STROKE NETWORK
of Southeastern Ontario

ENVIRONMENTAL SCAN OF
COMMUNITY SUPPORT SERVICE AGENCIES
IN SOUTHEASTERN ONTARIO

APRIL 2012 – MAY 2013

Gwen Brown
Regional Community & LTC Coordinator
Stroke Network of Southeastern Ontario
October 2014

BACKGROUND & OVERVIEW

In April, 2012 an environmental scan of the community support service (CSS) agencies in the southeast was initiated. The intent of the scan was to understand how the Stroke Network of Southeastern Ontario might best support CSS agency staff in the provision of care and services to persons with stroke and their care partners in the community. Similar scans have been conducted in previous years however in response to significant changes in CSS personnel and changes in the stroke-related resources available to CSS agencies, the decisions was made to initiate a renewed scan.

At the time of the scan, a total of 36 CSS agencies (Appendix A) were contacted and invited to participate in the scan. Of the 36 contacted, 21 (58%) completed the scan (note that several organizations had multiple locations (Alzheimer's 5 locations, Hospice 6 locations, VON 2 locations). Additionally, two organizations had established partnerships with the Stroke Network prior to initiation of the scan (Seniors Association of Kingston Region through the Kingston Stroke Survivor & Caregiver Support Groups and Community & Primary Health Care through shared work on funding proposals).

Organizations were provided the opportunity to participate in the scan via email, telephone or in person and 100% elected the in-person option. A survey tool (Appendix B) was shared with participants in advance of the visit and completed during the scheduled meeting. It became evident early in the process that organizations had an interest in learning more about the Stroke Network particularly opportunities for education including relevant on-line and hard copy resources. For this reason, the scan evolved into a valued opportunity to enhance the awareness amongst participating organizations of the role of the Stroke Network of Southeastern Ontario in partnering with CSS agencies to ensure the provision of best practice stroke care. Each organization was provided with at least one copy of *Tips and Tools for Everyday Living – A Guide for Stroke Caregivers* (Heart & Stroke Foundation, 2010) and other resources were also shared including:

- Geographically-specific Community Resource Directories to support stroke recovery
- *Getting on With the Rest of Your Life* (Canadian Stroke Network)
- *Let's Talk About Stroke* (Heart & Stroke Foundation)
- *Guidelines for Community Based Exercise Programs for People with Stroke*
- Geographically-specific Stroke Survivor & Caregiver Support Group brochures
- Website link for Stroke Network of Southeastern Ontario
- Community Reintegration Questionnaires for Stroke Survivors and Caregivers
- Flyer on Brain, Body & You (an education program for stroke care providers offered in collaboration with St. Lawrence College)
- Information on regional Learning Collaboratives
- Stroke Education posters

The visit structure for each organization was responsive to their specific requests and may have been a one-to-one discussion with a single individual, a meeting with several organization representatives or a broad discussion and sharing of resources with a larger group of staff and volunteers.

The most significant outcomes of the scan were:
- engaging community support service agencies in a discussion of the role of the Stroke Network of Southeastern Ontario
- highlighting the prevalence of stroke in the community including within their client population
- sharing resources

It is of note that subsequent to the completion of the scan, three CSS agencies (Community & Primary Health Care, Community Care for South Hastings and VON- Kingston Region) have now become host organizations for regional stroke survivor and caregiver support groups in their service areas.

RESULTS OF CSS SCAN

Note that actions in response to findings have been **bolded** however it is important to note that a critical component of this scan was the immediate, on-site sharing of resources and links and the subsequent dissemination of information (e.g. Tips & Tools DVDs) resulting in the increased awareness of supports and services available to individuals who have experienced stroke and their care partners as well as the educational supports and services available for organization staff and volunteers..

1. *Percent of clients within the organization's client base that have a stroke diagnosis.*

   Of the organizations surveyed that provided a percentage all had based this percentage on anecdotal information or estimate.

   Less than 10% - 21%
   10% to 25% - 11%
   26% to 50% - 11%
   Over 50% - 0%
   Don't know – 58%

   Statistics re incidence and prevalence of stroke shared with participants.

