

**SOUTHEASTERN ONTARIO  
REGIONAL STROKE SUPPORT GROUPS**

**OCTOBER 2014 EVALUATION**

**SUBMITTED TO SOUTH EAST LHIN**



**CANADA**

**STROKE NETWORK**  
*of Southeastern Ontario*



## OCTOBER 2014 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 April 2014 Evaluation Report:

- The facilitator for the Perth & Brockville groups has participated in The Brain, The Body and You education sessions. This is a stroke education program offered by St. Lawrence College in partnership with the Stroke Network of Southeastern Ontario and based on the best practice resource Tips & Tools for Everyday Living<sup>®</sup> (Heart & Stroke Foundation). The facilitator for the Perth & Brockville areas was newly hired in February, 2014.
- The facilitator for the Perth & Brockville groups will be attending education at The Aphasia Institute in Toronto in 2015 supported by the Stroke Network of Southeastern Ontario
- The facilitators for the the Kingston and Belleville groups participated in the March of Dimes Disability Conference in September 2014 with a table display to enhance awareness of community supports available
- A presentation on the evaluation findings was delivered at the annual Recreation Therapists in Ontario Conference
- A presentation by two facilitators on the support group evaluations at the May provincial stroke rounds (via OTN)
- 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
- The new informational brochure for the Perth group which has incorporated a design created by one of the group members is in the final formatting stages
- One Living with Stroke<sup>®</sup> (LWS) program is being delivered in Kingston and a second program is currently in the recruitment phase 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 in early spring 2015
- Peer Visiting Volunteer Programs are in place or in the process of training volunteers in Kingston and Perth



- 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.
- Media has been sourced to increase the profile of the support groups including use of Twitter and Facebook in Belleville. In Perth & Brockville, the facilitator has participated in two newspaper interviews, a radio interview and will be participating in an upcoming television spot

### **S.U.P.P.O.R.T.**

Stroke Understood: a Peer Program Optimizing Recovery Together

*"It [support group] has encouraged me greatly to continue my work at "getting better". Survivor*

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. Therefore, this report will include perceived recovery scores and the results of the satisfaction survey. Caregiver burden will be included in the April 2015 report.

#### **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
- 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 semi-annual 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**

- Administration of the Stroke Services Evaluation Tool to participants to evaluate satisfaction and changes to health status. Three additional questions were added to this evaluation to provide a better understanding of how stroke survivors and caregivers are supported when navigating the health and social support systems:
  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:
- Administration of the Perceived Recovery measure (a component of the Stroke Impact Scale) to stroke survivors

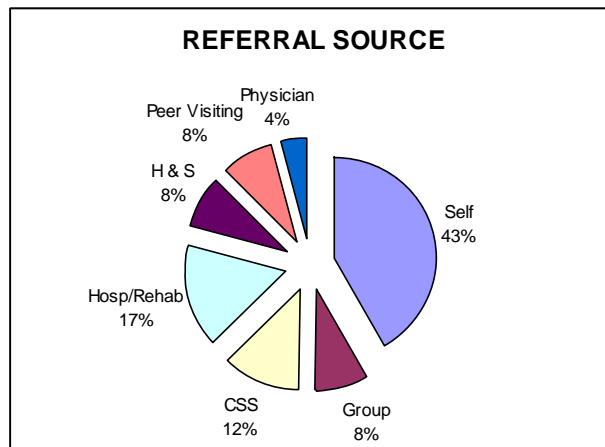
*Note that quotes included in this report are derived from responses to the Stroke Services Evaluation Tool.*

**SERVICES PROVIDED**

- 8 facilitated stroke groups
- 2 Heart and Stroke Foundation Living with Stroke™ series completed or in process
- 2 Peer Visiting Programs

**REFERRAL SOURCES**

**Fig. 1 Source of New Referrals**



Source: Stroke Services Evaluation Tool



A total of 24 new referrals have been received subsequent to the last report. The majority of referrals continue to be self-referrals as individuals become aware of the support groups through brochures, flyers and media exposure. Health care partners (hospital, rehab, community support services) continue to be significant referral sources and the 'host' agencies (i.e. VON, CCSH and CPHC) are also referral sources. The Peer Visiting Volunteer Program in Perth where current members of the Stroke Survivor & Caregiver Group receive training to visit new stroke survivors in the hospital setting continues to be a source for new referrals. The Heart & Stroke Foundation (H & S) has become a new referral source in the Quinte region. Efforts to engage family practitioners as a referral source are a priority in the Quinte region.

