Community Stroke Recovery: Programs & Resources
Making a Difference

Gwen Brown, RN, BA, BEd, MA
Regional Stroke Community & LTC Coordinator
Stroke Network of Southeastern Ontario

Lee Marchildon, BA, BST
Stroke Services Coordinator/Volunteer Coordinator
Community Care for South Hastings Inc.

Kathleen Pratt, RSW
Stroke Services Coordinator
VON Greater Kingston Site
[It’s important to get] connected back into life and the community. Sometimes he would just sit there, be in another world and then he would say something but it was not connected to what we had been doing or talking about. I tried to think of what would help...there’s a lot of isolation after a stroke – it kind of closes doors, it’s different. ~ Caregiver
Section 4 Community Reintegration Following Stroke

- Patients and families should be provided with information, support and access to services throughout transitions to the community following a stroke to optimize the return to life roles and activities.
Module 6 Predischarge/Discharge Planning
- 6.3.1, 6.3.2 Linking to supports and services

Module 8 Community Assessment
- General Considerations – referral to community services based on individual need

Module 9 Community Treatment
- 9.4.5, 9.13 - connecting to community services, leisure activities

Module 10 Cross-Continuum Processes
- 10.1, 10.5 – support services, peer support, support groups

Quality-Based Procedures for Stroke
SNSEO Community Consultation

What We Heard: Charting A Course For Successful Community Reintegration After Stroke
A New Normal

- [Community Program] provides an opportunity to socialize and talk to people in a comfortable setting with friends, providers. It gives spouse some respite and helps with aphasia as we keep talking. Helps with cognitive development. ~ Stroke Survivor

- As caregivers struggle to find their “new normal”, they may also be seeing a narrowing of their world as “their social life and interests” become limited. (Salter, 2013)

- “While “going home” is seen as an important milestone in the rehabilitation process, “being home” is accompanied by the development of greater self-awareness of deficits.” (Nanninga et al, 2014)
Reconnecting

- *It’s important to be able to do what you love, to find something that you love in this life. It gives you a sense of accomplishment, a reason for existence.* ~ Stroke Survivor

- Leisure activities can also “create commonality of experience”. It is the social interaction inherent in leisure activities that provides the additional benefit of “two individuals [that] accommodate each other and create a mutual interest that triggers relationships.” (Lee et al, 2001)
Peer Support

- Need to know about stroke support groups. Lots of people need it but are afraid to go out; to show the effects of their stroke. ~ Stroke Survivor

- Also need support groups for the families of stroke survivors – a place where they feel free to air their concerns. ~ Caregiver

- Study reported that peer support provided social validation and promoted feelings of empowerment. At the same time, peer support was found to be associated with “decreased loneliness and feelings of difference, as well as enhanced social competence, social acceptance, and increased acceptance of chronic conditions.” (Kessler et al, 2014)
Caregiver Support

- Respite is very important as I do most everything so get at the end of myself sometimes. Even when we go away on a holiday, it’s not really a holiday; it’s just me in a different place. ~ Caregiver

- Up to 70% of caregivers “have clinically significant depressive symptoms and of those, between one-quarter and one-half have major symptoms of depression...The impact on physical health also is profound...” (Lutz et al, 2010)

- While friends and family may provide good support to the caregiver initially; those same caregivers reported receiving few supports one year post-stroke. (Salter et al, 2013)
Navigating the System

- Nobody mentioned any supports. If things were available I was unaware at the time and am still unaware. ~ Caregiver

- I had to do an enormous amount of work on my own. The timing of information needs to be right; maybe in discharge package not early in hospital. You come home and you lay out all this stuff and you say, okay, now I need to look at all this stuff. ~ Caregiver

- Should be some way that in hospital the caregiver has immediate access to information, maybe peer visiting. Need to know how to live when you get home. ~ Caregiver

- System navigation provides several benefits including “lessening social isolation, supporting care partners and symptom management and decreasing use of both acute and long term care services.” (Montgomery et al, 2015)

- “Lack of education or the absence of a liaison with community services already available may contribute to the under use of important services available to stroke survivors.” (Lyons, 2002)
Community Reintegration

- Weren’t a lot of connections; we used to be more active but that changed after the stroke...people with stroke have to get out and do things. It makes you part of the community ... ~ Caregiver

