STROKE STRATEGY
of Southeastern Ontario

Building Capacity to Enhance Community Reintegration of People with Stroke

Final Report

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Submitted to the Regional Stroke Steering Committee of Southeastern Ontario

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ACKNOWLEDGMENTS

This report documents the rich discussion and shared analysis about the changes that are needed to support people with stroke and their families to more effectively reintegrate into the community post stroke.

As evidenced in the quotes throughout this document people with stroke and family members chose to share their experiences in the sincere hope that it would have a positive impact for those affected by stroke – people living with stroke now and those who will be affected in the future. It is often difficult to speak openly about experiences that have so profoundly changed people's lives. The honesty and willingness of all participants to share their stories is deeply appreciated.

We also thank the many providers who offer or could offer services and supports for people affected by stroke for their participation. A strong level of commitment and desire to support positive change was evident. New opportunities and ideas have emerged that could have a tremendous benefit for people affected by stroke. The forums also provided a venue to acknowledge the good work that many people do to make a real difference in people's lives.

The experience of participating in the process – local and regional forums - has likely had a more significant impact than any document could ever hope to describe. When we stop and listen to the stories of people with stroke and their family members, the emotional impact creates a personal and group motivation to act for local, regional and system improvements.

This initiative was conducted by Veradus Consulting on behalf of and in partnership with the Stroke Strategy of Southeastern Ontario and the Southeast Regional Stroke Steering Committee (RSSC). It was funded by the Regional Stroke Program based at Kingston General Hospital, Regional Stroke Centre. Pamela Smit, Veradus, worked closely with Cally Martin, Regional Stroke Program Manager and Gwen Brown, Community and Long-term Care Stroke Coordinator to design and implement the project in conjunction with a task group composed of stakeholders and community representatives from across Southeastern Ontario. Other members of the Regional Stroke team were actively involved.

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INTRODUCTION

The Regional Stroke Steering Committee and Southeast Regional Stroke Team recognize the critical need to build capacity across the region to support people post stroke to effectively re-integrate into the community.

While it is acknowledged that there are currently services and supports in place in different parts of the region, people with stroke, their families and providers continue to experience a number of significant challenges to effective community re-integration.

For this reason, the Regional Stroke Steering Committee decided to engage with their partners (including people with stroke and their families) to:

- develop a shared understanding of the changes required to better support people to re-integrate into their community;
- identify and assess opportunities to create positive changes;
- define priorities for change; and
- stimulate and support action for change.

Together we have created a shared vision, which will help to guide efforts to effectively support people with stroke as they re-integrate into the community.

OVERVIEW OF THE REPORT

This document provides an overview of the process undertaken and the results of that process. It outlines:

- the rationale for the design and the steps in the process;
- the principles and directions that have emerged;
- the current needs and actions related to each direction; and
- the leadership model for advancing action.

For each direction quotes from people with stroke and family members provide a context for understanding the challenges faced and the supports required.

To augment some of these perspectives and to provide further support for action excerpts from current research are included.

OVERVIEW OF THE PROCESS

There are many different organizations and individuals who have information about the experience of people with stroke, ideas about what could be changed to improve community reintegration and strategies to influence that change. It is imperative to hear a full range of perspectives about what changes are required, the priorities for change, the opportunities to build on and most importantly the possibilities for action.

Hearing about what changes are needed and the actions that could be taken does not always result in change. The process that was designed and implemented was intended to stimulate action. While this document summarizing the information and analysis is a critical component of the process, the experience of participating has been profound for many people and that is what will ultimately drive change. When people take the time to tell and listen to the stories, drawing the connections across the experience of many families who are affected, it evokes a personal and group motivation to act. We are all responsible for working together for change - people with stroke, their families, service providers and the greater community.

LOCAL FORUMS

Throughout October 2007, local forums were held in six locations across the South East Region:

- Brockville (for Leeds and Grenville);
- Smith Falls (for Lanark County);
- Kingston (for South Frontenac);
- Napanee (for South Lennox and Addington);
- Belleville (for South Hastings, Quinte West and Prince Edward); and
- Bancroft (for North Hastings, North Lennox and Addington and North Frontenac).

A representative from each area – either from a community care access centre, a community support service agency or a community health centre – worked collaboratively with staff of the Southeast Regional Stroke Team to organize the forum and recruit participants.

The intent of the local forums was to:

- identify the changes in services and supports needed to enhance reintegration of people affected by stroke into the community;
- identify possible actions that could be taken;
- identify assets and opportunities to build on; and
- stimulate energy for action.

The forums were designed to ensure that all participants had the opportunity to actively contribute to the process. Building on concepts and tools in collaborative research and social action, the facilitation techniques allowed a wide cross-section of stakeholders to learn together and engage in shared analysis – a critical step in moving toward action. The techniques supported participants to focus on the issues of primary interest to that group and their visual nature allowed people to easily track the outcomes of the dialogue.

In the morning participants focused on identifying desired changes that would improve the experience of people with stroke as they reintegrate into the community. A free-listing technique was used to generate significant information about the identified changes. Working in small groups, participants identified three to four key changes and documented them on cards. The larger group then re-convened and participants categorized the identified changes into themes. The resulting discussion focused on developing a shared understanding of the changes needed and why they were important.

All changes identified were brought forward into a preliminary report however participants in each forum were also given an opportunity to indicate which themes were of primary interest to them. The top two or three areas of change were used as the focus for discussion in the afternoon session. Depending on the priority changes identified different facilitation techniques were used to explore those topics. Many of the sessions focused on identifying what opportunities existed to build on, what actions could be taken and who would need to be involved.

REGIONAL FORUM

A *Preliminary Report* documenting the results of the local forums was developed and distributed in advance of the regional forum. Principles to guide action toward change and six directions to guide action had emerged.

The intent of the regional forum was to:

- validate the emerging directions and principles;
- review possible actions and modify them as needed;
- identify the connections to existing initiatives; and
- determine how to advance action.

In the morning an overview of the emerging principles and directions was presented. People with stroke and family members were then asked to indicate how well these reflected their experience and understanding of what needed to change. Subsequently, providers were given an opportunity to clarify what they had heard and offer their own reflections.

Overall the emerging directions were endorsed. Participants who had also attended one of the local forums confirmed that the directions were an accurate reflection of what had previously surfaced. People affected by stroke and their families indicated that their experiences and desires for change were accurately captured.

In the afternoon each direction and the associated actions were reviewed with a focus toward clarifying what actions could be taken, how they related to existing initiatives and what organizations or groups could lead change in specific areas.

Finally a leadership model was identified which would enable people affected by stroke, providers and representatives from the Regional Stroke Strategy Team to work together to advance action.

PARTICIPATION

A range of individuals and organizations were invited to participate in the local forums and the regional forum including people with stroke, their family members and providers working in community health centres, family health teams, community support service agencies, community care access centre, acute care and rehabilitation discharge planning services, rehabilitation services, specialized brain injury service and recreation services. The intent was to include people and organizations representative of the diversity of the region - people living in rural and urban areas, people of various ages, Anglophones and Francophones as well as Aboriginal people.

Over one hundred people (including Regional Stroke Team staff) participated in the six local forums – a significant number of them were people with stroke or their family members. Forty people participated in the regional forum – many of them were engaged in an initial forum but some were new to the process. The total number of participants was 154 - of these 59 were stroke survivors or family members. A profile of participants is included in Appendix A.

