

SOUTHEASTERN ONTARIO
REGIONAL STROKE SUPPORT GROUPS

JUNE 2018 EVALUATION

SUBMITTED TO SOUTH EAST LHIN



CANADA

STROKE NETWORK
of Southeastern Ontario



JUNE 2018 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 (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 2017 Evaluation Report:

- New Facilitator was retained for the Kingston site
- The Facilitator in Kingston received Living with Stroke[®] (LWS) Facilitator training and 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) continue to participate in the Regional Stroke Steering Committee as representatives of the CSS sector.
- Kingston and Belleville have introduced/sustained social/recreational groups. These groups are intended to further support community reintegration for members of the support groups who are at a stage in their recovery that supports a more independent experience. Belleville has initiated a group for younger stroke survivors (*Life Goes On*) and has also initiated a peer-led survivor group that occurs in parallel with a Facilitator-led caregiver group. Offering parallel groups promotes the attendance of caregivers as it provides a respite opportunity. Facilitation of these groups is supported by peers and student volunteers.
- Four Stroke Specific Community Exercise Programs have been sustained. Belleville, Trenton and Kingston are coordinated through VON and Perth through CPHC. The Brockville program coordinated by CPHC is currently on hiatus as a new program coordinator was recently retained and a new venue is to be confirmed. 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), Brockville and Belleville. Kingston is currently recruiting for a peer visiting program. Kingston also has peer visiting with a stroke survivor in LTC. Belleville has also initiated a process allowing the Facilitator to connect with stroke survivors approximately 2 months post-discharge. This supports linking to the support groups as well as other community-based supports and services.
- Stroke survivors have volunteered to participate in the Patient Program at Queen's University.



- The Belleville Stroke Support Group Facilitator and Community Care for South Hastings (CCSH) in partnership with Quinte District Rehab (QDR) have continued to support Aphasia Supportive Conversation Groups. Advocacy has continued in support of funding for the Belleville group and expansion of the model to other areas in the southeast.
- Five Living with Stroke[®] (LWS) programs were delivered in this reporting period (two in Kingston and one in each of the other three areas).
- A stroke survivor support group has been initiated in Napanee with the Kingston Facilitator.
- OT students completing a placement with the Kingston Facilitator completed a research project on the needs of younger stroke survivors (i.e. under 65 years of age) and subsequently developed a resource booklet listing relevant supports and services for all adult stroke survivors.
- OT students also created a presentation on driving after stroke and presented to the Kingston groups.

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 Couples Group, Belleville Caregivers Group, Kingston Caregivers Group, Kingston Couples Group, Kingston Stroke Survivors Group, Napanee Stroke Survivors Group). Support for Kingston & Belleville Social/Recreational Groups and *Life Goes On* Group in Belleville.
- 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

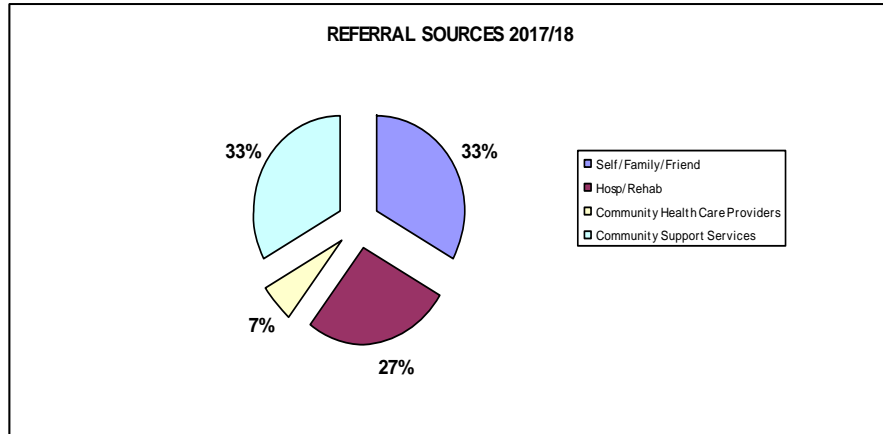
- 9 facilitated stroke groups (stroke survivors, caregivers and couples)
- 5 Heart and Stroke Foundation Living with Stroke[®] series
- 3 Peer Visiting Programs (Belleville, Perth & Brockville).
- 2 Social/Recreational Groups (Kingston & Belleville)
- 1 Young Stroke Survivors' Group (Belleville)
- 1 Aphasia Supportive Conversation Group (Belleville)