2. *Main challenges encountered by staff/volunteers when providing services to clients with stroke.*

   Many respondents (47%) had difficulty in responding to this question as they had not discussed this with staff/volunteers that were providing care/services nor had they received anecdotal/unsolicited feedback specific to the stroke population served by their organization. Lack of response to this question may also have been influenced by a lack of understanding by the respondents of the impacts of stroke making it problematic for them to identify specific challenges. Of those that did provide a response the following challenges were highlighted:

- Lack of social supports
- Stroke clients generally more ill and physically impacted
- Transportation and transferring of client
- Aphasia (2 respondents)
- Transfers & toileting
- Short term memory loss
- ADLs
- Accessibility into buildings (for clients and volunteer drivers)
- Problem-solving by client
- Client has incorrect perception of capacities and personality changes
- Caregiver burden
- Client self-conscious re aphasia/mobility impairments

Information provided on available educational services and supports.

3. *Tips and Tools for Everyday Living – Manual*

Of the survey participants, 74% were not aware of this manual. Of those that were aware, one had previously worked for the Heart & Stroke Foundation and learned about the manual during her time with that organization. Of those that did have knowledge of the manual, 100% were only aware of the hard copy version (i.e. none were aware of DVD or on-line versions). Those who did access the manual found it beneficial in the provision of care as well as a resource for the families of individuals with stroke. The manual was essentially used as a reference tool for staff, volunteers and families.

Each organization received at least one hard copy of the manual and was also provided with the relevant link to order additional copies.

4. *Tips and Tools for Everyday Living – Videos*

None of the survey participants were aware of the Tips & Tools Education videos.

At least one copy of the DVD was provided to each participating organization as was the link to on-line access of the videos.

5. *Brain, Body & You*
84% of the respondents were not aware of the *Brain, Body & You* educational modules. Of those that were aware, one organization had not had any staff/volunteers participate due to distance to the program sites. The respondents were not able to provide specifics with respect to which modules were attended. All agreed that the sessions were beneficial but were not able to provide details of how the learning was applied. No suggestions were received for additional modules or topics.

Each participating organization was added to the BBY distribution list. As well, flyers for upcoming BBY sessions were provided to agencies in the relevant geographic areas.

6. *Stroke Education Posters*

None of the survey participants were aware of the *Stroke Education Posters.* 42% of respondents would consider displaying a poster using topics relevant to their client populations. Posters would be displayed in congregate dining areas, footcare clinics or used to support targeted staff/volunteer education sessions. The remainder of the survey participants were unsure whether they would display a poster often due to space limitations. One suggestion was received to create a poster on behaviour changes and another to address the topic of vascular dementia.

Sample posters were shared during each interview and organizations were advised how to access copies of the posters and how to borrow posters for temporary displays. Subsequent to scan, a poster has been developed on behaviour changes.

7. *Community Based Exercise Guidelines for People with Stroke*

None of the survey respondents were aware of the *Exercise Guidelines.* One participant agency requested a repeat of the Adapting Exercise Programs workshop.

Hard copy of the Guidelines was provided to each participant as was the brochure for individuals with stroke. Link to access on-line versions was also provided. An additional Adapting Exercise Programs was offered in 2014.

8. *Community Reintegration Questionnaires*

None of the survey respondents were aware of the *Community Reintegration Questionnaires* and were not sure of the relevance to their organization given the reliance on standardized intake assessment processes and tools.

Copies of each of the three integration questionnaires was provided to the participants as contents may help to inform in-home assessments and highlighted the potential gaps in standardized assessment processes (e.g., emotional wellbeing of individual with stroke and care partner).

9. *Other Educational Supports*

No specific suggestions with respect to additional educational resources were provided. Note that the majority of participants had only become aware of the above learning supports/resources during the interview process and had yet to process that content and relevance to their respective organizations.

10. *Community Resource Directories*

None of the survey respondents were aware of the *Community Resource Directories* however all were interested in copies for the relevant geographies.

All participants were provided with the relevant directory(ies) for their geographic area(s) and were also advised how to access trough the Stroke Network website.

11. *Linking to Rehabilitation Supports & Services*

When asked re clients with changing rehabilitation needs, many organizations had difficulty in understanding.
- Their role in identifying rehabilitation needs/changes
- What 'rehabilitation needs' encompassed
- Aligning the identification of changing rehabilitation with the mandate of their organization

Of the survey respondents, only 16% (n=3) were comfortable responding 'yes' to the identification of changing rehabilitation needs and 'yes' in referring them to services when the issues arose.

