Case Management for Community Stroke Care
This publication was prepared with input from a number of health professionals who have reviewed the information to ensure its suitability. However, the information contained herein is for reference only, and is intended to supplement the learning provided by a recognized educational program and should not be relied upon exclusively.

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Foreword

Ontario has embarked on the development and implementation of a comprehensive, integrated stroke strategy, a groundbreaking initiative that is expected to decrease stroke mortality and residual disability across the province. By implementing this integrated stroke strategy, Ontario is leading the transformation of stroke care so that all individuals who suffer a stroke receive care based on best practices.

Beginning in the autumn of 1998, the Heart and Stroke Foundation of Ontario championed a 3-year demonstration project to develop and test a regionally based model of coordinated stroke care spanning the full continuum of care: recognition and prevention of stroke, emergency and acute care, rehabilitation, management of transitions in care, and community re-engagement. From that initial project, the integrated stroke strategy is becoming the standard way of organizing stroke services in Ontario. When the Ministry of Health and Long-Term Care allocated funds to support the development of regional stroke networks in June 2000, the Ontario Stroke Strategy was established.

Within the continuum of care, Community Care Access Centres (CCACs) play an important role in assisting stroke survivors, especially during the rehabilitation, transition, and community re-engagement stages of the continuum. CCAC case managers are central to the efficient provision of appropriate services to stroke survivors in the community.

In 2001, the Ontario Association of Community Care Access Centres (OACCAC) and the Heart and Stroke Foundation of Ontario developed a workshop for CCAC case managers to assist them in working with stroke survivors in the community. The material was later placed on the OACCAC Web site in the Best Practices section. This resource, Case Management for Community Stroke Care, builds on that initial work as well as on a series of workshops held in the autumn of 2003 in the Central South/Central West Stroke Region.

Case Management for Community Stroke Care draws upon several information sources, including Best Practice Guidelines for Stroke Care: A Resource for Implementing Optimal Stroke Care. Best Practice Guidelines for Stroke Care was published by the Heart and Stroke Foundation in 2003 to assist regions, communities, organizations, and individual healthcare providers in Ontario to contribute to the delivery of the best possible stroke care.

Case Management for Community Stroke Care has been designed to be an empowering and practical educational tool and information resource for case managers working with stroke survivors in the community and to incorporate best-practice stroke care.

As a practical tool, this resource incorporates current assessment approaches and strategies for managing resource availability. It also presents information from the case manager perspective, such as setting realistic goals for stroke survivors and optimal approaches to rehabilitation. In addition, it presents a holistic and multidisciplinary approach to service delivery guidelines, incorporating a client and family-focused attitude and the concept of agreed-upon goals. Finally, it acknowledges the need for flexibility to address inherent client differences based on the physiological variability in neurological recovery.
As a tool incorporating best practice guidelines, this resource uses the Stroke Rehabilitation Consensus Panel Report (Heart and Stroke Foundation of Ontario, May 2000) definition of rehabilitation as a:

“Progressive, dynamic, goal-oriented process aimed at enabling a person with an impairment to reach his or her optimal physical, cognitive, emotional, communicative and/or social functional level.”

In addition, it focuses on the role of the case manager as defined by the Ontario Case Managers Association definition of the case manager role:

“Case management is a form of care provision at the systems level where the care provision is that of coordinating and navigating complex systems of care “

Looking beyond: The case management evolution www.geronto.org/Vitalaging/May2002/ontassoc
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Understanding Stroke

IMPACT OF STROKE

In spite of treatment advances, stroke remains a devastating disease, a leading cause of morbidity and mortality, and one of the most expensive diseases to treat. In addition, as the population ages, the economic burden of stroke is expected to increase. Statistics analyzing health outcomes after stroke vary, but it has been estimated that 29% of individuals who experience a stroke die within a year, 20% within 3 months; 25% become dependent; and 46% remain independent.1

Stroke in Canada

Stroke mortality

Stroke is the fourth leading cause of death in Canada, with approximately 7% of all deaths in Canada attributable to stroke.2 In 1999, some 15,409 stroke-related deaths occurred in Canada. The overall population mortality rate for stroke, 47.8 per 100,000, increases substantially with age. For individuals 65–69 years of age, stroke mortality is 73.4 per 100,000, and for individuals over 90 years of age, mortality increases to 2003 per 100,000.2

Stroke morbidity

Although stroke is an increasingly treatable disease, the residual disability attributable to stroke remains significant. It is estimated that 4.1% of Canadians over 65 years of age, approximately 300,000 individuals, currently live with the effects of stroke.1 In a minority of stroke patients, impairments are severe enough to preclude living in the community. However, even many of those who return to the community suffer permanent consequences after stroke.

The Copenhagen Stroke Study, published in 1995, found that 21% of 1,197 acute stroke patients died during hospitalization, 15% were discharged to a chronic care facility, and 64% were discharged home.3 After completion of rehabilitation, 11% of survivors were left with severe or very severe neurologic deficits, 11% had moderate deficits, and 78% had either mild or no deficits. In activities of daily living, 46% had no disability, 26% were mildly disabled, 8% were moderately disabled, and 20% were severely disabled.

Approximately 25% of stroke survivors experience a recurrent stroke within 5 years.4 The risk of recurrent stroke is highest immediately after a stroke, and this risk decreases over time, with 3% of stroke survivors experiencing a second stroke within 30 days of the first event and 33% experiencing a second stroke within 2 years. The risk of severe disability and death increases with each recurrent stroke.

Cost of stroke

Stroke is one of the most costly medical conditions, accounting for a significant portion of overall Canadian healthcare dollars and costing the Canadian economy $2.7 billion annually.5
Stroke in Ontario

Incidence of stroke

It is estimated that 14,863 individuals were hospitalized for stroke in Ontario in 2000. The true incidence of stroke is higher, because this figure excludes individuals who were not hospitalized. The Heart and Stroke Foundation of Ontario estimates that between 15,000 and 20,000 strokes occur annually in Ontario.

Incidence of TIA

By definition, a transient ischemic attack (TIA) lasts less than 24 hours. However, 50% of individuals with TIA experience resolution of the deficit within 30 minutes of symptom onset. The risk of stroke for individuals with TIA is 5% within 48 hours, 8% within 1 month, 12% within 1 year, and up to 30% within 5 years.

Individuals who experience recurrent TIAs or minor strokes have an increased risk of having a devastating stroke.

Hospital data indicate that 3,496 TIA patients were discharged in 2000. This figure may substantially underestimate the true incidence of TIA, as the majority of TIA patients are no longer admitted to hospital. In fact, stroke experts estimate that only 10–25% of patients who experience a TIA are admitted, a percentage that has decreased sharply over the past decade. Applying age- and sex-adjusted incidence rates for TIA to the Ontario population yields an annual TIA incidence of 6,300.

Stroke mortality

In Ontario, mortality attributable to stroke is increasing annually, according to Canadian Institute of Health Information (CIHI) data. CIHI found that 4,955 deaths were due to stroke in 1997.

Stroke morbidity

Estimates of the number of stroke survivors in Ontario vary. Calculations based on the population prevalence of stroke survivors yield a figure of 50,000 stroke survivors in Ontario, whereas data from the National Population Health Survey (NPHS) 1996-97 suggest that 88,000 stroke survivors are living in the community in Ontario. The NPHS figure underestimates the true prevalence of stroke survivors, as it does not include individuals living in long-term care facilities.

Cost of stroke

The cost of stroke is a significant drain on the Ontario economy. The estimated annual acute care hospital cost of stroke in Ontario is $252.2-273.7 million. The total annual direct cost of stroke, which includes emergency health services, acute care, drugs, and other costs, is estimated at $528.7 million. Annual indirect costs of stroke, including productivity and pension losses, are estimated at $244.5-375.8 million. Stroke costs the Ontario economy a staggering $719-964 million every year.
ACUTE STROKE

Acute stroke is caused by a sudden interruption in the cerebral circulation. Acute stroke results in neurologic deficits and may cause death. Strokes can be either ischemic (80%) or hemorrhagic (20%) in origin.

Ischemic stroke

Ischemic strokes, which can be thrombotic, lacunar, or embolic in nature, are caused by a blockage of an artery resulting in decreased blood flow and cell death. Thrombotic stroke, the most common type of ischemic stroke, results from clot formation in a large artery due to atherosclerosis. Lacunar infarction results from thrombosis of small penetrating arteries. Embolic stroke is caused by rupture of an intravascular clot from a source outside the brain. The most common source of cerebral emboli is the heart. Clot fragments travel through the carotid artery until the blood vessel narrows enough that the vessel becomes obstructed.

Atherosclerosis

Atherosclerosis involves deposition of plaque within the arterial wall and results in progressive narrowing of the vessel lumen. Vascular occlusion and ischemic stroke may occur. Atherosclerosis often develops in areas of slow or turbulent blood flow, such as the branch points of large arteries, especially the internal carotid artery. Atherosclerotic plaque and the resulting inflammation damage the endothelial lining of the artery leading to plaque ulceration and thrombus and embolus formation.

Thrombus formation

Thrombus formation can also occur in large or small arteries in areas of endothelial damage, sluggish blood flow, or if various hematologic diseases are present. All of these conditions allow platelet adhesion and clotting factor activation. When a thrombus becomes large enough to block an artery, it will cause stroke. TIAs often precede thrombotic strokes.

Embolization

Rupture of a thrombus allows clot fragments to circulate in the bloodstream. Thromboemboli can lodged in large or small cerebral arteries and occlude them to cause stroke. Embolic strokes occur abruptly and may present with fluctuating symptoms. Sources of cerebral emboli are thrombi in carotid and vertebral arteries and in the heart.

Emboli formation can occur in the heart in several situations. Thrombi can form on insufficient, stenotic, or prosthetic heart valves. In atrial fibrillation, pooling of blood in the atria may also allow thrombus to form. Also, damage to the left ventricle as a result of myocardial infarction (MI) can predispose to thrombus formation. A thrombus forming in any of these locations can rupture and release emboli into the cerebral circulation.
Transient ischemic attack

Ischemic stroke may be preceded by a TIA, the sudden occurrence of a focal neurologic deficit that disappears completely within 24 hours. Symptoms of most TIAs resolve within an hour. As a result, patients with TIA typically present with a normal neurologic exam.

Hemorrhagic stroke

Hemorrhagic stroke, which is caused by arterial rupture, accounts for approximately 20% of all strokes and includes intracerebral hemorrhage and subarachnoid hemorrhage. Hemorrhagic stroke has a higher mortality rate than ischemic stroke. Compared with ischemic stroke, patients with hemorrhagic stroke appear more seriously ill initially, deteriorate more rapidly, and are more likely to present in a semiconscious or unconscious state.

Intracerebral hemorrhage

A hypertensive intracerebral hemorrhage is associated with prolonged and sustained hypertension and results from the rupture of a deep penetrating artery, such as the middle cerebral artery, the basilar artery, or the circle of Willis.

Subarachnoid hemorrhage

Subarachnoid hemorrhage is most commonly caused by rupture of an intracranial aneurysm. Arteriovenous malformation is another cause of subarachnoid hemorrhage. Aneurysms, which tend to form at the branch points of large intracranial arteries, and arteriovenous malformations are both thought to be developmental abnormalities.

Common neurologic deficits

The effects of stroke are unique to the individual and depend on a variety of factors: location and severity of the stroke, general health, age, and the presence of comorbid conditions. Certain deficits can be localized to specific sites and side of the brain (Table 1).
Table 1 Common neurologic deficits associated with right- and left-hemisphere stroke

<table>
<thead>
<tr>
<th>Neurologic deficit</th>
<th>Right-hemisphere stroke</th>
<th>Left-hemisphere stroke</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dysphagia</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Paralysis or paresis</td>
<td>Contralateral (left side)</td>
<td>Contralateral (right side)</td>
</tr>
<tr>
<td>Sensory deficit</td>
<td>Contralateral (left side)</td>
<td>Contralateral (right side)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Common</td>
<td>Common</td>
</tr>
<tr>
<td>Communication problems</td>
<td>Dysarthria</td>
<td>Dysarthria and aphasia</td>
</tr>
<tr>
<td>Perceptual impairments</td>
<td>Left neglect, right versus left discrimination, problems judging depth, distance, space, and passage of time</td>
<td>Uncommon, except for right neglect</td>
</tr>
<tr>
<td>Visual field deficits (both eyes)</td>
<td>Contralateral (left side)</td>
<td>Contralateral (right side)</td>
</tr>
<tr>
<td>Apraxia</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Memory impairments</td>
<td>New spatial information (location, time)</td>
<td>New language information (names)</td>
</tr>
<tr>
<td>Emotional lability</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Cognitive problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Judgment</td>
<td>Impaired judgment or insight into limitations</td>
<td>Uncommon</td>
</tr>
<tr>
<td>• Understanding of physical ability</td>
<td>Overestimate ability and underestimate disability</td>
<td>May appear to underestimate ability and overestimate disability</td>
</tr>
<tr>
<td>• Impulsivity</td>
<td>Impulsive with short attention span and perseveration</td>
<td>Normal attention span with slow and cautious reactions</td>
</tr>
<tr>
<td>• Emotional understanding</td>
<td>Difficulty comprehending or expressing emotions</td>
<td>Better able to comprehend and understand emotions</td>
</tr>
<tr>
<td>• Behaviour</td>
<td>May appear poorly motivated or exhibit behaviour problems</td>
<td>Behaviour normal for situation</td>
</tr>
</tbody>
</table>

Table adapted from Tips and Tools for Everyday Living

STROKE RECOVERY

Neurologic recovery

Neurologic recovery after stroke depends on age, comorbid medical conditions, and the location and severity of the stroke itself. As such, wide variability is seen in neurologic recovery. In the first 2 to 3 weeks following a stroke, some or all of a stroke survivor’s lost function begins to return. The time frame for recovery can be much longer, however, with gradual improvement occurring over a period of 1 year. If recovery is possible, approximately 50% of the recovery is likely to be seen within the first month after stroke, 75% within the first 3 months, and 100% by 12 months after the stroke. If function has not returned by a year after a stroke, it is unlikely to return.
Rehabilitation potential

Rehabilitation is a progressive, dynamic, goal-oriented process, and it is a key component of the stroke care continuum. It can significantly reduce disability and improve quality of life following a stroke. Rehabilitation focuses on improving motor/functional recovery and quality of life. It begins in the acute phase of stroke management and may continue after the stroke survivor has been discharged into the community. The goal of rehabilitation is to help the stroke survivor achieve optimal physical, cognitive, emotional, communicative, social and functional levels. Assessing individuals for rehabilitation potential is a complex endeavour and includes an evaluation of the following:

- Current status
  - Neurological deficits
  - Comorbid diseases
  - Functional status
  - Prestroke functional status
  - Mental status and ability to learn
  - Emotional status and motivation for rehabilitation participation
  - Functional communication
  - Physical activity endurance

- Social and environmental factors
  - Presence of spouse or significant other
  - Previous living situation
  - Ethnicity and first language
  - Adjustment of stroke survivor and family to stroke
  - Rehabilitation preferences and expectations of stroke survivor and family
  - Extent of support network for stroke survivor
  - Potential postdischarge environment

Stroke survivors may be assessed at various times. In the acute phase, stroke survivors are assessed as soon as they are medically stable, to identify rehabilitation potential and the most appropriate rehabilitation setting and intensity. Additional assessments may be performed during the rehabilitation phase to monitor progress and adjust therapeutic interventions.

