




# Canadian Stroke Best Practice Recommendations: Rehabilitation, Recovery, and Community Participation following Stroke. Part Two: Transitions and Community Participation Following Stroke

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## Abstract

The sixth update of the *Canadian Stroke Best Practice Recommendations for Transitions and Community Participation following Stroke* is a comprehensive set of evidence-based guidelines addressing issues faced by people following an acute stroke event. Establishing a coordinated and seamless system of care that supports progress achieved during the initial recovery stages throughout the transition to the community is more essential than ever as the medical complexity of people with stroke is also on the rise. All members of the health-care team engaged with people with stroke, their families, and caregivers are responsible for partnerships and collaborations to ensure successful transitions and return to the community following stroke. These guidelines reinforce the growing and changing body of research evidence available to guide ongoing screening, assessment, and management of individuals following stroke as they move from one phase and

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stage of care to the next without “falling through the cracks.” It also recognizes the growing role of family and informal caregivers in providing significant hours of support that disrupt their own lives and responsibilities and addresses their support and educational needs. According to Statistics Canada, in 2012, eight million Canadians provided care to family members or friends with a long-term health condition, disability, or problems associated with aging. These recommendations incorporate aspects that were previously in the rehabilitation module for the purposes of streamlining, and both modules should be reviewed in order to provide comprehensive care addressing recovery and community reintegration and participation. These recommendations cover topics related to support and education of people with stroke, families, and caregivers during transitions and community reintegration. They include interprofessional planning and communication, return to driving, vocational roles, leisure activities and relationships and sexuality, and transition to long-term care.

### Keywords

Stroke, transitions, practice guidelines, community participation, education, driving, caregiver support, communication, sexuality and relationships, longterm care

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### Introduction

In Canada, stroke is the third leading cause of death and a leading cause of adult disability with over 400,000 people living with the effects of stroke.<sup>1</sup> By 2038, the number of Canadians living with the effects of stroke is expected to increase and is estimated to be between 654,000 and 726,000.<sup>1</sup> Even more alarming, the complexity of patients being discharged from hospital following stroke is increasing<sup>2</sup>; one study revealed that approximately 80% of people who survive a stroke have on average five other conditions and a wide range of psychosocial issues.<sup>3</sup> Another study of patients with multiple conditions reported that their caregivers are frustrated with poor communication between care providers, a lack of care coordination and long wait times.<sup>4</sup> In Canada, one-third of people treated in an emergency department with stroke, usually with transient ischemic attack (TIA) and milder strokes, are discharged directly back to the community from the emergency department. Of those admitted to acute inpatient care: 42% will be discharged to their homes independently; 17% will be discharged home with arrangements for home care services; 16% will be transferred to an inpatient rehabilitation service; 10% will be transferred to long-term care or complex continuing care; and 13% will be transferred to another acute care facility.<sup>5</sup> Consequently, many patients will transition through several settings along the continuum of care, and in some instances, will move back and forth between different stages or settings of care during short-term and long-term recovery and return to the community.

These transitions are marked by periods of uncertainty and involve changes in patients' physical, mental, emotional, and cognitive capacities, often requiring them to learn new self-care management practices. In order for these transitional periods to be

seamless, information exchange between health-care professionals, and between health-care professionals to people with stroke and informal caregivers is required. Previous systematic reviews that examined models of transitions across several disease states have found that systems that involved more people or components,<sup>6</sup> and those that include components that foster learning and self-organization were more likely to result in successful transitions and help individuals to adapt and respond to their changing health status and support needs.<sup>6,7</sup> A survey of 800 caregivers in Ontario reported that half of all caregivers found transitioning to or from a health-care facility and home to be difficult, with the number increasing to 65% for those caregivers not living with the person they care for.<sup>8</sup> Therefore, all members of the health-care team engaged with individuals with stroke and their families are responsible for ensuring successful transitions across the care continuum and return to community, with the goals of maximizing person-oriented outcomes, such as quality of life and independence.

The 2019 update of the *Canadian Stroke Best Practice Recommendations (CSBPR): Rehabilitation, Recovery, and Participation following Stroke. Part Two: Transitions and Community Participation following Stroke* is a comprehensive summary of current evidence-based recommendations addressing issues surrounding transitions of care and resuming increasing levels of participation within the community. The theme of this edition of the CSBPR is *Partnerships and Collaborations*, which stresses the importance of integration and coordination across the health-care system to ensure timely and seamless care of stroke patients to optimize recovery and outcomes. The primary underpinnings of partnerships and collaborations in stroke transitions of care are to provide person and family-centered care across all transition points and to

ensure effective and efficient transfers to the next stage and setting of care. It also includes identifying areas with significant gaps in evidence to inform future research priorities.

### What's new in 2019?

The 2019 update of the *CSBPR Transitions and Community Participation following Stroke* module reinforces the growing and changing body of research evidence available to guide ongoing screening, assessment, and management of persons with stroke, their 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 significant updates as well as new additions to the recommendations for 2019 include: a checklist of key components of successful transitions ([www.strokebestpractices.ca](http://www.strokebestpractices.ca)); a new section on clinical considerations have been added to each topic where appropriate, acknowledging emerging therapies and consensus-based practices that lack a reasonable evidence base; consolidation of all recommendations for community participation and participation within this module (some pieces moved from Rehabilitation and Recovery Module for comprehensiveness), including return to driving, vocational roles, leisure activities, and relationships and sexuality; emphasis on the need to include social rehabilitation as part of assessments and interventions across all transitions; and inclusion of recommendations that discuss the involvement of telestroke in transitions of outpatient and community-based care.

