

**SOUTHEASTERN ONTARIO
REGIONAL STROKE SUPPORT GROUPS**

APRIL 2014 EVALUATION

SUBMITTED TO SOUTH EAST LHIN



CANADA

STROKE NETWORK
of Southeastern Ontario



APRIL 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 – Hastings/Northumberland/Prince Edward (for Kingston region).

Subsequent to the November 2013 Evaluation Report:

- Community Care for South Hastings (CCSH) has relocated to a venue where they are co-located with community partners and adjacent to the CCAC. The new location is also proximal to bus routes and has the potential for on-site meeting space and OTN capabilities.
- The facilitator for the Kingston Support Groups has reconnected with former group participants and has secured meeting sites for all three groups.
- Community & Primary Health Care (CPHC) has hired a new facilitator for the Perth & Brockville groups following the resignation of the previous facilitator in January 2014. The new facilitator has reconnected with the two support groups and has facilitated two sessions. Orientation of the new facilitator used a collaborative approach between CPHC, the Stroke Network of SEO and the CCSH and VON facilitators. Planning is in place for the Stroke Network to support the new facilitator's attendance at The Aphasia Institute in Toronto in October 2014.
- A presentation on the evaluation findings by the group facilitators at the December 2013 SEO Stroke Symposium was very well received. Planning is currently underway for a presentation in May 2014 for the Provincial Stroke Rounds by 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.
- A member of the PSF Support Group has designed a new informational brochure for that group.
- Two Living with Stroke[®] programs have been delivered and a third program is currently in process.
- An initial link has been made with March of Dimes, Stroke Recovery Canada with respect to accessing their peer support training resources.
- Shell-Lee Wert (Executive Director, Community Care for South Hastings) and Patti Lennox (Supervisor, Caregiver Support Program, CPHC) have joined the Regional Stroke Steering Committee as representatives of the CSS sector.



As the Kingston Stroke Survivor and Caregiver Support Groups only resumed activity in November, 2013, the Stroke Impact Scale (SIS) and Caregiver Burden Scale (CBS) were not performed for those groups for this report (i.e. not sufficient pre/post time frame). However, the Stroke Services Evaluation was conducted.

Please also note that the time frame for the collection of data in LLG and HPE for the SIS and CBS was cumulative since the November 2013 Evaluation Report (i.e. post results captured during this reporting period were compared with the pre-results captured for last reporting period). It is evident from this report that the positive results from November 2013 (and the earlier Kingston evaluation report) have been sustained.

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

Stroke Understood: a Peer Program Optimizing Recovery Together

"I have gotten stronger, and I am looking forward to learning new ways to cope." Stroke Survivor

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 (e.g. Occupational Therapy speaking on cognitive and perceptual challenges, financial advisor on Disability Tax Credit, Registered Nurse presenting on falls risk and prevention).
- Facilitators also bring forward 'stimulus' questions to prompt discussion of psychosocial concerns and issues within the groups.
- Management of referrals for potential group participants, completion of Stroke Services Evaluation tool, administering the stroke survivor Stroke Impact Scale and Montgomery-Borgatta Caregiver Burden scale and support for attendance.
- Outreach to and networking with community based partners.
- Transportation arrangements if required.
- Referral to community resources, as required, (with consent).
- Monitoring of individual group participants as required through phone calls and email.
- System navigation including the identification of appropriate community resources, how to access their local system, and initiating a referral.
- Case management when the 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.

