

## **Blueprint for Action 2010 to 2020**

### **Quality End-of-Life Care Coalition of Canada Members endorsing this document:**

ALS Society of Canada  
Alzheimer Society of Canada  
Canadian AIDS Society  
Canadian Association of the Deaf  
Canadian Association of Occupational Therapists  
Canadian Association for Pastoral Practice and Education (CAPPE)  
Canadian Association of Social Workers  
Canadian Breast Cancer Network  
Canadian Cancer Society  
Canadian Caregiver Coalition  
Canadian Healthcare Association  
Canadian Home Care Association  
Canadian Hospice Palliative Care Association  
Canadian Medical Association  
Canadian Nurses Association  
Canadian Pharmacists Association  
Canadian Society of Palliative Care Physicians  
Caregiver Network Inc.  
CARP: Canada's Association for the Fifty-Plus  
Catholic Health Alliance of Canada  
College of Family Physicians of Canada  
The GlaxoSmithKline Foundation  
Heart and Stroke Foundation of Canada  
Huntington Society of Canada  
Ovarian Cancer Canada  
Saint Elizabeth Health Care  
VON Canada

**January 2010**



## Introduction

Over the past 10 years, the 30 national organizations that are members of the Quality End-of-Life Care Coalition of Canada (QELCCC) have worked together to improve end-of-life care for all Canadians. Their goals were to improve access to care, increase the number of professionals and volunteers with the skills to provide high quality end-of-life care, promote research that would improve care, support the family members who care for people who are dying, and educate Canadians about their choices at end of life.

The QELCCC has observed some remarkable successes:

- In the last five years, the Canadian Institutes for Health Research have invested \$16.5 million in research on hospice palliative and end-of-life care, which is helping to improve care.
- The number of professionals and volunteers with the skills to provide hospice palliative end-of-life care has increased significantly: all 17 medical schools across the country now educate new physicians in palliative care and education programs for nurses, social workers, pharmacists and pastoral care providers include training in end-of-life care.
- The Canadian government introduced the Compassionate Care Benefit to give family caregivers six weeks of paid leave to care for a loved one at end of life, and some provincial governments have increased access to respite services. The Canadian Hospice Palliative Care Association in collaboration with The GlaxoSmithKline Foundation, has developed training materials for family caregivers.
- Across Canada, there has also been some progress in improving access to high quality hospice palliative end-of-life care. Between 2001 and 2006, the federal government funded the Strategy on Palliative and End-of-Life Care, and funding for palliative home care was part of the 2003 and 2004 Health Accord among First Ministers of Health. More hospitals and long-term care homes now offer high quality end-of-life care.
- Canadians are more aware of their choices at end of life.

While some progress has been made, there is still much more to be done.

More than 259,000 Canadians die each year.<sup>1</sup> Of those, only a small proportion receive high quality hospice palliative end-of-life care. With the aging of our population, by 2026, the number of Canadians dying each year will increase by 40% to 330,000. By 2036, Canada will see more than 425,000 deaths a year. Despite the fact that most Canadians would prefer to die at home, surrounded by their loved ones, most are still dying in hospitals or long-term care homes. The availability of high quality care at end of life varies widely in different parts of the country and in different settings.

Progress in hospice palliative end-of-life care over the past 10 years was largely due to governments recognizing the need for high quality care and investing in services for people who are dying. However, there are signs that hospice palliative and end-of-life care may no longer be a government priority. In 2007, the federal government disbanded the End-of-Life Care Secretariat and stopped work on the national palliative and end-of-life care strategy. Although palliative and end-of-life care have been included in other national strategies, such as the cancer, heart health and HIV/AIDS strategies, few specific steps have been taken to enhance services for people who are dying or support their caregivers. To continue to improve care at end of life for all Canadians, the QELCCC will focus on four priorities over the next 10 years.

## Moving Forward: The Next 10 Years

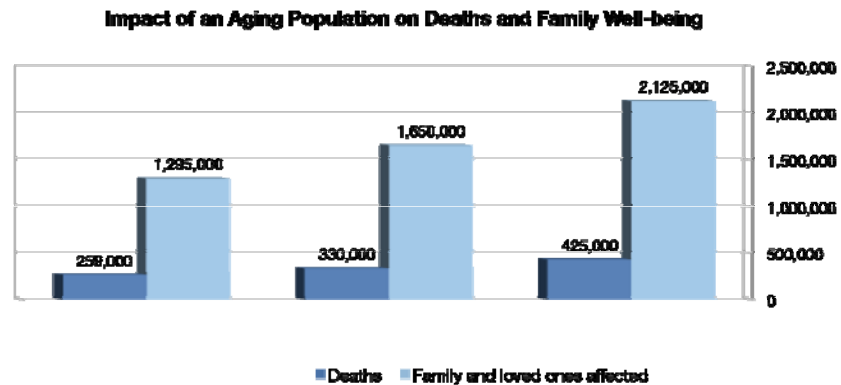
More than 259,000 Canadians die each year<sup>ii</sup>, and most die in old age. Of those, only a small proportion receive high quality hospice palliative end-of-life care.