### Guideline development methodology

The CSBPR development and update process follows a rigorous framework adapted from the Practice Guideline Evaluation and Adaptation Cycle<sup>9,10</sup> and addresses all criteria defined within the AGREE Trust model.<sup>11</sup> The CSBPR Transitions and Community Participation following Stroke 2019 Sixth Edition module supersedes all previous recommendations contained in the CSBPR Managing Stroke Transitions of Care 2015 Fifth Edition module.<sup>12</sup>

The methodology has been used in previously published updates<sup>12,13</sup> and can be found on our Canadian Stroke Best Practices website at [www.strokebestpractices.ca](http://www.strokebestpractices.ca). An interdisciplinary group of experts in the area of rehabilitation was convened and participated in reviewing, drafting, and revising all recommendation statements. Selected members of the group, considered to be experts in their fields, have conducted clinical trials on the topics addressed in this module and have extensive publication records. The writing group

included a physiatrist, researchers, stroke neurologists, family physicians, nurses, social workers, physical therapist, occupational therapist, speech-language pathologist, recreational therapists, stroke navigators, and evidence-based methodology experts. This interdisciplinary approach, which ensured that all perspectives were considered in the development of the recommendations, mitigated the risk of potential or real conflicts of interest from individual members. In addition, a Community Consultation and Review Panel, composed of 10 people with lived experience with stroke (including people with stroke, caregivers, and family members) also actively participated in the review and update process in a parallel review process where lived experiences, insights, and considerations for each section were shared back to the writing group at all stages.<sup>14</sup>

A systematic literature search was conducted by experienced personnel to identify evidence for each topic area addressed in the current module. The literature for this module was updated to June 2019. The writing group was provided with comprehensive evidence tables that included summaries of all high-quality studies identified through the literature searches (evidence tables are available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca)). Systematic reviews, meta-analyses, randomized controlled trials, and observational studies were included, where available. The writing group discussed and debated the value of the evidence and, through consensus, developed a set of proposed recommendations. Through their discussions, additional research may have been identified and included in the evidence tables if consensus on the value of the research was achieved.

All recommendations were assigned a level of evidence ranging from A to C, according to the criteria defined in Table 1. The authors recognize that for many of the topics and associated recommendations for transitions and community participation, 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 recommendations included in this module are based on qualitative and observational studies and expert opinion. People with stroke, families, and caregivers have expressed, both through formal and informal assessment, that transitions in care, that resuming life roles, and increasing community participation represent some of the greatest challenges faced after stroke. The CSBPR are responsive to this need; inclusion of some recommendations based on expert opinion and experience are intended to facilitate a holistic approach to person and family-centered care to promote optimal outcomes, as well to highlight the importance of further research into this important aspect of stroke care. When developing and including “C-Level” recommendations, consensus was obtained among the writing group and validated through the

**Table 1.** Summary of criteria for levels of evidence reported in the *Canadian Best Practice Recommendations for Stroke Care* (update 2019)

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 undesirable effects clearly outweigh desirable effects.
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 undesirable effects outweigh or are closely balanced with desirable effects.
C	Writing group consensus and/or supported by limited research evidence. Desirable effects outweigh or are closely balanced with undesirable effects or undesirable effects outweigh or are closely balanced with desirable effects, as determined by writing group consensus. Recommendations assigned a Level-C evidence may be key system drivers supporting other recommendations, and some may be expert opinion based on common, new or emerging evidence or practice patterns.

\*Adapted from Guyatt et al.<sup>15</sup>

internal and external review process. This level of evidence was used cautiously, and only when there was a lack of stronger evidence for topics considered important system drivers for stroke care. In some sections, the expert writing group felt there was additional information that should be included. Since these statements did not meet the criteria to be stated as recommendations, they were included under the term, *clinical considerations*, with the goal of providing additional guidance or clarity in the absence of evidence.

After a draft set of recommendations had been developed, they underwent an internal review conducted by the Canadian Stroke Best Practices and Quality Advisory Committee, followed by external review from several Canadian and international experts who were not involved in any aspects of the guideline development. All feedback received was given careful consideration during the editing process. All recommendations are also accompanied by five additional supporting sections devoted to: the rationale (i.e., the justification for the inclusion of the selected topics), system implications (to ensure the structural elements and resources are available to achieve recommended levels of care), performance measures (to monitor care delivery and person-centered outcomes), a list of implementation resources, and a summary of the evidence on which the recommendations were based. Brief summaries of current research evidence are provided at the beginning of each section below. More detailed evidence summaries and links to all evidence tables, and additional knowledge translation information for the recommendations included in this publication can be found at <http://www.strokebestpractices.ca>. For a more detailed description of the methodology on the development and dissemination of the *CSBPR*, refer

to the *CSBPR* Overview and Methodology documentation available on the *CSBPR* website at <http://www.strokebestpractices.ca>. The *CSBPR* continue to be a work in progress. They are updated every two to three years; whereby new recommendations are created, and old ones revised or deleted, in response to new and emerging evidence.

