

**SOUTHEASTERN ONTARIO
REGIONAL STROKE SUPPORT GROUPS**

APRIL 2015 EVALUATION

SUBMITTED TO SOUTH EAST LHIN



CANADA

STROKE NETWORK
of Southeastern Ontario



APRIL 2015 EVALUATION SOUTHEASTERN ONTARIO REGIONAL STROKE SUPPORT GROUPS

Background

In January of 2014, LHIN base funding was secured for the regional Stroke Survivor and Caregiver Support Groups:

- Community & Primary Health Care in Perth/Smiths Falls and Brockville (for LL&G Counties)
- Community Care for South Hastings (for H&PE Counties)
- VON Canada – Kingston, Frontenac, Lennox & Addington (for Kingston region)

Subsequent to the October 2014 Evaluation Report:

- The SE LHIN approved moving to annual report submission supported by the consistently positive results of all reports to date
- The facilitator for the Perth & Brockville groups is scheduled to attend education sessions at The Aphasia Institute in Toronto in 2015 supported by the Stroke Network of Southeastern Ontario
- The collaborative regional model which includes the three facilitators as well as representation from the Stroke Network of SEO continues to support the sharing of best practices and strategies through regular teleconferences. Facilitators also participate in the quarterly meetings of the Community Reintegration Leadership Team, a sub-committee of the Regional Stroke Steering Committee
- Members from all the support groups will be participating in the 2015 Community Consultation process facilitated by the Stroke Network of Southeastern Ontario. This consultation is intended to validate/modify and/or add to the key directions identified during a similar consultation process seven years ago and will help to inform the Network of future areas of focus to support community reintegration.
- Shell-Lee Wert (Executive Director, Community Care for South Hastings) and Patti Lennox (Supervisor, Caregiver Support Program, CPHC) continue to participate in the Regional Stroke Steering Committee as representatives of the CSS sector.
- The new informational brochure for the Perth group which has incorporated a design created by one of the group members has been completed
- An informational brochure created by and intended for caregivers has been developed by the Kingston Caregivers Support Group. The brochure will be available in English and French.
- In Kingston, two MScOT students have undertaken a project to develop a peer-led Social-Recreational Group to enhance the community reintegration of stroke survivors. The project has included consultation with current group participants about interests, assessment of suitable meeting venues and the identification of peer leaders.
- Kingston facilitator is currently investigating a collaborative opportunity with regional ABI navigator to pilot a Living with Stroke[®] 6-week session via OTN to reach rural areas



- The Belleville facilitator and the Stroke Network of SEO have both made initial contact with the Speech Language Pathologist who is hoping to pilot an Aphasia Conversation Group in the Belleville area
- Connections have been initiated with the leads for the 2015 implementation of the Stroke Specific Community Exercise Programs in Belleville/Kingston (VON) and Brockville (CPHC)
- One Living with Stroke[®] (LWS) program was delivered in Kingston and one in Belleville
- The facilitator for the Perth & Brockville groups will be participating in facilitator training for the LWS program with subsequent initiation of a LWS program anticipated in 2015
- Peer Visiting Volunteer Programs are in place in Kingston and Perth. In Kingston, 2 survivors have been newly trained to provide peer visiting in community and 4 survivors recruited to visit in hospital.

S.U.P.P.O.R.T.

Stroke Understood: a Peer Program Optimizing Recovery Together

As per the recommendations put forward in the April 2014 Evaluation Report, this and future reports will focus on perceived recovery scores for stroke survivors, an annual caregiver burden evaluation, and a caregiver and survivor satisfaction tool.