- 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

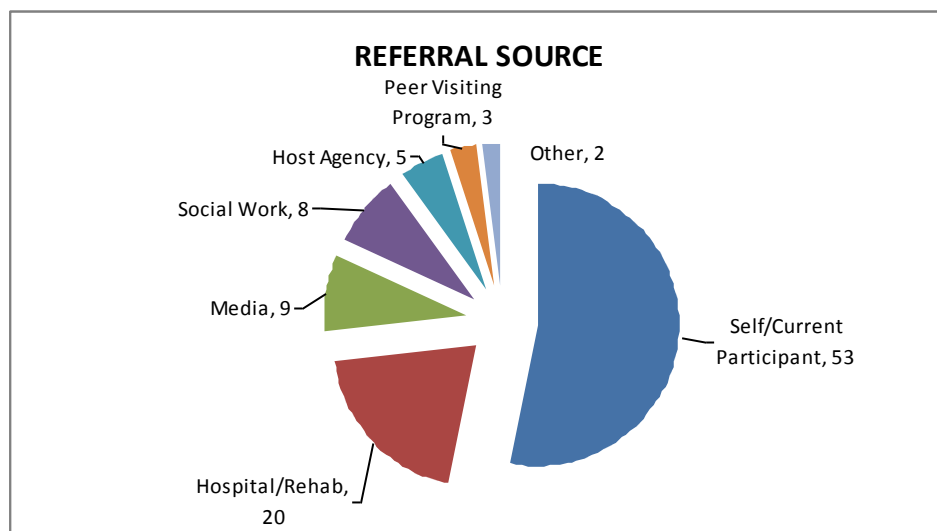
- Administration of the Stroke Services Evaluation Tool to participants in all three regions to evaluate satisfaction and changes to health status. (Tool developed by Kingston group).
- Stroke survivors in the LLG and HPE regions completed the Stroke Impact Scale (SIS), a recognized standardized tool (as the reinitiating of the **Kingston** group did not begin until November/December this did not provide adequate time for pre/post surveys).
- Caregivers in LLG and HPE completed the Montgomery Borgatta Caregiver Burden of Care, a standardized tool (as the reinitiating of the **Kingston** group did not begin until November/December this did not provide adequate time for pre/post surveys).
- Pre-survey scores were derived from the spring/summer evaluation process.
- The quotes are from the Stroke Services Evaluation tool from all three regions.

SERVICES PROVIDED

- 8 facilitated stroke groups
- 4 Heart and Stroke Foundation Living with Stroke™ series completed or in process
- 1 Peer Visiting Program

REFERRAL SOURCES

Fig. 1 Source of New Referrals (Kingston, LLG and HPE)



Source: Stroke Services Evaluation Tool



The majority of referrals are 'self' which includes those participants who were group members prior to the initial evaluation process. Health care partners (hospital, rehab, primary and community care) 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. Social workers providing services in the hospital, rehab and community settings recognize the value of the support groups and link clients to the facilitators.

STROKE SUPPORT GROUP MEMBERSHIP (Kingston, LLG and HPE)

- 64 survivors and 34 caregivers are attending support groups.
- 32 individuals completed or are participating in Living with Stroke[®] (LWS).

The value of the LWS Program is evident from the following participant comment, *"Discussions were great as life presents new challenges for all...the safer we feel the more relaxed we feel to grow and heal."*

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH IN LLG AND HPE- CAREGIVER BURDEN

As the number of caregivers completing both pre and post Caregiver Burden scales was very small (n=4), this data has not been included in the report. The numbers completing the survey were impacted by:

- Some respondents did not answer each question in each of the three domains (see below) thereby invalidating totals. While the Montgomery-Borgatta is a validated tool, consideration is currently being given to replacing that tool with the Kingston Caregiver Stress Scale (KCSS). The KCSS was designed for caregivers of individuals who have been diagnosed with dementia however there was some suggestion in the literature that it was applicable to caregivers of other populations.
- Caregivers in the Kingston groups were not included in the testing for this evaluation as the time frame was not sufficient.
- The transition between facilitators in the LLG region proved challenging as there was a gap between the resignation date of the previous facilitator and the hiring of the new facilitator. Compounding the situation, the new facilitator was on bereavement leave for a portion of the data collection period limiting her capacity to collect the data.

The Montgomery Borgatta Caregiver Burden Scale consists of three domains:

- Objective Burden which consists of 6 questions.
- Subjective Stress Burden which consists of 4 questions.
- Demand Burden which consists of 4 questions.

While, the caregiver burden is not reported in graphic format, the following quotes from caregivers completing the Stroke Services Evaluation speak to the ongoing value of the group for this population:

“I really enjoy the comments & discussions by our Group Leader & participants as I always hear of things I can do/use to improve my own situation as a Caregiver. We have had a wonderful variety of topics discussed to help us navigate through these difficult life situations!”

“They [the group members] have given me confidence to accept the inevitable lifestyle change and to pursue many of my former interests.”

“The Stroke Caregiver Group has helped me tremendously to accept life changes and move forward in my life. I have made good friends here.”

Caregiver Support Groups

As stated in the November 2013 Evaluation Report, 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 the same life journey.

