

***Never Giving Up:
Stroke Survivor and Caregiver Perspectives
of the Road to Recovery from Stroke***

August 2005

Heart and Stroke Foundation of Saskatchewan

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CONTENTS

Impact of Stroke in Saskatchewan	3
Purpose of Stroke Impact Study	4
Method	4
Data Collection: Focus Groups	5
Data Collection: Face to Face Interviews	6
Data Analysis	6
Profile of Stroke Survivors and Caregivers	7
The Road to Recovery from Stroke: The Analogy	8
Findings and Discussion	11
Missing Views on the Road to Recovery.....	11
Beginning the Journey on the Road to Recovery	12
The Road Not Taken	12
Loosing Their Way of Being in the World	14
A New Way of Being in the World.....	16
Factors that Helped Along the Way on the Road to Recovery.....	17
The Fierce Strength Within	17
Coming Along Side: Family/Caregivers	18
Health Care Services	20
Formal and Informal Support Groups	22
The Quiet Strength Within	24
Barriers and Challenges on the Stroke Recovery Road	25
General Lack of Information.....	26
Transportation	27
Beyond the Six Month Window Theory	28
Summary and Conclusions	29
References.....	33
Appendices	34

Impact of Stroke for Saskatchewan

Stroke is the fourth leading cause of death in Canada. In Saskatchewan, approximately 2000 people suffer acute stroke each year (Saskatchewan Stroke Research Centre, 1995). The longer life expectancy of an aging population will likely increase this number in the future as the risk of stroke doubles every ten years after age 55. Of these 2000 people who suffer acute stroke, 300 die, 200 are so severely disabled they require long-term care, 800 are left with a moderate to severe impairment, 500 recover with a minor impairment or disability and 200 fully recover.

Challenges to Delivery of Stroke Services in Saskatchewan

Saskatchewan challenges include geography, demographics, distribution of specialized health services as well as public and professional awareness of stroke risk factors and symptoms. Saskatchewan is a large province and more than 40% of the population still lives in small centres and on farms. While most people live within a half hour drive of a hospital or health centre, most of these facilities are not adequately equipped to deal with acute stroke (Heart and Stroke Foundation of Saskatchewan, 2001). Moreover, Saskatchewan does not have a provincial stroke strategy.

The Heart and Stroke Foundation of Canada and the Canadian Stroke Network have a vision that by the year 2010, every province and territory will have a coordinated, integrated strategy for stroke prevention, treatment, rehabilitation and community reintegration. Provincial Heart and Stroke Foundations are in a key position to lead the development of comprehensive and coordinated stroke strategies. In November 2003, the Heart and Stroke Foundation of Saskatchewan Board of Directors mandated the organization to proceed with the development of a comprehensive stroke strategy for Saskatchewan.

The Saskatchewan Scene

The mission of the HSFS is to improve health by preventing and reducing disability and death from heart disease and stroke through research and health promotion. Stroke has received little attention in Saskatchewan despite new treatment options that are available to reduce the effects of stroke. Stroke is an increasingly treatable disease and disability-free years are added to the lives of survivors through organized care that promotes healthier lifestyles, faster response to acute stroke and appropriate use of services. Timely treatment (CT scan and clot-busting drug) within three hours of the onset is critical for thrombotic stroke which accounts for 80% of strokes. Furthermore, many survivors of transient ischemic attacks (TIA) vanish into the population at large after an initial diagnosis and treatment. Do they know that a TIA may be a warning signal of full stroke yet to come?

Regrettably, 1500 Saskatchewan people, who survive but do not fully recover from their stroke event, will begin the journey of living with a stroke in 2006.

Purpose of the Stroke Impact Study

A clear understanding was needed from the perspective of those on the stroke recovery road. **The purpose of this qualitative research study was to describe the ongoing impact of a stroke event on stroke survivors and caregivers in their own words.**

The findings from this study documented the perspectives of stroke survivors and caregivers and supported the work of the Foundation in developing a provincial stroke strategy. The descriptive findings provide a human face and context for the in depth statistical research data simultaneously collected on strokes in Saskatchewan. More importantly, stroke survivors and caregivers were given an opportunity to tell their story. From their point of view on the road to recovery, what was the most important thing they wanted us to understand?

Method

Stroke survivors and caregivers were suddenly confronted with a diverse range of life situations they had to face and handle. This study was at a level of inquiry where the emphasis was on discovery, describing and understanding problems and issues self-reported by stroke survivors and caregivers.

Qualitative methods were selected by the Foundation to understand the experience from the emic point of view, the perspective of the everyday lifeworld of stroke survivors and caregivers. Primary selection was used to select participants according to their knowledge of stroke recovery. The Foundation had a relationship or contact with prospective participants through the *Living with Stroke* programs and facilitators throughout the province. The Foundation was aware of people who had the knowledge required (for example, experience with aphasia or a TIA), and who would be willing and able to participate in group or face to face interviews. The Foundation selected participants and stroke recovery support groups from known stroke survivors and caregivers in the community (rural and urban) according to specific qualities:

1. Participants had personal experience and knowledge about stroke recovery (recent and or past).
2. Participants were able to provide detailed information and talk about their stroke experiences.
3. Participants were willing and did participate in face to face interviews in the home setting or in a group interview in a stroke recovery support group.

The Foundation contacted participants, fully disclosed the purpose of the research and obtained permission for the researcher to conduct an interview. People with long term knowledge of stroke recovery, with particular information (ie. aphasia, caregiving), and with atypical stroke experiences were interviewed (strokes in younger individuals).

Given that this was an applied research study (rather than for theoretical formulation or substantive theory development), interview data was collected within existing financial, time and resource constraints rather than until theoretical saturation.

Data Collection: Focus Groups

The purpose of the focus groups was to examine the impact of stroke from the perspective of the stroke survivor and caregiver. The goal was to generate a free flowing sharing of opinions and conversation within each group about the impact of stroke and the road to recovery. Three focus groups were conducted. Full disclosure was achieved by sending the general interview questions ahead of time to the leadership of each group (see Appendix 1). A semi-structured group interview guide provided discussion guidelines (see Appendix 2). The sites for the focus groups (meeting rooms in public facilities) were non-threatening, convenient, comfortable, familiar/regular meeting spaces, confidential and accessible to those using wheel chairs and walkers for mobility.

The leadership of all three groups declined to use primary selection as a method of purposive sampling to select members to participate in the focus group. This was perceived as exclusionary or 'leaving out' members. As a result, all members were invited to attend the focus group rather than 12 to 15 from the overall group membership as originally planned.

The researcher moderated/conducted two focus groups. Detailed notes (as verbatim as possible) were taken during the discussions by a research assistant. The speech language pathologist moderated/conducted the focus group with participants who had aphasia. The views of stroke survivors with aphasia are often overlooked because of communication difficulties. The expertise of a familiar and skilled speech language pathologist provided the most effective way to include stroke survivors with aphasia. The speech language pathologist reworded and simplified guided questions, printed the questions in a larger visual format as required, and interpreted/helped the stroke survivors with aphasia to articulate their views. In this focus group, the researcher recorded verbatim the discussion and ensured that the process was similar to that of the other two focus groups.

35 stroke survivors and caregivers participated in the focus group with the Saskatoon Stroke Recovery Association. 25 members (15 stroke survivors and 6 caregivers and 4 volunteers) participated in the Aphasia Connections focus group. 11 members (9 stroke survivors and 4 caregivers) participated in the rural stroke recovery support group. In total, 71 stroke survivors and caregivers (31 men and 40 women) collaboratively described the impact of stroke in their lives. While they were a very diverse group of participants, no demographic information was collected at the time of the focus group. Only one stroke survivor was at both the Stroke Recovery Association focus group and the Aphasia Connections focus group.

In total, five hours of group discussion generated 40 pages of single-spaced handwritten notes. The detailed notes were confidential and examined only by the researcher. Anonymity was maintained with respect to data management and any identifying information attached to the data. The researcher was not in any staff position within the Heart and Stroke Foundation of Saskatchewan and had no power or influence over the focus group participants. The stroke survivors and caregivers were comfortable discussing key issues related to coping with stroke in these pre-existing group settings. Participants had something to say on the issue, were comfortable saying it to each other, and were willing to voice their views. They described both similar and differing perspectives of their journey on the road to recovery from stroke.

Data Collection: Face to Face Interviews

The purpose of face to face interviews was to examine the impact of stroke from the perspective of stroke survivors who were younger or lived in the rural area of Saskatchewan (atypical stroke recovery experiences). The goal was to examine the experience of living with a stroke from the perspective of a stroke survivor. The Foundation selected stroke survivors to participate in face to face interviews according to primary selection. Stroke survivors were selected who were: 1) knowledgeable about stroke recovery as a younger person or as one living in rural Saskatchewan; 2) able to provide detailed information about their stroke recovery; 3) willing to and did participate in a face to face interview in the home setting.

Full disclosure of the process was achieved by the Foundation contacting stroke survivors for permission to participate in face to face interviews. Participants also received the information sheet (see Appendix 3) as part of the informed consent process and the general interview guide (Appendix 1) before the face to face interview.

The researcher conducted in depth face to face interviews with four stroke survivors (4 women). The goal was to conduct eight interviews, however, three planned interviews fell through at the last minute (for one person the scheduled interview was too close to the anniversary of their stroke, one person became ill and was unable to keep the scheduled interview, one person declined for unspecified reasons). Semi-structured, informal telephone interviews provided the source of data (see Appendix 1 for the interview guide). Interviews lasted from 45 minutes to 90 minutes in length. Detailed notes were taken during the interviews. In total, 4 ¼ hours of interview time generated 46 pages of detailed interview notes. Detailed notes were confidential and examined only by the researcher. Anonymity was maintained with respect to data management, no identifying name or information was attached to any of the responses. The researcher was not in any staff position with the Foundation. Ethically, the stroke survivors' level of discomfort or strain in discussing the impact of stroke seemed equivalent to day-to-day discussions with friends and family about recovering from a stroke. As expected, for many stroke survivors this was an emotional discussion as they looked back on their journey on the road to recovery.

