

**SOUTHEASTERN ONTARIO
REGIONAL STROKE SUPPORT GROUPS
JUNE 2019 EVALUATION
SUBMITTED TO SOUTH EAST LHIN**



**STROKE NETWORK
of Southeastern Ontario**



JUNE 2019 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:

- Senior Support Services - Community & Primary Health Care (CPHC) in Perth and Brockville (for LL&G Counties)
- Community Care for South Hastings (CCSH) (for H&PE Counties)
- VON Canada – Kingston, Frontenac, Lennox & Addington (for Kingston region)

Subsequent to the June 2018 Evaluation Report:

- New Facilitator was retained for the Kingston site
- The Facilitator in Kingston attended The Aphasia Institute for training in supportive conversation (SCA™)
- 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 (CRLT), a committee of the Regional Stroke Network
- Shell-Lee Wert (Executive Director, Community Care for South Hastings) and Patti Lennox (Manager, Caregiver Support and Community Programs, CPHC) continued to participate in the Regional Stroke Steering Committee as representatives of the CSS sector during fiscal 2018/19. Brenda Adams (Care and Service Manager, Community Support Services, VON Kingston) assumed Patti Lennox's role following Patti's retirement in April 2019.
- Belleville has initiated an introductory support group for stroke survivors (*First Step*) with the goal of gradually transitioning these individuals into the larger support groups(s). Additionally, Belleville has a peer-led survivor group that runs in tandem with a caregiver group. This provides the caregivers with respite and an opportunity to share experiences in a safe environment while their loved ones also receive support from their peers. Kingston has initiated a younger stroke survivors' group (*The Warriors*). As of June 2019, support groups have been initiated in Sydenham, Napanee, Picton and Trenton.
- Four Stroke Specific Community Exercise Programs have been sustained. Belleville, Trenton and Kingston are coordinated through VON and Perth through CPHC. Senior Support Services CPHC is currently planning to re-initiate the Brockville program with the recent retention of a new coordinator. The Exercise Providers have been linked with the Facilitators of the support groups to promote the programs.
- Peer Visiting Volunteer Programs are in place in Perth (PSFDH Rehab and Day Hospital) and Brockville Rehab and Belleville is in the planning process with volunteers having completed the training program. Kingston is currently recruiting for a peer visiting program. Kingston also has peer visiting with a stroke survivor in LTC.



- Building on the Belleville model, Kingston has now initiated a process allowing the Facilitator to connect with stroke survivors after discharge. This promotes linking to the support groups as well as other community-based supports and services.
- Aphasia Supportive Conversation Groups are now in place in Belleville & Kingston and planning for Brockville has been initiated. As well, Kingston has Aphasia Buddy and Aphasia Peer Support Programs in place.
- Five *Living with Stroke*® (LWS) programs were delivered in this reporting period.
- Facilitators have contributed to education planning and have presented at SNSEO events including the KFLA Community Stroke Expo in November 2018.
- The Belleville OTN Outreach pilot has been deferred in response to the initiation of the Picton and Trenton groups and participants' preference for in-person group experiences. Exploration continues with respect to reaching other rural and remote areas.

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

Stroke Understood: a Peer Program Optimizing Recovery Together

SERVICES PROVIDED

- Planning, delivery, and evaluation of 9 support groups (Perth/Smiths Falls Stroke Survivors & Caregivers Support Group, Brockville Stroke Survivors & Caregivers Support Group, Belleville Stroke Survivors Group, Belleville Caregivers Group, Kingston Caregivers Group, Kingston Couples Group, Kingston Stroke Survivors Group, Napanee Stroke Survivors & Caregivers Group, Sydenham Stroke Survivors & Caregivers Group). Support for *Life Goes On* and *First Step* groups in Belleville as well as the *Folks with Strokes* and *The Warriors* groups in Kingston.
- 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
- 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
- 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 CRLT meetings on a quarterly basis

METHOD OF DATA COLLECTION

Perceived Recovery & Modified Caregiver Strain Index Scores

To enhance validity of the perceived recovery, a minimum of 6 months is required between the pre and post scores. The MCSI is administered as a point in time measure.

Stroke Services Evaluation Tool

Administered to stroke survivors and caregivers to evaluate their satisfaction with the support groups, how they perceived the impact of the support groups on various health and lifestyle domains and satisfaction with navigation by the Facilitators and community agencies.