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

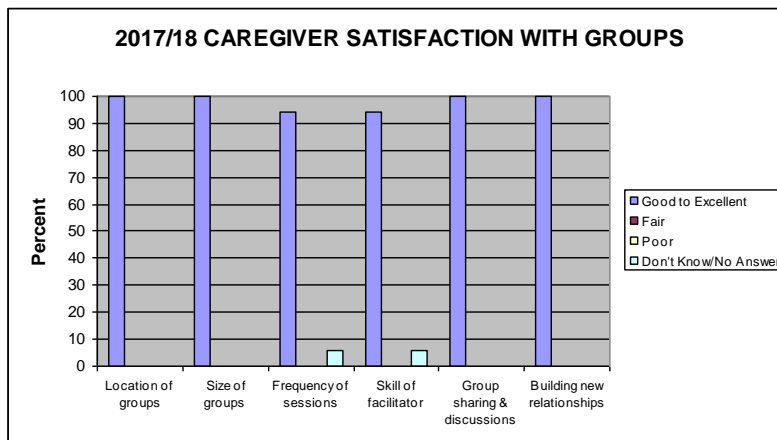
A total of 64 new referrals have been received subsequent to the last report. Self-referrals (survivor or family member) as well as hospital and community settings continue to be significant referral sources.

STROKE SUPPORT GROUP MEMBERSHIP

- 109 survivors and 51 caregivers attended support groups in this reporting period

DEMONSTRATED SATISFACTION - CAREGIVERS AND SURVIVORS

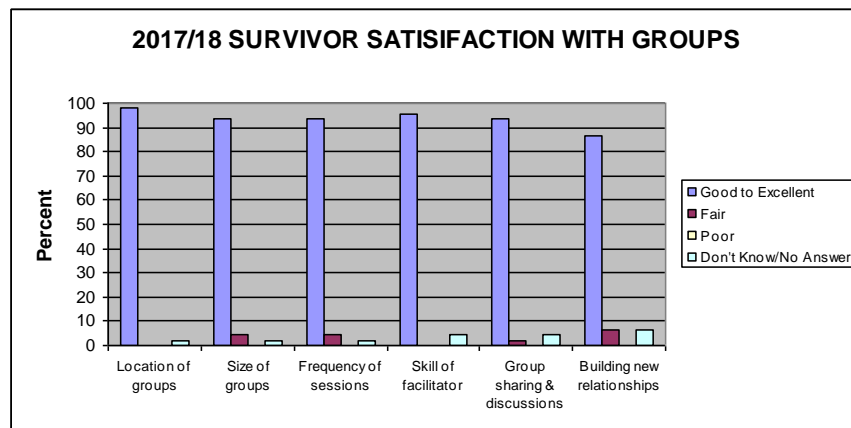
Fig.2 Caregiver Satisfaction Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

- “[Facilitator] is caring, supportive, and a wonderful help.” ~Caregiver
- “Our current facilitator is excellent and we are so thankful to have her. She takes her job very seriously”. ~Caregiver
- “[Facilitator is] very compassionate and caring.” ~Caregiver

Fig. 3 Survivor Satisfaction Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

- “[Facilitator] is a very good communicator and always has interesting topics.” ~Survivor
- “Sessions are very helpful. Learning how others adapt to stroke.” ~Survivor
- “Very informative, necessary for networking and sharing info and tips for living with stroke.” ~Survivor

Figures 2 and 3 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



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?”, 95% 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:

Organizations/Individuals Identified as Providing Navigation Support

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

- VON X 3
- Dietitian X 3
- Pharmacist X 2
- Community Brain Injury Services X 2
- Kingston Access Bus X 2
- Belleville Mobility Bus
- Physiotherapy
- OT
- SW
- Heart & Stroke
- SMILE
- Queens
- Providence Care Hospital
- VON meals
- Heart to Home meals
- March of Dimes
- Lanark County Mental Health Services
- Perth Enrichment Program
- Carolina Retirement Residence
- Hearing Society
- Quinte District Rehab

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

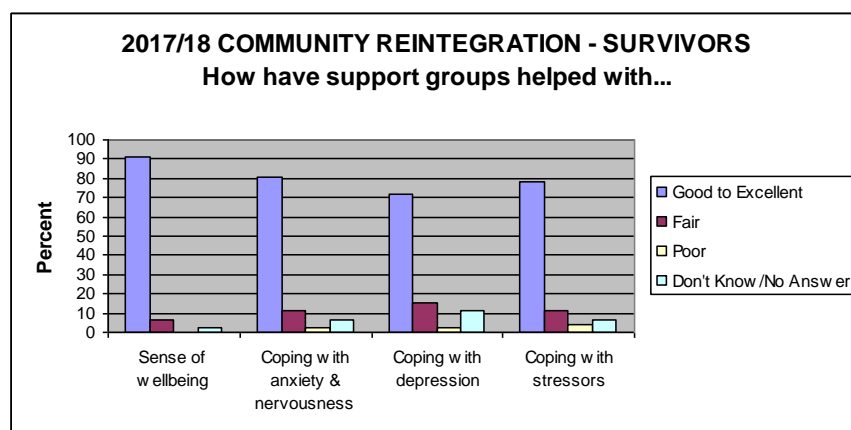
Survivor Perceived Recovery Score

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 twelve 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 75 and a post median score of 77.5.

