



HEART &
STROKE
FOUNDATION

CANADIAN
Stroke
BEST PRACTICE
RECOMMENDATIONS

CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Managing Transitions of Care Following Stroke

Update 2016

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Canadian Stroke Best Practice Recommendations Stroke
MANAGING STROKE TRANSITIONS OF CARE Writing Group*

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Canadian Stroke Best Practice Recommendations
MANAGING STROKE TRANSITIONS OF CARE
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Canadian Stroke Best Practice Recommendations

MANAGING STROKE TRANSITIONS OF CARE

Section One: INTRODUCTION and OVERVIEW

Introduction

The *Canadian Stroke Best Practice Recommendations* (CSBPR) are intended to provide up-to-date evidence-based guidelines for the prevention and management of stroke, and to promote optimal recovery and reintegration for people who have experienced stroke (patients, families and informal caregivers). CSBPR development is under the leadership of the Heart and Stroke Foundation, Canada (HSF) and involves a broad network of stroke professionals, healthcare providers, managers, patients, families and caregivers.

The goals of disseminating and implementing these recommendations are to reduce practice variations in the care of stroke patients across Canada, and to reduce the gap between current knowledge and clinical practice. Combined, these goals will lead to optimal levels of recovery and better outcomes for people who experience a stroke.

Why is better stroke management important?

- Every year, approximately 62,000 people with stroke and transient ischemic attack are treated in Canadian hospitals. Moreover, it is estimated that for each symptomatic stroke, there are nine “silent” strokes that result in subtle changes in cognitive function and processes.
- Stroke and other cerebrovascular diseases are the third leading cause of death in Canada.
- Stroke is a leading cause of adult disability, with hundreds of thousands of Canadians living with the effects of stroke.
- The annual cost of stroke is approximately \$3.6 billion, taking into account both healthcare costs and lost economic output.
- The human cost of stroke is immeasurable.

The HSF works closely with national and provincial stakeholders and partners to develop and implement a coordinated and integrated approach to stroke prevention, treatment, rehabilitation, and community reintegration in every province and territory in Canada. The CSBPR provides a common set of guiding principles for stroke care delivery, and describes the infrastructure necessary at a system level, and the clinical protocols and processes that are needed to achieve and enhance integrated, high-quality, and efficient stroke services for all Canadians. Through the innovations embodied within the stroke best practices, these guidelines contribute to health system reform in Canada and internationally.

The *Canadian Stroke Best Practice Recommendations* are developed and presented within a continuous improvement model and are written for healthcare professionals, administrators, health system planners, and funders, all of whom have important roles in the optimization of stroke prevention and care and who are accountable for results. A strong stroke research literature base is drawn upon to guide the optimization of stroke prevention and care delivery. Many implementation tools are provided to facilitate uptake into practice, and are used in combination with active professional development programs. By monitoring performance, the impact of adherence to best practices can be assessed and results then used to direct ongoing improvement. Recent stroke quality monitoring activities have compelling results which continue to support the value of adopting evidence-based best practices in organizing and delivering stroke care in Canada. These recommendations are updated every two to three years to ensure they remain current in supporting evidence-based stroke care delivery.

This is the fifth edition of the *Canadian Stroke Best Practice Recommendations*, which were first released in 2006. The theme for the 2014 – 2015 update is **Working Together with Stroke Survivors and their Caregivers to Achieve Optimal Outcomes**. This theme emphasizes the need for a committed interprofessional team approach to stroke care across the continuum, to ensure consistent patient-centred care delivery. With stroke patients and family members at the core, the entire team must be supported and actively engaged at every stage of care and in every setting. The HSF *Canadian Stroke Best Practice Recommendations* provide healthcare professionals with the most current evidence and expert guidance on how to engage in patient-centred optimal stroke care for patients and family members. Patients and family caregivers in particular should receive education and supported as active participants throughout their journey of recovery to ensure meaningful contributions to goal setting, treatment planning, and active therapy. This theme aligns with and supports the HSF survivorship mission priority and is included as part of each module for the 2014-15 update of the *Canadian Stroke Best Practice Recommendations*.

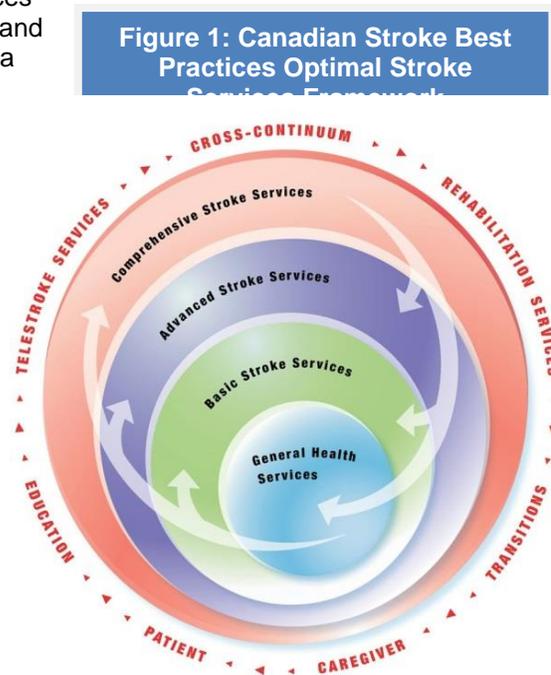
Organization of Stroke Care in Canada

The Heart and Stroke Foundation, in collaboration with the CSBPR advisory committee and key stakeholders have developed a framework to facilitate system improvement through the adoption of evidence-based best practices across the continuum of stroke care.

Optimal stroke services include access to stroke experts, diagnostic equipment and expertise, and a range of emergent and timely evidence-based acute and rehabilitation treatment options. These services can be considered along a continuum from minimal, non-specialized services in organizations that provide *general* health care, followed by higher levels with increasing levels of service and resources, such as providing *basic* diagnostic services and management, then *advanced* care at a single site, and at the highest level, to *comprehensive* stroke care across a region.

The Canadian Stroke Best Practices Optimal Stroke Services Framework, as visualized in Figure 1 is meant to organize and prioritize stroke services based on resource availability for a regional or geographic area. It is important to emphasize that the approach to stroke care delivery will necessarily differ across Canada. The overarching goal set forth within this framework is for each organization involved in the delivery of stroke care services to engage in an ongoing cycle of developing the expertise, processes and protocols needed to provide optimal stroke patient care, taking into consideration the organization's geographic location, patient population, structural and human resources, and relationship to other centres within their healthcare region or system. Once a level of stroke services has been achieved, the organization should strive to develop and incorporate components of the next higher level for ongoing growth of stroke services where appropriate, as well as continuous quality improvement within the level of service currently provided.

For more information, refer to the Canadian Stroke Best Practices Overview and Methodology Module at www.strokebestpractices.ca.



Managing Stroke Transitions of Care Module Overview

Working Together with Stroke Survivors and their Caregivers to Achieve Optimal Outcomes is imperative across stroke systems of care, and requires the participation of individuals with stroke, their families and caregivers, healthcare providers, and the broader community. The primary underpinnings of *Working Together* in stroke transitions of care are to provide patient and family-centered care across all transition points, and ensure effective and efficient transfers of care and information to the next stage and setting of care. Careful monitoring throughout recovery from stroke is an essential component in establishing a coordinated and seamless system of care that supports progress achieved during the initial recovery stages. In Canada, one-third of stroke patients, usually with TIA and milder strokes, are discharged back to the community directly from the emergency department. Of those patients admitted to acute inpatient care, 44% will be discharged to their homes independently, and additional 13% will be discharged home with arrangements for home care services, 16% will be transferred to an inpatient rehabilitation service, 11% will be transferred to long-term care or complex continuing care, and 13% will be transferred to another acute care facility (usually back to community hospital from a tertiary hospital) (HSFC Stroke Report 2014).

All members of the healthcare team engaged with stroke patients and families are responsible for ***working together*** to ensure successful transitions and facilitate a successful return to the community following stroke. Figure 2 depicts a pathway and steps for successful transitions, developed through an extensive consensus process (Gilmore et al, 2008).

Key components of successful transitions include:

- ✓ collaborative goal setting between the healthcare team, patients and families, where patients and family members actively participate in discussions and planning with the healthcare team and are involved in shared decision-making;
- ✓ ongoing education for patients, families and caregivers that reinforces key information and verifies understanding, regardless of setting; this includes in the emergency department, primary care, acute inpatient care (regardless of location of patient within the hospital), rehabilitation settings, outpatient and community settings;
- ✓ skills training appropriate to needs and goals of patients to facilitate safe transitions;
- ✓ discharge planning that begins soon after stroke admission and includes all relevant support services, such as home assessments and access to ambulatory and community-based rehabilitation;
- ✓ ongoing assessment of family and caregiver capacities to provide care for the patient with stroke, their individual support needs and potential burden of care;
- ✓ timely transfer of medical and recovery information between stages and settings of care;
- ✓ appropriate medical support by primary care physicians and team members, as well as stroke team members and stroke prevention services;
- ✓ stroke navigators or case managers in place to facilitate transitions of care and ensure continuity of care across settings, as well as appropriate access to needed resources and services; identification of and linkages to community resources, long term care and home-based care;
- ✓ ongoing surveillance of physical, psychological, social and emotional recovery, coping and adaptation following discharge from inpatient acute care and rehabilitation settings.

A coordinated and seamless system taking all these components into account will minimize challenges and complications for patients and families transitioning between stages and settings for stroke care, and lead to better recovery outcomes. Stroke case managers and/or stroke system navigators are valuable additions to the stroke care team, and where resources permit should be made available to patients, families and caregivers. Stroke navigators empower patients and families to be involved in their own care, build self-management skills and confidence, and aid in access to community resources, support groups and linkages. Providing supports such as navigators may reduce the burden to the health system and to health care professionals providing reactive care.

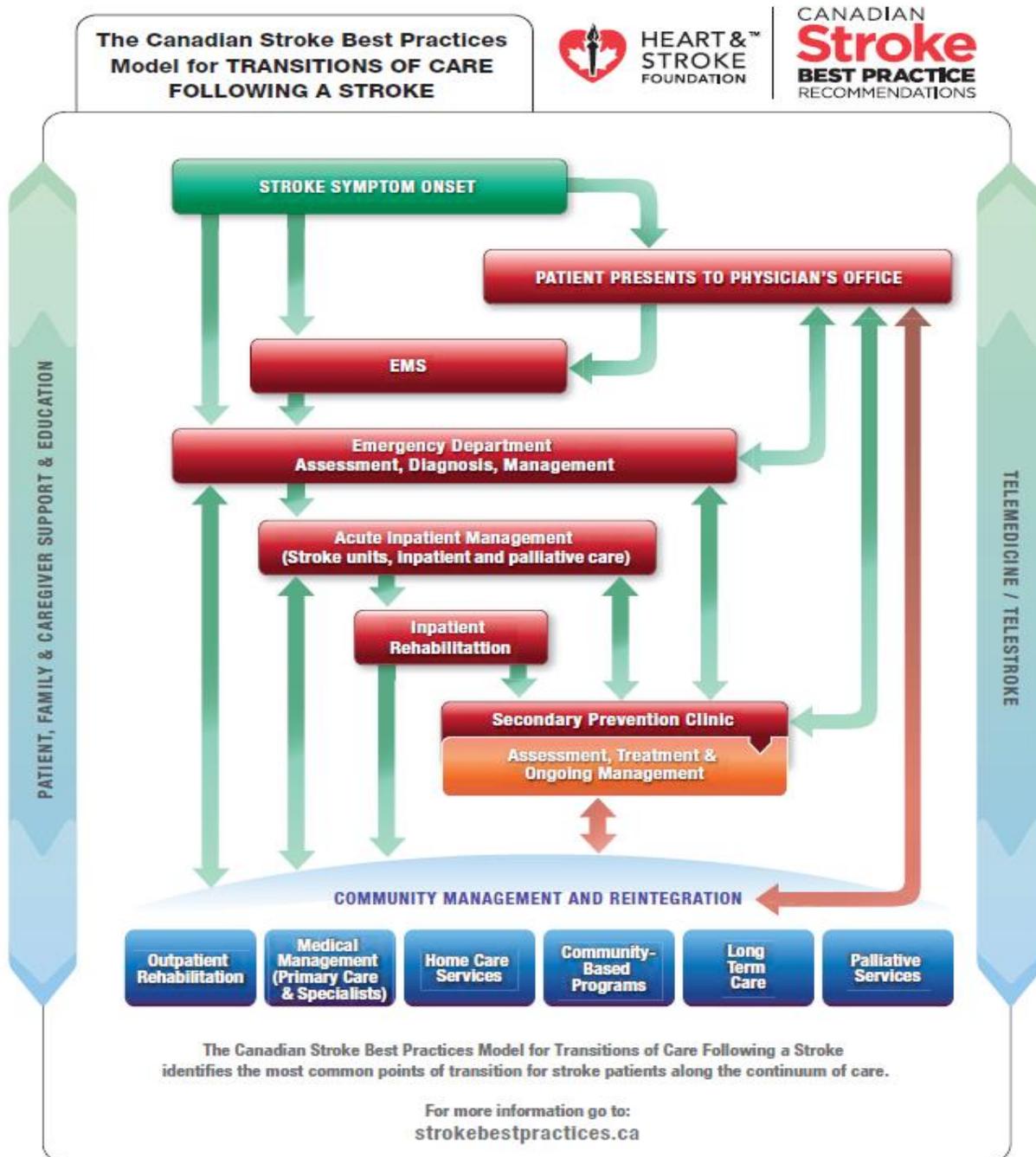
Working Together in the area of stroke care transitions is also directed to researchers and research funding organizations. The body of evidence for many of the topics addressed in this module is based on observational studies, small qualitative research initiatives and cohort studies. Randomized controlled trials and systematic reviews are lacking in this field. Despite the lower levels of evidence, the topics covered in this module have high importance for patients, families and caregivers, and are therefore presented based on moderate evidence and expert opinion.



Figure 2:
Pathways for People with Stroke to Live Fully in the Community
 Developed by Southwestern Ontario Stroke Strategy, 2008. *Reproduced with permission.*

Stroke Transitions of Care Model and Definitions

Figure 3: The Canadian Stroke Best Practice Guidelines Stroke Transitions of Care Model



The **Canadian Stroke Transitions of Stroke Care Model** identifies the most common points of transition for stroke patients along the continuum of care. The arrows are presented as unidirectional for simplicity of the diagram. However, in many instances stroke patients will move back and forth between different stages or settings of care during short-term and long-term recovery and reintegration.

Definitions

Transition refers to the movement of patients among healthcare locations, providers, different goals of care, and across the various settings where healthcare services are received. *Refer to Figure 3 The Canadian Best Practices Model for Transitions of Care Following a Stroke.*

Transition management includes working with patients, families, and caregivers to establish and implement a transition plan that includes goal setting and that has the flexibility to respond to evolving needs. Successful transition management requires interprofessional collaboration between healthcare providers, patients, families, and caregivers. It encompasses the organization, coordination, education, and communication required as patients, families and caregivers move through the stages and settings for stroke treatment, recovery, reintegration, adaptation, and end-of-life care.

The goal of transition management is to facilitate and support seamless patient, family, and caregiver transitions across the continuum of care, and to achieve and maintain optimal adaptation, outcomes, and quality of life for patients, families and caregivers following a stroke. This incorporates physical, emotional, environmental, financial and social influences.

Caregiver, within this module, refers to a more informal network of care that supports a person who has had a stroke, such as family, friends, and neighbours.

Community, within the context of the Canadian Stroke Best Practice Recommendations, is defined from a multi-dimensional perspective: as the physical, social, and care environment where individuals reside after experiencing a stroke. Community as an environment would include any setting that is outside the hospital settings, where one would reside and resume life roles and activities following a stroke. Therefore, community as an environment would include family home, assisted living, long-term care, and other residential settings. .

Community Reintegration involves return to participation in desired and meaningful activities of daily living, community interests and life roles following a stroke event. The term encompasses the return to active community living and contributing to one's social groups and family life. Community reintegration is a component in the continuum of stroke care; rehabilitation includes identifying meaningful goals for community reintegration and through structured interventions facilitates resumption of these activities to the best of patient abilities. The stroke survivor, family, friends, stroke recovery associations, rehabilitation programs and the community at large are all integral to successful community reintegration.

