been documented as effective approaches to actively involve patients in implementing appropriate, effective and informed self-care. (O'Connor, 2010)
- ◆ Patients who ask questions are more likely to elicit useful information which increases self-efficacy and a greater sense of confidence and control over their care. (Smith J, Forster A, House A, Knapp P, Wright JJ, Young J, 2008)
- ◆ Provision of information strategies which actively involve patients and caregivers should be used in routine practice. (Smith J, Forster A, House A, Knapp P, Wright JJ, Young J, 2008)

What's in it? What's changed?

- ◆ Topics have been augmented to address the breadth of factors that can impact successful community reintegration.
- ◆ It has been reframed to support patient/family education and behavior change with the inclusion of:
 - ◇ A 'map' to support navigation of the resource and to know what to expect at each stage of recovery.
 - ◇ Reflective questions to prompt and encourage dialogue with health care providers regarding needs.
 - ◇ Worksheets to set goals and track progress.
 - ◇ Pill stickers to support compliance with medications.
 - ◇ Links to resources with an emphasis on Toronto based supports for each topic area. Aphasia friendly supports have also been included where they exist.

My Guide for Stroke

Recovery covers 33 topic areas under the following sections:

- My Health
- Leaving the Hospital
- Preventing Another Stroke
- Managing the Effects of Stroke
- Getting Back Into Life

My Guide for Stroke Recovery has been created in a binder format and will be available in hardcopy and electronic pdf by November 2015 at www.tostroke.com. To obtain hardcopies, please contact us at info@tostroke.com

The Toronto Stroke Networks (TSNs) support printing and distribution costs to make the resource available.

Development of an interactive electronic version will begin in Fall 2015.

A snapshot of My Guide for Stroke Recovery

MY JOURNEY to STROKE RECOVERY MAP (newly added)

- ◆ A fold out 'map' is included at the front of the resource
- ◆ Provides an overview of the stages of stroke recovery so people learn what to expect
- ◆ References relevant sections within the resource to make the binder easier to navigate
- ◆ Encourages ongoing review and learning

My journey to stroke recovery



This visual allows you to identify the 5 main areas in the journey to stroke recovery. Each person's journey is different. You may or may not experience all 5 areas. Read further to learn more:

- What to expect;
- The health care team members you will meet; and
- Where you can find more information in My Guide for Stroke Recovery

Questions?
Speak to a member of your health care team



Emergency and Acute Care

I have been taken to the hospital because I have had a stroke.

- What will happen?**
- I will be cared for by a "stroke team". They will assess my medical needs and decide if I will be admitted to the hospital.
 - I will be assessed for the type of stroke I had and if a clot-busting drug will help me.
 - I will learn about the type of stroke I had, why I had it and what will happen next.

What tests are involved?
These may include: Computed Tomography (CT) scan, Computed Tomography Angiogram (CTA), Magnetic Resonance Imaging (MRI), Magnetic Resonance Angiogram, Echocardiogram, monitor, blood tests.

Stroke Prevention Clinic

It is important to monitor my health and risk factors to prevent another stroke from happening. If the doctors think that I have had a stroke, I may be referred to a Stroke Prevention Clinic.

- What will happen?**
- Review the type of stroke I had.
 - Review my test results, risk factors, medications.
 - Undergo a neurological exam. Discuss whether more tests are needed.
 - Develop a plan for how I can prevent another stroke.
 - Discuss the plan to follow up with my family doctor and/or another specialist.

Who will I see?

- My Health Care Team
- Nurse Practitioner or Clinical Nurse Specialist
- Other health care professionals depending on my needs (for example, physiotherapist, occupational therapist, speech-language pathologist, registered dietitian).

Sections to refer to:

- My Health
- Preventing Another Stroke
- Managing the Effects of Stroke
- My Health Care Team
- Glossary of Terms

Inpatient Rehabilitation

Recovery from a stroke begins right away. The goal of inpatient rehabilitation is to help me to regain as much of my independence as possible so I can return to live in the community. I may also learn ways to do things differently than before.

- What will happen?**
- I will stay in a rehabilitation hospital. As I improve, I may be able to go home on weekends.
 - I will receive therapy to help me to regain my ability to move safely inside and outside of my home, take care of myself, communicate my needs and interact with others.
 - I will participate in my therapy as much as possible.
 - I may spend several hours a day in individual and/or group activities.
 - I will spend time learning new skills that will help me to recover and be more independent.
 - It is helpful to have a family or friend (if available) to support me.

Who will I see?

- Nurses, physiatrist, physiotherapist, occupational therapist, speech-language pathologist, registered dietitian, recreation therapist, social worker, pharmacist, etc.

How long will I stay?

- Soon after I have been admitted, the care team will inform me how long I will stay in the rehabilitation hospital.
- I may be here for 1 to 7 weeks. The length of my stay will depend on my rehabilitation needs/goals.