SERVICES PROVIDED

- Planning, delivery, and evaluation of 8 support groups (Perth/Smiths Falls Stroke Survivors & Caregivers Support Group, Brockville Stroke Survivors & Caregivers Support Group, Belleville Stroke Survivors Group, Belleville Couples Group, Belleville Caregivers Group, Kingston Caregivers Group, Kingston Couples Group and Kingston Stroke Survivors Group)
- Identification of educational needs of stroke survivors and caregivers with subsequent provision of educational information to the groups verbally, written, and/or via guest speakers. Discussion topics have included:
 - Strategies and assistive devices to make life easier
 - Addressing the needs of long-term survivors
 - Heart & Stroke Foundation's FAST public awareness campaign
 - Sharing advice for new caregivers (a brochure has been developed to disseminate most valuable learnings)
 - Changes in roles and relationships after stroke
 - The importance of goals
 - Travel with a disability
 - Recognizing and dealing with depression
 - Exercise after stroke
 - Tips to get through the winter months



Guest Speakers have included:

- Tax specialist on disability tax credit and medical expenses
 - Registered Dental Hygienist on oral care after stroke (caregivers)
 - Pharmacist on stroke-related medications and how your pharmacist can help
 - Registered Dietician on reading nutrition labels
 - Tai Chi Instructor
- Therapeutic group discussions with respect to psychosocial concerns and issues which may be prompted by 'stimulus' questions brought forward by the facilitators
 - Management of referrals for potential group participants (which may include home visits)
 - Data gathering through the administration of evaluation tools for LHIN Evaluation Reports
 - Outreach to and networking with community based partners, healthcare professionals, and health/wellness fair presentations
 - Transportation arrangements for stroke survivors and/or caregivers if required
 - Referral to community resources, as required, (with consent)
 - Monitoring of individual participants as required through phone calls and email.
 - System navigation including the identification of appropriate community resources, how to access local supports and services and initiation of referrals
 - Case management when social and community resources are either non-existent or limited and the participant requires assistance, information and/or advocacy to meet their needs
 - Maintaining administrative records for groups including attendance and case notes
 - Responding to general/public requests for information about stroke and community resources and liaising with media
 - Participating in regional facilitator teleconferences to support sharing of successes and challenges and to support regional consistency
 - Attending regional meetings on a quarterly basis (Community Reintegration Leadership Team)

METHOD OF DATA COLLECTION

All three regions have been surveying caregivers and survivors on an ongoing basis for a minimum of three reporting periods (Kingston has exceeded this and had submitted a Kingston-specific report prior to the regional evaluation reports). The survey load on participants can become quite burdensome particularly for those respondents who have completed an evaluation component more than once. In an effort to reduce load and to increase the validity of survey results, future focus will continue to be on the perceived recovery scores for stroke survivors, caregiver burden evaluation, and the caregiver and survivor satisfaction tool. To enhance validity of the perceived recovery and caregiver burden scores, a minimum of 6 months will be required between the pre and post scores. Caregiver burden will not be included in this report as there were not sufficient respondents that met the 6-month qualification.

As with the October 2014 Evaluation Report, the Stroke Services Evaluation Tool was administered to stroke survivors and caregivers to evaluate their satisfaction with the support groups as well as how they perceived the impact of the support groups on various health and lifestyle domains.

This evaluation again included three additional questions intended to provide a better understanding of how stroke survivors and caregivers are supported when navigating the health and social support systems. The questions are as follows:

1. Are you satisfied with the individual information and/or the referral information that you have received from the group facilitator? Y/N
2. Are you satisfied with the assistance you have received from organizations/individuals other than the stroke group facilitator? Y/N
3. If yes, and you are comfortable saying so, please state the name(s)/organization(s) that provided you with the information/assistance:

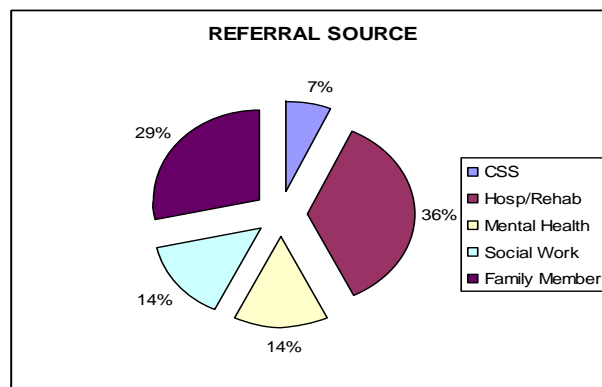
Note that quotes included in this report are derived from responses to the Stroke Services Evaluation Tool.

