

Equal Access to Community Support for Stroke Survivors & Caregivers

An Advocacy Toolkit for Ontario Stroke Survivors & Caregivers

January 2011

Ontario Stroke Survivors' Advocacy Toolkit Introduction

On June 14, 2010 stroke survivors from across Ontario came together to decide on an advocacy plan to bring forward the needs of stroke survivors and their caregivers to Ontario's elected representatives (MPPs) and candidates leading up to Ontario's 2011 election.

This advocacy toolkit is designed to help you engage in advocacy activities to influence the present and/or future Ontario government to take action on the issue of community support for survivors of stroke and their caregivers – a call to action which you took part in developing back in June.

You will find the following items to assist you in your advocacy efforts inside this toolkit:

1. Strategic Objectives
2. Statement/Briefing Note (Leave Behind for MPPs and candidates)
3. Elevator Pitch
4. Key Messages
5. Call to Action - "The Ask"
6. Sample MPP Letter
7. Step By Step MPP Meeting Guide
 - a. Prepare for the meeting
 - b. Request a meeting
 - c. In the meeting
 - d. Follow up

What is Advocacy?

- Speaking on behalf of others
- Influencing public attitudes
- Transforming public attitudes into action
- Gaining commitment to policies or programs

What can be achieved?

- Reallocation of government funds
- Government commitment to a set of actions
- New ways of doing things

What is a Coalition?

- Alliance, partnership, aggregation
- Exists due to a weakness or deficit
- Something that needs to be done, but cannot be done by just one group
- Support from others to fill gaps and bridge the opportunities.

Key Messages

1. Stroke survivors are being discharged from hospital-based care and set adrift in their communities across Ontario without adequate support services.
2. The Ontario government should act now to ensure equal access to affordable community support to foster successful community integration.
3. Providing equal access to community support can decrease hospital readmissions, help prevent depression, provide a better quality of life for stroke survivors and their families, and help save costs for Ontario's already overburdened health system.

Ontario Stroke Survivors' Advocacy Strategic Objectives

1. Identify key public figures to champion stroke survivor needs in key Ontario communities/ridings.
2. Influence the current and/or future government to prioritize the needs of stroke survivors in Ontario.
3. Educate the government and public on the issues of lack of community support, such as community-based rehabilitation and recreation programming, peer and caregiver support.

Ontario Stroke Survivors' Advocacy Statement

STATEMENT

Act now to ensure equal access to affordable community support for survivors of stroke and their caregivers.

ISSUE

Stroke survivors are being discharged from hospital-based care and set adrift in their communities across the province without adequate support services. Equal access to affordable community support makes all the difference to successful community integration.

RECOMMENDATIONS

Ensure "*Excellent Care for All*" includes access in all communities to affordable, timely and responsive support for stroke survivors and their caregivers.

1. Ensure there is a seamless transfer upon discharge from hospital to on-going support
2. Ensure all Stroke Survivors receive standardized follow-up communication post discharge from hospital
3. Guarantee affordable, timely, on-going rehabilitation and support in the community
4. Ensure all survivors and their caregivers receive stroke recovery orientation information

Support includes good transition, follow-up, information on resources for care, on-going rehabilitation, and on-going training for stroke survivors and their care partners. Providing equal access to community support can decrease hospital readmissions, help prevent depression, provide a better quality of life for stroke survivors and their families, and help save costs for Ontario's already overburdened health system.

BACKGROUND

It is well documented that access to community care, including rehabilitation, can have a very positive impact on a stroke survivor regaining the ability to function as independently as possible. Access to rehabilitation varies greatly across the province.

The Ontario Health Quality Council commented in their 2010 report on Ontario's Health System that "despite the damage stroke causes, too few stroke patients are getting transferred to the rehabilitation care they need." The percentage of stroke patients discharged from acute care to in-patient rehabilitation is only 28%, while the target is 60%. There has been little improvement in the past three years.

The report also points out that only one-quarter of patients discharged from hospital and patients leaving an emergency department get all the information they need after discharge. There have been minor improvements in the past five years, but there is still much room for improvement in this area.

Stroke survivors repeatedly identify several barriers that limit their ability to re-engage within their own communities. Lack of community support, such as community-based rehabilitation and recreation programming, peer and caregiver support, and supported conversation opportunities for people with aphasia are commonly identified. As a result, a high percentage of stroke survivors and their primary support person suffer from depression. Financial support is limited.

Ontario Stroke Survivors' Advocacy Elevator Pitch

An elevator pitch can be used to communicate the key messages of your ask in 1 minute or less – the amount of time you have if you find yourself in the same elevator with your MPP.

Be polite but concise, and stick to the facts.

Here's a sample pitch:

I am a stroke survivor/caregiver living in (town/riding). Stroke survivors like me are being discharged from the hospital without adequate support services. The Ontario government needs to act now to ensure equal access to affordable community support to foster successful community integration, which could decrease hospital readmissions, prevent depression, provide a better quality of life for stroke survivors and their families, and save money for our already overburdened health system. We need to fix this. When can we meet to discuss this?

This message should take about 25 seconds to deliver. It can be adapted for a voicemail, email or quick chat at an event. You may prefer to develop your own text. Try to craft it using this advice:

- Identify yourself and immediately link to the issues
- Express your “pain point” simply and forcefully
- Do not assume your audience knows much about stroke or community support
- Urge your MPP to work with you to learn more

Ontario Stroke Survivors' Advocacy

Key Messages

1. Stroke survivors are being discharged from hospital-based care and set adrift in their communities across Ontario without adequate support services.
2. The Ontario government should act now to ensure equal access to affordable community support to foster successful community integration.
3. Providing equal access to community support can decrease hospital readmissions, help prevent depression, provide a better quality of life for stroke survivors and their families, and help save costs for Ontario's already overburdened health system.