Discussion during interview process of rehabilitation components and capacity to refer to CCAC at any time (including self-referral).

12. *Referral to CCAC for Rehabilitation Needs*

The organizations' difficulty responding to the previous question also impacted on their answers to this question. While 89% indicated that they were aware that clients could be referred to the CCAC for rehabilitation services, only 26% (n=5) actually did so. However, 63% did refer to CCAC for various other support services (it was unclear if these support services might actually include a rehab component). Also, of note is the fact that many of the organizations surveyed received referrals from CCAC for their services so it seemed evident that there was some mutual knowledge of services provided.

Discussion of available CCAC services including the Enhanced Community Based Rehabilitation Services Discharge Link program. Information brochures on the program provided.

13. *Outpatient Rehab/Day Hospital*

None of the respondents were aware of *Outpatient Rehab/Day Hospital* services in their respective regions.

Participants advised of services available in their service area(s).

14. *Stroke Prevention Clinics*

None of the respondents were aware of *Stroke Prevention Clinics* in their respective regions.

Participants advised of services available in their service area(s) and brochure provided.

15. *Stroke Survivor Support Groups*

None of the respondents were aware of *Stroke Survivor Support Groups* in their respective regions.

Participants advised of services available in their service area(s) and brochure provided. One agency invited to speak to group in their geographic region.

16. *Living With Stroke Program*

None of the respondents was aware of *Living With Stroke Program* in their respective regions.

Participants advised of support group services available in their service area(s) and brochure provided.

17. *Post Stroke Depression*

Note that organizations responding to this question did not respond specifically to the stroke clients within their population but rather to general processes for depression screening. 21% (n=4) stated that they did not use a screening tool, 11% (n=2) did use a specific screening tool (1 simply referred to it as a self-rating tool and 1 used the NESDA tool). The remainder of organizations (84%) stated that depression screening was integrated into their intake processes versus a specific screening tool.

Discussion re prevalence of post-stroke depression and its impacts on physical status and potential for social isolation.

18. *Hypertension Services*

Of the organizations surveyed, 84% did not offer a discrete hypertension clinic or blood pressure screening service. Of the remaining organizations, 1 offered blood pressure measurement via the adult day program and through PSW home visits, 1 had a nurse-led service and 1 did blood pressure measurement on select individuals through the foot care clinic. In all cases, abnormal findings were referred to a physician (initial notification may be through a supervisor/coordinator).

19. *Intake Assessment*
The method of intake assessment varied across organizations but the majority (53%) used the RAI-CHA for many clients (with the exception of those that may not have been identified as frail elderly or high need). Internal tools were used for less complex clients. Other organizations used:
• First Link Intake Form or connected with CSS agency for the RAI-CHA (n=1)
• General admission process (n=2)
For the remainder of organizations (26%), the process was at least partially dependent on where referral originated as that referral form may also serve as the intake assessment (e.g., CCAC RAI Palliative, hospital SW referral) (n=5)

20. Education Approaches

Of the options for educational approaches provided to the respondents, 84% preferred classroom settings, 21% selected webinars/on-line modalities (including archived sessions), 1 organization suggested brochures and 1 suggested posters. Note that organizations may have chosen more than one option.

Reinforced role of Stroke Network as educational support and facilitator. Several educational sessions have been provided to participating agencies subsequent to completion of scan.

21. Education Topics

Suggested topics received from the participating organizations included:
- General information on stroke for volunteers/staff (6 respondents)
- Supportive connections/Stroke related services (2 respondents)
- TIAs (recognizing & responding)
- Vascular dementia (impacts, causes)
- Information on available community supports and services

Note also that the previous question related to challenges encountered by staff and volunteers when providing care to individuals who had experienced a stroke also helped to inform this question.

Reinforced role of Stroke Network as educational support and facilitator. Several educational sessions have been provided to participating agencies subsequent to completion of scan.