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

SERVICES PROVIDED

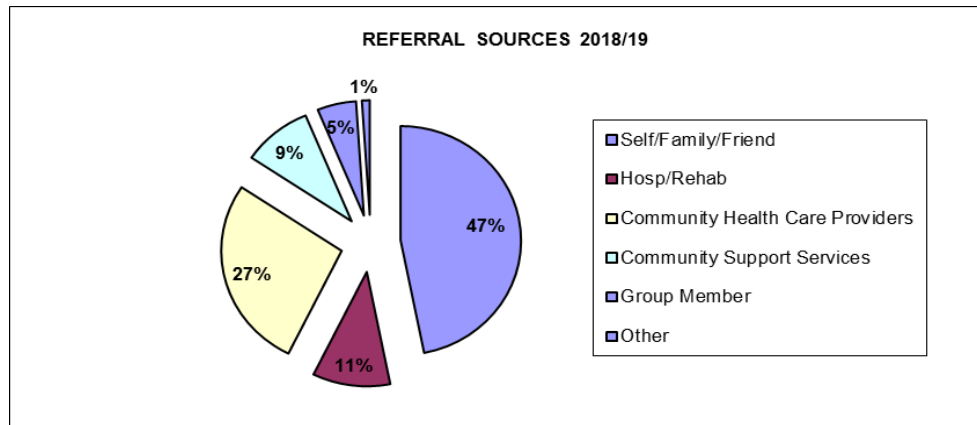
- 13 facilitated stroke groups (stroke survivors, caregivers, couples, young stroke survivors, introductory group and social/recreational)
- 5 Heart and Stroke Foundation Living with Stroke[®] series
- 3 Peer Visiting Programs (Belleville (pending), Perth (2) & Brockville).
- 2 Aphasia Supportive Conversation Groups (Belleville & Kingston (Brockville pending))

It should be noted that individuals not attending a support group may still receive Facilitator support. The reasons for not attending a group may include a decline in health, work or caregiving responsibilities, or bereavement. In cases of health decline, the Facilitator may make periodic phone calls to reassess, provide support and a continued connection to the group as well as referral to community resources.

New referrals may be followed for a period of time before they are able to attend a group or decide not to follow through with attending a group. Clients referred for stroke support soon after discharge from hospital often have many appointments which will interfere with their ability to participate in groups. Prior to discharge from the support group or individual support, the Facilitator ensures that clients are receiving adequate community support to deal with their circumstances. This approach respects client preferences, avoids premature discharge from service and also helps to manage a growing caseload.

REFERRAL SOURCES

Fig. 1 Source of New Referrals



SOURCE: STROKE SERVICES EVALUATION TOOL

A total of 96 new referrals have been received subsequent to the last report. Self-referrals (survivor or family member) as well as community settings continue to be significant referral sources.

STROKE SUPPORT GROUP MEMBERSHIP

- 174 survivors and 58 caregivers attended support groups in this reporting period

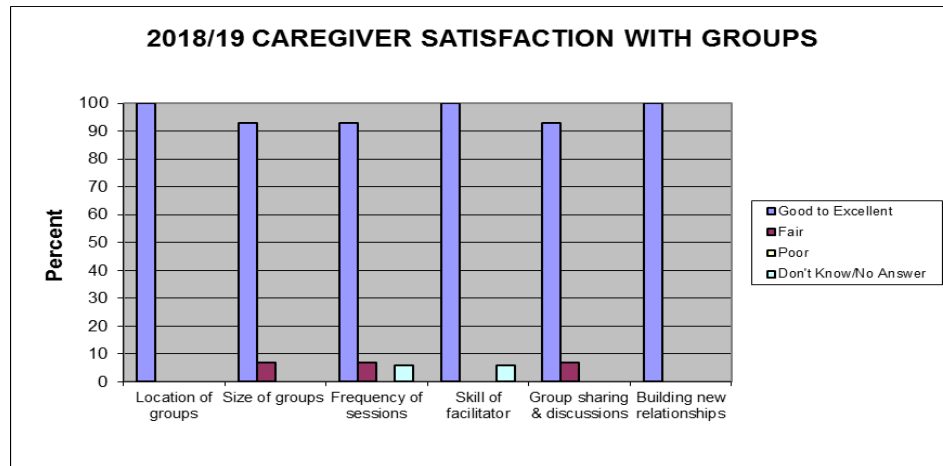
Fig. 2 Stroke Support Group membership & Referrals

AREA	POPULATION	STROKE SURVIVOR PARTICIPANTS	CAREGIVER PARTICIPANTS	REFERRALS	%REFERRALS/POPULATION
Belleville	~51,000	58	30	32	0.063
Brockville	~22,000	15	8	7	0.025
Perth	~6,000	9	9		
Kingston	~137,000	92	15	57	0.042

Referrals as a percentage of population vary across the regions with Belleville achieving the highest rate.