### **STROKE SUPPORT GROUP MEMBERSHIP**

- 56 survivors and 37 caregivers are attending support groups

### **PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH - CAREGIVER BURDEN**

This measure will be included in the April 2015 report.

### **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:

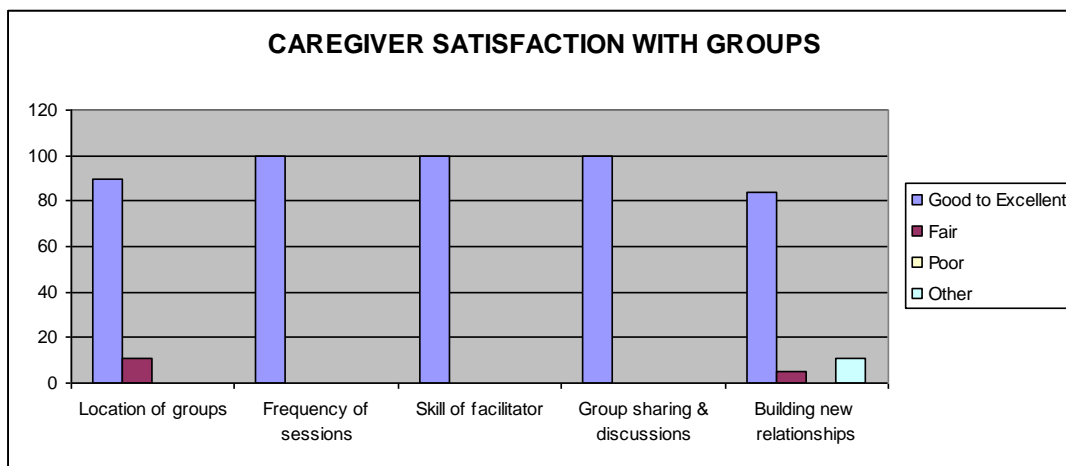
- Education re stroke to enhance understanding of the current health status of their loved one as well as tips to support illness prevention & health promotion to reduce the risk of another stroke or other disease (e.g. cardiac and diabetes).
- Information on identifying stressors and implementation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

*"We feel very lucky to have the help and support that we have received. It really has helped and everyone involved seems to care." - Survivor*

### **DEMONSTRATED SATISFACTION - CAREGIVERS AND SURVIVORS**

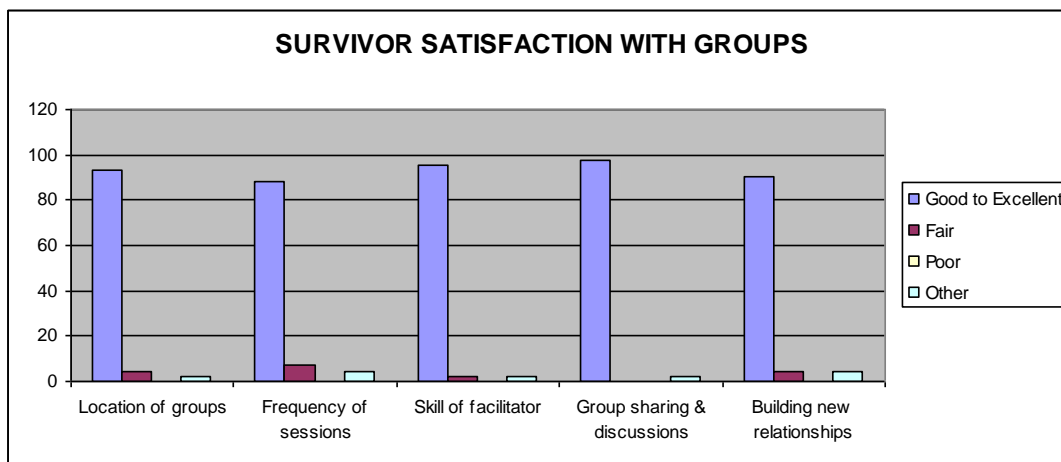
Note that 'other' in legends for the Stroke Services Evaluation Tool includes survey respondents who did not respond to question or indicated that question was either not applicable or didn't know the answer.