SERVICES PROVIDED

- 8 facilitated stroke groups
- 2 Heart and Stroke Foundation Living with Stroke™ series completed. The Kingston LWS program included facilitation by two trained stroke survivors
- 2 Peer Visiting Programs

REFERRAL SOURCES

Fig. 1 Source of New Referrals



Source: Stroke Services Evaluation Tool

A total of 14 new referrals have been received subsequent to the last report. Since the last report, additional referral sources have included mental health services and family members. Health care partners (hospital, rehab, community support services) continue to be significant referral sources.

STROKE SUPPORT GROUP MEMBERSHIP

- 49 survivors and 47 caregivers are attending support groups

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH - CAREGIVER BURDEN

Caregiver Support Groups

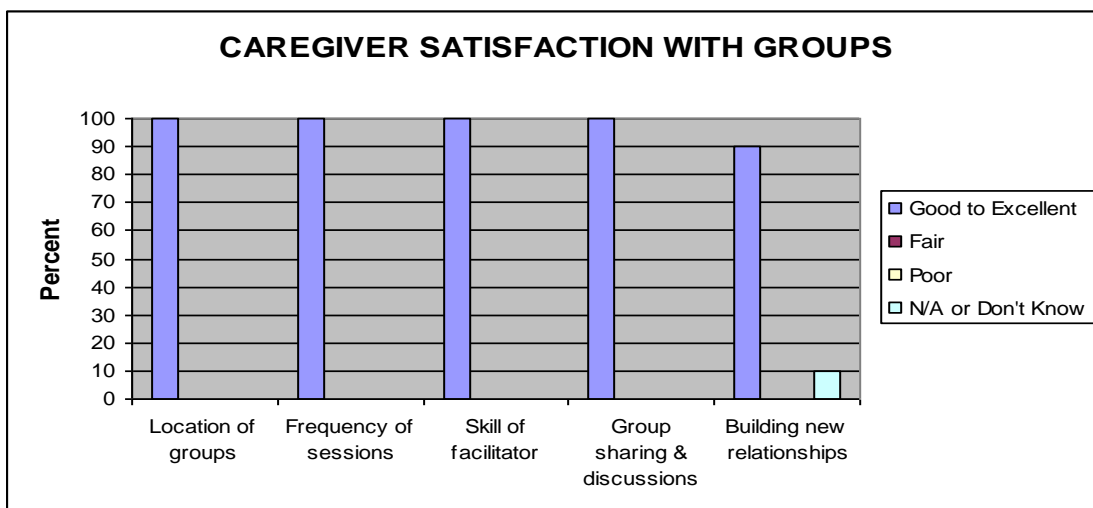
As stated in previous Evaluation Reports, the needs of the caregivers are recognized and addressed by the facilitators and through the support of their peers. Groups include:

- Education re stroke to enhance understanding of the current health status of their loved one as well as tips to support illness prevention & health promotion to reduce the risk of another stroke or other disease (e.g., cardiac and diabetes).
- Information on identifying stressors and implementation of coping strategies.
- Referral/facilitating connections to community supports and, when identified as a need, to additional counselling.
- Peer support and providing the opportunity to engage with others who are on a similar life journey/facing common issues and concerns

Note also that the Kingston Caregiver Support Group has responded to a recognized information gap by creating an informational brochure intended to anticipate and respond to caregivers' informational needs.

