

## Community Stroke Support Services: Southeastern Ontario Annual Report

"Extraordinary Services for Extraordinary People"

www.strokenetworkseo.ca



## Summary





This <u>annual report</u> provides an overview of Stroke Support Services in the Community and reflects the most recent fiscal year (FY) data (*April 1, 2023 – March 31, 2024*).

The Stroke Network of Southeastern
Ontario partners with <u>Community Stroke</u>
<u>Support Services Agencies</u> to monitor
and evaluate *Community Stroke Support*<u>Services</u>. This report reviews the
<u>outstanding and innovative work</u>
demonstrated by these agencies over the
past year.

#### **Key Accomplishments in 2023-24**

- Completed Community Consultation
- Community Reintegration Leadership Team (Patient and Family Advisory Team) set network priorities for improvement based on the Consultation
- Sustained large volumes of referrals and participation
- Continued to build connections between hospital and community settings
- Sustained region-wide Aphasia Supportive Conversation Groups with increased volumes
- Established region-wide Stroke Adult Day Programs

Need additional information? Please contact: **Sandra Liu,** Community and Long-Term Care

Coordinator (Stroke Network of Southeastern Ontario)
at 613-549-6666 ext. 6867 or

Sandra.liu@kingstonhsc.ca







#### SOUTHEASTERN ONTARIO COMMUNITY STROKE SUPPORT SERVICES

ANNUAL EVALUATION REPORT 2023-24

200

New referrals to Stroke Support Services



288

Participants in Stroke
Support Groups





"When you first get home, you don't know what services are available"

- Warm hand offs from hospital to community
- "Ask a Survivor" group connecting the hospital to community
- Peer volunteers in hospitals



"Being able to talk to a group of people that have been through something similar makes one feel not alone"

- Stroke support and caregiver groups
- Younger stroke survivor groups
- Evening group to support local needs

#### **Key Highlights and Innovations**

- Adapting programs to meet local needs
- Region-wide Stroke-focused Adult Day Program
- Regional Stroke Education Program
- Evening groups and Younger Stroke Survivor group
- Stroke-specific exercise groups (virtual and inperson) in KFLA and HPE





#### "You gave them a VOICE"

- Aphasia Supportive Conversation Groups running across the region
- Advocacy for aphasia accessibility in the community occurring locally





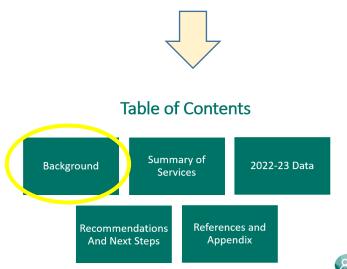


There has been a steady INCREASE in referrals and participation since 2021-22 Fiscal Year

## Navigating the Report

 Navigating this report can be done through the use of <u>buttons</u> on each page, allowing the reader to choose the content they would like to review

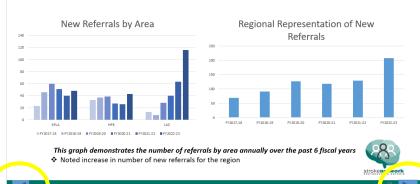
Home page: Allows reader to choose topic (section) of interest; includes 5 sections related to Community Stroke Services in Southeastern Ontario



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Individual pages: Utilize the "forward" and "back" buttons to advance through the selected section. You will return to the home page when you have completed the section

#### **Number of Referrals**





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## Background



Base Funding provided in 2014-15 for community stroke support services in Southeastern Ontario



Evaluation reports submitted annually to outline demographics, services offered, and participant satisfaction



This report provides data on stroke support groups in Southeastern Ontario for 2023-24