## Recommendations for transitions and community participation following stroke

### Section 1: Recommendations on supporting people with stroke, their families, and caregivers

People with stroke, families, and informal caregivers will experience multiple life changes and challenges as they navigate between the hospital and home, or other community settings. Transitions are associated with substantial emotional, social, and health-related challenges. With a focus on reducing costs at many health-care institutions, patients may find themselves discharged back to the community following only a short inpatient hospital stay. Not all patients are eligible for, or will receive a course of inpatient rehabilitation, which provides the opportunity to receive additional supports and resources. Consequently, people with stroke may feel overwhelmed and ill prepared to return home so soon after the event. Some populations are more at risk for experiencing challenges around transitions including Indigenous people, those living in rural and remote communities, transgender individuals, older adults, newcomers, and anyone who experiences systemic, cultural, or language barriers.<sup>16</sup> Caring for a person following a stroke may also have

a considerable impact on the health and vocational status of informal caregivers, who have reported spending significantly longer periods of time caring for persons with stroke, relative to pre-stroke levels. Depression and anxiety may also be increased. The prevalence of depressive symptoms and anxiety among stroke caregivers have been estimated to be 40.2% and 21.4%, respectively.<sup>17</sup> It is also important to note that women are the predominant providers of

informal (i.e., unpaid) care to children as well as to family members and friends with mental or physical limitations related to aging or chronic health conditions or disabilities.<sup>18</sup> The current guidelines emphasize the need for appropriate assessments, the importance of ongoing support, and the potential application of telemedicine interventions for rehabilitation and virtual support groups.

## Section I Recommendations

**I.0** Persons with stroke, their 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, awareness of and assistance in accessing community services and resources (Evidence Level B). Interventions must be person- and family-centered and tailored to their individual values and needs (Evidence Level C).

### I.1 Screening and assessment

- (i) People with stroke, their 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 and additionally when indicated. Refer to *Transitions of Care Checklist* available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca).
  - a. Validated screening tools or approaches can be used whenever possible to ensure a consistent approach to identifying potential issues during transitions (Evidence Level C). Refer to *Table 1: Tools to Assess Participation and Health-Related Quality of Life* available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca).
- (ii) People with stroke, their families, and caregivers should undergo *in-depth assessment* to determine readiness for education and ability to integrate knowledge, training, and psychosocial support, and ability to access appropriate health information and social services (Evidence Level B). Refer to *Section 2 for additional recommendations on education and training*.
  - a. Consider assessment of the following issues as they relate to a family member's or caregiver's ability to care for the person with stroke:
    1. Current health status, employment and social responsibilities, and how those will be managed in providing stroke care (Evidence Level B);
    2. Capabilities and experience in providing care to the person affected by stroke (Evidence Level C);
    3. Resource issues such as financial situation, housing, transportation, insurance, health-care benefits, medication cost coverage (Evidence Level C);
    4. Support from other family members, relatives and social networks (Evidence Level C);
    5. Ability to cope and manage the added stress of caring for another person following stroke (Evidence Level C).
  - b. The type and depth of assessments should be appropriate to the individual person's needs, issues identified during screening, and stage of transition (Evidence Level C).
- (iii) When issues are identified through screening and assessments, referrals to appropriate experts and services to address issues and optimize outcomes should be made for people with stroke (Evidence Level B), their families, and caregivers (Evidence Level C).

### I.2 Supporting people with stroke, their families, and caregivers

- (i) Support should be initiated from the onset of stroke and continue throughout all transitions and stages of care (Evidence Level B).

- (ii) The use of telemedicine (e.g., video, and web-based technologies and services such as web-based support groups, telerehabilitation) should be considered to increase access to ongoing support services, health-care services, and rehabilitation therapies following transitions to the community; especially in settings where people with stroke and their family members are unable to travel to access care and services (Evidence Level B). Refer to CSBPR *Telestroke Toolkit for additional information, available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca)*.
- (iii) People with stroke, their families, and caregivers should be provided with information about peer support groups in their community where available, descriptions of the services and benefits they offer, and be encouraged to consider participation (Evidence Level C).

## Section 2: Recommendations on education for people with stroke, their families, and caregivers

Educating people with stroke, families, and caregivers about stroke recovery is an important component of transitional care. Education can assist with secondary stroke prevention and facilitate successful chronic disease self-management. Active education, that enables people with stroke, family, and caregiver engagement, has been shown to result in improved knowledge of stroke services, greater satisfaction with stroke information and improvement in depression scores.<sup>12,13</sup>

Components of effective education strategies include hands-on skill training, opportunities to ask questions, or to request additional information, or involve the use of an interactive workbook and/or some means of follow-up reinforcement. The implementation of education and skills training programs in all settings across the stroke continuum ultimately aim to increase the self-efficacy of patients and informal caregivers through self-management. The results from two systematic reviews that assessed a wide range of self-management interventions following stroke reported improvement in physical domains, quality of life, and dependency.<sup>19,20</sup>

## Section 2 Recommendations

**2.0** Education for people with stroke, their families, and caregivers is an integral part of stroke care that should be included as part of all health-care encounters and during transitions (Evidence Level A). Individualized educational needs change over time and may need reassessment and updating on an ongoing basis (Evidence Level B).

### 2.1 Assessment of learning needs

- (i) Individualized learning needs and goals should be assessed and documented by members of the health-care team (Evidence Level B) and updated regularly as people move through the stages of care following stroke (Evidence Level B).

*Note: This applies to all settings including ambulatory care and emergency departments where there is shorter interaction time and greater risk of learning needs being unmet.*

### 2.2 Delivery of education

- (i) An individualized education plan should be developed and implemented based on the assessment of learning needs and goals of people with stroke and their families (Evidence Level B).
- (ii) It is recommended that the individualized education plan:
  - a. Cover all relevant aspects of stroke care and recovery (Evidence Level A) and include content specific to level of readiness and setting and stage of care (Evidence Level B). Refer to *Table 2: Core Education across the Continuum for People with Stroke available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca)*.
  - b. Be goal-oriented and facilitate shared decision-making regarding care and recovery (Evidence Level B).
  - c. Include information sharing, teaching of self-management skills, and training of family and caregivers to participate in and provide safe stroke care (Evidence Level B).