DEMONSTRATED SATISFACTION OR COMPLAINTS IN KINGSTON, LLG AND HPE- CAREGIVERS AND SURVIVORS

Fig.2 Caregiver Satisfaction Evaluation Tool Results

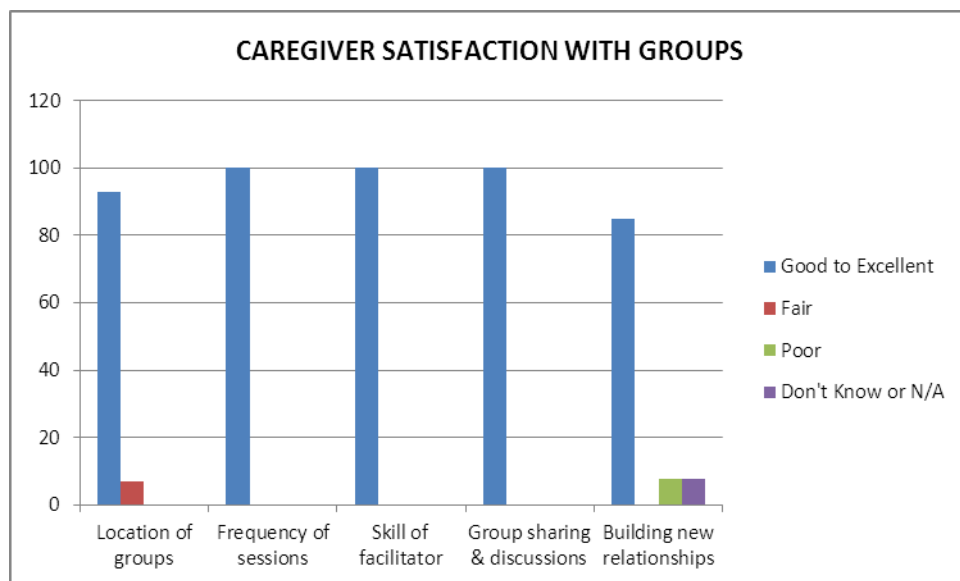
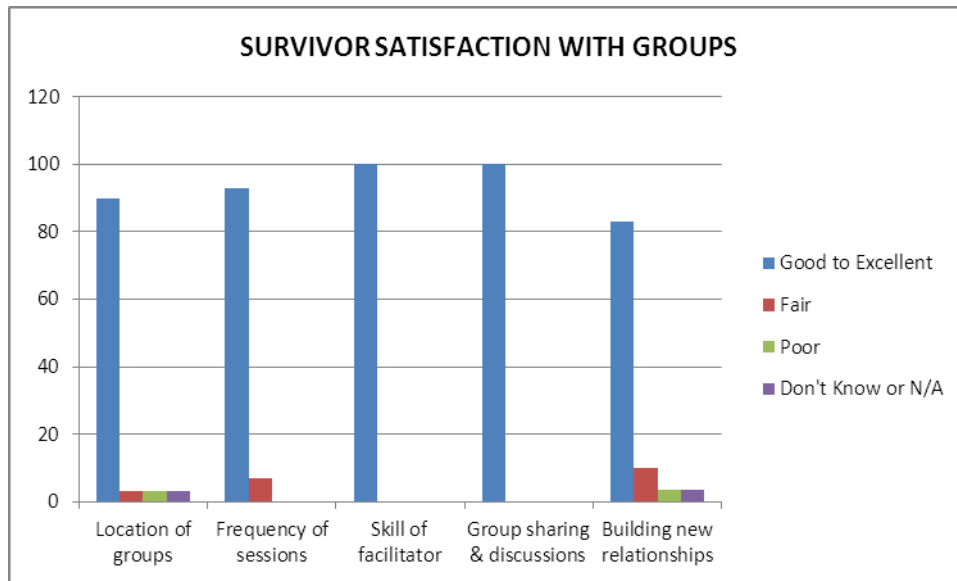


Fig. 3 Survivor Satisfaction Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

Figures 2 and 3 indicate a high level of satisfaction with groups for both stroke survivors and caregivers. Note that all respondents rated the skill of the facilitator as good to excellent – this rating is consistent with the previous Evaluation Report.

