

COMMUNITY REINTEGRATION LEADERSHIP TEAM

BIENNIAL UPDATE OCTOBER 2014

Executive Summary

In the fall of 2007, the Stroke Network of Southeastern Ontario hosted six local forums and one regional forum to hear and respond to the thoughts of persons with stroke, family members and service providers about what changes would be required to help with community reintegration following a stroke. Participants were asked to identify changes that would:

- help the person with stroke and family make a smooth transition from hospital or rehabilitation to home and
- help the person with stroke and family on an ongoing basis throughout their lifelong recovery.

There were six key areas identified by the community forum participants that would support community reintegration:

1. Support for recovery & active engagement;
2. System navigation (linking to supports and services);
3. Support to work through the emotions;
4. Support in the home;
5. Mobility & transportation in the community and;
6. Access to stroke rehabilitation.

A Community Reintegration Leadership Team (CRLT) was formed that includes persons with stroke and family members as well as community service providers. The purpose of the team is to support and initiate actions that would address the needed changes. A promise was also made to keep all those people who participated in the community forums updated on our progress. The following page provides information on 10 key highlights of work that has been done since our last report in 2012. Additional activities and projects can be viewed in Appendix A.

Full project reports and related information including the 2007 community consultation report entitled *Building Capacity to Enhance Community Reintegration of People with Stroke* and the Stroke Survivor & Caregiver Stroke Support Group Evaluations can be accessed through the website of the Stroke Network of Southeastern Ontario at <http://www.strokenetworkseo.ca/projnewprojects>

We encourage you to review this report. Should you have any questions, would like to provide feedback on this report or are interested in participating in our upcoming community consultation process, please contact Gwen Brown, Regional Community & LTC Coordinator with the Stroke Network of Southeastern Ontario at 613-549-6666 X 6867 or by email at browng2@kgh.kari.net.

KEY HIGHLIGHTS

1. Ongoing funding has been received from the SE LHIN to support facilitation for all four stroke survivor and caregiver support groups in the SE. The funding flows through community support service agencies in Kingston, Belleville, Brockville & Perth). This facilitates links to community programs and services offered by the local communities with the support group facilitators acting as system navigators. Evaluations of the effectiveness of the support groups can be found at <http://www.strokenetworkseo.ca/projnewprojects>
2. The Perth/Smiths Falls Support Group has sustained the successful Peer Visiting Volunteer Program where persons with stroke visit patients in hospital who have just experienced a stroke. This program is now being expanded to the Belleville and the Kingston areas.
3. The “Discharge Link” Enhanced Community Based CCAC Rehabilitation Service continues to include funding for rehabilitation services including social work services for eligible persons with new stroke transitioning to the community (including Long Term Care Homes). For further information on Discharge Link services click on <http://www.strokenetworkseo.ca/projnewprojects>
4. The Living with Stroke Program[®] (LWS) has been offered in Kingston, Belleville & Perth with plans to expand to Brockville. LWS, developed by the Heart & Stroke Foundation, consists of a six-week program that provides stroke survivors and caregivers with an opportunity to learn more about stroke, meet with peers and share experiences and knowledge. Interested persons with stroke are offered the opportunity to receive training in the LWS program to act as co-facilitators for the LWS Program. The Stroke Network is exploring potential to expand reach through use of technology. To find out more about LWS, click on http://www.heartandstroke.com/site/c.iKlQLcMWJtE/b.3936679/k.7231/Stroke_Living_with_StrokeTM_program.htm
5. Videos integrating stories & experiences of individuals with stroke have been created to provide an ongoing education opportunity for service providers. To view some videos click on <http://www.strokenetworkseo.ca/education-resources/resources/general-listings>
6. Kingston General Hospital has completed a Patient Resource for inpatients who have experienced a stroke. The Guide provides information on stroke and also on what to expect while in the hospital. Patient advisors were involved in the creation of this tool. Find the tool at <http://www.strokenetworkseo.ca/education-resources/patient-resources> or available in iBook format at <https://itunes.apple.com/us/book/partners-in-stroke-recovery/id872582026?ls=1&mt=11>
7. A representative from the stroke network has participated in the development of an education program for exercise instructors through VON which supports the inclusion of persons with stroke in exercise classes. As well, the provincially-developed *Guidelines for Community Based Exercise Programs for People with Stroke* (2010) are being updated and, in February 2014, a workshop was offered to community exercise providers in the southeast using the Guidelines as a framework. The *Guidelines* can be found at <http://www.strokenetworkseo.ca/education-resources/resources/guidelines-recommendations>
8. Plans are underway for a community consultation process in 2015 to ensure that key directions identified in the 2007 process remain valid and relevant today. Original 2007 report, *Building Capacity to Enhance Community Reintegration of People With Stroke* can be found at <http://www.strokenetworkseo.ca/projects/news/regional-projects/completed-projects>
9. Stroke Support Group facilitators are supported to receive training in supported conversation for persons with communication deficits as a result of their stroke. To learn more about aphasia, click on <http://www.aphasia.ca/>
10. Local Community Resource Directories updated in 2014 now include live links to resources where available. Available in hard copy and on SEO Stroke Network website the Directories provide listings that may be relevant to community reintegration for persons with stroke and their care partners. Find the directories at <http://www.strokenetworkseo.ca/recovery-resources>