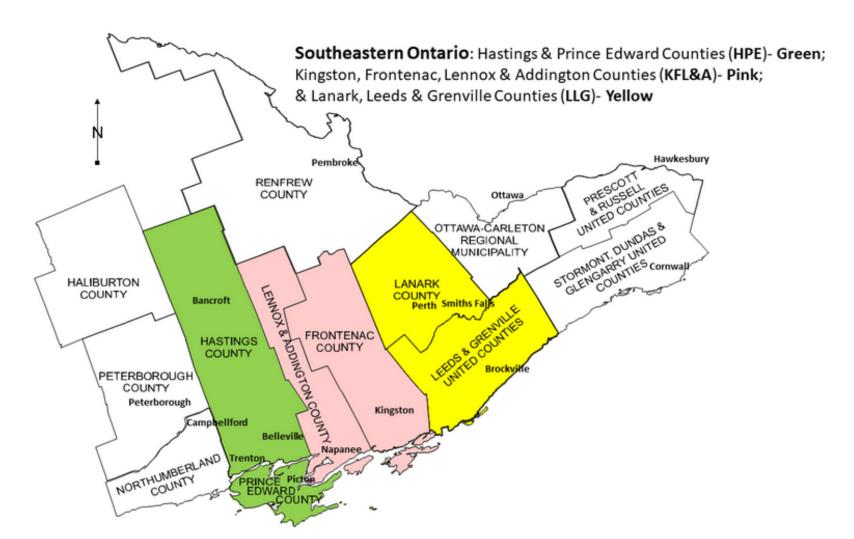
## Background

- Over 2000 individuals sustain a new stroke across Southeastern Ontario annually and volumes are increasing at a rate of an average of 5% per year.
- Stroke can lead to social, physical and psychological challenges for individuals and their family members. It abruptly changes lives and can impact quality of life and independence.
- It is estimated that **70%** of individuals who experience stroke are discharged to the home setting (Magwood et al., 2020).
- **Inadequate support** and care in the community can leave stroke survivors and their caregivers **feeling lost** and **abandoned** following discharge from hospital (Hartford et al., 2019).
- Given the level of disability experienced by stroke survivors and the added stress on their caregivers, <u>stroke support in the community is an essential part of the healthcare</u> <u>system</u>.





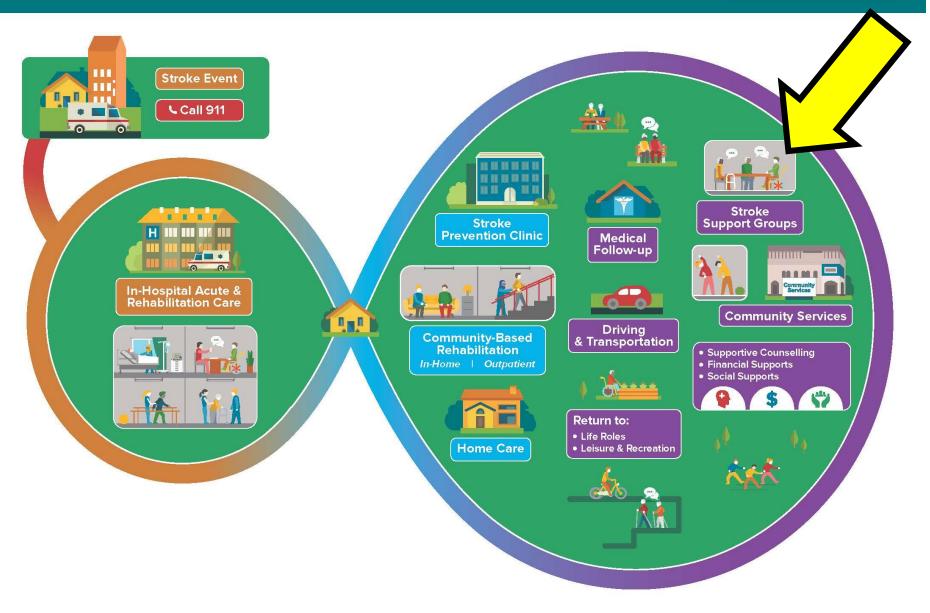
## Southeastern Ontario





#### YOUR RECOVERY JOURNEY AFTER STROKE





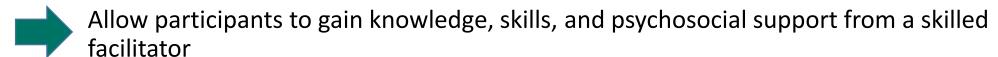






## Community Stroke Support Services

#### Stroke Support Groups:



- Enable connections with peers in the community on a similar recovery journey to expand knowledge, support and self-efficacy
- Help gain skills necessary to become a successful peer mentor and community advocate
- Support the healthcare system by keeping individuals well in the community

"Very helpful to meet others who've survived stroke experience – a wonderful feeling of community"







## 2023 Consultation Report

WHAT WE HEARD:
ENHANCING INDIVIDUALIZED
COMMUNITY STROKE
SERVICES









### Four themes that emerged from the consultation-

Wellbeing

and Mental Health

\*Although the results have been divided into themes, it is evident that the themes are interrelated and overlapping\*

Includes meaningful activity, exercise, nutrition and mental health supports. The desire for more mental health support was apparent, specifically from professionals who understand stroke.