Data Analysis

The researcher analyzed the interview data and used comparative analysis procedures fundamental to several types of qualitative data analysis. A combination of computer-assisted and hand coding techniques were used for data management and analysis. Coding (the process of analyzing the data) for this study involved level 1 (open coding or the process of breaking down, examining, comparing, conceptualizing and categorizing data) and level 2 (axial coding or the process of making preliminary connections between the coded categories) coding.

All of the findings were from data grounded in fact and reality as reported by the stroke survivors and caregivers in this study. This applied research study was not designed to generate detailed descriptive explanations, propositional statements or a theoretical or substantive theory. The 75 participants were credible representatives knowledgeable about the stroke recovery road. The views of stroke survivors who experienced TIA's, who were isolated and not participating socially, who were in long term care facilities, who suffered severe impairment, and Aboriginal stroke survivors were not included in

this study. Therefore, their experiences on the road to recovery from stroke are missing in this study. **This is a significant limitation.**

All words in *italic* are quotes taken from directly from the recorded interview notes. The following codes indicated participants in the aphasia focus group (fgint-aph), the stroke support focus groups (fgint-sra) and the face to face interviews (ffint-ind). All identifying information has been removed (names, locations).

Profile of Study Participants

The **Aphasia Community Connections** is a community program for adults with moderate to severe **aphasia** (inability to understand speech and/or communicate effectively through speech, reading, or writing). This program offers speech and language therapy on an on-going basis to those who have suffered a stroke or brain injury and have aphasia. Treatment programs are organized and overseen by a certified Speech-Language Pathologist and facilitated by volunteers. This program also offers support groups for both caregivers and stroke survivors. Members have the option of working on their speech, reading, and/or writing each time they attend. There is always an area set up where they can sit and socialize while having refreshments.

Membership in the Aphasia Community Connections group consisted of 28 stroke survivors (61%) and 18 care givers (39%). Of these 46 members, 38 (83%) were from Saskatoon and 8 (17%) were from communities outside of Saskatoon (primarily rural). The average age of the membership in 2004 was 70 years (**range from 30 years to 90 years of age**). Three of the members were 4, 5 and 7 months post stroke. The remaining 25 stroke survivors ranged from 1 year post stroke to 10 years post stroke (with an average of 4 years post stroke). Of these 46 members, 25 (54%) stroke survivors and caregivers participated in the focus group interview.

The **Saskatoon Stroke Recovery Association** is a self-help support group established in May 1983 for people, who have had a stroke, and their families. The emphasis of this self-help support group is on information, education, friendships/sharing, exercise, independence, recreation/outings, socialization/support and refreshments. In 2004, the Saskatoon Stroke Recovery Association membership consisted of 200 stroke survivors and caregivers. The majority of these members were from Saskatoon, however, some members were also from the surrounding rural towns and villages. On average, 75 members (range from 60 to 105 members) attended the outdoor outings and special functions held by the Saskatoon Stroke Recovery Association. These events were organized and conducted by a volunteer coordinator (non-professional) who has provided support (with no financial remuneration or honorariums) to the association members for almost 20 years. While the membership is steadily increasing and stroke survivors fulfill the association's executive roles, the burden and workload has also increased for the volunteer coordinator. On average, approximately 45 members attended the monthly meetings of the Association. Of the 45 members usually in attendance at any given monthly meeting, 35 (78%) stroke survivors and care givers participated in the focus group interview (or 18% of the total membership of 200).

The rural **Stroke Recovery Support Group** is also a self-help support group that was established in 2000 by participants who attended an eight week *Living With Stroke* program offered in the community by a *Living With Stroke* facilitator (program of the

Heart and Stroke Foundation of Saskatchewan). The *Living With Stroke* facilitator who helped this group to get established was no longer involved. The emphasis of this self-help support group is on information, support, exercise/activities and outings. No demographic information was available on the membership of this support group. The focus group consisted of 11 members from this support group, 9 stroke survivors and 4 care givers.

Face to face interviews were conducted with 4 stroke survivors (4 women) with an age range of 23 years to 60 years, 3 rural and 1 urban (2 who had their stroke under 30 years of age).

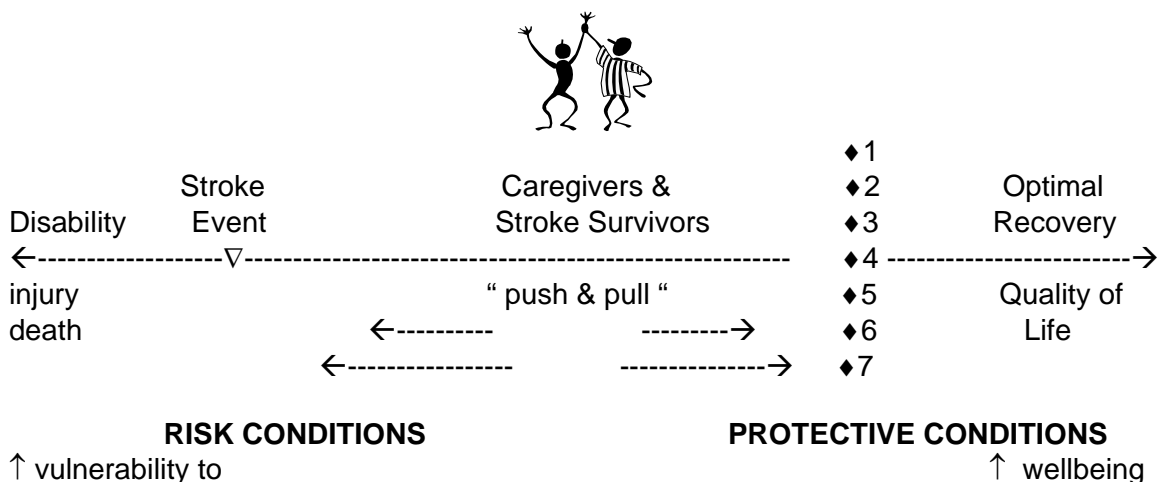
In summary, 75 stroke survivors and care givers participated in this study and ranged in age from 23 years of age to 90 years of age. There were 44 women and 31 men. The majority were from an urban setting, atypical experiences and perspectives included younger people who had experienced a stroke and those who lived in the rural area.

The Road to Recovery from Stroke: The Analogy

To facilitate participants' understanding during the focus group, the researcher used the 'road to recovery' terminology from the HSFS's *Living with Stroke* and *Heart to Heart* programs. A simple, clear analogy of the road to recovery was designed as a visual aid to help stroke survivors with aphasia during the focus group process. This was an analogy that all participants (urban and rural, young and old, male and female) could relate to (not to mention, as residents in Saskatchewan). The researcher adapted the concept of the health status continuum (Figure 1) using a long corded rope to visually demonstrate the essence of the focus group questions (Appendix 2). Recovery simply meant learning to live with changes and recover (where they were now) or come back from a stroke event (where they were then).

Figure 1: **Road to Recovery from Stroke: An Analogy**

What conditions must be created in Saskatchewan to support optimal well-being and recovery for stroke survivors?



First of all, the simple imagery of a road allowed for a marker representing their stroke event and the journey to where they were now; the idea of moving toward optimal wellbeing and recovery; and the idea of barriers and challenges along the way (potholes, wash outs, gravel versus highways, hills, valleys). What helped them and what hindered them on their journey to where they were today on their road to recovery? Secondly, this simple analogy captured the essence of risk and protective factors and the underlying complexity of working toward creating conditions in Saskatchewan to support optimal wellbeing and recovery for stroke survivors.

Health determinants or **protective factors** create conditions that are prerequisites for optimal wellbeing (Saskatchewan Health, 1999). The literature identifies many factors that are determinants of health in its broadest sense:

1. physical environment (shelter, housing, transportation),
2. social support networks (family, friends, social participation, care givers),
3. income (resources, disability support, meaningful paid work),
4. personal health practices and coping skills (healthy behaviors),
5. education and information,
6. health services (prevention, promotion, therapy, treatment, programs, supports).
7. Other

These protective conditions can help protect a stroke survivor by reducing the effect of some of the risk conditions, but they do not always prevent negative outcomes (disability, another stroke).

Risk factors or conditions create conditions that increase people's vulnerability to disease, disability, injury and ultimately death. The literature identifies many risk factors or **risk conditions** that increase vulnerability to strokes and/or hinder recovery from a stroke:

- physical root causes: nutrition, smoking, blood pressure, obesity, lack of physical activity.
- social factors or root causes: education, stress, poverty, lack of social support, working and living conditions.
- biology or genetics.

Most factors that have an impact on the road to recovery have in one sense, a **risk / protective dimension** (flip-sides of the same coin). For example, support/care giving is a determinant of recovery for many stroke survivors. Support/care giving is a need or strength. It can also be viewed as a prerequisite for optimal wellbeing and recovery. The description of a particular stroke survivor's support situation could range from being a protective condition (spouse with good health and ability to meet care needs) or a risk condition (no caregiver/family or a very elderly caregiver who is also not well). Each factor or condition can be on one side a protective condition that can exert a pull toward optimal wellbeing and recovery (increasing wellbeing) or on the flip side, a risk condition that can exert a push toward increasing the stroke survivor's vulnerability to injury, disability, another stroke or death. The question is, then, how do we maximize the conditions that support recovery and quality of life and minimize the conditions for risk of recurrent stroke and further disability?

Stroke survivors and caregivers were all on this continuum at some point. Different factors (physical, social, emotional and mental) came along side and exerted a push or pull on stroke survivors that helped them move forward toward optimal recovery and wellbeing. Similarly, certain factors acted as barriers or challenges that exerted a pull on stroke survivors such that it hindered their recovery and increased their vulnerability to poor outcomes, another stroke, disability, impairment or death.