DEMONSTRATED SATISFACTION - CAREGIVERS AND SURVIVORS

Fig.2 Caregiver Satisfaction Evaluation Tool Results



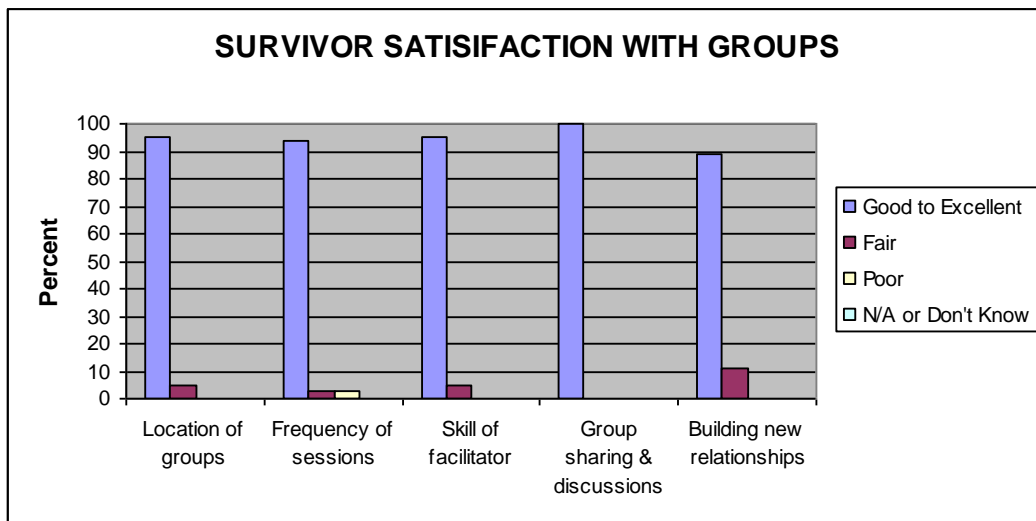
SOURCE: STROKE SERVICES EVALUATION TOOL

"[Name of facilitator] is an excellent facilitator and has been very helpful to me in numerous circumstances!" - Caregiver

"This is a very good forum for learning on many different levels and for meeting new people and making new friends." - Caregiver

I love [name of facilitator] enthusiasm. Keen interest in teaching and learning. - Caregiver

Fig. 3 Survivor Satisfaction Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

Figures 2 and 3 indicate a high level of satisfaction with groups for both stroke survivors and caregivers. The excellent ratings are consistent with previous reports and clearly demonstrate a very high confidence in the skills of the facilitators. Note that two survivors and one caregiver indicated a desire for more frequent meeting (e.g., *"Would like meetings twice a month. I always miss it if I don't come. I hate it to be over because it's a long time 'til the next time."* – Survivor).

"Facilitator is very sensitive to those that attend. Gives everyone a chance to speak to whatever is being discussed." - Survivor

"Our facilitator goes out of her way to research new info for a more meaningful life after stroke. My stroke survivor group gives me a comfortable place to feel comfortable about my stroke-related short-comings!" - Survivor

"A good program and excellent facilitator." - Survivor

"It's really good to get out and see other people." - Survivor

The facilitator continues to play a key role:

- Liaising with health and social services partners to enhance referrals.
- Conducting intake assessments to ensure an effective transition into the appropriate group and to gain an understanding of the needs of each individual participant.
- Coordinating the groups including responding to education and information needs by arranging speakers with the relevant expertise.
- Ensuring that all voices are heard in the group setting and that there is a therapeutic balance between an acknowledgement of this significant life event and the fostering of hope.
- Providing system navigation support to make certain that survivors and caregivers are linked to community resources and managing referrals where appropriate.