“I feel that [name of facilitator] is an excellent Coordinator and helper.” Survivor

“[Name of facilitator] is an absolutely wonderful group leader!” Caregiver

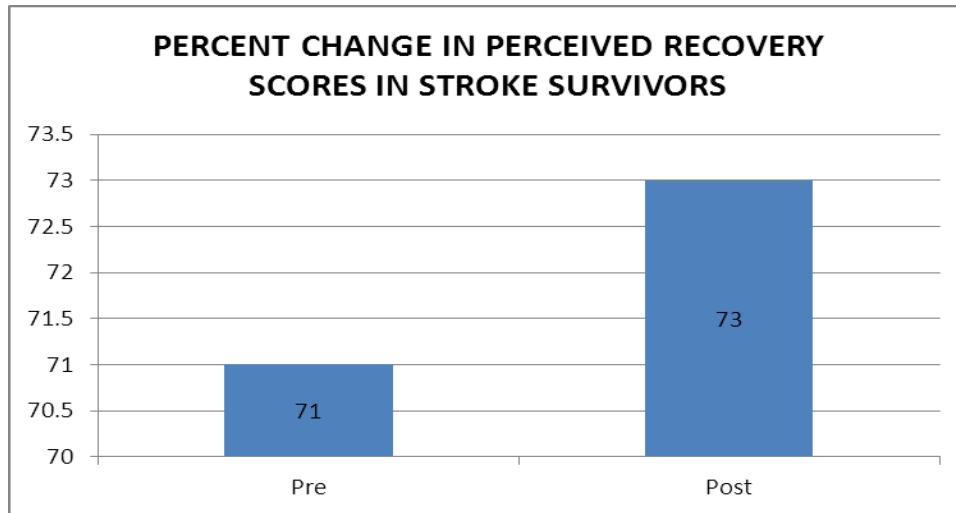
“The group was very well facilitated when I joined and it has helped me find a voice for my situation”. Survivor

The facilitator continues to play a key role:

- Liaising with health and social services partners to enhance referrals.
- Conducting intakes 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 navigation support to make certain that survivors and caregivers are linked to community resources and managing referrals where appropriate.

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH IN LLG AND HPE – STROKE SURVIVORS

Fig. 4 Survivor Perceived Recovery Scores

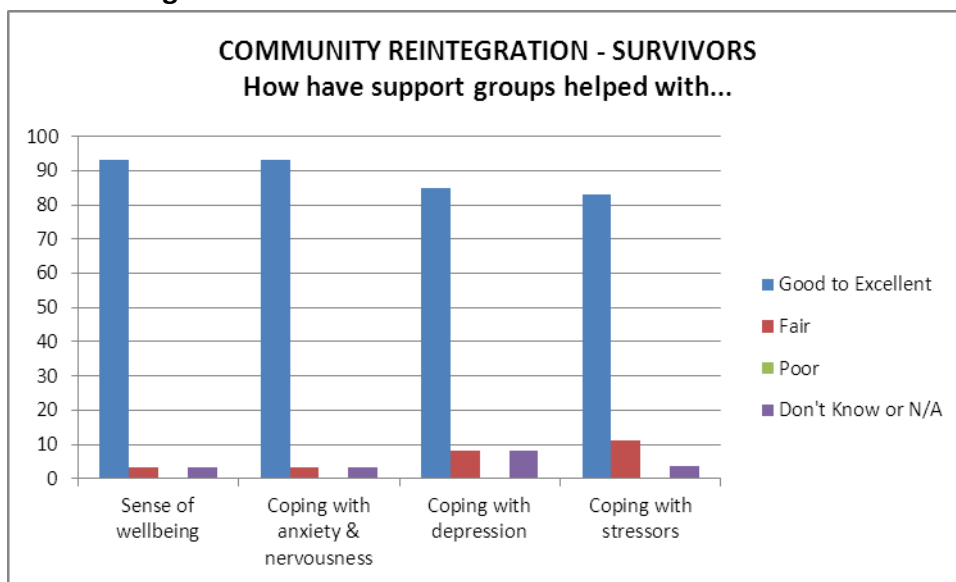


Source: SIS

Stroke survivors self-perceived recovery scores increased from 71 pre to 73 post on a scale of 0 - 100, with 100 representing full recovery and 0 representing no recovery. Note that pre-score was calculated on original survey conducted in spring/summer 2013 allowing for an evaluation period of up to 9 months. Improvements continue to be perceived by the stroke survivors.