Rehabilitation outcomes

Factors such as timing and intensity of rehabilitation can affect outcomes. Many studies and two reviews have clearly established a positive association between early rehabilitation and improved outcomes. A single comparative trial has confirmed that early admission to rehabilitation improves functional outcomes. Consensus exists that a clinician skilled in stroke rehabilitation should assess stroke survivors and that individuals considered suitable for rehabilitation should be admitted to a program as soon as medically feasible.

During the past decade, advances in technology, new drugs, hospital restructuring, and a shift from institutional to community-based care have dramatically altered stroke rehabilitation. Today, rehabilitation programs can be based in a variety of hospital inpatient and ambulatory programs, rehabilitation centres, complex continuing care units, and in the home.
Individuals who are appropriate candidates for rehabilitation:

- Require and can tolerate therapy to attain functional goals
- Display the potential to improve functional status
- Demonstrate sufficient cognitive skills to participate in therapy
- Demonstrate commitment to participation in therapy
- Have no need for acute care services.

It is also critical to assess the well being of caregivers and their ability to cope with the stroke survivor and to support caregiver participation in the rehabilitation program, as this may affect outcomes. Up to 50% of stroke-survivor caregivers suffer depression and psychological challenges. Factors affecting caregivers include stroke severity, caregiver health, socioeconomic status, the amount of care required, client age, behaviour, and mood, and the size of the caregiver’s social network.

**Stroke prevention**

A critical part of long-term management for stroke survivors involves prevention of a recurrent stroke, or secondary prevention. Identification and effective management of stroke risk factors may prevent recurrent strokes. Optimal management of stroke risk factors has been conclusively demonstrated to significantly reduce an individual’s risk of a first stroke and is critical to reduce the risk of recurrent stroke and other ischemic vascular events. Secondary prevention strategies encompass lifestyle modification, pharmacotherapy, and surgical interventions.

The foundation of stroke prevention is a healthy lifestyle, including smoking cessation, a healthy body weight, and a physically active life. Managing diabetes mellitus, hypertension, and hypercholesterolemia is essential, as is treating predisposing conditions, such as atherosclerosis, ischemic heart disease, and atrial fibrillation. Evidence supports the use of appropriate pharmacotherapy, including medications to manage any risk factors that are present, and specific stroke preventive therapy for all patients at risk of stroke (Table 2). Surgical interventions, such as carotid endarterectomy, are beneficial in some symptomatic patients.

Secondary prevention clinics are now being established to assist individuals with uncontrolled risk factors, whether or not they have experienced a stroke or TIA. These clinics play an important role in diagnosis, assessment, and access to appropriate interventions. A list of secondary prevention clinic locations is provided on page 19.

**Stroke risk factors**

- **Modifiable risk factors**
  - Behavioural
    - Physical inactivity
    - Cigarette smoking
  - **Predisposing conditions**
    - Stroke
    - TIA
    - Obesity
Acute myocardial infarction (MI)
Hypertension
Hyperlipidemia
Atrial fibrillation
Diabetes
Atherosclerosis
Coronary heart disease
Asymptomatic carotid stenosis
Peripheral vascular disease
Other cardiac disease
Coagulation disorders
Estrogen/progestin replacement therapy.22

Unmodifiable risk factors
Increasing age
Genetic factors
Male sex
Race

Probable risk factors
Migraine
Oral contraceptive use
Alcohol abuse
Stress
Sleep apnea
Sympathomimetic agents
Illicit drug use
Congenital cardiac anomalies

Table 2 Pharmacotherapy in stroke prevention

<table>
<thead>
<tr>
<th>Risk factor reduction</th>
<th>Antihypertensive agents</th>
<th>Antihyperlipidemic agents</th>
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<tr>
<td></td>
<td>various classes</td>
<td>statins and other classes</td>
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</table>

<table>
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<tr>
<th>Specific stroke preventive therapy</th>
<th>Angiotensin II receptor blockers</th>
<th>ACE inhibitors</th>
<th>Anticoagulant therapy</th>
<th>Antiplatelet therapy</th>
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<tbody>
<tr>
<td></td>
<td>losartan</td>
<td>ramipril</td>
<td>warfarin</td>
<td>ASA, clopidogrel, dipyridamole plus ASA</td>
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REFERENCES


ONTARIO STROKE SYSTEM

Overview

Organized stroke care, an integrated evidence-based approach to managing stroke, has been shown to reduce mortality and morbidity and improve functional ability and quality of life for stroke patients. Organized stroke care by its very definition includes the entire continuum of care, from prevention to community re-engagement. The objective of organized stroke care is to improve stroke outcomes by ensuring that the time to definitive diagnosis and treatment is minimized and that optimal treatment is offered.

In early 1997, the Heart and Stroke Foundation of Ontario convened a group of stroke experts from across the province and developed a framework for stroke care in the province. Through its work, the Heart and Stroke Foundation became aware of several local efforts to address the issues of enhancing stroke care. It was agreed that a collaborative project to develop and test the model of stroke care would maximize the impact of these efforts. As a result, the Heart and Stroke Foundation championed the Coordinated Stroke Strategy to develop and test a regionally based model of coordinated stroke care spanning the full continuum of care.

Four geographic areas served as demonstration sites for the 3-year pilot project which was launched in 1998: London Health Sciences Centre (South West), Hamilton Health Sciences Corporation (Central West), Queen's University Care Delivery Network (South East) and the West GTA. The West GTA group consisted of Humber River Regional Hospital, William Osler Health Centre, St. Joseph's Health Centre, Trillium Health Centre, West Park Healthcare Centre and the CCACs for the area.

The overall goal of the stroke strategy is to decrease the incidence of stroke and improve care and outcomes by reorganizing stroke care to ensure that all Ontarians have timely access to appropriate and high-quality stroke care.


In June 2000, the Ministry of Health and Long-Term Care allocated up to $70 million for the 4-year implementation phase to support the development of a provincial stroke strategy, the Ontario Stroke System. The success of the Coordinated Stroke Strategy was a major factor in the Ministry's commitment to a province-wide strategy for organizing stroke care, the Ontario Stroke System.

The Ontario Stroke System promotes a model that is

- *Comprehensive*, to improve stroke services across the entire continuum of care, from prevention programs to long-term care or community settings
- *Integrated*, so that essential services and providers function as a unified whole, with formal linkages established across the continuum of care and across Ontario to minimize duplication of services and optimize existing resources
- *Evidence-based*, to build on practices and care that have been supported by scientific evidence or are considered the gold standard (“best practice”) according to prevailing knowledge
- *Province-wide*, to ensure that care is available to all Ontarians in all parts of the province (through designations, telemedicine etc.).

The Ontario Stroke System is based on a 3-tier model consisting of regional stroke centres (RSCs), district stroke centres (DSCs) and community hospitals. Each regional stroke centre and district stroke centre must meet designation guidelines and readiness criteria, including requirements based on what is currently accepted as the ‘gold standard’ in acute stroke care. These designated sites have additional roles, including a role in organizing the human and medical resources for their region. The RSCs also have the responsibility of providing leadership for the growth and development of the Ontario Stroke System in their region in partnership with the DSCs, community hospitals, community systems and other key stakeholders. The DSCs work with their RSC and local partners to provide leadership for the coordination and supervision of the continuum of stroke care within their region.

In 2003/04 the Ontario Stroke System consists of the following:

- 9 regional stroke centres
  - Hamilton Health Sciences
  - Kingston General Hospital
  - London Health Sciences Centre
  - The Ottawa Hospital
  - Michael's Hospital
  - Sunnybrook and Women’s College Health Sciences Centre
  - Trillium Health Centre
  - Thunder Bay Regional Hospital
  - University Health Network, Toronto Western
- 17 district stroke centres
  - Bluewater Health, Sarnia
  - Brantford General Hospital
  - Grand River, Kitchener
  - Grey Bruce Health Services, Owen Sound
  - Niagara Health System, Niagara General
  - North Bay General Hospital
  - Peterborough Regional
  - Pembroke General Hospital
  - Quinte Healthcare, Belleville
  - Royal Victoria Hospital, Barrie*
  - St. Joseph’s, Chatham
  - Sault Area Hospitals
  - Stratford General Hospital
  - Sudbury Regional Hospital*
  - Timmins and District Hospital
  - Windsor Hotel Dieu Grace*
  - York Central Hospital, Richmond Hill* Enhanced District Stroke Centres (EDSC). The EDSC has been established to provide the leadership and integration in the regions of
Ontario where the designation of a Regional Stroke Centre (RSC) cannot be met. The Ministry’s regional expectations of the EDSC are comparable to that of the RSC.19 Secondary Prevention Clinics (15 Prevention Clinics and 4 Community Prevention Clinics)

Secondary prevention clinics are responsible for working in partnership with primary care, acute care, stroke rehabilitation, community care access centres and other stakeholders in planning regional stroke prevention strategies and for providing an integrated, comprehensive, interdisciplinary approach to stroke prevention and case management for high-risk patients.

During 2004/05 the Ministry plans to transition the management of the Ontario Stroke System from a centralized provincial approach to a regional provider approach with central monitoring. The development of the ongoing management model for the Ontario Stroke System will include a robust accountability framework built upon an evidence-based foundation.

Designated RSCs will have fiduciary responsibility for regional coordination and integration for all patient care sectors and services. The regional steering committee, in partnership with the regional stroke centre, will govern the patient care sector funds in order to maintain and sustain the regional stroke strategy. Accountability for this regional model will be through the regional executive team:

- Regional steering committee chair
- Medical director
- Regional stroke centre senior executive
- Regional program manager

The Heart and Stroke Foundation continues to work with the Ministry and Regional Stroke Centres to organize stroke care in Ontario. There are 3 major components of the stroke strategy: systems change, public awareness, and professional education.

The overall goal of systems change is to increase access to stroke services, improve the quality of stroke care and increase efficiency in the organization and delivery of stroke care.

The public awareness component includes a combination of television advertising and public relations to establish awareness of the signs and symptoms of stroke. Walter Gretzky is the stroke spokesperson for the Heart and Stroke Foundation.

Numerous professional education resources and programs have been developed along the continuum of care for stroke care providers to ensure that best practices for stroke care are implemented. For more information about professional education resources or to obtain copies, call 416-489-7111, 389, e-mail csor@hsf.on.ca or visit www.heartandstroke.ca/profed

Pilot projects

A variety of stroke strategy pilot projects have been implemented throughout Ontario to test different approaches to enhancing stroke care. Selected projects with relevance for CCAC case
CONTINUUM OF STROKE CARE

Continuum description

Reducing morbidity and mortality from stroke involves a concerted effort at all stages of what is known as the continuum of care, comprised of the stages described below.\(^2\)

Recognition

Improving stroke outcomes by increasing the number of stroke survivors eligible to receive time-dependent stroke therapy depends on broad recognition by the public and healthcare professionals of the possibility of stroke in an individual case and on taking immediate action, such as calling 911 or local emergency services.

Prevention

Increasing stroke prevention efforts is of paramount importance, because of the high prevalence of risk factors in the Canadian population. In fact, 75% of Canadian adults have at least one stroke risk factor. Stroke prevention relies on risk factor reduction, both at a population and an individual level. Health promotion addresses stroke prevention at a population level, whereas primary and secondary prevention address an individual’s risk of stroke. Implementing optimal stroke prevention, using consistent and effective preventive strategies, has the potential to significantly reduce the incidence of stroke in Ontario, perhaps by as much as 50%.

Prehospital care

Effective and rapid prehospital care is a critical part of the continuum of care for stroke patients. Paramedics can play a major role in improving overall stroke care by minimizing scene times, providing optimal prehospital assessment and treatment, and rapidly transporting the patient to the most appropriate hospital. Implementing prehospital protocols for early identification and notification of the receiving hospital can also substantially reduce the time to definitive treatment, thus improving outcomes.

Emergency management

Rapid and appropriate emergency management during the first few hours after a stroke can substantially improve health outcomes. Urgent triage and diagnosis are critical to distinguish ischemic stroke from hemorrhagic stroke, diagnose stroke-mimicking conditions, such as hypoglycemia, and ensure access to time-dependent stroke therapies, such as thrombolytic therapy. Regardless of the type of stroke, *time is brain*. The earlier that definitive treatment is instituted, the more likely the outcome will be favourable.
Acute treatment

Stroke is a medical emergency requiring immediate hospitalization and specialized supportive care in a stroke unit. Evidence exists that an interdisciplinary team approach to acute stroke care in a dedicated stroke unit results in the best outcomes, reducing mortality and improving functional ability of stroke survivors. The process of setting up stroke units and training staff has been implemented.