As noted earlier, three additional questions have been included in the SSE tool. Respondents indicated 100% agreement when asked if they were satisfied with the individual information and/or the referral information that they received from the group facilitator. In response to the question, “Are you satisfied with the assistance you have received from organizations/individuals other than the stroke group facilitator?” 79% indicated that they were satisfied (a slight decrease from last evaluation where satisfaction was at 83%) When respondents were also asked to provide the name(s) or organization(s) that had provided the information, the following were cited:

- Community Care for South Hastings (4)
- CCAC (4)
- Heart & Stroke Foundation (3)
- Queen’s students/university researchers (2)
- Facilitator (2)
- Hospice
- Spouse’s LTC Home and staff
- VON
- Limestone School Board
- PSW students
- Mobility information & businesses
- Day Rehab
- Stroke Group
- Crossroads
- Stroke survivor
- Brain Injury Society
- Easter Seals
- PEP (Perth Enrichment Program for Older Adults)

Two comments were included in response to this question:

“Only sometimes satisfied [with the CCAC], depends on what it (info/assistance) is”

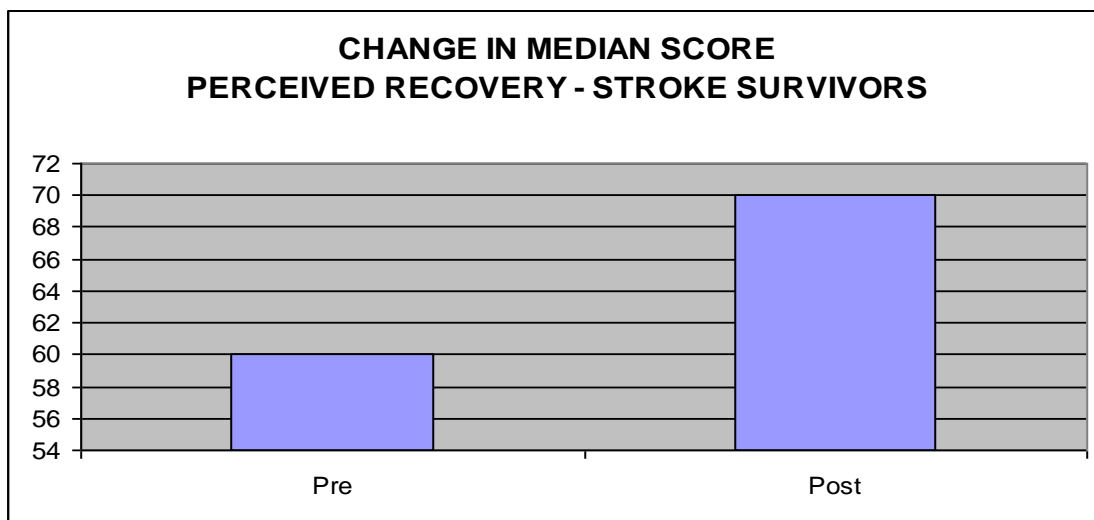
“While in the hospital my husband had to deal with all the paper work and found it overwhelming and there was no person who came forward to help him.”

These survey responses continue to highlight a rather fragmented and random navigation system (consistent with results from the October 2014 survey) as well as confirming the benefit of having the facilitators fulfill a knowledgeable and consistent access point for system navigation that is responsive to the needs of each individual.

“I have been made aware [by the support group facilitator] of the many possible resources in the community that I wouldn't have known about.” - Caregiver