“My time here is great, keeps me excited to be around others who are in the same situation I am in.” Survivor

Fig. 5 Survivor Well-Being Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

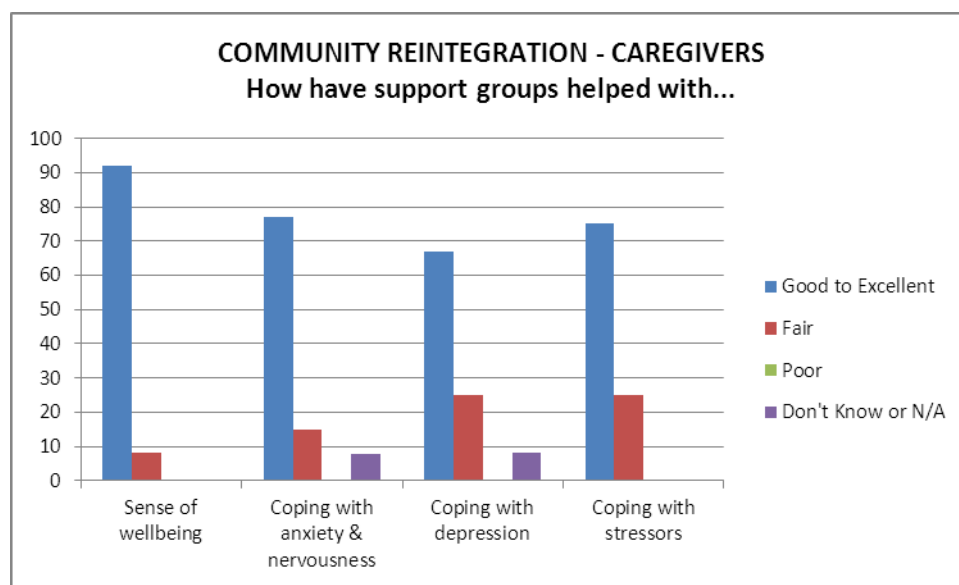
- The majority of stroke survivors saw the group as “good to excellent” in contributing to a sense of well-being as well as helping them cope with anxiety/nervousness, depression and stressors.
- Having an opportunity to share feelings, experiences and successes in a ‘safe’ venue supports emotional well-being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

“It’s good to be able to talk to other people who have had strokes!!” Survivor

“This is an excellent program. I highly recommend this program. Thank you!! I love it. Thank you!” Survivor

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH IN KINGSTON, LLG AND HPE- CAREGIVERS

Fig. 6 Caregiver Well-Being Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

As noted earlier, the small number of completed Montgomery-Borgatta surveys did not support inclusion in this report however the above graph demonstrates the value of the groups as perceived by the caregivers. 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. For some caregivers, they may opt not to attend a group but having their spouse attend the survivors’ group provides some much needed and valued respite.

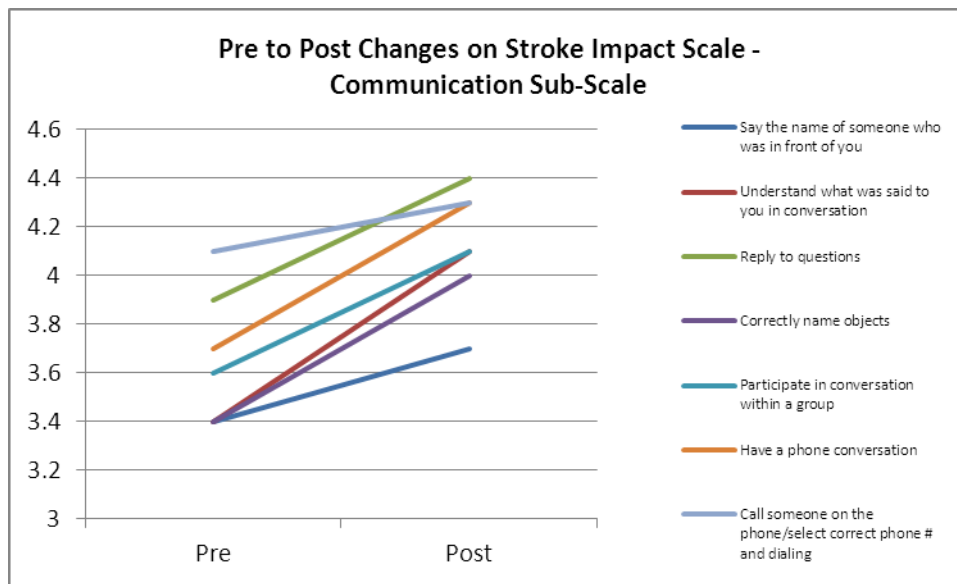
"I appreciate [the] chance to meet with others in same situations and able to "vent" my feelings and frustrations." Caregiver