Includes stroke support groups as well as connections to family, friends and community. The need for more stroke support groups was frequently expressed.

Person-Centred

Rehabilitation

Two underlying <u>principles</u> within all four themes:

- 1. Access to Equitable Services
- 2. Education and Awareness

On and Awa Navigation and Transitions Includes outpatient rehabilitation and homecare rehabilitation. The importance of listening to the person with stroke was emphasized. Individualized care is key.

"Every stroke is like a snowflake or grain of sand" – requires a <u>unique approach</u>

Includes navigating the healthcare system and transitioning out of the hospital and community stroke rehabilitation. Many reported being unaware of services and having difficulty transitioning across the healthcare services.



\*\*Community Stroke Support Services Agency (VON, CCSH and CPHC) Facilitators, Stroke Survivors and their Caregivers were critical in the creation of this report\*\* Stroke network





### **Priorities**

**A poll** was completed at a **Community Reintegration Leadership Team** Meeting (CRLT) and these **priority actions** for moving forward were **identified**:

- 1. Secure funding for stroke services
- 2. Improved supports for mental health
- 3. Equitable access to rehabilitation
- 4. Stroke prevention, living well and follow-up\*
- Tool and/or supports to navigate the system\*
- 6. Improve resources for return to driving







<sup>\*</sup>Number 4 and 5 were tied in terms of level of importance

## Summary of Stroke Services

- Current Stroke Support Groups include stroke survivor, caregiver, introductory, young survivor, social/recreational, educational, aphasia supportive conversation and aphasia peer support
- These groups are delivered in the three areas through Community Support Services Agencies:



Kingston, Frontenac Lennox and Addington Counties (KFLA): Victorian Order of Nurses (VON) - Greater Kingston area



Hastings and Prince Edwards Counties (HPE): Community Care for South Hastings (CCSH)



Lanark, Leeds and Grenville Counties (LLG): Senior Support Services (CPHC)



## Stroke Support Group Facilitator



#### The Role of the Stroke Support Group Facilitator:

- Conduct intake assessments
- ✓ Provide one-on-one support as needed
- Coordinate and facilitate group sessions; adapt to local needs
- Offer education; self-management sessions
- ✓ Promote awareness of community stroke support services
- Collaborate with the hospital and other community agencies
- ✓ Deliver system navigation/case management/advocacy
- Trained in Supported Conversation for Adults with Aphasia™

Stroke survivors are to be referred to community-resources for "engagement and self-management for ongoing physical, social, emotional, intellectual and spiritual activities and participation in the community" Canadian Stroke Best Practices, 2019







# Kingston, Frontenac, Lennox and Addington



#### Stroke Support Groups

- Stroke survivor and caregiver groups
- In-person groups (Sydenham, Kingston and Napanee)
- Virtual groups

new

**Evening groups** 

#### Aphasia Supports

- Aphasia Supportive Conversation Groups
- Aphasia Buddies and Aphasia Support Groups

#### • **Hospital to Community Connection**

 Hospital and Community Support Group at Providence Care Hospital

#### • Stroke-Specific Exercise

- Virtual program
- Stroke-Specific Day Program
- Community Partnerships
  - Queen's University and St. Lawrence College









#### • Stroke Support Groups

- Information groups
- Caregiver groups
- Peers to Peers Stroke Talk
- Evening groups
- Younger stroke survivor groups
- Social Recreational, BINGO
- Music and Art Therapy groups

#### Aphasia Supports

- Aphasia Supportive Conversation Group
- **Hospital to Community Connection** 
  - "Ask a Survivor" group weekly at Quinte Health Belleville
- Stroke-Specific Exercise
  - Virtual and In-person (Belleville and Trenton)

#### Stroke-Specific Day Program

- In partnership with Pathways to Independence
- Community Partnerships
  - Loyalist College OTA/PTA Program to offer virtual and in-person seated exercise and cognitive stimulation groups





## Lanark, Leeds and Grenville



#### Stroke Support Groups

- Stroke Survivor and Caregiver groups
- In-person (Brockville and Perth)
- Hybrid option

