# Bridging the Gap: Helping Stroke Survivors and Family Caregivers from Hospital to Long Term Recovery

Community Stroke Navigator Program: Phase 2 - Final Report – February 2017

## Executive Summary

Stroke survivors and family caregivers still consistently lack a supportive and informative connection to the healthcare system upon being discharged from hospital. This report's major finding is that use of a Community Navigator service shows great promise for assisting stroke survivors and caregivers with community reintegration after discharge from hospital following stroke. It helps in the understanding of their symptoms, assists them in finding the help and resources they need and has enormous potential for saving the health care system large sums of money because it can reduce the length of hospitalisation and help prevent future re-admissions.

The Community Stroke Navigator Program bridges the gap in transitions by providing a hospital peer visitation program and community navigation services and by strengthening partnerships with health and community organizations to improve support to stroke survivors and family caregivers once back in the community. It isn't uncommon for people affected by stroke to share common physical, emotional, social and financial needs. But every stroke is different and so a one-size fits all approach doesn't work. The Community Stroke Navigator helps stroke survivors and caregivers develop a personalized recovery plan with strategies to set goals, access community resources, fill information gaps and help build community and social networks.

The Community Navigator Program Phase 2 aimed to meet the needs of people affected by stroke post-hospital from Ladysmith and Campbell River through navigation services, peer visitation in hospital and education. Collaborative partnerships with Nanaimo Brain Injury Society (NBIS), March of Dimes Canada (MODC) and Nanaimo Regional District Hospital (NRGH) were developed to provide a stronger service in bridging the gap from hospital to home

The program served:

- 35 stroke survivors in hospital
- 83 stroke survivors and their caregivers from Ladysmith to Campbell River post-hospital discharge
- 60 participants in monthly stroke recovery/community integration education sessions

**Key Findings**

- REFERRALS: There were 95 referrals into the program. 77% of referrals came from NRGH and 23% were from the community. Of those referrals from the hospital, 42% were from the Intensive Outpatient Rehabilitation Program (IORP), 30% from Inpatient Rehabilitation and 5% were from Acute/Rapid Stroke Clinic. Of the 122 discharges from rehab, 57.3% were referred into the program.
- ENROLLMENT: There was a 95% enrollment rate and a 92% completion rate. In other words, of the 95 referrals received, 86 participants enrolled in Phase 2. Of those 86 assessments, 83 were completed.
- RESPONSE TIME: The average initial contact response time was 15 days.

- REQUESTS FOR INFORMATION: Finding resources (76.9%), goal setting (64.1%), caregiver support and decision making (51.3%) and stroke peer support (44.9%) were among the most frequently recurring requests for information. Just over half of participants are satisfied with their current level of assistance, suggesting a large gap in appropriate community-based services and resources to support ongoing long term recovery.
- CAREGIVING: Caregivers seem to have lower sense of self-worth or value attributed to their role in caring for the person affected by stroke. Family support and schedule interruptions seem to be most negative aspects of caregiving for those participants completing the assessment.
- EDUCATION: Education sessions for stroke survivors and family caregiver are an important element to provide timely education and ongoing support.

**Recommendations**

- CORE FUNDING IS ESSENTIAL: Core funding is required for continuity and quality programming. This core funding needs to find a home within the health authorities, the Ministry of Health or needs a dedicated fundraising activity attached to the program. However, the kind of community development skills this program requires are more likely to be found in community based organisations that operate at a grassroots level.
- REVIEW BRAIN INJURY FUNDING MODELS: Health authorities provide core funding to Brain Injury societies to deliver community program for ongoing support and management of brain injuries. We need to explore this model to see if a similar approach can be taken to support Navigator services. We need to determine what Health Authorities or the Ministry of Health require in terms of evidence that Navigation is a core and essential program in transitional management from hospital to home. We need to point to reductions in health costs this approach can achieve associated with readmission rates to hospital and unnecessary medical appointments
- RESOURCE VOLUNTEER DEVELOPMENT COMPONENT: There is growing and continued support that skilled volunteers are underutilized in service and program delivery. Developing a well-resourced and well utilized volunteer management program could help offset costs associated in program delivery of the Navigator program.
- EXPAND HOSPITAL PEER VISITATION: Expanding the Peer Visitation model to the community is another method to improve transitional management. Many of the stroke survivors requested a visit from a peer once they were back home. Well trained peer volunteers could assist with goal setting and community reintegration. This would dovetail with lay navigation.
- TEST LAY NAVIGATION MODEL: Possible areas to assist with transitions include:
    - Follow up in-home visit or telephone call within 60 days post discharge
    - Completion of Brief Action Plan (see Appendix J)
    - Provision of community resources and link to stroke recovery support programs
    - Identification of additional support required and flagging for professional care coordination if needed
    - Caregiver support kit and information on Family Caregiver series workshops/education sessions