Transition management

Effective transitions are an integral part of improving stroke management across the entire continuum of care. The transition process determines the most appropriate next step in care and manages both the transfer in responsibility for care and the physical transfer of the stroke survivor. Transitions may be made within or between organizations, or from an organization to home, complex continuing care, or to long-term care. A stroke survivor may undergo several transitions in care, and optimal management of transitions can reduce hospital stays, facilitate rehabilitation, and speed recovery.

Rehabilitation management

Stroke rehabilitation, a progressive, dynamic, goal-oriented process, is a key component of the stroke care continuum, as it can significantly reduce morbidity and improve quality of life following a stroke. Beginning in the acute phase of stroke management, rehabilitation continues in the community. The objective of rehabilitation is to help the stroke survivor realize optimal physical, cognitive, emotional, communicative, and social functional levels.

Community re-engagement

Community re-engagement is the anticipated end result of rehabilitation and the goal for stroke survivors. Community re-engagement requires an environment facilitating empowerment and re-integration of a stroke survivor and caregiver into family, social and community relationships and activities. Throughout the continuum of stroke care, care providers play an important role in facilitating ultimate community re-engagement by empowering and supporting stroke survivors to fulfill their hopes and dreams, assisting stroke survivors to develop goals and a plan to achieve them, ensuring that rehabilitation progresses, and sustaining their clients’ feelings of optimism about their recovery.

Best practice guidelines and CCAC implications

The guidelines outlined in Best Practice Guidelines for Stroke Care have been developed to assist healthcare professionals and provincial healthcare administrators to identify and implement optimal stroke management strategies and to deliver optimal stroke care. These guidelines are based on available clinical trial evidence and are listed below by stage of the continuum.

CCAC case managers generally work with stroke survivors in the following stages of the continuum of care: transition management, rehabilitation management, and community re-engagement. CCAC case managers have opportunities to become involved in prevention by distributing resources to stroke survivors and caregivers.
Practical implications for case managers of the best practice guidelines for these continuum stages are described within the appropriate section below.

**Stroke recognition**

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

**Stroke prevention**

2. Develop an optimal stroke prevention strategy in a timely manner for all individuals at high risk of stroke, all individuals with TIA, and all stroke survivors. The strategy should include the optimal use of stroke prevention services, a plan for lifestyle modification, pharmacotherapy, and a plan for effective communication between the client, primary care physician, and stroke prevention services.

3. Educate individuals at high risk of stroke, those who have experienced a TIA or stroke, family members, and healthcare providers about stroke prevention, relevant information resources, and how to gain access to them.

**Prehospital care**

4. Develop formal bypass or diversion protocols and transfer agreements, so that individuals meeting inclusion criteria for time-dependent therapy have the opportunity to receive it.

5. Conduct a rapid assessment that includes use of the acute stroke protocol inclusion criteria and determine the patient destination, using the acute stroke protocol, including the Emergency Medical Services destination policy.

**Emergency management**

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

**Acute treatment**

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

**Transition management**

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

9. Manage transitions with an interdisciplinary team all using standardized information and processes, to ensure that relevant documentation is transferred with the client to facilitate continuity of clinical and case management.
10. Identify and confirm the primary healthcare provider before the stroke survivor is discharged from acute care, and keep this individual informed throughout all phases of care.

11. Provide opportunities for ongoing access to rehabilitation and community services for stroke survivors and their families, during all phases of care.

**CCAC implications**

Effective transition planning requires a holistic approach and a complete picture of the client and family or caregiver to understand the physical and psychosocial aspects of movement to the next setting and determine the preparation required. Other factors affecting the appropriate service transition plan include the functional status of the stroke survivor, the prognosis and the family support available. Ultimately, it is the stroke survivor and family who must make the final decision about the transition plan.

Standardized provincial protocols for transitions do not currently exist, although some CCACs and hospitals may have developed their own transition procedures. Several provincial projects focusing on client transitions from acute care to rehabilitation, rehabilitation to home, and acute care to long-term care are underway, and results of these projects are expected to be available by the end of 2004.

In the interim, CCACs are encouraged to work with local hospitals and rehabilitation centres in their area to standardize information transferred on discharge. At a minimum, the information gathered would allow an assessment of rehabilitation potential (See Outcome measures and assessment tools, Appendix D). Results of the RAI-HS (Resident Assessment Instrument-Home Care) and related MAPLe results (Method for Assigning Priority Levels (MAPLe), support case manager decision-making for transitions in service provision.

It is recommended that, at admission, the CCAC case manager identify the client’s primary healthcare provider. The case manager is then able to work with the physician to support client community re-engagement, participation in secondary prevention programs and the development of standard practices for provider communications with the client’s physician.

When working with stroke survivors, it is important that case managers include a goal specific to community re-engagement. The client service plan should therefore include appropriate linkages to community programs. To facilitate this goal, it is recommended that CCAC case managers develop an awareness of available programs and resources within their communities and assist with linkages either directly or through provider service plans.

**Rehabilitation management**

12. Evaluate the rehabilitation potential of each client and include a complete assessment conducted by the stroke rehabilitation team. Develop a comprehensive rehabilitation plan for each client that reflects the severity of the stroke and the needs and goals of the stroke survivor.

13. Ensure that access to the appropriate intensity of rehabilitation services is available to stroke survivors throughout the continuum of care.
14. Assess the ability of the family and caregiver to support a stroke recovery process. Develop a strategy that includes an educational component to address the caregiver’s burden.

15. Discharge stroke survivors from rehabilitation units in a timely manner, once realistic goals have been achieved and intensive inpatient rehabilitation is no longer required.

*CCAC implications*

It is critical that CCACs obtain appropriate information from the referring institution or organization to enable them to evaluate the rehabilitation potential of each client. Results of the CCAC assessment (RAI-HC) should be reflected in the goals developed for the service providers.

It is also important for case managers to ensure that rehabilitation providers develop shared goals with the participation of the client and maintain communication with each other and with the CCAC. In addition, the global rehabilitation goals and message communicated to the client by the providers must be consistent.

Adjustment of the family and caregiver to the new situation is important to the client’s optimal stroke recovery. It is therefore recommended that the case manager assess the psychosocial impact of the client’s stroke on the household members, and initiate referrals to CCAC or other community services for social work (SW) or occupational therapy (OT) if required.

*Community re-engagement*

16. Assist the stroke survivor and family to develop and implement an evolving care plan by conducting 6-week, 3-month, and 1-year follow-up assessments of all aspects of health status, community participation, and links to prevention services.

17. Create strategies to enable healthcare professionals and caregivers in community and long-term care settings to develop stroke care expertise to support stroke survivors in achieving their goals.

18. Support caregivers in balancing personal needs and caregiving responsibilities by providing community programs, respite care, and educational opportunities, and by linking caregivers to these programs.

19. Assist stroke survivors to maintain, enhance and develop appropriate social support.

*CCAC implications*

Timeframes for follow-up assessments of health status, community participation, and links to prevention services listed in the guidelines refer to time elapsed since the stroke. Within the CCAC setting, timeframes for interventions may differ. However, the key implication of the guideline recommending follow-up assessment is that the service plan should be adjusted as client needs change, based on appropriate reassessment.

CCACs can play an important role in encouraging providers to develop stroke expertise by considering expertise in stroke care in all requests for proposal; by including service provider
organizations in any training programs that are conducted; and by ensuring that service providers are aware of resources available through the Heart and Stroke Foundation.

Case managers in CCACs can also play an important role in supporting caregivers by linking caregivers to community programs, respite care, and educational opportunities. In addition, case managers are central to assisting stroke survivors to develop and maintain appropriate social supports through comprehensive discharge planning and linkages to community programs.

CASE MANAGEMENT AND THE STROKE SURVIVOR

CCAC case management overview

The CCAC is a single point of access to community services. Because CCACs interact with the entire healthcare system, these organizations are in an optimal position to facilitate service integration and information sharing. Case management, a core CCAC service, allows clients access to a range of services. The relationship between case manager and client fosters client independence and the ability to make healthcare choices (Table 1). Case management also promotes service consistency, coordination, quality and accountability, while optimizing health and human potential and resource utilization (Table 2).

Case management includes a broad range of activities carried out by professional case managers, placement professionals, information and referral staff, team assistants and management staff employed by CCACs. Case management is available to all CCAC clients whether they require in-home services or placement in a long-term care facility. Case management includes the following functions:

- **Assessment**: Gathering and analyzing information in a standardized, systematic manner from clients, caregivers, physicians and others to identify specific needs and goals of individual clients. Assessment begins with the first encounter with a client and continues until discharge.
- **Information provision and referral**: Providing information about available health and support services and assisting clients to obtain access to appropriate services to meet immediate and ongoing needs.
- **Service planning**: Designing a plan of action to meet identified client needs and goals, using a variety of formal and informal services and redesigning the plan as client needs evolve.
- **Coordination**: Providing client advocacy and education about responsibilities and rights, planning for future healthcare needs and establishing linkages to other services to ensure continuity of care. Effective coordination depends on regular and ongoing communication with clients, family physicians, caregivers and service providers.
- **Service evaluation**: Reviewing the service plan regularly with the client and community team members to ensure that it continues to meet client needs and to measure outcomes against previously agreed-upon goals and commitments.
- **Resource management**: Optimizing available formal and informal resources to achieve agreed-upon goals; determining which services are required and in what quantity and duration; and following principles that ensure fairness and equity in resource allocation.
- **Discharge planning**: Implementing ongoing discharge planning throughout the time services are provided as specific goals are achieved.
- **Community outreach**: Working with other health system partners to identify and solve system integration and coordination issues; to develop and implement innovative approaches.
to service delivery; to evaluate service and system effectiveness; to identify unmet needs and recommend service options; and to educate stakeholders about the role of CCACs.

Table 1 Case management objectives and the client/caregiver

<table>
<thead>
<tr>
<th>Meaningful client interaction</th>
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<tr>
<td>• Optimize health and human potential of clients</td>
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<td>• Involve clients in service planning and decision making</td>
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<tr>
<td>• Address health and social needs of each client</td>
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<tr>
<td>• Increase awareness of mutual expectations</td>
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<thead>
<tr>
<th>Comprehensive assessment</th>
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<tr>
<td>• Assess client and caregiver needs using standardized assessment tool</td>
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<td>• Reduce assessment duplication by sharing standardized assessment results</td>
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<table>
<thead>
<tr>
<th>Improved access to services and support</th>
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<tbody>
<tr>
<td>• Activate and promote wide variety of informal and formal support systems</td>
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<tr>
<td>• Provide information and referral to wide range of supportive services</td>
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<tr>
<td>• Improve access to care for clients and communities</td>
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<td>• Provide advocacy support</td>
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<tr>
<th>Caregiver support</th>
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<tbody>
<tr>
<td>• Recognize and support caregiver role formally</td>
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<td>• Address caregiver needs and limits in service plan</td>
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<tr>
<td>• Balance formal and informal supports to support and maintain caregiver role</td>
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<tr>
<th>Improved client outcomes</th>
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<tr>
<td>• Maintain client in environment of choice</td>
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<tr>
<td>• Promote independence and client actualization</td>
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<tr>
<td>• Foster development of health-promoting relationships</td>
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<td>• Create client satisfaction</td>
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<tr>
<th>Coordination of care</th>
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<tbody>
<tr>
<td>• Coordinate informal, service provider and community support for client</td>
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<tr>
<td>• Mediate and facilitate issue resolution with service providers and agencies</td>
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<tr>
<td>• Evaluate and monitor service quality</td>
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<tr>
<td>• Ensure a seamless transition of service delivery across continuum of care</td>
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<tr>
<th>Continuity of care promotion</th>
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<tbody>
<tr>
<td>• Connect and promote cross-system continuity in provision of care to client</td>
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<tr>
<td>• Support and promote provider links to improve client service</td>
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<tr>
<td>• Ensure integration of service delivery models between CCAC and providers</td>
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<tr>
<td>• Promote cooperation, communication and coordination across care providers</td>
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<th>Support of service providers</th>
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<tr>
<td>• Support service providers in their roles</td>
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<tr>
<td>• Promote communication, coordination and partnerships in care delivery between providers and other parts of the continuum</td>
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Table 2 Case management objectives and the system
Independent resource stewardship
- Maintain objective resource stewardship promoting appropriate use of services and resources
- Remove conflict of interest inherent to direct service provider being responsible for resource allocation decisions
- Centralize fiscal accountability and responsibility associated with provision of community-based health care

Resource use optimization
- Promote effective use of resources: provide right service at right time at right cost
- Promote environment providing lowest cost, highest quality care for clients
- Coordinate and optimize formal and informal resources across continuum of care

Service standardization
- Standardize approach to assessment, eligibility determination and service provision
- Standardize care provided to clients with similar needs
- Standardize service provision environment to enable evaluation and research
- Promote development and commitment to service provision standards

Quality improvement
- Provide systemic approach to identification and resolution of service quality issues
- Promote evaluation and research to improve community-based health services

System coordination and communication
- Promote coordination and communication across organizations and systems of care
- Provide central access point for care providers and for evaluation, payment and delivery of publicly funded community-based health services

Population and individual health service identification
- Work with communities, populations and individuals to identify unmet healthcare needs
- Collaborate with organizations across the continuum to develop innovative and cost-effective responses to unmet needs

Case management considerations relevant to stroke

In many ways, working with stroke survivors is similar to working with other clients. In other ways, however, stroke survivors differ as a group. Additional information on working with stroke survivors with various impairments is contained in *Tips and Tools for Everyday Living: A Guide for Stroke Caregivers*.4

Not only does stroke have a dramatic physical effect, but also it can have significant psychosocial effects on both stroke survivors and their families.4 Stroke survivors often feel fearful and anxious about their future. Impairments may be seen as a significant threat to self-image and self-esteem. As time goes on, stroke survivors may become depressed and grieve for lost abilities. They may become tired, frustrated and disinterested in social contact. Often, family members feel stress and worry about the stroke survivor’s future. The family may also feel grief, sadness, anger, and frustration over the changes in their lives as a result of the stroke, or guilt when they take time for themselves, rather than focusing on the stroke survivor. Both stroke survivors and their family members need support, encouragement, and positive feedback. They may also need education and assistance in coping. When working with stroke survivors, it is
important to watch for signs of stress, depression, and other emotions that may negatively affect outcomes.