APPENDIX A

In June, 2014 the CRLT finalized a Logic Model (Appendix B) to visually represent focus areas and inform future directions. Key considerations in developing the model included regional need for:

- Equity of services
- Psychosocial supports
- Quality of Life measures
- System navigation support
- Advocacy
- Recognition of the critical role played by support groups, peer visiting programs and the *Living with Stroke Program*[®]

Most importantly, it was recognized that persons with stroke and caregivers must be involved in co-design processes that inform planning and decision-making at all levels. At the same time, challenges in moving forward were acknowledged particularly the paucity of data related to community reintegration.

The logic model retains the six key directions as categorization points for related activities but also includes anticipated outcomes that reflect the overarching goal of “*Living in the community supported by programs and services that optimize quality of life.*” As well, the logic model integrates impact measures providing an embedded accountability framework.

Given that the last formal community consultation process (which informed both the original six key directions and the recent logic model) occurred in 2007, the CRLT has also determined that another community consultation is necessary to receive further community input and to validate the logic model (particularly the six key directions and the outcomes). To that end, a project plan has been developed to complete a community consultation process with subsequent report to be produced by September 2015.

The following report integrates the overarching goal of “*Living in the community supported by programs and services that optimize quality of life.*” from the logic model. As well, the five identified outcomes and related measures can be used to evaluate progress and are broadly applicable to all activities to varying degrees.

Note that throughout the report, the terms ‘stroke survivor’ and ‘individuals with stroke’ have been used interchangeably. The term ‘care partner’ or ‘caregiver’ refers to family members and friends who are involved in care. ‘Service providers’ refers to health and support services personnel. Additional terms and definitions have been provided in the appended glossary (Appendix C)

Goal: Living in the community supported by programs and services that optimize quality of life	
Key Directions	Activities
Support for Recovery & Active Engagement	<ul style="list-style-type: none"> • Continue to promote linkages to CSS and local recreation facilities • The Living with Stroke Program[®] (LWS) has been offered in three of the four southeast areas (Kingston, Belleville & Perth) with plans to expand to Brockville. LWS was developed by the Heart & Stroke Foundation and consists of a six-week program that provides stroke survivors and caregivers with an opportunity to learn more about stroke, meet with peers and share experiences and knowledge. Interested persons with stroke are offered the opportunity to receive training in the LWS program and subsequently act as co-facilitators for the LWS Program. Exploring potential to expand reach through use of technology. • Persons with stroke and care partners participate in the CRLT and the Regional Stroke Steering Committee (RSSC) • Twice-yearly evaluations of the effectiveness of the Stroke Survivor & Caregiver Stroke Support Groups are conducted and results shared with the LHIN and support group participants (also posted on SEO Stroke Network website). These evaluations include participant satisfaction. • Person with stroke (member of CRLT and RSSC) has participated in meetings with the SE LHIN re service delivery for persons with stroke in the community • Person with stroke (member of CRLT and RSSC) participates in provincial working group informing Community Based Quality Based Procedures (QBP) and related service delivery expectations for persons with stroke • Persons with stroke present (share their stories) at regional and provincial events • Videos (regional and provincial) integrating stories & experiences of individuals with stroke have been created to provide an ongoing education opportunity for service providers • Kingston General Hospital has completed a Patient Resource for inpatients who have experienced a stroke. The Guide provides information on stroke and also in what to expect while in the hospital. Patient advisors were involved in the creation of this tool. • A new education poster on <i>Meaningful Activity</i> has been created for use in community and LTC settings. • Support Group Facilitators in the SE work with the SE Stroke Network have used regular teleconference meetings and CRLT meetings to support a regional approach and share best practices and knowledge • The provincially-developed <i>Guidelines for Community Based Exercise Programs for People with Stroke</i> (2010) are being reviewed in 2014 to ensure continued alignment with best practice • Workshop for community exercise providers in the southeast using the Guidelines as a framework (February 2014). • CRLT Chair has participated in development of education program for exercise instructors through VON which supports the inclusion of persons with stroke in exercise classes. This will be available nationally both within VON and also available to other providers of community exercise.