WHAT WE HEARD

While there were some differences that might be considered unique to the local areas within the region the common experiences of people with stroke and their families across the region was very evident. Six key directions have emerged as the primary areas for change along with a set of principles to be considered in all efforts at supporting enhanced re-integration.

The emerging principles and directions are followed by an overview of each direction – what is needed and the actions that could be taken. The voices of people with stroke and their families carry a clear message that needs to be heard.

EMERGING PRINCIPLES

A set of principles emerged to guide service delivery approaches that support active community re-engagement of people with stroke.

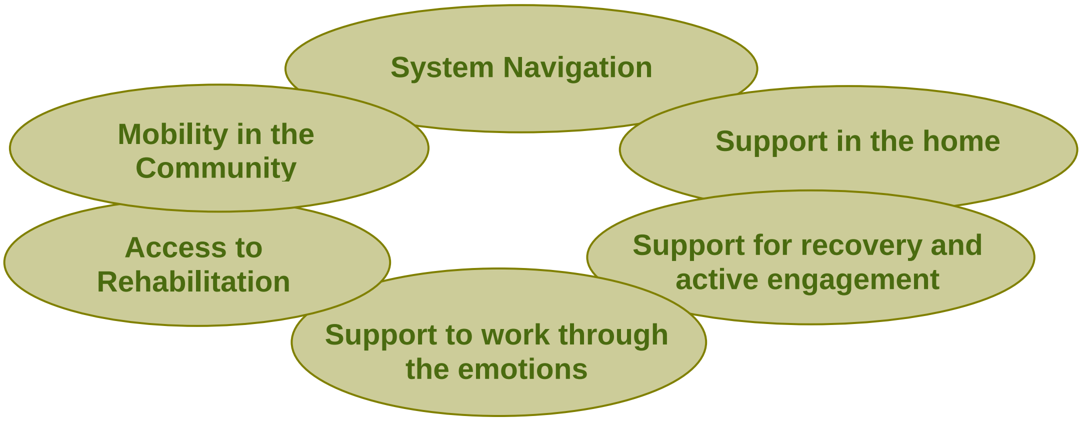
- Assume an orientation toward supporting people to thrive - rather than survive
- Consider the unique needs of people with stroke as well as the commonalities they have with people with other physical disabilities when developing service delivery models
- Provide holistic client/family centred services – an orientation toward the whole person and their family - with flexibility to meet unique needs
- Recognize the desire for independence and to make a meaningful contribution - promote and create opportunities for ongoing recovery after professional rehabilitation services are no longer provided or no longer available
- Expand understanding amongst people affected by stroke and providers of the potential for people to recover over an extended period of time
- Support an equitable approach to the provision of services and supports – consider differences in geography, local supports and services, culture, income level and age
- Recognize the significant costs associated with stroke (private rehabilitation, transportation, community services, recreation, adapted equipment, home renovation, loss of income) and strive to overcome finance as a barrier to accessing the services and supports
- Recognize the valuable role peers can assume for people with stroke and for family members throughout the re-integration process
- Develop a shared understanding of stroke, the levels of severity and the various ways it may be manifested (physical capacity, communication and cognitive function) and the implications for supporting reintegration
- Build on existing and create new partnerships and linkages amongst the myriad of community services and supports available including social and recreational
- Foster stroke expertise amongst providers and volunteers in the community sector
- Create opportunities for all stakeholders (including people with stroke and their families) to connect with providers to share developments that will retain the impetus to enhance community re-integration

DIRECTIONS

The six directions that have emerged are all interrelated and need to be considered together for their overall impact on people's lives. At the same time to achieve some traction and stimulate change, each direction should be an area of concerted focus.

1. Establish a new approach to guide and support access to community services and supports for all individuals and families affected by stroke when the person with stroke re-enters the community
2. Provide enhanced supports to people with stroke and their families during the initial transition period to the community and over the long-term as needed
3. Acknowledge the need and create opportunities to support families affected by stroke to work through this tremendous life change and the associated grief, loss and anger they may experience as they adjust to their new reality post stroke
4. Establish transition supports and opportunities to enable people with stroke to continue on their journey to recovery
5. Expand access to rehabilitation services
6. Expand the options and reduce the financial barriers to enable people to be mobile within the community

Figure 1: Interrelated Strategic Directions



Direction 1: Establish a new approach to guide and support access to community services and supports for all individuals and families affected by stroke

WHAT IS NEEDED

Families are seeking consistent case coordination, follow-up and follow-through from staff dedicated to providing a system navigation function for all people with stroke re-entering the community– including those with milder strokes. A client/family centred service is required with case coordinators who have the time to be proactive and the flexibility to meet individualized needs in unique circumstances and over the long-term. Currently many people do not access the services they need for various reasons (e.g. are unaware that the service exists, are uncertain if they qualify for the service, assume there is a cost to the service) or they find the services through default (e.g. become aware of the service through casual conversations with peers or community members).

The case coordination function needs to incorporate:

- ongoing assessment of needs and coordination of services and supports;
- monitoring and initiating reassessment of function;
- support to engage actively in the community through recreation/leisure activities and volunteering;
- support to access vocational rehabilitation;
- support for the whole family to ensure that services are in place including respite and support in the home where needed;
- advocacy for families seeking access to the services and supports they require;
- assistance to apply for funding to cover the costs associated with stroke; and
- coordination of services when more than one provider is involved - case reviews involving the providers and family members are needed to ensure the needs/interests of families affected by stroke are being met and to avoid duplication of services.

While there are many community services available there is considerable concern that they do not currently function as a system – it is often fractured, diverse and problematic to access. Families would benefit from a defined and commonly understood continuum of community services with service delivery coordinated across community-based providers and tailored to the unique needs of individuals.

…in the words of individuals and families affected by stroke	
"Only certain people get referred to the CCAC. We need it even if we are not eligible for CCAC services."	*"As a passenger on this train I don't know what to expect: things change. I need someone to check on me."*
"We need to have an initial contact in the community earlier."	*"Physicians don't know and are too busy to find out."*

Fragmentation of services is a significant challenge for the Aboriginal population due to various factors including language barriers, previous negative hospital/health care experiences, lack of technical knowledge and cultural differences and disparity. Approximately 80% of health services accessed by Aboriginals are off reserve however referral sources are not always aware of the services available to and desired by this population (e.g. healing and wellness programs) and as a result appropriate referrals are not made.

People need access to up to date information about what services are available at the time when the information is most relevant. Too often it is provided at or before discharge when the family is too overwhelmed to really benefit. Information and referral services are needed from staff trained to ask the probing questions that will ascertain a real understanding of what services are required. A comprehensive, current resource listing is required to support this information and referral function – which is related to the case coordinator's role.