**Addressing neurologic recovery status**

As part of their caseload, case managers may work with stroke survivors at various stages of rehabilitation. Some individuals will have had a recent stroke, that is, within the previous 2 months. Service goals for these clients relate primarily to rehabilitation and community re-engagement. As a result, these individuals often stay on the CCAC caseload for only 2 to 3 months. Another population of persons with stroke is admitted after a period of long-stay rehabilitation. The service goals for these individuals may focus on rehabilitation or on development of a life program to maintain the client at an optimal functional level. The final population of stroke clients includes long-stay or maintenance clients, many of whom may have been on the caseload for personal support for several years. These clients may require brief rehabilitation intervention to increase functional levels.

**Implementing a client-centred approach**

In the management of stroke, client-centred care has been shown to reduce client anxiety; facilitate the establishment of trust; and improve client satisfaction, compliance, and functional outcomes. A client-centred approach to care is based on a philosophy of respect for, and partnership with, individuals receiving services. This approach also recognizes the importance of individual autonomy and choice and service flexibility and accessibility. This perspective is an important part of effective case management for stroke survivors.

**Managing communication issues**

Stroke survivors may have to cope with a variety of communication problems, including aphasia, dysarthria, or lack of a translator if they are not fluent in English or French. In addition, they must often cope with the common misconception that the stroke has made them less competent or intelligent, neither of which is true. It is critical to recognize that these individuals know much more than they can articulate. They can be helped if the caregivers and healthcare professionals with whom they come in contact treat them as competent and intelligent and exercise patience and persistence.

Effective communication requires a partnership between stroke survivors and their caregivers, and it involves adaptive techniques and devices and caregivers who understand the survivors’ abilities and need for support. Such a partnership improves communication and quality of life for both survivors and caregivers.

Ensuring that stroke survivors’ values, strengths, desires, and needs are communicated increases self-esteem and may help to eliminate behaviours resulting from anger and frustration. Improved communication may also increase survivors’ independence, their enjoyment of leisure and recreational activities, and overall self-care. Both survivors and caregivers are more satisfied with the increased understanding that results from improved communication.
Understanding cognitive dysfunction

The process of working with stroke survivors may be complicated by cognitive dysfunction resulting from the stroke. Cognitive dysfunction has been described as an invisible barrier. It can, however, be a formidable barrier to rehabilitation. Because cognitive dysfunction is not obvious, family and caregivers may overestimate the survivor’s capabilities and become frustrated when their expectations are not met. It is important that the case manager recognize these problems as an effect of stroke. Only then will it be possible to identify and implement strategies to assist stroke survivors with cognitive difficulties to succeed in performing tasks. Cognitive dysfunction may be manifested in insight problems, or difficulties with attention or memory.

Coping with personality and behaviour changes

A stroke may have little or no effect on behaviour or personality, or it may have dramatic effects. To further complicate the matter, behavioural and personality changes may be intermittent. Nevertheless, specific patterns of behaviour and personality changes have been noted in stroke survivors. Appropriate strategies to manage these changes depend on the underlying cause.

Personality changes

Stroke can reduce an individual’s emotional control, which can alter the way stroke survivors interact with people. Stroke survivors may have wild mood swings; become easily irritated; or be indifferent, stubborn or disinterested in things around them. It is important for case managers to remember that these changes, which can be very frustrating to family and friends, are due to the stroke and that they may not reflect the individual’s true feelings. Adapting to changes resulting from a stroke takes time, for both the stroke survivor and the family. The negative emotions experienced by stroke survivors and their families can have a profound effect. These reactions should be respected and the individuals treated with kindness, patience, and respect.

Emotional lability

Emotional lability, or loss of emotional control, is often due to brain injury caused by the stroke, rather than being a reaction to perceived losses. In fact, the stroke survivor may feel different emotions than those being expressed. In this situation, it is useful to ask the stroke survivor whether in fact he is feeling the emotion he is expressing. It is also helpful to reassure the stroke survivor that loss of emotional control after a stroke is common.

Withdrawal

Diminished self-esteem, self-image, and confidence may result in the stroke survivor withdrawing from social contact, even as routine activities of daily living are relearned. Encouraging and assisting the stroke survivor to participate in life in a variety of ways is an important part of supporting a positive outcome. Participation in self-care, discussions and decisions, and involvement in social and church activities are all ways that social isolation can be reduced.
Anger and aggression

Triggers for angry outbursts and aggressive behaviour include frustration over tasks the survivor is unable to perform, embarrassment over a toileting accident, pain in the affected limb, and frustration with communication problems. By working with the stroke survivor, it may be possible to identify the cause of the anger and to develop a strategy to resolve it.

Lethargy

Survivors of a right-hemisphere stroke may appear to lose interest in daily activities and leisure pursuits. In addition, if their initial attempt to perform a task was unsuccessful, they may give up and resist encouragement to try again. It is often helpful to adapt activities to the interests of the stroke survivor, to provide positive reinforcement for expressed interest in activities, to support any involvement in activities and to encourage the stroke survivor to try a task again.

Frustration

Frustration is a common response to communication difficulties. It is important not to overestimate or underestimate communication and comprehension skills, to provide the time and opportunity to communicate at the client’s pace, and to use short simple messages.

DEVELOPING AND IMPLEMENTING A SERVICE PLAN

Developing an effective service plan for a stroke survivor in the community depends on an understanding of the effects of stroke on the stroke survivor and the family, a comprehensive assessment of the client and knowledge of the service implications, a clear understanding of processes involved in service delivery implementation, and knowledge of available resources.

Assessment of the stroke survivor

The standard assessment for the case manager to implement with the stroke survivor is the RAI-HC, which includes the MDS-HC and the Client Assessment Protocols (CAPs). An accurate MDS-HC is essential, as it is the foundation for CAPS and for determining the risk of adverse health outcomes, using the MAPLe algorithm. Additional valuable information may be obtained from a review of the discharge summary and client scores on different assessment tools and outcome measures (See Outcome measures and assessment tools Appendix D).

Service delivery considerations

Individual CCACs may have different authorization rules or approaches to identifying and stating goals and outcomes, within the provincial standards for case management. However, as early rehabilitation has been shown to improve outcomes, it is important that stroke survivors be considered a mid-range priority for rehabilitation service urgency. Individuals with acute stroke should receive rehabilitation services within 2 weeks of referral to the CCAC from the hospital. A broad range of information is available to assist case managers in determining service priorities with the client and in identifying the optimal therapeutic disciplines to activate.

When working with stroke survivors who require rehabilitation, the main goals are education, self-responsibility for activity, and exercise with a focus on function within the home and
community. Within the context of the CCAC service mandate, in-home rehabilitation must be both time limited and specific. In addition, the case manager should ensure that all client goals are SMART (Specific, Measurable, Achievable, Realistic, and Timely) goals. Only in this way is it possible for the client, the case manager, and the service provider to develop a shared understanding of the scope of the service. When working with long-stay clients with stroke, the case manager should monitor client functional level over time using provincial assessment standards and evaluate the service plan as necessary. A change in client status should prompt alteration of the service plan to meet current client needs.

**Team coordination**

The variety of impairments that an individual client may have as the result of stroke and the interplay between physical and psychological factors can make the stroke survivor a challenging client. In addition, the impact of the stroke on the family can be substantial. These factors create a situation where effective team coordination and follow-up can significantly affect the outcome. As a result, the case manager must maintain close contact with the client and service providers and ensure that effective communication strategies are in place.

**Accessing community resources**

A wide variety of resources are available to the case manager dealing with stroke survivors. These resources can be accessed through the Heart and Stroke Foundation, associations focused on specific impairments, such as aphasia, and through the district and regional stroke networks. In addition, numerous pilot projects in community care for stroke survivors, such as the one evaluating the role of self-help groups for stroke survivors, can provide ideas and insights for the creative case manager searching for community resources.

**REFERENCES**

Applying Principles: Case Studies

CASE STUDY #1

Client description

Mrs CW is a 42-year-old married mother of 2 children, a daughter 5 years of age and a son 7 years of age. A few years ago, she and her family immigrated to Canada from northern Europe. She is fluent in English (her second language) and she has been employed as a cashier in a large grocery store. Her husband is employed as a construction worker during the day and moonlights working at home renovation in the evening to augment the family income. The family lives in a 2-storey rented home in a rural area 10 miles outside the town.

Mrs. CW has had type 1 diabetes since childhood. She has not been monitoring her sugar closely, due to the cost of glucose test strips. As a result, her diabetes has been poorly controlled. She was first diagnosed with hypertension a year ago, and has been advised to restrict her salt intake.

Two weeks ago, Mrs CW suffered a moderate left middle cerebral artery (MCA) ischemic infarct. Prior to the stroke, she functioned independently, managed a busy household and worked part-time.

Acute care discharge summary

Mrs CW was treated at her district stroke centre for 8 days and began rehabilitation at a high-intensity inpatient unit where she has been for the past 2 weeks. She was scheduled for another week of intensive rehabilitation, but both the client and her spouse were insistent that she be discharged home, as they believed she could resume her parenting and homemaking duties. She is still independent for managing her insulin injections.

She has shown marked improvement from the initial presentation at emergency. Mrs CW currently presents with the following residual limitations: expressive aphasia; mild right-sided weakness (ambulates with a quad cane under supervision for short distances), and eating pureed foods.

Initial plan

The rehabilitation hospital CCAC case manager assessed the client’s need for services at home and included the following services as high priority in the initial plan:

- Physiotherapy (PT) to address mobility and stabilization
- OT to address vocational integration and activities of daily living (ADLs)
- Speech-language pathology (SLP) to address dysphagia and aphasia
- Nursing to address issues related to diabetic control.

She also counselled the client and her caregiver on the need for constant supervision and requested the community case manager to visit as soon as possible. The family was given information as to where they might purchase a quad cane on the way home from hospital.
RAI results

The community case manager visited 4 days after the client left hospital. Nursing and PT had already visited and the SLP was expected the following week. Mrs. CW was on a waiting list for OT services. Mr CW was present and expressed his frustration with needing to earn a living but not being able to leave his wife alone for fear of falls and choking. The case manager explored with them their informal supports but there seemed to be few available. At this time, the client was not ready for a daycare program.

The RAI was completed triggering 12 out of a possible 30 CAPs, with client agreement to address 9:

1. ADL rehabilitation potential
2. Instrumental ADLs (IADLs)
3. Health promotion
4. Communication disorders
5. Falls
6. Oral health
7. Brittle support system
8. Medication management
9. Environmental assessment

Service plan and goals

For discussion

1. As the community case manager, what service plan would you develop for this client?
2. What challenges would you expect to encounter in dealing with this client and how would you address them?

Service plan

The case manager established the following with the agreement of the client.

A. Continue with services already authorized

1. PT to improve mobility, strength, endurance and safety
2. OT to promote maximum independence in ADL
3. SLP to promote improved verbal skills; to assess and advise on management of dysphagia, in consultation with dietitian
4. Nursing to review with client independence in all aspects of diabetic management.

B. Add following services

1. Dietitian to visit jointly with SLP to advise on management of dysphagia and to educate on appropriate diet, considering family’s financial situation
2. SW to work with client and spouse to assist in adjustment to her changed status, family impact of that change, and financial issues.
3. Personal service worker (PSW) under direction of OT to promote independence with hygiene, dressing, and involve client in IADLs; 2 hours daily, 5 days weekly for 2 weeks; to be reassessed by case manager after 2 weeks and reduced as client regains independence. Husband would supervise breakfast and dinner and PSW would supervise lunch.

4. Lifeline: recommended because client would be alone for several hours daily. Family was asked to consider a biweekly cleaning service.

5. A drug card and information on the Trillium Drug Program were provided.

Case evolution

Progress reports

All providers commented on client determination to regain her previous independence. However, her tendency to be unrealistic about her present capabilities was leading to personal risk and frustration. Although she was ambivalent when her mother, Mrs AL, announced that she was coming from Europe for a 3-month visit to help her daughter during her recovery, her mother’s arrival provided the support the family needed at this time. In fact, Mrs AL became an active participant in her daughter’s rehabilitation.

PSW service was discontinued, as the client and her mother agreed it was not needed. Nursing was also discontinued after completion of client teaching. The OT continued working with the mother in progressing the client towards independence with ADLs and IADLs. Dietitian services were also discontinued, and the client’s mother was able to follow through with the nutritional advice. Swallowing difficulties had resolved. The client was able to eat normal food without incident, and her speech was slowly improving. Mrs AL was also able to assist her daughter with the strengthening exercises prescribed by the PT.

The SW worked with the client and her husband to assist them in making realistic return-to-work plans and in evaluating their financial options. The client and her husband were searching for rental accommodation in town to simplify the client’s reintegration into community life and the children’s participation in after-school activities. In addition, the client agreed to have the SW speak to her employer about an eventual return to work. The client also applied for sickness benefits from Employment Insurance.

Three months after the stroke, and before Mrs AL planned to return to Europe, the case manager arranged a case conference at a time the client’s husband could attend.

Reassessment: 3 months

Participants in the case conference concluded that Mrs CW was now ready for outpatient PT and speech rehabilitation at the local hospital, and application to these programs was made. However, as waitlists were approximately 2 to 6 weeks, the client would continue with home-based therapy until openings became available. The client required transportation to participate in these programs and to attend her medical appointments. The case manager agreed to investigate and share the community options available to her and she and her husband agreed to investigate potential personal transportation options. Individuals from their church had already asked if there was anything they could do to help.

The OT planned to make 3 more visits and then discharge the client. Although Mrs CW could now sponge bathe and dress independently, the OT recommended that she not attempt a tub
transfer by herself. A PSW was authorized once a week to provide this assistance. The client also inquired about resuming driving, and the OT provided information about the retesting process.

The client was now able to verbalize the importance of diet and medication to manage her diabetes and hypertension and prevent a second stroke. She also expressed interest in a weekly swim program offered by the local stroke recovery group. As her therapists agreed the swim program would be beneficial, the case manager agreed to make the initial contact for her.