Home Health Care, also referred to as 'home care', is defined as providing medical, nursing, rehabilitation and personal care services to patients in a home setting rather than in a medical facility. Home care services enable patients to remain safely in their home by increasing their independence to tend to their everyday needs at home, continuing their rehabilitation therapy, promoting ongoing recovery, identifying risks, facilitating home-modifications, and providing assistance for personal care and mobility.

Home health care may include skilled nursing services and social workers, in addition to speech-language pathologists, occupational and physical therapists, and personal care workers. In many cases, it includes assistance with cooking and other household chores, and assistance with financial management. Home health care professionals monitor ongoing medical and rehabilitation needs, medication compliance and management, access to disability services, vocational assistance, and caregiver support and burden. Home-based care may be provided exclusively in the home or combined with care in the community (such as in day centres or under arrangements made for respite care). In parts of Canada, some home care services, such as rehabilitation services, are also available for residents in assisted living and long-term care settings.

Long-term care is the provision of formal organized institutional care for three or more unrelated people in the same place. Long term care is provided for people of all ages who have long-term health problems and need assistance with the activities of daily living (ADL) in order to enjoy a reasonable quality of life (World Health Organization [WHO], 2000). The goal of long-term care is to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment, and human dignity.

The need for long-term care following a stroke is influenced by changing physical, mental, and/or cognitive functional capacities, their abilities and levels of independence prior to the stroke, and the availability of family and caregivers. Many people may regain lost functional capacities over a shorter or longer period of time following stroke, while others decline. The type of care needed and the duration of such care are thus often difficult to predict (WHO).

Each long term care home provides an organized 24 hour program of nursing, personal support, medical, pharmacy and interdisciplinary care services based on the assessed needs of residents and guided by an individual written plan of care. Appropriate long-term care includes respect for each individual's values, preferences, and needs. In many provinces in Canada, each long term care home is considered to be primarily the home of its residents. It is to be operated to promote and maximize independence of each resident as well as to provide dignity and security, safety and comfort and to meet the physical, psychological, social, spiritual and cultural needs of its resident population. Admission to a long term care home is based on provincial health insurance eligibility and an independent assessment by a case manager or community-care service provider (Ontario Long Term Care Association).

Self-management, in this document, refers to the ability of individuals to manage all aspects of their health following a stroke. It includes knowledge, skills, attitudes and behaviours for managing physical, cognitive and lifestyle changes, in addition to managing symptoms, treatment (rehabilitation), and secondary prevention strategies. It involves active participation of the individual in a plan developed collaboratively with healthcare professionals. The goal of self-management is to empower the individual to have a better quality of life by developing self-efficacy, which is the level of confidence than an individual has in their ability to succeed in coping with their condition.

Stroke Navigator/Case Manager is a specific health care professional role which provides patient and family-centred support to stroke survivors and their families needed to successfully transition across the continuum of stroke care (including stages and settings of care). The stroke navigator/case manager is often a social worker or similarly trained professional, and is often engaged in the acute care phase, and in many regions, continues on for the first six months following stroke, depending on patient and family needs.

The stroke navigator/case manager works closely with other health, social care, voluntary and community providers to ensure a seamless delivery of care and service. This is accomplished by providing information on available services, processing referrals, linking with primary care providers and other medical specialists required by the patient, and assisting patients and families to address and access financial, transportation, and other concerns that may negatively impact recovery and successful transitions. Additional roles should also include facilitating contact with stroke support organizations and local peer support groups for patients and families following stroke. The stroke navigator/case manager also provides emotional support to stroke patients, families and caregivers, and assists with the practical aspects of adaptation following stroke (Stroke Foundation, United Kingdom).

Support for patients, families and caregivers following stroke refers to providing direct care, access to required services, and facilitating linkages to resources to ensure that patient, family and caregiver needs are met throughout the continuum of stroke care. The goal of patient, family and caregiver support is to equip each individual with the tools and information required to manage their recovery or

the recovery of a family member after stroke and optimize participation and fulfillment of life roles; tailored to unique needs, coping mechanisms, strengths, challenges and living situation.

Supported Living Environments refers to residential living locations where individuals may transition following acute and sub-acute care for a stroke, and where they continue to receive healthcare services within a coordinated and organized system. The levels of support and service received are dependent on the individual's physical, functional and cognitive abilities and ongoing health care needs, as well as available social support from family members and caregivers. Supported living environments are settings where individuals can maintain as much control over their lives as possible, while receiving the supports they need to maintain their health and safety.

Supportive living environments may include a range of settings and support service levels, such as: private home or residence where health care services are brought to the stroke survivor; group settings such as lodges, transitional care or respite centres where the stroke survivor resides with others with similar care and support needs; assisted living settings where the individual has their own private room(s) within a residential setting and access to personal care support, group meals, organized social activities, and transportation; advanced assisted living and full care environments such as nursing home settings.

Training, within the context of this module, training refers to activities aimed at acquiring knowledge and skills necessary for the person with stroke, families and caregivers. Training activities are bidirectional and collaborative between the healthcare providers, patients, family and caregivers.

Updates and Changes in *Managing Stroke Transitions of Care* 2015 Update

The 2015 update of the *Canadian Best Practice Recommendations* Managing Stroke Transitions of Care module reinforces the growing and changing body of research evidence available to guide ongoing screening, assessment and management of patients who have experienced a stroke, families, and caregivers to ensure they move from one phase and stage of care to the next without 'falling through the cracks' or 'getting lost out of the system'.

Highlights of the moderate and significant updates as well as new additions to *Managing Stroke Transitions of Care* module recommendations for 2015 include:

- ✓ A focus on patient-centred care, with the patient, family members and caregivers included as active members of the stroke team, being involved in decision-making, goal setting and care planning throughout the stroke care continuum;
- ✓ Recognition that stroke affects the whole family unit, and places a burden on family members; ensuring caregiver capacity, coping, and risk for depression are assessed and monitored;
- ✓ The importance of educating patients and families to understand the nature and causes of/risks for stroke, the signs and symptoms, the impact and the ongoing needs of the patient who has experienced a stroke;
- ✓ A call to action for all healthcare professionals for delivering education and support on an ongoing basis, regardless of patient location within the healthcare system, including providing new information at the right teachable time, reinforcing previously taught information, and assessing ongoing learning needs; these information needs evolve as the patient moves through the continuum of care and into longer term recovery;
- ✓ Promotion of self-management and active participation in ongoing care, adhering to rehabilitation plans and actively engaging in recovery, and following through with decisions to take prescribed medications;

- ✓ An emphasis on improving communication: between healthcare professionals and the patient, family and caregivers; and between healthcare professionals, particularly when patients are transitioning between care settings or discharged home.

Guideline Development Methodology:

The *Canadian Stroke Best Practice Recommendations* present high-quality, evidence-based stroke care guidelines in a standardized framework to support healthcare professionals across all disciplines. Implementation of these recommendations is expected to reduce practice variations and close gaps between evidence and practice.

The recommendations are targeted to health professionals throughout the health system who care for those affected by stroke. Health system policy makers, planners, funders, senior managers, and administrators who are responsible for the coordination and delivery of stroke services within a province or region will also find this document relevant and useful to their work.

The methodology for updating the recommendations includes twelve distinct steps to ensure a thorough and rigorous process. These steps are overseen by the CSBPR Advisory Committee, and include the following (details available online):

1. Establish an expert interprofessional writing group for module, as well as stroke survivors and/or caregivers
2. Systematic search, appraisal and update of research literature.
3. Systematic search and appraisal of external reference guideline recommendations.
4. Update of evidence summary tables.
5. Writing group review and revision of existing recommendations and development of new recommendations as required.
6. Submission of proposed module update to the Canadian Stroke Best Practices Advisory Committee.
7. Internal review of proposed module update, feedback to writing group, and completion of edits.
8. External review, and final edits based on feedback.
9. Update of educational materials and implementation resources.
10. Final approvals, endorsement and translation of module.
11. Public release and dissemination of final updated module.
12. Continue with ongoing review and update process.

The detailed methodology and explanations for each of these steps in the development and dissemination of the *Canadian Stroke Best Practice Recommendations* is available in the *Canadian Stroke Best Practice Recommendations Overview and Methodology* manual available on the Canadian stroke best practices website at http://www.strokebestpractices.ca/wp-content/uploads/2014/08/CSBPR2014_Overview_Methodology_ENG.pdf

Conflicts of Interest: All potential participants in the recommendation development and review process are required to sign confidentiality agreements and to declare all actual and potential conflicts of interest in writing. Any conflicts of interest that are declared are reviewed by the Chairs of the Advisory committee and appropriate HSF staff members for their potential impact. Potential members of any writing group who have conflicts that are considered to be significant are not selected for advisory or writing group membership.

Assigning Evidence Levels: The writing group was provided with comprehensive evidence tables that include summaries of all high quality evidence identified through structured literature searches. The writing group discusses and debates the value of the evidence and through consensus develops a final set of proposed recommendations. Through their discussions, additional research may be identified and added to the evidence tables if consensus on the value of the research is achieved. All recommendations are assigned a level of evidence ranging from A to C, according to the criteria defined in Table 1 (below). When developing and including “C-Level” recommendations, consensus is obtained among the writing group and validated through the internal and external review process. “C-level” evidence is used cautiously, and only when there is a lack of stronger evidence for topics that are agreed to be important system drivers for stroke care (e.g., transport using ambulance services or some screening practices). Recommendations with “C-level” evidence may also be made in response to requests from healthcare professionals who seek guidance and direction from national stroke experts in *the absence* of strong evidence regarding certain topics that are of high clinical importance.

Throughout this Transitions module, it is acknowledged that a body of sound research evidence is in the early stages of development for some of the topics addressed. Randomized controlled trials are challenging to complete for many the topics addressed. There are a growing number of qualitative studies and observational studies that have provided the basis for some recommendations, and others are based on the expert opinion of the writing group members. Although the evidence is less mature, these areas have been identified through formal and informal interviews with patients and families, where they have stated that these topics often cause the greatest challenges for them and require significant amounts of time and resources by healthcare providers to address. Therefore, these topics are included in these Canadian Stroke Best Practice Recommendations. Their inclusion is intended to facilitate a holistic approach to stroke patient care, and ensure all issues important to patients and families which will promote optimal recovery are addressed.

Table 1: Summary of Criteria for Levels of Evidence Reported in the *Canadian Stroke Best Practice Recommendations (Update 2015)*

Level of Evidence	Criteria*
A	Evidence from a meta-analysis of randomized controlled trials or consistent findings from two or more randomized controlled trials. Desirable effects clearly outweigh undesirable effects or vice versa.
B	Evidence from a single randomized controlled trial or consistent findings from two or more well-designed non-randomized and/or non-controlled trials, and large observational studies. Desirable effects outweigh or are closely balanced with undesirable effects or vice versa.
C	Writing group consensus and/or supported by limited research evidence. Desirable effects outweigh or are closely balanced with undesirable effects or vice versa, as determined by writing group consensus.

* (adapted from Guyatt et al. 2008)

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Performance Advisory Committee members for their work in reviewing and updating the performance measures that accompany each recommendation. We acknowledge Norine Foley and Katherine Salter for their work on the evidence tables and evidence summary updates; and, we thank Christelle Desgranges-Farquhar and Roula Abboud for their work on the French translations.

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Citing the Managing Stroke Transitions of Care 2015 Module

Cameron JI, O'Connell CM, on behalf of the Managing Stroke Transitions of Care Writing Group. *Managing Stroke Transitions of Care Module 2015*. In Lindsay MP, Gubitz G, Bayley M, and Smith EE (Editors) on behalf of the Canadian Stroke Best Practices and Advisory Committee. *Canadian Stroke Best Practice Recommendations*, 2015; Ottawa, Ontario Canada: Heart and Stroke Foundation.

Comments

We invite comments, suggestions, and inquiries on the development and application of the *Canadian Stroke Best Practice Recommendations*.

Please forward comments to the Heart and Stroke Foundation's Stroke Team at strokebestpractices@hsf.ca

Canadian Stroke Best Practice Recommendations

MANAGING STROKE TRANSITIONS OF CARE

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Canadian Stroke Best Practice Recommendations

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Canadian Stroke Best Practice Recommendations

MANAGING STROKE TRANSITIONS OF CARE

Section Two: RECOMMENDATIONS

Note about Assignment of Levels of Evidence:

The authors recognize that for many of the topics and associated recommendations for transitions of care, there is a paucity of Level A evidence. Randomized controlled trials are difficult to conduct in this area of care, and the evidence for most of the following recommendations is based on qualitative and observational studies and expert opinion. Patients, families and caregivers have expressed, both through formal and informal assessment, that transitions in care represent some of the greatest challenges faced after stroke. The Canadian Stroke Best Practice Recommendations are responsive to this need; their inclusion is intended to facilitate a holistic approach to patient and family-centred care to promote optimal outcomes, as well to highlight the importance of further research into this important aspect of stroke care.

1. Supporting Patients, Families and Caregivers Following Stroke

Managing Stroke Transitions of Care Update 2015

1. Supporting Patients, Families and Caregivers Following Stroke

1.0 Patients, families, and caregivers should be assessed and prepared for transitions between care stages and settings through information sharing, provision of education, skills training, psychosocial support, and awareness of community services [Evidence Level B]. Interventions must be patient-centered and tailored to patient values and needs [Evidence Level C]. *Refer to Figure Three – Stroke Transitions of Care Model*

1.1 Screening and Assessment

- i. Patients, families and caregivers should be **screened** for their level of coping, risk for depression, and other physical and psychological issues [Evidence Level B]. Ideally screening should take place at each transition. *For additional information, refer to the following CSBPR modules: Mood, Cognition & Fatigue; Stroke Rehabilitation; Acute Inpatient Stroke Care.*
 - a. Validated screening tools should be used whenever possible to ensure a consistent approach to identifying potential issues during transitions [Evidence Level C]. *Refer to Appendix, Table 1: Tools to Assess Participation and Health-Related Quality of Life.*
- ii. Patients, families and caregivers should be **assessed** at each transition (starting with first contact with the healthcare system) to determine their needs, readiness for information and ability to integrate knowledge related to education, training, psychosocial support, and health and social services [Evidence Level B]. They should be reassessed when there is a change in health status or other appropriate indication [Evidence Level B]. *Refer to Section 2 for additional recommendations on education and training.*
 - a. Family members and caregivers may be assessed for the following issues as they relate to their ability to care for the patient with stroke:
 - caregivers' current health status, employment and social responsibilities, and how those will be managed in providing stroke care [Evidence Level B];
 - caregiver capabilities and experience in providing care to the person affected by

stroke [Evidence Level C];

- resource issues such as, financial situation, housing, transportation, insurance, healthcare benefits, medication cost coverage [Evidence Level C];
- support from other family members, relatives and social networks [Evidence Level C].

- b. The type and depth of assessments should be appropriate to the individual patient's needs, issues identified during screening, and the care setting to where the patient is transitioning (such as home with or without home care services, inpatient rehabilitation, assisted living, and long-term care) [Evidence Level C].
- iii. When issues are identified through screening and assessments, patients [Evidence Level B], families and caregivers [Evidence Level C] should be considered for referral to appropriate care professionals to address the issues and promote optimal outcomes (for example, mental health experts, social services.).