- d. Be interactive, evidence-based, accurate, 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 be accessible for people with aphasia and cognitive deficits or impairments (Evidence Level A).
- (iii) Education provided should be documented in the health record and accessible by all members of the health-care team (Evidence Level B).
- (iv) Assess and document understanding and retention of information regularly (Evidence Level A).
- (v) Include reinforcement of information that has not been retained (e.g., medication information and management) (Evidence Level B).
- (vi) Education and information for people with stroke, family and caregivers should be provided both formally and informally in individual and group settings as appropriate (Evidence Level B).
- (vii) Family and caregiver education, hands on training, and skills development should be provided using an interdisciplinary approach based on the individual's learning needs (Evidence Level A).

### 2.3 Supporting self-management following stroke through skills training

Refer to *Definitions and Descriptions within the Introduction and Overview for the definition of self-management available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca).*

- (i) Self-efficacy can be supported by providing opportunities to learn and master self-management skills (Evidence Level B). Refer to *Box 2 for additional information regarding self-management topics for people with stroke, their family and caregivers available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca).*
- (ii) With consent, family members, and caregivers may be invited and encouraged to attend care and therapy sessions and given the opportunity to learn proper skills to support self-management (Evidence Level C).
- (iii) All care settings should have up-to-date inventories of community resources available to support self-management and offer guidance and assistance in obtaining needed services (Evidence Level C).
- (iv) People with stroke, their families, and caregivers should be provided with resources and information which will enable self-management and the ability to navigate through the health care and social system (Evidence Level B).

### Section 3: Recommendations on interprofessional care planning and communication

Transitioning between inpatient and outpatient care health-care settings is a complex process, dependent on many professionals communicating and coordinating care to avoid fragmentation and delays. If poorly executed, safety and quality of care can be compromised, with increased risks of adverse drug-related events<sup>21</sup> and hospital readmissions. Increased communication between physician and nurse regarding discharge instruction has been associated with a significantly lower number of 30-day hospital re-admissions.<sup>22</sup> A discharge summary, communicated between hospital-based care providers and primary care physicians (PCP) and health teams, is a standard and critical component of care. Unfortunately, they tend to be incomplete, lacking test results from the inpatient

admission and follow-up plans, and are not provided to community care organizations.<sup>19</sup> In addition, PCP may not always receive notification of hospital discharge plans.<sup>19</sup>

Transition planning, of which discharge planning is a component, is another crucial component to support transitions and should begin as soon as possible during each phase of care. It should involve the person with stroke, families, caregivers, and all members of the interprofessional team. The goal of transition planning is to ensure a safe and efficient transition between care settings while maintaining a continuity of care and coordination of services that optimize recovery and secondary prevention. Transition planning activities should include a pre-discharge needs assessment, home visits, meetings between the care team with the person with stroke, their families, and caregivers, a post-discharge follow-up plan, and communication

**Table 2.** Key components of successful transitions of care (update 2019)

1.	Collaborative goal setting between the health-care team, people with stroke and their families, where there is active participation in discussions, planning, and shared decision-making
2.	Ongoing education for people with stroke, their 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 within the hospital), rehabilitation settings, outpatient and community settings
3.	Skills training appropriate to individual needs and goals to facilitate safe transitions
4.	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
5.	Ongoing assessment of family and caregiver capacities to provide care for the person with stroke, their individual support needs and potential burden of care
6.	Timely transfer of medical and recovery information between stages and settings of care
7.	Appropriate medical support by PCPs and team members, as well as stroke team members and stroke prevention services
8.	Ongoing surveillance of physical, psychological, social and emotional recovery, coping, and adaptation following discharge from inpatient acute care and rehabilitation settings

with team members at the next phase of care. In a recent Cochrane review, Gonçalves-Bradley et al.<sup>23</sup> identified 30 randomized controlled trials including patients admitted to any type of hospital (acute, rehabilitation, or community) with any medical or surgical condition. Trials evaluated discharge plans from hospital that included assessment, planning, implementation, and monitoring components, initiated at some

point prior to discharge. Hospital length of stay (MD = -0.73, 95% CI: -1.33 to -0.12) and unscheduled three-month readmission rates (RR = 0.87, 95% CI: 0.79 to 0.97) were significantly reduced for elderly patients with a medical condition who received discharge planning, compared to usual care.

### Section 3 Recommendations

**3.0** Interprofessional care planning and effective communication is essential to ensure continuity of care, safety for the person with stroke, and to reduce risk of complications and adverse events during stroke care particularly at transition points (Evidence Level C).

**3.1 Individualized care plan:** The person with stroke, their family and caregivers should be actively engaged in development of an up-to-date care plan:

- (i) The care plan should be person-centered; culturally appropriate; include person-centered goals; and define ongoing individualized care needs (Evidence Level C).
- (ii) The care plan should be reviewed with the person with stroke and updated to reflect changing needs, evolving goals, progress at each transition, when changes and/or improvements in health status occur and when the person is not progressing in recovery (Evidence Level B).

#### 3.1 Clinical consideration

- (i) The care plan should be initiated at the first point of contact with the health-care system, such as the emergency department, and be refined and updated as the person progresses through the continuum of care.



**3.2 Transition planning** should begin as soon as possible following initiation of care at each applicable stage and setting (Evidence Level B).