<p>System Navigation</p>	<ul style="list-style-type: none"> • Plans are currently underway for a community consultation process in 2015 to ensure that key directions identified in the 2007 process remain valid and relevant today • The funding for all regional stroke survivor and caregiver support groups flows through community support service agencies (VON in Kingston, Community Care for South Hastings in Belleville and Community & Primary Health Care in Brockville & Perth). This facilitates links to community programs offered by these organizations with the support group facilitators acting as system navigators. • Regional Resource Directories for KFLA, HPE and LLG have been updated in 2014 and now include live links to resources where available. Directories are available in hard copy and on SEO Stroke Network website. Directories provide listings to local, regional, provincial and national organizations that may be relevant to community reintegration for person with stroke and their care partners. Directories include rehabilitation, primary care, psychosocial, recreation and financial information. • Peer Visiting Volunteers provide information folders to those patients receiving visits in the hospital. Folders include Resource Directories and other support information (e.g., Heart & Stroke’s <i>Living with Stroke</i>, a guidebook for person with stroke and care partners in the community and a brochure on selecting appropriate and safe exercise programs in the community.) • CRLT Chair participated on a provincial Registered Nurses’ Association of Ontario expert group that developed <i>Best Practice Guidelines for Care Transitions</i> published 2014. The <i>Guidelines</i> recommend best practices to support clients who may be moving between care settings or between care providers. • Provincial work is underway towards housing stroke-specific resource directories on all Community Care Access Centre (CCAC) Healthlines. Healthlines offer electronic access to information on supports and services. SE CCAC has an app for accessing the Healthline through iPhones and android devices. • Provincial Work is underway to support two areas of best practice: Early Supported Discharge (ESD) and a Navigation Model to Support Effective Transitions to the Community. This work will assist regions to identify how best to support early discharge from the hospital following a stroke and how best to provide navigation support to persons with stroke and care partners in the community.
<p>Support to Work Through the Emotions</p>	<ul style="list-style-type: none"> • Ongoing funding has been received from the SE LHIN to support facilitation for all four stroke survivor and caregiver support groups in the SE • 2014/15 SEO Stroke Network Workplan includes investigating feasibility of implementing access to support groups via remote access (e.g., Skype and Ontario Telemedicine Network) to facilitate participation by persons with stroke and care partners in rural and isolated areas of the SE • Individuals with stroke from the Kingston Support Group have presented to the social worker program at St. Lawrence College.

<p>Support to Work Through the Emotions cont'd</p>	<ul style="list-style-type: none"> • Workshops have been held in the SE to inform service providers regarding best practice assessment tools when working with persons with stroke including tools to screen for post-stroke depression • A new education poster on Behaviour Change has been created for use in community and LTC settings. • The SE Acquired Brain Injury (ABI) Program has received funding for psychiatry services for which persons with stroke in the community are eligible. The ABI System Navigator is a member of the CRLT and the CRLT Chair is a member of the regional ABI partnership. • The Perth/Smiths Falls Support Group has sustained the successful Peer Visiting Volunteer Program where persons with stroke visit patients in hospital who have just experienced a stroke. This program is now being expanded to the Quinte and the Kingston regions including the Kingston General Hospital and St. Mary's of the Lake. • The "Discharge Link" Enhanced Community Based CCAC Rehabilitation Service continues to include funding for social work services for eligible persons with stroke in the community (including LTC) • Exploring potential to develop LTC support group programs
<p>Support at Home</p>	<ul style="list-style-type: none"> • Continuing to promote SMILE, respite, CSS and CCAC programs • Two new educational posters have been developed for use in LTC and other parts of the continuum and one is in the planning stages. A total of 9 posters are now available (wheelchair seating, safe feeding & oral care, post-stroke depression, communication, blood pressure, stroke risk & impacts, cognition & perception, meaningful activity and behaviour change). All SE LTC Homes have displayed at least one poster and community agencies are also now accessing this resource. Plans are underway to develop a new poster on transfers (e.g. from wheelchair to bed) • Education sessions delivered to community care providers across the region to build stroke care expertise • The <i>Brain, The Body and You</i> St Lawrence College education program provides hands-on stroke workshops to care providers annually with support from the Stroke Network of SEO
<p>Mobility in the Community</p>	<ul style="list-style-type: none"> • CRLT members and Committee as a whole continue to advocate for equitable access to transportation
<p>Access to Rehabilitation</p>	<ul style="list-style-type: none"> • The Discharge Link Enhanced Rehabilitation Service has been sustained and supports the provision of rehabilitation services in the community (including LTC) following discharge • Provincially developed best practice stroke care plans for LTC Homes have now been adopted in four LTC Homes in the SE. Working to have these plans included in the care plan libraries of all LTC Homes and to adopt the care plans as an Accreditation best practice. • Advocacy continues for equitable access to day rehabilitation programs across the SE. • Stroke Support Group facilitators are supported to receive training in supported conversation for persons with communication deficits as a result of their stroke