**Fig.2 Caregiver Satisfaction Evaluation Tool Results**



SOURCE: STROKE SERVICES EVALUATION TOOL

**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.

*"[Name of facilitator] is very caring and helpful."*

*"Very helpful – [name of facilitator] is an excellent facilitator"*

*"I enjoy this group very much and [name of facilitator]. I hope they never end!"*

*"Facilitator/location are perfect."*

It should also be noted that two respondents indicated an interest in more frequent support group meetings.

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.

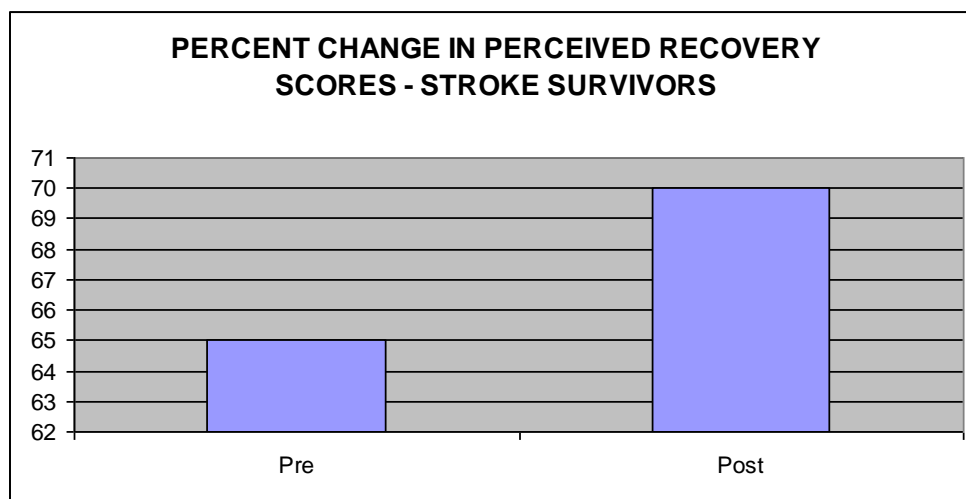
As noted earlier, three additional questions have been included in the SSE tool. Respondents indicated 100% agreement when asked if they were satisfied with the individual information and/or the referral information that they received from the group facilitator. In response to the question, “Are you satisfied with the assistance you have received from organizations/individuals other than the stroke group facilitator?” 83% 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:

- ABI/RCBIS (5)
- CCAC (2)
- Physician (2)
- Revved Up (2)
- H & S (2)
- Motion Specialities
- Medigas
- Pathways
- Kaymar (OT)
- Hospice Kingston
- SMILE
- Retire-At-Home
- VON
- Paramed (SW)
- CCSH
- CLSC (Quebec)
- CPHC
- LDS Church
- St. Elizabeth
- Rehab Management Services
- Superintendent

While it is positive that stroke survivors and caregivers can receive navigation services from a variety of sources, it also points to a rather fragmented and random navigation system. As well, given that some of the sources cited as navigators (e.g. church, superintendent) may not have a familiarity with the health and social support system, the directions provided to the stroke survivors/caregivers may not be accurate. This rather extensive listing also highlights 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**