DEMONSTRATED SATISFACTION - CAREGIVERS AND SURVIVORS

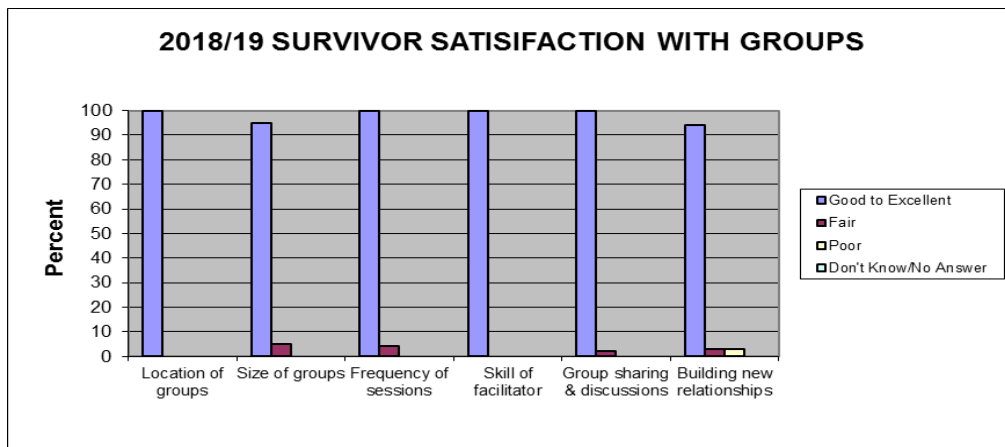
Fig.3 Caregiver Satisfaction Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

- *"Our facilitator is very professional, well-informed and helpful to all of us". ~Caregiver*
- *"Great group and super facilitator." ~Caregiver*

Fig. 4 Survivor Satisfaction Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

- *"Our facilitator is fabulous." ~Stroke Survivor*
- *"Many thanks to [facilitator] for her help and organization." ~Stroke Survivor*

Figures 3 and 4 indicate a continued 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. The Facilitator continues to play a key role in:

- 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

“... I could have used a visit before hospital discharge as we were lost as a couple. Never been to a support group before (but) most information (I received) was after I joined the group.” ~ Stroke Survivor

With respect to system navigation, 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?”, 92% indicated that they were satisfied. When respondents were also asked to provide the name(s) or organization(s) that had provided the information, the following were cited:

Numbers indicate how many times the organization or individual was cited by a survey respondent.

- VON X 5
- Community Brain Injury Services/OBIA X 4
- Stroke Specific Exercise X 3
- Quinte District Rehab X 3
- Dietitian X 2
- Tax/CRA X 2
- OT
- SW
- March of Dimes
- Mental Health Services
- Care Partners
- Quinte Healthcare
- Lifeline
- Pharmacist
- Stroke Network
- Fellow Caregivers

These survey responses continue to highlight a rather fragmented and random navigation system (consistent with results from previous surveys) 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.

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH – STROKE SURVIVORS

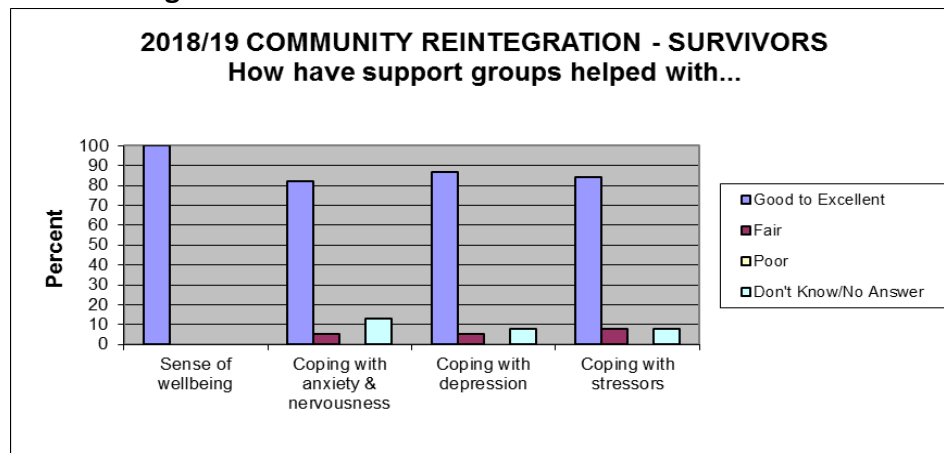
Survivor Perceived Recovery Score

The Perceived Recovery Score (PRS) 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. Data from seven stroke survivors was analysed. To be included in this analysis, stroke survivors must have completed a PRS at least six months prior to this evaluation in addition to the current PRS. Results showed a pre median score of 80 and a post median score of 75. Of the seven respondents, four reported either a stable status (n=1) or an increased perceived recovery score (n=3).