#### Aphasia Supports

Weekly Aphasia Supportive Conversation Groups

#### Hospital to Community Connection

- Warm hand-offs with hospitals
- "Ask a Survivor" at Brockville General Hospital and at Perth and Smiths Falls District Hospital

#### • Stroke-Specific Exercise

- Currently on hold
- Stroke-Specific Day Program
  - Well-established (with wait-list)





## **Innovative Programs**



# \*\*The Stroke Support Group Facilitators continue to develop innovative ways to connect and support persons with stroke and their caregivers\*\*

- "Ask a Survivor" group connecting hospital to community
- Regional Meet and Greet (quarterly)
- Regional Stroke Education Program (virtual and in-person)
- Stroke-Specific Adult Day Programs (now across the region)
- Art and Music Therapy Programs
- Evening groups and Younger Stroke Survivor groups
- Connections with local Colleges and Universities
- Stroke and Aphasia Awareness Month Activities:
  - Advocacy via Accessibility Committee Meetings
  - Local news interviews/awareness
  - Illumination/proclamation
  - T-shirts/FAST cards/BBQ



The Right to Accessible

Communication with Aphasia

Its a Basic Human Right

Regional events allow stroke survivors and caregivers to connect and learn from peers throughout Southeastern Ontario



## 2023-24 Data

Quarterly data collected by Community Stroke Support Agencies:

Number of Stroke Support Group Participants

Number of Aphasia Supportive Conversation Group Participants



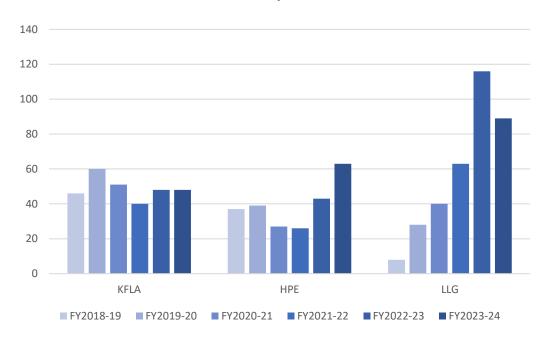
## 2023-24 Regional Data

Continued **200** New Referrals High Volumes **288** Stroke Support Group Participants Continued Growth \*Total unique participants 73 Aphasia Supportive Conversation Group Continued **Participants** Growth

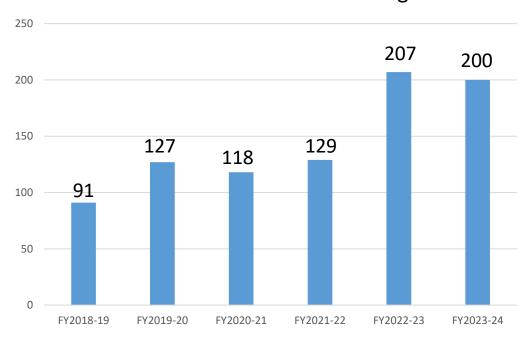


## Number of Referrals

#### New Referrals by Local Area



#### New Referrals - Southeast Region

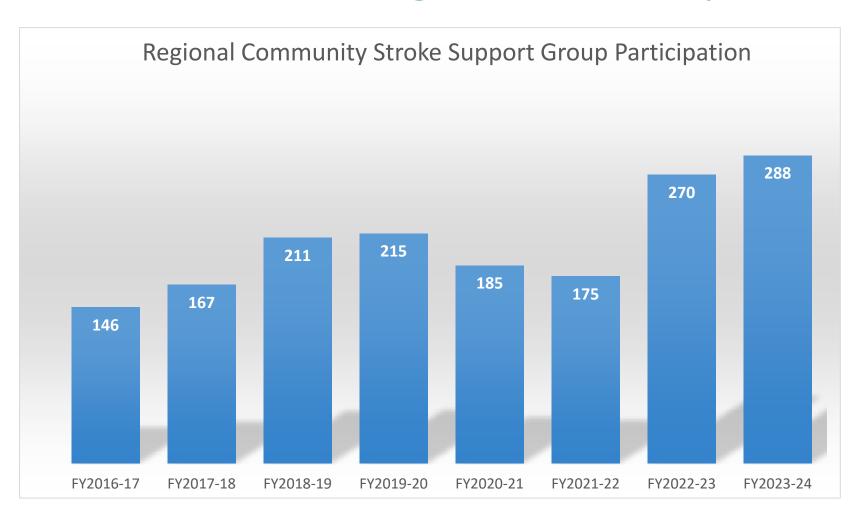


This graph demonstrates the number of referrals by area annually over the past 6 fiscal years