- Once I found out about the support group then I was able to link in to other services and supports like additional care and a scooter for my husband. This meant he could go out without me; it increased his independence and safety. You have to take you hands off at some point and let the person be free. ~ Caregiver

- As stroke survivors continue to move through challenges, confidence in community living also increases due to the stroke survivor’s expanded experiences combined with exposure to “other confidence-building sources.” (Wood et al, 2010)
## Resources

### Community Resource Listing

<table>
<thead>
<tr>
<th>RESOURCE</th>
<th>DESCRIPTION</th>
<th>WHERE TO ACCESS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aphasia Institute (Toronto)</td>
<td>Web-based resource providing information and tools to support individuals with aphasia and their families. Note that there may be a cost for some resources.</td>
<td>The Aphasia Institute at <a href="http://www.aphasia.ca">http://www.aphasia.ca</a>/The Aphasia Centre <a href="http://aphasiaottawa.org">http://aphasiaottawa.org</a>/</td>
</tr>
<tr>
<td>Aphasia Group</td>
<td>Program for stroke survivors who are experiencing aphasia. Groups are facilitated by a speech-language pathologist.</td>
<td>Community Care for South Hastings (013) 809-5130 -</td>
</tr>
<tr>
<td>Community-Based Exercise Programs for People with Stroke</td>
<td>Brochure designed for persons with stroke and families to assist them in determining if a community-based exercise program will meet their needs. Brochure is based on the provincially developed Guidelines for Community-Based Exercise Programs for People with Stroke.</td>
<td>Stroke Network of Southeastern Ontario website under Best Practice &amp; Education at <a href="http://strokenetworkseo.ca/best-practice-education/guidelines-recommendations">http://strokenetworkseo.ca/best-practice-education/guidelines-recommendations</a></td>
</tr>
<tr>
<td>Healthline – Stroke Resources</td>
<td>Web-based resource. Stroke Resources tab provides information for individuals with stroke and families/caregivers in ten different domains including communication, a child with a stroke, financial &amp; social support, transportation and health.</td>
<td>Southeast CCAC Healthline at <a href="http://strokesresources.southeasthealthline.ca">http://strokesresources.southeasthealthline.ca</a> or <a href="http://strokesoutheasthealthline.ca">http://strokesoutheasthealthline.ca</a></td>
</tr>
</tbody>
</table>
| Heart & Stroke Publications | Several publications are available at no cost through the HSF including:  
- Your Stroke Journey  
- Taking Charge of Your Stroke Recovery  
- Stroke in Young Adults (includes returning to work/school)  
- A Family Guide to Pediatric Stroke  
Additional information sheets, interactive programs and booklets may also be accessed on the site including information on driving after stroke. | Heart & Stroke website at [www.heartandstroke.com](http://www.heartandstroke.com) (Go to Health Information > Publications > Stroke) |
A CAREGIVER’S GUIDE TO STROKE RECOVERY
The Stages of Caregiving

"Caregiving is a linear process in a sense that it has a beginning and an end, but the journey is dynamic and full of ups and downs. Any changes in the patient’s health status, or the caregiver’s mental and physical health or personal life, mean that the caregiver needs to go through an adjustment process to redefine and recontextualize their role based on the new situation...the patient’s recovery or death does not mark the end of the caregiving instead it shows that there follows another adjustment period, in which family caregivers need to redefine their life again in order to move forward and start a new chapter in their life."

From The Change Foundation Report - Shedding New Light, 2010

Where am I on my Journey?

Becoming a Caregiver:
- I became a caregiver on...
- I provide care for...
- I can get help from...

Adjustment Periods:
(Examples - Hospital discharge, Nursing home placement, etc.)
- Have I taken on too much?
- What kind of support do I need right now?

New Beginning
- Have I settled in my role?
- If not, what would help me?
- What are my plans for the future?

What Do We Do?

Sara Sheerikhani and Carol Ann Alloway are Co-Founders of Family Caregivers Voice. After our difficult experiences as caregivers, we wanted to help other caregivers who are distressed.

We learned and then educate you, so you can learn and educate other caregivers, creating a caregiver village.

Both Sara and Carol Ann have won awards for their advocacy work. They volunteer for Health Quality Ontario, The Change Foundation, Ministry of Health and Long Term Care and others, to help improve the health care system. They also meet with organizations supporting caregivers, talking about their journeys and giving advice and support.