In reviewing individual data, 50% of stroke survivors either maintained or improved their scores. 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. 4 Survivor Well-Being Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

“The meetings have helped me quite a lot. Encouraging.” ~Survivor

“Keeping in touch on a monthly basis for the supports.” ~Survivor

“Doing great, good group of people, discussing things is beneficial, everyone gets along. I’m happy with the group.” ~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 has been used as the caregiver burden measure for the first time during this evaluation period (previously the Montgomery-Borgatta tool had been used). The decision to move to the MCSI was prompted by two factors:

- Facilitators had noted that completion of the Montgomery-Borgatta could be both stressful and confusing for the caregivers
- The MCSI is a validated tool that is more widely used

The 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.

FIG. 5 CAREGIVER STRAIN INDEX PART I

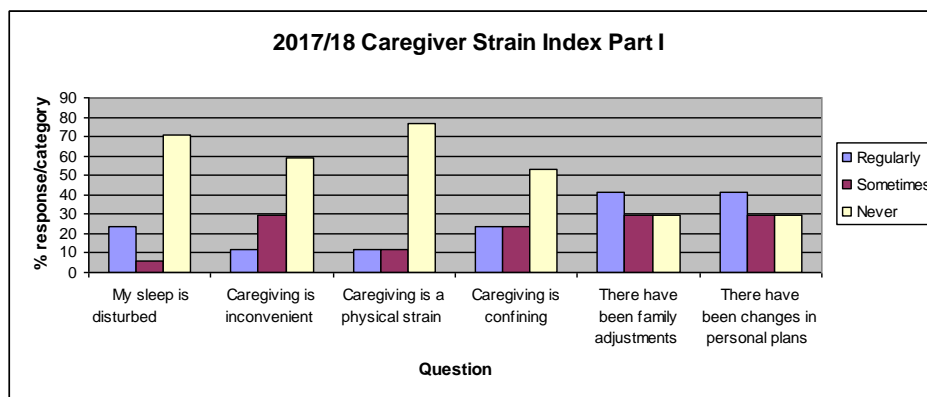
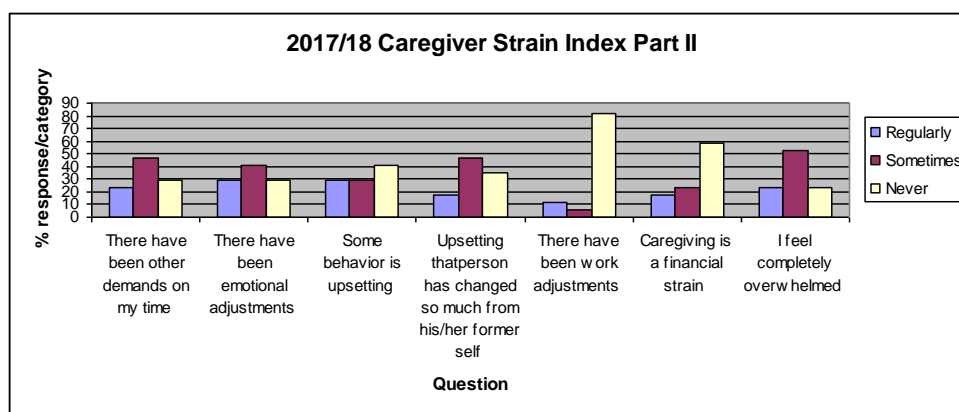


FIG. 6 CAREGIVER STRAIN INDEX PART II



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 adjusting to behavioural and other changes in the loved one. A caregiver who is elderly and/or also experiencing illness adds to this already complex situation. It should also be noted that attending a community support group may not even be an option for 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.

Caregiver Burden & Support Groups

Caregiver Burden is addressed through various strategies including:

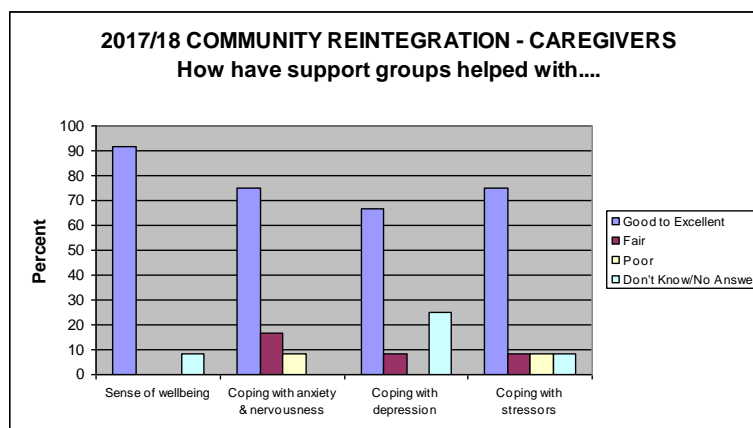
- Education re stroke to enhance understanding of the current health status of their loved one as well as tips to support illness prevention & health promotion to reduce the risk of another stroke or other disease (e.g. cardiac and diabetes)
- Information on identifying stressors and implementation of 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

