Navigation During Community Stroke Rehabilitation

Guidance Document

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Introduction

A Model of Care for Community Stroke Rehabilitation (CSR) in Ontario was established to serve as a standard for best practice community stroke rehabilitative care. This model of care promotes an integrated, equitable, person-centred approach, to enhance population health outcomes.

Embedding navigation into CSR is essential to support persons with stroke to reintegrate into their communities. This includes designing CSR programs that connect, support, educate, and empower individuals to reach their goals and return to meaningful life activities and roles within their homes and communities. Canadian Stroke Best Practice recommends "all members of the health-care team engaged with people with stroke, their families, and caregivers are responsible for partnerships and collaborations to ensure successful transitions and return to the community following stroke."[1]

About this document

The purpose of this guidance document is to provide a consistent understanding of navigation during CSR by outlining the common navigation activities and supports persons with stroke and their care partners should have access to. This document is grounded in the Canadian Stroke Best Practice Recommendations (CSBPR) and is intended to complement the provincial Model of Care for CSR. This is not intended to be a directory of resources nor a prescriptive guide for delivering navigation services.

Experiences and feedback from persons with stroke, their families and care partners were foundational to this document. These inputs were gathered through focus groups conducted during the CSR current state assessment by Heart and Stroke in partnership with Ontario Health. The key activities within were then validated by persons with lived experience from select Regional Stroke Networks through engagements facilitated by the Regional Network's leadership team.

Objectives

1. To define key stroke navigation activities during CSR to enable community reintegration.
2. To assist CSR teams to effectively plan and implement navigation supports within their programs.

Guiding Principles

These guiding principles were used to create the vision, objectives and activities outlined in this document:[2]

- Informed by best practice.
- Promotes empowerment of persons with stroke and their care partners by engaging in goal setting and care planning.
- Encourages education that is based on learning needs and goals to build knowledge, skills, self-efficacy, and enabling self-management.
- Supports timely connections to appropriate resources that are individualized to optimize community reintegration.
- Facilitates provider communication across the care continuum to support person-centred care planning.
- Supports a holistic approach to care that addresses the uniqueness of the individual including the physical, emotional, psychological, linguistic, and cultural needs, and environment of the individual and care partner.
- Optimizes the use of technology to support information sharing and access to resources

Core Functions

Navigating the post-stroke continuum of care can be a challenging journey for persons living with stroke and their care partners. Stroke navigators act as a trusted point of contact before, during, and for a period after CSR offering personalized guidance, education, and improved access to, and/or coordination of healthcare services as well as other needed resources. This support can improve the quality of life of those impacted by stroke, as well, economic, psychosocial, and functional benefits for persons with stroke have also been associated with navigation.[1]

Health care professionals, or those with equivalent experience and skills (see implementation considerations), providing navigation support should be directly linked with CSR team members, if not embedded as a part of the core team. Coordination of navigation services should be developed within the local context.

Appendix A: illustrates examples of navigation delivery models during CSR.

The key activities included in this document should be considered during the CSR program time frame with connections to community resources to continue these activities in the future. These activities have been developed through the analysis of Canadian Stroke Best Practice Recommendations and other research. They have been categorized into **four core functions:**[3,4]

Figure 1. Core Functions of Navigation During CSR

Key Activities: Connect

Navigation support builds meaningful connections with health care providers and community resources to foster collaborative, integrated care focused on recovery, enhanced quality of life, and independence.

Connect to Health Care Providers

- Coordinate communication and care with various health care providers, including physicians, rehabilitation therapists, specialists, community resources, and services (e.g., coordinate appointments, advocate for consultation and prioritization).
- Attend CSR interprofessional rounds or a family meeting to gain a better understanding of the person and to facilitate information sharing, collaborative care planning, coordination, and prioritization of referrals.
- Promote equitable access to culturally safe care by building trusting partnerships with all health care providers (e.g., Indigenous traditional health practitioners).[5]

Assist with Transportation Needs and Getting Around

- Facilitate access to dependable transportation options, both public and private, by providing support with applications, scheduling, obtaining parking passes, and more.
- Provide resources and information on return to driving such as driver's training and assessment.

Connect to Community Resources

- Be a knowledgeable resource about local, regional, and provincial programs for persons with stroke.
- Provide personalized, up-to-date information on community resources that cater to the individualized needs of the person with stroke and/or care partners (e.g., location, cost, accessibility) such as supportive communication programs, support groups, exercise, recreational programs, vocational rehabilitation services, and social service agencies.
- Provide a warm handover to community resources to ease transitions (e.g., tour facilities with person with stroke, accompany the individual to the first session of a program, and follow up to ensure the resource is meeting their needs).