1.2 Patient, Family and Caregiver Support

- i. Support for patients, families and caregivers should begin at admission and continue through discharge to the next stage or setting of care [Evidence Level B].
- ii. The core elements defined in the **Pathways for People with Stroke to Live Fully in the Community model (Figure 2)** should be addressed at each transition point as appropriate to the setting [Evidence Level C]. *Refer to Box 1: CSBP Transitions of Care Checklist.*
- iii. The use of telemedicine technology modalities (e.g., video, and web-based technologies and services such as web-based support groups, tele-rehabilitation), should be considered to increase access to ongoing support services, healthcare services and rehabilitation therapies for patients following transitions to the community or setting from which patients and family members are unable to travel to access care and services [Evidence Level B]. *Refer to CSBPR Telestroke module for additional information.*

Box 1: Transitions of Care Checklist

Support for patient, families and caregivers may include:

- Written discharge instructions and recommendations that identify collaborative actions plans, follow-up care and goals
- Access to a designated contact person in the hospital or community for care continuity and queries
- Ongoing access to and advice from health and social service organizations appropriate to needs and stage of transition and recovery
- Links to and information about local community agencies such as stroke survivor groups, peer survivor visiting programs, meal provider agencies, and other services and agencies
- Shared decision making/participation regarding transitions between stages of care
- Counseling, preparation and ongoing assessment for adjustment to change of living setting, change in physical needs and increased dependency, change in social roles and leisure activities, impact on other family members (e.g., spouse or partner, children), loss of home environment, and potential resource issues
- Access to restorative care and active rehabilitation to improve and/or maintain function based on the individualized care plan
- Advance care planning, palliative care and end-of-life care as applicable

- Where possible, access to peer (survivor/family), who has experienced the transition and who can help the patient better understand the transition
- Accurate and up to date information about the next care setting, what the patient and family can expect, and how to prepare.

Rationale

This recommendation supports the following goals: to emphasize the need for a holistic approach to care; to help patients, families and caregivers to navigate the healthcare system, particularly following the initial acute stage of stroke care; to define the various components of support; to focus on patients and their families, highlighting the patient and family-centered care approach; and to address needs beyond the physical impact of stroke.

Stroke is a life-altering event that may require an extended recovery period and often leaves patients with ongoing functional impairments. It also has an impact on others close to the patient, as increasingly, families and caregivers are expected to assume roles, tasks and responsibilities that may be beyond their current skills and knowledge. This increases the caregiver burden, which can result in depression among caregivers of stroke patients (as high as 60 percent has been reported). Similar post-stroke depression rates occur in patients and are linked to poorer recovery outcomes.

Increased screening, assessment and surveillance of patient, family and caregiver needs and coping will provide a holistic patient and family-centered approach to stroke care and optimally lead to better outcomes and adaptation.

System Implications

Care transitions take place across the stroke continuum, including primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. Processes and mechanisms should be in place in all these settings to address patient, family and caregiver support using an individual approach, including:

- Protocols to involve patients and families in healthcare team transition planning meetings and collaborative decision-making regarding goal setting at all transition points.
- Resources and mechanisms to plan and deliver community-based services which consider the needs of the survivor and family/caregiver (e.g., home care services, psychological support).
- Models of care that include technology such as telemedicine, regular telephone follow-up and web-based support.
- Appropriately resourced hospitals, rehabilitation facilities, home care services, long-term care and other community facilities that care for stroke patients, with identified contact people and case managers/system navigators to coordinate manage stroke care transitions.
- Ongoing education and training of healthcare professionals on patient and family-centred stroke care in all settings that care for stroke patients.
- Opportunities for education and training for stroke survivors, families and caregivers to provide peer support when requested.
- Access to self-management support services through telemedicine technologies, especially in rural areas and where there are local resource gaps.

Performance Measures

1. The change in burden of care for family members and caregivers measured at transition points throughout the recovery period and following changes in patient health status.
2. The number and proportion of patients diagnosed with post-stroke depression, measured at each transition point as a proportion of all stroke patients.

3. The number and frequency of patients readmitted to an emergency department or acute inpatient care for reasons related to physical decline or failure to cope, following an initial stroke hospital stay.

Measurement Notes

- Standardized and validated measures of depression and caregiver burden should be used to track occurrence and changes to these areas.
- Failure to cope diagnosis should be made based on appropriate ICD10 codes.
- Data on readmissions can be accessed through the Canadian Institute for Health Information NACRS and DAD databases.

Implementation Resources and Knowledge Transfer Tools

Health Care Provider Information

- Taking Action for Optimal Community and Long-Term Stroke Care: A resource for healthcare providers: available on www.strokebestpractices.ca
- Timing it Right (Cameron & Gignac 2008): <http://www.ncbi.nlm.nih.gov/pubmed/?term=18155388>
- RNAO Best Practice Guideline *Care Transitions*: <http://rnao.ca/bpg/guidelines/care-transitions>
- Registered Nurses' Association of Ontario Guideline: Person and Family-Centred Care: <http://rnao.ca/bpg/guidelines/person-and-family-centred-care>
- Ways of Coping Questionnaire: <http://www.mindgarden.com/products/wayss.htm>

Patient Information

- Taking Charge of Your Stroke Recovery: A survivor's guide to the Canadian Stroke Best Practice Recommendations: http://www.strokebestpractices.ca/wp-content/uploads/2014/08/HSF_SBP_PatientsGuide_F14_EN_July2014-FINAL.pdf
- Your Stroke Journey: A guide for people living with stroke: http://www.strokebestpractices.ca/wp-content/uploads/2015/03/YOURSTROKEJOURNEY.FINAL_ENGLISH.pdf
- Post-Stroke Checklist: http://www.strokebestpractices.ca/wp-content/uploads/2014/06/HSF%20Post%20Stroke%20Checklist_WEB.pdf
- HSF Stroke Resources Directory: http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.8598311/k.97BA/Stroke_Resources_Directory/apps/kb/cs/contactsearch.asp
- Living with Stroke™ program: http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.3936679/k.7231/Stroke_Living_with_StrokeTM_program.htm
- A Family Guide to Pediatric Stroke: <http://www.strokebestpractices.ca/wp-content/uploads/2011/10/PEDSGuide-EN.pdf>
- Life After Stroke: <http://www.canadianstroke.ca/en/resources/patients-and-carers/>
- Getting on with the Rest of Your Life after Stroke: http://www.strokebestpractices.ca/wp-content/uploads/2014/01/CSN_GettingOnV2_English_WEB_3.pdf
- National Stroke Association. Care Living: Caring for yourself and a stroke survivor: http://www.stroke.org/site/DocServer/CareLivingGuide_Full.pdf?docID=9070
- World Stroke Organization Stroke Support Site: <http://www.world-stroke.org/for-patients/stroke->

[support-organizations](#)

- My Stroke Passport: <http://www.strokebestpractices.ca/wp-content/uploads/2013/10/My-Stroke-Passport.pdf>
- Stroke recovery: www.heartandstroke.ca/strokerecovery
- Stroke in Young Adults: http://www.strokebestpractices.ca/wp-content/uploads/2015/01/Stroke_Young_FINAL.pdf
- Stroke Engine: strokengine.ca

Summary of the Evidence

Following stroke, patients, families and caregivers are typically faced with multiple life changes and challenges as the patient transitions between the stages of recovery. Gallacher et al. (2013) reviewed 69 qualitative studies examining the concept of patient burden following stroke, highlighting the impact it may have on the effectiveness of interventions and patient satisfaction with health care services. The authors identified the components of stroke recovery that were particularly burdensome to patients including receiving information, interacting with others, comparing treatment options, managing in different environments (acute care, inpatient rehabilitation, community, society) and adjusting to daily activities. Caring for a person following a stroke may also have a considerable impact on the health and vocational status of caregivers. Hayes et al. (2009) conducted telephone interviews with 275 veterans who had sustained a first-ever stroke and their informal caregivers to explore the association between caregiver characteristics and the development of injuries. Caregivers who reported a physical injury were more likely to report higher levels of burden, provided more hours of care per week, exhibited more depressive symptoms and fewer healthy days per month compared to caregivers reporting no injury. The most common type of injury reported was a back injury and 53% of injured caregivers stated that the injury interfered with their ability to provide care. Significant predictors of injury were higher caregiver burden (OR=1.62, 95% CI 1.14-2.31, p=0.008) and depression (OR=1.10, 95% CI 1.04-1.17, p=0.001). Ko et al. (2007) interviewed 132 caregivers and reported that while 52% were working full time or part-time, prior to the stroke, the majority of working caregivers reported reducing their hours of paid work, or missing work, while 9 caregivers retired or resigned. Rochette et al. (2007) reported that 6 months following stroke, 35.2% of spouses, of a sample of 54 had a high level of burden (Caregiver Strain Index score ≥ 7) and 17% were identified with possible depression (Beck Depression Inventory BDI score ≥ 10).

Families and caregivers are often highly engaged in supporting the stroke patient through their recovery. In addition to a patient requiring support as they recover, families and caregivers will often experience needs at equivalent time points. The “timing it right” framework conceptualized by Cameron & Gignac (2008) highlighted the stages that a caregiver may experience as the patient recovers from a stroke. The authors identified 5 stages in the framework, defined by the changing information, training, emotional and feedback needs of caregivers. These phases include (Cameron & Gignac, 2008): 1) Event/Diagnosis, 2) Stabilization, 3) Preparation, 4) Implementation, and 5) Adaptation. The first two phases (event/diagnosis and stabilization) typically occur in the acute care setting, preparation in the acute or rehabilitation setting, and the last two phases in the home. As a patient moves from the hospital to the home environment, the information and training needs of the caregiver increase in scope and complexity. The “timing it right” framework is helpful in demonstrating that the needs of patient, family and informal caregiver are constantly changing and evolving and should therefore be reassessed at each stage of care.

The needs of patients and their caregivers have been explored in several qualitative studies using in-person or telephone interviews. Similar themes emerged across studies. Cameron et al. (2014) included 16 patients recruited from an inpatient rehabilitation stroke facility and 15 informal caregivers, who were interviewed following their first weekend pass from inpatient rehabilitation and again 4 weeks following discharge home. Twenty health-care professional (HCP) were also interviewed. Three key themes emerged including issues surrounding preparing patients for safe return home. Patients discussed the need to feel safe in the home environment while caregivers discussed their need to feel supported. Assessing the patient for readiness was a key theme discussed by HCPs. Patients noted gaining insight

into what life would be like, and caregiver evaluated their abilities to care for stroke survivor. Patients and caregivers discussed the range of emotions they experienced and how their experienced changes before and after the weekend pass. In a similar study including 24 informal caregivers to stroke survivors and 14 HCP (Cameron et al. 2013), the themes emerged from both the caregivers and the HCP concerned the type and intensity of support needed, who provides support and the method of providing support and the primary focus of care. Creasy et al. (2013) interviewed 17 family caregivers close to the point of discharge from hospital and the again within 4 months of discharge. In the first interview, caregivers expressed information needs related to their role as caregiver in preparation for discharge home and expressed concerns for their own emotional support needs and their ability to provide emotional support. During the second interview caregivers discussed their experiences with caregiver-provider interactions, some of which were positive, others, negative. The caregivers of 90 patients were interviewed one year following stroke (Smith et al 2014). Caregivers reported delays and barriers waiting for applications/funding for alterations to make the home more accessible, having to provide care in the immediate post-discharge period with no skills training and lack of follow-up with GPs. They also described difficulties coping with patients' quick anger and emotional lability and lack of attention to their physical and emotional ability to provide care.

Interventions to provide support to patients and caregivers during the transition from hospital to home have been examined, which include telephone contacts, online support and home visits from a support worker. The results of many of these studies have been equivocal, with improvements on psycho-social outcomes, without significant improvements in physical functioning. In the YOU CALL-WE CALL trial (Rochette et al. 2013), 186 patients discharged home within 3 weeks of admission to hospital following a mild stroke were randomized to a YOU CALL group or a WE CALL group. Patients in the YOU CALL group were provided with the name and phone number of a trained healthcare professional whom the patient could call with questions. Patients in the WE CALL group received scheduled telephone, internet and paper documentation support, initiated by the trained professional over a 6-month period. During the study period, only 6 patients in the YOU CALL group phoned. Although patients in the WE CALL group perceived the intervention positively, there were no significant differences between groups on any of the primary (unplanned use of health services and QoL) or secondary outcomes (planned use of health services, depression, social participation) at 6 months. The benefits of a Family Support Organizer (FSO), a service in the UK that provides information, emotional support and prevention advice for families and patients, have been evaluated in several trials. Tilling et al. (2005) randomized 340 patients with first-ever stroke and their caregivers to receive support from a FSO or standard outpatient care. There was an average of 15 telephone or face to face contacts with the FSO. There were no significant differences between groups in mean overall Patient Satisfaction Scale scores, the primary outcome, at either 3 months (7.6 vs. 7.4, $p=0.80$) or one year (8.0 vs. 7.8, $p=0.80$). Patients in the FSO group fared worse on some of the secondary outcomes. In another trial examining FSO services (Lincoln et al. 2003), there were no differences between groups in median General Health Questionnaire 12 scores, BI scores or Nottingham EADL scores at either 4 or 9 months following an average of 6.4 in-person, or telephone contacts. However, patients in the FSO group were more knowledgeable about stroke, stroke prevention, community services, and emotional support. Grant et al. (2002) randomized 74 primary, informal caregivers to either a Social Problem Solving Telephone Partnership (SPTP) intervention, sham intervention, or a control group, shortly following discharge from hospital. The STPT intervention involved the caregiver training to manage problems and cope with stress, with a trained nurse in the home, followed by weekly and bi-weekly telephone contacts to maintain skills. The sham intervention group received telephone contacts, enquiring about health services they had received, while the control group received discharge planning services only. By 13 weeks following discharge, caregivers in the intervention group had significantly higher sub scores on 4 components of the SF-36 (vitality, mental health, emotional role functioning and social role functioning), and demonstrated better preparedness, and less depression.

[Link to Evidence Table and References for Section 1](#)

2. Patient, Family and Caregiver Education

Managing Stroke Transitions of Care

2. Patient, Family and Caregiver

Update 2015

Education

2.0 Stroke patient, family and caregiver education is an integral part of stroke care that must be addressed at all stages and settings across the continuum of stroke care [Evidence Level A].

2.1 Assessment of Patient, Family and Caregiver Learning Needs

- i. Throughout each stage along the continuum of stroke care, patient, family and caregiver learning needs and goals should be assessed and documented by members of the healthcare team [Evidence Level B]. *Note: This applies to all settings including ambulatory care and emergency departments where there is shorter interaction time with patients and greater risk of learning needs being unmet.*

2.2 Delivery of Education

- i. Based on findings of educational assessments, a process for delivering education should be implemented for stroke patients, families and caregivers [Evidence Level B].
- ii. It is recommended that individualized patient, family and caregiver education:
 - a. include information sharing, teaching of self-management skills, and training of family and caregivers to participate in and provide safe stroke patient care [Evidence Level B].
 - b. be goal-oriented and facilitate decision-making regarding care and recovery [Evidence Level C].
 - c. cover all aspects of stroke care and recovery [Evidence Level A], and include content specific to the stage of care or recovery, and be appropriate to the readiness and needs of the patient, family, and caregiver [Evidence Level B]. *Refer to Appendix, Table 2: Patient Education across the Continuum.*
 - d. be interactive, current, ongoing, repetitive, evaluative, and available in a variety of languages and formats (e.g. written, oral, pictorial, instructive, and group counseling approaches); it should address varying levels of health literacy and ensure access to communication devices for patients (e.g. appropriate resources to help patients with aphasia and cognitive deficits or impairments communicate more effectively) [Evidence Level B].

2.3 It is recommended that processes be in place to monitor education needs and reinforce education provided:

- i. Individualize and coordinate ongoing education across transition points, and across stages along the continuum [Evidence Level B].
- ii. Ensure that patient, family and caregiver educational episodes are documented in the patient record and accessible by all members of the healthcare team [Evidence Level B].
- iii. Assess patient, family and caregiver understanding and retention of previously taught information [Evidence Level A].
- iv. Include reinforcement of information previously taught, especially critical information that has not been retained (e.g., medication information and management) [Evidence Level B].
- v. Ensure all care settings have up-to-date inventories of community resources available to stroke patients, families and caregivers, and offer assistance in obtaining needed services [Evidence Level C].

2.4 Promoting Self-Management for Patients, Family and Caregivers following Stroke

- i. Patient education should promote self-efficacy through mastering self-management skills, [Evidence Level B]. *Refer to Box 2 for additional information regarding self-management topics*

for patients, family and caregivers.