APPENDIX B
COMMUNITY REINTEGRATION LEADERSHIP TEAM LOGIC MODEL

RESOURCES

- Persons with stroke & caregivers
- Stroke Network Community Reintegration Leadership Team (CRLT)
- Local Stroke Support Groups
- Heart & Stroke Foundation
- Canadian Best Practice Recommendations; RNAO Transitions Best Practice Guideline; Community Stroke Quality Based Procedures (QBP)
- Health Partners: acute/rehab hospitals and Stroke Prevention Clinics, SECCAC & provider agencies, Community Support Services (CSS), Long Term Care Homes (LTC), primary health care, retirement homes, ABI Network, Pathways to Independence
- Regional Stroke Steering Committee & Subcommittees
- Regional Stroke Team
- Ontario Stroke Network (OSN)
- Ontario Telemedicine Network (OTN)
- LHIN & MOHLTC
- Post-secondary institutions
- Funding – Regional Stroke Team (education, KT tools)
- Funding – within partner budgets
- Space and equipment – partner facilities
- Transportation
- Media
- Municipal, county & local resources
- Adaptive exercise programs (e.g., Revved Up, YMCA)
- Veteran Affairs and other benefits support programs

ACTIVITIES

Support for Recovery & Active Engagement

- Promote Linkages to CSS & local recreation facility programs
- Sustain Living with Stroke programs & pilot OTN outreach
- Link stroke survivors and families to volunteer opportunities
- Promote healthy living through facilitated self-management
- Promote use of Guidelines for Community Based Exercise

System Navigation

- Sustain system navigation role of Support Group Facilitators
- Co-design navigation model with stroke survivors/caregivers
- Promote access to local resource guides, programs & services
- Expand Peer Visiting to all hospitals across SEO

Support to Work Through the Emotions

- Sustain and build reach of Community Support Groups
- Promote depression screening in community settings
- Promote ABI Psychiatry Link
- Discharge Link/Enhanced CCAC Rehab – promote SW
- Expand Peer Visiting across SEO - build a mentorship model
- Assess capacity to develop LTC support group programs

Support at Home

- Promote SMILE and Respite Programs, CCAC services
- Promote CSS and other services for non-medical supports
- Develop stroke-specific skills in the provision of stroke care

Mobility in the Community

- Advocate for equitable transportation access
- Support stroke survivor/caregiver input into accessibility policy
- Build health service provider awareness re: accessibility

Access to Rehabilitation

- Sustain Discharge Link/ CCAC Community Rehab
- Promote uptake of LTC Stroke Care Plans
- Establish or sustain Day Rehab Programs
- Pilot a Communication Group (with OTN outreach)
- Promote equity of access across region

OUTCOMES

Equitable access to the appropriate community programs and services at the right time for persons with stroke and caregivers.

Persons with stroke and caregivers are informed re available supports and services through discharge planning and ongoing system navigation.