Facilitate Continuity of Care

- Consider opportunities for continuity of care such as follow-up at 6 months and 1-year post-discharge from CSR or establish a pathway to other navigation supports or community partners who can act as a point of contact after CSR to respond to new and ongoing needs. [6]

Key Activities: Support

Navigation supports living with the impacts of stroke by helping persons with stroke and care partners manage their holistic needs and link them to the necessary services to support community reintegration.

Support Emotional & Mental Health

- Share information on emotional health post-stroke and check-in regularly using validated screening tools to monitor and address emotional well-being over time.
- Offer active listening, empathy, and validation to help relieve feelings of loneliness, isolation, and anxiety.
- Share information on coping strategies, resilience-building techniques, link to peer support groups.
- Coordinate referrals to psychosocial supports.

Link to Peer Supports

- Facilitate connection with peer groups and peers, where individuals with similar experiences can share insights, encouragement, and practical tips for coping with life after stroke. This can provide a sense of camaraderie, understanding, and validation that is invaluable in the recovery journey and can instill a sense of hope.

Support Care Partners

- Consider both the person with stroke and care partner(s) as clients.
- Provide emotional support, validation, and regular check-ins for care partners.
- Connect to peer support groups specifically for families and caregivers, respite care services, and psychosocial supports, if needed.
- Offer individualized information, emotional and practical support as needed versus all at once ("Timing it Right"), topics may include everyday management of ongoing activities, impact of providing care on life and health, emotional support, training to manage care in home.[7]

Assist with Financial Matters

- Provide guidance to financial resources such as government programs and benefits (e.g., Non-Insured Health Benefits [NIHB] and Ontario Disability Support Program [ODSP]), insurance coverage, income tax forms, and charitable organizations.
- Offer information on typical wait times for disability approvals, budgeting, and managing medical and medication expenses.
- Assist with identifying funding sources (e.g., financial assistance grants to attend programs, Assistive Devices Program [ADP]), completing applications, and connecting to financial counseling services.

Key Activities: Educate

Education is an integral part of stroke care and should be tailored to individual learning needs and reassessed over time. Education should be offered in a variety of languages and formats, address varying levels of health literacy, and be accessible for people with aphasia and cognitive deficits or impairments.[1]

Provide Individualized Education

- Be a dependable and knowledgeable source of information leveraging Canadian Stroke Best Practice Recommendations for Transitions and Community Participation Following Stroke (e.g. Table 2 Core Education Across the Continuum for People with Stroke).[1]
- Provide or ensure access to individualized education based on needs, topics may include the effects of stroke in the months following the index event such as cognitive changes, sleep apnea, relationships and intimacy, post-stroke fatigue, depression, communication supports, and information about resuming vocational, educational, and driving activities. [1]
- Consider the accessibility and relevancy of educational materials and resources (e.g., written materials, videos, journey maps, and apps) to accommodate different learning styles, literacy, culture, sexuality, languages, aphasia, vision, and hearing. [1]

Encourage Stroke Prevention and Risk Factor Management

- Ensure person with stroke are connected to a stroke prevention clinic and/or health care providers where appropriate.
- Offer ongoing support and encouragement to promote adherence to lifestyle modifications (e.g., maintaining a healthy diet, engaging in regular physical activity, and managing stress).
- Reinforce or provide education in conjunction with standard materials used by the CSR team (*role to align with the navigator's scope of practice*).

Promote Ongoing Rehabilitation and Activity

- Reinforce education on the importance of ongoing rehabilitation and exercise to improve functional outcomes and reduce risk of recurrent stroke.
- Collaborate with the CSR team to provide information on ways to continue therapy at home and facilitate access to community rehabilitation services, stroke exercise programs, or other rehabilitation opportunities.
- Support individuals in setting realistic, meaningful goals, overcoming barriers to participation in rehabilitation or exercise programs and in daily life.

Key Activities: Empower

Navigation support equips persons with stroke with the knowledge and skills to make informed choices, self-advocate, manage their own health and exercise influence over events that affect their lives during their recovery and beyond.