With the aging of our population, by 2026, the number of Canadians dying each year will increase by 40% to 330,000. By 2036, Canada will see more than 425,000 deaths a year.<sup>iii</sup>

Each of those deaths will affect the well-being of, on average, five other people – family and loved ones – or more than 1.25 million Canadians this year and more than 2 million Canadians in 2036.

The need is urgent and our capacity to respond limited.

How can we ensure that all Canadians have access to high quality end-of-life care? What strategy should the QELCCC pursue to make a difference in living and dying for Canadians?



### Our Priorities

Over the next 10 years, the QELCCC will focus on 4 priorities. The priorities are listed in no particular order.

#### 1. Ensure all Canadians have access to high quality hospice palliative end-of-life care

High quality palliative and end-of-life care must be an integral part of health care, and available in all settings of care, including hospital, long-term/continuing care, residential hospices, shelters and individual homes. When someone is diagnosed with a life-limiting illness, involving palliative care providers early can improve quality of life and reduce suffering.

In particular, the QELCCC will continue to ask federal, provincial and territorial governments to:

- 1.1 Develop a national palliative and end-of-life care strategy and encourage other national health strategies – including the cancer, heart health, diabetes, lung, HIV/AIDS, chronic disease management, mental health, Aboriginal health and seniors strategies – to show leadership in end-of-life care.
- 1.2 Fulfill their commitment to provide first dollar coverage for palliative home care services
- 1.3 Provide essential hospice palliative care services in all settings, based on the person's and the family's needs, including:
  - access to hospice palliative care professionals, including volunteers, 24 hours a day/7 days a week
  - all necessary medical equipment
  - prescription medications
  - non-prescribed therapies
  - support provided by consistent care providers

- access to respite care for family caregivers.
- 1.4 Establish a multi-sectoral task force or working group that crosses health and social services (e.g., health, education, finance, human resources, First Nations, veterans, and non-governmental organizations, such as unions and insurance associations), whose role is to consult with communities and make recommendations to advance hospice palliative end-of-life care.

## **2. Provide more support for family caregivers**

Family caregivers often provide care for a family member who is dying at great cost to themselves personally, financially and in terms of their health and well-being. The health and social system and our communities must provide more support for family caregivers. Although more people are dying at home, there is not enough information about the impact on family members.

The QELCCC will work with governments to implement the recommendations in the 2009 Senate Report on Aging, the Canadian Caregiver Coalition – Canadian Caregiving Strategy and other recommendations to provide more support for family caregivers. One of our goals is to minimize the excessive financial burden for family caregivers. Another is to ensure they have other supports to help them maintain their health.

- 2.1 Create a comprehensive set of caregiver programs that bundles a variety of financial and other supports for caregivers that they can access, according to their needs (that better reflect the variety of realities for caregivers). The bundled program should include:
- 2.1.1 A revised Compassionate Care Benefit that would:
- Eliminate the two-week waiting period to receive the benefit
  - Increase the benefit to 75% of workers' earnings
  - Increase the benefit period to a maximum of 52 weeks within the last year of life (as currently exists for maternity leave). One year is given for the beginning of life – why not for the end of life as well?
  - Build more flexibility into the program, such as allowing partial weeks over a longer period, rather than blocks of weeks at a time
- 2.1.2 A companion program to the Compassionate Care Benefits that is not based on employment (e.g., a program like CPP) that people can pay into, whether they are self-employed, part-time employed, unemployed or retired, and draw on when they need income to sustain them through a period of caregiving for a loved one.
- 2.2 Create a Caregiver Benefit, similar to the Child Tax Benefit (a tax-free monthly payment made to eligible families to help them with the cost of raising children under age 18) that caregivers can apply for when a patient with life-limiting or life-threatening illness is under their care in their home. This would make it easier for them to cover expenses throughout the year, such as hiring nursing or housekeeping help.
- 2.3 Ensure Canadians are aware of the benefits available to them when caring for someone at end of life.
- 2.4 Ensure family caregivers have access to information and education, and services such as respite care that help safeguard their health.