"Gained insight and hopefully helped others because of my experience." Caregiver

"I find now I just don't care about anything or anybody that tries to give me any stress." Caregiver

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH IN LLG AND HPE – STROKE SURVIVORS
STROKE IMPACT SCALE PRE AND POST CHANGES

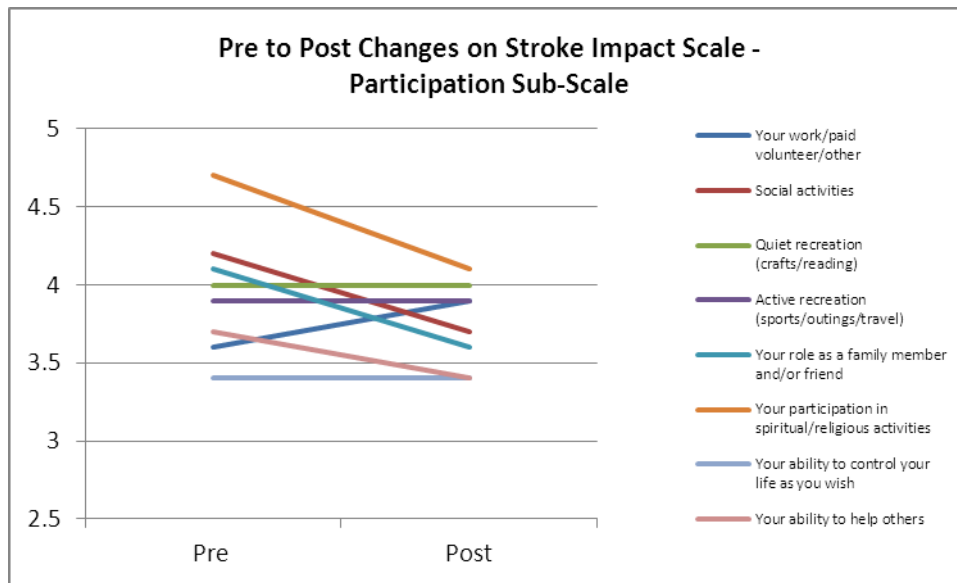
Fig. 7 Pre-to Post-Test Changes on Communication Sub-Scale – LLG and HPE



Source: Stroke Impact Scale

- Figure 7 shows that survivor perceived abilities to communicate improved on all eight communication domains.
- The prevalence of aphasia in stroke survivors necessitates supportive communication strategies (by trained facilitator) in the group (note that training through The Aphasia Institute in Toronto is provided to all facilitators supported by the SEO Stroke Network).

Fig. 8 Pre-to Post-Test Changes on Participation Sub-Scale – LLG & HPE



Source: Stroke Impact Scale

Figure 8 shows an improvement or relative stability post-test on four of the eight participation domains

