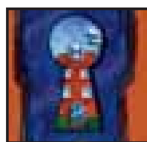

Key Case

# System Change in Healthcare: The Ontario Stroke Strategy

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## Introduction

In the mid-1990s, stroke was described as Canada's most "forgotten disease." Too often it was viewed as a hopeless condition, with little to be done to prevent and mitigate its potentially life-altering effects. This view appeared to affect many pre-hospital, hospital and community care practices in Ontario. It also impacted negatively on quality care improvements, the development of "leaders" in stroke research and healthcare and investments in stroke research.

Within five years, this picture of stroke changed dramatically. The Ontario government adopted the Ontario Stroke Strategy as the expected way to organize stroke services in the province, and committed substantial start up and ongoing funding.

## What Happened?

The Heart and Stroke Foundation of Ontario took on the challenge of changing the way stroke was viewed and treated in the province. The Foundation laid the groundwork, established strategic alliances and worked closely with the Ontario Ministry of Health and Long-Term Care to make stroke unforgettable.

The development of the Ontario Stroke Strategy was due to a combination of strategic decisions, hard work, good timing and luck. This article reviews the development of the strategy from its early days to the present, outlines the approaches used in working with government to influence its policy and investment decisions and reflects on the future.

## Coming out of the Starting Gate

In 1996, the United States Federal Drug Administration approved the use of tPA for emergency ischemic stroke. This "clot busting" drug had a narrow window of opportunity: it had to be administered within three hours of onset of a non-bleeding stroke, and it had to be supported with specialized technologies, such as a CT scanner.

The pressure to approve and promote tPA in Canada was felt by the Heart and Stroke Foundation, a well-recognized organization with a mission of reducing the risk of premature death and disability from heart disease and stroke by raising funds for research and health promotion. Healthcare providers, especially neurologists and the healthcare marketplace, specifically the pharmaceutical industry, encouraged the Foundation to increase awareness of stroke symptoms and the importance of responding quickly with effective treatments.

In response to the pressure to "do something," the Foundation conducted a market analysis of stroke and found that

- The concept of "timely and effective stroke care" seemed to be a contradiction in terms
- Public leadership in stroke research and care was almost non-existent
- On a per capita basis, research dollars spent on stroke were low

The Foundation had no doubt that it could effectively increase public awareness about stroke and stroke care; however, it faced the ethical dilemma of increasing the demand for timely and effective care that was not available. For example, only 4% of acute hospitals had dedicated stroke units and only 24% of acute hospitals had an emergency room stroke protocol in place (Heart and Stroke Foundation et al. 1998). Healthcare providers and the system were ill equipped to respond to strokes without professional education and system changes.

The Foundation began with the philosophy that government needed to show leadership in healthcare and take on the stroke challenge, but it quickly discovered that government's healthcare agenda was oversaturated. There was little likelihood that stroke would garner attention, much less achieve prominent recognition in the health arena.

The Foundation was faced with an interesting challenge. Investing in system change fell outside the mission and traditional day-to-day business of the organization. Further, the Foundation did not have a working relationship with government.

Capturing the attention and commitment of government was critical for system change for stroke care. Since stroke was an "ask of" rather than a "win for" government, the Foundation decided to focus attention on developing stroke as a tangible "win" that government could adopt. The work needed to go beyond building a paper case to actually demonstrating the case based on tangible evidence to support a stroke strategy. Using a marketing approach, the Foundation

- Commissioned a burden of illness study to assess the consequences of stroke (Chan and Hayes 1994/95)
- Met with the Minister of Health and Long-Term Care, which led to the Ministry partnering in an audit of current stroke practices in hospitals (with the Ontario Hospital Association and the Institute for Clinical Evaluative Sciences) (Heart and Stroke Foundation et al. 1998)
- Commissioned research on public awareness about "stroke messages" that would best resonate with the public, and on donor/public attitudes toward a government-Foundation partnership on stroke care
- Approached healthcare professionals and organizations to participate in demonstration pilots to test a model of regional coordinated stroke care across the continuum

The pilots were critical. They became cornerstones for a wide range of developmental activities, attracted government's attention and built credibility for a coordinated system of stroke care. Healthcare organizations in four areas of southern Ontario showed leadership by agreeing to invest in three-year pilots of the Coordinated Stroke Strategy, without any promise of future funding. Three pilots were launched in 1998 (London Health Sciences Centre, Hamilton Health Sciences and the Care Delivery Network: Queen's University, Kingston), followed by a fourth pilot in 1999 (a consortium of community hospitals and community care access centres in the West Greater Toronto Area).