22. Stroke Related Services

There was a wide variety of services provided by the respondent organizations that were identified as relevant to the stroke population including:

- Footcare
- Meals on Wheels/Congregate Dining
- Exercise
- Reassurance/Support Phone Calls
- Transportation
- Respite
- Home Help/Home Maintenance
- Attendant Care
- Friendly Visiting
- Grief & Bereavement and Other Support Groups
- Adult Day Programs
- Nursing & PSW Services

23. *Staffing Complement*

Staffing complement varied widely across agencies with some having high dependence on volunteers (several agencies had over 300 volunteers and one had over 600) and others a blend of volunteers and paid staff. Paid staff ranged from less than 5 to over 100.

24. *Communication (respondents could select more than one answer)*

The majority (95%) of responding organizations indicated that email was the most effective method of communication. Two organizations also suggested Stroke Network attendance at CSS regional meetings, 1 organization suggested Stroke Network attendance at staff meetings, 1 organizations suggested information through newsletters and one indicated that phone calls were also effective.

Distribution list updated for email communication.

RECOMMENDATIONS

Note that despite two previous community-based scans, it was evident that the knowledge and awareness of stroke network resources was low indicating a need for ongoing contact with CSS agencies to ensure optimization of resources and collaborative partnering to support the recovery journey experienced by persons with stroke and caregivers.

1. Given the CSS agency personnel turnover and the changing library of resources available through the stroke network, it is recommended that there be ongoing contact maintained with all CSS agencies to enhance and sustain mutual awareness of supports and services. Contact may include phone calls, emails and newsletters).

2. Continue to build links with CSS agency leaders and promote an ongoing relationship with the stroke network.

3. Request attendance at CSS regional meetings on an annual basis to update participants on network resources and to support relationship-building.

4. Recognize and optimize the potential for knowledge dissemination by the three CSS agencies currently hosting the stroke survivor and caregiver support groups in the southeast region.

APPENDIX A

*Those CSS agencies with a * participated in the scan.*

*Alzheimer Society of Belleville – Hastings
Alzheimer Society of Kingston
*Alzheimer Society of Lanark County
*Alzheimer Society of Leeds – Grenville
*Alzheimer Society of Prince Edward County
*Bayshore Home Health
*Canadian National Institute for the Blind – SEO
*Cheshire Homes (Hastings-Prince Edward) Inc.
Community & Primary Health Care
*Community Care for Central Hastings
*Community Care for North Hastings
*Community Care for South Hastings
*Community Home Support – Lanark County
Gananoque and Area Services to Assist Independent Living Inc.
*Hospice Kingston
Hospice Lennox & Addington
*Hospice Perth
*Hospice Prince Edward
*Land O'Lakes Community Services Corporation
*Lennox & Addington Seniors Outreach Services
*North Frontenac Community Services Corporation
*Paramed Home Health Services
Pathways to Independence – ABI
Providence Continuing Care Services ABI
Providence Continuing Care Services Attendant Care
Providence Continuing Care Services Hildegard Centre
Ontario March of Dimes East Region
Seniors Association Kingston Region
Southern Frontenac Community Services Corporation
*St. Elizabeth Home Health Care
The Canadian Hearing Society
The Heart of Hastings Hospice
The Prince Edward County Community Care for Seniors Association
The Regional Hospice of Quinte Inc.
*VON Eastern Lake Ontario Branch
*VON Hastings, Northumberland, Prince Edward Branch

APPENDIX B

COMMUNITY SCAN
SEO STROKE NETWORK 2011

The Stroke Network of Southeastern Ontario (the Network) is one of 11 regional networks established across the province to implement the Ontario Stroke System (OSS). The vision of the OSS is *"Fewer strokes. Better outcomes"*. The mission is *"to continuously improve stroke prevention, care, recovery, and reintegration"*.

This survey will help inform the Network of strategies, resources and supports that would be of value to community support agencies in southeast Ontario.

The Network has a number of free resources available to organizations in Ontario. The following questions are intended to determine your organization's familiarity with and use of these resources.

All of the following resources may be accessed via the Network's website at http://www.strokenetworkseo.ca and clicking first on Professional Education and then on Professional resources and scrolling down to Community and Long Term Care.

1. What percentage of clients for whom you provide service, have a stroke diagnosis?
   a) less than 10%
   b) 10 % to 25%
   c) 26% to 50%
   d) over 50%
   e) don't know

2. What are the main challenges encountered by your staff/volunteers when providing service to clients with stroke in the community?