The team agreed on the importance of regular medical care to reduce the risk of another stroke, and the case manager suggested attendance at the new stroke prevention clinic at the district stroke centre. The client agreed this would be helpful.

The SW would continue to assist the family with budgeting and would follow up the initial positive employer response.

All team members, most of all the couple themselves, expressed their appreciation for the valuable contribution Mrs AL had made to her daughter’s rehabilitation.

Reassessment: 6 months

The case manager’s 6-month reassessment found that the client had continued to improve. Recommendations made at the case conference had been carried out and medical reports were encouraging.

After several PT sessions, Mrs CW was able to walk independently and was discharged. She reported that she was gradually increasing her endurance. She also felt she no longer needed the PSW to assist her with bathing. Her speech therapy continued, and the client was also working on her speech between appointments. Mrs CW and the SW met with her employer, who was willing to participate in a return-to-work program whenever the physician determined that the client was ready. Within the next few weeks, the family planned to move to a small rented bungalow near the school. With these arrangements underway, the SW planned to discharge at the end of the month.

Lessons learned

Clients and their families have strengths and resources of which they are unaware.

Stroke rehabilitation is most successful when it is multidisciplinary in nature.

Client motivation and strong family support of rehabilitation activities are critical to a successful outcome.

Note: At times resources may be limited and/or unavailable and the case manager may need to modify service plans and use other community resources and disciplines to meet the needs of the client and/or caregiver.
CASE STUDY #2

Client description

Mrs HB is a 73-year-old widow who lives alone in an apartment and has a daughter who lives on the other side of town. She has generally been healthy, with the exception of mild osteoarthritis and mild hypertension controlled with a diuretic. Approximately 1 week ago, Mrs HB was travelling to visit a friend on the bus when she experienced sudden onset of left hemiparesis. The bus driver called 911, and she was taken to hospital, in spite of her denials that there was anything wrong. Mrs HB did not recognize her daughter when she came to the hospital. Mrs HB was diagnosed with a right-hemisphere stroke with left hemiparesis affecting upper and lower extremities.

During the first day of hospitalization, she was observed to choke while drinking water. As a result, she was referred to the SLP who evaluated her for dysphagia. She was also seen by psychiatry, because of suspected depression, but her demeanour was felt to be symptomatic of a right hemisphere deficit, rather than depression. Mrs HB also received PT and OT. Attendance at a rehabilitation facility was recommended, but Mrs HB denied any problems and insisted on going home.

Acute care discharge summary

Return of lower extremity function was steady during hospitalization, and Mrs HB was able to walk slowly with a quad cane the length of the hospital hallway, approximately 100 feet. Return of upper extremity function matched that of the lower extremity, but left neglect and spatial judgment problems affected her ability to dress herself and her ability to gauge distances and environmental objects such as doorways. The SLP observed poor eye contact, a tendency to speak in a monotone, and some difficulty understanding conversation. Reading comprehension was also affected, because of left neglect, which resulted in omission of the left side of pages. A videofluoroscopic swallowing assessment helped to determine that small sips and use of a chin tuck when drinking fluids effectively reduced the risk of aspiration. Mrs HB failed to use these strategies consistently, however.

RAI results

Within the first week after discharge, the community case manager visited Mrs HB and completed the RAI. The following CAPS were triggered.

1. ADL rehabilitation potential
2. IADL
3. Cognition
4. Falls
5. Oral health
6. Preventive health care measures
7. Communication

The MAPLe algorithm indicated a moderate risk of adverse health outcome.
Service plan and goals

For discussion:

1. As the community case manager, what service plan would you develop for this client?
2. What challenges would you expect to encounter in dealing with this client and how could you address them?

Service plan

1. PSW: 5 days a week, 1 hour each time
2. OT: Improve ADLs, including dressing, bathing, and cooking
3. PT: Improve ambulation
4. SLP: Address swallowing, communication, and auditory and reading comprehension.

Mrs HB was discharged from the hospital with no CCAC equipment. She bought a quad cane and bath bench.

Case evolution

Progress reports from service providers

The SLP continued to reinforce use of the chin tuck and small sips while drinking, but client continued to ignore these strategies unless cued verbally immediately prior to a swallow. SLP therefore suggested thickening all liquids, but the client denied a problem and rejected this approach. Although verbal cues were given regarding eye contact during conversation, the client only looked at the speaker when directly reminded. SLP was unable to address auditory and reading comprehension, as the client said she did not need speech therapy.

The OT was concerned about kitchen safety and advised the client to use only the microwave, not the stove. As the client was ignoring this advice, the OT suggested that, to improve safety, the stove be unplugged or that she consider a meal service, such as Meals on Wheels. The client was reluctant to accept these suggestions. The OT therefore expressed her concerns to the case manager and a case conference was planned.

The PT was to address ambulation, balance, and left-sided neglect. As the client was at risk for falls and she was alone in the home, Life Line was suggested. The client refused, as she did not recognize a problem. In addition, no progress was occurring with respect to ambulation and gait, and the client did not appear to be performing the exercises recommended daily.

Psychosocial and family issues

The client’s daughter called the case manager with concerns about her mother’s safety and questions about the safety measures that could be put in place. A conference was arranged with the client, her daughter, and all service providers. The client wished to fire all providers, including the case manager. After much effort, she agreed to continue working with the OT and SLP. It was determined that the OT was critical to meet her functional needs and her desire for minimal assistance. The SLP asked other service providers and the daughter to include verbal cueing about making eye contact in their conversations with her. The SLP advised interlocutors to use simple language, avoiding the use of metaphors, to facilitate client understanding. The
daughter insisted to her mother that in order to stay in her own home she would need to agree to safety restrictions regarding meal preparation, to Meals on Wheels, and to wearing a Life Line at all times. In addition, the daughter asked the CCAC to continue the PSW services for safety while bathing, and she agreed to pay privately for supplementary PSW hours provided by the CCAC. The client agreed to the services discussed because of the daughter’s insistence.

Reassessment: 6 months

With reinforcement from the care team, the client’s eye contact improved. She also learned to cue herself to look to the left when reading and so was able to read with improved comprehension. She still insisted on taking regular fluids and often forgot to use her drinking strategies, resulting in occasional choking, but no negative consequences have occurred. Most interlocutors learned to modify their language to facilitate her comprehension.

Lessons learned

Consultation between providers is especially important in caring for clients with right-hemisphere stroke, as these individuals tend to be unaware of their difficulties.

It is important to limit the number of services when dealing with someone who is reluctant to accept care, while still addressing safety and function maximally.

Clients with right-hemisphere lesions must be assessed for subtle communication difficulties even in the absence of dysphagia or dysarthria.

Note: At times resources may be limited and/or unavailable and the case manager may need to modify service plans and use other community resources and disciplines to meet the needs of the client and/or caregiver.
CASE # 3

Client description

Mr JS is a 65-year-old widower who lives alone in a condominium in downtown Toronto, Ontario. He has 3 adult children: a son in New Brunswick, a daughter in Calgary, Alberta and a daughter in Newmarket, Ontario. He was employed as a senior insurance company executive until his retirement this year, shortly after the death of his wife.

Currently, Mr JS suffers some relatively mild residual deficits from a left-hemisphere stroke 2 years ago. He has mild visual-perceptual deficits, right-sided weakness of both upper and lower extremities, decreased fine motor skills in the right hand, and problems with balance, especially when fatigued. He contacted CCAC after being urged to do so by a neighbour, who noticed bruising on his arm and face. Mr JS had fallen in the bathroom walking to the toilet 10 days ago and again a few days later in the bedroom while changing his sheets.

At the initial CCAC interview, Mr JS reported feeling isolated and depressed since his wife’s death, especially as he has been unable to drive since the stroke. He complained of decreased appetite, and it is probable that Mr JS has lost weight recently. He had previously been obese but now appeared to have a normal body weight. He had stopped smoking when he was diagnosed at 52 years of age with type 2 diabetes and hypertension. Since the diabetes was diagnosed, he has also developed angina and a cardiac arrhythmia. Although his medical conditions had been well managed in the past, he reported that he had not been taking good care of himself or taking his medications regularly since his wife’s death.

RAI results

The CCAC case manager performed an in-home assessment using a laptop RAI-HC. The RAI triggered 12 of a potential 30 CAPS, and the client agreed to address the 5 most critical ones:

1. Falls
2. ADL
3. Depression
4. Nutrition
5. Environmental assessment.

Service plan and goals

For discussion

1. In your opinion, what are the key elements of a service plan for this client?
2. What would be your time-limited expected outcomes for this client?

Service plan

1. OT: Maximize independence and safety related to ADL, IADL, and functional mobility and assess equipment needs
2. SW: Address role changes related to loss of wife and retirement and assess support network
Case evolution

Progress reports from service providers

The OT worked with the client to eliminate tripping hazards by removing throw rugs from the hallway and kitchen and removing the bath mat (the cause of the first fall). She also changed the living room phone to a cordless one, as the phone wires previously crossed the hallway. The furniture in the living room was rearranged to increase safety and efficiency of movement and the bed was moved away from the wall to permit safer, more efficient access when changing the sheets (the cause of the second fall). The OT also worked with the client to create a more ergonomic arrangement of frequently used dishes and small appliances in the kitchen and shoes in the bedroom closet. Adaptive devices were also purchased and installed: an electric can opener for meal preparation, 2 grab bars (inside and outside the tub), a versa frame around the toilet, a shower handle extension, and a non-slip tub mat. Finally, the OT recommended that Mr JS follow an exercise routine within the condominium complex using a quad cane, that he become involved in activities at the local seniors centre to increase his exercise level, and that a PSW assist with baths.

The SW addressed issues surrounding depression, social isolation, and grief. These issues included adjusting to the loss of his wife by addressing his bereavement and developing a support network composed of family, friends, and members of his church. She also addressed adjustment to the change in his role in the home with the death of his wife, issues related to loss of identity associated with retirement, and dealing with extra free time during the day.

The dietitian worked with the client to develop an appropriate diet to manage his medical conditions. She also educated him about monitoring his blood sugar and addressing abnormalities. Mr JS was subsequently able to plan and prepare meals. To simplify these tasks, he agreed to have Meals on Wheels deliver 1 meal a day and to use a grocery delivery service, which increased his independence and decreased his reliance on neighbours and his daughter.

The PSW began working with Mr JS, visiting the client once weekly to assist with bathing and to change the bed linens.

Reassessment: 6 months

Mr JS has been discharged from OT, SW and the dietitian, but the PSW continues to see him weekly. Upon reassessment, the case manager finds the client improved and safety in the home is no longer a concern. Mr JS has not fallen again, and he has maintained his weight. His depression scores have normalized, changing from 6 to 2 on the Depression Rating Scale (DRS), and he is accessing community supports. Twice weekly, a neighbour takes him to the local community centre for an exercise program and social activities, and his daughter takes him to his church on Sundays. The case manager recommended that the PSW continue with the weekly visits.

Lessons learned

In retrospect, the SW intervention turned out to be the most critical, as the primary underlying problem was depression.
Note: At times resources may be limited and/or unavailable and the case manager may need to modify service plans and use other community resources and disciplines to meet the needs of the client and/or caregiver.
CASE # 4

Client description

Mr DK is an 82-year-old man living with his 75-year-old wife in a 3-bedroom bungalow. Mr DK and his wife immigrated to Canada from Europe 52 years ago. Both are Canadian citizens and speak English fluently. Until retiring at age 65, Mr DK worked in banking. Mr DK has no chronic medical conditions except for type 2 diabetes diagnosed 15 years ago and moderate hearing loss in the right ear. Mrs DK is a frail woman with osteoporosis who does not drive and has never worked outside the home. The couple has 2 adult children, a 55-year-old daughter who lives nearby and is supportive, and a 58-year-old son living in a different city.

Mr DK suffered a severe left-hemisphere stroke during the night 2 months ago and was taken by ambulance to the local hospital. The stroke resulted in right hemiparesis of upper and lower limbs, dysarthria and mild dysphagia. By 3 weeks after the stroke, he stabilized medically and was transferred to rehabilitation within the same facility for an additional 5 weeks. During his hospitalization, Mr DK received PT, OT, and SLP services and a consultation with a dietitian. Mrs DK was advised to place her husband in a long-term care (LTC) facility. However, the family was extremely resistant to this idea, insisting that they would be able to look after him at home. Mr DK was admitted to CCAC services on his discharge from hospital.

Acute care discharge summary

At discharge, Mr DK’s progress had been minimal. He was emotionally labile, but he expected to make good progress once he was home. Using an ankle-foot-orthosis and a quad cane, he was able to ambulate short distances only (less than 20 feet). He continued to have moderate spasticity in his right arm, and his hand was often clenched. During his hospitalization, he and his wife were trained in safe transfers and appropriate exercises.

Mr DK was able to answer simple questions directly and appropriately, but he spoke with moderate slurring. The SLP reported pocketing of food on the right side of the oral cavity, as the client was unable to perform an efficient lingual sweep due to tongue weakness. However, he generally remembered to present food to the left side of the oral cavity.

Mr DK was discharged from the hospital with the following services.

1. PSW: Provide personal care 6 days weekly, 1 hour in the morning and 1 hour in the afternoon
2. OT: Assess home safety and equipment needs with 2 visits ordered

Rental of a bath bench, commode, wheelchair, and Saska poles for 28 days was arranged. As the hospital coordinator was only able to order essential services on discharge, the CCAC case manager was to assess Mr DK for PT and SLP needs.

RAI results

Mr and Mrs DK and their daughter were present during the home visit, which was completed 1 week after Mr DK’s discharge home. At that time, Mr DK’s family had moved a bed to the living room, so that he did not have to cope with climbing stairs. The family was pleased with
the PSW and the OT, who had visited to start the safety assessment. Mr DK had not done the exercises they were taught in the hospital. Mrs DK indicted that she could not remember how to do them properly, and she was afraid of hurting her husband. She continued to experience a great deal of difficulty understanding Mr DK, and they were both becoming frustrated. Family members continued to resist applying for LTC, but they were interested in the possibility of respite care.