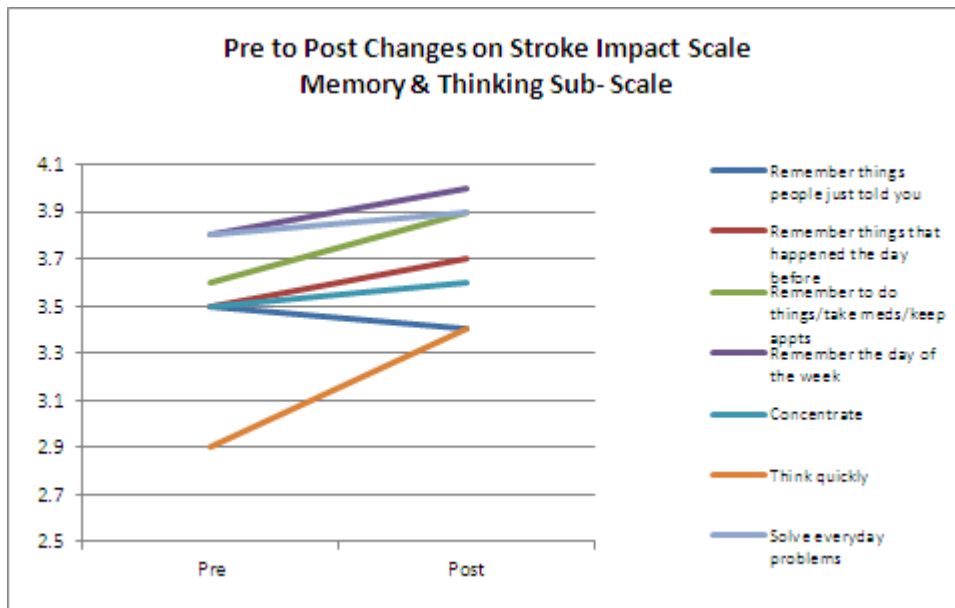
- This figure demonstrates how critical a support group can be in that it may be one of the few social opportunities that the survivor feels comfortable participating in (i.e. decreases in social activities, religious/spiritual activities, role as family member/friend and ability to help others).
- Transitioning home following a stroke is not experienced as a moment in time, but rather as lengthy (often lifelong) process. The stroke survivor may have experienced a relatively rapid and significant recovery in hospital/rehab and this recovery will naturally slow 3-4 months post-stroke. This may be a time when both the survivor and the caregiver must adjust yet again to a changing trajectory of recovery which can have significant psychosocial impacts. This can be a time when caregiver and survivor groups provide a critically important venue for emotional support and an opportunity to build new relationships, interests and goals. The LWS Program can play a valuable role in this process.

“I wish we could have more meetings. It would help with keeping depression away.” Survivor

“I look forward to each visit. This has helped me very much. “ Survivor

*“The support group in [location] is a wonderful group. We share, we help each other, we have a lot of laughs.”
Survivor*

Fig. 9 Pre-to Post-Test Changes on Memory and Thinking Sub-Scale



Source: Stroke Impact Scale

Memory and thinking are often negatively impacted by stroke and can increase caregiver burden as well as decrease the independence and confidence of the stroke survivor.

- Figure 9 illustrates improvement in 6 of the 7 memory and thinking domains. The capacity to concentrate and to process ideas/thoughts is pivotal to successful reintegration as the survivor re-learns how to manage daily life processes.
- Note the dramatic rise in thinking quickly and increases in solving everyday problems and remembering to do things/take meds/keep appointments; skills that are pivotal to many daily activities and may also reduce dependence on the caregiver while increasing the survivor’s self-confidence.

“A very informative group.” Survivor

“I am enjoying and need this group- living alone can become isolating.” Survivor

“Every experience is good, and learning a lot.” Survivor

Pre- and Post-Scores on Stroke Impact Scale – Mood Sub-Scale

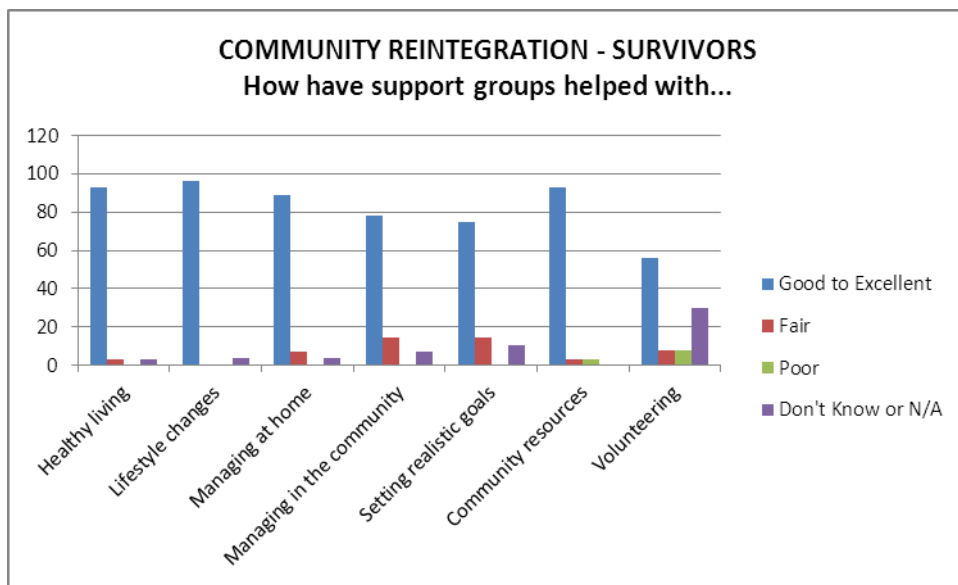
Respondents noted an increase in five out of the nine domains for mood. This particular set of questions can sometimes prove problematic as the scale is reversed in three of the nine questions. The changes were relatively small with the greatest being 0.3 on a scale of 1 to 5.