A variety of factors may contribute to a lower post-score including:

- expectations for recovery/recovery goals
- co-morbidities and aging
- length of time since stroke event

Fig. 5 Survivor Well-Being Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

"I believe this group helped in my recovery and I recommend it any time I can." ~Stroke Survivor

"It is good to associate with people who have experienced similar problems." ~Stroke Survivor

"I was hesitant about joining the groups but now I look forward to them." ~Stroke Survivor

- 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.

CAREGIVER BURDEN & PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH – CAREGIVERS

The Modified Caregiver Strain Index (MCSI) poses a number of questions related to common caregiver experiences and asks the respondent to score each experience as occurring regularly, sometimes or not occurring. A higher cumulative score indicates a higher degree of caregiver burden. Note that many caregivers opted not to respond to select questions. A process is currently underway to review the current evaluation tool and to consider moving to a different survey instrument. The caregivers will be engaged in this conversation.

FIG. 6 CAREGIVER STRAIN INDEX PART I

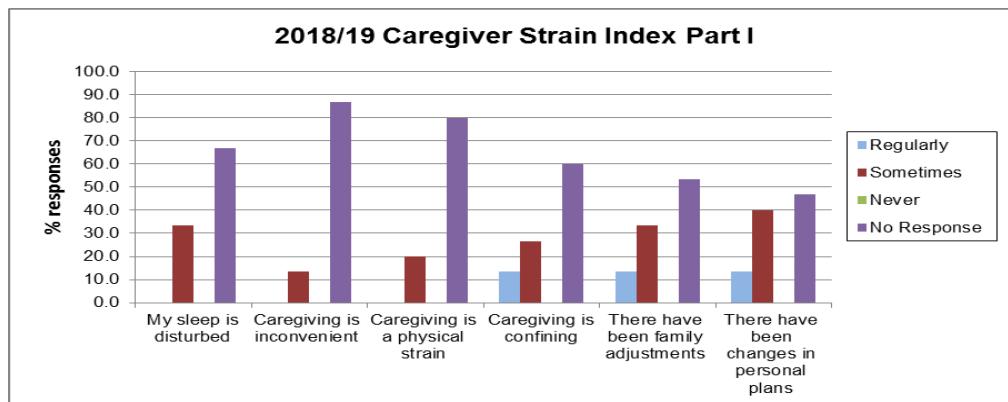
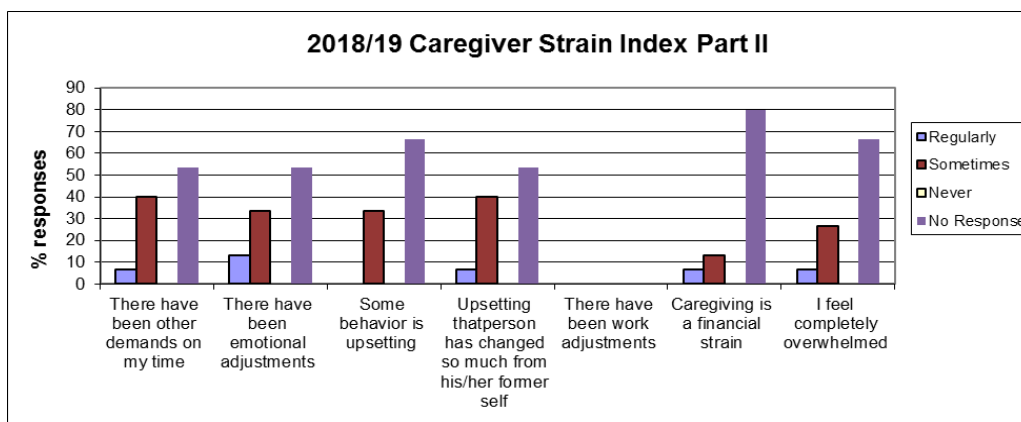