The case manager completed the RAI-HC, which triggered the following CAPs:

1. ADL rehabilitation potential
2. IADL
3. Institutional risk
4. Communication disorders
5. Cognition
6. Behaviour
7. Depression and anxiety
8. Falls
9. Oral health
10. Preventive health care measures
11. Urinary incontinence

The MAPLe algorithm indicated a very high level of risk of adverse outcomes.

**Service plan and goals**

**For discussion**

1. In your opinion, what are the key elements of a service plan for this client?
2. What challenges would you expect to encounter in dealing with this client and how might you address them?

**Service plan**

1. PT: Teach caregivers (wife and PSW) safe transfer techniques and good body mechanics; teach client to ambulate safely for short distances in the house and within bathroom, as wheelchair does not fit through bathroom door; teach caregivers to help client with exercises initiated in hospital to improve balance and, if not addressed by OT, exercises to improve upper extremity function; initiate purchase of wheelchair through Assistive Devices Program (ADP); encourage client to participate in day program, to provide both respite for Mrs DK and activity for Mr DK (linkages would be made if acceptable); weekly for 6 weeks
2. SLP: Train client in oral exercises to strengthen musculature, increase precision of articulation, and improve management of oral dysphagia; weekly for 4 weeks.
3. PSW: Assist with bathing, dressing, toileting, and light housework related to client, such as changing sheets if soiled overnight; 12 hours weekly for additional 2 weeks, then decreased to 8 hours weekly.
4. OT: Address safety and equipment funding; additional 2 visits.
Case evolution

Assistance issues

After 5 weeks, Mrs DK contacted the case manager requesting more assistance. She was finding it difficult to cope with Mr DK, as he has become more depressed since returning home and complains to her daily about the food she serves and the time it takes for her to respond when he calls. Mrs DK complains of exhaustion, as she has to get up several times nightly to assist Mr DK with a urinal. As a result of the time it takes her to look after her husband, she has become isolated from her usual support system and must rely on her daughter for all shopping, banking and other errands.

The case manager made several suggestions: using an adult diaper during the night; asking her husband to speak to his physician about medication for depression; and sharing her concerns with her children and asking for their assistance. The case manager also reinforced the use of respite care and the possibility of purchasing additional PSW hours privately.

Progress reports from service providers

No case conference has been held since discharge, but the OT and PT have consulted to clarify their roles.

The PT discharge report after 6 weeks therapy indicated that Mrs DK and the PSW had learned to assist safely with transfers and demonstrated good body mechanics. She noted that the client could ambulate safely within the bathroom using a quad cane and that he was walking from the living room to the kitchen for meals 3 times daily. Mrs DK now reliably assists her husband with his daily exercise program, but Mr DK had decided against attending a day program. Mr DK now owns an appropriate wheelchair, as he received funding through ADP.

The SLP reported that Mr DK was swallowing safely and had learned to use a liquid wash to remove pocketing of food in the mouth. He has also learned to speak more slowly, with resultant improvement in intelligibility, but his speech deteriorated when fatigued. He was discharged, as progress had reached a plateau.

The OT reported that the home safety assessment had been completed and that appropriate equipment was in place.

The PSW reported that Mr DK had grabbed her breasts on several occasions, and continued to do so in spite of being told that his behaviour was unacceptable. When the PSW mentioned the behaviour to Mrs DK, she denied that her husband was capable of such behaviour. The PSW also noted that Mrs DK often asked her to spend more time on housecleaning. The case manager contacted the agency employing the PSW concerning appropriate focus on personal care, rather than housecleaning and the behaviour complaints. The agency replaced the original female PSW with a male.

Psychosocial issues

Private insurance funded equipment purchases but no additional PSW time.
Mr DK’s son agreed to pay privately for a cleaning woman every 2 weeks and for a neighbourhood boy to do most of the outdoor work. The case manager assisted the family in completing LTC papers for short-stay respite, and Mr DK attended 1 week of respite after 4 months at home. The case manager was unable to address the client’s isolation, as he continued to refuse to attend a day program. However, Mrs DK’s priest arranged for a volunteer to visit with Mr DK for 2 hours every second week, while a second volunteer took Mrs DK shopping.

Reassessment: 6 months

Mrs DK continues to manage to look after her husband, although with increasing difficulty. Due to the success of the respite stay, and with the support of her children, she agreed to have LTC placement papers submitted.

Lessons learned

Sometimes families must experience firsthand the difficulties associated with home management of an individual with severe impairments, before they agree to LTC placement.

Client and caregiver teaching during hospitalization often needs to be modified and reinforced at home.

The role of the PSW may require frequent reinforcement.

Note: At times resources may be limited and/or unavailable and the case manager may need to modify service plans and use other community resources and disciplines to meet the needs of the client and/or caregiver.
Appendix A: Ontario Stroke Strategy Pilot Projects

REHAB PILOT PROJECTS

Creation of a system that provides stroke rehab with appropriate and timely services for stroke rehab: Central South/Central West

This project involved the development and implementation of a standardized assessment and triage tool and client tracking using a database to assist in the creation of a system to provide appropriate and timely stroke rehabilitation services. Both clinical and system indicators were monitored. Clinical indicators included functional outcomes, patient satisfaction, goal attainment, and quality of life. System indicators included volumes, utilization, wait times for assessment and services, and cost and length of stay.

Outreach and outpatient rehab team: Southwestern Ontario

To enhance stroke rehab close to the client's home, a team comprising of one physiotherapist, one occupational therapist and one speech-language pathologist augmented existing ambulatory-based stroke rehab for severely cognitively or communicatively challenged stroke survivors, a population whose needs were not being addressed. This team also provided outreach consultation, education, training and support to service providers in 10 counties, and case management support to enhance communication and coordination during the client's transition phase. A formalized evidence-based triage system was implemented and evaluated.

Discharge link project: Southeastern Ontario

This pilot established a "front-loading" rehab team to act as a liaison with patients discharged to the community. It consisted of a four-week course of case management and training by the occupational therapist to the assigned personal support worker (PSW), and treatment sessions by a physiotherapist, occupational therapist and speech language pathologist. The objective was to prevent deterioration of functional status caused by a prolonged wait for home care, and provide appropriate training of the PSW to maintain functional gains.

Building a regional stroke rehab system and integrated core coordination linkages via development of a pilot stroke telerehab network: North and East GTA

The first component of the project was the development of a telerehab network among providers in urban and rural sites to enhance communication and coordination of stroke rehab; facilitate standardization of tools and data; help promote recruitment and retention of professional staff in remote areas; and reduce client transportation challenges through the use of televideo technology. The second component was to trial a community-based Stroke Self Management Program at a rural site. This involved community delivery of telehealth technology as well as recruitment of trained volunteers.
Facilitating transitions in stroke rehabilitation clients. The SCRIPT (Stroke Coordinated Referral Initiative Pilot, Toronto) project: Toronto West

This project developed a centralized referral process using a common assessment form and triage tool for stroke clients moving through the system from acute care to rehabilitation. Only clients being discharged to rehabilitation were tracked, and these individuals were tracked until discharge from rehabilitation using a Web-based database.

Both clinical and system indicators were monitored and assessed at baseline and after implementation of the new system. Clinical indicators included functional outcomes, client satisfaction, and community reintegration. System indicators included client wait times for service, response time to referral, availability of services to meet client needs, adherence to standards of wait times, admission criteria, and length of stay.

Navigating the seams: identification of stroke survivor and care giving needs using FIM-FRG: West GTA Stroke Network

"Navigating the Seams" focused on developing a more seamless transition from institutional care to home-based rehab. The project identified stroke survivor and caregiver needs using standardized assessment tools (and application of the FIM-FRG) to develop the most appropriate level and form of services and support for stroke survivors being discharged to the community. Collaborative goal setting, evaluation and follow-up, as well as education for survivors, caregivers and service providers, were key components of this project.

LONG-TERM CARE PILOT PROJECTS

Community re-engagement: North West

Among other activities, this project explored community-specific processes involved in delivering stroke care in long-term and community settings and implemented best practices educational workshops. The workshops generated objectives and practical strategies for implementing best practices for stroke care and for maintaining partnerships.

Rehabilitation in the community and long-term care: North East

Workshops explored optimal management strategies for stroke survivor transition into the community and long-term care and for management of family issues. The workshops increased awareness of the stroke strategy and its resources; increased engagement of stakeholders as active participants; and identified priorities for the regional work plan with actionable next steps for enhancing stroke care.

Community reintegration: East

This project examined existing regional services and supports for stroke survivors in community and long-term care settings. Discussions conducted with community and CCAC-contracted agencies, long-term care facilities, and stroke survivors and their families identified changes needed to enhance community re-engagement. The project developed strategic directions and recommendations to guide the development of regionally sensitive, client-focused initiatives. It
also identified policies to improve outcomes for stroke survivors and their families and opportunities for continued involvement of stroke providers in the stroke strategy and the provincial rehabilitation project.

**Building relationships between community support services and regional stroke centres**

This provincial initiative focused on developing relationships between agencies providing community support services and regional stroke centres. The project developed service listings, tools and other supports on a regional basis. It also educated healthcare professionals about community services to support stroke clients; about ways of increasing awareness of, and involvement in, the stroke strategy; and about development of collaborations to create seamless approaches for stroke care.

**Continuing stroke care in the community: transition management from Community Care Access Centre to Long-Term Care: West GTA**

The West GTA project examined existing practices and processes involved in the transition of stroke survivors (through CCAC) from home-based and hospital environments to long-term care. It assessed the effectiveness of current transition management practices and offered recommendations to improve the system for stroke survivors’ transition.

**Enhancing the transition of stroke survivors from acute care to long-term care: Toronto West, South East Toronto and North & East GTA**

Three Toronto Regional Stroke Networks, Toronto West, South East Toronto and North and East Toronto, worked collaboratively on this project to examine and improve the system for stroke survivor transition from acute care to long-term care. Project activities focused on developing and evaluating regional versions of a communication template, a tool to communicate current, care-relevant information and to facilitate continuity of care at transition. The project developed and tested a tool and also noted that region-specific education was needed to ensure use of the communication template.

**Partnerships for stroke care in long-term care: Southwestern Ontario**

This initiative focused on implementing strategies to improve linkages among acute care, rehabilitation, and community services. Initial discussions identified the need for enhanced communication, awareness and collaboration to improve the transfer of stroke survivors between sectors. A regional working group developed versions of a goal-oriented communication tool to serve as a template for managing transitions. The project also enhanced collaboration between sectors in sharing information and formalizing arrangements for stroke-focused activities in the community and long-term care sectors.

**Stroke care in communities in rural eastern Ontario: Southeastern Ontario**

This pilot project, jointly initiated by the Southeastern Regional Stroke Steering Committee and the Ontario Community Support Association (OCSA), focused on building the capacity for stroke response in rural communities where available resources and health services are limited.
Building on this project, OCSA undertook further work. OCSA supported 6 new and existing self-help groups in both urban and rural communities, using a variety of strategies and resources. A major component of the initiative was the use and testing of a previously developed guide: *Starting a Self-Help Group for People Who Have Had a Stroke and for Caregivers*. The project also demonstrated the benefits of self-help groups to stroke survivors and their caregivers.

**Stroke care in adult day programs: Central South/Central West**

This Central South/Central West Regional Stroke Steering Committee and Ontario Community Support Association joint pilot project focused on identifying and responding to the education needs of Adult Day Program (ADP) providers dealing with the communication difficulties of their stroke clients. The project produced a model for training and support in the management of aphasia that may be applied by ADP providers in other parts of the province.

More information about the pilot projects is available through the Heart and Stroke Foundation of Ontario at 416-489-7111, 456 or css@hsf.on.ca
Appendix B: Glossary of Terms

- **Anomia**, or word-finding problems: Common in individuals with aphasia; similar to the experience of having a word on the tip of your tongue but not being able to retrieve it. An individual with anomia may not be able to produce the word *comb* even though he or she can show you how to use it.

- **Aphasia**: A communication disorder caused by damage to the language centre of the brain, which impairs the ability to understand and/or to express language. Stroke is the most common cause of aphasia. Common types of aphasia include the following:
  - **Receptive aphasia**: Impaired ability to understand spoken and/or written language
    - **Wernicke’s aphasia**, or fluent aphasia: A type of receptive aphasia in which speech is well articulated, with appropriate melodic intonation, but lacking in content and often including meaningless or jargon words (My petackles are muffled and I can’t see the things)
  - **Expressive aphasia**: Impaired ability to speak and/or write
    - **Broca’s aphasia**, or non-fluent aphasia: A type of expressive aphasia in which speech is produced with difficulty and the style is often telegraphic (Cold. Need sweater)
    - **Global aphasia**: Severe expressive plus receptive aphasia. By far the majority of aphasics have both a receptive and an expressive component to their disorders, but they would only be classified as having global aphasia if the loss of language was almost complete.

- **Apraxia**: An inability to carry out a requested complex or skilled movement, caused by lesions in the associative motor areas of the parietal lobe. Apraxia is not caused by paralysis, ataxia, sensory changes, confusion or deficiencies of understanding.

- **Apraxia of speech**, verbal apraxia, or dyspraxia: A disruption of motor planning or programming of articulatory-kinematic parameters, with the neuromuscular system for realizing articulatory command assumed to be intact.

- **Ataxia**: Inability to produce coordinated muscle contractions necessary to move smoothly and maintain posture; a tendency to lose balance.

- **Bilateral brain injury**: Damage to both sides of the brain, which may produce cognitive impairments complicating rehabilitation, such as impairments of insight, organization, recall, memory and executive functioning.

- **Body scheme**: An individual's capacity to perceive his or her own postural model; defective perception of body position, including and involving the relation of body parts to each other.

- **Cognitive communication disorder**: Impaired cognitive or thinking skills, such as attention, behaviour, executive function, memory, judgment, organization, problem solving, reasoning, sequencing, or visual motor skills affecting communication ability

- **Cognition**: Capacities enabling thinking, including concentration, knowledge, learning, insight, judgement, reasoning, abstract thinking, understanding, and memory.

