Pathways for People with Stroke to Live Fully in the Community
Executive Summary
September 25, 2008

There are approximately 20,000 strokes each year in Ontario and close to 115,000 people are living with stroke. In 2005-06 the incidence of stroke in the Erie St. Clair Local Health Integration Network (LHIN) region was 1,279 and the incidence of stroke in the South West LHIN was 1,565.

A goal of the Southwestern Ontario Stroke Strategy is to build capacity across the Erie St. Clair and South West LHINs to support people with stroke to live more fully in their communities. Modeling on successful projects in the Champlain and Southeastern Ontario Stroke regions, a community engagement process was initiated. The purpose was to obtain a more detailed understanding of the barriers to inclusion and participation that people with stroke and their families experience, and identify possibilities for action. Six community engagement sessions were held with the intent to learn from the experience of people affected by stroke and community providers and develop a shared vision for the changes required.

In the sessions people with stroke, their family members and providers identified what was needed to enable successful community reintegration. Common themes developed which have been described as pathways. While each pathway requires specific actions to ensure change, they are interrelated and an integrated strategy is required to ensure an impact on people's lives. The four pathways are:

Proactive Support and Follow-up to Transition to the Community

This pathway involves the transition from hospital into the community and is critical to enabling the community reintegration process. Proactive support will ensure people have access to timely services and supports that will facilitate their transition to living fully in the community.

The key elements to this pathway include:

- active involvement of families in planning for the transition home
- "just in time education" for individuals and families affected by stroke
- comprehensive and consistent care coordination
- comprehensive, accessible and up-to date resource listing of services and supports
- knowledge of stroke and community services and supports amongst health care providers

Enabling the Person to Live at Home

This pathway refers to the elements required to support the care of the stroke survivor at home. The pathway requires that certain elements are in place – personal care, respite and education for family caregivers as well as home-making support.

The key elements to this pathway include:

- access to personal care
- awareness, training and capacity building of family members
- formal and informal opportunities for respite
- enhanced support during the transition phase when the person with stroke first comes home
- income support for family caregivers

Access to Rehabilitation Services

Rehabilitation services in the community are fundamental to the stroke experience. People want to progress to their maximum potential and recognize that rehabilitation is a critical first step in the recovery process.

The key elements to this pathway include:

- enhanced access to rehabilitation services in the community
- increased intensity and duration of therapies
- specialized stroke expertise of professionals
- integrated approach between hospital and community rehabilitation services
- access to reassessment
- access to social work
- access to vocational rehabilitation
- education for families

A Community Environment that Supports Active Engagement and Continued Recovery

This pathway ensures that people can be active in their community. A return to the community is the initial part of the recovery process. People seek opportunities to engage in activities that will support their continued recovery, enable them to regain their independence and interact with other people affected by stroke as well as the broader community. It requires accessible spaces, societal acceptance and understanding of the capacities and deficits associated with stroke or disability as well as transportation options.

The key elements to this pathway include:

- opportunities to continue the recovery process - community groups such as exercise groups, pool programs and aphasia / conversation groups
- opportunities to socialize, provide mutual support and volunteer
- processes to support the transition into community activities
- welcoming and accessible community spaces that support engagement
- orientation towards building on the assets and skills of people with stroke
- understanding of stroke amongst providers and volunteers working in the community
- accessible low cost transportation options and an affordable approach to regaining a drivers license
- access to appropriate assistive devices
- societal acceptance of people with disabilities
- affordable, accessible housing as well as supportive housing

There is significant existing capacity within the region – many organizations are offering services and working toward changes that will benefit people with stroke and their families. The stage has been set to advance more change if the passion of key stakeholders including people with stroke and their families is supported. Given the scope of actions outlined in the report it is the intent of the Southwestern Ontario Stroke Strategy to share the report with organizations where the mandate and goals are aligned as some of the actions are beyond the influence of the stroke strategy.

The next steps will include:

- Identify priorities for action that are within the Southwestern Ontario Stroke Strategy to influence and determine the associated actions.
- Determine how the work to be advanced aligns with existing initiatives including the current stroke strategy structure.
- Be responsive to the partner organizations / agencies that may wish to move forward on actions outlined in the report.
- Identify how people with stroke and their family members can be engaged in the process - working on specific initiatives and advocating for the changes needed.
- Develop a process to monitor and evaluate progress and share with key stakeholders the changes that are being made and their impact on people with stroke and their families.

For more information

Paula Gilmore
Southwestern Ontario Stroke Strategy
Community and Long Term Care Coordinator
paula.gilmore@lhsc.on.ca
1-800-265-1445 ext 6245

Pamela Smit
Veradus Consulting
psmit@veradus.com
613-820-7036

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