3. Tips & Tools for Everyday Living – A Guide for Caregivers
   This manual was designed to provide the practical knowledge and skills needed by the people who provide care and support to stroke survivors.

   a) Were you aware of this manual?
      Yes   ☐
       No ☐
   b) Have you accessed this manual through:
      Hard copy   ☐
      DVD   ☐
      On-line   ☐
   c) Did you find this manual beneficial for your staff/caregivers?
      Yes   ☐
      No   ☐
      Somewhat   ☐
      Not applicable   ☐
   d) How did you use this resource?

4. Tips & Tools Education Videos
    These six education videos are designed to complement popular sections of the Tips and Tools for Everyday Living: A Guide for Stroke Caregivers (2010). Five of these videos are designed for front line staff and one has been developed for family and community education. Topics include:
    - Recognize & React to the Signs & Symptoms of Stroke for Health Care Providers
    - Communication
    - Meal Assistance & Hydration
    - Cognitive, Perceptual & Behavioural Problems
    - Mobility
    - Family & Community Education
    a) Were you aware of these videos?
        Yes   ☐
         No ☐
    b) Did you find this resource beneficial for your staff/caregivers?
        Yes   ☐
        No   ☐
        Somewhat   ☐
        Not applicable   ☐
    c) How did you use this resource?

5. Brain, Body & You
    This 5 module interprofessional, continuing education workshop series is designed for regulated and unregulated providers. It focuses on caring for or interacting with stroke survivors and/or other complex client populations in the community, long-term care and other care settings. Individuals may elect to participate in any number of the 5 modules. Each module is 4 hours in length. These workshops are currently being offered at St. Lawrence College in Kingston (consider including Belleville-Loyalist College) The module topics include:
    - Stroke Care - Prevention to Life After a Stroke
    - Continence Care
    - Mobility
    - Nutrition, Swallowing, Feeding and Hydration
    - Communication and Behaviour
    a) Were you aware of this program?
        Yes   ☐
         No ☐
    b) Have any of your staff/volunteers participated in any of the modules?
        Yes ☐
         No ☐ If 'no', please explain
    c) Did you find this program beneficial for your staff/caregivers?
        Yes   ☐
        No   ☐ If "no' please explain.
        Somewhat   ☐
        Not applicable   ☐
    d) How did you use the learning from this program?

e) Which module(s) did you find of particular interest/usefulness?
f) Is there a module that you haven't completed that you think will be of interest/benefit?
g) Are there other topics that would be of interest that aren't included in the current program?

6. Stroke Education Posters
   Educational posters are available for display at your location. These posters are available on loan at no cost. The posters have been developed for the education of frontline care providers and are formatted to visually highlight learning points. Current posters include:
   - wheelchair positioning
   - safe feeding & oral care
   - communication & aphasia
   - post-stroke depression
   - blood pressure
   - stroke prevention & care
   - cognition & perception
   a) Were you aware of these posters?
      Yes ☐
       No ☐
   b) Have you displayed any of these posters?
       Yes   ☐
       No ☐
   c) Did you find these posters beneficial for your staff/caregivers?
      Yes   ☐
      No   ☐
      Somewhat   ☐
      Not applicable   ☐
   d) How did you use the learning from these posters?
   e) If you have not displayed any of these posters, would you consider doing so?
      Yes ☐
       No ☐ If 'no', please explain.
   f) Is there a topic that you would like to see demonstrated on a poster?

7. Guidelines for Community Based Exercise Programs for People with Stroke
   These Guidelines are intended to help exercise providers deliver safe and effective exercise programs to stroke survivors in a variety of community and other settings. Supporting this document is the Guide for Choosing a Community Exercise Program for People with Stroke. This Guide will assist people with stroke and their families in selecting a safe and effective exercise program in the community. Included in the brochure is a checklist to aid in assessing exercise programs as well as other helpful tips. The Guidelines and brochure can be accessed at www.strokenetworkseo.ca under Community Resources.

   a) Were you aware of these Guidelines?
      Yes ☐
       No ☐

   b) Have any you applied the Guidelines to any programs?
      Yes ☐
       No ☐

c) Did you find the Guidelines easy to follow and implement?
   Yes ☐
   No ☐ If 'no', please explain.