Ontario Stroke Survivors' Advocacy Call to Action or "The Ask"

Government MPPs:

The Ontario government should act now to ensure equal access to affordable community support for survivors of stroke and their caregivers to foster successful community integration.

Call to Action:

- Raise our concerns in caucus
- Speak about this issue in the legislature
- Speak with the Minister of Health and the Premier

Opposition MPPs:

The Ontario government needs to do more to ensure equal access to affordable community support to foster successful community integration for survivors of stroke and their caregivers.

Call to Action:

- Raise our concerns in caucus
- Speak to your Party's Health critics
- Raise this issue in the legislature, or ask a question during Question Period

Ontario Stroke Survivors' Advocacy

Sample MPP Letter

Dear Ms./Mr. [insert name], MPP [insert riding],

I am writing to you as a concerned constituent to bring to your attention an issue of great importance to me. Stroke survivors are being discharged from hospital-based care and set adrift in their communities across the province without adequate support services. Equal access to affordable community support makes all the difference to successful community integration.

ENTER YOUR PERSONAL STORY

Ex. My husband was recently discharged from hospital after he survived an ischemic stroke. We didn't know how to access resources, or who to call for support. No one called to see how my husband was doing. He became depressed and I had difficulty maintaining my full-time job while trying to care for him.

Please act now to ensure that “*Excellent Care for All*” includes access in all communities to affordable, timely and responsive support for stroke survivors and their caregivers. Support includes good transition, follow-up, information on resources for care, on-going rehabilitation, and on-going training for stroke survivors and their care partners. Providing equal access to community support can decrease hospital readmissions, help prevent depression, provide a better quality of life for stroke survivors and their families, and help save costs for Ontario's already overburdened health system.

Many barriers face stroke survivors that limit an individual's ability to re-engage within their own communities. Lack of community support, such as community-based rehabilitation and recreation programming, peer and caregiver support, and supported conversation opportunities for people with aphasia are commonly identified. As a result, a high percentage of stroke survivors and their primary support person suffer from depression. Financial support is limited.

As your constituent, I'm calling on you to urge the Ontario government to ensure equal access to affordable, timely and responsive community support for survivors of stroke and their caregivers. From my experience some of the most important things are:

- Ensuring a seamless transfer upon discharge from hospital to on-going support
- Ensuring all stroke survivors receive standardized follow-up communication post discharge from hospital
- Guaranteeing affordable, timely, on-going rehabilitation and support in the community
- Ensuring all survivors and their caregivers receive stroke recovery orientation information

I look forward to your timely action on this critical issue, and would appreciate any updates you could provide on your progress moving this issue forward.

Sincerely,
Name
Address
City, Province
Postal Code
Email
Phone Number

cc: Hon. Deb Matthews, Minister for Health and Long-Term Care



Ontario Stroke Survivors' Advocacy MPP Meeting Guide

1. Prepare for the meeting

It's easy to find information about your MPP. Do some research by visiting:
http://www.ontla.on.ca/web/go2.jsp?Page=/members/members_main&menutem=mpps_header&locale=en

Find out what committees your Member is on, what their interests are, and how these have been reflected in their recent activities. Read their community newsletter and biography.

2. Request a meeting

- i. Send a letter or email requesting a meeting, and follow up with a phone call to the scheduling assistant at the constituency office
- ii. Find out what public activities your MPP is participating in and show up
- iii. Introduce yourself and be prepared to briefly state the issue (see elevator pitch), and ask for a meeting to discuss in greater detail
- iv. Follow up with MPPs constituency assistant

3. In the meeting

- i. MPPs are busy and appreciate hearing well-prepared positions. They also appreciate you taking a genuine interest in their work. Listening is very important and increases your chance of having a productive conversation. Get your MPP talking.

The more they talk, the more likely they are to remember your conversation and issue at hand.

ii. Outline of meeting:

- a. Thank the MPP for their time, introduce yourself, group and the issue
- b. Ask the MPP if they are familiar with the impact of Stroke in his or her community. Listen, and adapt your approach depending on their familiarity.
- c. Briefly state the issue
- d. Anticipate questions and have your answers prepared. Write down any questions you can't answer and promise to provide these in a follow up to the meeting.
- e. State what exactly you are asking for
- f. Reinforce the Ask with a Call to Action
- g. Ask your MPP to let you know what steps they will be taking
- h. Thank your MPP for the opportunity, and leave behind your statement

4. Follow up

- i. Follow up with a thank you letter or email
- ii. Follow up on any action items you agreed to (like providing more information or answers to any questions)
- iii. Whenever there is news on the issue of stroke survivor community support, send a copy to your MPP
- iv. Stay in touch, and attend community events

Ontario Stroke Survivors' Advocacy

Additional Resources

Advocacy Workshop Video Tutorial:

To learn more about how to do advocacy on stroke survivor issues please see the attached link to sessions from the Stroke Survivor Advocacy workshop which took place in June, 2010.

You will find the following presentations:

- *What is Advocacy - Mary Lewis, Director, Government Relations, Heart and Stroke Foundation of Ontario*
- *Group Discussion of Issues for Advocacy Efforts*
- *Build the Case - Ruth Hall, Evaluation Specialist, Ontario Stroke Network*
- *Build the Coalition - Steven Christianson, Manager, Government Relations & Advocacy, March of Dimes Canada*
- *Implement the Strategy - Nadia Yee, Manager, Government Relations, Heart and Stroke Foundation of Ontario*
- *Bringing it all Together - Mary Lewis, Director, Government Relations, Heart and Stroke Foundation of Ontario*

http://www.heartandstroke.on.ca/site/c.pvl3leNWJwE/b.6179189/k.49D9/Stroke_Survivor_Support_Group_Initiatives.htm