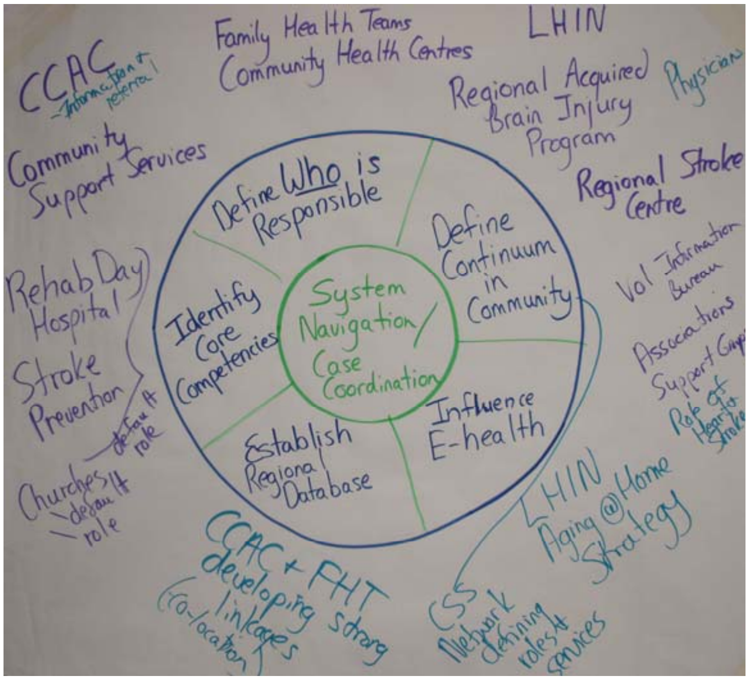
Information tools are needed which support enhanced continuity of care for the person with stroke and reduce the need for families to be reassessed by the range of providers working with them. This need aligns with the government direction toward e-health.

…in the words of individuals and families affected by stroke	
"It is tricky in the community. It is the first one and a half years that you really need help."	*"Do we need to be resigned to grieve and live marginally? We need more than that. We need help to coordinate care."*
"A community coordinator needs to be maintained over time. Our needs change as our understanding of our stroke changes."	*"I had all the support in the world. I can't say enough about the access centre. The case manager is wonderful."*
"We don't need a booklet. We need a person with knowledge."	*"How will someone know what I need if no one is reviewing my case?"*
""Your needs change just as they have always changed. You need one person who will see how this was different from 5 years ago and what services might be needed at this point in time."	*"The services are there but are not linking. People fall through the cracks."*

RECOMMENDED ACTIONS

a. Establish a system navigator/case coordinator function to assume a proactive role in supporting all people affected by stroke:

    - define the roles and responsibilities of all of the service provision partners engaged – community health centres, family health teams, community care access centre or specialized services (i.e. regional geriatric team, regional acquired brain injury service);



    - define the core competencies and training needed to enable case coordinators to fulfill their crucial role[1];
    - establish guidelines for assessing client needs, initiating possible service pathways and determining appropriate referrals – for the full scope of community services;
    - establish a process for linking all people with stroke/families (existing and new cases) to a defined case coordinator; and
    - communicate the process to enable multiple points of entry from partners.

b. Support people with stroke who do not have primary care providers to become clients of the new family health teams or community health centres – given their mandated role in chronic disease management. Continue to expand the number of family health teams and community health centres that exist in the region.

c. Define the continuum of service in the community:

    - identify what services are available and possible service linkages; identify areas of fragmentation (duplication or confusion) and seek clarification; and
    - confirm what services are available to what populations (age, culture[2], ability, catchment area).

d. Monitor developments in e-health to ensure that the needs of people with stroke and their families are being considered. Significant work has been done to develop a portable information tool(s) in the past including a Stroke Diary without real success due primarily to

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[1] Explore the feasibility of funding support from HealthForce Ontario to do the foundational work.

[2] Within the Aboriginal population for example alternative health practices are considered to be important to the healing process. Within the formal health system alternative medicine is often not embraced and referral sources are not aware of or making the desired linkages. Change would require cultural education about Aboriginal health and healing and awareness that healing encompasses the entire family and often the community.

the issues of resources, duplicate documentation, privacy and portability of health information across organizations.

e. Develop a regional electronic database of services available to people with stroke:
    - determine what organization or network is responsible for maintaining the database[3];
    - clarify how partners can support them to carry out this function;
    - determine who will access the information and how;
    - establish the process for updating the database;
    - inform people about the database so they can access it;
    - determine what information should be provided in paper copy to families who will not access electronic versions or via an information and referral service; and
    - consider how best to address possible language barriers.

f. Support peer initiatives related to stroke including support groups for people with stroke and caregivers, opportunities for sharing information and practical advice, and a newsletter/website. While they cannot replace a case coordinator, peers can provide a valuable information and support role – speaking to each other on a personal level given their shared experience.

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[3] Various databases and resource listings are now maintained by: the Southeast Regional Stroke Team; Southeast Community Care Access Centre which recently launched an expanded information and referral service; Community support service agencies; and Stroke Survivor Groups.

SUPPORTING RESEARCH

a. Compared to a group that did not receive professional support from a stroke association (home visits, telephone contacts and stroke information), primary caregivers of stroke survivors with professional support reported a significant increase in social activities and QOL (quality of life). (Rombough et al, 2007)

b. Kalra et al reported that caregivers who received training experienced less burden, anxiety or depression and had a higher QOL within one year post stroke. (Kalra et al, 2004)

c. ...the occurrence of a stroke affects the lives of other family members and the transition process is chaotic, resulting in changes in family relationships, caregivers coping with exhaustion, and survivors taking one day at a time and struggling to hang onto hope for recovery. (Rittman et al, 2007)

d. The majority of carers stated that they felt "let down" by the hospital discharge process because they found out about community support services only through avenues other than hospital staff such as friends, the internet or other carers. (Ski et al, 2007)

Direction 2: Provide enhanced supports to people with stroke and their families during the initial transition period to the community and over the long-term as needed

WHAT IS NEEDED

Families want to be actively involved in planning and preparing for re-entry into the community. They seek information and education about the level of care and rehabilitation, medications and community supports available to support them at this stage. They also want clarity about what is expected of families.

Families require enhanced support during the transition from acute/rehabilitation to home. They are often overwhelmed and not ready for the new reality of having the person with stroke return home. The expectations for caregiving can be daunting – physically, emotionally and psychologically. A range of supports - personal care, respite, case coordination, home assessments and home modifications - are particularly needed in the first period of time as the family adjusts.

Family members require respite from caregiving for personal time to rejuvenate and to engage in daily living - shopping, banking, medical appointments and recreation/social activities. Both the person with stroke and their family members are fearful and stressed about the possible impact of the caregiver becoming unwell due to the ongoing strain and the resultant need for institutionalization of the person with stroke. Existing respite guidelines are very strict and respite is only available to families when the person with stroke cannot be alone for more than 15 minutes. In some cases families believe that they qualify for respite but professionals have not identified it as an option. In other cases the family members have had difficulty requesting or accepting the service because of feelings of guilt or a fear that the substitute caregiver will not provide the same level of care and support.

Some families – particularly those with no or limited family members nearby – require enhanced support for activities such as home maintenance, cleaning and grocery shopping. If there is partner but that person does not drive the family also has enhanced needs for support.

Families desire more consistency in timing of personal care so they can be more active and plan their time.