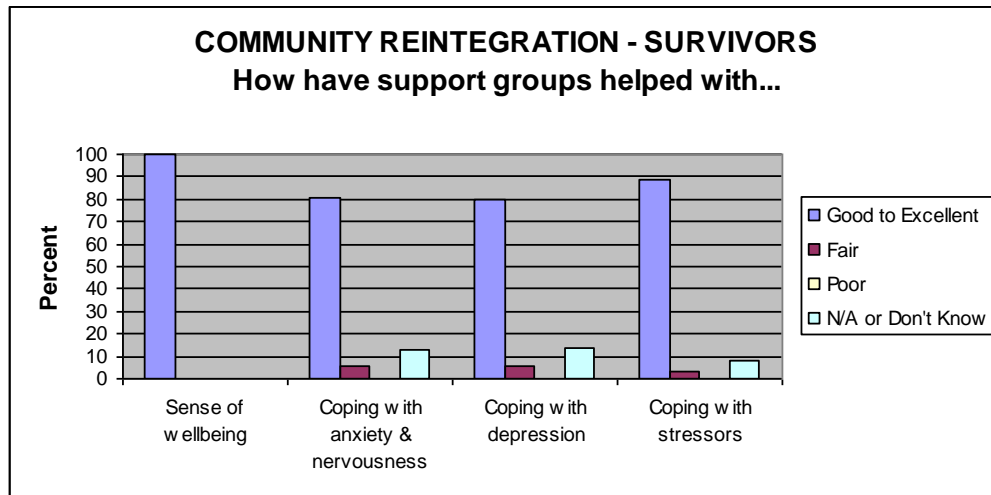
PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH – STROKE SURVIVORS

Fig. 4 Survivor Perceived Recovery Scored



The Perceived Recovery Score asks stroke survivors to provide an overall perception of their recovery using a scale of 0 to 100 with 0 indicating no recovery and 100 indicating full recovery. Results for Figure 4 are from Kingston and Brockville/Perth areas only as no Belleville participants new to the group subsequent to the last Evaluation Report had been with group a minimum of six months. Results in median scores continue to show an improvement pre/post surveys.

Fig. 5 Survivor Well-Being Evaluation Tool Results



Source: Stroke Services Evaluation Tool

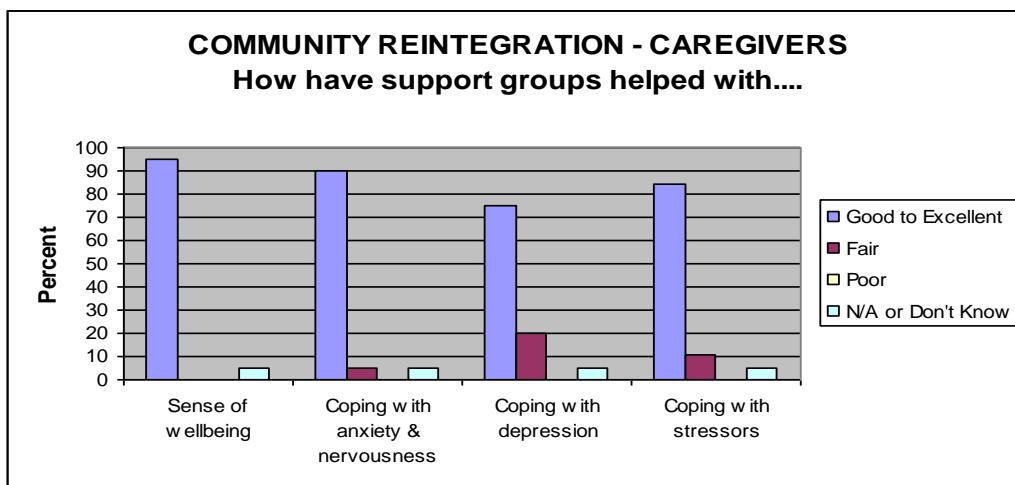
- The majority of stroke survivors saw the group as “good to excellent” in contributing to a sense of well-being as well as helping them cope with anxiety/nervousness, depression and stressors.
- Having an opportunity to share feelings, experiences and successes in a ‘safe’ venue supports emotional well-being and personal capacity to cope.
- Peers are often significant sources of support and experiential advice; they are also walking that recovery journey.

“I enjoy the conversation and feel safe in the group. It is always a positive atmosphere.” - Survivor

“The help that I've been given has been great and have followed through with recommendations.” - Survivor

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH – CAREGIVERS

Fig. 6 Caregiver Well-Being Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

There is a significant 24/7 burden of care placed on informal caregivers (most typically a spouse). Often, the role of caregiving is new to the individual and the stroke event has impacted on their other life roles as well (e.g., volunteering, career, social & recreational activities). As well, future plans must be altered, financial status re-evaluated, modifications made to the home environment and a myriad of other adjustments. All of this often takes a toll on the caregiver’s own health. Attending a support group provides an opportunity to share challenges and successes and can also lead to new relationships and less social isolation.