Moreover, there can be more than one or several risk conditions that cluster together and make the journey on the road to recovery very difficult for some stroke survivors. This is **risk clustering** in the day to day life world of stroke survivors and their caregivers. For example, a stroke survivor with aphasia, no closely connected caregiver (communication partner), isolated in rural Saskatchewan with no rehabilitative therapy services and no accessible transportation struggles on the road to recovery with risk conditions that can seem insurmountable. Stroke survivors and their families can be overwhelmed by several risk conditions, and the health care providers who are trying to help and support the stroke survivor and their family can be overwhelmed, too.

This analogy captured complex questions underlying the simple questions we were asking stroke survivors and caregivers in focus groups and face to face interviews. What were the key factors that impacted on stroke survivors and caregivers on their road to recovery from a stroke from their point of view? What did all stroke survivors need in their lives to help them move toward optimal wellbeing and recovery? What conditions must be created or be in place in Saskatchewan to prevent strokes and to support optimal recovery and wellbeing and increase stroke survivors' control over the road to recovery? How do we address these issues along the entire continuum of care from prevention, promotion, health protection, diagnosis, emergency care, treatment and acute care?

This road to recovery analogy allowed for the complex nature of risk factors and supports and services that impacted on stroke survivors, not to mention the complexity of stroke outcomes and deficits in individuals. While each stroke survivor and caregiver had very unique and individual experiences of having and living with a stroke, there were common elements that were shared by many. They could be discussed in a group setting as first steps in understanding the underlying nature of factors impacting on stroke survivors and their caregivers in Saskatchewan.

Findings and Discussion

In this study, 75 stroke survivors and caregivers provided information on the key factors that have helped them get to where they are today on the road to recovery from stroke. Participants ranged in age from 23 years of age to 90 years of age. There were 44 women and 31 men. The majority of participants were from an urban setting, however, atypical experiences and perspectives included younger people who had experienced a stroke and the rural road to recovery from stroke. The majority of these participants were reflecting back over many years on the stroke recovery journey (up to 20 years since post stroke), a smaller number were looking back over the past several months or just over a year since their stroke event. Over one third (35%) of the participants were stroke survivors and caregivers who were living with aphasia.

Missing Views on the Road to Recovery

First of all, it is important to note who was not included in this study. All of the stroke survivors in this study, except for one, were members of stroke recovery support groups in rural or urban settings. The participants in this study were from the group of stroke survivors in Saskatchewan who were receiving support and giving support. Focus groups or interviews were not conducted with stroke survivors who were isolated in the community, who were in long term care facilities, who lived in Aboriginal communities, or who were not involved in some type of formal or informal support group. The views of these stroke survivors are missing and their views may be very different from the stroke survivors in this study.

Secondly, as would be expected, no stroke survivors in this study reported receiving CT brain scans **and** clot-busting drug therapy within three hours of the onset of their stroke symptoms. In other words, the people in Saskatchewan who received time-dependent and best practices in stroke treatment strategies for transient ischemic attacks and brain attacks were **not** in this study. The gripping stories of some recent stroke survivors, who were aware of the urgent need to get to the necessary hospital within three hours, highlight the tragedy that they still did not receive timely treatment to prevent a life-threatening stroke. Their stories are of hospital emergency and imaging departments that were not prepared to treat stroke as an emergency with a time-limited window for life-altering treatment. One young stroke survivor summed it up:

When I look back I wonder if they would have kept me in when I first went to the hospital and if they would have given me tPA, they could have given me that. It would have changed everything. I always wonder, but this is all hindsight and it is not good to go there. [ffint-ind]

This participant's words seemed to echo the final phrase of Robert Frost's poem, *The Road Not Taken*,

I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a wood, and I –
Took the one less traveled by,
And that has made all the difference.

Sometimes people find themselves on the road less traveled by no choice of their own. Regrettably, brain attacks happen to people in provinces with integrated stroke strategies in place (Nova Scotia) and in provinces without (Saskatchewan). The stroke survivors in this study lived in Saskatchewan, a province without a comprehensive stroke strategy.

Beginning the Journey on the Road to Recovery

The Road Not Taken

Sharon Kirkey from CanWest News Service reported in the Star Phoenix (March 30, 2004) that “Canadians who suffer fleeting mini strokes are often being sent home from hospital without the urgent care they need to prevent a full-blown brain attack according to recent medical studies. . . . Many patients are discharged from emergency departments without so much as an Aspirin. . . . Less than one third received a CT brain scan before going home and only about half were able to get one within thirty days of their mini-stroke. . . yet current recommendations call for both tests to be completed within the first week after a warning stroke. . . even that may be too late. One in 20 patients suffered a stroke within the next 30 days. Half of the strokes occurred within 48 hours of a TIA.”

This is what people in our province are reading in our local newspapers, not to mention related articles entitled “Don’t Have a Stroke In Saskatoon” (Bernhard Juurlink, Saskatoon Star Phoenix, April 2004). People are getting the media’s message or wake-up call to not underestimate the dangers of transient ischemic attacks. However, while stroke symptom recognition is critically important, at the same time there needs to be an integrated stroke strategy in place with recognition that time-dependent treatment is of the essence in hospital emergency and imaging departments. Suzanne Boyer’s article (February 2005) on a young stroke survivor’s experience in Saskatchewan reported that she “knew the symptoms better than probably anybody, but you were at the mercy of the doctors in terms of what can be done” and the regret that comes in retrospect with not being more insistent on getting the needed stroke care sooner.

In March of 2002, I woke up one morning and started to bounce off everything and I didn’t know what was wrong with me. I went to the hospital and was told everything was normal. Then ten days later I had a stroke on my right side. I could not speak or walk.

My main symptom was a severe headache. I had a mini stroke six weeks before my stroke. I had a pounding headache and foot dragging, so I went to the specialist, he put me on aspirin and steroids and within 3 weeks everything was back to normal. I just kept on going to school and then I had another headache. I went to the emergency, but the wait at emerg was too much, so I left and went to the medi clinic and the doctor there told me I had the flu and to go home. The headache got worse so my sister took me to emergency again. I saw a neurologist, they did a CT scan and it showed nothing. They told me it was stress, told me to go home and rest. But it was the same kind of headache, - it was blinding, it was horrible and I knew it. I told him over and over and he said no. By this time my mom was worried she came in to stay with me and the next morning I could not stand up and she brought me back to emergency. . . I was

paralyzed on my left side, I couldn't move but I could speak . . . my second stroke took my speech, I couldn't move, I couldn't speak, I was devastated. [ffint-ind]

I moved from the farm in August and in September I had my stroke. I was really stressed, it was all my stuff, I had so much stuff and everyone was trying to move me, stress was a big part of it. I kept going to the doctor saying I was tired and just was exhausted, no one bothered to take my blood pressure. One day I was sitting in the car waiting for my brother while he was in the lumber yard. When he came back, my mouth was crooked so he took me to the hospital. The doctor on call told us to go home, it was Friday afternoon, and to go see my family doctor on Monday. Then on Monday they sent me to a doctor in Saskatoon and I got into University Hospital on Monday at 5 p.m. [ffint-ind]

The night before my stroke we had company, as I said goodbye I was, going down to the Co-op to get milk and bread. Got there, stopped to talk and then said I had to get home, I knew something was wrong because I did not feel well, I should have called for help. I got to my car, I was losing strength, got car parked, I got out and I could not walk without hanging onto things, I called my daughter and said I need help and was having these symptoms. She said the ambulance will be right there. Fortunately, the doctor was at the hospital for another call and I was sent directly to Saskatoon to get that special drug. My daughter was a nurse and she went with me and the doctor said that there will be someone there waiting for me. I made it on time but then I did not get the drug because there was a mix-up. They put me on a stretcher and then they never came to get me. My kids could not figure out where I was taken. My daughter in law asked what the hold up was and they said they cancelled the appointment for the scan for the drug because there was no need because I had not been there within time period. I was there in time but there were so many waiting for the scan, I did not get in for the scan in time, there should be a backup or stroke should be a priority for the scan. [ffint-ind]

Several participants who received rehabilitative services compared and noted the discrepancy in care before and after a stroke.

The care was amazing once you are up here (in therapy or rehab), once you have had your stroke. But, there is a lot that needs to be done with the whole emergency thing, the process I went through was awful, the care was not great before my stroke. [ffint-ind]

For many stroke survivors, there was an unspoken, but palpable thread of anger beneath the surface about their stroke recognition, pre-hospital care and emergency management/treatment. While these seem somehow beyond our reach in rural Saskatchewan, the maximum target times for emergency management of ischemic stroke have been established as follows (HSF0, 2003):

Door-to-triage	1 minute
Door-to-doctor	10 minutes
Door-to-stroke team notification	15 minutes
Door-to-CT scan	30 minutes
Door-to-needle (tPA)	60 minutes
Admission to monitored bed	3 hours

Many stroke survivors and their caregivers reported stories of seeking medical care, being told everything was fine and then within a specific number of days that they can all numerically recall, they had a full-blown stroke. When asked what was the one thing they wanted health care professionals to know from their point of view, members of one stroke recovery support group made this plea:

We need medical people to pay more attention and not just say it is a headache, you'll be fine. . . it is serious and could develop into a stroke. That has happened to some of us, we went to the doctor and never got help and then later we had a stroke. We come in with the symptoms to be examined . . . There is a big difference between heart and stroke survivors. 90% of people with heart trouble who survive will live on pretty normal, but with stroke 85% of us will have a disability after, people don't understand this and medical personnel don't seem to know this either. [gint-sra]

Moreover, in the Living With Stroke program evaluation (Heart and Stroke Foundation, June 2004) facilitators were concerned at the numbers of people with transient ischemic attacks who were slipping away invisibly into the Saskatchewan population at large without warning information, secondary prevention and treatment. While their voices were not included in this study, a great many of the stroke survivors in this study self-reported that they had a mini-stroke before their full-blown stroke. Mini-strokes are not mini anything, they are precursors or warnings of the danger that may lie ahead and need to be treated as serious danger signals.

As in any struggle to recover, there is always something that is the hardest part or most difficult part of the journey. Participants described the hardest part of recovering from a stroke. This provided the context for further reflection on what helped them move further down the recovery road toward optimal wellbeing. While stroke survivors were at many different points on the road to recovery from stroke, ranging from within four months of their stroke to twenty years since their stroke, they described similar key factors that they believed helped them to get where they were today on the stroke recovery road.