Currently, they are working on a project with a Toronto hospital to recognize and support caregivers as the care recipient enters the hospital, through discharge and entering homecare.

Contact us at:
Sara Sheerikhani (647) 542-9528
sara.sheerikhani@gmail.com

Carol Ann Alloway (616) 427-9080
c.a.alloway@rogers.com

www.familycaregiversvoice.ca

Family Caregivers Voice

Who is a family caregiver?

A caregiver is a family member or friend who, while unpaid, provides emotional, physical, spiritual or financial assistance to an individual who is unable to take care of all or parts of their life. This assistance could be one hour a week or 24/7. The caregiver could be a parent, child, spouse, sibling, brother, friend or neighbour.

Educate yourself on your journey!

Over 8.1 million Canadians aged 16 years and older provided care to a chronically ill, disabled, or aging family member or friend in 2012. Those numbers are growing.

The Change Foundation and Health Quality Ontario have recently found that caregiver distress is reaching critical proportions, resulting in anger, depression and, in some cases, the inability to continue providing care. Understanding your caregiving journey is the first step to addressing this growing problem.

What’s On Your Wish List?

Family Caregivers Voice
KGH iBook

Partners in Stroke Recovery
A guide to help you begin your journey
Stroke Prevention Clinics

Q. What is a Stroke Prevention Clinic?
A. A Stroke Prevention Clinic (SPC) is an outpatient clinic for people who are at risk of having a TIA or stroke or who have risk factors for stroke.

Q. What can I expect when I go to the Stroke Prevention Clinic?
A. A health care team at the clinic will work with you to develop a plan of care to reduce your risk factors for TIA or stroke. For example, the team may support you to quit smoking or lose weight. You may be sent for some blood work and diagnostic tests such as a CAT scan or carotid Doppler before your SPC appointment.

Q. How can I be referred to a Stroke Prevention Clinic?
A. You need a referral from a doctor such as your family doctor, a specialist or a doctor you have seen in the emergency department or after hours clinic.

Q. If I am referred to the Stroke Prevention Clinic will I continue to see my family doctor?
A. The Stroke Prevention Clinic does not replace your family doctor. Your family doctor is a partner in your stroke prevention plan and will be notified about your visit to the SPC.

Southeastern Ontario Stroke Prevention Clinics

Q. Is there a Stroke Prevention Clinic in my community?
A. Stroke Prevention Clinics are located in:

- Hastings and Prince Edward Counties
  Quinte District Stroke Prevention Clinic
  Quinte Health Care-Sidney General Site
  265 Dundas Street East, Sills 2
  Belleville, ON K8N 5A9
  Tel: 613-961-7400 ext 2871
  Fax: 613-961-2544

- Leeds and Grenville Counties
  Brockville Stroke Prevention Clinic
  Brockville General Hospital
  75 Charles Street
  Brockville, ON K6V 1S8
  Tel: 613-345-3843 ext 1410
  Fax: 613-345-8148

- Lanark County
  Vascular Protection Clinic
  Perth and Smith Falls District Hospital
  Perth Site
  55 Dunroin Street West
  Perth, ON K7H 2K1
  Tel: 613-267-1500 ext 4263
  Fax: 613-267-7138

- Frontenac, Lennox and Addington Counties
  KGH Stroke Prevention Clinic Office
  Kingston General Hospital
  76 Stuart Street
  Kingston, ON K7L 2V7
  Tel: 613-546-6666 ext 6320
  Fax: 613-548-2397

Visit www.strokenetworkseo.ca
Enhanced CCAC Community Rehab

ENHANCING SERVICES

Timely, enhanced community and LTC rehabilitation services have been provided to stroke survivors in Southeastern Ontario since February 2009 with the launch of an innovative LHIN-funded project. In April 2011, recognizing the critical role the enhanced service plays in both improving stroke survivors’ functional outcomes and health system utilization as evidenced by reduced lengths of stay, the LHIN committed to ongoing funding for this regional standard of service in support of best practice in stroke care.