“I was so overwhelmed at first that without this group I would not have coped very well at all. It was such a devastating change to my life and my partner's life.” - Caregiver

“I have learned many helpful things from our group discussions and the support has sustained me several times.” - Caregiver

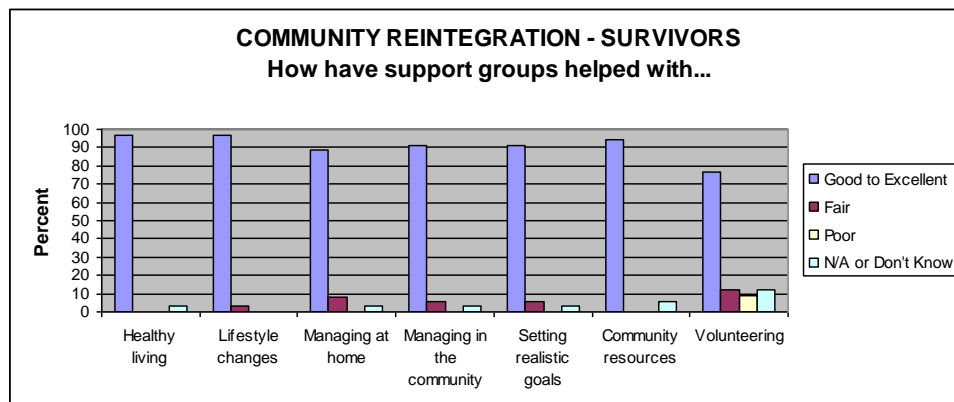
“Enjoy listening to others and can relate.” - Caregiver

PARTICIPANTS RECEIVING DISCHARGE LINK

Of the 9 new referrals to the stroke survivor support groups, five stated that they had received therapy services through the Discharge Link Program. Note that some support group participants will have experienced their stroke event several years ago, prior to the implementation of the Discharge Link Program in 2009 and others may be unsure if they received the service or not (some may not have been aware that they had received ‘enhanced’ therapy services). As well, the Discharge Link Program for enhanced rehabilitation services would not have been required by all those participating in the support groups.

PARTICIPANTS ABLE TO TRANSITION BACK TO COMMUNITY SETTING

Fig 7 Survivor Community Re-Integration Evaluation Tool Results – Kingston, LLG & HPE



Source: Stroke Services Evaluation Tool

“I enjoy our get togethers & learning new ways of coping & how other survivors manage.” - Survivors

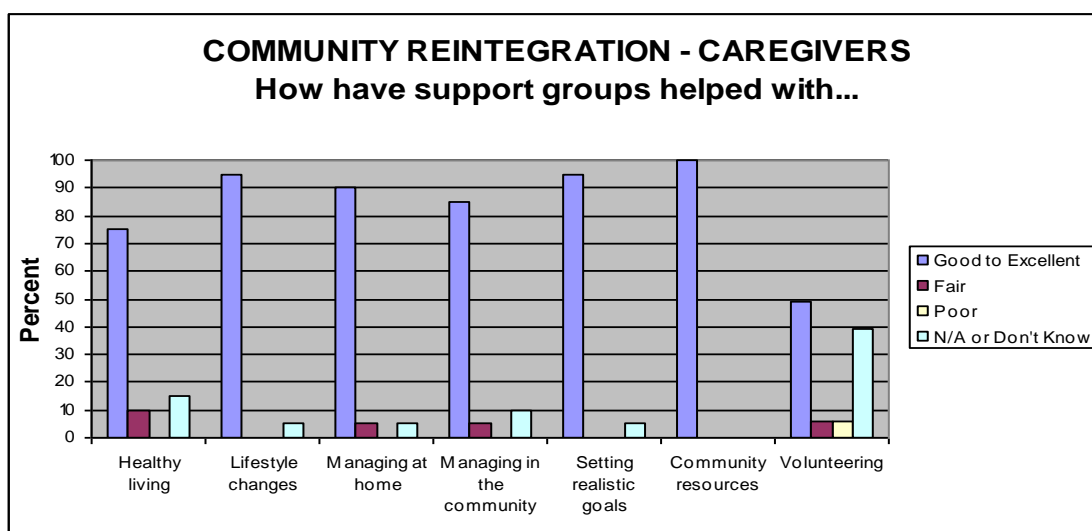
“Sessions are informative and worthwhile, money well spent by gov't on behalf of taxpayers.” – Survivor