Persons with stroke and caregivers are engaged in co-designing system changes required to deliver stroke best practices in community

Equitable access to sustained, facilitated support groups across SEO that effectively meet the needs of persons with stroke and caregivers

Community and in-home services encompass the holistic needs of persons with stroke and caregivers including psychosocial needs

GOAL

Living in the community supported by programs and services that optimize quality of life

OUTCOME MEASURES

- % with Stroke discharged to outpatient rehab
- CCAC Discharge Link/Rehab
- CSS services
- Stroke and Caregiver Support Group Services
- Peer support services
- Directly from acute to LTC

Satisfaction of persons with stroke and caregivers with information and system navigation

- Stroke Survivor Support group evaluation:
- Source of referrals
 - Quality of Life – Stroke Impact Scale perceived recovery
 - Caregiver Burden
 - Stroke Services Questionnaire
 - # of LWS programs offered/yr
 - Documented gaps in access to stroke support groups including # rural communities

- CHA RAI assessment to be used to investigate Quality of Life measures such as:
- Stress reduction
 - Psychosocial support
 - Depression
 - CCAC Enhanced Rehab
 - Referrals by discipline
 - Visits by discipline
 - Wait to 1st CCAC rehab visit
 - Hospital Readmission rates
 - 30 day mortality rates

ENABLERS: Communication/Information Management, Knowledge Translation, Collaboration, Evaluation, Advocacy

APPENDIX C
GLOSSARY

ABI	Acquired Brain Injury
Caregiver Burden	This refers to the 'burden' of care held by care partners in the community. The evaluation of the Stroke Survivor & Caregiver Stroke Support Groups includes a measure of caregiver burden as perceived by the caregiver and to measure any improvement following participation in the groups.
CCAC	Community Care Access Centre. This is the organization funded by the Ministry of Health to assess for care needs in the community and to coordinate the needed services. The CCAC also provides information on resources in the community and manages all placements to Long Term Care Homes.
CCAC Healthline	This is an on-line resource that can be accessed by the public and provides information on supports and services available in the community. A stroke-specific section is being developed.
CRLT	Community Reintegration Leadership Team
CSS	Community Support Services
Discharge Link	Also known as the Enhanced Therapy Program for persons with stroke. This is a program that is funded by the Ministry of Health through the CCAC. The program provides enhanced (more frequent and more intense) therapy services to eligible persons with stroke on discharge from the hospital. The program includes occupational therapy, physiotherapy, speech language pathology and social work. The program can be accessed by persons with stroke living in the homes in the community including long term care.
Hospital Readmission Rates	This is a measurement of how many times an individual (person with stroke) is readmitted to the hospital within 30 days following discharge for selected conditions.

HPE	Hastings Prince Edward counties
KFLA	Kingston, Frontenac, Lennox and Addington counties
LHIN	Local Health Integration Network. The Southeast (SE) LHIN is the body that is funded by the Ministry of Health to plan and to allocate funds for health services in our region. Each area of the province has a LHIN and there are 14 LHINs in total.
LLG	Lanark, Leeds and Grenville counties
LOS	Length of Stay. This is the time a patient remains in hospital.
LTC	Long Term Care
LWS	Living with Stroke
OT	Occupational Therapist
OSN	Ontario Stroke Network. This is the body that is funded by the Ministry of Health to
OSS	Ontario Stroke System. This refers to the Ministry of Health funded networks (such as the Stroke Network of Southeastern Ontario) across Ontario that support the provision of best practice stroke care across the care continuum (e.g., emergency care, hospital care, rehabilitation, primary care, community care and LTC)
Peer Visiting Volunteer Program	These are persons with stroke who are members of one of a Stroke Survivor & Caregiver Support group who have received special training to visit persons in hospital who have newly experienced a stroke and their families. Peer Visiting Volunteers share their stories and provide information and support.
Perceived Recovery	This is a measure of how a person with stroke perceives their own recovery. It is usually rated using a 0 (no change) to 10 (significant change). It is one of the measures used in the evaluation of the Stroke Survivor & Caregiver Support Groups in the SE.

PT	Physiotherapist
QBP	Quality Based Procedures. This is a new way that the Ministry of Health will be using to fund parts of health care. It is based on what has been identified as best practice care.
Registered Nurses Association of Ontario (RNAO)	This is a professional organization for registered nurses and registered practical nurses in Ontario.
RSSC	Regional Stroke Steering Committee. This is the governing body of the Stroke Network of Southeastern Ontario. The RSSC oversees the work of the Stroke Network and sets strategic directions.
SE	Southeast
SEO	Southeastern Ontario
SLP	Speech Language Pathologist
Stroke Network of Southeastern Ontario	This is the team that is funded by the Ministry of Health to support best practice stroke care across the SE across the care continuum. Each region of the province is part of a stroke network.
SW	Social Worker
VON	Victorian Order of Nurses
30 Day Mortality Rates	This is a measure of the relative number of deaths within a 30-day time frame.