**Fig. 4 Survivor Perceived Recovery Scores**



Source: SIS

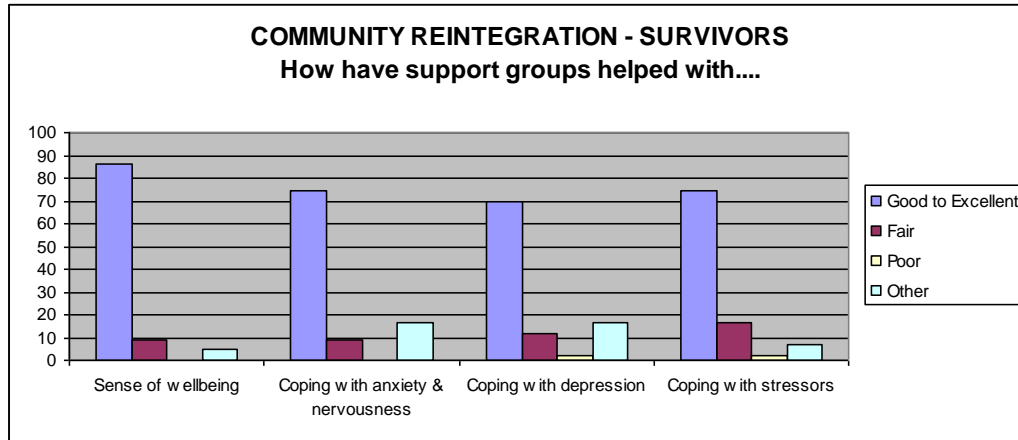
As with previous evaluations, stroke survivors self-perceived recovery scores have increased pre/post (for this report, from 65 pre to 70 post on a scale of 0 - 100, with 100 representing full recovery and 0 representing no recovery).

*“Just talking with members about experiences is encouraging for paralysis and emotional issues.” - Survivor*

*“Stroke group has been a great help to me. Thank you.” - Survivor*



**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.

*“A stroke survivors group is exactly what people need in our community. When your life changes we need support in the right direction.” - Survivor*

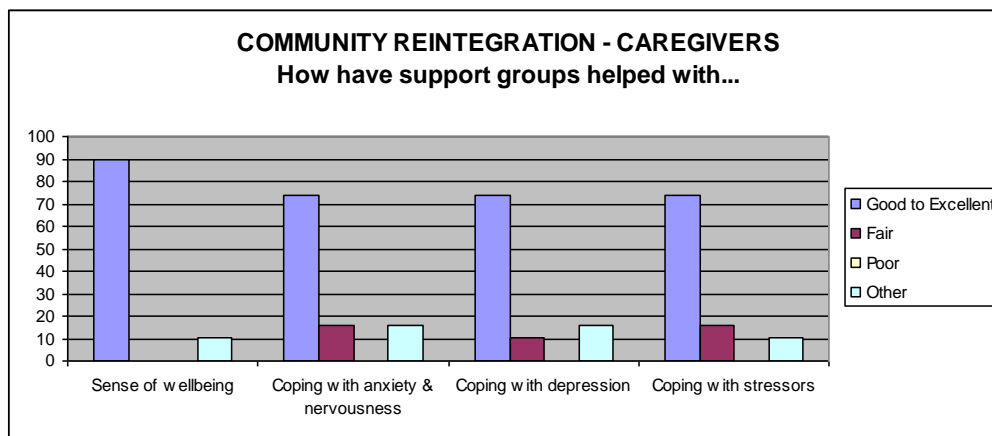
*“Feel comfortable talking and know I'm not being judged.” – Survivor*

*“Able to come out of “shell”. – Survivor*

*“I look forward to pooling of ideas.” - 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.

*“Practical advice on finances on a basic level. Same for eating/living.” – Caregiver*

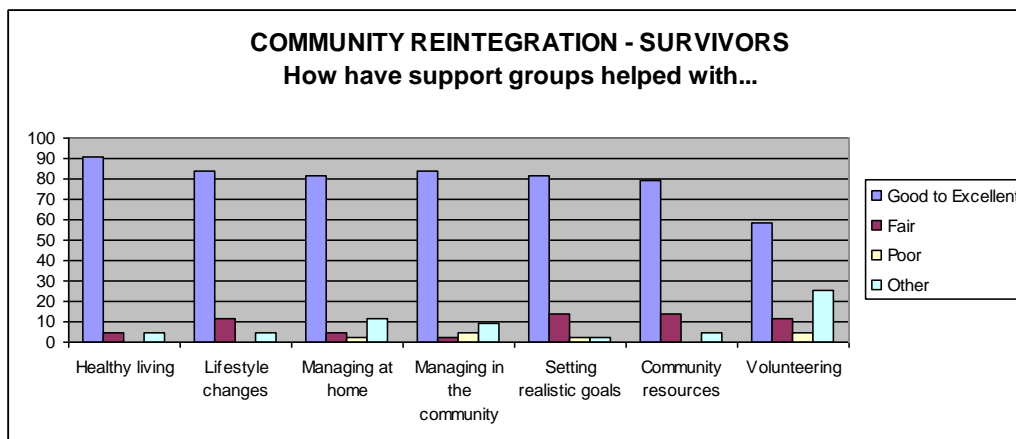
*“I find the presentations, education, information sharing and discussions etc very helpful in a lot of ways.” - Caregiver*