- (i) Transition planning discussions, decisions, and activities should be ongoing to reflect changing needs, evolving goals, and progress through the recovery process (Evidence Level B).
- (ii) A transition planning process should be established as a well-organized collaboration between health professionals, the person with stroke, their family, and caregivers (Evidence Level B).
- (iii) The following should be considered throughout transition planning:
  - a. Formulation of a goal-oriented transition plan (e.g., discharge date) with the person with stroke, family, and caregivers (Evidence Level B).
  - b. Identification of possible transition issues for the person with stroke and their family, and other needs which could potentially delay discharge. These should be addressed early in transition planning (Evidence Level B).
  - c. Assessment of caregiver capacity, decision-making ability, and ability to meet the physical and psychosocial needs of the person with stroke (Evidence Level C). *Refer to Section 1 and Section 2 for additional information.*
  - d. Addressing transition planning needs and booking of appointments prior to leaving current setting, especially short stay settings including emergency department and acute care for those discharged directly back to the community (Evidence Level C).
  - e. Utilization of telemedicine modalities where available to increase access to timely and appropriate stroke care follow-up (Evidence Level B). *Refer to CSBPR Telestroke Toolkit for additional information.*
- (iv) Specific transition planning activities that should be completed as appropriate include:
  - a. A home assessment to identify home modifications required for accessibility and safety (Evidence Level B).
  - b. Caregiver skills training specific to the current and ongoing needs of the person with stroke (Evidence Level B). *Refer to Section 1 and Section 2 for additional information.*
  - c. Planned and goal-oriented day, weekend, and/or overnight visits to the identified discharge location (Evidence Level B), in order to:
    - help identify potential barriers,
    - assess readiness for discharge,
    - and to inform therapy and discharge planning activities.
  - d. Written discharge instructions as a component of an individualized care plan that addresses 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, follow-up care provider contact information, and information for one point of contact post-discharge (Evidence Level B).
  - e. All communications should be available in aphasia-friendly formats as required and appropriate to the health literacy of people with stroke, their families, and caregivers (Evidence-Level B).
  - f. 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).

**3.3 Health professional communication:** Processes should be in place to ensure timely and effective transfer of relevant information at all points of access and transition in the health-care 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 health-care providers at the next stage of care (Evidence Level B).
- (ii) The transfer of information should be:
  - a. Comprehensive with all relevant information on the person with stroke including medications, and progress to date, planned appointments, ongoing recovery needs and goals (Evidence Level B).
  - b. Provided to the PCP in a formal, typed, detailed, discharge summary (from the most responsible physician) (Evidence Level B). *Note, not all patients may have a primary care provider, and if not, this should also be addressed. Refer to Box 3 for core content to be considered for inclusion in discharge summaries available at [www.strokebest-practices.ca](http://www.strokebest-practices.ca).*
  - c. Timely and occur prior to the time of transition to next care setting (Evidence Level C).

- d. When possible, accessible through electronic health records (Evidence Level C).
- e. Include the use of telemedicine technology when appropriate (Evidence Level C). Refer to CSBPR Telestroke Toolkit for additional information available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca).

- (iii) A designated member of the team should facilitate the transfer of information and referrals to appropriate follow-up services for the person with stroke (Evidence Level B).

#### Section 4: Recommendations on community participation following stroke

The post-discharge period is a difficult time of adjustment for both people with stroke, as well as their families, as they reintegrate to and participate in their former personal, vocational and social life roles. For persons returning home to live with their families following a stroke, the transition period may be challenging as the social, emotional, and practical support offered by inpatient care is lost. The resumption of vocational, leisure, and social pursuits are important components of participation through community participation. Since driving was part of many persons' daily routine prior to stroke, returning to driving is often a high priority for people with stroke and their families; however, motor, sensory, and cognitive impairments and visual fields defects can limit a person's ability to drive safely. Beyond its use for completing everyday tasks and travelling to work, driving is often seen as a symbol of independence and freedom. For those who have had a minor stroke or TIA, temporary restrictions placed on driving may be confusing, frustrating, and seem unwarranted. Return to work (RTW) is one of the most important issues for those who were working at the time of their stroke. Following stroke, the reported rates of RTW vary widely. The overall frequency of return to either full

or part-time work assessed up to 12 years following stroke ranged widely from 7.3% to 74.5% in a recent systematic review.<sup>24</sup> Up to six months following stroke, 41% of persons had returned to work, increasing to 66% at four to six years.<sup>24</sup> Interventions to help improve the odds of successful RTW have not been well studied. A six-week individualized workplace intervention program group was associated with an increase in the number of persons who had returned to work following a recent stroke (<8 weeks), compared with persons receiving usual care, at six months (60% vs. 20%,  $p < 0.001$ ).<sup>25</sup> Many people recovering from stroke are unable to resume their previous leisure activities. Factors including physical limitations, attributable to residual disability, decreased motivation, environmental barriers, including transportation, and affordability have been cited as reasons for decreased participation. A variety of programs and interventions have been evaluated to help improve participation following stroke, although few have used an assessment of leisure as the primary outcome. Reports of sexual dysfunction following stroke are common. Among several surveys including declines in sexual activity have been reported.<sup>26</sup> Patients who were given the opportunity to address frequently asked questions and who were provided tips to avoid sexual dysfunction were more sexually active and experienced greater sexual satisfaction following stroke.<sup>27</sup>

### Section 4 Recommendations

**\*Note:** The topics covered in this section include elements of active rehabilitation as well as community and participation. They are presented in this module to streamline our recommendations. These recommendations should be considered as part of all comprehensive rehabilitation, recovery, and community participation planning following stroke.

**4.0** People with stroke, their families, and caregivers should be provided with information, education, training, support, and access to services throughout transitions to the community to optimize the return to life roles, activities, and social participation (Evidence Level B).