- ii. With the patient's consent, family members and caregivers may be invited and encouraged to attend care and therapy sessions with the patient, given the opportunity to learn proper patient care skills, and have their questions addressed [Evidence Level C].
- iii. Patients should be encouraged to participate in rehabilitation related to vocational, leisure, and social reintegration /reengagement needs [Evidence Level C]. *Refer to Section 4 of this module and CSBPR Stroke Rehabilitation module Section 11 for additional information.*

Box 2: Self-Management for Patients, Family and Caregivers

Patient education topics*:

- Exercise
- Symptom management techniques
- Risk factor management (including drug adherence)
- Secondary stroke prevention
- Nutrition
- Fatigue and sleep management
- Medication management
- Coping with physical changes
- Coping with emotions such as fear, anger and depression
- Coping with cognitive and memory changes
- Coping with perceptual deficits
- Training in communication
- Health-related problem-solving and decision making
- Relationships and sexuality
- Community reintegration including leisure and driving

Family and caregiver education topics:

- Training in personal care techniques (e.g., feeding techniques)
- Communication strategies
- Physical handling techniques (e.g., transfers from bed to chair, positioning of a hemiplegic limb)
- Food preparation and modifications for patients with dysphagia
- Education on the self-management model to encourage patient independence when possible
- How to access community services and resources
- Problem-solving techniques
- Respite care options
- Ongoing health system navigation
- End-of-life and palliative care options

* topics may be applicable to families and caregivers as well as patients

Rationale

Education is an ongoing and vital part of the recovery process for stroke for survivors, family members and caregivers. Research demonstrates that patients generally retain less than 25% of information and education provided in hospital. Education about stroke facilitates better understanding and supports coping and self-management, and must be repeated and reinforced with consistency across transitions of care. Skills training for caregivers may increase participation and safety, clarify expectations, improve quality of life, and reduce depression and perceived burden. The information provided at each phase of acute care, rehabilitation, community reintegration, long-term recovery and end-of-life should be relevant to the patient's and the family's changing needs. Simple distribution of pamphlets is not sufficient; the delivery should be interactive and adapted to the cognitive and communication challenges faced by some

stroke survivors, including receptive and expressive language, processing speed, hearing, or visual impairment.

System Implications

Transitions of care support and actions are applicable across the continuum of care, including in primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. Processes and mechanisms should be in place in all these settings to address patient, family and caregiver educational needs, including:

- Coordinated efforts among stakeholders such as the Heart and Stroke Foundation, Canadian Partnership for Stroke Recovery, public health agencies, ministries of health, non-government organizations (NGOs), hospitals and clinics, and individual care providers across the continuum of stroke care to produce patient, family and caregiver education materials with consistent information.
- Community resources, such as stroke recovery support groups, to provide ongoing support and education following hospital discharge.
- Coordinated processes for ensuring access to and awareness of educational materials, programs, activities and other media related to stroke by healthcare professionals, patients and caregivers, including advertising the availability of educational material, effective dissemination mechanisms and follow-up.
- Coordinated processes for ongoing communication between departments/organizations/agencies of learning needs and education that has been provided.
- Access for care providers to training to facilitate communication with stroke survivors with aphasia.
- Access to educational resources that are culturally, ethnically, and linguistically appropriate.
- Access to self-management support services through telemedicine technologies, especially in rural areas and where there are local resource gaps.

Performance Measures

1. Proportion of stroke patients with documentation of education provided to patient, family and/or caregivers at each stage throughout the stroke management and recovery process (core).
2. Total number of encounters focused on education for each patient, and the time spent on patient/family education during a healthcare encounter for stroke.
3. Change in patient and family knowledge of stroke-related content before and after a teaching session.
4. Percentage of patients discharged with a copy of their discharge plan and patient educational materials.
5. Change in self-management behaviour at 6 weeks, 3 months and 6 months following stroke, using validated measurement tools.

Measurement Notes

- Quantity and method of patient education are very important elements of this recommendation. Measurement of patient and family education should be expanded when feasible to capture these aspects, although this is challenging to accomplish.
- For Indicator #3, here possible, standardized mechanisms for testing patient, family and caregiver knowledge pre- and post-education should be included in the education sessions.
- Data sources include all documents, charts, and records related to patient care across the healthcare system (primary care, acute care, follow-up clinics, inpatient and outpatient rehabilitation programs, community programs and services) and may be obtained through primary

chart audit or review, and various logging and audit practices of individual groups.

- Documentation quality (generally weak) by healthcare professionals involved in the patient's care may affect ability to monitor this indicator reliably.

Implementation Resources and Knowledge Transfer Tools

Health Care Provider Information

- Taking Action for Optimal Community and Long-Term Stroke Care: A resource for healthcare providers: available on www.strokebestpractices.ca
- Accreditation Canada Stroke Distinction Program: Stroke Services Client and Family Education: <http://www.strokebestpractices.ca/wp-content/uploads/2013/10/Accreditation-Stroke-Distinction-Client-and-Family-Education-Sep-2010.pdf>
- Timing it Right study (Cameron & Gignac 2008): [\[http://www.ncbi.nlm.nih.gov/pubmed/?term=18155388\]](http://www.ncbi.nlm.nih.gov/pubmed/?term=18155388)
- Aphasia institute: <http://www.aphasia.ca/health-care-professionals/>
- Registered Nurses' Association of Ontario: Self-Management Guidelines: <http://rnao.ca/bpg/guidelines/strategies-support-selfmanagement-chronic-conditions-collaboration-clients>

Patient Information

- Taking Charge of Your Stroke Recovery: A survivor's guide to the Canadian Stroke Best Practice Recommendations: http://www.strokebestpractices.ca/wp-content/uploads/2014/08/HSF_SBP_PatientsGuide_F14_EN_July2014-FINAL.pdf
- Your Stroke Journey: A guide for people living with stroke: http://www.strokebestpractices.ca/wp-content/uploads/2015/03/YOURSTROKEJOURNEY.FINAL_ENGLISH..pdf
- Post-Stroke Checklist: http://www.strokebestpractices.ca/wp-content/uploads/2014/06/HSF%20Post%20Stroke%20Checklist_WEB.pdf
- A Family Guide to Pediatric Stroke: <http://www.strokebestpractices.ca/wp-content/uploads/2011/10/PEDSGuide-EN.pdf>
- HSF Stroke Resources Directory: http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.8598311/k.97BA/Stroke_Resources_Directory/apps/kb/cs/contactsearch.asp
- HSF Health Information: Stroke <http://www.heartandstroke.ca/stroke>; Stroke recovery: www.heartandstroke.ca/strokerecovery
- Living with Stroke™ Program: http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.3936679/k.7231/Stroke_Living_with_StrokeTM_program.htm
- Life After Stroke: <http://www.canadianstroke.ca/en/resources/patients-and-carers/>
- Getting on with the Rest of Your Life after Stroke: http://www.strokebestpractices.ca/wp-content/uploads/2014/01/CSN_GettingOnV2_English_WEB_3.pdf
- Stroke Support Group Toolkit: <http://www.canadianstroke.ca/wp-content/uploads/2013/09/SupportGroupToolkit-EN1.pdf>
- Stroke in Young Adults: http://www.strokebestpractices.ca/wp-content/uploads/2015/01/Stroke_Young_FINAL.pdf

- Stroke Engine: strokenine.ca

Summary of the Evidence

Education across the continuum of care is an important component of support for patients, families and informal caregivers, particularly with regard to secondary stroke prevention and chronic disease self-management. A 2012 Cochrane review (Forster et al. 2012) assessed interventions related to the provision of information, compared with usual care and included the results from 21 RCTs (2289 patients and 1290 carers). In 14 trials, the intervention was focused on either the patient or carer exclusively. In the remaining trials, the intervention was focused on both groups. Patients and caregivers receiving an intervention had improved knowledge of stroke services (SMD=0.29, 95% CI 0.12 to 0.46, $p<0.001$ and SMD=0.74, 95% CI 0.06 to 1.43, $p<0.05$, respectively) and patients expressed greater satisfaction with stroke information (OR=2.07, 95% CI 1.33 to 3.23, $p<0.001$) compared to patients in the control group. Patients receiving an intervention also experienced improvements in depression scores (MD=-0.52, 95% CI -0.93 to -0.10, $P<0.05$) with greater effects associated with interventions that were considered “active”. Interventions were considered active if there was patient or caregiver engagement during the sessions. Engagement could include the opportunity to ask questions, request additional information, be provided with hands-on training, or involve the use of an interactive workbook and/or some means of follow-up reinforcement.

Several randomized trials have evaluated the effects of information and support packages for patients and their caregivers following stroke. Those trials that simply provided participants with written information as the intervention tended to be less effective compared with programs that included additional components. Eames et al. (2013) randomized 138 patients and their carers to receive an individually tailored education and support package with verbal reinforcement for 3 months, or to a usual care group, which received unstructured, informal education. Patients in the intervention group reported significantly greater self-efficacy (access to stroke information domain, $p<0.04$), feeling of being informed ($p<0.01$), and satisfaction with medical ($p<0.001$), practical ($p<0.01$), service/benefit ($p<0.05$), and secondary prevention ($p<0.001$) information received. Lowe et al. (2007) evaluated the use of a “CareFile”, an information package containing relevant support services and secondary prevention resources that was individualized for each patient. One hundred patients participated in the study, 50 randomized to the intervention group and 50 to the control group. At six months, 98% patients in the intervention group reported that the CareFile provided useful information and 53% said that they used it as reference material regarding their stroke. Patients in the intervention group demonstrated greater knowledge of stroke risk factors than patients in the control group at both 3 and 6 months after stroke (Mean difference=0.5, 95% CI 0.0 to 1.1; Mean Difference 0.8, 95% CI 0.3 to 1.4). Hoffman et al. (2007) randomized 138 patients to receive either computer-generated tailored written information or generic written information. At three months, there were no significant differences between groups in mean change scores for stroke knowledge, self-efficacy or depression.

Telephone- based interventions have also been examined as a method of providing support and education; Bakas et al. (2009) randomized 50 caregivers of stroke survivors with ongoing needs to a Telephone Assessment and Skill Building Kit (TASK) group or to a usual care group. Participants in the TASK group received a notebook containing skill building tips, a stress management workbook and a brochure on family caregiving, plus weekly phone calls from a nurse for a period of 8 weeks that involved discussion of patient identified priority areas. Participants in the control group received a brochure on family caregiving, as well as weekly calls from a nurse who did not provide any advice or information. Caregivers in the intervention group were significantly more optimistic at 4, 8 and 12 week follow up, experienced significantly lower levels of task difficulty at 4 weeks and had significantly improved threat appraisal skills at 8 weeks and 12 weeks, although there were no significant changes in depressive symptoms, life changes or general health perception.

Studies assessing the impact of caregiver education and skills training have also reported the benefits of active or “hands-on” interventions. A randomized controlled trial by Kalra et al. (2004) allocated patient/caregiver dyads to receive structured caregiver training (hands-on training in basic nursing techniques that emphasized skills essential for daily management of ADL) or conventional instruction

(information and advice). The length of the intervention was dependent on patient need, consisting of between three to five sessions in the inpatient rehabilitation setting. Patients experienced reductions in anxiety and depression at 12 months ($P<0.001$) and increased quality of life at 3 and 12 months ($P<0.05$). No differences between mortality, institutionalization or functional ability were reported between intervention and control groups. Using a similar intervention, Forster et al. (2013) randomized 928 patients, expected to return home following acute stroke, to participate in the London Stroke Carers Training course (LSCTC) (same protocol as Kalra et al. 2004), or to usual care. At 6 months there was no significant difference in the mean patient Nottingham EADL scores between groups (27.4 vs. 27.6, $p=0.866$) or Caregiver Burden Scores (45.5 vs. 45.0, $p=0.660$). While the intervention did not appear to be effective, the authors speculated that the timing, in the immediate period after stroke, might not be ideal.

The implementation of education and skills training programs ultimately aim to increase the self-efficacy of patients and informal caregivers for their own self-management. Lennon et al. (2013) conducted a systematic review of studies (including randomized and non-randomized controlled trials) that assessed “self-management” interventions for patients recovering from stroke. Interventions included in the review were quite variable, ranging from group programs to one-on-one interventions consisting of workbooks, DVDs or exercise sessions. Several interventions were based on the Stanford Chronic Disease Self-Management program, which consists of workshops, a companion book and a relaxation CD. However, due to the variability in outcomes assessed, pooling of results was not possible. Some of the largest randomized controlled trials included in the review demonstrated improvement in physical domains, quality of life, and dependency. A Cochrane review (Forster et al. 2007) included the results from 18 studies examining self-management programs for participants with multiple chronic conditions (e.g. arthritis, chronic pain, stroke, hypertension, heart failure etc.). There were small but statistically significant improvements in pain, disability, fatigue and depression and anxiety associated with the intervention group. There were also small but statistically significant increases in levels of exercise and in the frequency of practice of cognitive strategies for symptom management associated with the intervention.

The “Moving on After Stroke” (MOST) program is another example of a self-management focused program, consisting of 16 group sessions with an hour of education and an hour of exercise. Education sessions included topics such as secondary prevention, medications, sleep, nutrition, and self-management. Huijbregts et al. (2008) compared this program to the Living with Stroke (LWS) program that offered 6 group education sessions consisting of 90 minutes of education on topics such as the causes of stroke, physical effects, and therapies. There were no statistically significant differences in outcomes between the groups; however, patients in the MOST group had increases in FIM scores ($F=3.97$, $P<0.05$), improvements in the reintegration into normal living index ($F=3.43$, $P<0.05$) and improvements in the activity-specific balance scale ($F=8.94$, $P<0.005$).

[Link to Evidence Table and References for Section 2](#)

3. Interprofessional Care Planning & Communication

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3. Interprofessional Care Planning &
Communication

- 3.1 **Patient Care Plan:** It is recommended that the patient and family have an up-to-date care plan that is patient-centered, culturally appropriate, defines ongoing medical, functional, rehabilitation, cognitive, communication, and psychosocial needs [Evidence Level C]. *Ideally, the care plan should be initiated at the first point of contact with the healthcare system, such as the emergency department, and continue through the continuum of care with the patient.*
- i. The patient and healthcare providers should review the care plan regularly at each transition, when changes/improvements in health status occur, when patient is not progressing in recovery, and update the care plan together to reflect changing needs, evolving goals, and progress. [Evidence Level B].
- 3.2 **Discharge planning** should be initiated as soon as possible after the patient is admitted to each stage and setting of care [Evidence Level B].
- i. Discharge planning discussions, decisions, and activities should be ongoing to reflect the patient's changing needs, evolving goals, and progress through the recovery process [Evidence Level B].
 - ii. The discharge planning process should be a well-organized collaboration between health professionals, patients, families, and caregivers [Evidence Level B].
 - a. Formulate goal oriented discharge plan and discharge date with patient, family, and caregiver [Evidence Level B].
 - b. Identify possible discharge issues and patient needs which could potentially delay discharge and address early in the discharge planning process [Evidence Level B].
 - c. Patients discharged back to the community directly from the emergency department should have their discharge planning needs addressed, and appointments booked prior to leaving the emergency department [Evidence Level C]. *Refer to CSBPR Hyperacute Stroke Care module, Section 3.0 (ii).*
 - iii. Discharge planning activities may include the following, as appropriate to patient needs:
 - a. Home assessment to identify home modifications required for accessibility and safety [Evidence Level B].
 - b. A pre-discharge assessment of patient physical needs caregiver capacity, patient and family/caregiver psychosocial needs, and decision-making needs [Evidence Level C]. *Refer to Sections 1 and 2 for additional information.*
 - c. Caregiver training specific to the current and ongoing needs of the individual patient with stroke [Evidence Level B]; *Refer to Sections 1 and 2 for additional information.*
 - d. Planned, goal oriented day, weekend and overnight visits, to identify potential barriers and assess readiness for discharge, and inform therapy and discharge planning to facilitate the transition home. [Evidence Level B].
 - e. A post-discharge follow-up plan, initiated by a designated team member, such as a case manager or stroke navigator, to ensure continuity of care [Evidence Level B].
 - f. Written discharge instructions as a component of patient care plans which address the following issues as appropriate: functional ability at the time of discharge, risks and safety considerations, action plans for recovery, medications at discharge and instructions for

adjustment, follow-up care, and follow-up care provider contact information [Evidence Level B].