…in the words of individuals and families affected by stroke	
"It is a shock when you return home."	*"There is only so much the government can do. They can't look after everything."*
"A couple's dialogue - "I worry if she doesn't get respite she'll have a breakdown and then I'm sunk and I'll be in a home." "I'm fine." "But there is a change in you. You are so tired." "It would be nice to get a good night's sleep."	*"When my husband had his stroke I had to do everything. I had never even used a bankcard. I couldn't drive. All of a sudden I had so much to learn including looking after him. I needed support."*
"I worry. What am I doing to this man? His blood pressure is up. I am so dependent on him."	*"I needed help in the early stages to discuss the frustrations within me to be a better caregiver. I want to do this well."*

RECOMMENDED ACTIONS

a. Ensure that the connection to the case coordinator/system navigator occurs prior to re-entry into the community. The case coordinator would assume a proactive coordinating function to ensure the necessary services and supports are in place and that the family and person with stroke are actively engaged in the planning process.

b. Ensure that the role of the case coordinator includes a focus on supporting the whole family by establishing regular contact to monitor what families need at different points in time – home care, personal care, respite, access to activities that will facilitate their recovery process. A trusted established relationship will assist families to identify when they need support and enable them to accept the support available. There may be opportunities to build on the evolving chronic disease management strategy of community health centers and the work of the new family health teams that are being established. They have the capacity to provide comprehensive care and support for clients through a multi-disciplinary primary health care team that includes physicians, nurse practitioners, nurses, social workers, dietitians, occupational therapists, physiotherapists - all of whom can provide home visits if needed.

c. Work toward enhancing the availability of respite care:
   - define the continuum of respite services needed and most appropriate models of service[4] to meet the unique needs of families (i.e. four hours, one day, two days, one or two weeks);
   - identify gaps in service within the region;
   - review guidelines to ensure that existing service levels are equitable within the region (in process through the CCAC); and
   - work toward changes in service where needed.

d. Establish a model of service, which increases home supports - personal care, respite care and home maintenance - during the transition phase to home[5].

e. Work toward establishing increased levels of support in home: establish a business model for enhanced support - the relative costs of providing respite and home supports compared to institutionalization; examine other models of best practice; develop a possible service delivery model for discussion with the LHIN; and advocate for enhanced funding for services.

f. Input into the “Aging at Home” planning and funding framework to ensure the needs of families affected by stroke are considered.

…in the words of individuals and families affected by stroke		
“I had a TIA myself. If I keep going this way, someone will be looking after me and I don’t want that.”	*“I would feel myself getting pretty uptight on the way home after a time of respite. I needed more time.”*	*“We put up a good front and people do not understand the full need. They don’t ask the right questions.”*
“He is scared that something will happen to me.”	*“My own stubbornness only goes so far. You get worn too thin.”*	*“I am worn out.”*

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[4] Review the Lanark, Leeds and Grenville Caregiver Study led by the Dementia Network.

[5] Review and build on the experience of the Easier Plus Pilot Project - a program for seniors 75+ being released from hospital and receiving extra home support for free for a 30 day period.

SUPPORTING RESEARCH

a. Despite the uniqueness of every situation, what caregivers have in common is the experience of putting someone else's needs ahead of their own, not occasionally or briefly, but constantly. Caregivers frequently give up their jobs and lose their professions. Caregiving becomes, in effect, their career. Because they take so little care of themselves, their own health suffers. (Cameron, 2003)

b. Caregivers never cease to care, even when they are physically absent. They will not truly relax and focus on their own well-being if they have even the faintest sense that they may be neglecting their responsibilities. (Cameron, 2003)

c. One caregiver remarked that she hadn't ever asked for respite because "when you're overwhelmed, just calling to ask for help is too big a mountain to cross." (Cameron, 2003)

d. The same strategies will not work for everyone. More attention is required to support caregivers in identifying what will result in respite for them. (Meredith, 2003)

e. Anderson examined the effect of stroke on 173 patients and their family carers. More than a third of people who support stroke patients at home regarded their own health as only fair or poor. Care became a burden rather than a pleasure, social function and personal relationships deteriorated, and contact with the outside world slipped away. Low mood was a major influence of outcome and a main component of quality of life. To carers it contributed substantially to the burden of care. In order to alleviate the suffering of illness, the social, psychological, family and economic aspects of stroke must be directly addressed. (Anderson, 1992)

Direction 3: Acknowledge the need and create opportunities to support families affected by stroke to work through this tremendous life change and the associated grief, loss and anger they may experience as they adjust to their new reality post stroke.

WHAT IS NEEDED

Stroke has a traumatic impact on families. People with stroke experience physical and sometimes cognitive deficits and may experience a change in personality. The person with stroke and their families need to work through this life change and the associated emotions of anger, grief and loss as they readjust their expectations to a new reality. This process can take time as families learn what deficits may exist over the long-term and learn to accept them while at the same time working to maximize potential.

Families need support to acknowledge and validate their feelings and sometimes to process those feelings. This support can come from a range of sources - family members and friends, peers going through the same experience, support groups, faith communities and professionals. Different people will respond to different approaches at different times.

While some families indicated that they had access to mental health professionals when it was needed – others indicated that they did not. The availability of mental health services through the publicly funded health system is limited in the region. The other challenge identified is that mental health services are not integrated with the rest of the health system.

The spiritual aspect of people's lives is critically important to many people including the Aboriginal community yet little if any focus is placed on spirituality within the formal health care system. Cultural sensitivity - to the balance in physical, mental, emotional and spiritual aspects of life - of health care providers is essential to supporting effective community re-integration.

Peer support can also be critically important. While some peer support groups exist - Kingston, Belleville and Smiths Falls – other communities do not have them. Bancroft did have a support group for caregivers at one time but the loss of professional support resulted in the group disintegrating since participants did not have the energy required to maintain the group as they worked through the issues they were experiencing.

Although peer support groups can have tremendous benefits some people noted that not everyone seeks a group experience – preferring established or self created buddy relationships or connections with peers. Distance and travel costs can also be a deterrent. For others their satisfaction with a group experience is very dependent on the make up of the group, its leadership, the topics discussed and how it is being facilitated.

…in the words of individuals and families affected by stroke	
"Even after 3 years we are grieving the loss of what we were and what we had. He had just retired. There were things we wanted to do and now we can't do them. We get very angry and emotional about the situation we are in."	*"I wasn't aware it was grief that I was going through. I have lost everything and I do not know what I will get back. Just realizing it is grief will help."*
"The stroke is very hard on relationships."	*"Stroke – damn it."*

RECOMMENDED ACTIONS

a. Work toward increasing the sensitivity of professionals to the grieving process experienced by families affected by stroke – acknowledge the tremendous impact on people’s lives.

b. Ensure that providers inquire about and monitor people’s emotional/psychological/spiritual health and make appropriate referrals. Consideration should be given to the cultural identity of the person with stroke.

c. Enhance the availability of publicly funded mental health services so people can have timely access to mental health professionals if they require it.

d. Support people with stroke who do not have primary care providers to become clients of community health centers and family health teams - many will have social workers. They will then be able to access the full scope of primary health care services including mental health counselling and support groups. Continue to expand the number of family health teams and community health centres that exist in the region.

e. Foster opportunities for peer support:

   - identify the range of peer support options that benefit people affected by stroke given unique needs/interests/culture i.e. link families who have experience living with stroke to families new to the process, establish buddy relationships (in person or by phone to support home bound people) and support groups;
   - identify what peer support initiatives exist within the Southeast Region[6];
   - identify gaps and possible actions to meet diverse needs including alternative ways to facilitate contact in rural areas or amongst those who are more housebound – chat lines, phone buddies.

f. Acknowledge the strong link between mental health, meaningful activity and opportunities to socialize for the person with stroke.