#### 4.1 Physical and psychological health management following stroke:

*Note:* For additional information on management of people for secondary prevention of stroke, refer to CSBPR Secondary Prevention of Stroke module for additional information available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca).

- (i) People living in the community post-stroke should have access to regular and ongoing medical follow-up appropriate to their individual needs, which may address evaluating 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 the primary care provider would ideally occur within the first month following hospital discharge and address the key secondary prevention, medical and functional issues, and provide ongoing follow-up as required (Evidence Level C).
- b. People with stroke should be screened and treated for new and/or ongoing cognitive concerns, mental health issues (i.e., depression, anxiety), and psychosocial issues as required (Evidence Level B). *Refer to CSBPR Mood, Cognition & Fatigue following Stroke module for additional information available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca).*

- (ii) Secondary prevention of stroke should be optimally 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 could be initiated where appropriate (i.e., at hospital discharge and once back in the community) (Evidence Level C).

#### 4.2 Functional health management

- (i) People with stroke 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. *Refer to CSBPR Stroke Rehabilitation and Recovery following Stroke module for targeted interventions available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca).*
- (ii) Processes should be in place for people following a stroke to re-access rehabilitation or mental health services if required during longer term recovery (Evidence Level B). *Refer to CSBPR Stroke Rehabilitation and Recovery following Stroke module and CSBPR Mood, Cognition and Fatigue Following Stroke module for additional information.*
- (iii) People with stroke should be encouraged to participate in evidence-based community exercise programs as appropriate (Evidence Level A).

#### 4.3 Participation in social and life roles following stroke: *Driving*

##### A. Education and screening

- (i) People should be advised to stop driving for at least one month after a stroke, in accordance with the Canadian Council of Motor Transport Administrators (CCMTA) Medical Standards for Drivers (Evidence Level B).
- (ii) The person with stroke should be made aware whether the local licensing authority has been informed that they have had a change in their medical status that will affect their ability to drive (Evidence Level C).
- (iii) People who have had one or multiple TIAs should be instructed to stop driving until a comprehensive neurological assessment (including sensorimotor function and cognitive ability) shows no residual loss of functional ability and discloses no obvious risk of sudden recurrence that could create a hazard while driving, in accordance with the Canadian Council of Motor Transport Administrators (CCMTA) Medical Standards for Drivers (Evidence Level C).
  - a. As well, any underlying cause of stroke has been addressed with appropriate treatment (Evidence Level C). *\*Refer to individual provincial and territorial laws for requirements for reporting a person's fitness to drive to driving authorities, and requirements to return to driving.*
- (iv) People with stroke may be screened for their interest in returning to driving at transitions and follow-up visits (Evidence Level C).

##### B. Assessment for fitness to drive

- (i) People interested in returning to driving following a stroke should be assessed for driving abilities and rehabilitation needs using valid and reliable methods for any residual functional, sensory-perceptual, motor,

or cognitive impairments (Evidence Level B) in accordance with provincial-territorial criteria for return to driving.

- a. Sensory-perceptual assessment should focus on vision, visual fields, and visual attention;
- b. Motor assessment should focus on strength, range of motion, coordination, and reaction time;
- c. Cognitive assessment should focus on problem solving, speed of decision-making, judgment, and reading/symbol comprehension.

(ii) For people who have residual neurological deficits impacting driving ability following stroke, a full comprehensive driving evaluation, including a government-sanctioned on-road assessment, should be considered to determine fitness to drive (Evidence Level B).

- a. People with stroke may be referred to training programs, such as simulator-based training, to help prepare for return to driving (Evidence Level B).

### **C. Rehabilitation and management for return to driving**

(i) Following a stroke, people who are functionally able and interested in returning to driving should be offered appropriate rehabilitation therapies as individually required to address functional, perceptual, and cognitive issues and increase the likelihood of being able to return to driving (Evidence Level B).

(ii) Persons unable to return to driving may be informed about and assisted to access transportation alternatives (Evidence Level C).

(iii) Persons unable to return to driving may be offered support and/or counseling on coping with the loss of the ability to drive (Evidence Level C).

#### **4.4 Participation in social and life roles following stroke: Vocational roles**

(i) Following stroke, people may be considered for assessment of vocational interests (i.e., work, school, volunteering) and for their potential to return to their vocations (Evidence Level C).

- a. This initial screening may take place early in the rehabilitation phase and should be reassessed at transitions as appropriate (Evidence Level C).
- b. Findings can be included as part of the person's individualized goal setting and planning for early and ongoing rehabilitation (Evidence Level C).

(ii) Encourage resumption of vocational interests where possible. A gradual resumption could occur when appropriate (Evidence Level C).

(iii) Initiation of referrals and or counseling may be considered as appropriate (such as to vocational services) to assist with re-engagement in vocational activities as part of transitions to the community (Evidence Level C).

(iv) A detailed cognitive assessment including a neuropsychological evaluation or occupational therapy evaluation, where appropriate and available, can be considered to assist with determining the person's ability to meet the needs of their current or potential employment requirements and contribute to vocational planning (Evidence Level C).

(v) Referral to vocational rehabilitation services may be considered, as appropriate (Evidence Level C).

- a. A designated member of the care team may provide counseling and information on employment benefits and legal rights to people with stroke (Evidence Level C).

(vi) Review financial concerns, sustainability and benefit options during admission and/or prior to discharge, and later in follow-up assessments and transitions (Evidence Level C).

(vii) With consent and where possible, the health-care team may work with employers/educators to devise an appropriate RTW/school plan (Evidence Level C).