3.3 Health Professional Communication: Processes should be in place to ensure timely and effective transfer of relevant patient-related information at all points of access and transition in the healthcare system, to ensure seamless transitions and continuity of care [Evidence Level B].

- i. All members of the interdisciplinary stroke team should share timely and up-to-date information with healthcare providers at the next stage of care [Evidence Level B].
- ii. The Information transferred should be:
 - a. timely, and ideally occur prior to the time of patient discharge or transfer to next care setting [Evidence Level C].
 - b. comprehensive with all relevant patient information, medications, and progress to date as well as planned appointments, ongoing recovery needs and goals [Evidence Level B].
 - c. a formal, typed, detailed, discharge summary (from the most responsible physician) sent to the primary care physician [Evidence Level B]. *Refer to Box 3 for core content to be considered for inclusion in discharge summaries.*
- iii. A designated member of the care team should facilitate transfer of patient-related information, and patient referrals to appropriate follow-up services [Evidence Level B].

Box 3: Checklist of Core Discharge Summary Information

Discharge Summary Check List

- Stroke diagnosis and date of stroke
- Secondary complications
- Co-morbid illnesses
- Stroke risk factors
- Prevention strategy
- Social and family history
- Past medical history
- Medications on discharge
- Summary of hospital course
- Physical, emotional, and cognitive status at discharge
- Level of independence for mobility, ADLs, decision-making, including any supervision and assistance needs (driving ability if applicable)
- Equipment and resources prescribed, including what has been provided, and what is pending
- Recommended management plan, including therapies, home program, community activities and outstanding medical consultations
- Ongoing and long-term patient goals
- Follow up appointments
- Identification of primary care provider stroke follow-up responsibilities
- Direct communication between most responsible physician and the primary care provider

Rationale

Stroke patient care tends to be complex and require ongoing monitoring and management. Clear communication in a timely manner is essential to ensure continuity of care, patient safety, and to reduce risk of complications and adverse events resulting from the confusion and ambiguity that can arise during

transition points.

Effective discharge planning is essential for smooth transitions through the continuum of stroke care. Delayed or incomplete planning leads to prolonged hospital stays and an increased risk of adverse events following discharge. Patients, family members and healthcare providers involved in each phase of care should all be involved in discharge planning to ensure effective and safe transitions.

System Implications

Transitions of care support and actions are applicable across the continuum of stroke care, including in primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. Processes and mechanisms should be in place in all these settings to address efficient communication between settings and healthcare providers, including:

- Development of processes across healthcare institutions and settings for the coordination of discharge planning and ongoing medical management through to primary care, community services, follow-up, and access to required healthcare services (e.g., ongoing rehabilitation or acute care).
- Processes, protocols, and resources for conducting home assessments by interprofessional team members prior to discharge.
- Access to patient self-management and caregiver training and support services as required ensuring a smooth transition.
- Resource capacity to enable appropriate and timely access to services at the next stage of care with the required specialties, intensity, and frequency.
- Strong relationships and formal agreements among healthcare providers within regions to increase the efficient and timely transition of patients.
- Implementation of standards, processes, and tools to ensure timely discharge summaries sent to primary care and other relevant healthcare professionals and/or agencies to facilitate continuity of care at transition points.
- Adequately resourced community health and support services for stroke patients.
- Providing the right care and services in the right settings at the right times following stroke.
- Capacity for social workers and other case management or healthcare personnel with dedicated responsibilities for discharge planning.
- Staff who are aware of patient/client's right to privacy and who comply with privacy legislation and patient preferences when releasing patient/client information.

Performance Measures

Discharge Planning

1. Proportion of acute stroke patients who have at least one alternate level of care day during their index acute care admission for stroke.
2. Average number of alternate level of care days per stroke patient in acute care settings.
3. Median length of stay of stroke patients in acute inpatient care (core).
4. Percentage of patients who are given a copy of their completed discharge plan at the time of discharge from acute inpatient care or inpatient rehabilitation.
5. Proportion of stroke patients who return to the hospital post-discharge for non-medical reasons (i.e., failure to cope).
6. Readmission rate for stroke patients discharged from hospital for all reasons, within 90 days, 6 months and one year.

Interprofessional Communication

1. Percentage of patients who are given a copy of their completed care plan and discharge summary at the time of discharge from acute inpatient care or inpatient rehabilitation.
2. Percentage of patients for whom a discharge summary is completed prior to or within 48 hours of discharge from one care setting to the next and received by the care provider at the next stage of care.

Measurement Notes

- Length of stay should be calculated as total length of stay, and then also measured against active and alternate level of care components.
- Median values should be reported for length of stay.
- Use Canadian Institute for Health Information standardized definitions and methods to calculate alternate level of care days in hospital.
- Interprofessional communication Performance measure 1: A copy the discharge summary should be included in acute care or inpatient rehabilitation chart, and in the chart of the primary care provider. It can be electronic or hard copy.
- Interprofessional communication Performance measure 2: Applies at all transition points across the continuum.

Implementation Resources and Knowledge Transfer Tools

Health Care Provider Information

- Taking Action for Optimal Community and Long-Term Stroke Care: A resource for healthcare providers: available on www.strokebestpractices.ca
- Registered Nurses' Association of Ontario *Developing and Sustaining Interprofessional Health Care: Optimizing patients/clients, organizational, and system outcomes:* <http://rnao.ca/bpg/guidelines/interprofessional-team-work-healthcare>
- Patient-oriented Discharge Summary: <http://www.torontocentrallhin.on.ca/~media/sites/tc/New%20media%20folder/Resources/PODS%20Report.pdf?la=en>
- Adopting a Common Approach to Transitional Care Planning: <http://www.hqontario.ca/Portals/0/Documents/bp/bp-traditional-care-planning-1404-en.pdf>
- Discharge Summary Outline: <http://mcmasterpa.weebly.com/how-to-discharge-summaries.html>
- Centre for Interprofessional Education (University of Toronto): <http://www.ipe.utoronto.ca>
- Canadian Interprofessional Health Collaborative: <http://www.cihc.ca>
- A National Interprofessional Competency Framework: http://www.cihc.ca/files/CIHC_IPCompetencies_Feb1210.pdf
- Centre for Advancement of Interprofessional Education: <http://www.caipe.org.uk/>
- Stroke Foundation Discharge Planning Tool: My Stroke Care Plan: http://strokefoundation.com.au/site/media/NSF_MyStrokeCarePlan_web2.pdf
- Re-Engineered Discharge (RED) Toolkit: <http://www.ahrq.gov/professionals/systems/hospital/red/toolkit/index.html>
- Handbook of Operating Procedures: Patient Discharge Planning:

<http://www.rncasemanager.com/articles/PatientDischargePlanning.pdf>

- Care and Discharge Planning: A Guide for Service Providers:
<http://www.ncss.gov.sg/documents/careanddischargeguide-jan-final6.pdf>

Patient Information

- HSF Stroke Resources Directory:
http://www.heartandstroke.com/site/c.ikiQLcMWJtE/b.8598311/k.97BA/Stroke_Resources_Directory/apps/kb/cs/contactsearch.asp
- Taking Charge of Your Stroke Recovery: A survivor's guide to the Canadian Stroke Best Practice Recommendations: http://www.strokebestpractices.ca/wp-content/uploads/2014/08/HSF_SBP_PatientsGuide_F14_EN_July2014-FINAL.pdf
- Your Stroke Journey: A guide for people living with stroke: http://www.strokebestpractices.ca/wp-content/uploads/2015/03/YOURSTROKEJOURNEY.FINAL_ENGLISH..pdf
- Post-Stroke Checklist: http://www.strokebestpractices.ca/wp-content/uploads/2014/06/HSF%20Post%20Stroke%20Checklist_WEB.pdf
- Getting on with the Rest of Your Life after Stroke: http://www.strokebestpractices.ca/wp-content/uploads/2014/01/CSN_GettingOnV2_English_WEB_3.pdf
- A Family Guide to Pediatric Stroke: <http://www.strokebestpractices.ca/wp-content/uploads/2011/10/PEDSGuide-EN.pdf>
- Stroke recovery: www.heartandstroke.ca/strokerecovery
- Stroke in Young Adults: http://www.strokebestpractices.ca/wp-content/uploads/2015/01/Stroke_Young_FINAL.pdf
- Talking Care of Myself: A Guide for When I Leave the Hospital: <http://www.ahrq.gov/patients-consumers/diagnosis-treatment/hospitals-clinics/goinghome/goinghomeguide.pdf>
- Stroke Engine: strokengine.ca

Summary of the Evidence

Discharge Planning

In a recent Cochrane review investigating discharge planning for patients discharged from hospital, 24 RCTs, representing 8,039 patients were identified (Shepperd et al. 2013). In most cases, trials evaluated a discharge plan either as a stand-alone intervention, or as a component of a broader intervention vs. usual care in most cases (n=19). In a single trial (Sulch et al. 2000) the sample was restricted to discharge from hospital following a stroke. In all other studies, patients with other medical conditions were included. The use of discharge plans was associated with a significantly reduced LOS (MD -0.91; 95% CI -1.55 to -0.27) and a significant reduction in readmissions at 3 months (RR= 0.82; 95% CI 0.73 to 0.92). No significant between group differences were reported in terms of discharge destination (RR 1.03, 95% CI 0.93 to 1.14) and mortality (RR 0.99, 95% CI 0.78 to 1.25).

Within 48 hours of admission to acute care, Shyu et al. (2008) randomized 208 patient/caregiver dyads to one of 4 wards where they received a caregiver-oriented discharge planning program or routine discharge planning. The discharge planning program was conducted by trained research nurses who evaluated caregiver needs during hospitalization and used results to guide individualized interventions, which included both health education and referral services. Once discharged, carers were contacted within one week by telephone and two home visits were made (one week, one month) to advise and support caregivers in the home environment. Caregivers in the intervention group demonstrated significantly

greater caregiver preparedness on both nursing and self-reported evaluations at discharge. At the one-month follow-up, those in the intervention group demonstrated significantly greater satisfaction with discharge needs than those in the control group. In a follow-up study (Shyu et al. 2010), the overall quality of care was reported to be significantly superior in the intervention group over the 1-year follow-up period. No significant group differences were reported with respect to self-care ability or hospital readmissions. However, patients in the intervention group were significantly less likely to be institutionalized between 6 and 12 months post-discharge, compared to those in the control group ($p < 0.05$).

In the only RCT identified that specifically recruited stroke patients, Sulch et al. (2000) randomized 152 patients within two-weeks of stroke onset to receive discharge planning according to an integrated care pathway or care as usual. No significant between group differences were reported with respect to six-month mortality (13% vs. 8%), institutionalization (13% vs. 21%), or length of stay (50 ± 19 vs. 45 ± 23 days).

Interprofessional Communication

Transitions between and within health care settings pose a safety and quality of care concern for patients recovering from stroke. A consensus policy statement by the American College of Physicians in 2009 highlighted concerns of patient safety at transition points, particularly between inpatient and outpatient care (Snow et al. 2009). A stroke survivor is vulnerable to many of these transition points as they progress through the acute, sub-acute and chronic stages of recovery, interacting with a range of physicians in several different health-care settings. Communication between these physicians and care settings is critical for ensuring patient safety and quality of care. In a controlled study of 3,248 hospitals, Mitchell (2015) explored the association between physician/nurse communication with the patient regarding discharge instructions and readmission. An average of 84% of patients reported receiving discharge instructions. Hospitals that had smaller bed numbers were non-profit and located in non-urban areas were more likely to provide discharge instructions. Patients reported that, on average, nurses and doctors communicated well with them 78% and 82% of the time. Controlling for other factors, increasing frequency of communication surrounding discharge instructions was associated with significantly lower number of 30-day hospital re-admissions.

Areas of communication deficits were reported in a systematic review by Kripalani et al. (2007), which included the results of 73 studies examining communication deficits between hospitals and primary care providers, and interventions to improve communication during this transition. While a median of 53% of discharge letters had arrived at the physician's office within one week of discharge, only 14.5% of discharge summaries were received the same timeframe. However, 11% of discharge letters and 25% of discharge summaries never reached the primary care physician. Discharge letters were missing a main diagnosis in 7%-48% of cases, hospital treatment details in 22%-45% of cases, medications at discharge for 7%-48% of cases, plans for follow-up in 23%-48% of cases, and notes on patient or family counselling in 92%-97% of cases. In terms of effectiveness of interventions, a significantly higher percentage of discharge summaries that were hand delivered (compared with mailing) were received by week 4 following discharge (80% vs. 57%, $p < 0.001$). The overall quality of the summaries was perceived to be higher and the summaries were longer when computer generated, using a standard template, and were received by the primary care physician sooner.

Halasyamani et al. (2006) described the development of a discharge checklist, based on a literature review, expert committee and peer review, designed to identify the critical components in the process when discharging elderly patients from hospital. The final checklist includes 3 types of discharge documents: the discharge summary, patient instruction and communication on the day of discharge to the receiving care provider. Data elements included on the final checklist were: problem that precipitated hospitalization, key findings and test results, final primary and secondary diagnoses, condition at discharge (functional and cognitive), discharge destination, discharge medications, follow-up appointments, list of pending lab results and person to whom results will be sent, recommendations of sub-specialty consultants, documentation of patient education and understanding, identification of atypical problems and suggested interventions, 24/7 call-back number, identification of referring and receiving

providers, resuscitation status

[Link to Evidence Table and References for Section 3](#)

4. Community Reintegration Following Stroke

Managing Stroke Transitions of Care

4. Community Reintegration Following Stroke

Update 2015

4.0 Patients and families should be provided with information, support and access to services throughout transitions to the community following a stroke to optimize the return to life roles and activities [Evidence Level B].

4.1 Physical and Psychological Health Management Following Stroke:

- i. People with stroke living in the community should have access to regular and ongoing medical follow-up after stroke appropriate to their individual needs, which may address: progress of recovery, preventing deterioration, maximizing functional and psychosocial outcomes, preventing stroke recurrence, and improving quality of life [Evidence Level B].
 - a. Initial review with primary care provider ought to occur within first two to four weeks following hospital discharge, and address the following: screening patients for ongoing physical issues including dysphagia, nutrition, hydration, continence, and pain, medication review, stroke prevention management, and ongoing follow-up as required [Evidence Level C]. *Refer to CSBPR Secondary Prevention of Stroke module for additional information.*
 - b. Primary care providers should screen patients for new or ongoing cognitive concerns, mental health issues (i.e., depression), and psychosocial issues, and manage issues that arise appropriately [Evidence Level B]. *Refer to CSBPR Mood, Cognition & Fatigue module for additional information.*
- ii. Secondary prevention of stroke should be aggressively managed and risk factor reduction strategies optimized in all settings including long term care [Evidence Level A].
- iii. Referrals to stroke prevention clinics and services should be initiated where appropriate and available at hospital discharge and once back in the community, at the discretion of the primary care provider [Evidence Level C]. *Refer to CSBPR Secondary Prevention of Stroke recommendations for additional information.*
- iv. It is recommended that infants and children who have experienced a stroke have ongoing surveillance throughout their development, especially if new motor, language, behavioral or cognitive deficits emerge [Evidence Level B].
 - a. Developmental screening and assessments may include cognitive, motor, social, behavioral, emotional and physical aspects, as the full extent of stroke-related deficits may not become apparent until different ages and stages of development [Evidence Level C]. *Refer to CSBPR Stroke Rehabilitation module Section 12 for additional information.*

4.2 Functional Health Management:

- i. Post stroke patients living in the community who experience a decline in functional status should receive targeted interventions, as appropriate [Evidence Level B], even if the decline occurs many months/years post-stroke.
 - a. It is recommended that processes be in place for stroke survivors to re-access rehabilitation services, if indicated/appropriate, during longer-term recovery [Evidence Level B]. This may include psychiatry, physical therapy, occupational therapy, speech therapy, recreation therapy and other services as required to address individual patient needs. *Refer to CSBPR Stroke Rehabilitation module for additional information.*

- ii. It is recommended that stroke survivors be monitored for communication capacity and be referred to speech and language services as required to address continuing communication impairments [Evidence Level C]. *Refer to CSBPR Stroke Rehabilitation module recommendation 10 for additional information.*

4.3 Reintegration to Social and Life Roles Following Stroke

A. Vocations

- i. It is recommended that patients be asked about vocational interests (i.e., work, school, volunteering) and be assessed for their potential to return to their vocations [Evidence Level C]. *Refer to CSBPR Stroke Rehabilitation module Section 11 for additional information.*
 - a. A detailed cognitive assessment including a neuropsychological evaluation or occupational therapy evaluation, where appropriate and available, is recommended to assist in determining the patient's ability to meet the needs of their current or potential employment requirements, and contribute to vocational planning [Evidence Level C].
 - b. A designated member of the care team should provide counseling and information to patients on employment benefits and legal rights. Referral should be initiated as appropriate (such as to a vocational therapist) to assist patients and families in re-engaging in vocational activities as part of transitions to the community [Evidence Level C].
- ii. Resumption of vocational interests should be encouraged as tolerated [Evidence Level C].
- iii. With consent from the patient and where possible, the healthcare team should work with employers/educators to devise an appropriate return to work/school plan at the request of an employer and/or person with stroke [Evidence Level C].
- iv. Review of benefit options related to ongoing financial concerns should be initiated by the healthcare team (e.g. social worker) in hospital and during follow-up for all stroke patients. [Evidence Level C].
- v. It is recommended that school age stroke survivors in the community have ongoing assessments of educational and vocational needs [Evidence Level C].