“A huge struggle. Husband is difficult and personality has changed so much. Feel alone and tired most days.” ~Caregiver

“I have it very good because my wife does everything for me.” ~Survivor

“Realized being in a group setting and hearing other people's stories that she is lucky to only have minor changes post stroke.” ~Caregiver

Fig. 7 Caregiver Well-Being Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

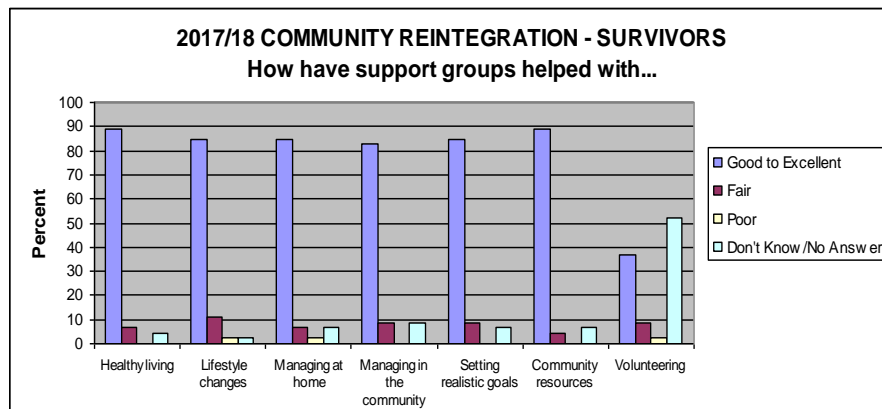
“The group is a place where others can relate to our situation and offer comfort and advice, good for social interactions. ” ~Caregiver

“They all are quite willing to share their experiences and point to personal experience.” ~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 8 Survivor Community Re-Integration Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

“Nice to hear what other people in the group have to say.” ~Survivor

“Group has been beneficial to me.” ~Survivor

“Keep sharing contacts and support systems.” ~Survivor

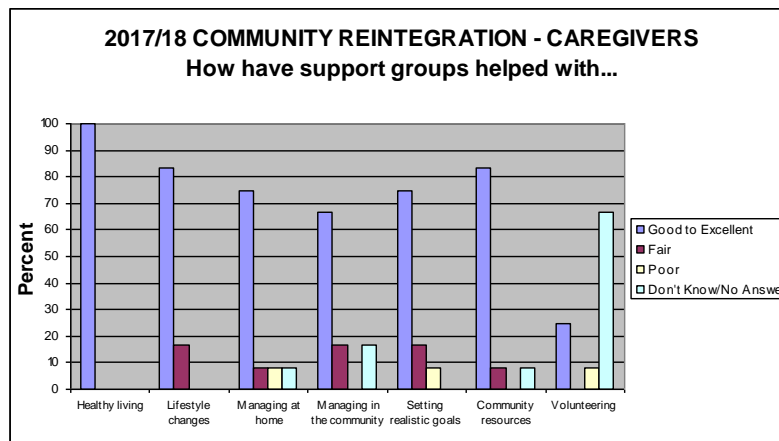
Results continue to illustrate the value of support group participation with respect to several domains of community reintegration.

HOSPITAL ADMISSIONS

- During this reporting period, 2 of the 51 caregivers attending support groups reported an admission to hospital (one for a dog bite and one for a bleeding ulcer)
- 13 of the 109 stroke survivors attending the support groups reported hospital admissions during the evaluation period. Reasons for hospital admission included two falls resulting in fractures, one hypertension, one pneumonia/COPD, one chest infection and 7 with stroke or

TIA (note that 2 of those experiencing stroke were admitted prior to attending the support groups).

Fig. 9 Caregiver Community Re-Engagement Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

“Excellent resources and we are fortunate to have these programs.” ~Caregiver
“It’s been a wealth of information.” ~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 may 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 younger stroke survivors through a separate group experience. 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).

- **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.

- **Aphasia Conversation Groups**

Base funding to sustain the Belleville community-based Aphasia Supportive Conversation Groups and expand the model to Kingston, Brockville and Perth/Smiths Falls. The needs of Adults with Aphasia continue to be underserved in the southeast as evidenced by comments received during this evaluation process:

"Need help with writing and speaking." ~Survivor

"Doing really well. Just wish that the aphasia program would get up and running in Kingston."

~Caregiver