Noted is the steady large volume of new referrals



## Regional Participation



#### **Interpretation Considerations:**

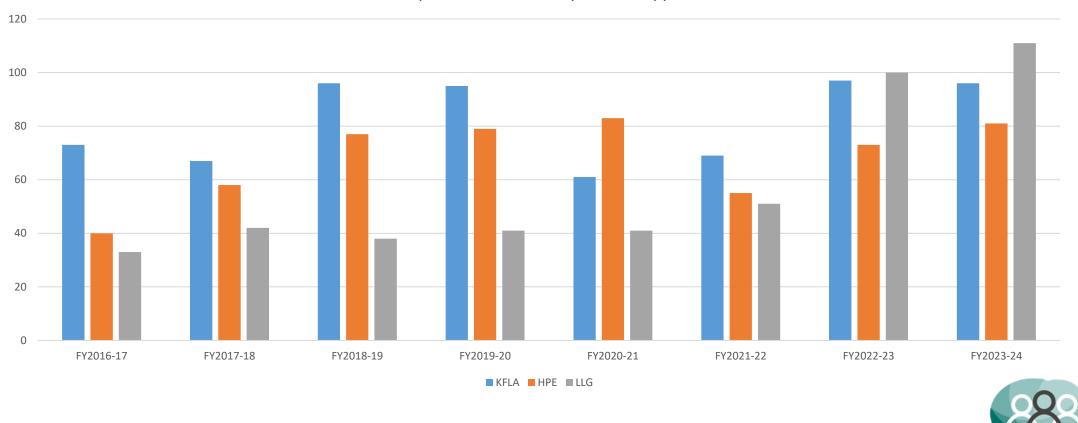
- Comparison of participation levels over the last 8 fiscal years
- Represents total unique participants
- !ncrease in participation levels
- Participant volumes impacted due to COVID-19
- Gradual resumption of inperson groups



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# Participation By Local Area

Annual Participation in Community Stroke Support Services

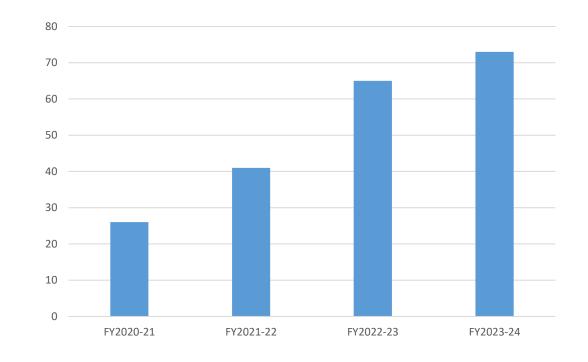


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# Region-wide Participation in Aphasia Supportive Conversation Groups

#### **Interpretation Considerations:**

- Notable <u>increase</u> in participation
- Service running across the region







# Participation by Local Area - Aphasia Supportive Conversation Groups



## 2023-24 Key Achievements



#### **Comments:**

Stroke Awareness and Aphasia Advocacy Work



**Hospital and Community Collaboration** 



**Aphasia Supportive Conversation Groups** 



Stroke-Specific Day Program



**Regional Initiatives** 



**Establishing Partnerships** 









- ❖ Adapting to meet local needs
- Increasing growth in referrals and participation
- Connecting hospital to community groups
- \* Resuming In-person groups
- Aphasia Supportive Conversation Groups running across the region
- ❖ Stroke-Specific Day Program running across the region
- Partnerships with other community agencies, **Colleges and Universities**



## **Annual Report Recommendations**

Recommendation 1

Sustain and enhance services in response to the Community Consultation priorities.

\*Funding to support full-time positions, expand groups and offer a therapeutic group size

Recommendation 2

Advocate and promote linkages to resources that promote well-being (e.g. stroke-specific exercise groups, interest groups, mental health resources)

Recommendation 3

Promote linkages to services in the community with a focus on navigation supports.