Use a Person-Centred Approach

- Provide respectful individualized care by getting to know each person as an individual, understand their goals, relationships, histories, valued activities, concerns, cultural background, and unique circumstances to develop a holistic plan of care.
- Encourage goal setting and action planning to promote self-efficacy.
- Be responsive to new and ongoing needs or wants by connecting before, during, and for a period after CSR (6 months to one year) if the person with stroke consents to be contacted.[6]

Support Development of Self-Management Skills

- Build self-management skills through problem-solving, sharing information and resources to help persons with stroke, their families and care partners navigate the health care system.
- Support self-advocacy to voice their needs and wants, and actively participate in decision-making (e.g., navigator may attend appointments to support difficult conversations and support their self-advocacy).

Encourage Social Involvement

- Explore individuals' interests to identify meaningful leisure activities to facilitate community engagement. Assist in overcoming obstacles like transportation, lack of confidence, or post-stroke self-image concerns to encourage participation.
- Consider a variety of community groups, including cultural and spiritual options, volunteering, and friendly visitor programs.

Support Navigating Life Roles

- Support adjustment to life roles, such as parenting, returning to school, or being a care partner. Consider factors (e.g., family dynamics or cultural belief) that could impact their role within the family or community.[8,9]
- Explore if the person with stroke is planning to return to work or interested in learning new skills. Offer to connect to peers/groups with similar experiences in-person or via virtual linkages (local, regional, provincial).

Implementation Considerations

When implementing navigation within CSR, program leaders should consider enabling factors, adequately resourcing navigation roles and activities. Persons providing stroke navigation should:

Be a health care professional or have equivalent experience and stroke-specific knowledge to understand impacts of stroke, the rehabilitation plan, and stroke journey. [10,11] The navigator should be linked to the CSR interprofessional team and their stroke expertise. Desirable personal traits include strong communication skills, cultural competence, respect, team player, enthusiasm for coaching, compassion, acceptance, reliability, dedication, flexibility, commitment to education, person-centeredness, ethical work, and the ability to work with all persons without bias.[11,12]

Receive training and ongoing education to ensure the knowledge, skills, and resources to provide comprehensive stroke navigation services (e.g., stroke best practices, motivational interviewing, supported conversation techniques for persons with aphasia.)[10,13] The navigator should have a clearly defined role in relation to other healthcare providers including an understanding of the CSR team's roles and areas of expertise.[14]

Identify and maintain up-to-date information on available resources and services within the community that can support persons with stroke in their recovery journey. This includes a local directory of resources including local health care facilities, community rehabilitation services, support groups, leisure activities, transportation options, financial assistance programs, and other relevant resources.

Develop collaborative relationships and effective communication with health care providers, community organizations, local navigation supports and other care partners to facilitate care coordination. This may involve establishing partnerships, building resources in conjunction with Ontario Health Teams or local stroke partners, educating community partners about stroke, and establishing referral pathways into and out of CSR (Appendix B).

Ensure navigation supports are culturally sensitive and responsive to the diverse needs and backgrounds of individuals and their families. This includes recognizing and respecting cultural beliefs, values, and preferences, and adapting navigation strategies to promote trust, engagement, and positive outcomes.[5]

Ensure navigation supports are accessible and equitable as people who live in rural areas may have difficulties in accessing care due to lack of services, isolation, or a lack of mobility.[15] This may include offering virtual delivery options or in-person supports, promoting health literacy, and advocacy.

Utilize technology and digital platforms to enhance communication, coordination, and access to information such as a shared care record, care team notes (e.g., EMR for the hospital stay, CSR Team, home care service summary, and referral/ appointment tracking applications).

Support opportunities for ongoing evaluation and quality improvement to assess the impact of stroke navigation services. This may involve collecting feedback (e.g., patient experience), monitoring key indicators, tracking outcomes, identifying areas for enhancement, and advocating for and/or developing additional services to address the needs of person with stroke and care partners.[11,16]

Appendix A: Examples of Navigation Models in CSR

To illustrate how stroke navigation fits within the CSR Model of Care, the four models below depict examples of how to deliver navigation during CSR, noting other innovative models are likely to be developed. Stroke navigation may also link to navigation supports offered through Ontario Health Teams (OHTs) or community support services (Appendix B).