…in the words of individuals and families affected by stroke		
“The therapist or the doctor stopping and asking how we were doing meant the world to me. I could open up when asked.”	*“I am not a joiner. I don’t want to go to a group. When I did join I expressed anger and was told I shouldn’t. I have a right to be angry. I need support to express that anger.”*	*“My own schedule does not fit with the schedule of recovery of my stroke. I have to keep adjusting my expectations. I thought I could fight it.”*
“I kept thinking it would get better. It took a long time to accept it would just go on. For me what helped was my faith.”	*“I stayed angry and depressed for a long time. I needed someone to talk to earlier than I acknowledged.”*	*“She is a mother, a grandmother and a great-grandmother - a value to us all. Sometimes it is hard for her to remember that.”*
“You feel guilty when you lose it. When you feel you can’t do it anymore.”	*“I grieve the loss of our companionship - our physical companionship.”*	*“The biggest loss for me is being so angry. The change was so drastic and unexpected.”*
“She can drive me crazy crying. I don’t know what to do or what will support her?”	*“Just having a coffee with another caregiver helped.”*	*“I went to a therapist and it worked out good.”*

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[6] The Heart and Stroke Foundation has modified “Living with Stroke” and is now offering training within every region. Community Health Centres are developing support groups as part of their chronic disease management strategy.

SUPPORTING RESEARCH

a. Studies by Morimoto and coworkers and White et al reported a decline in HRQOL (health related quality of life), particularly mental health, in primary caregivers. Similarly, Bethoux et al reported a 20% prevalence of depression for caregivers. (Rombough et al, 2007)

b. Bethoux et al found that stroke had a significant negative effect on caregivers who experienced higher internal strain, anxiety, physical burden, socioeconomic consequences, and a decrease in their marital satisfaction. (Rombough et al, 2007)

c. Caregivers pay a price for their dedication, which can be personally catastrophic. Marriages fail, families are plunged into poverty and caregivers' psychological and physical health deteriorates. (Cameron, 2003)

d. Social isolation not only inhibits the experience of connectedness with others but can also promote depression and physical illness for individuals managing transition at one month post stroke. The inability to regain full participation in leisure and community activities appears to be more closely linked to poor psychosocial outcomes such as depression and poor quality of life than do difficulties in performing basic activities of daily living. (Rittman et al, 2007)

e. When the psychosocial needs of patients and their caregivers are regularly addressed through social support, improved outcomes are observed, including reduced caregiver burden, reduced incidence of anxiety, reduced emotionalism and depression, reduced hospital readmissions and failed discharges, and facilitated reintegration of the patient in family and social roles. (Anderson, 1992; Duncan et al, 2005)

Direction 4: Establish transition supports and opportunities to enable people with stroke to continue on their journey of recovery.

WHAT IS NEEDED

People with stroke are looking for opportunities to continue their recovery process. For many this means opportunities to engage in physical activity. People want to continue to be physically active as they work to regain or maintain their function. For some people it means opportunities to communicate – to stimulate their language and cognition abilities. For many it is learning new skills or relearning old skills as they adapt to their new reality.

Many people with stroke want opportunities to socialize with peers – at least in the short-term. They want to be with others who share the stroke experience and the resulting changes that can happen in speech, cognition and physical capacity. Over time as people socialize and renew or establish relationships with peers and in the broader community their network expands. If opportunities are not available to connect into the community, the person with stroke and their family members can become increasingly isolated - over time it becomes even more difficult to re-enter the community.

Some people want a place to go several days a week – a place that is safe, provides social interaction with peers and offers opportunities to be physically active and to learn skills.

Most people want to contribute to society in some way – by volunteering or through work. Some people with stroke have indicated that they seek volunteer opportunities. Others want to go back into the workforce and they need vocational rehabilitation services to accomplish this goal.

A clearly established process to support people to transition into community activities is needed. People who are vulnerable and who may not have a strong history of participating in community activities often require some initial assistance to establish the first linkages.

…in the words of individuals and families affected by stroke		
“I want to walk. I need the Y and someone there to show me what equipment to use.”	*“Just to walk down the road is an effort. Do you think I am going to get out and do great big exercises? Forget it.”*	*“We need to address our unique needs and then groups will naturally come together to meet group needs.”*
“A lot of people who were your friends before – they scatter.”	*“The stroke has changed me. I was more of an extrovert before.”*	*“There is a connection between quality of life and productivity.”*
“I want something stimulating. I need that.”	*“He needs to go out on his own. To do something.”*	*“I want to go ballroom dancing so badly.”*
“My partner is not social. She does not want to go out. If she had more help to get into things earlier on that might have made a difference. She has more or less lost interest in trying to help herself now.”	*“She was a wonderful knitter. She loved to do crochet and macramé. Once she lost her arm and her ability to do these things, she lost confidence in everything.”*	*“We need to be with other people – get a boost. We don’t want to be with a group of people who are complaining. We want to get away from that.”*
	“I don’t want to be in a day program with people who have Alzheimer’s”.	*“I feel alone and isolated.”*

RECOMMENDED ACTIONS

a. Establish a focus toward people with stroke thriving rather than surviving and provide active support within the community to enable them to do so. Move towards a ‘participate to learn’ approach that facilitates learning by doing, activity, independence and reflects the reality of daily living.

b. Create community-based opportunities for people to participate in physical activities with the assistance of exercise specialists who can develop adapted programming. Establish linkages for referral and case consultation with rehabilitation services.

c. Establish groups for people with aphasia to communicate together and offer peer support in areas of the region where they do not currently exist.

d. Building on existing programs and services (see Appendix B) design a model of engagement for people with stroke and other physical disabilities. Consider the following:

  - how to respond to the unique needs/interests of people with stroke - people who want 1:1 contact and those who prefer groups and activity interests;
  - a process to support people to participate - the fear of new experiences is often amplified by disability and people may need initial support to go;
  - the need for consistent programs of a sufficient duration which people can depend on and that can also serve as respite for family members;
  - programming during all times of the year;
  - the need for professional involvement in planning and delivery of programs and services to sustain them rather than relying exclusively on people with stroke and their families;
  - the need for personal care, mobility and/or communication supports;
  - the cost of participating; and
  - transportation availability and the associated costs.

e. Building on existing volunteer coordination services, establish a process to match interested people with stroke to volunteer opportunities.

f. Ensure that people who seek employment are supported through vocational rehabilitation: identify what services exist and how they can be accessed; identify possible gaps in service and how those gaps can be addressed to meet unique needs.