“I have learned a great deal. Really enjoyed the diet info.” – Survivor

HOSPITAL ADMISSIONS

- All group participants have succeeded in remaining in the community. Currently, most live in their own homes, or with family members.
- During this reporting period, three of the 47 caregivers attending support groups reported an admission to hospital (suspicion of duct cancer, triple bypass, tests)
- Five stroke survivors of the 49 attending the support groups reported hospital admissions during the evaluation period. (many reasons, unrelated to stroke, infection, mini stroke, possible second stroke).

Fig. 8 Caregiver Community Re-Engagement Evaluation Tool Results



Source: Stroke Services Evaluation Tool

Caregivers continue to view the support groups as helpful to daily living across many domains and the positive contributions that support groups make to the health status of the caregivers will, in turn, improve the health of the stroke survivors for whom they care.

“Helpful strong response to our stated preferences for discussion and specialized speakers.” - Caregiver

“Gaining information about community resources is helpful.” --- Caregiver

“This support group is very important to me - I have received information that I wouldn't have otherwise.” – Caregiver



With respect to the low scores for volunteering, it is evident that the care burden held by the family members of stroke can leave little time for volunteering. Having said that, it is interesting to note that one respondent saw volunteering as an opportunity to publicize the support groups.

"I canvassed for the Heart & Stroke fund recently, and I had the opportunity to tell people about this group." - Caregiver

EVALUATION SUMMARY

- Sense of well-being supported by participation in the groups rated as good to excellent for the majority of both caregivers and stroke survivors
- Individual abilities to cope with anxiety, nervousness and depression were rated as good to excellent for the majority of both caregivers and stroke survivors
- Consistent positive feedback on the skills of the facilitators and the valuable role they play for successful and therapeutic groups as well as system navigation

RECOMMENDATIONS FOR CONTINUED SUCCESS:

- Consideration for future expanded base funding to support the growth of existing groups as the upper therapeutic numbers for a group setting is usually suggested to be 15- 20.
- Consideration for additional funding to support Speech Language Pathologist consultation to provide the professional services for an Aphasia Support Group to meet the functional communication needs of those stroke survivors experiencing aphasia. This model could include an outreach OTN component for rural areas.
- Consideration for additional funding to support the coordination and equipment for OTN outreach of this valued service in each current community to less populated rural areas within the respective catchments where the critical mass may not exist to support a group. For example, requests for this service have already been received from Bancroft, Picton, Napanee, and Sharbot Lake. Investigation of different outreach models is currently underway by the Stroke Network of Southeastern Ontario.
- Consideration for some funding support to arrange and provide a respite component to operate in conjunction with the caregiver support group in each area in order to facilitate participation of caregivers who are unable to leave their loved one home unattended. Current discussion of this component includes a partnership option with Adult Day Programs and existing respite programs.
- Review of recommendations generated by the Stroke Network's community consultation.

"Our facilitator is very supportive!! The ability to reach out, when you see someone stressed in group, was/is critical. Everyone has a story, and each story is unique, you are able to relate to all of them." – Caregiver