## **3. Improve the quality and consistency of hospice palliative end-of-life care in Canada**

The quality of hospice palliative end-of-life care services can vary dramatically in different settings and different regions. To improve quality, the QELCCC supports the recommendations of Senate Committee

on Aging, the Pallium Foundation of Canada and the Canadian Society of Palliative Care Physicians and will advocate for:

- 3.1 Wide-spread adoption of the gold standard in palliative home care developed by the Canadian Hospice Palliative Care Association and the Canadian Home Care Association
- 3.2 A partnership among the federal government, provinces, territories and community organizations to develop and promote standards and best practices for hospice palliative end-of-life care
- 3.3 Education and support for all health care providers, home support workers, volunteers and family caregivers.
- 3.4 Funding to continue to support research in palliative and end-of-life care, and to integrate findings into policy and practice
- 3.5 Funding to help communities and providers develop the capacity to meet the unprecedented increase in demand for end-of-life care.

#### **4. Encourage Canadians to discuss and plan for end-of-life**

Hospice palliative end-of-life care will not be a priority in our health care system until it is a priority for Canadians. With the aging of the population, more attention will be focused on this issue.

The type and quality of care that people receive at end of life depends in large part on their ability and willingness to talk about and plan for death while still enjoying life.

The QELCCC will continue to:

- 4.1 Educate Canadians and raise awareness about the importance of advance care planning.
- 4.2 Encourage patients to talk about end-of-life care, and go through the process of advance care planning
- 4.3 Encourage more public discussion about death and dying, and the importance of high quality end-of-life care.

## A Progress Report on the *Blueprint for Action*

### **Preface**

*The Quality End-of-Life Care Coalition of Canada (QELCCC) is a group of 30 national organizations concerned about quality of end-of-life care. The QELCCC provides a forum for its members to share information, identify needs and gaps in end-of-life care, and advocate – with federal and provincial governments -- for better hospice palliative and end-of-life care for all Canadians.*

In December 2000, the QELCCC developed a blueprint for action on end-of-life care for Canada, which consisted of five priority areas for action:

1. **Availability and Access:** Ensure all Canadians have access to good end-of-life care.
2. **Professional Education:** Have an adequate number of trained professionals and volunteers to provide end-of-life care for all Canadians.
3. **Research and Data:** Have an adequate research base for high quality health service delivery.
4. **Family and Caregiver Support:** Support families and caregivers so they will be able to provide care and maintain their health.
5. **Public Education and Awareness:** Inform Canadians about their care choices.

Almost a decade later, what progress has been made? Has the QELCCC achieved its goals? What has been accomplished? What has changed? What remains to be done?

This report summarizes, for each priority area: the original goals and objectives; the progress made to date; and current knowledge, issues, and gaps. It then sets out some possible next steps: actions and strategies that the QELCCC will pursue for the next ten years to improve hospice palliative and end-of-life care for all Canadians.

## Executive Summary

Over the past 10 years, the 30 national organizations that are members of the Quality End-of-Life Care Coalition of Canada (QELCCC) have worked together to improve end-of-life care for all Canadians. Their goals were to improve access to care, increase the number of professionals and volunteers with the skills to provide high quality end-of-life care, promote research that would improve care, support the family members who care for people who are dying, and educate Canadians about their choices at end of life.

The QELCCC has observed some remarkable successes:

- In the last six years, the Canadian Institutes of Health Research invested \$16.5 million in research on hospice palliative and end-of-life care, which aims to improve care.
- The number of professionals and volunteers with the skills to provide hospice palliative end-of-life care has increased significantly: all 17 medical schools across the country now educate new physicians in palliative care and education programs for nurses, social workers, pharmacists and pastoral care providers are planning to include training in end-of-life care.
- The Canadian government introduced the Employment Insurance Compassionate Care Benefits to give family caregivers who qualify six weeks of paid leave to care for a loved one at end of life, and some provincial governments have increased access to respite services. The Canadian Hospice Palliative Care Association, in collaboration with The GlaxoSmithKline Foundation, has developed training materials for family caregivers.
- Across Canada, there has also been some progress in improving access to high quality hospice palliative end-of-life care. Between 2002 and 2007, the federal government funded the Canadian Strategy on Palliative and End-of-Life Care, and funding for palliative home care was part of the 2003 and 2004 Health Accords among First Ministers of Health. More hospitals and long-term care homes now offer high quality end-of-life care.
- Canadians are more aware of their health care choices at end of life.