B. Leisure Activities

- i. Patients should be asked about pre-stroke leisure pursuits and be assessed for rehabilitative needs to resume these activities. Participation in leisure activities should be encouraged where possible [Evidence Level B]. *Refer to CSBPR Stroke Rehabilitation module Section 11 for additional information.*
- ii. It is recommended that patients who experience difficulty engaging in leisure activities receive targeted therapeutic interventions and individualized plans for participation in leisure activities based on collaborative goal-setting with their healthcare team [Evidence Level: Adult-Level A; Pediatric-Level C].
- iii. It is recommended that patients, with their families and caregivers, be encouraged to engage in leisure activities, and prior to discharge be provided with a list of and/or referral to community-based resources for engaging in ongoing physical, social, emotional, intellectual and spiritual activities in the community [Evidence Level C]. *Refer to Section 2 of this module for additional information.*
- iv. After one month, patients interested in returning to driving should be screened, ideally by an occupational therapist, using valid and reliable methods for any residual sensory, motor, or cognitive deficits [Evidence Level B]. *Refer to CSBPR Stroke Rehabilitation Module, Section 11*

for additional information.

- v. It is recommended that children affected by stroke be offered advice and treatment aimed at achieving play and leisure related skills that are developmentally relevant and appropriate in their home, community, and school environments [Evidence Level C].

C. Sexuality

- i. Patients should be given the opportunity to discuss sexuality and sexual functioning with their healthcare provider. Discussion should occur during acute care, rehabilitation and as the patient transitions back into the community. Verbal and written information should be provided and adapted to patients who have communication limitations such as aphasia [Evidence Level C].
- ii. Education sessions for patients and/or partners may be considered that address expected changes in sexuality, strategies to minimize sexual dysfunction, and frequently asked questions regarding relationships following a stroke [Evidence Level C].

D. Disability Supports in the Community

- i. It is recommended that community based healthcare professionals across disciplines provide patients, families and caregivers with information and linkages regarding access to disability support services within their region [Evidence Level C].
 - a. Healthcare providers should work with patients, families, and caregivers to develop accessibility plan prior to transition to a home or community-based living setting [Evidence Level C]. This plan would incorporate the patient's functional, communicative, emotional and/or cognitive deficits following stroke.
 - b. It is recommended that disability legislation and guidelines be explained to patients, families and caregivers in preparation for transitions; appropriate documentation and applications should be completed by healthcare professionals as required in a timely manner in collaboration with patients and families to minimize delays in access to eligible services [Evidence level C].
 - c. Designated members of the healthcare team should collaborate with persons with stroke, families and caregivers to ensure appropriate services and equipment are accessed in a timely manner [Evidence Level C].

4.4 Reassessment of Advance Care Plans

- i. The stroke healthcare team is responsible to ensure the patient's goals of care and advance care planning decisions are reviewed periodically with the patient, family and caregivers, and updated if needed, such as when there is a change in the patient's health status [Evidence Level B]. *Refer to CSBPR Acute Inpatient Stroke Care module Section 3 for additional information.*
 - a. Advance care planning may include a substitute decision-maker (proxy or agent), and should reflect provincial legislation [Evidence Level C].
 - b. Advance care planning discussions should be documented in the patient's chart and on the discharge summary [Evidence Level C].

4.5 Community-Based Palliative Care

- i. Referral and liaison with community care and hospice services may be coordinated as appropriate based on the patient's goals of care and condition [Evidence Level C]. *Refer to*

CSBPR Acute Inpatient Stroke Care Module Section 4 for additional information.

4.6 Family and Caregiver Support and Well-being

- i. It is recommended that patients and families be provided with information regarding peer support groups in their community, and initial connection with these groups should be encouraged where available [Evidence Level C]. *Refer to Sections 1 and 2 of this module for additional information.*

Rationale

The post-discharge period is consistently reported by stroke survivors and their families to be a stressful and challenging time as they adjust to new roles and potentially altered functional and cognitive abilities of the stroke survivor. Patients and their families often lose the social, emotional, and practical support offered by an inpatient stroke service. Evidence shows that when there is coordination of care beyond the inpatient setting and community support services are provided, patient outcomes and patient and caregiver satisfaction improves.

In children, regular follow-up is necessary to screen for other neurologic sequelae, as 30 percent of pediatric stroke survivors develop concurrent neurologic complications, including seizures, migraine, headaches, and movement disorders that may not manifest in the acute phase of stroke.

The addition of recommendations for long term care are a response to data showing that stroke patients are among the largest patient population receiving long-term care, and their number is steadily increasing worldwide. Stroke patients who transition to long-term care should continue to have rehabilitation and recovery goals and plans that focus on restorative care, maintenance of function, and support for health declines, and be cared for by staff knowledgeable in stroke to maximize outcome goals.

System Implications

Successful reintegration into the community for stroke survivors requires:

- Education and training in shared decision making skills and strategies for all healthcare professionals, patients, families, and caregivers.
- Adequate and timely follow-up stroke care in all provinces and territories to support community reintegration of stroke survivors.
- Assistance for patients, families, and caregivers with an evolving care plan and regular follow-up assessments.
- Coordination between primary care provider and community agencies for referral to appropriate programs and services for assessment of ability to resume driving.
- Access to appropriate (public) transportation that supports people with disabilities.
- Programs that support timely and affordable access to mobility and other assistive devices for patients with stroke.
- Healthcare professionals and caregivers in the community and long-term care settings with stroke care expertise and access to ongoing education.
- Ongoing support in the form of community programs, respite care, and educational opportunities available to support caregivers who are balancing personal needs with caregiving responsibilities.
- Strategies to assist stroke survivors to maintain, enhance, and develop appropriate social support, and to re-engage in desired vocational, social, and recreational activities.
- Information regarding community resources and processes to access these resources provided to all patients and families.

Performance Measures

1. Proportion of stroke patients who are discharged from acute care who receive a referral for home

care or community supportive services.

2. Proportion of readmissions to acute care for stroke-related causes following discharge to the community, stratified by type of stroke.
3. Proportion of stroke patients who return to the emergency department or hospital setting for non-physical issues following stroke (e.g., failure to cope).
4. Number of stroke patients with documentation that information was given to patient or family on formal and informal educational programs, care after stroke, available services, process to access available services, and services covered by health insurance.
5. Documentation of shared and collaborative decision-making between healthcare professionals and patients regarding individualized transition plans.
6. Number of patients referred to a secondary prevention team by the rehabilitation team.
7. Number of visits to primary care within specified time frames for stroke-related issues.
8. Number of visits to an emergency department within specified time frames.
9. Percentage of patients who return home following stroke rehabilitation who require community health services (e.g., home care or respite care).
10. Length of time from hospital discharge (whether from acute care or inpatient rehabilitation) to initiation of community health services.
11. Frequency and duration of community health services, stratified by the type of service provided.
12. Number of readmissions from stroke rehabilitation to acute care for stroke-related causes.
13. Percentage of patients who return to the community from acute hospital stay or following an inpatient rehabilitation stay who require admission to long-term care or a nursing home within six months or one year.
14. Median wait time from referral to admission to nursing home, complex continuing care or long-term care facility.
15. Documentation to indicate that assessment of fitness to drive and related patient counseling was performed.
16. Number of patients referred for driving assessment by occupational therapist in the community.
17. Measure of burden of care for family and caregivers of stroke survivors living in the community.

Measurement Notes

- Performance measure 1: data may be obtained from inpatient chart documentation or community support services documentation. Informal education or education received by primary care providers may be difficult to track unless specific audit tools are developed and implemented in local areas. Also refer to some of the performance measures listed in recommendation 2.1.
- Emergency department visits can be tracked through the Canadian Institute for Health Information database for participating institutions or hospital records if the patient returns to the emergency department of the hospital where inpatient stay occurred.
- The Canadian Institute for Health Information holds an administrative data set for complex continuing care and long term care, which uses a minimal data set that is mandated in several regions across Canada. This data set uses the Resident Assessment Instrument tool for assessing functional status. At this time there are no validated comparison models between the Functional Impact Measure and the Resident Assessment Instrument.
- Hospital readmissions from inpatient rehabilitation to acute care can be obtained from hospital administrative data nationally and provincially.

- Visits to primary care and indicators related to information and education are difficult to measure. They could be obtained through surveys and standardized audit tools at the local or regional level.

Implementation Resources and Knowledge Transfer Tools

Health Care Provider Information

- Table 1: Tools to Assess Participation and Health-Related Quality of Life
- Taking Action for Optimal Community and Long-Term Stroke Care: A resource for healthcare providers: available on www.strokebestpractices.ca
- The Functional Independence Measure (FIM®):
http://www.udsmr.org/WebModules/FIM/Fim_About.aspx
- The Chedoke-McMaster Stroke Assessment:
<http://www.rehabmeasures.org/PDF%20Library/CMSA%20Manual%20and%20Score%20Form.pdf>
- The Craig Handicap Assessment and Reporting Technique (CHART):
<https://craighospital.org/programs/research/research-instruments>
- The Community Integration Measure:
<http://www.disabilitypolicyalliance.ca/?s=community+integratoin+measure>

Patient Information

- Taking Charge of Your Stroke Recovery: A survivor's guide to the Canadian Stroke Best Practice Recommendations: http://www.strokebestpractices.ca/wp-content/uploads/2014/08/HSF_SBP_PatientsGuide_F14_EN_July2014-FINAL.pdf
- Your Stroke Journey: A guide for people living with stroke: http://www.strokebestpractices.ca/wp-content/uploads/2015/03/YOURSTROKEJOURNEY.FINAL_ENGLISH..pdf
- Post-Stroke Checklist: http://www.strokebestpractices.ca/wp-content/uploads/2014/06/HSF%20Post%20Stroke%20Checklist_WEB.pdf
- HSF Stroke Resources Directory:
http://www.heartandstroke.com/site/c.ikiQLcMWJtE/b.8598311/k.97BA/Stroke_Resources_Directory/apps/kb/cs/contactsearch.asp
- Living with Stroke™ program:
http://www.heartandstroke.com/site/c.ikiQLcMWJtE/b.3936679/k.7231/Stroke_Living_with_StrokeTM_program.htm
- A Family Guide to Pediatric Stroke: <http://www.strokebestpractices.ca/wp-content/uploads/2011/10/PEDSGuide-EN.pdf>
- Life After Stroke: <http://www.canadianstroke.ca/en/resources/patients-and-carers/>
- Stroke Support Group Toolkit <http://www.canadianstroke.ca/wp-content/uploads/2013/09/SupportGroupToolkit-EN1.pdf>
- My Stroke Passport: <http://www.strokebestpractices.ca/wp-content/uploads/2013/10/My-Stroke-Passport.pdf>
- Stroke Engine: strokengine.ca

Summary of the Evidence

The post-discharge period is consistently reported by stroke survivors and their families to be a difficult time of adjustment. Reintegration to former vocational and social life roles is an important goal for the stroke survivor. Using the results from 42 studies published from 1974-2011 Wang et al. (2014) reported positive and negative predictive factors of return to work (RTW) following stroke. Factors that were positively associated with RTW included higher ADL function, a good match between current capabilities and job tasks, strong family support, stroke survivors with realistic goals, availability of vocational services, a flexible work environment, white collar work and disability benefits. Depression and increasing stroke severity were negative factors. The rates of RTW vary widely. In a study including 441 patients, recruited from 20 hospitals, aged 18-64 years, 202 (75%) persons previously employed at the time of stroke had returned to work at one year. Hannerz et al. (2011) reported that of 19,985 persons included in the Danish Occupational Hospitalization Register who were 20-57 years and had sustained a stroke, 62.1% were employed 2 years post stroke. At 4 years following stroke, Trygged et al. (2011) reported that 4,867 (69%) of 7,081 patients, aged 40-59 years had successfully returned to work. Interventions to help improve the odds of successful RTW have not been well studied. Baldwin & Brusco (2011) included the results from 6 studies, which examined rehabilitation programs that included vocational training post stroke. Vocational rehabilitation program were defined as those that included medical, psychological, social, physical and/or occupational rehabilitation activities with the purpose to return to work. Following completion of the programs, the RTW rates varied among the studies from 12% to 49%. The pre-stroke vocation status was reported in 3 studies and ranged from 48% to 100%.

The resumption of pre-stroke social and leisure pursuits is an additional component of reintegration back into pre-stroke life. Interventions to help improve participation following stroke have been examined in several trials. Desrosiers et al. (2007) randomized 62 participants residing in the community who'd had a stroke within the past 5 years and were experiencing some limitations in leisure participation or satisfaction to an intervention or control group. The intervention involved 8-12, 60 minute, weekly education sessions, while participants in the control groups received home visits from a recreational therapist following the same schedule as the intervention group. At the completion of the study, participants in the intervention group reported significantly more time spent in active leisure activities (MD=14.0 minutes, 95% CI 3.2-24.9, p=0.01) and involvement in a greater number of different activities (MD= 2.9, 95% CI 1.1-4.8, p=0.002). Participants in the intervention group had gained significantly more points on the Leisure Satisfaction Scale (MD= 11.9, 95% CI 4.2-19.5, p=0.003) and in the satisfaction of leisure needs and expectations (MD=6.9, 95% CI 1.3-12.6, p=0.02) but not on the satisfaction with use of spare time section (p=0.22). In the Trial of Occupational Therapy & Leisure (TOTAL), Parker et al. (2001) included 465 patients, recruited from 5 hospitals that attended an outpatient clinic within 6 months of stroke onset and were living in the community. Participants were randomized to a leisure therapy group, an ADL group or a control group. The two treatment groups received home-based occupational therapy (OT) for up to 6 months with a minimum of 10, ≥30 minute sessions. At 6 and 12 months there were no significant differences among groups in any of the primary outcomes assessed (General Health Questionnaire, Nottingham Extended ADL, and Nottingham Leisure Questionnaire).

Reports of sexual dysfunction following stroke are common. Among several surveys including small samples, declines in sexual activity have been reported. Stein et al. (2013) surveyed 35 patients who agreed to participate, out of 268 who were included in a stroke rehabilitation research registry. Of those, 100% of men and 58% of women met the criteria for sexual dysfunction, 42% indicated their sexual functioning was worse following stroke, 94% reported that physical limitations impacted their sexual activity and 58.8% reported feeling less sexually desirable following stroke. Buzzelli et al. (2007) also reported that among 60 patients (83.3%) reported a decline in sexual activity during the first year following stroke. Variables associated with disruption of sexual activity were: fear of relapse, belief that one must be healthy to have a sex life and partner who is "turned off" at the prospect of sexual activity with a "sick person". When compared with age-matched norms, Carlsson et al. (2007), reported that life satisfaction, assessed at 1 week and one year following stroke by both patients and spouses using the LiSat-9, was significantly worse. A greater percentage of patients indicated they were not satisfied with: life as a whole (39% vs. 77%, p<0.05), ability in self-care (71% vs. 93%, p<0.05), sex life (34% vs. 58%, p<0.05), leisure time (38% vs. 71%, p<0.05), and vocation (45% vs. 67%, p<0.05). Compared with the

norm group, a greater percentage of spouses indicated they were not satisfied with life as a whole (64% vs. 77%, $p<0.05$), closeness with partner (67% vs. 86%, $p<0.05$), sex life (41% vs. 58%, $p<0.05$) and leisure time (52% vs. 71%, $p<0.05$).