PARTICIPANTS RECEIVING DISCHARGE LINK

Twenty-two stroke survivor support group participants reported that they had received therapy services through the Discharge Link Program. Note that a significant number of support group participants had experienced their stroke event several years ago, prior to the implementation of the Discharge Link Program in 2009 and others were unsure if they had 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 IN KINGSTON, LLG AND HPE

Fig 10 Survivor Community Re-Integration Evaluation Tool Results – Kingston, LLG & HPE



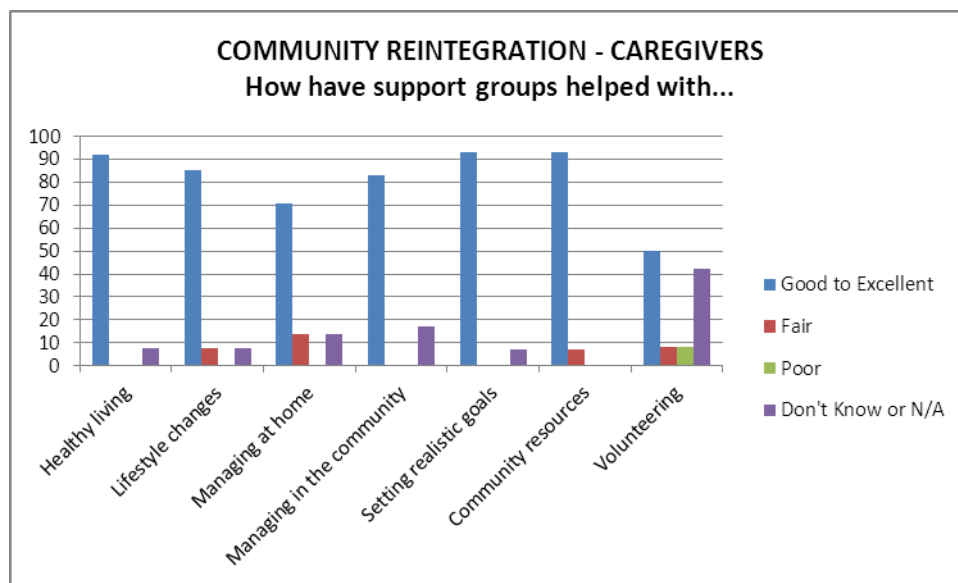
Source: Stroke Services Evaluation Tool

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 evaluation period, two caregivers reported an admission to hospital (one for day surgery and one for tests).
- Eight stroke survivors were admitted to (and discharged from) the hospital during the evaluation period. One was for dental surgery, one for a concussion related to a fall on ice, one for a shoulder replacement and a TIA (separate admissions), one respiratory distress, one for

CHF, one for a Botox injection, one for pneumonia and one reported being admitted for a stroke although it was unclear if this was prior to participating in a stroke support group (i.e. initial stroke) or a recurrent stroke.

Fig. 11 Caregiver Community Re-Engagement Evaluation Tool Results – Kingston, LLG & HPE



Source: Stroke Services Evaluation Tool

“I’m very happy to be a part of this group meeting. It is very informative, friendly, and not just that but, very welcoming too. I’m looking forward to keep attending this group and I’m hoping that I as a stroke caregiver to continue this monthly meeting group always with no stop. I met good friends whom we get together for lunch and socializing once a month too. We like our group coordinator very much too.” Caregiver

SUMMARY

- Sense of well-being 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 Stoke Impact Scale scores for abilities in communication, participation, memory and thinking.
- Consistent positive feedback on the skills of the facilitators and the valuable role they play for successful and therapeutic groups.

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 have replicated the data in the two previous reports, future reports will focus on perceived recovery scores for stroke survivors, a caregiver burden evaluation (tool to be determined), and a caregiver and survivor satisfaction tool. It is further 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.