While some progress has been made, there is still much more to be done.

More than 259,000 Canadians die each year.<sup>iv</sup> Of those, only a small proportion receive high quality hospice palliative end-of-life care. With the aging of our population, by 2026, the number of Canadians dying each year will increase by 40% to 330,000. By 2036, Canada will see more than 425,000 deaths a year. Despite the fact that most Canadians would prefer to die at home, surrounded by their loved ones, most are still dying in hospitals or long-term care homes. The availability of high quality care targeted to meet the needs of those at the end of life varies widely in different parts of the country and in different settings.

Progress in hospice palliative end-of-life care over the past 10 years was largely due to governments recognizing the need for high quality care and investing in services for people who are dying. However, there are signs that hospice palliative and end-of-life care may no longer be a government priority. In 2007, the federal government disbanded the Secretariat on Palliative and End-of-Life Care and stopped work on the national palliative and end-of-life care strategy. Although some aspects of palliative and end-of-life care have been included in other national strategies, such as the cancer, heart health and HIV/AIDS strategies, few specific steps have been taken to enhance services for people who are dying or support for their caregivers, and these strategies lack a coordinated, comprehensive approach to end-of-life care.

To continue to improve care at end of life for all Canadians, the QELCCC will focus on four priorities over the next 10 years. The priorities are listed in no particular order.

1. **Ensure all Canadians have access to high quality hospice palliative end-of-life care.** High quality palliative and end-of-life care must be an integral part of health care, and available in all



settings of care, including hospital, long-term/continuing care, residential hospices, individual homes and shelters. It must also be available to all people with life-limited conditions.

2. **Provide more support for family caregivers.** The health and social service systems and our communities must reduce the financial burden family caregivers face, and provide supports that help them maintain their health and well-being.
3. **Improve the quality and consistency of hospice palliative end-of-life care in Canada.** Canadians should expect to receive high quality care in all parts of the country. All organizations involved in end-of-life care must promote standards and best practices as well as education for health care providers, home support workers, volunteers and family caregivers.
4. **Encourage Canadians to discuss and plan for end of life.** Hospice palliative end-of-life care will not be a priority in our health care system until it is a priority for Canadians. People must be able to talk about and plan for death, while still enjoying life. With the aging of our population, more attention must be focused on this issue now.

## Priority #1: Availability and Access

### *Ensure all Canadians have access to good end-of-life care*

#### The Blueprint

In 2000, the Canadian Senate issued a report reinforcing that quality end-of-life care is the right of every Canadian.<sup>v</sup> That report documented that Canada fell far short of providing equitable access to quality end-of-life care: only about 15% of Canadians who required hospice palliative care services had access to them; the types of services available varied considerably from province to province; and access was a particular problem for Canadians living in remote and rural areas, and for people with disabilities. Despite the fact that most Canadians would prefer to die at home, surrounded by their loved ones, in 2000, 75% were dying in hospitals or long-term care homes.

Blueprint strategies to improve access and availability of good end-of-life care included: moving this issue up the political agenda; developing services to meet needs without discrimination; giving Canadians choice about when and where to access end-of-life care; ensuring core funding for end-of-life care (hospice palliative care programs depended on charitable donations for their funding); and ensuring end-of-life services are community-driven and needs-based.

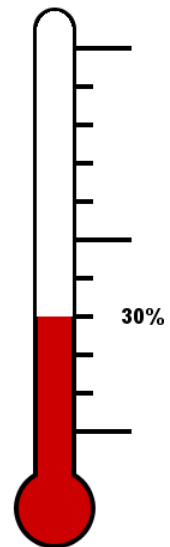
#### 10 Years Later: Our Progress

Over the past 10 years, organizations involved in the QELCCC have made some progress in moving hospice palliative and end-of-life care up the political agenda and reinforcing standards for end-of-life care. In some parts of the country, palliative and end-of-life care is being delivered in more settings, but access is still uneven.

**Political will.** Health care services are primarily the responsibility of provincial and territorial governments. The federal government also plays a role by setting policy and direction, and by providing funding. Over the past 10 years, hospice palliative care was on the agenda of key groups and meetings, including the Romanow Commission on the Future of Health Care in Canada, and the 2003 and 2004 Health Accords reached among First Ministers of Health. From 2002 to 2007, the federal government funded the Strategy on Palliative and End-of-Life Care (\$1 to \$1.5 million a year). Palliative care is now also one of the four pillars in the national cancer strategy and is identified as a priority in the national heart health and HIV/AIDS strategies.