SUPPORTING RESEARCH

a. Quality of life three months post stroke was associated with functional ability, satisfaction with social support and the number of support persons available to the patient. (Mackenzie & Chang, 2002)

b. The presence & size of social support networks as well as the perceived effectiveness of the social support network have a positive influence on physical recovery and quality of life post stroke. (Clarke et al, 2002)

c. Because of the difficulty of mobility, perceived social stigma related to physical and cognitive deficits or depression, many stroke patients become socially isolated. Social isolation is also strongly correlated with post stroke depression. When withdrawn socially, stroke patients are not likely to venture into the neighbourhood for walks, use the public swimming pool or travel to a local gym. Studies have shown that even in stroke survivors with a significant degree of recovery social isolation was still evident. To enhance exercise compliance the issue of social isolation will need to be addressed and resolved. (Gordon N, et al., 2004)

d. There is strong evidence that interventions designed to increase social support by accessing community-based support services help stroke survivors to increase social activity. (Salter et al, 2004)

e. Community-based group-exercise interventions that include agility or stretching/weight shifting exercises were effective in enhancing functional balance, mobility and standing postural reflexes, which reduces the risk of falls in the older age group with chronic stroke. These programs increase regular physical activities for older adults with chronic conditions and could offset secondary complications that often occur after a sedentary lifestyle. (Marigold et al, 2005)

f. An 8 week water-based exercise program indicated a 22% improvement in cardiovascular fitness in a small group of people with stroke with relatively high function. It also showed increases in maximal workload, gait speed and paretic lower extremity muscle strength. The researchers concluded that a water based exercise program may be an effective way to promote fitness in people with stroke (Chu et al, 2004).

g. Three major rehabilitation goals for the stroke patient are preventing complications of prolonged inactivity, decreasing recurrent stroke and cardiovascular events and increasing aerobic fitness. Recent studies support the use of regular exercise to improve cardiovascular health and fitness after stroke, which is consistent with consensus statements on exercise for the able-bodied. Stroke patients can increase their cardiovascular fitness by a magnitude similar to healthy older adults who engage in endurance training programs. Studies of exercise programs consistently indicate improvements if the exercises are performed a minimum of twice per week (Gordon, N. et al., 2004).

h. Rehabilitation after stroke must also address ‘participation’. This may require planned withdrawal of medical and rehabilitation services and substituting them with leisure and social activity to encourage independence and reintegration to normal life. (Canadian Stroke Network and the Heart and Stroke Foundation of Canada, 2006)

i. For many stroke patients and their families, the real work of recovery begins after formal rehabilitation. (Duncan et al, 2005)

Direction 5: Expand access to rehabilitation services.

WHAT IS NEEDED

There is a desire to increase awareness of the benefits of rehabilitation and the progress made by people with stroke over long periods of time. Many families indicate that professionals are frequently surprised when they see how much function they have recovered. Current research findings about the impact of rehabilitation need to be widely disseminated and new research undertaken to demonstrate results beyond the initial rehabilitation period.

People with stroke placed a strong emphasis on access to community-based rehabilitation services – both in-home and outpatient. They seek increased intensity and duration of therapy as they regain their endurance and continue to progress. Access to an inter-professional team is considered critical to ongoing recovery from stroke. Out-patient rehabilitation services have been cut back significantly over the past ten years and where out-patient programs do exist, they are frequently not inter-professional in nature. Day rehabilitation programs are serving a critical need but are not available in all communities – while Perth and Belleville have day rehabilitation programs, Kingston, Brockville and Bancroft do not have this service. The CCAC rehabilitation therapy services available are more limited in both intensity and duration. Community health centre rehabilitation therapy services are limited as well. Families who are fortunate enough to have access to a benefits plan indicate greater satisfaction with the therapy levels they are able to access for the person with stroke. There was evidence that people getting intense private specialized speech and language and physiotherapy services had higher levels of satisfaction. Other people were frustrated about not being able to access intensive services.

At a minimum people seek consistent levels of service. Enhancing community based stroke rehabilitation services through the CCAC - demonstrated to be effective through the Regional Stroke Rehabilitation Pilot Project - across the region is considered to be critical.

Families are seeking local access to rehabilitation providers with stroke expertise. In some parts of the region – North Hastings, North Lennox & Addington, North Frontenac, Leeds and Grenville - access is more limited than in other parts. Clients are forced to travel very long distances at considerable cost and difficulty in terms of personal stamina to access providers with stroke expertise in out-patient day programs. For some the cost and distance prevent them from accessing the service and realizing their full potential. The ongoing challenge of recruitment for rehabilitation providers such as physiotherapists constrains the ability of providers to offer local access to rehabilitation service.

The recovery process extends far beyond the period when people typically receive rehabilitation therapy services. Many people recover function that was unexpected and may then benefit from therapy to continue the progress. Others lose function and require some therapy to regain it. Families are seeking functional reassessments on a regular basis to guide decisions about access to rehabilitation therapy needs. A proactive approach led by a case coordinator who will monitor changes in condition is desired regardless of whether the stroke survivor is a client of the CCAC or not.

Personal support workers have the potential to assist in the person's recovery. To do so they need to provide assistance with the activities of daily living in a way that promotes independence. To be successful in this approach requires both education in the principles and techniques of rehabilitation and adequate time to effectively fulfill their responsibilities.

…in the words of individuals and families affected by stroke	
"Not one physician friend that I have has not contacted me and been surprised when I tell them that I can walk – they don't believe me. There is a big reality gap about rehab and what it can do."	*"There is an issue with centralised services. When do we decentralise so people can get it locally?"*
	"It makes me sad that I didn't get the speech therapy I needed."

RECOMMENDED ACTIONS

a. Link to the evolving Health Human Resource Strategy in the Southeast Region to expand the number of rehabilitation professionals with neurological expertise in the community.

b. Establish new models of service delivery to enhance access to rehabilitation services in areas with limited or no rehabilitation services available i.e. role of paraprofessionals in models of care, use of telemedicine (e.g. tele-physio)

c. Consider consistent provision of enhanced rehabilitation services via the CCAC rehabilitation providers for those in need of this service - demonstrated to be feasible and effective in the Stroke Rehabilitation Pilot Project of Southeastern Ontario (2004).

d. Consider funding and implementing day rehabilitation services that would service stroke survivors in those parts of the region where they do not currently exist.

e. Where outpatient programs do exist, such as outpatient physiotherapy, consider the feasibility of including other outpatient rehabilitation services such as Occupational Therapy and Speech Language Pathology services to promote an inter-professional approach to stroke care.

f. Establish a shared principle – toward independence and participating to learn. Engage personal support workers in case planning and education so they provide assistance with the activities of daily living in a way that promotes independence. Advocate for increases in allotted care times to allow the person with stroke to actively participate to their full potential.

g. Support the establishment of peer support groups such as an aphasia group in areas of the region where they do not currently exist. Building opportunities for peer support into community-based physical activities may also serve to motivate people to participate in activities that will help them to maintain or regain their functioning.

h. Explore the feasibility of an enhanced role for community health centers and family health teams in rehabilitation.

i. Build connections between adapted physical activity and recreational programs to support ongoing recovery and rehabilitation services to promote cross referral and consultation and to ease the transition between services.