**PARTICIPANTS RECEIVING DISCHARGE LINK**

Seven of the 12 new referrals to the stroke survivor support groups in the Kingston and Belleville regions since last report stated that they had received therapy services through the Discharge Link Program (note that Perth/Brockville is not included in this number due to missing data). 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 8 Survivor Community Re-Integration Evaluation Tool Results – Kingston, LLG & HPE**

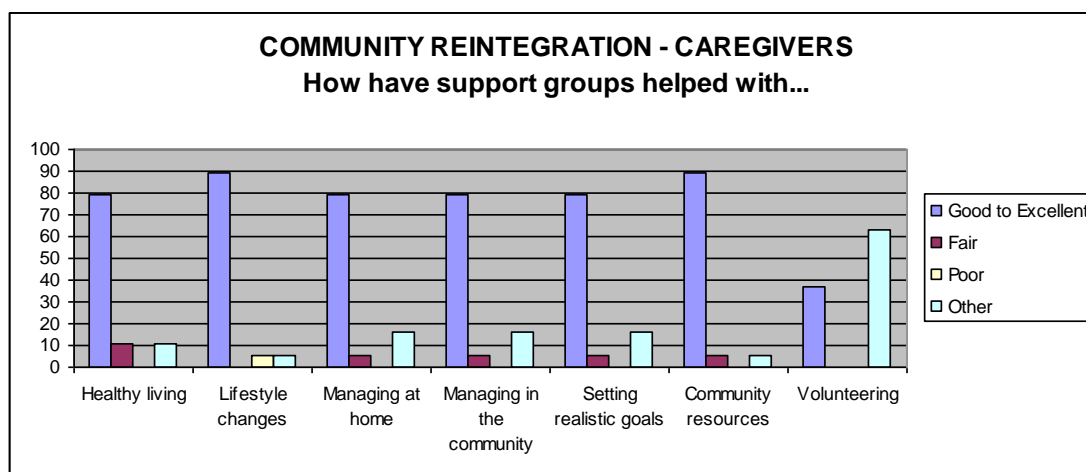


Source: Stroke Services Evaluation Tool

**HOSPITAL ADMISSIONS**

- All group participants have succeeded in remaining in the community. Currently, most live in their own homes, or with family members.
- During the last twelve months,, three of the 37 caregivers attending support groups reported an admission to hospital (Strep throat and blood infection, gallstone, triple bypass)
- Nine stroke survivors of the 56 attending the support groups were admitted to (and discharged from) the hospital during the evaluation period. (kidney, fall (2), TIA, tests, colonoscopy, stroke (2), unknown). Note that it is not clear if those admitted to hospital for TIA and stroke experienced this prior to or during their participation in the stroke group)

**Fig. 9 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.

*“Gives me a reason to look forward to social interaction/brainstorming.” – Caregiver*

*“Very helpful and informative.” - Caregiver*

With respect to the low scores for volunteering, it is evident that the care burden held by the family members of stroke survivors is considerable and often precludes them from participating in such activities.

*“I would like to volunteer my services in some way when I am in position where I can. Right now I have a lot going on so it makes it difficult.” Caregiver*

*“Care of partner = little time to volunteer.” - 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
- Improved Perceived Recovery Score for survivors
- Consistent positive feedback on the skills of the facilitators and the valuable role they play for successful and therapeutic groups
- Recognition of the valuable role facilitators play in 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.
- As the results in this evaluation and previous evaluations have consistently demonstrated positive results, it is recommended that evaluation be conducted on an annual basis as more frequent surveying of survivors and caregivers is burdensome to these groups and very labour-intensive for the group facilitators. Should changes to the current programs be initiated or new programs be added, specific evaluations could be implemented.



- 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.
- The Stroke Network of SEO is planning a regional community engagement exercise in 2015 that will include focus groups and interviews to investigate what stroke survivors and caregivers experience in relation to community reintegration. This will provide further information that will help to inform the above recommendations.

*"I couldn't live without [the support groups]." - Survivor*