**Setting quality standards.** The Canadian Hospice Palliative Care Association (CHPCA) developed a *Model to Guide Hospice Palliative Care*, which is now the basis for accreditation standards for hospice palliative and end-of-life care programs in all settings.

**Funding/providing end-of-life care in more settings.** Fewer Canadians are dying in hospital and more are dying at home. According to a 2007 report by the Canadian Institute for Health Information (CIHI), *Health Care Use at the End of Life in Western Canada*, 58% of Western Canadians died in hospital in 2003-04. There is



no comparable information for other parts of Canada, but the QELCCC assumes the same trends are occurring across the country. While more Canadians may be dying at home, we do not know whether they are receiving high quality hospice palliative end-of-life care at home.

More **hospitals** have developed hospice palliative and end-of-life care programs to provide more appropriate, cost-effective care for patients dying in hospitals.

Training and workshops are helping to improve the quality of end-of-life care in **long-term care settings**, particularly for people with dementia.

The 2004 Heath Accord set expectations for hospice palliative **home care services** that would be available in all provinces. In 2006, the QELCCC established Gold Standards for Hospice Palliative Home Care in Canada and, in 2008, the coalition surveyed provinces and territories to assess their progress in meeting those standards. There were positive findings. For example:

- 12 of 13 jurisdictions cover the cost of some medical supplies and equipment for people dying at home
- 11 of 13 cover the cost of a wide range of pharmaceuticals
- 11 of 13 promote a team-based approach to care.

To provide care without discrimination and to meet community needs, some organizations are now developing **hospice for the homeless services** for people on the street who are facing life-threatening illnesses. Services are also being provided for other Canadians who are marginalized or disabled.

## Challenges and Issues in 2010

**Political will.** Progress over the past 10 years was largely driven by governments recognizing the need for and investing in end-of-life care. However, there are signs that interest may be waning, particularly at the federal level: in 2007, the federal government disbanded the Secretariat on Palliative and End-of-Life Care and stopped work on the national palliative and end-of-life care strategy, although it maintained an office and continues to fund selected activities.

**Funding.** Only a small number of provinces have designated hospice palliative care as a core service under their provincial health plans. Hospice palliative care programs are still at least 50% funded by charitable donations, and families must bear part of the cost of dying at home, in long-term care – almost anywhere outside a hospital. Funding pressures created by the global recession threaten to limit new initiatives and investments.

**Access to services.** While there have been improvements in the end-of-life care services available through home care, Canadians still struggle to navigate the system, access services that are available and move from one setting to another, depending on their needs.

Recognizing that Canadians will continue to die in a variety of settings, Canada urgently needs a systems approach to end-of-life care: one that ensures that high quality care is available in all settings and that people and families have the information and support to move from one setting to another based on their needs – and that services are funded in ALL settings, so the decision about where people die is based on their needs and the cost effectiveness of care, rather than their ability to pay.

**Changing health needs.** In general, hospice palliative and end-of-life care services do a better job of meeting the needs of people with diseases such as cancer that have a more predictable trajectory. They have been less effective in helping people with chronic, life-threatening illnesses that do not follow a predictable trajectory – such as cardiovascular disease, respiratory diseases and renal diseases – about the role of palliative and end-of-life care. High quality end-of-life care should be available to all, regardless of their health condition.

## Priority #2: Professional Education

*Have an adequate number of trained professionals and volunteers to provide end-of-life care to all Canadians*

### The Blueprint for Action

Better access to quality hospice palliative and end-of-life care depends on having health care providers and volunteers with the right knowledge and skills. Education is essential to help health care providers: understand the limitations of active treatment for people who are palliative; gain skills in pain and symptom management; feel more comfortable talking with patients and families about death and options for end-of-life care; and understand the skills that different professions bring to palliative and end-of-life care.

Strategies to increase the number of professionals and volunteers with skills in end-of-life care which the QELCCC advocates include:

- making palliative medicine an accredited specialty for physicians including end-of-life care in medical education and on final medical exams
- introducing mandatory continuing education in end-of-life care for physicians
- supporting changes in billing/fee structures to attract more physicians to end-of-life care
- incorporating palliative care into the core curriculum for all health professions
- increasing training for support workers and volunteers
- developing peer education modules for people who are dying and family caregivers
- expanding training opportunities and methods for caregivers through school boards and community colleges

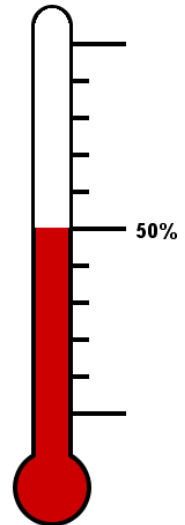
### 10 Years Later: Our Progress

Over the past 10 years, the number of professionals and volunteers with the knowledge and skills to provide hospice palliative and end-of-life care has increased significantly.