Loosing Their Way of Being in the World

Teresa Goff (2002) eloquently interpreted for her father and other stroke survivors with aphasia that the hardest part of coping with a stroke was in essence “loosing their way of being in the world” because “language tells others who we are”. Stroke survivors with aphasia lost their voice and were isolated in a world where everything revolves around language. Occupation, income, abilities to speak, talk, read, write, sing, or simply join in day to day conversation were changed or as Teresa Goff captured it, “aphasia blows up the rules by which people live their lives”. Similarly, abilities to walk, move, run, dance, drive, paint, knit, sew, work and be independent were lost for stroke survivors with paralysis.

Stroke survivors “wake up one day and they are changed. They sit, silent, putting themselves back together with different building blocks, to think beyond themselves and who they were, to who they are now. What is gone and what remains?”(Goff, 2002). Similarly, the *Living With Stroke* program described its role as “helping you put the pieces back together after a stroke”.

The biggest struggle is the aphasia. I get started talking and then I can't stop, so the aphasia was a real barrier for me to recovery. I can't express what I want to say, the stroke aphasia is like a barrier that lives inside of me. [fgint-aph]

You are supposed to feel wonderful when your heart is breaking. People think they are encouraging you by comparing you to everyone else, you are alive, you know remember so and so he was left a paraplegic. Yet I remembered my life before the wheel chair, and I still miss it. Have you forgotten what I am not knowing, not doing? Take for example, a mandarin orange, I can't peel them, I deny myself because it's too much of a hassle to find someone to peel a banana for me. There are so many little things you don't think about. My daughter has to make the two dozen dainties for something at school, it may be no problem for everyone else, but it is a big problem for me I am the mom, it is not a big deal but yeah it is a big deal to me. [ffint-ind]

Rehab never took the time to investigate or find out who you are, what makes you tick, no one cared, this was not me, you were just a number and then six weeks later they shipped me home. Straight home and don't bother us. Rehab rehabilitated the way you were. What I was expecting was a full recovery, no one explained it to me. I was asking when I could go back to work and then the head nurse said, no, honey you won't be going back to work. When I found out the truth, I felt that they had just lied and lied to me. [ffint-ind]

What frustrated me the most was not being able to communicate. I could understand everything, I knew what was being said, but I couldn't get out what I wanted to say. I hated being unable to move or to speak. I was trapped in this body that didn't work... [ffint-ind]

The hardest part was learning how to do the things I already knew how to do, to talk, to get dressed, to walk, because I had no memory of ever learning how to do these things. Suddenly I had to relearn where my tongue would go for each sound - things, things I never knew how I learned or ever even thought about. It took all of my energy and effort, it was so hard. Speech was the hardest to learn and the most difficult. I had speech therapy in the hospital and at rehab they really got me talking. My mom made me a letter board to point to so we could spell out words, my mom worked with the speech therapist to find ways that we could use to communicate. I received a lot of creative therapy from the speech language pathologist. [ffint-ind]

One of the toughest things is losing your independence, you have to be dependent on others for the simplest of things, getting a drink of water, changing a light bulb and you can't do that. [fgint-sra]

The hardest part of having a stroke is to accept my shortcomings, what I cannot do anymore, how things have changed, what I have lost. I can't play the organ anymore or write letters. I lost that and miss that enjoyment. Just when you think you have accepted it all, you find out you haven't. This takes a long, long time. It wasn't until last year that I realized I couldn't set goals to do things I would never do again. I can't replace playing my organ, I have to find something new I can do instead. [ffint-ind]

One of the hardest parts about having a stroke was the depression, it was very difficult and I did not know how to deal with until I talked to a specialist who could help me. [fgint-sra]

One participant reflecting back over many years on the road to recovery, in speaking about all of the things she lost and still missed, summed it up:

Everyone thought I should be grateful to be alive, everyone and their dog. This is what was expected, you couldn't acknowledge the loss, it was a big deal. But it is important to grieve and to have permission to grieve, there is a brokenness that needs to take time to heal before you can be thankful. The essence of the person is still in there, unfortunately could not convince my husband. . . grieving is the beginning of road to recovery . . . [ffint-ind]

Moreover, several stroke survivors who had more recently experienced a brain attack (within the last few years) identified that a key part of the struggle on the road to recovery was facing and living with the fear of having another stroke.

I live with fear it might happen again, I am always telling myself that I can't live like that. I wouldn't wish this on anyone, it is a nightmare to go through. It has changed me, I was always a far ahead planner, but now I know we don't know if we have tomorrow, I don't do that and plan my life so far ahead anymore. Now, I am on Warfarin, I feel safer on Warfarin, it is my security blanket. I check my blood levels and it feels like I am safe. I bruise easily, bleed for a long time, but I'd never never want to go off of it. [ffint-ind]

A New Way of Being in the World

Caregivers emphasized that a stroke event not only happened to the stroke survivor but it also happened to the family. Families were often overwhelmed by fear, by sorrow, by anger and resentment as their lives were turned upside down. Many families felt like they had also lost who their husband/wife/parent/sibling was, they felt like they had in some way lost the person, not just the stroke survivor's ability to speak or to move.

Participants also described how stroke survivors had to learn to move or speak through family members and key supporters. Aphasia drastically changed family relationships and families had to learn a new way of communicating, they had "to hear what stroke survivors were saying by learning to read them" (Goff, 2002). Now, a few words, exclamations, facial expressions, voice tones, gestures, charade-like actions, drawings (pencil and paper) and hand motions became the new way of talking between family members and the stroke survivor.

People needed to understand that I understand them. I don't need them to speak more slowly, or more loudly, or more pronounced. I just can't respond. People with strokes do not have feeble minds. [fgint-aph]

One of the things that was hard, not so much for my family after awhile, but with my friends, is that my friends did not know how to treat me. A friend who used to phone every day . . . I have not heard from him for two years now and I know why he doesn't call me anymore, he doesn't know what to say. [fgint-aph]

My room-mate and my best friend came to see me, but no one else, none of classmates but I understand it was scary, I was not really me at that point I couldn't talk. Also my research group I went to them, they were the only ones I kept up with, I wanted to be normal. It hurt because we were together for four years in university and now it was like they were alienating me. [ffint-ind]

While isolation and lack of social participation are outcomes for many stroke survivors, the participants in this study reported that they had support on the road to finding a new way of being in the world. What and who came along side of stroke survivors and caregivers in the journey that was their particular road to recovery?

Factors that Helped Along the Way on the Road to Recovery

The Fierce Strength Within

First and foremost, across all focus groups and face to face interviews, one key finding kept emerging. Participants described something within themselves or within their caregivers that helped them to get where they were today. Over and over they said that this was one of the most important factors. They called this by a variety of emotionally – laden terms, that they were determined, stubborn, persistent, fighters - the idea that no matter what, they or their caregivers 'never gave up'.

In comparing themselves to others, they observed that this fighting spirit did not emerge from the ruins of a stroke in everyone.

What was most important? I just wanted to fight, it came from within. My stubbornness, my determination, whatever you want to call it. I never thought I was not going to recover. I was the most stubborn person, everyday I wanted to walk when the therapist asked me what I wanted to work on. I didn't give up on what I wanted to do, I wanted to walk. [ffint-ind]

Now in my work, I see the people who give up and don't want to try, there are two extremes. For me it was really on some days, I'd say I've had enough and Mom would ask me, do you really mean that. No I did not. I wanted to talk, to eat, to walk and be my normal self. All along the way the journey seemed so long, but when I finished my course then I felt like myself, finally recovered. [ffint-ind]

I guess the key thing was I well I guess it was persistence, I was absolutely determined to get back as much as possible. I always live in fear of another. I go to the doctor to have my blood pressure taken. It is still up and down and we are trying to keep it at an even keel of 120/74. I walk three times a week. I try to eat more fruit, I never did smoke or drink or eat a lot of fat and carbohydrates. [ffint-ind]

The most important thing to get where I am today, was to be determined and you'll survive. [fgint-aph]

It has been ten years since my stroke. My advice to everyone who has a stroke is TO NEVER GIVE UP. That's the key. You must have determination within yourself. [fgint-sra]

In my wife's case, everyone was very helpful and we got the services and all that some others here didn't get, but it was her own determination, that was what helped my wife to overcome and get this far . . . the services alone can't do it for you, you need to be determined to recover. [fgint-aph]

At the start in the hospital the doctor told me I might walk again and I might not, but I am walking now. My wife was a very stubborn wife and she helped me. (wife joins in) I got after him. The health care professional told us about the stroke swim, my husband wasn't stubborn but I got things going and I worked with him for a year and a half to get him where he is now. I never let up. [fgint-aph]

It is all about determination, it is a lot of hard work and endurance to keep on wanting to go on and to fight and then to fight again, it was so hard to keep on keeping on. [fgint-sra]

My husband and daughters, we have two daughters who had come home, were what got me where I am today. They were very good, they got me into rehab, it was my husband and my daughter who were determined for me to get better. This group has helped me a lot too. I would not have come out of this stroke without my family's determination and talking with other people here. . [fgint-sra]

My recovery was really a lot of it was me being my own therapist. [ffint-ind]

While the majority of stroke survivors described this special inner determination, some stroke survivors found this strength or push from their family's determination on their behalf. One participant noted that if stroke survivors gave up at the start, they never really began the journey on the road to recovery. Moreover, following this concept of never giving up, the majority of participants reported that the support of family/caregivers was critical to their journey as they came back from a stroke event.

Coming Along Side: Family / Caregivers

Stroke survivors noted that family members were there for them in a way that helped them cope with the day in and day out, week in and week out, twenty-four hours a day life-changing experience of a stroke. This was a type of support above and beyond the services provided by a wide range of stroke experts and health care professionals. Families (spouses, children, parents, siblings) provided emotional, functional and practical support.