- a. Encourage employers and education providers to follow therapists' recommendations with regard to work/school modifications and provide the flexibility to allow a RTW/school at an appropriate pace (Evidence Level C).

#### **4.5 Participation in social and life roles following stroke: *Leisure activities and social participation***

- (i) Following stroke, people should be screened for pre-stroke and current leisure goals, interests, and social participation (Evidence Level B).
- (ii) A comprehensive multi-dimensional assessment for skills and abilities to resume previous or new leisure and social activities should be performed (Evidence Level B).
- (iii) People with stroke who experience difficulty engaging in leisure and other social activities should receive targeted therapeutic interventions and individualized plans for participation based on collaborative goal setting with their health-care team (Evidence Level A).
- (iv) People with stroke may ideally be provided with information and/or referral to community-based resources for engagement and self-management for ongoing physical, social, emotional, intellectual, and spiritual activities and participation in the community (Evidence Level C).

#### **4.6 Participation in social and life roles following stroke: *Relationships and sexuality***

- (i) People with stroke, their family, and caregivers should be educated and counseled on the potential impact of stroke on relationships (Evidence Level B).
- (ii) Following stroke, people should be given the opportunity to discuss intimacy, sexuality, and sexual functioning with their health-care provider (Evidence Level B).
  - a. Topics to address in discussions may include safety concerns, changes in libido, physical limitations resulting from stroke, and emotional consequences of stroke (Evidence Level B).
  - b. Consider initiating discussions prior to inpatient discharge and as the person transitions back into the community (Evidence Level C).
  - c. Consider providing verbal and written information adapted according to a person's cognitive or communication abilities or deficits (Evidence Level C).
- (iii) Education sessions for people with stroke and/or partners may address expected changes in intimacy and sexuality, strategies to maximize sexual function, and frequently asked questions regarding relationships following a stroke (Evidence Level C).
- (iv) Referral to a sexual health specialist can be considered for people with persistent sexual dysfunction (Evidence Level C).
- (v) Medical practitioners may discuss use and contraindications of medications to address sexual dysfunction (Evidence Level C).

#### **4.7 Participation in social and life roles following stroke: *Disability supports in the community***

- (i) Health-care professionals across settings may provide people with stroke, their families, and caregivers with information and linkages regarding access to disability support services within their region (Evidence Level C).
  - a. Health-care team members, people with stroke, their families, and caregivers should work together to develop an accessibility plan prior to transition to a home or community-based living setting (Evidence Level C).
    - l. This plan should consider the person's physical function, communication, emotional, cognitive, and/or perceptual abilities and impairments following stroke.
  - b. Disability legislation and guidelines may be explained to people with stroke, family members, and caregivers, by designated health-care providers in preparation for transitions (Evidence level C).

- c. Timely completion of appropriate documentation and applications by health-care team members as required in collaboration with people with stroke, their families, and caregivers can help to minimize delays with accessing eligible services (Evidence level C).
- d. Collaboration between designated members of the health-care team and persons with stroke, families, and caregivers can help navigate systems and ensure appropriate services and equipment are accessed in a timely manner (Evidence Level C).

#### 4.8 Participation in advance care plans

- (i) The health-care team should ensure that person's goals of care and advance care planning decisions are reviewed periodically with the person with stroke, their family, and caregivers (as appropriate), and updated if needed, such as when there is a change in health status (Evidence Level B). Refer to CSBPR Acute Stroke Management Module Section 10 for additional information available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca).
  - 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 and reassessed regularly, including at transition points or when there is a change in status, with the active care team and the person with stroke or substitute decision-maker and included on the transition (discharge) summary (Evidence Level C).
  - c. Respectful discussion of values and wishes should be balanced with information regarding medically appropriate treatment related to ongoing stroke management, prognosis and future medical care (Evidence Level C).

#### 4.9 Participation in community-based palliative care

- (i) Referral and liaison with community-based hospice or palliative care services can be coordinated as appropriate based on the person's goals of care and condition (Evidence Level C). Refer to CSBPR Acute Stroke Management module Section 11 for additional information available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca).
- (ii) The needs of people with stroke, their families, and caregivers, including physical, spiritual, cultural, psychological, ethical, and social aspects may be addressed using appropriate communication skills (Evidence Level C).

### Section 5: Recommendations on transition to long-term care following a stroke

Following stroke rehabilitation, high levels of residual disability may warrant admission to a long-term care institution. Independent predictors of discharge to a nursing home include increasing age, increasing dependency for ADLs and absence of a caregiver.<sup>28-30</sup> 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. Pooling the results from 18 studies, Burton et al.<sup>28</sup>

reported the median percentage of patients transferred to long-term care was 17% following discharge from an acute care hospital with a diagnosis of stroke.<sup>31</sup> Brodaty et al.<sup>30</sup> followed 202 participants who had suffered an ischemic stroke. Among those who survived, nursing home admission rates were 24% at 5 years and 32% at 10 years. When accompanied with a comprehensive discharge plan, individuals transitioning from inpatient care to long-term care may experience a quality of life that is comparable, if not more favorable, to individuals discharged home.<sup>32,33</sup>

### Section 5 Recommendations

*Note: These recommendations apply specifically to persons with stroke living in long-term care or chronic or continuing 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 chronic, continuing, or long-term care. Recommendations included in other sections of this module, such as Supporting People with Stroke, Their Families, and Caregivers (Section 1) and Education for People with Stroke, Their Families, and Caregivers (Section 2) also apply to these settings.*