A coordinated approach to stroke care was beginning to gain momentum in Ontario.

## Solidifying a Winning Strategy

The Foundation actively engaged the political and bureaucratic leaders, and continued to oversee a wide range of ongoing activities with a broad range of stakeholders in its efforts to solidify a winning strategy.

### Political and Bureaucratic Leaders

The Coordinated Stroke Strategy needed to capture the imagination of the politicians as well as the commitment of the civil servants for the ongoing work. Engaging the political leaders occurred on a number of fronts:

- The Foundation scheduled meetings with the Minister of Health and Long-Term Care to discuss stroke initiatives.
- At the local level, Foundation volunteers (many of whom were stroke survivors) visited their members of provincial parliament in ridings across the province. A relatively young stroke survivor (who was a facilitator of a Living with Stroke group and an influential advocate for improved stroke care) visited the newly appointed Minister in her riding. Likewise, another strong advocate stroke survivor visited the treasurer in his riding.
- At the provincial level, the Empire Club in Toronto hosted a lunch for the Foundation in March 2000, and featured two prominent stroke survivors – Ian Scott, the former Attorney General of Ontario, and Phil Lind, the Vice-Chair of Rogers Communications Inc. The audience included key government representatives as well as the two health critics of the day.

On the bureaucratic level, Ministry staff co-chaired key committees with the Foundation and participated on all committees, working groups and panels. This helped ensure a fit between recommended directions for stroke care and the Ministry's policies and priorities, and resulted in Ministry ownership of the initiatives. Ministry staff became advocates of the strategy, doing the essential internal work to build Ministry commitment. Luckily, the strategy also had a Ministry champion in the bureaucracy who effectively presented the stroke case to senior management.

### Ongoing Activities with Many Stakeholders

The Foundation oversaw a wide range of ongoing activities with a broad range of stakeholders:

- The audit of hospital stroke practices resulted in the creation

of the Joint Stroke Strategy Working Group, a provincial steering committee co-chaired by the Foundation and the Ministry. The group recommended a comprehensive and coordinated approach to provincial stroke care (Ontario Ministry of Health and Long-Term Care and Heart and Stroke Foundation of Ontario 2000).
- The Foundation convened the Stroke Rehabilitation Consensus Panel, which made recommendations on a provincial system of stroke rehabilitation (Heart and Stroke Foundation of Ontario 2000).
- The Stroke Steering Committee, convened by the Foundation, oversaw the development of the four pilot projects. The Committee was made up of organizations, such as the Ontario College of Family Physicians, the Registered Nurses' Association of Ontario, the Ontario Physiotherapy Association, the Ontario Society of Occupational Therapists and the Ontario Association of Speech Language Pathologists and Audiologists, which added further credibility and prominence to its work. The Committee visualized a provincial coordinated stroke strategy as the "field of dreams," working on the premise that the success of the four pilots would naturally lead to a network of other sites throughout the province.

The pilots were the focus of many developmental activities, for example:

- The Foundation regularly brought together staff from the four pilots to build on each other's experiences and share lessons learned. This included Annual Collaborative Forums to encourage collaboration, identify common issues and address areas, such as professional education, public awareness and evaluation.
- The Foundation launched a pilot to determine the most effective media methods to increase public awareness about the signs and symptoms of stroke.
- The Health Transition Fund provided support to help evaluate the model of stroke care in the pilot sites (Heart and Stroke Foundation of Ontario 2001).
- With additional Ministry funding, the Foundation produced a series of manuals to support implementation of coordinated stroke care. (One example is A Guide for Establishing a Regional Coordinated Stroke Strategy, Heart and Stroke Foundation of Ontario, January 2001.)

### The Announcement

The activities surrounding the pilots were impressive and were building a critical base for immediate implementation of the strategy. Further, some early pilot results were striking. For example, the South East Ontario pilot, the site of a full public awareness campaign, implemented a bypass protocol, whereby 12% of stroke patients received tPA. This was significantly higher than other areas in Canada and the United States. When one influential civil servant commented, "it's working in the regions," the Coordinated Stroke Strategy seemed to fly off the Ministry's shelf.

In June 2000, government adopted the Joint Stroke Strategy Working Group's Report, *Towards an Integrated Stroke Strategy for Ontario,* describing it as the "road map" for a comprehensive provincial stroke strategy. The announcement was accompanied by a commitment of provincial funds of $70 million over four years and $30 million annually ongoing after start up.

The strategy had become a tangible win for government.