Teresa Goff (2002) described a key person in her father's life, a key supporter who came along side, who was able to see and support her father as he was before the stroke and as he was now after the stroke. "Carol is a key person in his life and not everyone has a 'Carol' in their lives." (Goff, 2002). The majority of stroke survivors in this study seemed to have a "Carol" in their lives.

I (caregiver) said to him, you were a plumber and an electrician, you loved people, you worked at _____, and now I have a disabled husband, please, pleeeeeease try. Then my eyes would fill up with tears, he didn't understand my words, but he knew my tears and then he would try to do what I was pushing him to do . . . stand, take steps, try to walk, pick up the pins, practice the buttons or whatever. . . for one and one half years. (Husband, stroke survivor, joins in) . . She had these tears in her eyes, I understood. [fgint-aph]

Support came mainly from my family at the start. My mom was here with me every day except for one week when my sister came to give her a break, and my sister came every night after work. . . . I would have really bad nights sometimes and at 1 am I would tell the nurse to call my mom and she would come whenever I called her, she was always there for me. . . My mom was at therapy with me everyday, my oldest sister came on her holidays. After rehab I went home to my parents for nine months . . . [ffint-ind]

How I did it, got here today, was because my wife was always bawling me out, always there for me, and she would just not let me quit. [fgint-aph]

You need the support of family because the health care professionals are giving you their expertise on whatever, but I found that doctors would not listen to what I wanted. For example, they put a pic line in my weak arm and then I couldn't use my arm in therapy. I fought and fought. I fought with the doctors over it, and they took it out and put it in my good arm - but they threatened me about finding a vein. I fought with the doctors – we fought over lots of things, I won, I was stubborn but in some of the battles I had to get my dad to help me. [ffint-ind]

I was mainly affected on my left side, when I got out of bed on the floor I had no balance. It was hard to balance and I talked really slow. They kept me for two weeks and then sent me home. My daughter came to stay with me. I did not have any rehab, only what I did myself and what my daughter told me to do. I did it on my own. I used a squeeze ball and walked. I cried so much when my daughter left. When my daughter would help me walk, she would tell me to pick up my foot, so I just kept saying that to myself when I walked after she left, pick up your foot, pick up your foot, try again, pick up your foot . . . [ffint-ind]

I think expectations from my family and children have helped – they kept urging me on, their constant concern, their constant prodding about going for a walk, they were always insisting on getting answers and they kept trying to understand me . . . [fgint-aph]

The most important help came from my family, family were there first. As time goes on people forget that you have had a stroke, it is like your stroke becomes normal and they forget you still might need some help. My five grandchildren have been a great help, they have school activities and they give support as they can. I am surviving and they spend less time now. I think the need now is more for company, especially when you've always been involved with everything. But with family, even if they are busy, you know they are there if you need them. [ffint-ind]

The majority of stroke survivors overwhelmingly described how committed their spouses were as caregivers. In contrast, Teresa Goff (2002) also mentioned that for some stroke survivors, their losses included the reality that a stroke event eventually cost them their spouse. A few stroke survivors painfully and belatedly described the importance of a support network for the caregiver/spouse and family. While stroke survivors were coping with the overwhelming physical, emotional, mental and verbal changes after a brain attack, their spouses had simultaneously lost support and taken on a new and challenging role as caregiver. This was a fundamental life change with caregivers of younger stroke survivors assuming the triple burden and isolation of parenting, earning an income, managing the home and caregiving.

A grief support group could have made a difference. It would have been helpful to have family to grieve for what we lost. This did not just affect me and my household, also affected my family and my sister, it was tough to go through. They suggested some therapy for the whole family, but they said no, pride got in the way. Maybe it would be better not to call it therapy. . . [ffint-ind]

. . . The essence of the person is still in there, unfortunately could not convince my husband. . [ffint-ind]

My kids and husband had no one to turn to, they were not prepared for what we went through. My husband was working full time and now he had to do everything. The day my husband walked out he said that everyone always asked how I was but no one ever asked how he was doing. [ffint-ind]

Before I had my stroke, my best friend had a stroke. Now I look back and realize that I was not helpful, I did not understand how she thinks or what she was going through. Now I can look back and think of hundreds of ways that I could have helped her. We need to learn more about how to help stroke survivors. Her husband is the caregiver to this day, people do not always see that the caregiver needs support, and education and knowledge, too. [ffint-ind]

Families and caregivers could not provide all of the types of support and help that stroke survivors needed. Participants also described how health care services helped them as they started their journey on the road to recovery from stroke.

Health Care Services

In terms of the road to recovery analogy, supports and services are a foundation or underlying support that can help stroke survivors and caregivers to move toward optimal recovery. However, health services cannot be there day in and day out on the journey to recovery. Supports and services, no matter how diverse, cannot provide the day in and day out support that family, friends, and neighbors provide. Similarly, family cannot usually provide the critical expertise, treatment, knowledge, therapy and rehabilitation that health services provide.

Overall, participants described health care services that helped them: to recover (rehabilitation and treatment services such as speech therapy, occupational therapy, physiotherapy, aquatics therapy); to increase their independence in activities of daily living in the home setting (Home Care); and by providing supportive services for the

caregiver (Day Care). Urban stroke survivors were more likely to identify rehabilitation and treatment services as a key part of their road to recovery.

Daycare helped us get here today. I praise it with all my heart. My husband went to day care twice per week, he had something in common with people. It helped me to have a break and to get other things done that I needed to do. [Several people agreed with this, that daycare gave them, as a care giver, a much needed break, especially if they had limited support]. [fgint-sra]

I had a stroke five years ago. My husband had paralysis and he had no balance and he would tremble and it also affected his memory and then he had a mini stroke. Physio was really helpful, at first he went twice a week then daily. We spent a lot of time in the hospital. [fgint-sra]

Some of the key things that have helped as far as I can figure out are some of the services I have received, the occupational therapy, the physio, these have helped me and the services that the speech language pathologist has provided. I think though I could have used more of these services. [fgint-aph]

Working with health care professionals who cared, the one who was working with my wife, asked her to stand up and take a step along the table, this was after working with her for three months, and when she took her first step, the intern was in tears, too, because my wife finally took her first step. She really cared. [fgint-aph]

Many stroke survivors in the same stroke support group were at a loss to explain or understand why their experiences varied so greatly. Some were easily and quickly admitted to rehabilitation therapy, whereas others had to wait with much difficulty for the opportunity to get admitted to any therapy services. Over and over participants told of not being referred for any rehabilitation, treatment or follow up services.

One of the most important things and one of the hardest things, is to find out what services are available. I had my 1st mini-stroke and then 10 days later I had a bigger one. For almost 2 months I was not directed to any services, my doctor at University Hospital did not refer me to any services. I was a soccer coach and I one of my friends, who is a physio, she came to visit me at home. I couldn't walk or talk, and she asked me what help I was getting, I said none. She told me to go make a call to a lady named _____, a social worker at City Hospital. If I would not have been sent to _____, it would have been a long time before I got any help, if I got any. My own doctor did not even know where I could get the help I needed, when I asked him for a referral he sent me to the wrong place. In the 18 months, I then got all the help I could ask for, I now can walk and speak because of the help I got. . . [fgint-aph]

One of the things that I struggle with and still have to is how to deal with pain. The doctor prescribed drugs (4 different meds for the pain) that make me sleepy. About 9 or 10 months ago a pain clinic opened up at the old Buckwold Clinic. There was a 4 month waiting list right off the bat and I have been waiting for five months now, living with pain everyday. It is ridiculous that there is only one specialty clinic to deal with pain in a city this size. [fgint-aph]

I had home care support for two years before my stroke. I miss it terribly. Had home care after some surgery, home care nurse changed dressing everyday for two and one half months and then was discontinued just before my stroke. After my stroke I had home care in to do housekeeping. I miss the help with things I can't do and I miss the visit. The workers did not get much time to visit, the work had to get done. But, I looked forward to it but then it gets cut. [ffint-ind]

It is hard to get home care to help. I tried to hire someone privately for awhile, still do, but it is harder to find serious people to come regularly. My thirteen year old grand daughter was looking for a job, but she doesn't really know how to do what I need done. My family does try to help out but I miss home care. [ffint-ind]

The general perception was that rehabilitation and therapy services, especially speech therapy, were not accessible for the rural population. Rural stroke survivors were more likely than urban stroke survivors to describe services as difficult to get, lacking and inadequate. Home Care services were often described by many in the rural area as restricted and limited in terms of meeting everyday needs that stroke survivors could no longer do safely for themselves. Dramatically underscoring the importance of receiving the therapy services they needed, one participant described the lengths they had to go to obtain these services.

*My husband had a stroke in August and suddenly we found out it was really important to be in the city where you could get help. We moved from _____ to Saskatoon just so we could go to City Hospital for the occupational and speech therapy. Where we were living there was no therapy available. Outside Saskatoon you don't have therapy available. My husband has made leaps and bounds because of getting therapy here in the city. We were fortunate to be in a situation where we could just get up and move. We tried driving back and forth to the hospital but it was not the same. **People shouldn't have to uproot their whole life and move while living through a stroke, there should be services to all people in Saskatchewan no matter where we live.** [fgint-sra]*

In addition to family/caregivers and rehabilitation and treatment services, participants described the central help that they received from stroke recovery support groups in their journey to recover from a stroke event.

Formal and Informal Support Groups

Stroke survivors and caregivers identified some of the emotional, functional and practical benefits from being involved in a stroke recovery support group. They were encouraged, socially supported, understood and felt safe. They reached out to others, learned to deal with difficult issues and faced what they could not do and what they could still do.

Teresa Goff (2002) noted that stroke survivors with aphasia “feel paralyzed without a community of people to speak to”. Stroke survivors with aphasia in particular needed a “communication partner” or they will be trapped in a world where they are isolated and cannot communicate. Moreover, Teresa Goff described the importance of aphasia programs where “volunteers act as communication partners so stroke survivors can talk with out the fear of being judged”. People who have trouble speaking, understanding, writing or reading can get together with others to practice and to discover a new

language and a new way of communicating with those around them. The participants in this study were very definite and clear on what the Aphasia Community Connections support group meant to their recovery.