FIG. 7 CAREGIVER STRAIN INDEX PART II



Providing care to a loved one who has experienced a stroke can be both physically and emotionally taxing and the caregiver is often providing that care 24/7 with minimal respite. As evidenced by the graphs above, caregiving can impact on various components including sleep, finances, psychosocial wellbeing and adjustment to behavioural and other changes in the loved one. A caregiver who is elderly and/or is also experiencing illness adds additional complexity to this already daunting situation. It should also be noted that attending a community support group may not even be an option for some individuals providing care to a loved one who has experienced a significant stroke and is living with serious impairments due to lack of respite, lack of accessible transportation and other challenges. In response to this challenge, Belleville has created a model where a peer-led stroke survivor group (supported by the Facilitator) runs in tandem with a caregiver group. This provides an opportunity for the caregivers to share stories, challenges and strategies with their peers at the same time that their loved one is in a supported environment.

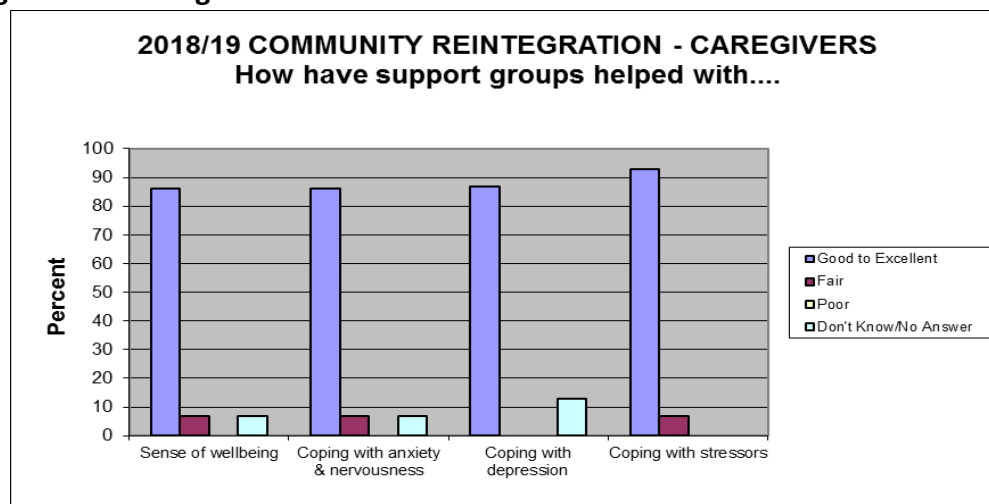
Caregiver Burden & Support Groups

Caregiver Burden is addressed through various strategies including:

- 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 the same life journey

"I learn something new and very applicable at every session." ~Caregiver

Fig. 8 Caregiver Well-Being Evaluation Tool Results



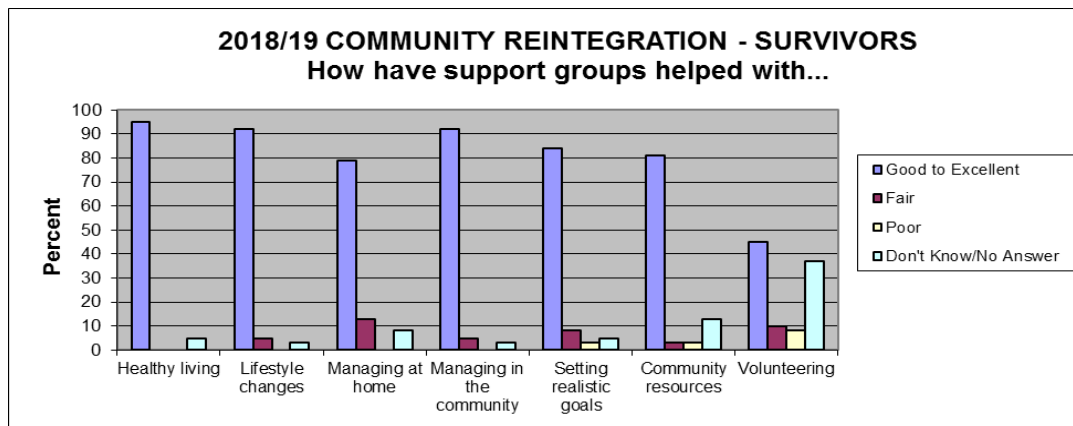
SOURCE: STROKE SERVICES EVALUATION TOOL

"The group has given me lots of support. " ~Caregiver
"Wish I'd known about the groups sooner." ~Caregiver

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.