Sections to refer to:

- Leaving the Hospital
- Managing the Effects of Stroke
- My Health Care Team
- Glossary of Terms

Outpatient Rehabilitation

Recovery from a stroke is ongoing. The goal of outpatient rehabilitation is to help me to be independent and participate in meaningful activities when I am back living in the community.

- What will happen?**
- I will attend an outpatient program on average 2-3 times per week.
 - I will participate in therapy as much as possible.
 - I will learn how to continue to manage my health and well-being.
 - I will learn how to find resources in the community to support my interests.
 - I may be assessed for my ability to return to driving or return to work when appropriate.
 - It is helpful to have a family or friend (if available) to support me.

Who will I see?

- Physiatrist, physiotherapist, occupational therapist, speech-language pathologist, registered dietitian, social worker, etc.

How long will I stay?

- Soon after I start therapy, the care team will inform me how long I will attend outpatient rehabilitation.
- The length of time will depend on my rehabilitation needs/goals.

Sections to refer to:

- Managing the Effects of Stroke
- Getting Back into Life
- My Health Care Team
- Glossary of Terms

Life After Stroke

Ongoing recovery is possible. There is life after stroke.

- What will happen?**
- I will continue to work on improving my skills and abilities to participate in everyday life.
 - I will continue my home exercise programs.
 - I will get involved with community programs.
 - I will ensure my caregiver (if available) is managing and getting assistance when needed.
 - I will continue to make informed lifestyle choices to stay healthy and reduce my risk of another stroke.

Who will I see?

- Community care providers will assess my ability to return to meaningful leisure or social activities, to driving and/or working if appropriate.
- Ongoing visits with my care providers to reduce the risk of another stroke and ensure I am managing my concerns well.

Sections to refer to:

- Preventing Another Stroke
- Managing the Effects of Stroke
- Getting Back into Life
- My Health Care Team
- Glossary of Terms

Each of the 33 topic areas follow a consistent layout which includes information, question prompts and resources as illustrated in the examples shown here

My Tests

There are many tests that can help the health care team find out the type of stroke you had, and why you had a stroke. Knowing this information allows you to better manage your health and lifestyle, and reduce your risk of having another stroke.

This chart can help you keep track of your tests. Your doctors may want to see this chart so they will know which tests have been done (about test results, what they mean for you, and what please speak with your doctor.

Refer to the **Glossary of Terms** for a description of each test.

Questions about my tests

Choose an answer to each question and write down what you can do. If you have trouble answering a question, read the Information section, use resources from the Help section, or ask your health care team.

Question	My answer	What I can do is...
Do I know the types of tests that the doctor has ordered?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure	
Do I understand the results of the tests?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure	
Do I know what I need to do next and why?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure	

Resources about my tests

HELP These 'Key Resources' are helpful:

Aphasia Institute

- Call 416-226-3636 or visit www.aphasia.ca/shop and search for the books "Medical tests" and "Transitions".

Heart and Stroke Foundation

- Visit www.heartandstroke.com. Click on "Health Information", look under "Stroke" and click on "Tests".

The Internet Stroke Center

- Visit www.strokecenter.org. Click on "Patients and families", then "Stroke Diagnosis".

Your Stroke Journey: A Guide for People Living with Stroke

Learn more about My Guide for Stroke Recovery and how to use it

A resource package is being created to orient health care providers to My Guide for Stroke Recovery and support its implementation and use. This package will be housed on the TSNs [Virtual Community of Practice](#) and will be available Fall 2015.

The package includes:

- ◆ An introductory video on the resource;
- ◆ A video on how to introduce the resource to persons with stroke and caregivers;
- ◆ Tip sheets with implementation strategies;
- ◆ A slide deck to support implementation;
- ◆ A case study.

Mentorship and implementation support will also be provided by the Toronto Stroke Networks.

Upcoming 'Choices and Changes' Workshops:

My Guide for Stroke Recovery accompanies a provincially recognized education framework and workshop, *'Choices and Changes: Motivating Healthy Behaviours'*, aiding health care providers to promote a healthier lifestyle and self-management for persons with stroke.

Sponsored by the Ontario Ministry of Health and Long Term Care, this workshop equips clinicians with skills to motivate change in patients/clients for better health outcomes. Dedicated peer mentors will also be available for local follow-up support or check-ins.

The TSNs, in partnership with Toronto Central Self-Management Program (South Riverdale Community Health Center), will be offering this workshop with an integrated application for stroke using My Guide for Stroke Recovery over the next 3 years. The first workshops are December 2nd, 2015, February 3rd and March 30th 2016. The workshops are free of charge and available to health care providers working in stroke care. For further information, please contact Gail Avinoam at gail.avinoam@uhn.ca

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For more information, please visit our website at www.tostroke.com or contact us at info@tostroke.com