I would like to say that this group is excellent, because we focus on our aphasia and it helps because we care, we like it and we need it. [N.B. visual thumbs up from 3-5 who could not speak and were not able to speak in the group interview. At first, we just worked on it individually, but now for the past two years we have had this group and we all meet together. I think it is valuable to have all these people in the group because I can see so many doing well, some better than others, so it is good for me to know what is possible and I can learn from people what works well for them and it gives me ideas and an example what I can work toward. We watch others get better and gives us hope too. [fgint-aph]

I am new to this group, and I'd like to say it helps to be able to meet people that you can talk to and interact with. After my stroke, I couldn't go home and so they put me in a private care home, I stayed there 5 or 6 months and it was total isolation. I was always lonely and I missed my company, it was rough on me to stay there. My roommates were 86 and 95 and they were not much entertainment. I needed to practice my speech and practice talking and walking. We need private care homes with people who can talk and interact and help us practice. Care homes could do a lot more and use volunteers to interact with and support stroke survivors. The girls that work in these places where we stay they don't have 2 minutes to themselves or to talk. [fgint-aph]

Need to match volunteers with stroke survivors in care homes who can visit us at least once per week or more and give support, help, caring, conversation and practice talking to help us get our speech back. [fgint-aph]

I don't know whether we tell you (name of SLP) often enough what a good thing this is with you and all the volunteers. Are all people who have strokes and have aphasia told about this group? We had lots of friends, we don't see them as often as we used to, now these are our friends now that we see here. [fgint-aph]

Moreover, stroke survivors and caregivers in the Aphasia Community Connections group had a unique type of social support, the peer to peer support offered by other stroke survivors and caregivers (with first hand stroke experience), in tandem and traveling together with a unique type of frequent and ongoing support over time provided by a health professional, the speech therapist (with the expertise that comes from working with a large number of stroke survivors). This was clearly the best of all worlds, social support, knowledge and the expertise for problem solving.

I had a mini stroke and then a full blown stroke. I was a _____, it ended my career. What got me through to where I am today, was my faith in God, my wife, and family. Even if I failed, I kept on trying, that made me keep moving forward. The people in this group helped me get where I am today, it was encouraging to be part of this group. I discovered that stroke is not the end of the world. You live on day to day, you adapt and adjust. Life goes on after stroke, it is just different. [fgint-sra]

We have a stroke recovery group here that I go to. It helps because we can tell our stories, and help other people too. [ffint-ind]

I am involved in the local stroke recovery support group, we walk, we talk. When we talk, I truly know what she is talking about, she is not just paying lip service to me, I really know and she really knows what having a stroke is really all about. They know how your emotions are shot. There is not a lot of info out there. [ffint-ind]

I have been a stroke member since 1985, since my husband had his stroke. I had no family support so I have the programs and this group has been wonderful to help me. [fgint-sra]

Perhaps one of the key kinds of support stroke recovery support groups offer is the type of support that comes from the lived first hand experience of a stroke and the insider knowledge this provides about the subsequent road to recovery.

My favorite thing to do is to visit other stroke survivors in rehab, after they pass their swallowing assessment on rehab. I like to visit them and say congratulations, enjoy your first meal. I congratulate them and tell them that you will not believe how good food will taste, even though it is hospital food, you just can't believe how good food tastes, to actually eat and swallow again. I know, I have been there, too. I know what it is to recover and come back from a stroke. I know, I really know, in a way other health care professionals don't. [ffint-ind]

Stroke survivors and caregivers also described other strategies or things, in addition to determination, family/caregivers, and support groups, that helped on the road to recovery from stroke.

The Quiet Strength Within

Participants talked about determination and stubbornness being essential to their journey, the fierce strength within needed especially during the long hard uphill battles on the road to recovery. In contrast, participants also described a quiet strength within that was also fundamental to the long winding journey ahead of them. Somehow stroke survivors found a way to be able to endure or move forward on the stroke recovery road so that it no longer required an inner protest, resistance or intense energy reaction, a new type of inner acceptance that strengthened what they did, said and thought. Teresa Goff (2002) described this as “fundamental to accepting things beyond our control, an accepting, understanding, and yielding to aphasia” or other stroke-related limitations.

The more I tell my story, the easier it is for me. I had trouble when I came to my anniversary and it was a really tough day, even now it brings back those bad memories and you relive it all. I deal with it by talking through it and dealing with it. I found it was too soon and too painful to talk about my story during the first year of my stroke, I waited until the second year before I could share my story with others . . . [ffint-ind]

Before I didn't use my cane when I went out because I did not want it to be obvious that I had a stroke and don't have good balance. Then one day at

Smitty's, my friend told me I had better start using my cane because people were saying I had one too many!! I learned that the cane helps tell my story. I have trouble signing my name, so I just tell everyone when it happens so they know what is taking me so long. I learned to do that. [ffint-ind]

When you are reaching out you know I always say never ask a stroke survivor, never say do you want to come because they will think it is an inconvenience and put you out and is not necessary. I always say just say I will pick you up in an hour, you inform them because I know what goes on and how it was after I had my stroke. They feel people think they are burden to have along. Don't ask, just insist and include them. The longer they stay in the house and never get out, the worse it gets. [ffint-ind]

I still remember when I was so thrilled because I was sent home for a weekend visit and we managed some how, people were trying to help out, it was so good to be out of the hospital atmosphere. I am a perfectionist, I am impatient and want it done yesterday, I don't want to wait, well maybe I had too much pride, and now everything was a humbling experience. No one understands how long it takes, once you start asking for help it gets easier. [ffint-ind]

You have to get busy, get forgetful because life goes on. You have to get yourself involved in relationships and with friendships, you have to make an effort if you don't work at it you will die. I have learned to make the first move. [ffint-ind]

It is the small steps that keep me on the road to recovery, at class last time I was able to write my full name _____ and my postal code for the very first time, I was able to concentrate for the first time... the small steps keep you going . . . [fgint-aph]

One of the key things that has helped me is that after I had a stroke, I became a volunteer, helping others with aphasia, so my words have improved because I am doing the exercises at the field house and at home. [fgint-aph]

It makes sense that this type of acceptance would be reached by stroke survivors who were involved in stroke recovery support groups, in receiving support from others and in giving support to others who were on a similar pathway or life journey.

Barriers and Challenges on the Road to Recovery from Stroke

For the most part, the participants in this study seemed to have more to say about the factors that helped them get where they were today, than on barriers and obstacles. Woven throughout their discussions of determination, family/caregivers, health services, support groups and personal strengths were the unspoken implications of how any of these factors could also have been a major obstacle or barrier in their recovery (for example, as they described how critical their spouse's support was to their recovery, the unsaid message was that without this caregiver they would not be where they were today). The participants in this study overwhelmingly talked at length about the factors that got them where they were today.

In contrast, they spent less time and talked in less depth about the barriers and challenges that they faced along the road to recovery. This was somewhat unexpected. However, this may be partially explained by the fact that these study participants were well supported and connected to others in the community on the road to recovery. A focus group with stroke survivors who were isolated, not well supported, not connected to family, services or others in the community may have generated a great deal more depth on the day to day reality of barriers and obstacles to stroke recovery. For example, those who face insurmountable transportation barriers would be less likely to be members in stroke recovery support groups in the first place.

General Lack of Information

As stroke survivors and caregivers reflected back they described the things they needed to know. **Knowledge about stroke**, knowing what to expect and how to cope was a key source of strength on the road to recovery. Moreover, what stroke survivors and caregivers did not know hindered their road to recovery back from stroke.

One of the biggest barriers was lack of information when a stroke happens. We needed back up material for me as the caregiver, on what things to do at home. Speech therapy needs to give us more stuff to work on at home so we can be working on it all the time, not just when we receive services. [fgint-aph]

We need to learn more how to prevent strokes, we need more help learning to prevent strokes, what medications to use to help prevent strokes from happening to people. Is there a way you can prevent stroke? [fgint-aph]

Stroke survivors needed appropriate, timely, and accessible **services**.

We need to all get the same services and help at the right time. There, like some sort of best practice checklist right in the hospital, where the staff can check off if we have seen the speech language pathologist, been referred to the Living With Stroke Program, or the Aphasia Connections or whatever. [fgint-aph]

We need more awareness about the programs that are out there. We need to somehow get pamphlets out to everyone. People have no idea what is out there. [fgint-sra]

Another thing we need you to know is that there needs to be more communication between the doctor and the speech therapy and the physical therapy people. Our doctors need to know what is out there too. [fgint-sra]

We need more follow up, more people contacting us after our stroke to see if we have recovered or are getting therapy, or how we are doing? [fgint-sra]

There was not enough information about **financial situations**, yet there is a great deal of stress related to finances. Participants described a hit and miss approach to finding out about the disability credit and how to apply for it.

Does the government pay you any employment insurance benefits to help with the financial barriers? It was hard to get a disability pension when I had been working because when I had the stroke it was hard to prove that I was not going to get better enough to work, especially when I was young. [fgint-aph]

The disability pension some people get it and some people do not, seems to be no rhyme or reason to it, and when you are accepted, it takes three months before you get your first cheque . . . what do you do for 3 months while you have no income... [fgint-aph]

We made a claim on income tax for coming to these meetings and we got money back from income tax. People need to know about disability income tax credit, we need to know this kind of information. [fgint-aph]

Drug plan information, although critical for many stroke survivors, seemed to be difficult to find out about. Pharmacists were cited as the source of information for stroke survivors regarding help with drug costs.

Only one participant in a face to face interview mentioned that **sexuality information** after stroke was not an area that anyone talked about. Simply put, health professionals need to discuss sexuality with stroke survivors and caregivers.