### 5.1 Assessment and care planning

- (i) All people 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). Refer to *Rehabilitation module and other sections of this module for information on assessments*.
  - 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. Consider aligning the initial assessment of functional, physical, emotional, cognitive, and perceptual status with existing assessment processes (such as the Minimum Data Set-Resident Assessment Inventory (RAI-MDS 2.0); or Multi-clientele Autonomy Assessment in Quebec) where possible (Evidence Level C).
  - c. Assessment results can be used to modify individualized care plans to optimize quality of life and meet functional, physical, emotional, cognitive, and perceptual needs and goals of people who are admitted to long-term care following a stroke (Evidence Level C).
  - d. Individualized care plans may be updated to incorporate changes in care requirements, address issues of safety, and the potential need for referrals to appropriate health-care professionals for further consultation when declines or improvements are identified during the initial assessment or subsequent reassessments (Evidence Level C).
- (ii) Chronic, continuing, and long-term care staff members should be knowledgeable in stroke care, maintenance and recovery goals, therapies, and stroke best practice recommendations and be provided with updated education in these areas on a regular basis (Evidence Level C). Refer to *HSF's Taking Action for Optimal Community and Long-Term Stroke Care resource for training content available at [www.strokebestpractices.ca](http://www.strokebestpractices.ca)*.

### 5.2 Rehabilitation and restorative care

- (i) People who have ongoing rehabilitation goals post-stroke should continue to have access to specialized stroke services (such as physiotherapy, occupational therapy, and speech-language therapy) following admission to a community living setting (Evidence Level A), including within a long-term care setting.
- (ii) At any point in their recovery, people with stroke 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 exercise, leisure opportunities, and support to engage in personally valued activities (Evidence Level B).

### 5.3 Support and education for the person with stroke and their family

- (i) To encourage active participation in care-planning consider providing training, education, and support on:
  - a. How to advocate and participate in care planning including access to rehabilitation and restorative care as appropriate and how to be involved in shared decision-making (Evidence Level C).
  - b. Process for appointing a substitute decision-maker (proxy or agent), developing advance directives for care, and palliative care options as appropriate (Evidence Level C). Refer to *Acute Stroke Management Module 2018 Sections 10 and 11 for additional information*.

## Summary

The 2019 update of the *CSBPR on Transitions and Community Participation Following Stroke* is a comprehensive set of evidence-based guidelines addressing issues surrounding transitions of care, resuming life roles, and engaging in community participation. Returning to the community can be a stressful time. People with stroke have reported that fear, anxiety,

depression, and generally being overwhelmed are magnified after they leave hospital, at a time when they need to be focused on their continuing rehabilitation and recovery (feedback from Heart & Stroke Community of Survivors Facebook Group). New and innovative approaches to care and support that is delivered in the community and includes the unique needs of the increasing number of people having strokes at a younger age are needed. The changing stroke

demographic provides further rationale for universal access to prescription medications. Canada is the only developed country with a universal health-care system that has no universal prescription drug coverage outside of hospitals, leaving 20% of Canadians (7.5 million) with no or inadequate prescription drug coverage.<sup>34</sup> This care gap has repercussions on patients, caregivers, and the health-care system as non-adherence to drug prescriptions is associated with significant increases in mortality, hospitalizations, and costs.<sup>35,36</sup>

Roles such as stroke case managers and/or stroke system navigators are valuable additions to the stroke care team. Stroke navigators empower people to be involved in their own care and the care of their family members, build self-management skills and confidence, and aid in access to community resources, support groups, and linkages. Resources for roles such as navigators are limited across Canada, even though providing supports such as navigators may reduce the burden to the health system and to health-care professionals providing reactive care. Studies to more fully examine the broad impact of these roles should be encouraged and funded. Other system constraints such as fewer transitional services available in more rural and remote parts of Canada, lack of evidence on effective strategies specific to women and or men, and challenges with affordable medications for many people increase the risk for people in the community following stroke.

Focusing on partnership and collaboration, this module emphasizes the importance of integration and coordination across the health-care system to ensure timely and seamless care for people with stroke to optimize recovery and outcomes. Key components of successful transitions are identified in Table 2. It is also essential that people with stroke, their families, and caregivers are provided with the skills and knowledge needed to promote successful transitions between all care settings and providers and to ensure continuing access to services and support in the community to maximize recovery and optimize function, quality of life, and participation following stroke.

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### Author contributions

Anita Mountain (First author) and Jill I Cameron (Senior Author) are co-chairs of the *Transitions and Community Participation following Stroke* expert writing group and lead authors contributing to all aspects of the development, data analysis, writing, editing, and final approval of this manuscript; M Patrice Lindsay is corresponding author, senior editor of the guidelines and this manuscript, involved in all aspects of scientific literature review, writing group deliberations, external review process, manuscript preparation, and a writer of supplementary documentation. Naresh Bains, Rebecca Bowes, Donna Cheung, Hélène Corriveau, Lynn Joseph, Dana Lesko, Ann Millar, Beena Parappilly, Aleksandra Pikula, David Scarfone, Annie Rochette, Trudy Taylor, and Tina Vallentin are all members of *Transitions and Community Participation following Stroke* expert writing group and contributed by reviewing, analyzing, and discussing the evidence and collectively finalizing the wording of all included recommendations. Andrea de Jong supported the external review process and the final revisions of the guidelines and manuscript. Norine Foley and Sanjit Bhogal conducted the evidence searches and completed the evidence tables and evidence summaries supporting this guideline update and contributed to writing of this manuscript. Leanne K Casaubon, Dar Dowlatshahi, and Gord Gubitz are senior leaders of



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