Eligible stroke survivors will continue to be considered for enhanced Physiotherapy (PT), Occupational Therapy (OT), Social Work (SW) and Speech Language Pathology (SLP) services through the CCAC for two months following discharge home. For stroke survivors discharged to Long Term Care (LTC), PT will be provided by the LTC Home with enhanced OT, SLP and SW being provided through the CCAC.

Enhanced Service Objectives:

For Stroke Survivors: to improve access to timely enhanced community and LTC rehab services for improved function, emotional support and satisfaction with transition to home.

For Healthcare Providers: to improve information flow and stroke care expertise.

For the Health Care System: to decrease length of stay, Emergency Room visits and hospital re-admissions by supporting transition to home for those with new stroke, providing timely enhanced community and LTC rehabilitation support.

CONTACTS

Stroke Network of Southeastern Ontario:
Gwen Brown, Regional Stroke Community and LTC Coordinator
(613) 597-6666 x 6867
browna2@kankalan.net

South East Community Care Access Centre:
Parti Dixon-Medora, Client Services Manager
(613) 844-8200 x 8210
parti.dixon-medora@se.ccac-ont.ca

Funded by the South East LHIN
Support group helped me a lot. Other people asking questions that I hadn’t thought of. All strokes are a different experience and we can help each other. Sometimes just the talking helps. ~ Stroke Survivor
Reintegration - Survivors

COMMUNITY REINTEGRATION - SURVIVORS
How have support groups helped with...

“Am grateful to have this support system since I am living alone and my family is far away!” ~ Survivor
“Our care group is very good and a comfort to be involved in.” ~ Caregiver

“The group is always useful and a good social gathering of like minds.” ~ Caregiver
Folks With Strokes

- Social-recreational group for people with stroke
- Aims to provide opportunity for socialization and therapeutic activity
- OT students helped with capacity building
- Longer-term goal to facilitate leisure experiences in the community
Peer Visiting Volunteers
Acquired Brain Injury
Support Group - Outreach

- Pilot began in November 2015
- One couple from Wellington on the Lake joined existing Couples Group
- Coordinated by Belleville & Quinte West Community Health Centre
- Future plans include other sites, OTN group
Living With Stroke™ Program

Heart & Stroke LIVING with STROKE

Living with Stroke is a free group learning program that consists of 6 two-hour workshops conducted weekly. It has been developed for people who have had a stroke and for the individuals who care for them.

Topics include:
- Understanding Stroke
- Physical changes and challenges
- Swallowing and nutrition
- Cognition, perception and communication
- Emotions
- Activities and relationships
- Reducing the risk of stroke
- Moving forward

Living with Stroke
Living With Stroke & Aphasia

- 8 week program held in spring 2016
- co-facilitated by Stroke Services Coordinator and Speech Language Pathologist
- 11 participants – 6 clients with aphasia and 5 caregivers
- used a variety of different assistive tools
Exercise & Stroke

- There was person [at an activity centre] who believed in and pushed me. She got me to believe in myself and she got me to swim and to walk again. She gave me my legs. ~ Stroke Survivor
Stroke Specific Exercise Programs

In Partnership with

VON is offering a FREE
Stroke Recovery Fitness Program

When: Monday
10:30-11:30 am

Where: YMCA West
745 Progress Ave.
Kingston

Caregivers are welcome to join!

Classes are designed to be safe and effective for people living with stroke.
Location is fully accessible with ample parking.

For more information, please call: 613-634-0130 ext 3414

The VON would like to thank our funders, the Ministry of Health and the SE LHIN (South East Local Health integrated Network) to bring this program to participants in the Greater Kingston community.
Community Exercise Guidelines

Exercising after your stroke

Exercising after a stroke can help recovery, prevent a second stroke, and improve physical and emotional health.

Consider looking for a program that incorporates several components such as aerobic exercise, strengthening, stretching, coordination and balance activities.

The Ontario Stroke System has developed guidelines to assist community exercise providers design quality exercise programs to meet the needs of people who have had a stroke.

Helpful Tips For Choosing An Exercise Program

- Book time to meet with the facility staff or class instructor.
- Bring a caregiver or friend along.
- Observe a class prior to enrolling.
- Bring this checklist in this brochure with you.

SAFETY FIRST!

It is important that:
- You feel safe at all times when participating in an exercise program.
- The instructor has first aid and emergency training.
- The instructor understands your condition and specific needs.