A lot of people have it on their minds, but they don't bring it up. Professionals need to bring it up and talk about it no matter what ages people are. Regardless of age, even my parents at 77 and 80 plus years are active, and then all of a sudden if they have a stroke and now everything is taboo. The nurse put me at ease by just simply talking about it and telling me to just enjoy myself and I would be fine. I was all worried about going into a seizure or something. [ffint-ind]

Transportation

Strong transportation services (handi-van) that were accessible (48 hours advance notice), reasonable, flexible and dependable helped stroke survivors and caregivers to participate in the community, increased their independence, and decreased the sense of isolation. For the most part, the stroke survivors in this study did not describe transportation as a difficult barrier or challenge. Their committed attendance at the support groups indicated that for the most part they had access to transportation services that were reliable, accessible, reasonable and timely. They were not stroke survivors who were isolated in the community setting.

All of the concerns expressed about transportation focused on being able to drive, suddenly not being able to drive, and the process of regaining their driver's license.

Beyond the Six Month Window Theory

Stroke survivors also described that one of the most stressful parts of recovering from a stroke was the knowledge that the best recovery period was immediately following the stroke. This was particularly stressful because this knowledge was up against a backdrop of continually long waiting times (for treatment, for tests, for therapy), *the waiting times were too long for everything*. Moreover, the very essence of this window of opportunity for recovery was described as a barrier in itself, both at the onset of the stroke and years later down the road.

In the *Living with Stroke* program evaluation (Heart and Stroke Foundation, June 2004), one care giver described the frustration and panic that builds in tandem when you are told the best recovery period is immediately after the stroke and then you come up against long waiting times for everything (for example, her mother received her echocardiogram exactly two months after her stroke).

In contrast, several participants in this study also expressed how this window of opportunity can destroy their hope and optimism for the years to come on the road to recovery.

Most of us or many of us here have experienced the doctor and the business of slamming the door... they told us that you have had your six months and now your time is up and you are not going to get any better than this. That is a barrier to recovery to be told this is it . . . most of us here kept on going and here we are today . . . [fgint-aph]

I think the government came up with the 6 month window theory, you have had your six months and you are not going to get any better than this, just so they could cut you off after that from money, from services, from help . . . I want them to know...that with strokes... health care professionals may not know what they are talking about all of the time. [fgint-aph]

One of the participants tried to speak and share her thoughts five times during the focus group. While she appeared to be following the group discussion, each time she tried to join in, she was unable to express herself. Finally, at this closing point about a six month window theory in the group discussion, she slowly struggled to stand and walked a few determined if somewhat shaky steps for everyone (to a round of applause). She could not speak her thoughts with words, but through her actions she demonstrated that although it has been ten years since her stroke, she is still making progress, ten years later she is walking (context and actions interpreted by SLP).

While most recovery happens in the first six months to one year, participants in stroke recovery groups continually saw recovery in people, one small step at a time. While these small steps were not as dramatic as those in the first year of recovery, they were evidence that many stroke survivors never give up. They believed that health care professionals, doctors or otherwise, did not necessarily know the end of an individual's particular stroke story at the beginning.

In Summary

This stroke impact study documented the views and anecdotal self-reported experiences of 75 stroke survivors and care givers on the road to recovery in Saskatchewan in 2004. Stroke survivors and caregivers provided information on the key factors that have helped them get to where they were on the road to recovery from stroke in the fall of 2004. In the road to recovery analogy, recovery simply meant learning to live with changes and recover or come back from a stroke event. What helped them and what hindered them on their journey to where they were today on their road to recovery in Saskatchewan?

Participants ranged in age from 23 years of age to 90 years of age. There were 44 women and 31 men. The majority of participants were from an urban setting, however, atypical experiences and perspectives included younger people who had experienced a stroke and the rural road to recovery from stroke. The majority of these participants were reflecting back over many years on the stroke recovery journey (up to 20 years since post stroke), a smaller number were looking back over the past several months or just over a year since their stroke event. Over one third (35%) of the participants were stroke survivors and caregivers who were living with aphasia.

The 75 participants were credible representatives knowledgeable about the stroke recovery road. They participated in focus groups conducted with the Aphasia Community Connections, the Saskatoon Stroke Recovery Association and a rural Stroke Recovery Support group. Stroke survivors who experienced transient ischemic attacks, who were isolated and not participating socially, who were in long term care facilities, who suffered severe impairment, and Aboriginal stroke survivors did not participate in this study. They may have provided very different views and perspectives of the road to recovery.

While the participants in this study did not specifically state their recovery goals, the underlying implied goals seemed to be similar to those reported by many stroke survivors and caregivers. The Heart and Stroke Foundation of Ontario (2003) notes that a stroke survivor may have a variety of personal goals, but typically, these goals would include the following:

- to resume roles filled prior to the stroke or establish meaningful new ones
- to enjoy satisfying social relationships and recreational or leisure activities
- to carry out necessary health-related activities
- to feel hopeful and optimistic about his or her life
- to regain as much independence as realistically possible.

The caregiver, often the stroke survivor's spouse or another family member, also faces many life changes. Personal goals for the caregiver may include the following (HSFO, 2003):

- to maintain quality of life
- to balance caregiving responsibilities with other responsibilities and personal needs
- to create opportunities to address personal needs.

In their own words, stroke survivors provided anecdotal evidence that the time to consultation and stroke recognition, the time to diagnostic tests, the time to treatment, and the time/access to rehabilitation was not what many would have wanted or expected it to be. The people in Saskatchewan who received time-dependent and best practices in stroke treatment strategies for transient ischemic attacks and brain attacks were **not** in this study. Some participants who received rehabilitative services compared and noted the discrepancy in care before and after a stroke.

The care was amazing once you are up here (in therapy or rehab), once you have had your stroke. But, there is a lot that needs to be done with the whole emergency thing, the process I went through was awful, the care was not great before my stroke. [ffint-ind]

Participants reflected back over many years on the road to recovery and described that one of the hardest parts of recovering from a stroke was coping with the initial loss of their way of being in the world. Occupation, income, abilities to speak, talk, read, write, sing, or simply join in day to day conversation were affected when “aphasia blows up the rules by which people live their lives”. Similarly, abilities to walk, move, run, dance, drive, paint, farm, knit, sew, work and be independent were lost for stroke survivors with paralysis. Several stroke survivors identified that a key part of the struggle on the road to recovery was facing and living with the fear of having another stroke.

Caregivers emphasized that a stroke event not only happened to the stroke survivor but it also happened to the family. Participants described how stroke survivors had to learn to move or speak through family members and key supporters, a new way of being in the world. While isolation and lack of social participation were often outcomes for many stroke survivors, the participants in this study reported that they had support on the road to finding a new way of being in the world.

First and foremost, participants described determination, stubbornness, or perseverance within themselves (or in some cases, within their caregivers) as the most important factor that helped them to get where they were today. The essence of this idea was that no matter what, they or their caregivers ‘*never gave up*’. The degree to which this determination was important did not seem to vary with length of time post stroke.

The majority of stroke survivors described how the support of family/caregivers (primarily the spouse) was critical in a way that was day in and day out over the long winding road of stroke recovery. Again, the degree to which a key supporter was important did not seem to vary with gender, length of time post stroke, or age. The degree to which health services were discussed as a key part of the recovery road seemed to vary with the location of the stroke survivors. Urban stroke survivors were more likely to identify rehabilitation and treatment services as a key part of their road to recovery. Stroke survivors in the same support group were at a loss to explain or understand why their experiences in accessing therapy services varied so greatly. Over and over participants described not being referred to any rehabilitation, treatment or follow up services. The general perception was that needed therapy services (especially speech therapy) were not accessible in rural Saskatchewan. One stroke survivor uprooted his life and moved from a rural community to the city to receive therapy.

Stroke survivors and caregivers in this study overwhelmingly identified the emotional, functional and practical support they received from stroke recovery support groups. The degree to which formal or informal support groups were experienced as helpful did not seem to vary by the type of group or location (rural or urban). Stroke survivors with aphasia in particular needed a safe place to learn to speak or they would be trapped, isolated and unable to learn a new way to communicate with people around them.

Stroke survivors and caregivers in the Aphasia Community Connections group had a unique type of social support. They received (and provided) the peer to peer support offered by stroke survivors and caregivers, in tandem and traveling together with a unique type of frequent and ongoing support over time provided by a health professional, the speech therapist. This was clearly the best of all worlds, social support, knowledge and the expertise for problem solving. In contrast, the volunteer coordinator for one support group perceived that the outcomes for the self-help group would be strengthened if professional support was available.

Stroke survivors also described a type of quiet strength within (accepting, understanding and yielding) that enabled them to endure and move forward on the stroke recovery road in a way that was different from the determined fighting spirit so necessary to make it through the long hard uphill parts of stroke recovery. The degree to which this factor was experienced on the road to recovery seemed to vary with the length of time post stroke. This was more likely to be identified as important on the road to recovery by stroke survivors who were over two to three years post stroke.

For the most part, the participants in this study seemed to have more to say about the factors that helped them get where they were today, than on barriers and obstacles. The stroke survivors and caregivers in this study were well supported and connected to others in the community (with the exception of one stroke survivor, they were all active members in formal or informal stroke recovery support groups). A focus group with stroke survivors who were isolated, not well supported, not connected to family, services or others in the community may have discussed in more depth the day to day reality of barriers and obstacles to stroke recovery. Barriers to stroke recovery focused on lack of information and knowledge about: stroke; appropriate, timely and accessible services; financial supports; drug plans; and sexuality.

Unexpectedly, stroke survivors described that one of the most stressful parts of recovering from a stroke was the knowledge that the best recovery period was immediately following the stroke. This knowledge was perceived as stressful because it was against a backdrop of continually long waiting times (for treatment, for tests, for therapy). The very essence of this window of opportunity for recovery was described as a barrier in itself, destroying their hope and optimism both at the onset of the stroke and years later down the road.

Most of us or many of us here have experienced the doctor and the business of slamming the door... they told us that you have had your six months and now your time is up and you are not going to get any better than this. That is a barrier to recovery to be told this is it . . . most of us here kept on going and here we are today . . . [fgint-aph]

For the most part, stroke survivors and care givers did not bring up their day to day efforts in risk factor reduction (smoking, obesity, physical activity, nutrition) or specific drug therapy (hypertension, hyperlipidemia, anticoagulant or antiplatelet therapy) as key factors on the road to recovery from stroke. This was somewhat unexpected. Furthermore, anecdotal evidence suggested that not all stroke survivors seemed to understand their risk of another stroke and the importance of secondary prevention.