8. What other educational supports would be helpful to you in providing services to stroke survivors?

9. Community Reintegration Questionnaires
   The Questionnaires are designed to highlight areas of need for the stroke survivor and caregiver. Community Resource Directories (see below) are available to link needs with available community resources.
   The questionnaires and Resource Directories can be accessed at
   www.strokenetworkseo.ca under Community Resources.
   a) Were you aware of these Questionnaires?
      Yes ☐
      No ☐
   b) Have you found the Questionnaires useful?
      Yes ☐
      No ☐ If 'no', please explain.

10. Community Resource Directories
    There are 3 Community Resource Directories; one for each region in the southeast (i.e. HPE, LLG and KFLA). The Directories provide information on community resources that are relevant to stroke survivors.
    a) Were you aware of these Directories?
       Yes ☐
       No ☐
    b) Have you found the Directories useful?
       Yes ☐
       No ☐ If 'no', please explain.

11. Linking with Community-based Rehabilitation Supports & Services
    a) Do you have clients with changing rehabilitation needs?
    b) Do you refer them to services when new issues arise?

    Community Care Access Centre (CCAC)
    a) Are you aware that clients can be referred to the CCAC for rehabilitation therapy services?
    Yes   ☐
    No   ☐
    b) Have you referred your clients to any of these CCAC services?
    Yes   ☐ If 'yes', please specify what services
    No   ☐ If 'no', please explain why

Outpatient Rehabilitation/Rehabilitation Day Hospital Services (as opposed to adult day programs)

a) Are you aware of any such outpatient rehabilitation services in your area?

Yes ☐

No ☐

12. Stroke Prevention Clinics

There are four stroke prevention clinics in Southeastern Ontario located in Kingston, Brockville, Perth and Belleville. The clinics provide urgent services including diagnostic work- up to those who have experienced a mini stroke or transient ischemic attack (TIA).

a) Were you aware of the Stroke Prevention Clinics?

Yes ☐

No ☐

13. Stroke Survivor Support Groups

There are four support groups in the southeast region – Belleville, Brockville, Perth and Kingston. These groups offer information and support to stroke survivors and their families. Some of the groups (Kingston & Belleville) also offer Living with Stroke programs.

a) Were you aware of the Stroke Survivor Support Groups?

Yes ☐

No ☐

b) Were you aware of the Living with Stroke Programs?

Yes ☐

No ☐

14. Post Stroke Depression

Stroke survivors are at high risk for clinical depression. Post stroke depression may affect at least 1 in every 4 people who have had a significant stroke. It usually occurs within the first 3 months but may occur up to 2 years (greatest risk – first 6 months). Less than half the stroke survivors with depression are identified.

a) Does your agency use a tool to screen for depression?

Yes ☐ Please identify the tool that is used.

No ☐

15. Hypertension (High Blood Pressure)

a) Does your agency operate a hypertension clinic/service?

Yes ☐ If 'yes', please provide a brief description of clinic and process used to respond to findings of high blood pressure.

No ☐

16. Intake Assessment

a) Does your agency perform an assessment on all referred clients?

Yes ☐

No ☐ If 'no', please describe intake process.

b) What assessment tool is used for intake?

The next questions will help us to understand what supports would be of most interest and value to community support agencies.

17. What education approaches are most effective for your staff/volunteers (circle all that apply)?
    a) on-line
    b) brochures
    c) classroom
    d) posters
    e) other (please explain)

18. Are there specific topics related to stroke that would be of benefit to your staff/volunteers

19. What stroke-related services does your agency currently offer?

20. What staffing complement do you currently have (e.g. volunteers, paid staff)?

The last question relates to communication:

21. What would be the best communication strategy to ensure that all CSS agencies/organizations are advised of stroke-related information pertinent to their mandate?
    a) Email "blasts"
    b) Newsletters
    c) Updates at CSS Regional Meetings
    d) Other (e.g. www.4CSS.org)

The Stroke Network's liaison person for CSS agencies/organizations is Gwen Brown who can be contacted at browng2@kgh.kari.net or by calling 613-549-6666 Ext. 6867.