- **Dysarthria**: A motor speech disorder resulting from weakness, paralysis, or lack of coordination of the muscles of the mouth, face, or respiratory system that can affect respiration (breathing), phonation (voicing), articulation (pronunciation), resonance (nasality), and intonation (prosody).

- **Dysphagia**: A swallowing disorder which can affect one or more of the following stages or phases of swallowing:
  - **Oral phase**: Involves sucking, chewing, and moving food or liquid into the throat
• Pharyngeal phase: Triggering the swallowing reflex, squeezing food down the throat, and closing off the airway to prevent food or liquid from entering the airway (aspiration) and to prevent choking.
• Esophageal phase: Relaxing and tightening the muscular openings (sphincters) at the top and bottom of the esophagus (the tube through which food passes to the stomach) and squeezing food through the esophagus into the stomach.
• Emotional lability: The sudden change or instability of emotional state that may occur as a result of a stroke, such as sudden laughter or tears.
• Executive functioning: A group of higher-level cortical capacities and mental processes, such as self-monitoring, recognition of errors, insight, time sense, abstract reasoning, planning, organizing, initiating activities, goal setting. In conjunction with self-awareness, executive functions are included in metacognition.
• Hemiparesis: Partial paralysis, or weakness, affecting one side of the body.
• Hemiplegia: Flaccid or spastic paralysis, or complete loss of movement, of one side of the body.
• Homonymous hemianopsia: A common visual field defect seen after stroke that may involve loss of the left or right half of the visual field in one or both eyes. The individual may learn to compensate for the visual loss by regularly turning the head to the side of the defect and exaggerating normal visual scanning patterns.
• Insight and impulsivity: Insight is an individual’s self-awareness, including awareness of impairments, disabilities, skills and abilities. Insight may be lost after a stroke, with the individual denying any physical dysfunction despite evidence to the contrary. Decreased insight may result in impulsiveness and accidents, as an impulsive patient may attempt to transfer unaided from a wheelchair to a bed despite paralysis and a total inability to stand independently.
• Judgment: The capacity to make realistic decisions based on environmental information. After a stroke, judgment is often impaired, which may lead to accidents or falls, especially if insight is also limited.
• Language: One of two components of communication, along with speech. Language includes our dictionary of vocabulary, word meanings, and grammar rules.
• Left-hemisphere stroke: A left-hemisphere stroke may result in right hemiparesis or hemiplegia; problems with speech and language, such as aphasia or dysarthria; and a tendency to be slow, cautious and disorganized when attempting new tasks.
• Neglect, or unilateral neglect, or inattention: The inability to attend to, orientate to, or interact with stimuli (including objects and the self) on the side contralateral to the stroke. Neglect is not due to a primary motor or sensory loss.
• Organizational dysfunction: A decreased ability to maintain proper perspective on events; to express thoughts, feeling and ideas in an organized way; or to differentiate the significant from the insignificant in social situations.
• Perception: The capacity to transform sensory information (touch, hearing, vision, smell, taste and kinesthesia) and use this information to interact appropriately with the environment. Perceptual deficits may affect functioning in the activities of daily living (ADL) and the ability to learn and/or transfer information appropriately. Examples of perceptual skills include stereognosis, right-left discrimination, praxis, body scheme, graphesthesia, and proprioception.
• Perseveration: Inappropriate persistence or repetition of a thought or act. Perseveration can manifest itself in activities of daily living (ADL) or speech tasks, such as repeating the answer to one question when asked subsequent questions.
• Proprioception: Unconscious information about joint position and motion arising from receptors in muscle, joints, ligaments, and bone that allows knowledge of the motion or position of the body or of its parts in space. Equilibrium, or vestibular sensation, is part of proprioception. A partial or complete loss of position and motion sense impairs movement, even if muscle function is normal.
• Reflex sympathetic dystrophy (RSD): A reflex neurovascular disorder, often called shoulder-hand syndrome, which is characterized by pain; limitation of movement in the shoulder, wrist and hand; edema; vasomotor instability; and trophic changes in the skin.
• Right-hemisphere stroke: The right hemisphere of the brain controls analytical and perceptual tasks, such as judging distance, size, speed, or position and determining how parts are connected to wholes. Individuals with right-hemisphere stroke may have problems with spatial and perceptual abilities. These problems may lead to misjudging distances, possibly resulting in a fall; an inability to guide their hands to pick up an object, button a shirt, or tie their shoes; or an inability to differentiate upside-down from right side-up when trying to read.

Judgment difficulties may be evident, and behaviour may become impulsive. Survivors of right-hemisphere stroke may be unaware of their impairments and confident of their ability to perform tasks as expertly as before the stroke. This behavioral style can be extremely dangerous, as it may lead the left hemiplegic stroke survivor to attempt walking without aid or the survivor with spatial and perceptual impairments to attempt driving a car. These individuals may also experience left-sided neglect, a problem resulting from visual field impairments that may lead the stroke survivor to "forget" or "ignore" objects or people on their left side. Survivors of a right-hemisphere stroke may also experience problems with short-term memory, although long-term memory may be unaffected.
• Social communication disorders: Disorders affecting an individual’s ability to participate appropriately in conversations. Social communication disorders may alter the ability to take turns in conversation, maintain a topic of conversation, use an appropriate tone of voice, interpret the subtleties of conversation, and follow the conversation in a fast-paced interaction. Emotional factors may also be involved in social communication disorders. Stroke survivors may overreact and seem overly emotional or impulsive; they may seem emotionally flat, or without affect; or they may say or do inappropriate things in conversation. Families and friends find it extremely frustrating that affected individuals may have little to no self-awareness of the inappropriateness of their actions.
• Speech: One of two components of communication, along with language. Speech is the process of using the muscles of the lips, tongue and throat to produce the sounds that make up words.
• Stereognosis: The ability to recognize objects by touch alone. Impaired stereognosis may affect the ability to perceive shape, texture, temperature, weight, and density. Impaired stereognosis may present a safety risk, especially if it is accompanied by impaired sensation. In this situation, sharp objects and extreme temperatures encountered during activities of daily living (ADL) may present hazards.
• Tone: The resistance of muscles to passive elongation or stretch.
• Visuospatial dysfunction: A collection of disorders including defective judgment of depth and distance; difficulties with spatial relations, or the ability to relate objects to each other and to oneself; topographical disorientation; and unilateral spatial neglect.
REFERENCES

Appendix C: Glossary of Disciplines

CLINICAL DIETITIAN

Nutrition is often an important aspect of care for stroke survivors. Dietary management of stroke risk factors such as hypertension, hypercholesterolemia, obesity and diabetes usually accompanies drug therapy. The clinical dietitian is the individual with the training to develop the appropriate dietary plan. In addition, many stroke survivors experience dysphagia, or difficulty swallowing, as a result of the stroke. Dysphagia is associated with an increased risk of aspiration of solid or liquid foods, inadequate nutrition, and dehydration. Some individuals with dysphagia can safely consume food of only specific textures, whereas others may require tube feeding to maintain nutritional status. The clinical dietitian works with the speech-language pathologist to determine a safe diet for individual clients. In addition, the dietitian monitors the client to ensure adequate intake and educates the client and family about the most appropriate diet.

OCCUPATIONAL THERAPIST

The occupational therapist (OT) uses purposeful activity or interventions designed to achieve functional outcomes that promote health; prevent injury or disability; and develop, improve, sustain or restore the highest possible level of independence to their clients. These clients may have an injury, illness, cognitive impairment, psychosocial dysfunction, mental illness, developmental or learning disability, physical disability, or other disorder or condition. In conjunction with the client, the occupational therapist develops goals related to self-care, productivity, and leisure activities. Various assessment and treatment techniques are used to address these goals. Interventions may include training in activities of daily living (ADL) and community life skills; prescription of specialized equipment; evaluation and modification of home, work or school environments; and related education and counselling.

Adapted from the College of Occupational Therapists of Ontario, 2001

PERSONAL SUPPORT WORKER

The Personal Support Worker (PSW) is responsible for assisting clients with activities of daily living (ADL) related to personal care, hygiene, and household management. Primary goals are promotion of client dignity, independence, comfort, mobility, personal appearance and safety. PSWs work with client requirements and wishes within the established service plan.

PHYSIATRIST

A physiatrist is a physician specializing in physical medicine and rehabilitation. This medical speciality deals with evaluation, diagnosis and treatment of patients whose functional abilities have been impaired. Stroke survivors may have disabilities and impairments resulting from the stroke and also from other concurrent diseases or conditions. The goal of the physiatrist is to improve individual functional capabilities using a variety of interventions as part of a comprehensive rehabilitation program. Social, community and vocational reintegration are an important part of a physiatric assessment. A physiatrist would also be involved in the management of the following medical problems and issues that are common after stroke:
• Motor, sensory and communication impairments
• Pain in the affected extremity
• Spasticity of the affected side
• Contractures
• Bladder and bowel dysfunction
• Post-stroke depression
• Nutritional problems, possibly related to dysphagia
• Problems with skin integrity
• Lack of understanding of the client and family related to living after stroke
• Stroke risk factors.

PHYSIOTHERAPIST

The physiotherapist (PT) is a healthcare professional whose expertise is directed at evaluating, maintaining and restoring physical function. Physiotherapists are trained to assess function and determine a specific treatment plan designed for each individual's degree of motion and/or sensory loss. After a stroke, the first goal of a physiotherapy program is to maintain mobility in the joints affected by the stroke. Joints that are not moved on a daily basis begin to stiffen, which can damage the joints and hinder recovery. By moving the affected limbs, the physiotherapist maintains mobility of the soft tissues and joints. Physiotherapy also helps the patient relearn muscle control through a series of practised, repetitive movements and ensures that muscle balance is regained.

Adapted from: You & the Physiotherapist, Canadian Physiotherapy Association

REGISTERED NURSE

The Registered Nurse (RN) is responsible for the assessment and provision of skilled nursing care for client comfort and well being and for fostering maximum client independence. For clients requiring nursing care, the RN is responsible for completing a comprehensive nursing assessment, formulating a nursing diagnosis and developing nursing objectives and goals together with the client. The RN also develops and implements a care plan that reflects the goals and steps toward achieving successful outcomes. This may involve improving nursing services in the home and promoting and providing necessary health teaching for clients and families.

SOCIAL WORKER

The social worker (SW) in stroke rehabilitation assists stroke survivors and their families in coping with the psychosocial implications of their illness and impairments. The social worker enhances the client’s ability to use his own problem-solving and coping capabilities through client and family education, linkage to community resources, and counselling and ongoing emotional support.

SPEECH-LANGUAGE PATHOLOGIST

The Speech-Language Pathologist (SLP) is a regulated health professional with specialized knowledge, skills and clinical training in the assessment and management of communication and swallowing disorders. The expertise of the SLP includes prevention, identification, evaluation,
and treatment of congenital and acquired communication and swallowing disorders in clients of all ages in a variety of healthcare, education and private settings. The SLP can manage the following disorders:

- Language disorders: Improve ability to understand spoken and written language, convey ideas verbally and in writing, and communicate in social situations
- Speech disorders: Improve articulation, pronunciation, and stuttering
- Cognitive communication disorders: Improve reasoning, problem solving, memory and organization skills required for effective communication
- Voice disorders: Improve vocal quality, pitch and loudness
- Swallowing disorders: Ensure a safe and efficient diet texture.

The SLP also provides client and caregiver counseling on communication and swallowing disorders, abilities and challenges, and strategies for improving function.

Adapted from Ontario Association of Speech-Language Pathologists and Audiologists
Appendix D: Assessment and Outcome Measurement Tools

INTRODUCTION

Recent efforts by the Joint Stroke Strategy Working Group; the Joint Policy and Planning Committee (JPPC) of the Ministry of Health and Long-Term Care and the Ontario Hospital Association; the Rehabilitation Working Group; the Canadian Institute for Health Information (CIHI); and the Ontario Stroke Registry Pilot Project have all focused attention on the need for coordinated care and coordinated outcome measurement. A coordinated provincial monitoring system for evaluating stroke care, patient outcomes, and resource utilization in stroke is being developed. These initiatives highlight the importance of using standardized outcome measures to monitor stroke patients across the continuum. Standardized outcome measures that are chosen should:

- Be applicable to a broad range of stroke survivors.
- Have adequate sensitivity to capture all levels of independence.
- Facilitate the evaluation of the impact of the stroke on the individual.
- Complement other assessments, while avoiding duplication.
- Become part of the patient’s medical record.
- Be valid, reliable, responsive, and sensitive to change.

Selecting appropriate outcome measurement tools can be a complex task, as each measure has limitations, a single measure is usually insufficient, and outcome measurement tools should complement each other. Also, some tools are restricted to specific disciplines or are designed to be used by individuals trained to administer them and evaluate and interpret the results. For example, the evaluation of cognition is a complex area and is usually performed by a specially trained psychologist or an occupational therapist, who is experienced in screening patients for cognitive and perceptual deficits.

The use of integrated interdisciplinary assessment tools allows integration of the assessment process, which has several benefits. Integrated assessment provides an interdisciplinary assessment that:

- Avoids duplication, reducing effort and resource use.
- Increases time available for therapy.
- Prevents client and caregiver frustration associated with repeated assessments.
- Supports seamless transitions and improves information sharing by using compatible outcome measures.
- Allows the development of a clinical consensus for decision making.

Important integrated assessment tools that are being used more frequently now include the National Institutes of Health Stroke Scale (NIHSS) in acute care and the Canadian Institutes of Health Research National Rehabilitation Reporting System (CIHI NRS) in rehabilitation.

This module provides a brief overview of commonly used assessment tools.
The measurement of client satisfaction is an important component of care, but tools to measure client satisfaction are not included in this manual, because institution-specific measures are usually used.