## Maintaining the Win

In 2001, the three-year demonstration pilots were finished, the Stroke Strategy had evolved from a demonstration into the expected way to organize stroke services in Ontario. The Ministry formalized what was now known as the Ontario Stroke Strategy by designating six regional centres in the province. By 2003, the number of designated regional stroke centres had grown to nine, along with 15 designated district stroke centres and 13 secondary prevention clinics. A Joint Stroke Implementation Advisory Committee, co-chaired by the Ministry and the Foundation, was struck to oversee the implementation of the strategy. The Foundation continued working with community partners to develop a strategy for long-term and community stroke care, and to further a system of stroke rehabilitation. (For example, the Heart and Stroke Foundation developed a handbook, video and facilitator's guide called *Tips and Tools for Everyday Living: A Guide for Stroke Caregivers*, 2001.)

The Foundation achieved its goal of capturing the attention and commitment of government for organized stroke care and system change. Was its work done? No – wins can be subsequently lost. The importance of maintaining the win for stroke care argued for a continued partnership between the Ministry and the Foundation.

- The Ministry continues to have a crowded agenda with increasing pressures and demands. Stroke is only one Ministry priority, whereas stroke is a top priority for the Foundation. Various stakeholders have expressed concerns that without the Foundation strongly advocating for stroke, it may get lost among the competing voices. Hard-won stroke investments may disappear within hospital global budgets. The fear is that stroke may, once again, become the "forgotten disease."
- Individuals involved in the stroke strategy have always perceived the Foundation as an "honest broker." The Foundation can continue to capitalize on the commitment and participation of this broad range of volunteers, including clinical and program experts, for the benefit of the system.

- The Foundation and the Ministry have developed an effective working partnership. Examples include: with Ministry support, the Foundation has launched a major public education campaign on high blood pressure; the Ministry and the Foundation have co-funded the first Stroke Nursing Chair; and building on a successful Foundation pilot, the Ministry has funded a provincial public awareness campaign on the signs and symptoms of stroke. Although the continued involvement of the Foundation can lead to "creative tension" with the Ministry, the benefits seem to outweigh the risks.

## Concluding Comments

The philosopher Kierkegaard once wrote, "Life can only be understood backwards, but it must be lived forwards." Looking back at the development of the Ontario Stroke Strategy, what can be learned from the past that might be useful for the future?

Could anything have been done differently? Probably yes. As with the development of many new programs, the main focus was on building the strategy with little attention paid to incorporating a method to evaluate performance. Although there is anecdotal evidence to suggest that the strategy is making a difference, little measurable evidence currently exists. This will soon change. In the spring of 2003, the Ministry awarded a proposal to develop a comprehensive stroke database to support monitoring and evaluating the progress made by the strategy; thus, provincial, regional and organizational levels will be able to identify service improvements in stroke care.

Could the stroke strategy have achieved the prominence it has in Ontario in such a short time using a different approach? Probably not. The Foundation effectively got profile for stroke in an overcrowded government agenda by

- Demonstrating a winning case with tangible evidence
- Capturing the imagination of the politicians and the commitment of the civil servants
- Engaging the efforts of a broad range of people working throughout the system at different levels

It also helped that the strategy had an "honest broker" – the Foundation – that was perceived as a credible champion with no agenda other than to build a system for improved stroke care. This helped to overcome any initial suspicion about the strategy from healthcare providers and government.

The success of the strategy and the need to maintain the win may challenge the Foundation to assess this experience in relation to its core mission – to raise funds for research and health promotion. It may also challenge other organizations to assess the roles they can potentially play and the methods they can use to bring about successful system change in healthcare.

### Description of the Strategy

The Ontario Stroke Strategy aims to decrease the incidence of stroke and to improve patient care and outcomes for persons who experience stroke. By reorganizing stroke care delivery, the goal of the Ontario Stroke Strategy is to ensure that all Ontarians have access to appropriate, quality stroke care in a timely manner.

The Strategy is based on four principles:

- *Comprehensive.* The Strategy seeks to improve stroke services across the entire continuum of care from prevention programs to care in a long-term care or community setting.
- *Integrated.* The Strategy seeks to create an integrated or co-ordinated system of care where different services and sectors function as a unified whole, across the continuum of care and across Ontario.
- *Evidence-based.* To ensure that all Ontarians receive high quality stroke care, the Strategy promotes the use of practices and care that have been supported by scientific evidence, or are considered the gold standard according to prevailing knowledge.
- *Province-wide.* Improvements to stroke care should benefit all Ontarians irrespective of their geographic location.

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