**Physician education.** Although palliative medicine is not yet an accredited specialty for physicians, end-of-life care has been integrated into medical training and is part of final exams. The Canadian Hospice Palliative Care Associations (CHPCA), in partnership with the Association of Faculties of Medicine of Canada, co-sponsored the Educating Future Physicians in Palliative and End-of-Life Care program, which is now in place in all 17 medical schools across the country. Practicing physicians also have opportunities for continuing education in end-of-life care (Learning Essential Approaches to Palliative and End of Life Care or LEAP). Although LEAP is not mandatory, it is building capacity and supports the role of primary care in palliative and end-of-life care.

**Physician funding.** The fee-for-service structure for funding physician service was addressed in submissions to the Romanow Commission and in the Commission's report. Across Canada, there are now a growing number of alternative approaches for funding physician services – particularly team-based primary care services – that make it more attractive to work in end-of-life care. These alternative funding models are an integral part of the transformation of health systems that is occurring across the country.

**Health professional education.** Efforts have been made to integrate end-of-life care skills and training into all health professional education. These efforts are proving successful in nursing



and social work. In April 2004, the Canadian Nurses Association began to offer Hospice Palliative Care Nursing Certification to Canadian nurses, and Canada's schools of nursing are also implementing plans to offer formal training as part of their curriculum. End-of-life curriculum for social workers is currently being written. Other professions, such as pharmacy and pastoral care, have indicated that end-of-life care is already covered in their training.

**Training for support workers.** Home support workers are often the primary caregivers for people and families at the end of life. They spend the greatest amount of time in the home, and have the most contact with the dying person and family members. The CHPCA has developed a manual and training program for home support workers, which is available online and is now in use in several provinces and territories. Materials have also been developed to train support workers and volunteers in First Nations communities.

Training has been developed and delivered to professionals working in Telehealth programs.

**Training for volunteers.** Training materials have also been developed for volunteers, particularly hospice volunteers, but more must still be done to train and support volunteers.

**Family caregiver training.** While the increase in hospice palliative home care gives people more choice about where they die, it also shifts a significant burden of end-of-life care onto family caregivers. To help them provide care and advocate for their loved ones, the CHPCA, in collaboration with The GlaxoSmithKline Foundation, developed the *Living Lessons® Influencing Change: A Patient and Caregiver Advocacy Guide*, a handbook and other training materials for family caregivers. Provincial palliative care associations also offer training for family caregivers

## Challenges and Issues in 2010

Professional education will be even more important in a systems-wide approach to hospice palliative and end-of-life – where Canadians will receive quality care in all care settings where they die.

The trend towards inter-professional education and inter-professional care teams creates an opportunity to ensure that all members of the team have the appropriate skills in end-of-life care. The shift to chronic disease management also represents a potential opportunity to integrate advance care planning and end-of-life care into services for people with chronic life-threatening conditions.

There is also an urgent need to develop workplace education programs that reinforce the value of hospice palliative and end-of-life care everywhere care is delivered, and that also train all health care staff in the competencies required.

In BC alone, volunteers contribute more than \$10 million worth of hospice palliative end-of-life care services every year. They are a crucial part of the care team, and need education to fulfill their role.

## Priority #3: Research and Data Collection

### *Develop an adequate research base for high-quality health service delivery*

#### The Blueprint

Quality care depends on having accurate, reliable data and information on how and where Canadians die, the type of care they receive, the type of care that leads to a “good” death, the supports that families and caregivers require, effective pain and symptom management, the cost effectiveness of end-of-life care in different settings, the impact of team-based care, and other information.

In the past, Canada has invested very little in hospice palliative and end-of-life care research, and little in gathering data on where people die and the care they receive in the last weeks and days of life. The country did not have a critical mass of skilled researchers working in the field to improve care.