…in the words of individuals and families affected by stroke	
“Providers are not as optimistic as they should be. It is amazing what rehab can do.”	*“Are expectations higher than are realistic? There is a tension with not getting the message of hope.”*
“The community lacks people with expertise in stroke. *“The therapists in the day hospital have been our saviours.”*	*“The CCAC limits the number of visits but that is not always appropriate to the individual needs of the person with stroke.”*

SUPPORTING RESEARCH

a. The most notable concern held by carers was the waiting time between hospital discharge and initiating therapy in the home. A number of carers felt abandoned during this period and that the stroke survivor had 'gone backwards'. (Skit et al, 2007)

b. The Stroke Rehabilitation Pilot Project of Southeastern Ontario demonstrated improved functional outcomes at a year post stroke and decreased hospital readmissions in the group that received timely and enhanced intensity of rehabilitation services on transition from inpatient rehabilitation into the community. (Regional Stroke Steering Committee of Southeastern Ontario, 2004)

c. Ongoing rehabilitation (beyond six months post stroke) can further improve activities of daily living (ADL) and fitness. Stroke rehabilitation involves programs to reduce impairments, enhance recovery and adapt to persisting disabilities. The risk of deterioration in ability can be reduced or reversed by further rehabilitation input. Therapy-based rehabilitation services can: reduce poor outcomes (i.e., prevent hospital readmission); promote participation in desired activities; increase ADLs; and reduce external home care supports. Canadian Best Practice Recommendations for Stroke Care include:

    - Any stroke survivor with reduced activity at six months or later after stroke should be assessed for appropriate targeted rehabilitation (National Clinical Guidelines for Stoke, Royal College of Physicians of London, 2004); and
    - People living in the community who have difficulty with ADL should have access, as appropriate, to therapy services to improve, or prevent deterioration in ADL (Australian Clinical Guidelines for Stoke Management Stroke Rehabilitation and Recovery, 2005)

    (Canadian Stroke Network and the Heart and Stroke Foundation of Canada, 2006)

d. An emphasis on physical recovery and the management of self-care tasks in rehabilitation appears to be insufficient to facilitate the achievement of clients' goals. Access to rehabilitation services in the clients' home and community environment may help clients and partners remove barriers that limit resumption of past activities, break the "downward cycle that can lead to partner exhaustion and depression" and improve quality of life. (Stanton, 2000)

e. In a systematic review of randomized controlled trials of stroke patients, the effects of therapy-based rehabilitation services targeted towards patients residing in the community was analyzed. Reviewers sought to identify the proportion of patients who had deteriorated or were dependent in personal activities of daily living and performance in personal activities of daily living at the end of follow-up. The main results identified a heterogeneous group of 14 trials including 1617 patients. Therapy-based rehabilitation services reduced the odds of a poor outcome and increased personal activity of daily living scores. (Outpatient Service Trialists, 2002)

f. Comprehensive understanding and involvement of the person, family/caregiver, and environmental system are required for stroke rehabilitation. Without adequate resources and support it is difficult for patients to sustain the gains made during inpatient care or to make further progress in the community. It is essential that the treatment team know the patient (including history, expectations, coping style, resources and emotional support system in order to fully engage him/her in the treatment process. Motivation and hope for improvement is a critical factor for functional improvement. (VA/DoD Clinical Practice Guidelines 2002; Duncan et al 2005)

g. The Report of the Consensus Panel on the Stroke Rehabilitation System “Time is Function” outlines the following standards which should be considered in planning of rehabilitation services:

- Standard #4: Stroke survivors should have a mechanism to access or re-access the rehabilitation environment, if clinically indicated, regardless of the time that has elapsed since the stroke.
- Standard #9 Once it is determined that a stroke survivor will benefit from Community rehabilitation and once rehab ready, the stroke survivor will have access to an interprofessional rehabilitation team with expertise in stroke care.
- Standard #13: All stroke survivors, regardless of where they live, will have equitable access to the same standard of care at the appropriate intensity and duration.
- Standard #16: Stroke Survivors who are discharged to the community with home-based stroke rehabilitation services will be provided with these services as per available evidence-based guidelines. (Heart and Stroke Foundation of Ontario, 2007)

Direction 6: Expand the options and reduce the financial barriers to enable people to be mobile in their communities.

WHAT IS NEEDED

Families need accessible transportation options that are low cost. In many cases the cost of transportation prevents or limits people from using it. Although community support services provide transportation at a relatively low cost on a per mileage basis the travel distances in rural areas make the final costs prohibitive. People make choices about the finances they can allocate and opportunities for socialization - while critical - become a reduced priority.

Given the challenges of retaining local stroke expertise in rural areas people often do not get the rehabilitation they require given the limiting costs of transportation as well as the physical toll that long distance travel has on the person with stroke and the family members. New options are needed for families - either transportation costs are covered or local models of service delivery need to be established to bring stroke expertise where it is needed. In some cases boundaries for transportation service delivery need to be changed to facilitate access.

In communities where accessible transit is available people would like to have more flexibility in their ability to book transit service – opportunities to be less planned and spontaneous. Service which is pre-scheduled tends to work relatively well. There is also a need for people to have assistance to get in and out of homes – recognizing there are implications for liability and training of drivers that require consideration.

People with stroke seek a streamlined approach to regaining a driver's license at a reduced cost. The current cost exceeds $500 for testing the ability to drive plus lessons if they are deemed necessary. The total cost of regaining the license often exceeds $2000 and is a significant burden. There is no financial support for people who cannot afford the associated costs. Privatization of the system appears to have resulted in increased costs for the people affected – a penalty for having a stroke. Families also indicated concern about the apparent lack of accreditation, competition and appeal process.

Families are seeking genuinely accessible spaces in the community – washrooms, ramps, doorways, sidewalks, parking. Too often even those spaces, which have been designated accessible, do not meet the standards of real accessibility. Key spaces that should be accessible include community centres, restaurants, clubs and malls.

…in the words of individuals and families affected by stroke	
"How can the person who fails me in my test be the same person who gets paid to give me driving lessons? It isn't right. The government downloaded this service and we are stuck with it."	*"Whenever my husband and I have a fight it is about the car – me driving and him not driving."*
"We all have a role in advocacy to make the system better."	*"We lose our flexibility."*

RECOMMENDED ACTIONS

a. Enhance the availability of non-urgent transportation services in areas where accessible transportation systems do not exist:

   - Establish a link to the Non Urgent Transportation Working Group.
   - Advocate for reduced costs of transportation services offered by community support service agencies - while fees can be waived not everyone is aware of that.
   - Identify and inform people of opportunities to access transportation support i.e. community health centre gas vouchers, service club subsidies and community support service programs which include the cost of transportation with program fees.

b. Work through existing Municipal Accessibility Committees to:

   - engage providers of accessible transportation systems in dialogue about what is working (service for regular clientele, drivers) and what is not (lack of flexibility, lack of assistance to get in and out of homes, liability issues, training issues) and the changes needed.
   - request consumer input and assessment into the design of accessible spaces such as a consumer accessibility consultant and to ensure that municipalities consider the needs of people with physical disabilities when designing spaces for sport, recreation and leisure.
   - inform businesses of the importance of creating accessible spaces including the benefits to their business and provide positive feedback about spaces that have been well-designed.

c. Request a government review of the current process for regaining a driver's license with a focus toward accreditation of service delivery and reducing the costs.

