

# Peers Fostering Hope: A Peer Support Model for Stroke Recovery

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## BACKGROUND

Stroke is a life altering experience. People living with stroke (PLWS) and caregivers often lack the necessary skills, awareness and knowledge to cope with the changes to self-identity, personal relationships and life after stroke. Qualitative interviews conducted in 2010 with PLWS and caregivers revealed the need for peer support, more individualized hopeful care, system navigation support and improved healthcare provider relationships<sup>1</sup>. Below are some examples of these expressed needs:

*"Better support for emotional work ahead"*

*"Seeing someone who embodies survival"*

*"Positive hope from someone who has gone through it"*

*"More opportunities to meet with people who've had a stroke earlier in the process – right from acute – to better understand and anticipate what might be happening"*

Engaging in conversations with others who share a similar experience can profoundly affect the course of recovery by initiating optimism and new possibilities for the future. Research demonstrates that offering peer support throughout the care continuum can positively impact the quality of life for those living with stroke and their caregivers, reduce social isolation, gain understanding of stroke recovery, enhance their ability to cope, and provide motivation and hope<sup>2,3</sup>.

**Peers Fostering Hope** focuses on emotional support and knowledge exchange to provide hope, empowerment and adjustment to life post stroke as well as improve recovery and quality of life.

Peers Fostering Hope is part of a larger systems change initiative called *Transition Improvement for Continuity of Care*. Its purpose is to improve the life experience of people and families living with stroke by creating an improved, integrated and sustainable person-centred model of care across the system in Toronto.

For over a year, a dedicated group of PLWS, caregivers and cross-continuum healthcare providers co-created the vision and design of this innovative program. Learnings from other peer support programs (MS Society, Ontario Brain Injury Association, Linking Survivors with Survivors – Stroke Recovery Canada) were also incorporated in our design.

## WHO ARE THE PEERS?

Peers are experienced PLWS and caregivers who are well into their recovery and who have undergone extensive training to provide in-hospital visits to people who have just had a stroke and their caregivers.

To date, 10 peers have been recruited through various advertisements.

Interested peers must undergo a screening process and orientation.

## PEER EDUCATION

Peers are expected to participate in a formal education program. It includes:

- A comprehensive 8 week education program totalling 16 hours;
- A Peer Reference Guide specifically developed to serve as a resource for peers, and complements the training. This Guide was developed by healthcare providers, PWS and caregivers and underwent plain language editing.

The following education topics are being delivered by an interprofessional team:

Week 1	<b>Learning about peer support</b> <ul style="list-style-type: none"> <li>• What is peer support?</li> <li>• What are the goals of peer support?</li> <li>• What is the role of a peer and their responsibilities?</li> <li>• What is expected of me as a peer?</li> <li>• What are the rules about confidentiality?</li> <li>• How do I check-in and out with staff?</li> <li>• Introduction to strength based approaches</li> </ul>	Week 2	<b>Your Visit</b> <ul style="list-style-type: none"> <li>• How do I meet the person with stroke?</li> <li>• How do I connect with the family, friends or caregiver?</li> <li>• How do I build hope, confidence</li> </ul>	Week 3	<b>Stroke and its effects – Physical</b> <ul style="list-style-type: none"> <li>• What are the warning signs of a stroke?</li> <li>• What is a stroke?</li> <li>• What are the types of stroke?</li> <li>• What are the effects of stroke?</li> <li>• What are the physical changes after a stroke?</li> <li>• How can thinking change after a stroke?</li> <li>• How can vision and perception change after a stroke?</li> <li>• How can swallowing change after a stroke?</li> </ul>	Week 4	<b>Stroke and its effects – Communication</b> <ul style="list-style-type: none"> <li>• How can communication change after a stroke?</li> <li>• Supportive Communication for Adults with Aphasia</li> </ul>
Week 5	<b>Stroke and its effects – Emotional</b> <ul style="list-style-type: none"> <li>• What are the emotional changes after a stroke?</li> <li>• What are the stages of emotional adjustment?</li> <li>• How do emotions change over time?</li> <li>• What should I do if someone is suicidal?</li> <li>• What should I do if someone is being abused?</li> <li>• What about feelings of loss and grief?</li> </ul>	Week 6	<b>Effective peer support conversations</b> <ul style="list-style-type: none"> <li>• How can I communicate effectively?</li> <li>• How do I start a conversation?</li> <li>• How do I keep a peer support conversation going?</li> <li>• How should conversations change as the person with stroke recovers?</li> <li>• How should conversations with caregivers change during recovery?</li> </ul>	Week 7	<b>Ending the visit</b> <ul style="list-style-type: none"> <li>• How do I encourage new ideas and activities</li> <li>• What is "My Stroke Passport"?</li> <li>• How do I help the person use the Stroke Passport</li> <li>• What resources are available in the community?</li> <li>• Community re-engagement</li> </ul>	Week 8	<b>Closing Session</b> <ul style="list-style-type: none"> <li>• An experienced peer shares her story</li> <li>• Answering questions</li> <li>• Discussing next steps</li> <li>• Availability of ongoing support to peers</li> </ul>

## ROLE OF PEERS

- Provide hope, inspiration and optimism
- Accept people as they are. Respects their privacy, wishes, values, rights and beliefs
- Know the balance between helping self and others and is continuously learning to be self-aware.
- Give reassurance and encouragement for positive actions.
- Listen, clarify and help identify choices for making decisions.
- Encourage others to express their feelings.
- Be patient and understanding.
- Keep information confidential.
- Be attentive, caring and sensitive to the feelings of others.

## PROGRAM BENEFITS

Below is a sample of some of the ways in which the model might support PLWS, caregivers, healthcare providers (HCP) and the peers themselves.

*I just want to give something back as I have so much gratitude to Toronto Western Hospital for all that they did for me*

Peer

*Peers Fostering Hope reflects a true peer model by using the survivors themselves*

HCP

*So many people are alone in the recovery experience and they just want someone to listen. Healthcare providers do not always have the time*

HCP

*I could have really used a person to talk to. Someone who knew just what I was feeling.*

Caregiver

*We need more opportunities to meet with people who have had strokes earlier in the process – right from acute – to better understand and anticipate what might be happening to us*

PLWS

## NEXT STEPS

- Peer visiting will begin in November 2012 in 5 (3 acute care and 2 rehabilitation hospitals within Toronto, Canada)
- Collect feedback from healthcare providers on the perceived impact of peer visitors and how they have been integrated into the broader team.
- Evaluate the impact of this program on PWS/caregivers experience and of the peers themselves.
- Refine the education program and Peer Reference Guide based on participant feedback.
- Expand peer support to include support groups in Toronto's downtown core.

### References

1. Creed, C et al, The Potential Group in partnership with the Toronto West Stroke Network (2010) Transition Improvement for Continuity of Care Initiative, Primary Research with Persons with Stroke and Caregivers and healthcare providers, Unpublished
2. Morris R, Morris P. (2012) Participants' experiences of hospital-based peer support groups for stroke patients and carers, *Disabil Rehabil*;34(4):347-54.
3. Stewart MJ, Doble S, Hart G, Langille L, MacPherson K., (1998) Peer visitor support for family caregivers of seniors with stroke. *Can J Nurs. Res*; Summer;30(2):87-117.

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