**ASSESSMENT AND OUTCOME MEASUREMENT TOOLS**

**Acute diagnosis and assessment**

**Alberta Stroke Programme Early CT Score (ASPECTS)**

To score baseline CT scans of individuals who present with an acute stroke and meet the inclusion criteria for thrombolytic therapy, ASPECTS is used. ASPECTS quantitatively keeps tally of the amount of early ischemic change in the middle cerebral artery territory (MCA). The CT scan should also be assessed for the presence or absence of hemorrhage, edema or swelling, effacement, a hyperdense MCA sign, vertebrobasilar (VB) artery territory hypodensity, posterior cerebral artery (P) hypodensity, and anterior cerebral artery (A) hypodensity. ASPECTS assesses the MCA territory on the basis of two standardized axial cuts, one at the level of the thalamus and basal ganglia, and one superior to this level but such that ganglionic structures are not involved.

The baseline ASPECTS value predicts functional outcome and intracerebral hemorrhage. This CT scoring system is simple, reliable, and identifies individuals unlikely to make an independent recovery despite thrombolytic treatment.


**Glasgow Coma Screening (GCS)**

The GCS is used to assess decreased levels of consciousness, and it is therefore not useful in alert stroke patients. It evaluates physiological deficits associated with stroke and assesses basic neurological function at the cortical, midbrain and brainstem levels. This well-validated tool is suitable for rapidly evaluating improvement or deterioration in neurological status in the acute phase of stroke. Scores are highly correlated to those seen on CT scan, and the GCS is predictive of short- and long-term mortality and major morbidity from stroke. It is endorsed by the Clinical Practice Guidelines for Stroke published in the US by the Agency for Health Care Policy and Research (AHCPR, 1995). The GCS only evaluates impairment at a basic level, not activity, ADL limitations or limitations to participation. It is not suitable for rehabilitation or community settings.

Canadian Neurological Scale (CNS)

Impairment or physiological deficit is measured by the CNS. Measuring cognition and motor response in stroke, it is suitable for use in an acute care setting. The CNS is sensitive to change and predictive of death, re-infarction, and functional independence at 6 months. It is endorsed by the Clinical Practice Guidelines for Stroke published in the US by the Agency for Health Care Policy and Research (AHCPR, 1995).


National Institutes of Health Stroke Scale (NIHSS)

The NIHSS is a 15-item scale that measures various physiological deficits associated with stroke. It is primarily suited to the acute care setting. The NIHSS measures LOC, vision, extraocular movements, facial palsy, limb motor responses, ataxia, sensation, neglect, dysarthria, and aphasia. Results correlate well with anatomic changes and physiological deficits. It does not measure activity, ADL, or participation limitations. The NIHSS is well validated in the literature and is predictive of resource utilization. It is recommended by the Clinical Practice Guidelines for Stroke published in the US by the Agency for Health Care Policy and Research (AHCPR, 1995). The NIHSS is not well suited to rehabilitation or community settings.


Global functional ability

Functional Independence Measure (FIM)

The FIM is a generic calculation of disability applicable to many different patient populations and is the most widely adopted functional status measure today. The FIM assesses self-care, transfers, locomotion, sphincter control, communication, and cognition, assessing physical and cognitive function in the context of relative burden of care.

The FIM gauges the amount of assistance and resources a disabled person will use in their living environment, and the FIM score is a basic indicator of disability, not impairment. Severity of disability changes during rehabilitation, therefore the data generated by the FIM can be used to track such changes and analyze the outcomes of rehabilitation. It is most useful in rehabilitation, but it is also used in acute care and in community settings. The FIM is exceptionally well validated in international trials. It is reliable, valid and responsive in all of these settings.
Significant training and certification are required to standardize assessment. The FIM should not be used in isolation, but as an indicator of activity limitations.


Alpha Functional Independence Measure (Alpha FIM)

The Alpha FIM is a brief version of the FIM. It measures a subset of FIM items — 4 motor items (eating, grooming, bowel control, and toilet transfer) and 2 cognition items (expression, memory) — and the results are highly correlated with the FIM score as a whole. The Alpha FIM is useful in acute care, because it takes less time to administer than the full FIM.


Canadian Institutes of Health Research National Rehabilitation Reporting System (CIHI NRS)

The CIHI NRS is an instrument that includes the FIM, measures of pain, and instrumental ADL. It also includes system indicators, such as length of stay and resource utilization. The Ministry of Health and Long-Term Care has mandated the use of CIHI NRS for institutions with designated inpatient rehabilitation beds.


Canadian Institute for Health Information Minimum Data Set-Home Care (CIHI MDS-HC)

The CIHI MDS-HC is being implemented throughout CCACs in Ontario to determine the resource level required for rehabilitation of various populations, including stroke survivors.


Barthel Index (modified)

In North America, the Barthel Index has largely been replaced by FIM. The modified Barthel Index assesses functional independence in personal care and mobility. This index measures mobility, stair climbing, self-care, and incontinence, using a 5-point rating scale ranging from fully independent to unable to perform task.

The Barthel Index is a valid and reliable measure that is useful in both acute care and in rehabilitation settings, and it has been widely used throughout the stroke literature. It is sensitive
to change and is well documented throughout literature as able to demonstrate both change and progress over time. However, it should not be used alone for predicting outcomes, as it is possible to over- or under-estimate independence. The Barthel Index does not test cognitive function.


**Rankin Handicap Scale (modified)**

The modified Rankin Handicap Scale assesses and grades the level of disability of stroke patients. Independence is measured using a 6-grade scoring scale, ranging from no symptoms to severe disability. This scale is often used in emergency and acute care as a gross measure of disability. However, it is not sensitive or comprehensive enough to be used in rehabilitation or community care.


**Oxford Handicap Scale**

The Oxford Handicap Scale, which is a modification of the Rankin scale, is a simple way of assessing disability.


**Reintegration to Normal Living Index (RNLI)**

The RNLI assesses global functional status and measures both the stroke survivors’ perceptions of their own capabilities and objective indicators of physical, social, and psychological performance. The index is responsive to changes in the clinical status of patients, especially for the subscales Daily Living and Perceptions of Self. In terms of criterion validity, the index is somewhat related to work status and disease status. The RNLI is primarily useful in rehabilitation and in the community setting.

Mobility, balance, and motor function

Chedoke McMaster Stroke Assessment Scale

Specifically designed for use in stroke, the Chedoke McMaster Stroke Assessment Scale measures motor function in the upper and lower extremity.


Clinical Outcome Variables Scale (COVS)

The COVS is a functional mobility assessment, scoring 13 items, such as bed mobility, transfers, ambulation, and upper extremity function. COVS is applicable to a variety of rehabilitation populations, including stroke survivors.


Motor Assessment Scale (MAS)

Designed specifically for use in stroke, the MAS is a brief assessment of movement and physical mobility. Its reliability has been assessed only in stable individuals.


Stroke Rehabilitation Assessment of Movement (STREAM)

Designed specifically for use in stroke, STREAM measures motor function in the upper and lower extremity and ability to change position. STREAM tends to measure the impairment level rather than the activity level.


Berg Balance Scale

The Berg Balance Scale measures the ability of an individual to maintain balance while performing movements, such as transfers from bed to chair, standing from a sitting position, picking up objects, turning, and other common actions. It helps determine changes in functional standing balance over time and is a useful tool for assessing a patient’s risk for falls and the need for an assistive device.
The Berg Balance Scale is most useful as a predictor of falls in the elderly and in stroke survivors, and it can also be used as an objective, qualitative measure of improvement through clinical intervention.


**Timed Up and Go Test (TUG Test)**

TUG is a validated balance test that measures the ability of patients to perform sequential locomotor tasks incorporating walking, turning, and moving from sitting to standing.


**Cognitive and perceptual ability**

**Mini Mental State Exam (MMSE)**

The MMSE is used for the screening, diagnosis, and assessment of cognition in psychogeriatric patients. It evaluates orientation, attention, immediate and short-term recall, language, and the ability to follow simple verbal and written commands. The total score, combined with years of education, can detect impairment in cognition. The MMSE cannot be used alone for diagnostic purposes. It is useful for detecting significant cognitive impairment, but it is not sensitive enough to detect more subtle cognitive and perceptual deficits that may be seen in stroke survivors.


**Motor-Free Visual Perception Test (MVPT)**

The MVPT is designed to assess visual perception in individuals with possible learning, cognitive, motor, or physical limitations. It evaluates 5 types of visual perception: spatial relationships, visual discrimination, figure-ground discrimination, visual closure, and visual memory. The MVPT requires special training and is usually administered by an occupational therapist.


**Rivermead Behavioural Memory Test (RBMT)**

The RBMT is a clinical memory test that provides an objective measure for various everyday recall problems reported and observed in patients with memory difficulties. This test provides
two scores, a screening score and a more detailed profile score. The screening score estimates whether an individual is likely to have everyday memory problems, and the profile score offers a more sensitive measure of change. The RBMT can be used for repeated assessment to monitor stability, improvement, or deterioration over time.


**Weschler Adult Intelligence Scale®—Third Edition (WAIS®–III)**

The WAIS®–III is a general test of intelligence. The WAIS®–III consists of 11 subtests divided into two parts, verbal and performance. The verbal tests are information, comprehension, arithmetic, digit span, similarities, and vocabulary. The performance tests are picture arrangement, picture completion, block design, object assembly, and digit symbol. The WAIS®–III must be administered by a trained psychologist.


**Psychogeriatric Assessment Scale (PAS) (cognition)**

The PAS assesses cognition and depression in the elderly on a continuum and compares the results to the normal range of the elderly in the community. The PAS consists of an interview with the stroke survivor and an interview with a relative, caregiver, or other individual who knows the subject well. The interviews provide different perspectives on the subject's functioning. The PAS assesses cognition on a continuum that ranges from normal cognitive aging at one end to severe dementia at the other.


**Mood**

**Beck Depression Inventory (BDI)**

The BDI is a widely used and easily administered scale for measuring depression in stroke patients. It is less useful in elderly individuals and in patients with aphasia or neglect. A high rate of false positives is seen, and somatic scores may be unrelated to depression.


**Brief Assessment Schedule Depression Cards (BASDEC)**

BASDEC is a useful tool for assessing depression in individuals who have suffered a stroke, as the ability to verbalize is not required because cards are used. BASDEC should be administered according to the standardized instructions. A patient scoring 7 or more points may be suffering from a depressive disorder.

**Hospital Anxiety and Depression Scale (HADS)**

The HADS is a self-report questionnaire developed to detect anxiety and depressive states in hospitalized individuals. Therefore, it has limitations in aphasic populations. Because it was developed for use in non-psychiatric departments, it does not rely upon symptoms that may be present in people with physical illness alone, such as pain and weight loss. HADS is equally effective in hospital, outpatient or community settings. HADS is relatively unaffected by concurrent physical illness and designed for repeat administration, so that progress or outcomes can be compared.


**Psychogeriatric Assessment Scale (PAS) (depression)**

The PAS assesses cognition and depression in the elderly on a continuum, and it compares the results to the normal range in the elderly in the community. The PAS consists of an interview with the stroke survivor and an interview with a relative, caregiver, or other individual who knows the subject well. The interviews provide different perspectives on the subject's functioning. The PAS assesses mood on a continuum ranging from positive well-being in old age to severe depression.


**Quality of life**

**Caregiver Strain Index**

The Caregiver Strain Index is a questionnaire that can help identify the need for intervention and is used with individuals who are caring for someone at home. This index correlates with caregivers' perceptions of the caretaking relationship and with the physical and emotional health of the caregiver and of the person receiving care.


**Short-Form 36 (SF-36)**

The SF-36 is a generic and subjective measure of health-related quality of life. The physical composite score includes measures of physical function, physical role, bodily pain, and general health. The mental composite score includes social function, emotional role, mental health, and vitality. It is usually self-administered, but has been validated in interview and mail formats as well. Because it has been well validated in the international literature for a wide variety of patient populations and for normal individuals, the SF-36 is useful for comparing populations. The SF-36 has been studied in acute, rehabilitation, and community settings.
Results are correlated with return to work, symptomatology, and resource utilization, and they are responsive to change. The SF-36 is particularly suited to the community setting when clients reintegrate into the community and attempt to resume normal roles. However, communication deficits may create difficulties in administering the SF-36 to some stroke survivors.


**Short-Form 12 (SF-12)**

The SF-12 is a 12-item, 2-minute questionnaire developed from the SF-36 to monitor health-related quality of life. The summary physical and mental health outcome scores are interchangeable with those from the SF-36. The SF-12 is used extensively as a screening tool and is frequently embedded into longer, condition-specific surveys.


**Stroke Impact Scale (SIS)**

The SIS assesses several aspects of health-related quality of life that are important to stroke survivors, caregivers, and healthcare professionals. These aspects include physical factors (strength, hand function, mobility, and activities of daily living), emotion, communication, memory and thinking, and social participation.


**Pain**

**Visual Analogue Scale (VAS)**

The VAS is a simple and accurate way of subjectively assessing pain along a continuous visual spectrum. VAS consists of a straight line on which the individual being assessed marks the level of pain. The ends of the straight line are the extreme limits of pain with 0 representing no pain and 10 representing the worst pain ever experienced. Research is needed to determine the ability of the VAS to consistently measure pain in stroke patients.


**Client-centred assessment**

**Canadian Occupational Performance Measure (COPM)**

The COPM is an individualized, client-centred outcome measure designed to detect changes in an individual’s perception of progress against self-set goals over time. It can be used for clients
with a variety of disabilities and across all developmental stages. Changes in scores between assessment and re-assessment provide the most meaningful information using this instrument.

In a study with community-living adults, significant correlation between COPM scores and scores on the RNLI, the Life Satisfaction Scale, and the Satisfaction with Performance Scaled Questionnaire was seen. Changes in the COPM scores for Performance and Satisfaction are correlated with changes in overall function. The COPM is usually administered by an occupational therapist.


Skin breakdown

Braden Scale for Predicting Pressure Sore Risk

The Braden Scale for Predicting Pressure Sore Risk is a widely used tool for foretelling the development of pressure ulcers in bedridden individuals. It assesses 6 risk areas for developing pressure ulcers:

- Sensory perception
- Skin moisture
- Activity
- Mobility
- Nutrition
- Friction or shear.

Each risk area is assigned a score ranging from 1 (highly impaired) to 4 (no impairment). Low scores indicate high risk. The Braden Scale for Predicting Pressure Sore Risk tool can be used at any stage of stroke care.


GENERAL REFERENCES