…in the words of individuals and families affected by stroke	
"I want more spontaneity."	*"The paratransit in Brockville is excellent but we need more of it."*
"Bus drivers need to wait until we are seated before they move."	*"They won't pick us up because we are on the wrong side of the road – their boundary."*

SUPPORTING RESEARCH

a. Successful re-engagement involves ensuring the patient's mobility in the community, attention to the patient's emotional well-being & support to take part in purposeful activities. (Wilson et al, 2001)

b. The decline in active participation in outside community and leisure activities is often attributed to physical and psychological barriers, including fear of falling, being afraid to leave the house and transportation difficulties. A study by Holbrook and Skilbeck found that 75% of the 122 post stroke patients they surveyed reduced most of their community and leisure activities they had done before the stroke and never resumed them later in the recovery process. (Rittman et al, 2007)

MOVING FORWARD

There is a strong commitment from people with stroke, family members and service providers to advance action as a result of this process. Participants in the Regional Forum agreed to form a Leadership Team that will be responsible for advancing action, potentially through associated workgroups.

Participants were invited to indicate their interest in working together toward implementation. A number of people have indicated interest in participation in either the Leadership Team or in action related to specific directions.

COMMUNITY RE-INTEGRATION LEADERSHIP TEAM

A leadership team will be established to advance action on the directions that have been identified through this process.

The leadership team will assume the following responsibilities:

- lead action on directions where needed;
- link to and influence related initiatives;
- advocate for action on the directions and related actions that have emerged;
- monitor developments and progress; and
- consult with and report to the larger community of people with stroke, family members and service providers.

People with stroke or their family members and service providers with a service delivery mandate related to community reintegration of people with stroke will participate in the Leadership Team. It will be supported by staff from the Southeast Regional Stroke team. A request will be made to the Regional Stroke Steering Committee to have the Leadership Team report to that Committee as it works to fulfill its mandate. The action plans developed will be included in the Regional and Local Stroke Best Practice Work plans for 2008-9 and yearly thereafter as needed. The progress on these work plans is overseen and monitored through the Regional Stroke Team and its partners on the Regional Stroke Steering Committee.

…in the words of individuals and families affected by stroke	
"I do not want this to be paper on a shelf."	*"I want to see action. You heard us well. Come back in 2009 and let's see what progress has been made."*
"I have been talking with people involved with stroke for over 15 years. This picture (directions and actions to be taken) is wonderful."	*"We need those affected, those who fund and those who provide in the same room – a small room."*

WORKING GROUPS

It became clear through the review of the directions that emerged and the associated actions that some organizations are appropriate to lead or be engaged in further analysis and decisions on the actions to be taken. In some cases it is because the work fits within their mandate and in other cases it is because related initiatives are already underway. In some cases actions may be specific to local areas within a region.

Short-term actions teams with a defined and limited mandate will be established as needed to advance/recommend actions in specific areas. The teams would be expected to report progress to the Leadership Team to ensure that activities are aligned as needed.

CALL TO ACTION

Advancing the strategic directions identified requires action at many levels for local, regional and system improvements. Many people and organizations – including service delivery and system planning and funding organizations - have an obligation to act.

Real change will involve:

- clarifying roles and responsibilities of service providers;
- shifting the way current services and supports are offered;
- building better linkages between services and supports; and
- shifting funding guidelines and investing in services that will have maximum impact.

The changes that are required can be locally as well as regionally driven. Some actions can be readily taken and simply require dialogue between the relevant organizations. In other cases more work may be required to ensure that the system is responsive to needs across the region. In other cases change may be required at the provincial level and education and advocacy may be needed to inspire that change.

There is a solid foundation to build upon in Southeastern Ontario and a real commitment to action. If stakeholders maintain a focus on the priorities for change as identified by people who are directly affected by stroke they will be able to build the momentum - toward better outcomes for people with stroke and their families.

> The Ontario Stroke System is a client-centered, collaborative network that leads, plans, coordinates and delivers stroke prevention and care across the age-life continuum and across the continuum of stroke care.
>
> Our Vision…Fewer strokes. Better outcomes.
> Our mission…To continuously improve stroke prevention, care, recovery and re-integration
>
> Ontario Stroke Strategy, 2007

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APPENDIX A: PARTICIPATION

Representative	**Brockville**	**Smith Falls**	**Kingston**	**Napanee**	**Belleville**	**Bancroft**	**Region**
Person with stroke	9	3	6	1	4	1	10
Family Member	6	4	2	1	4	3	5
Sub-total persons with stroke and family	15	7	8	2	8	4	15
Community Health Centre			1		2		5
Family Health Team	1						
Physician	1						1
Community Support service agency	2	1	2	4	2	3	3
Community Care Access Centre managers and case managers	1	1	1	1		2	2
Acquired Brain Injury Service	1		1	1			1
Recreation organization	2				1		1
Hospital/Rehabilitation Centre - discharge planning	1	1	1				2
Hospital/Rehabilitation Centre – nursing and therapy providers	2	1	3	2	1		2
Community rehabilitation provider	1		1	1			
Local Health Integration Network							1
Other			2 HSFO and student	1 student			1 dementia network
Sub-total health care providers	12	4	12	10	6	5	19
Regional Stroke Team members	3	3	3	4	5	3	6
Grand TOTAL	**30**	**14**	**23**	**16**	**19**	**12**	**40**

Total Attendance: 154 * Note: I person with stroke and 1 provider also consulted through individual interviews

APPENDIX B: ASSETS TO BUILD ON

Possible assets, which could form a foundation to support action in Strategic Direction 4, were identified in 4 of the 6 forums. Further work would be required to develop a complete list.

Belleville	Brockville	Smith Falls	Bancroft
▪ Community support services agencies: ▪ Care for: adult day program; exercise programs – in community and in–home; ▪ Friendly visitor program; walking program at a local high school; volunteer program ▪ YMCA: cardiac rehabilitation program; aquafit; aqua jogging; stretch and strengthen; walking programs; ▪ Seniors group – Club 105, Club 39 ▪ City Recreation: walking programs; waterfront paved paths; ▪ Sporting Organizations: ▪ Libraries: shut-in program to deliver books ▪ Service Organizations ▪ Churches ▪ Retired Engineers – creating adaptive equipment	▪ CPHC/VON: family health team; adult day program; Smart Program – exercise programs ▪ Stay Well ▪ YMCA: range of programs, willing to offer adapted programs ▪ Walking Programs: Prescott Walking Program; Thousand Islands Mall Walking Program; Cardinal Church Gym ▪ Country Roads CHC: Chronic Disease Management Programs; health promotion programs ▪ Churches ▪ Acquired Brain Injury Program - support groups for people 18-65 years; vocational support program; individual assessment and rehab	▪ CSS agencies: friendly visiting; support groups; diners clubs; meals on wheels; Volunteer programs; ▪ Rideau Regional: use site to benefit community members; ▪ Seniors clubs: Harmony Centre; Older Adult Centres of Ontario; Perth McMartin House ▪ Community Health Centers – Lanark and Merrickville: health promotion activities; chronic disease management programs ▪ Acquired Brain Injury Programs ▪ CCAC day away programs ▪ Churches: pastoral care; parish nurses ▪ Private business: Virtual golf, malls ▪ Association, clubs ▪ Municipal recreation providers - Arenas and Pools ▪ March of Dimes –practical assistance ▪ Private practise therapists offering group programs to support recovery	▪ Faraday Community Centre ▪ Club 580 for Seniors ▪ Manor – auditorium, kitchen, accessible bathrooms ▪ VON 1:1 respite program