Return to driving is also an important component of community reintegration, given that cognitive impairment and visual field deficits will restrict a patients' ability to drive safely following stroke. Performance of cognitive measures such as the Trail Making Test and the Snellgrove Maze Test have been used to predict fitness to drive (Barco et al. 2014, Devos et al. 2011). Interventions to help stroke survivors improve driving skills have not been well studied. A Cochrane review (George et al. 2014) included the results from 4 RCTs. The interventions examined included driving simulators ($n=2$) and skills development using the Dynavision device ($n=1$) and Useful Field of View training ($n=1$). No pooled analyses of the primary outcome, performance (pass/fail) during on-road assessment, were possible due to heterogeneity. Based on the results from a single trial, there was no significant difference in the mean on-road scores between groups at 6 months (MD=15.0, 95% CI -4.6 34.6, $p=0.13$), although participants in the intervention group had significantly higher scores on road sign recognition test (MD=1.69, 95% CI 0.51-2.87, $p=0.0051$).

Navigating through the post-stroke continuum has been highlighted as a frequent source of dissatisfaction, for patients and informal caregivers, particularly during the transition from hospital to community. Several studies have been conducted to evaluate the benefit of individuals who coordinate access to appropriate services for patients recovering from stroke, who go by many names including stroke navigator, case manager, care coordinator, or system navigator). Manderson et al. (2011) conducted a systematic review including 15 publications, representing 9 RCTs examining system navigation models for older adults living with multiple chronic diseases making transitions across healthcare settings. The services provided included care planning, coordination of care, phone support, home visits, liaison with medical and community services, and patient and caregiver education. In most of the studies, economic, psychosocial and functional benefits were associated with system navigation. While the services of a registered occupational therapist, who functioned as a community stroke navigator, resulted in significant improvements in the mean daily functioning subscale of the Reintegration to Normal Living Index RNLI among 51 patients at the end of four months, (54.1 to 59.3, $p=0.02$), there were no significant improvements in other outcomes (2-minute walk test, depression outcomes), or any caregiver outcomes (Egan et al. 2010).

[Link to Evidence Table and References for Section 4](#)

5. Transition of Patients to Long-Term Care Following a Stroke

Managing Stroke Transitions of Care

5. Transition of Patients to Long-Term

Update 2015

Care Following a Stroke

Note: These recommendations apply specifically to persons with stroke living in long-term care settings. These recommendations are intended to be implemented in addition to standard care (e.g. physical, functional, emotional, cognitive and social needs) provided in long-term care. Recommendations included in other sections of this module, such as Patient, Family and Caregiver Support (Section 1) and Patient, Family and Caregiver Education (Section 2) also apply to this setting.

5.1 Patient Assessment and Care Planning

- i. All patients who transition to a long-term care setting following a stroke should have an initial assessment, conducted by medical, nursing and rehabilitation professionals, as soon as possible after admission [Evidence Level A].
 - a. A discharge summary along with the care plan should accompany the individual to long-term care [Evidence Level B]. *Refer to Box 3 regarding information to include in the discharge summary.*
 - b. It is recommended that the initial assessment of functional status, physical status, and cognitive status be aligned with existing assessment processes (such as the Minimum Data Set-Resident Assessment Inventory (RAI-MDS 2.0); or Multi-clientele Autonomy Assessment) where possible [Evidence Level C].
 - c. Assessment results can be used to modify individualized care plans to optimize quality of life and meet physical, functional, emotional, cognitive and social needs and goals of people who are admitted to long-term care following a stroke [Evidence Level C].
 - d. When areas of decline are identified in reassessments, individualized care plans should be updated to incorporate changes in care requirements, address issues of safety, and the potential need for referrals to appropriate healthcare professionals for further consultation [Evidence Level C].
- ii. It is recommended that long-term care staff members be educated and knowledgeable in stroke care, maintenance and recovery goals and therapies, and stroke best practice recommendations [Evidence Level C]. *Refer to HSF's Taking Action for Optimal Community and Long Term Stroke Care resource for training content.*

5.2 Rehabilitation and Restorative Care

- i. Stroke survivors with ongoing rehabilitation goals should continue to have access to specialized stroke services (such as physiotherapy and occupational therapy) following admission to a community living setting [Evidence Level A], including within a long-term care setting. *Refer to Recommendation 5.4 for additional information.*
- ii. At any point in their recovery, stroke survivors living in long-term care who have experienced a change/improvement in functional status and who would benefit from new or additional rehabilitation services should be offered a trial of active inpatient or outpatient rehabilitation [Evidence Level B].
- iii. Residents in long-term care should have access to recreation therapy, leisure opportunities, and exercise [Evidence Level C].

5.3 Patient and Family Support and Education

- i. Provide patients, families and caregivers with training on how to advocate for active participation in care planning and shared decision-making [Evidence Level C].
- ii. Provide patients living in long-term care and their families with information and counseling on appointing an Alternate Decision Maker, developing advance directives for care, and palliative care options as appropriate [Evidence Level C]. *Inpatient Stroke Care module sections 3 and 4 for additional information.*

Rationale

Health care surveillance data indicates that stroke patients are among the largest patient population receiving long-term care, and their number is steadily increasing worldwide. This transition often involves emotional concerns for patients, families and caregivers that are not necessarily experienced with other transitions. Stroke patients who transition to long-term care should be cared for in an environment that is supportive, with staff knowledgeable and competent in meeting the specific needs of stroke patients and their families within this setting. This will enable the stroke survivor to maintain quality of life and dignity, and have rehabilitation and recovery goals and plans that focus on restorative care, maintenance of function, support for health declines, and sensitivity to family needs. The post-discharge period is consistently reported by stroke survivors and their families to be a stressful and challenging time as they adjust to new roles, altered functional and cognitive abilities, and changes in living setting for patients admitted to long-term care following an acute stroke.

System Implications

Successful transition to long-term care for patients, families, and caregivers requires:

- Processes to support timely and efficient transfer from acute care to long term care, avoiding multiple transfers before reaching planned destination.
- Adequate follow-up by care providers in all provinces and territories to support ongoing access to rehabilitation services for stroke survivors allowing transition to long-term care settings.
- Assistance for patients, families, and caregivers with an evolving care plan and regular follow-up assessments.
- Communication strategies and processes to ensure timely sharing of information across all healthcare providers, including between long-term care team and community/hospital healthcare teams.
- Programs that support timely and affordable access to mobility and other assistive devices for patients with stroke in long-term care.
- Ongoing stroke specific education and training for healthcare professionals and caregivers in the community and long-term care settings to increase stroke care expertise. Training to be provided by a range of healthcare disciplines, such as physiotherapy, occupational therapy, speech language pathology, and dietitians.
- Strategies and services to assist stroke survivors to maintain, enhance, and develop appropriate social support, and to re-engage in desired social, and recreational activities.

Performance Measures

1. Proportion of patients who are discharged from acute care directly to a long-term care setting following an acute stroke.
2. Proportion of stroke patients who were living independently (e.g., at home) prior to stroke who are admitted to long-term care following stroke.
3. Proportion of readmissions to acute care for stroke-related causes following discharge to long-term care, stratified by type of stroke.

4. Changes in functional status from time of admission compared at 3 months, 6 months and one year following admission to long-term care.
5. Number of visits to an emergency department within 3 months, 6 months and one year following admission to long-term care, stratified by reason for visit or hospital admission.
6. Measure of burden of care for family and caregivers of stroke survivors living in the community, and change in burden scores from before long-term care admission, and at 3 months, 6 months and one year following admission to long-term care..

Measurement Notes

- The Canadian Institute for Health Information holds an administrative data set for complex continuing care and long term care, which uses a minimal data set that is mandated in several regions across Canada. This data set uses the Resident Assessment Instrument tool for assessing functional status. At this time there are no validated comparison models between the Functional Impact Measure and the Resident Assessment Instrument.
- Hospital readmissions from inpatient rehabilitation to acute care can be obtained from hospital administrative data nationally and provincially.

Implementation Resources and Knowledge Transfer Tools

Health Care Provider Information

- Table 1: Tools to Assess Participation and Health-Related Quality of Life
- Registered Nurses' Association of Ontario: Long-Term Care Best Practices Initiative: <http://rnao.ca/bpg/initiatives/longterm-care-best-practices-initiative>
- Registered Nurses' Association of Ontario: Positioning Techniques in Long-Term Care http://rnao.ca/sites/rnao-ca/files/Positioning_Techniques_in_Long-Term_Care_-_Self-directed_learning_package_for_health_care_providers.pdf
- The Functional Independence Measure (FIM®): http://www.udsmr.org/WebModules/FIM/Fim_About.aspx
- The Functional Autonomy Measurement System (SMAF): <http://www.expertise-sante.com/nous-joindre.htm>
- The Chedoke-McMaster Stroke Assessment: <http://www.rehabmeasures.org/PDF%20Library/CMSA%20Manual%20and%20Score%20Form.pdf>

Patient Information

- Taking Charge of Your Stroke Recovery: A survivor's guide to the Canadian Stroke Best Practice Recommendations: http://www.strokebestpractices.ca/wp-content/uploads/2014/08/HSF_SBP_PatientsGuide_F14_EN_July2014-FINAL.pdf
- Your Stroke Journey: A guide for people living with stroke: http://www.strokebestpractices.ca/wp-content/uploads/2015/03/YOURSTROKEJOURNEY.FINAL_ENGLISH..pdf
- Post-Stroke Checklist: http://www.strokebestpractices.ca/wp-content/uploads/2014/06/HSF%20Post%20Stroke%20Checklist_WEB.pdf
- HSF Stroke Resources Directory: http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.8598311/k.97BA/Stroke_Resources_Directory/apps/kb/cs/contactsearch.asp
- Life After Stroke: <http://www.canadianstroke.ca/en/resources/patients-and-carers/>
- Getting on with the Rest of Your Life after Stroke: <http://www.strokebestpractices.ca/wp->

content/uploads/2014/01/CSN_GettingOnV2_English_WEB_3.pdf

- Deciding on Long-Term Care: <http://www.strokecenter.org/patients/caregiver-and-patient-resources/caregiving-guide-for-african-americans/deciding-on-long-term-care/>
- Preparing For the Move Into Long-Term Care; “A Checklist”:
http://www.southeasthealthline.ca/healthlibrary_docs/LTC%20-%20Preparing%20for%20the%20Move.pdf

Summary of the Evidence

Following a stroke event, high levels of disability may warrant admission to a long term care institution. Independent predictors of discharge to a nursing home have been identified and include increasing age, increasing dependency for ADLs and absence of availability of a caregiver (Pereira et al. 2014, Brodaty et al. 2010, Portelli et al. 2005). The numbers of patients admitted to a long-term care facility, both immediately upon discharge from hospitals, and up to 10 years post stroke have been examined. At one month following discharge from hospital, Chuang et al. (2005) reported that of 714 patients admitted to hospital following stroke, 1 month after discharge 4.5% of patients had died and 10.4% had been admitted to a LTC facility. Brodaty et al. (2010) followed 202 participants, mean age of 72 years, without dementia who had suffered an ischemic stroke. Among those who survived, nursing home admission rates were 24% at 5 years and 32% at 10 years. Walsh et al. (2008) reported that among a group of 136 patients admitted to a stroke unit of a single hospital (median age was 77 years), 40.3% of patients were institutionalized at 4 years.

Patients discharged to long term care require discharge planning much like individuals returning to their own homes. Several studies have examined factors for effective discharge communication between inpatient hospital care and institutional care facilities. Clear communication between facilities regarding nutritional needs, functional status, communication abilities, risk assessment, and medical management is necessary for an optimal transition. (Sackley & Pound 2002; Sackley & Pound 2002).

Individuals residing in skilled nursing facilities with staff trained in stroke management, and who have access to post stroke therapy resources, may experience better quality of life. In a study (Brajkovic 2009) examining individuals living in a nursing home who received 24 hour care including access to psychiatric care, physician visits, daily physiotherapy, and weekly massage services, nursing home residents experienced greater quality of physical, psychological, social, and environmental quality of life scores compared with individuals living in their own homes receiving many of the same services. Individuals residing in nursing homes also experienced better perceived quality of life and health status than their residentially residing counterparts.

[Link to Evidence Table and References for Section 5](#)

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Section 1 Table: Tools to Assess Participation and Quality of Life