Strategies to provide the information to support high quality services have included:

- establishing a research committee and building on the CHPCA research agenda
- building capacity/infrastructure
- advocating with research granting agencies to support hospice palliative and end-of-life care research
- learning from other models that have been effective in stimulating research and research investment, such as the Canadian Breast Cancer Research Alliance and the Canadian Study on Health and Aging
- developing an inventory of hospice palliative care programs
- exploring effective ways to collect data and identify indicators to measure the quality, impact and effectiveness of end-of-life care (e.g., surveillance system)

#### 10 Years Later: Our Progress

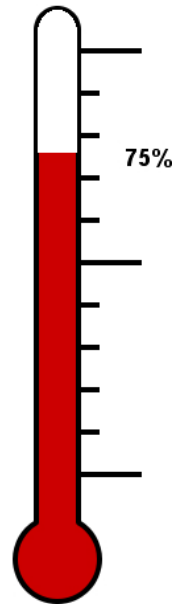
Over the past 10 years, Canada has had dramatic success in encouraging hospice palliative and end-of-life care research and data collection.

**Research funding and capacity.** In September 2004, the Canadian Institutes of Health Research announced \$16.5 million over six years to fund research in hospice palliative and end-of-life care focusing on, for example: palliative and end-of-life transitions, family caregiving, tackling difficult pain, cancer-associated cachexia and anorexia, vulnerable populations, and improving communication and decision-making.

CIHR also allocated \$25,000 a year to create a peer review committee to set research priorities and establish a standardized review process. As a result, the number of funded proposals increased from four to 12 to 21 a year. The evaluation of this research investment will be made public soon.

**Service inventory.** CHPCA has developed an inventory of hospice palliative and end-of-life care services, and the number of programs has increased from 200 to at least 530 over the past 10 years. CHPCA is now looking for funding to maintain the directory.

**Data collection.** CHPCA produces a national fact sheet that pulls data on hospice palliative care from a number of sources, including research studies, CIHI data and surveys. Health Canada was initially involved in discussions about developing a surveillance system for hospice palliative care, and a strategy to collect data – however, this initiative ended with the federal Secretariat.



## **Challenges and Issues in 2010**

The CIHR investment has been instrumental in creating interest and expertise in hospice palliative and end-of-life care research. Unfortunately, the funding commitment ended in 2009, and the gains that have been made may be lost.

Based on the research findings over the past ten years, more research is still required in a number of areas, including hospice palliative care for people with dementia, and the uptake/usefulness of knowledge translation tools.

The QELCCC must do more to push out research findings, and use them to influence policy and practice.

Much more must also be done to collect and analyze data on the hospice palliative and end-of-life care services that Canadians receive now and their impact and effectiveness, and needs for the future.

## Priority #4: Family and Caregivers Support

### *Support families and caregivers so they will be able to provide care and maintain their health*

#### The Blueprint

Regardless of where Canadians die – at home, in a hospice, in hospital or in a long-term care setting – a significant proportion of the responsibility of providing end-of-life care falls on family caregivers.

Demands on families are increasing in a time when, with smaller families and greater mobility, people often have fewer family members close by. More informal caregiving is falling on older, frail spouses and partners, and on older children who often have other work and caregiving responsibilities.

According to research conducted by Health Canada, 70% of family caregivers find providing end-of-life care stressful, and many experience a drop in income, an increase in costs and a loss of social activities.<sup>vi</sup> In US studies, family caregivers who provide 36 or more hours of care each week are six times more likely than non-caregivers to experience depression or anxiety.<sup>vii</sup>

QELCCC strategies to support family caregivers included:

- providing more job security for family caregivers
- extending the Canada Pension Plan child care drop-out provisions to include caregivers
- providing an income supplement for people caring for a dying family member
- offering tax credits to families who convert their home to provide care
- expanding the Canada Health Act to include home care
- changing the definition of disability
- distributing CHPCA family protection kit
- providing additional support and respite services for family and other caregivers, and acknowledging their role as part of the care team
- improving coordination of family supports and services.

#### 10 Years Later: Our Progress

Canada has made some important progress in supporting families and caregivers.

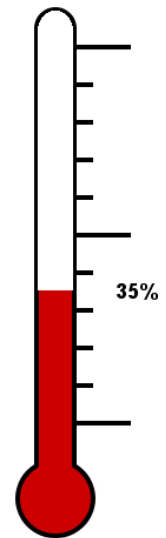
##### **Job security/income support.**

Effective January 2004, Human Resources and Skills Development Canada introduced the Compassionate Care Benefits through the Employment Insurance Program. The benefits provide eight weeks of leave (six weeks of paid leave) to eligible Canadians to care for a gravely ill loved one. In addition, some companies (e.g., GlaxoSmithKline Inc.) offer up to 13 weeks of paid leave for employees who need time away from work to care for a dying family member.