The determination, perseverance and drive to recover did not seem to necessarily generate a similar determined and relentless effort toward risk factor reduction as part of a strategy to prevent recurrent stroke (given that individuals who have experienced an ischemic event have a significantly increased risk of subsequent ischemic events both in the same and in other vascular beds, as atherosclerotic disease is usually progressive and generalized [HSFO, 2003]). It is known that virtually all individuals who experience a stroke have at least one risk factor, and the prevalence of stroke risk factors in the Canadian population is high (HSFO, 2003). For example, the behavioral change strategies and actions taken on risk factors by people after they experienced a coronary event did not appear to be as evident in this population of people who had experienced a stroke event.

Appendix 4 provides the Heart and Stroke Foundation of Ontario's Best Practice Guidelines for Stroke Care. In light of these best practices, 75 stroke survivors and care givers have documented that we are only beginning the journey toward a comprehensive stroke strategy in Saskatchewan that will provide best practice stroke care in prevention, treatment and rehabilitation for all people in Saskatchewan.

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APPENDICES

APPENDIX 1
Stroke Impact Study: Fall 2004
Interview Guide & Descriptive Questions

This is intended as an informal, semi-structured interview guide only. The overall purpose of the focus group is to understand the key factors (from the stroke survivor's point of view) that have helped the stroke survivor or caregiver to get where they are today on their road to recovery from a stroke in Saskatchewan.

1. How long has it been since your stroke? Can you tell me what happened when you had your stroke . . .?
2. Although we know some of the difficulties people face on the road to recovery from stroke, we are interested in understanding what has helped you get to where you are today? As you look back on these past _____ (months, years since stroke):
 - a) What are the key issues or things that have helped you to get where you are today in recovering from your stroke?
 - b) What are some of the barriers or obstacles that you have faced that have made the road to recovery difficult for you?
3. What has your experience been with the support and care you have received from health care professionals? Friends? Family? community?
4. In all of these things that we have talked about today, what is the hardest part or most stressful part of recovering from a stroke?
5. What has been the best part or most helpful part of recovering from a stroke?
6. What is the **one thing** you would really want **people who help** stroke survivors and caregivers [health professionals, government] to understand or know from your point of view as a stroke survivor or caregiver?

APPENDIX 2
Stroke Impact Study
Focus Group Interview Guide: Fall 2004

This guide builds upon and connects to previous work with stroke survivors and caregivers in the *Living with Stroke* evaluation. The two key foci of the group interview are: 1) the recovery needs of stroke survivors and 2) the recovery conditions stroke survivors face in the community. Recovery simply means ‘learning to live with changes and recover or come back from a stroke’.

Focus Group Interview Guide: informal; semi-structured

<p>Why do this? First hand experience of living with stroke What do we want to find? Key issues in terms of challenges & obstacles people face. What do we want participants to experience? 1. respect & recognize their wisdom 2. inclusive participation 3. with/for not to/on</p>	<p>Your perspective as a person travelling on the road to recovery from a stroke in your community:</p> <p>VISUAL: rope illustration (toward health/optimal wellbeing)</p> <p>before----- stroke -----where you are event now, today</p> <p>WHAT ARE THE KEY FACTORS [physical, emotional, social, env] THAT HAVE HELPED THE STROKE SURVIVOR OR CAREGIVER TO GET WHERE THEY ARE TODAY ON THEIR ROAD TO RECOVERY FROM STROKE?</p>	<p>Focus group is a guided free-flowing group conversation (indepth, information gathering of opinions & experiences) focused on specific issues.</p> <p>Move through together as a group in an ordered way that everyone can follow & understand</p>
<p>Objective: “the what”</p> <p>Remembering back to when they had their stroke . . .</p>	<p>How long since your stroke?</p> <p>What are the key things that have helped you to get where you are today in recovering from your stroke? *</p> <p>Who or what has come along side and helped you work toward recovery and optimal wellbeing?</p>	<p>Shared view of the reality that is living with stroke.</p>
<p>Objective: As many different perspectives as possible. There are many diverse yet everyday common experiences on the road to recovery.</p>	<p>What are some of the barriers or obstacles that you have faced that have made the road to recovery difficult for you?</p>	<p>Everyday situations people deal with and confront.</p>
<p>Reflective: Everything out on the table</p>	<p>What is the hardest part or most stressful part of recovering from a stroke?</p>	<p>Group feelings versus hidden emotions</p>
<p>Interpretive: explanations & meaning Beyond individualism or isolation</p>	<p>In all of these things that we have discussed today, what is the one thing you would really want people who help (health professionals, government) to understand or know from your point of view as a stroke survivor or caregiver?</p>	<p>Free to see and discuss issues</p>
<p>Closing . . .</p>	<p>ANYTHING ELSE YOU NEED US TO KNOW?</p>	

*What does support look like for people recovering from a stroke? informational, practical and emotional?

APPENDIX 3

Information Sheet for Participants in Stroke Impact Study

The Heart and Stroke Foundation of Saskatchewan is in the process of working on a provincial stroke strategy. While the Heart and Stroke Foundation offers programs to help people on the road to recovery from stroke, the views of people who are coping with stroke recovery are important. Colleen Zubkow is a community-based researcher who will be talking with stroke survivors and caregivers for the Heart and Stroke Foundation. You have been invited to participate in this study. The following are answers to questions that you may have.

1. What is the purpose of the study?

The main purpose of this study is to understand the road to stroke recovery from the viewpoint of stroke survivors and caregivers.

2. What would I need to do?

After reading this information sheet, if you are willing to participate in the interview, Colleen Zubkow will phone you to make an appointment to visit with you in your home. She will listen to your story and experience as a stroke survivor. She will take notes while you are talking with her.

3. What good will the study do me?

While there will be no direct benefit to you, you will have an opportunity to share your thoughts and experiences about recovering from a stroke. You will be providing information that will help support the work of the HSFS toward a provincial stroke strategy.

4. What will be done with the information I share?

You are one of 6 to 10 people participating in this small study. The information you provide will be carefully studied by the researcher and a report will be written. Your name and identifying circumstances will not be used anywhere on the report to ensure your anonymity and confidentiality.

5. Will participating in the interview take a long time?

No. The average time for an interview is about one hour. Interview times can be planned to meet the needs of you and your caregiver.

If you have any additional questions you would like answered, please call Gwen Gordon at the Heart and Stroke Foundation of Saskatchewan 1-888-473-4636.

APPENDIX 4

Best Practice Guidelines for Stroke Care – Heart and Stroke Foundation of Ontario

Stroke recognition

1. Increase and maintain awareness among the public and healthcare providers of the warning signs of stroke and the appropriate actions to take (p 19).

Stroke prevention

2. Develop an optimal stroke prevention strategy in a timely manner for all individuals at high risk of stroke, all individuals with TIA, and all stroke survivors. The strategy should include the optimal use of stroke prevention services, a plan for lifestyle modification, pharmacotherapy, and a plan for effective communication between the client, primary care physician, and stroke prevention services (p 24).
3. Educate individuals at high risk of stroke, those who have experienced a TIA or stroke, family members, and healthcare providers about stroke prevention, relevant information resources, and how to gain access to them (p 24).

Prehospital care

4. Develop formal bypass or diversion protocols and transfer agreements, so that individuals meeting inclusion criteria for time-dependent therapy have the opportunity to receive it (p 37).
5. Conduct a rapid assessment that includes use of the acute stroke protocol inclusion criteria and determine the patient destination, using the acute stroke protocol, including the Emergency Medical Services (EMS) destination policy (p 37).

Emergency management

6. Establish protocols for the immediate clinical investigation of all strokes, including use of appropriate neuroimaging, and for access to, and initiation of, time-dependent stroke therapy (p 41).

Acute treatment

7. Manage individuals with acute stroke using the principles of organized stroke care, including management in a unit with specially trained staff, with the goal of preventing complications, to ensure early mobilization and rehabilitation, and improve outcomes (p 47).

Transition management

8. Develop and follow protocols at each transition point across the continuum of care to ensure appropriate and timely access to services (p 56).

9. Manage transitions with an interdisciplinary team all using standardized information and processes, to ensure that relevant documentation is transferred with the client to facilitate continuity of clinical and case management (p 56).
10. Identify and confirm the primary healthcare provider before the stroke survivor is discharged from acute care, and keep this individual informed throughout all phases of care (p 56).
11. Provide opportunities for ongoing access to rehabilitation and community services for stroke survivors and their families, during all phases of care (p 56).

Rehabilitation management

12. Evaluate the rehabilitation potential of each client and include a complete assessment conducted by the stroke rehabilitation team. Develop a comprehensive rehabilitation plan for each client that reflects the severity of the stroke and the needs and goals of the stroke survivor (p 61).
13. Ensure that access to the appropriate intensity of rehabilitation services is available to stroke survivors throughout the continuum of care (p 61).
14. Assess the ability of the family and caregiver to support a stroke recovery process. Develop a strategy that includes an educational component to address the caregiver's burden (p 61).
15. Discharge stroke survivors from rehabilitation units in a timely manner, once realistic goals have been achieved and intensive inpatient rehabilitation is no longer required (p 61).

Community re-engagement

16. Assist the stroke survivor and family to develop and implement an evolving care plan by conducting 6-week, 3-month, and 1-year follow-up assessments of all aspects of health status, community participation, and links to prevention services (p 67).
17. Create strategies to enable healthcare professionals and caregivers in community and long-term care settings to develop stroke care expertise to support stroke survivors in achieving their goals (p 67).
18. Support caregivers in balancing personal needs and caregiving responsibilities by providing community programs, respite care, and educational opportunities, and by linking caregivers to these programs (p 67).
19. Assist stroke survivors to maintain, enhance and develop appropriate social support (p 67).