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
Health Status				
<p>Stroke Impact Scale (SIS)</p> <p>Duncan et al. 2003</p>	<p>The SIS is a measure of health status following stroke</p>	<p>59-items representing 8 domains: strength, hand function, ADL/IADL, Mobility, Communication, Emotion, Memory and Thinking, and Participation/Role Function. Each item is rated on a 5-point ordinal scale, with the exception of a single item rated on a 100-point visual analog scale.</p> <p><u>Score Interpretation:</u> Scores are summed for each domain and range from 0-100, with higher scores indicating more recovery.</p> <p><u>Administration:</u> Self-report; 15-20 minutes to administer</p>	<p>The SIS is easy to administer, does not require any additional equipment, and can be administered by mail or telephone. The measure can also be completed by proxy respondents, although there is some evidence that proxies tend to rate patients as being more impaired.</p> <p>Some ceiling effects have been observed for individuals with mild impairment, particularly, in the Emotion, Communication, and Memory and Thinking domains.</p> <p><u>Specialized Training:</u> None required.</p>	<p>Free for non-profit use after signing a licensing agreement</p> <p>http://www.strokengine.ca/assess/sis/</p>
<p>Medical Outcomes Study Short Form 36 SF-36</p> <p>(Ware & Sherbourne 1992)</p>	<p>The SF-36 was designed as a generic health survey for the assessment of health status in the general population.</p>	<p>36 items are organized into 8 subscales; physical functioning, role limitations- physical, bodily pain, social functioning, general mental health, role limitations – emotional, vitality, and general health perceptions. 2 additional questions estimate change in overall health status over the past year. With the exception of the general change in health status questions, subjects are asked to respond with reference to the past 4 weeks.</p> <p>Items are scored using a weighted Likert system. Items are summed to provide subscale scores which are transformed linearly to provide a score from 0-100 for each subscale. In addition, a physical component (PCS) and mental component (MCS) score may be derived. The 2 health status questions remain separate from the 8 subscales and are not scored.</p> <p><u>Score Interpretation:</u> There are normative subscale scores based on population data available for a number of different countries. In addition, component scores have also been standardized with a mean of 50 and a standard</p>	<p>The SF-36 questionnaire can be administered by self-completion questionnaire or by interview (either on the telephone or in-person). It has been used as a mail survey with reasonably high completion rates reported, however, data obtained are more complete when interview administration is used. It should be noted that some items have been questioned as less relevant for use in the assessment of elderly populations.</p> <p>The SF-36 has been studied for use by proxy, however, reliability of the test decreased when proxy respondents completed assessments.</p> <p><u>Specialized training:</u> None required.</p>	<p>Available without charge</p> <p>http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html</p> <p>There are terms and conditions for use posted on the site.</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		<p>deviation of 10.</p> <p><u>Administration:</u> Approx. 10 minutes. Self-report or by interview.</p>		
Participation/Extended Activities of Daily Living				
<p>Assessment of Life Habits (LIFE-H 3.1)</p> <p>Fougeyrollas et al. 2001</p>	<p>The LIFE-H is a measure of the accomplishment of daily activities and social roles.</p>	<p>77-items representing 12 domains. Items are rated on two-scales: 1) level of difficulty/type of assistance required (10-point ordinal scale) and 2) satisfaction with performance (5-point ordinal scale).</p> <p><u>Score Interpretation:</u> Scores are summed and presented as an average of items answered, with lower scores indicating less optimal subjective participation. Ratings on the Satisfaction with Performance scale are not included as part of the total score.</p> <p><u>Administration:</u> self-report; 20-30 minutes to administer.</p>	<p>The LIFE-H is easy to administer and does not require specialized equipment.</p> <p>The scale is not available for free, is somewhat lengthy, and some concern has been expressed regarding ceiling effects in patients with mild stroke (Rochette et al. 2007).</p> <p><u>Specialized Training:</u> Recommended.</p>	<p>Available for purchase by request</p> <p>http://www.strokengine.ca/assess/lifeh/</p>
<p>Frenchay Activities Index (FAI)</p> <p>(Holbrook & Skilbeck 1983)</p>	<p>The FAI provides an assessment of a broad range of activities associated with everyday life.</p>	<p>The FAI contains 15 items or activities that can be separated into 3 factors; domestic chores, leisure/work and outdoor activities. The frequency with which each item or activity is undertaken over the past 3 or 6 months (depending on the nature of the activity) is assigned a score of 1 – 4 where a score of 1 is indicative of the lowest level of activity.</p> <p><u>Score Interpretation:</u> Summed scores range from 15-60.</p> <p><u>Administration:</u> 5 minutes or less. Self-report or interview.</p>	<p>Simple and brief. Well suited to use in most clinical settings. However, lack of standardized guidelines for administration or interpretation may reduce comparability between settings, groups or studies.</p> <p>The FAI extends information about function along the ADL continuum in terms of item difficulty. It should be noted that FAI scores may be influenced by both gender and age.</p> <p>The FAI is suitable for use with proxy respondents. The scale is based on behaviour and the emphasis placed on frequency rather than quality of activity. This reduces elements of subjectivity which can undermine</p>	<p>Free of charge</p> <p>http://www.strokengine.ca/assess/fai/</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
			reliability of proxy assessment. <u>Specialized Training:</u> None required.	
<p>London Handicap Scale (LHS)</p> <p>Harwood & Gompertz, 1994</p>	<p>The LHS is a measure of the degree of disadvantage perceived by an individual as the result of an illness/handicap.</p>	<p>6-items, each representing a single dimension: Mobility, Physical Independence, Occupation, Social Integration, Orientation, and Economic Self Sufficiency. Responses are rated on a 6-point ordinal scale relating to the degree of perceived disadvantage.</p> <p><u>Score Interpretation:</u> The LHS provides a profile of handicap based on the responses within each of the 6 dimensions as well as a weighted total handicap score. This overall weighted score should be interpreted as an estimate of the desirability of the health state described by the respondent's profile.</p> <p>Scale weights are used to calculate total scores, which range from 0 to 1.0, with lower scores indicating more disability.</p> <p><u>Administration:</u> Self-report; approximately 5 minutes to administer</p>	<p>LHS appears to facilitate the assessment of 'participation', though response statements span all domains of the ICF. Statements that describe body functions are typically associated with greater degrees of restriction in participation (Perenboom and Chorus 2003).</p> <p>The LHS is brief, easy to administer and does not require any specialized equipment. It can be administered via mail or completed by a proxy respondent.</p> <p>Use of a weighted scale makes calculation of total scores relatively arduous, as compared to other measures. More independent research is required to assess the psychometric properties of the LHS (Salter et al. 2012).</p> <p><u>Specialized Training:</u> Not required.</p>	<p>Free</p> <p>http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=929</p>
<p>Reintegration to Normal Living Index (RNLI)</p> <p>Wood-Dauphinee et al. 1988</p>	<p>The RNLI is a measure of reintegration to normal activities following illness of trauma.</p>	<p>11 declarative statements rated by respondents on a 10cm visual analogue scale.</p> <p><u>Score Interpretation:</u> Summed scores are reported as a percentage out of 100, with lower scores indicating poorer perceptions of reintegration. Scores can also be calculated for Daily Functioning and Perceptions of Self subscales.</p>	<p>The tool focuses on the perception of the individual with regard to personal capability and/or autonomy. It may be considered a person-centred assessment of re-integration.</p> <p>Quick, easy to administer, and does not require any additional equipment.</p>	<p>Free</p> <p>http://www.strokenline.ca/assess/rnli/</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		<p>Administration: Self-report; approximately 10 minutes to administer.</p>	<p>The visual analogue response format may not be appropriate for use with some stroke patients (e.g., those with neglect or visuospatial deficits). Concern has been expressed regarding the use of proxy respondents (Tooth et al. 2003).</p> <p>Specialized Training: Not required.</p>	
Health-related Quality of Life				
<p>EuroQoL Quality of Life Scale (EQ-5D)</p> <p>EuroQoL Group, 1990</p>	<p>The EQ-5D is a measure of health-related quality of life.</p>	<p>Part 1 consists of 5 domains: Mobility, Self-care, Usual Activities, Pain/Discomfort, and Anxiety/Depression. For each domain, respondents are asked to indicate which 1 of 3 statements best describes their current health state. Part 2 consists of a 100 cm visual analog scale representing “your own health state today.”</p> <p>Score Interpretation: Weights are applied to calculate a summary index score, which range from 0 to 1, with higher scores indicating more quality of life.</p> <p>Administration: Self-report; approximately 3 minutes to administer.</p>	<p>The EQ-5D is short, easy to administer, and does not require any specialized equipment. The measure can be administered in person or by mail</p> <p>Although the EQ-5D can be completed by a proxy respondent, decreased reliability has been reported (Dorman et al. 1998). Patient-proxy agreement rates have also been reported to be low on the more subjective domains (e.g., anxiety/depression, and pain/discomfort) (Picard et al. 2004).</p> <p>Specialized Training: Not required.</p>	<p>Licensing fees may be required</p> <p>http://www.euroqol.org/</p>
<p>Stroke Specific Quality of Life Scale (SS-QOL)</p> <p>Williams et al. 1999</p>	<p>The SS-QOL is a measure of health-related quality of life.</p>	<p>49-items representing 12 domains: energy, family roles, language, mobility, mood, personality, self-care, social roles, thinking, upper extremity function, vision, and work/productivity. Items are rated on a 5-point ordinal scale.</p> <p>Score Interpretation: Summation yields a total score ranging from 49 to 245, with higher scores indicating better functioning. Subscale scores can</p>	<p>Quick, easy to administer, and does not require any additional equipment.</p> <p>The SS-QOL can be completed by proxy respondents; however, agreement rates have been reported to be weaker for items that are more subjective as compared to those that are more observable (Williams et al.</p>	<p>Free</p> <p>http://www.strokingengine.ca/assess/ssqol/</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		<p>also be calculated.</p> <p><u>Administration:</u> Self-report; approximately 10-15 minutes to administer.</p>	<p>2000). Some concern has been expressed regarding floor and ceiling effects (Czechowsky & Hill, 2002).</p> <p><u>Specialized Training:</u> Not required.</p>	
<p>Stroke-Adapted Sickness Impact Profile (SA-SIP-30)</p> <p>Van Straten et al. 1997</p>	<p>The SA-SIP-30 is a measure of health-related quality of life</p>	<p>30-items representing 8 domains: Body Care and Movement, Social Interaction, Mobility, Communication, Emotional Behavior, Household Management, Alertness Behavior, and Ambulation. Respondents are asked to mark “yes” for each item that is descriptive of the impact of illness on their daily life.</p> <p><u>Score Interpretation:</u> Items are weighted, summed, and expressed as a percentage, with higher scores indicating less quality of life. Subscale cores can also be calculated. The scale authors have suggested a cut-off score of >33 as being indicative of poor health.</p> <p><u>Administration:</u> Self-report; approximately 10 minutes to administer.</p>	<p>The SA-SIP-30 is much shorter and easier to administer than the original 136-item scale. However, evidence suggests that the shorter version may not perform as well when used with patients with more severe stroke (van Straten et al. 1997).</p> <p>No specialized equipment is required.</p> <p><u>Specialized Training:</u> Not required.</p>	<p>Free</p> <p>http://www.stroking.ca/assess/sasip30/</p>
Assessment of Caregiver Burden				
<p>Bakas Caregiving Outcomes Scale</p> <p>(Bakas et al. 1999, 2006)</p>	<p>Assesses adaptation to caregiving in informal carers of individuals with stroke.</p>	<p>Originally a 10 item scale, the 15-item version is used more often. Items reflect changes in social functioning, subjective well-being and perceived health attributable to fulfilling the role of informal carer. Each item is rated on a 7-point Likert scale ranging from -3 (changed for the worst) to +3 (changed for the best).</p> <p><u>Scores and interpretation:</u> Item scores transformed to 1-7, then summed to provide total scale scores ranging from 15 – 105.</p>	<p>Assesses both the positive and negative aspects of the caregiving role. Emphasis is placed on the subjective, social aspects of change associated with caregiving.</p> <p><u>Specialized training:</u> None required</p>	<p>The 15-Item BCOS is available upon request from Dr Tamilyn Bakas (Bakas et al. 2006)</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		Administration: Self-report. Requires 2-4 minutes to complete		
Caregiver Strain Index (Robinson 1983)	Originally developed as a screening instrument to detect strain (stress) in carers of individuals with hip surgery and heart disease.	13 items rated as yes or no. Positive responses receive 1 point; negative receive no score. Scores and Interpretation: Item scores are summed to create total scores out of a possible 13. Administration: Self-report.	Short and simple. Most commonly used scale for the assessment of burden, particularly in research settings. Although used frequently, its psychometric properties have not been well-studied in populations of individuals with stroke. Specialized Training: None required.	Free. Available via: http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=1099
Zarit Burden Interview (Zarit et al. 1980)	Measures the degree to which responsibilities associated with informal caregiving role have affected health, personal and social well-being. Originally developed to assess carers of individuals with dementia.	29-item instrument includes items addressing caregiver health, well-being, finances, social life and the relationship between carer and the individual being cared for. 25 questions represent negative aspects of caring; 4 items represent positive aspects. Items are scored on a 5-point Likert scale (0-4). There are no subscales. Scores and Interpretation: Scores for 'negative' items are totaled, then 'positive' items subtracted to create an overall total score. Total scores are intended to reflect degree of burden. Administration: Self-report. Pen and paper or interview-administered.	Shorter 22, 18 and 12-item versions of the interview are also available. The 22-item version is used most frequently. Scores appear unaffected by age, gender language, marital or employment status, geographic locale suggesting the scale may be acceptable for a variety of assessment populations (Hebert et al. 2000). The Interview examines burden that is associated with both functional and behavioural impairments and with the situation in the home. Items focus on the subjective response of the carer. Specialized training: None required.	Free for use in non-funded studies only. Funded research or commercial use requires purchase/permission. http://www.proqolid.org/instrument/zarit_burden_interview_zbi

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Section 2 Table: Patient Education across the Continuum

STROKE AWARENESS AND ACTION	HYPERACUTE CARE	ACUTE INPATIENT CARE	STROKE REHABILITATION	STROKE PREVENTION	TRANSITIONS	COMMUNITY INTEGRATION
Review and reinforce all information previously provided that is relevant to the patient and their unique situation						
<ul style="list-style-type: none"> • Signs of Stroke <ul style="list-style-type: none"> • Face • Arms • Speech • Time • Call 911 immediately if signs of stroke observed • Never drive self or someone with stroke to hospital on your own • Risk factors for stroke <ul style="list-style-type: none"> • High Blood Pressure • Obesity • High Sodium Diet • Diabetes • High Cholesterol • Lack of Exercise • Smoking • Sleep Apnea • Family History • Risk of stroke for all age groups from newborns to children, young adults and older adults 	<ul style="list-style-type: none"> • Types of Stroke • Cause of stroke for individual patient • Diagnostic tests <ul style="list-style-type: none"> • CT Scan • MRI • Carotid imaging • ECG for AFib detection • Acute thrombolysis • Endovascular interventions • Involvement of neurosurgery if applicable • Potential outcomes – expectation management • For patients discharged directly from the ED: <ul style="list-style-type: none"> • Need for follow-up with primary care and stroke specialists (refer to prevention education) • Risk of recurrence and review of stroke signs and symptoms • Accessing resources and stroke support following discharge 	<ul style="list-style-type: none"> • Current deficits – what areas may be involved • Patient safety • Family and caregiver safety • Tests and interventions • Initiate discharge planning • Potential for home modifications prior to discharge • Discuss potential pathway for care and likely next setting of care • Focus on self-management and involvement of family and informal caregivers in daily activities • Medications: purpose, schedule, interactions, compliance • Activities to prevent complications • Accessing resources and stroke support following discharge from acute care • Expectations for recovery following discharge, addressing issues including depression, post- 	<ul style="list-style-type: none"> • Educate patients about goal-setting so they can actively participate in goal setting and care planning • Information regarding specific individualized rehabilitation needs • Roles of each of the rehabilitation team members involved in care • The types or rehabilitation exercises and activities that could and should be done between scheduled sessions with therapists • Patient, family caregiver safety while participating rehabilitation • Self-management skills for mobility and activities of daily living • Discharge planning, type of care needed after discharge, and required modifications to living setting prior to discharge from inpatient rehabilitation • Information 	<ul style="list-style-type: none"> • Signs of Stroke <ul style="list-style-type: none"> • Face • Arms • Speech • Time • Importance of calling 911 if any stroke signs and symptoms appear again after initial stroke • Risk factors for stroke <ul style="list-style-type: none"> • High Blood Pressure • Obesity • High Sodium Diet • Diabetes • High Cholesterol • Lack of Exercise • Smoking • Sleep Apnea • Family History • Effects of stroke in months following index event – risk for depression, cognitive changes, sleep apnea, post-stroke fatigue; and provide strategies and self-management skills so patients, families and caregivers can manage in community and home settings • Medication management 	<ul style="list-style-type: none"> • Self-management skills for activities of daily living • Types of services and primary contact for health care professionals at the next stage and/or setting • Appropriate expectations for recovery of deficits, time frames and likely transition points appropriate to the individual • Physical adjustments including medication compliance, post-stroke fatigue, strategies to prevent complications and recurrent stroke • Address functional issues – ongoing rehabilitation and physical activity recommendations, personalized plan of care and goal setting • Address psychosocial issues, i.e., depression, family support, referrals to community 	<ul style="list-style-type: none"> • Self-management skills for mobility, symptom management, medication compliance and activities of daily living • Types of services available in the community and how to access them – e.g., mobility assistance, meal delivery, communication support • Need for follow-up with primary health care providers for ongoing monitoring and management • Appropriate expectations for recovery of deficits, time frames as appropriate to individual situations • Physical adjustments including medication compliance, post-stroke fatigue, preventing complications, preventing recurrent stroke • Addressing functional issues –

STROKE AWARENESS AND ACTION	HYPERACUTE CARE	ACUTE INPATIENT CARE	STROKE REHABILITATION	STROKE PREVENTION	TRANSITIONS	COMMUNITY INTEGRATION
Review and reinforce all information previously provided that is relevant to the patient and their unique situation						
		<p>stroke fatigue, rehabilitation needs and access, and issues for social reintegration</p> <ul style="list-style-type: none"> • Access to community resources and stroke support groups • Re-access to healthcare system • Advance care planning and personal health directives 	<p>regarding resuming vocational, educational and driving activities</p> <ul style="list-style-type: none"> • Access to therapists and programs for ongoing rehabilitation in out-patient and community settings • Access to community resources and stroke support groups • Re-access to healthcare system 	<ul style="list-style-type: none"> • Atrial fibrillation risks and management as appropriate • Adherence to drug therapy • Access to community resources and stroke support groups • Re-access to healthcare system • Advance care planning and personal health directives 	<p>resources</p> <ul style="list-style-type: none"> • Self-management preparation for the next phase of care • Timeframes for transitions • Importance of information transfer and provision of written core information about previous stroke related episodes of care to share with stroke experts and recovery team members in next phase of care • Advance care planning and personal health directives 	<p>ongoing rehabilitation and physical activity recommendations, personalized plan of care and goal setting</p> <ul style="list-style-type: none"> • Social and leisure activity review and importance of resuming social interactions • Information regarding resuming vocational, educational and driving activities • Information on sexuality following stroke • Advance care planning and personal health directives