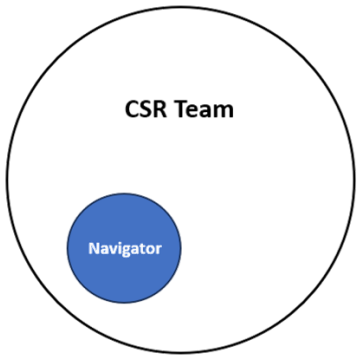

Figure 2. A dedicated navigator is a member of the CSR core team

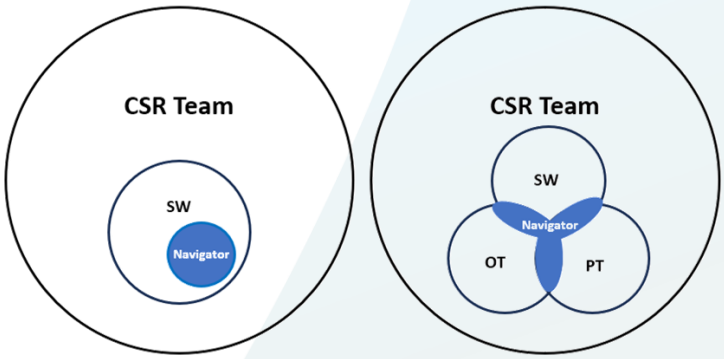

Figure 3. A member(s) of the CSR core team supports navigation activities (e.g., the social worker (or other team member) provides navigation as part of their role, or activities are shared across multiple team members)

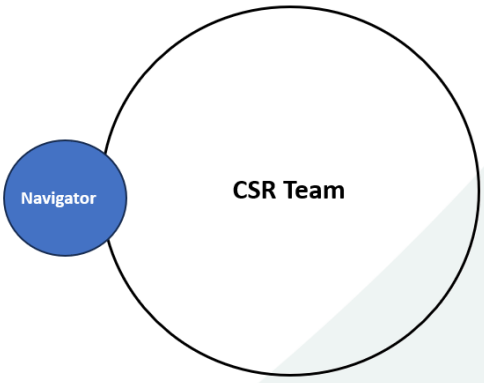

Figure 4. A community stroke navigator collaborates with the CSR core team (e.g., may attend case conferences, access to team documentation and processes)

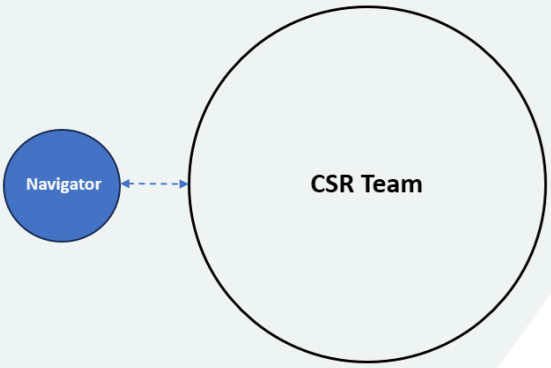

Figure 5. Community navigation is provided by an agency outside of the CSR core team with established referral pathways to and from each other

Appendix B: System Navigation – Ontario Health Teams (OHTs)

This appendix provides an overview of general health system navigation functions aimed at assisting individuals in navigating the healthcare system. Establishing connections between local OHT navigation services and CSR programs will create a network of support that empowers persons with stroke to navigate their recovery journey more effectively.

Navigation is defined as a service that assists the public/clients/patients with:

- Needs assessment/screening for eligibility (in some cases);
- Finding available health and social services to meet individual needs;
- Assisting with access to those services (warm transfers).

It may be provided on the internet (e.g., virtual care, chat, potential for mature AI algorithms to be leveraged), through live phone services, or in-person. Services can be provided anonymously or non-anonymously and can involve on-going support and follow-up in some cases.

In 2019, the Ministry of Health directed Ontario Health Teams (OHTs) to work towards implementing an OHT navigation model. Currently, nearly all OHTs have been asked to implement initial navigation improvements and varying innovative models have proliferated. Ontario Health's OHT Strategy and Patient Access & Navigation teams are working to release refreshed guidance on OHT Navigation to further provide provincial expectations. Extensive consultations with all OHTs through Regional tables validated the different functions of various system navigation that exist.

Ontario Health Navigation Function	Brief Description
Health 811	• Digital Front Door for Ontario • Focused on episodic needs and symptom assessment, high level navigation • Available 24/7
OHT Navigation	• Information, referral and intake service • assessment/advice not in scope) • In depth knowledge and established relationships of coordinated care pathways with local/OHT service providers • Provides warm transfers to appropriate local health care and social services and Health811, if appropriate • Supports available for complex and/or unattached patients (e.g., development of central intake processes) • Service available during business hours
Health Service Provider	• First point of contact for most patients • Embed navigation supports into clinical pathways for target populations (e.g. stroke-specific navigation activities during CSR and community reintegration) • Ensure patients know who to contact on their care team

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Collaborators
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North East Ontario Post Stroke Transitional Care Program
Ontario Regional Stroke Networks' Persons with Lived Experience

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