Program Checklist

Use this checklist when you are inquiring about a new exercise program. The program you choose will have more responses in the "yes" column. Think about how the "no" responses will affect your condition. Speak to the instructor to see if they can meet your needs.

<table>
<thead>
<tr>
<th>Exercise Equipment</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipment is designed to accommodate special needs.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Staff</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff are inclusive, emergency is first aid, including use of automated external defibrillator.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff can identify the signs of fatigue and stroke warning signs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff understand my condition.</td>
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</table>

<table>
<thead>
<tr>
<th>Facility</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facility is convenient.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is enough accessible parking.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The parking lot is well lit.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The main entrance is easy to open.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The facility is clean.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The locker room is accessible.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The facility is accessible.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is a shower/steam access.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A bite on a towel or a first orientation class offered.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There are flexible payment options or subsidies.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The room temperature is comfortable.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency phones are available.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>An automated external defibrillator is available.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drinking water is available.</td>
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</table>
Revved Up - Kingston

Kingston’s Assisted Exercise Program

Currently funded by...

A twice weekly exercise program for adults with mobility impairments
Perth Enrichment Program (PEP)

A therapeutic, daytime program for older adults living independently as well as respite care for their caregivers. In addition on Tuesdays, a therapeutic program to support and improve lung function.

Thank you for taking the time to learn more about the Perth Enrichment Program for Older Adults. We were developed in response to both the growing needs in the Perth and Smiths Falls communities, as well as the mandates of the Seniors Strategy of Ontario’s Action Plan for Health Care. We are a program of care, direction and therapy which focuses on helping older Ontarians stay healthy and stay at home longer. Our mandate is to equip and provide respite to caregivers, and to support the older adults they care for through physical, cognitive, social and emotional therapies.

We currently have 3 different programs running at our location on Elliot Street, Perth:
1. Older Adult Day Program
2. Breathe Well Live Well Program (COPD Day)
3. Community Exercise Classes
Heart & Stroke Foundation Publications
Stroke Engine
www.strokengine.ca
Conversation Group

- Partnership between CCSH and Quinte Rehab
- Speech Language Pathologist (SLP) with Communication Disorders Assistant (CDA) support
- Maximum 6 participants per group
- One day a week for 8 weeks
- Participants recruited from BGH, Quinte Rehab and self referral
- Various conversation topics
- Caregiver group offered
Return to Work Toolkit

Return to Work

There are over 21,000 people who experience a stroke each year in Ontario(1) and approximately 25% of stroke survivors are people under the age of 65, some in the prime of their working life. Research indicates that return to work rates after stroke are as low as 7% (4).

Employment is one of the most important social roles that a person fulfills and not working has negative impacts on a person’s overall quality of life, health, finances, social isolation and self-efficacy (5,6). Stroke survivors and health care professionals need resources to help them navigate the process of return to work after stroke.

This informative website will provide stroke survivors, family members and healthcare providers with assistance to navigate the process of return to work local and provincial resources that provide guidance, support and assistance an online self assessment guide to focus individual recovery efforts and provide information about ability or readiness to return to work.

Please return to this website as many times as you wish! Get started by clicking on the link

Return to Work Toolkit
What We Heard…

- You don’t get told what is available, they just give you pieces of paper...you have to think of things yourself. [They] don’t really explain things, you’re given a book and they make an issue out of things that aren’t important and don’t address things that are.

- Sometimes they let you know what community supports are available but then leave you to make the connections. It would be good to do this before discharge; this would make an easier transition. To integrate the post-discharge links (e.g., support groups) into the rehab process.
What We Heard…

- When first was out of hospital I felt that we fell through the cracks. No one was there to help us. I saw an ad in the paper for the support group.

- The individual experiences fear at discharge [so it’s important to prepare] the individual for a positive experience after discharge; ensuring services and equipment are in place in one’s own community with follow-up home based care. [It’s important to ask] the individual “What do YOU need to go home?” and then including the person in the planning to give the person some control.
References

Questions
Contacts

Gwen Brown
(613) 549-6666 ext. 6867
browng2@kgk.kari.net

Lee Marchildon
(613) 969-0130 ext. 5207
leem@ccsh.ca

Kathleen Pratt
(613) 634-0130 ext. 3469
1-800-301-0076
kathleen.pratt@von.ca