Recommendation 4

**Promote inclusiveness in stroke support groups** (e.g. Indigenous populations, young caregivers, aphasia).



# Stroke**Understood**

## **Next Steps**

- Continue to move forward priorities for action from the results of Community Consultation
- Continue to seek out **funding** opportunities for stroke support services and building partnerships
- Develop a mental health and well-being resource document
- **Return** to including qualitative information regarding participant sense of health and well-being in **regional evaluation**
- Collaborate with community partners to enhance community stroke services via navigation supports





## **Next Steps**



- Continue to build connections between hospital and community settings to help with navigation and transitions
- Review Return to Driving Resources
- Support the **inclusiveness** in stroke support groups (e.g. Indigenous populations, young caregivers, aphasia)
- Support establishing and sustaining stroke-specific exercise groups
- Include stroke-specific exercise group data in annual evaluation







## References

- Canadian Stroke Best Practices. (2019). Recommendations: Transitions and Community Participation Following Stroke, 6<sup>th</sup> Edition – 2019 Updated. <a href="https://www.strokebestpractices.ca/recommendations/managing-stroke-transitions-of-care">https://www.strokebestpractices.ca/recommendations/managing-stroke-transitions-of-care</a>
- Christensen, E. R., Golden, S. L., & Gesell, S. B. (2019). Perceived Benefits of Peer Support Groups for Stroke Survivors and Caregivers in Rural North Carolina. *North Carolina medical journal*, 80(3), 143–148. https://doi.org/10.18043/ncm.80.3.143
- Government of Canada (2022). *Stroke in Canada*. <a href="https://www.canada.ca/en/public-health/services/publications/diseases-conditions/stroke-in-canada.html">https://www.canada.ca/en/public-health/services/publications/diseases-conditions/stroke-in-canada.html</a>
- Hartford, W., Lear, S., & Nimmon, L. (2019). Stroke survivors' experiences of team support along their recovery continuum. *BMC health services research*. 19(1), 723. https://doi.org/10.1186/s12913-019-4533-z
- Krueger, H., Koot, J., Hall, R.E., O'Callaghan, C., Bayley, M. & Corbett, D. (2015). Prevalence of individuals experiencing the effects of stroke in Canada: Trends and projections. *Stroke*, 46(8), 2226-31.
- Magwood, G. S., Nichols, M., Jenkins, C., Logan, A., Qanungo, S., Zigbuo-Wenzler, E., & Ellis, C., Jr (2020).
  Community-Based Interventions for Stroke Provided by Nurses and Community Health Workers: A Review of the Literature. The Journal of neuroscience nursing: journal of the American Association of Neuroscience Nurses, 52(4), 152–159. <a href="https://doi.org/10.1097/JNN.0000000000000112">https://doi.org/10.1097/JNN.00000000000000112</a>

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# Appendix A: Canadian Stroke Best Practice Recommendations

#### Canada Stroke Best Practice Recommendations: Transitions and Community Participation Following Stroke

- Persons with stroke, their families and caregivers, should be assessed and prepared for transitions between care stages and settings through information sharing, provision of education, skills training, psychosocial support, awareness of and assistance in accessing community services and resources [Evidence Level B]. Interventions must be person- and family-centered and tailored to their individual values and needs [Evidence Level C].
- People with stroke, their families and caregivers should be provided with information about peer support groups in their community where available, descriptions of the services and benefits they offer, and be encouraged to consider participation [Evidence Level C].
- Education for people with stroke, their families and caregivers, is an integral part of stroke care that should be included as part of all healthcare encounters, and during transitions [Evidence Level A]. Individualized educational needs change over time and may need reassessment and updating on an ongoing basis [Evidence Level B].
- People with stroke, their families, and caregivers should be provided with information, education, training, support and access to services throughout transitions to the community to optimize the return to life roles, activities and social participation [Evidence Level B].
- People with stroke may ideally be provided with information and/or referral to community-based resources for engagement and self-management for ongoing physical, social, emotional, intellectual and spiritual activities and participation in the community [Evidence Level C].



# Appendix B: Abbreviations

Abbreviation	Meaning
BGH	Brockville General Hospital
CCSH	Community Care for South Hastings
СРНС	Community Primary Health Care, Senior Support Services
HPE	Hastings Prince Edward
KFLA	Kingston, Frontenac, Lennox and Addington
LLG	Lanark, Leeds and Grenville
PC	Providence Care
PSFDH	Perth and Smiths Falls District Hospital
ОНТ	Ontario Health Team
ОТ	Occupational Therapist
SLP	Speech Language Pathologist
VON	Victorian Order of Nurses