PARTICIPANTS ABLE TO TRANSITION BACK TO COMMUNITY SETTING

Fig 9 Survivor Community Re-Integration Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

"I've received the most support since joining the stroke support groups; would have joined sooner if I'd known. First meeting I attended was a year after my stroke. I could have used the support earlier."

~Stroke Survivor

"Group sharing and discussions are required and important." ~Stroke Survivor

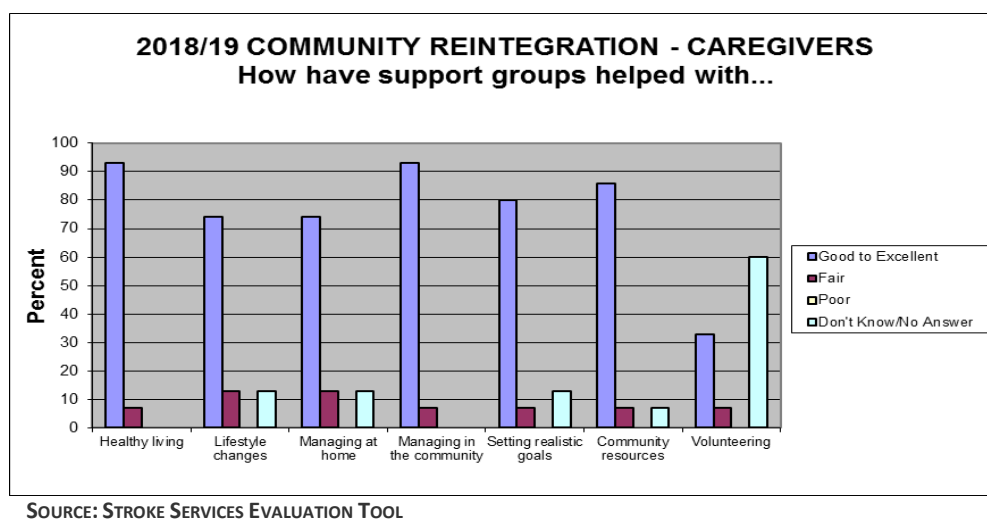
"Our stroke groups kept our brains working overtime at the meetings and we received helpful hints from other participants." ~Stroke Survivor

Results continue to illustrate the value of support group participation with respect to several domains of community reintegration.

HOSPITAL ADMISSIONS

- During this reporting period, 2 of the 58 caregivers attending support groups reported an admission to hospital (one for a fractured wrist and one to investigate syncope)
- 14 of the 174 stroke survivors attending the support groups reported hospital admissions during the evaluation period. Reasons for hospital admission: stroke/TIA (n=3), bleed/hemorrhage (n=2), depression (n=2), pacemaker removal, cardiac issue, day surgery (biopsy), fractured shoulder, cellulitis, surgery, constipation

Fig. 10 Caregiver Community Re-Engagement Evaluation Tool Results



“The group has given me lots of support.” ~Caregiver

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.

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.

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:

- **Resources to Support Increased Growth**
Referrals to the support groups continue to grow and the profile of need is expanding with the number of younger stroke survivors increasing. Younger stroke survivors typically face quite different challenges including child care/parenting and need for vocational supports. Future expanded base funding would support the growth of existing groups while ensuring that group size remains within recommended therapeutic numbers and would provide an opportunity to meet the needs of diverse stroke survivors through separate group experiences. Given the complexity of stroke and associated multifactorial impacts, the recommended participant number for the southeast support groups would be 15. Many resources cite smaller numbers. For example, in *Discovery Circles, The National Stroke Association's Guide to Organizing and Facilitating Stroke Support Groups*, it is suggested that 6 to 10 people is the most effective. (National Stroke Association, 1997). Current group sizes substantially exceed this number.
- **Outreach for Rural Areas**
Additional funding to support the coordination/facilitation necessary to further explore and sustain an outreach initiative for stroke survivors and caregivers in rural and remote locations where distance and/or cost of transportation are significant barriers to support group participation.
- **Caregiver Respite**
Additional funding to arrange and provide a respite component to operate in conjunction with caregiver support groups in each area in order to facilitate participation of caregivers who are unable to leave their loved one home unattended.
- **Recruitment**
Referrals as a percentage of population in each of KFLA, HPE and LLG are varied with LLG receiving the lowest percentage. The Stroke Network in collaboration with Senior Support Services CPHC will continue to promote the support group services to various stakeholders including hospitals, Stroke Prevention Clinics, primary care and community care.