Unfortunately, not all provinces have updated their labour laws to guarantee job security for people who take a leave to care for a family member.

**Changing legislation and definitions.** The QELCCC was not successful in expanding the Canada Health Act to include home care or in changing the definition of disability. As a result, families still face extraordinary costs when caring for a member at home.

**Supporting families.** The model for hospice palliative care is based on person-centred care, where family caregivers are active members of the care team. A number of jurisdictions have increased access to respite services. Although, services for families are well-coordinated in some parts of the country, it still remains an issue for many Canadians.





## **Challenges and Issues in 2010**

Canada's population is aging so, over the next 40 years, the demand for hospice palliative and end of life care will grow. About 259,000 Canadians die each year now. By 2020, that number will increase by 33% to more than 330,000 deaths a year. It is estimated that each death in Canada affects the immediate well-being of, on average, five other people.

Because of changes in the health care system, including the trend to provide more care at home and in the community, family caregivers will continue to shoulder a growing burden of care. In addition to providing personal care, such as feeding and bathing, family caregivers will be administering medications and providing more complex care for family member with two or more chronic conditions – including intrusive procedures such as giving injections: caregiving that often requires training and skills.

The demands and stresses on family caregivers will continue to grow. The Compassionate Care Benefits – while helpful – is limited in terms of the number of weeks of coverage and eligibility. While it helps compensate anyone who is employed for wage losses and protects job security, it is only available to those covered by unemployment insurance and does not help with the added cost of providing care. It is not available to the growing number of Canadians who are self-employed, unemployed, or to the approximately 36% of caregivers who are over the age 70.

Canada will need to develop a basket of services that Canadians can use to help them care for family members who are dying. For example, there are high-impact, low-cost services already available – such as Meals on Wheels, assisted transportation services and the professional counseling services offered by hospice professionals – that can have a profound impact on family caregivers. Over the next 10 years, volunteers will become increasingly important in end-of-life care. Organizations like the Victorian Order of Nurses (VON) have developed “neighbours helping neighbours” programs and initiatives that encourage seniors to help seniors. These programs will be essential to help individuals and families cope.

## Priority #5: Public Education and Awareness

### *Inform Canadians about their care choices and encourage them to participate in creating these choices*

#### The Blueprint

In 2000, most Canadians were not aware of the end-of-life care choices available to them. Most did not have advance care plans to guide their care if they did develop a life-threatening condition.

QELCCC strategies to make Canadians more aware of their choice at end of life included:

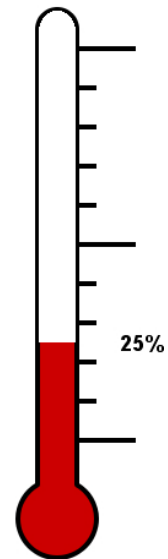
- developing a document to address changing beliefs and attitudes
- conducting an environmental scan and surveying Canadians to understand their education needs
- developing a public awareness framework for action/strategy
- working with corporate sponsors to raise public awareness

#### 10 Years Later: Our Progress

In 2004, the QELCCC surveyed Canadians – based on a previous survey conducted in 1997 – about hospice palliative care and advance care planning.

In general, they found that Canadians were more aware of their choices at end of life: 75% of Canadians knew about palliative care, up from 30% in 1997.

Despite having more knowledge, people who are eligible for hospice palliative and end-of-life care are not getting to these programs quickly enough, and there are few or no programs for people with chronic, life-limiting diseases other than cancer.



In 2005, the QELCCC developed a public awareness strategy, which includes National Hospice Palliative Care Week, the *Living Lessons*® awareness campaigns sponsored by The GlaxoSmithKline Foundation, and media and public relations efforts by CHPCA.

The CHPCA has also recently begun a five-year project to create advance care planning resources and tools for health professionals, designed to ensure more Canadians have advance care plans.

While the QELCCC has made progress in public awareness, its efforts have been limited by lack of resources.

## **Challenges and Issues in 2010**

One of the key challenges over the next 10 years will be persuading Canadians that end-of-life care planning is important for everyone, not just those diagnosed with an illness like cancer. It will be crucial to persuade people with chronic, life-limited conditions such as cardiovascular disease and respiratory disease that they, too, can benefit from appropriate, quality end-of-life care planning and from some hospice palliative care services.

Some of the organizations that champion specific illnesses, such as heart disease and HIV/AIDS, have identified the importance of end-of-life care in their strategies but more must be done to give people access to information, support and services.

Non-governmental organizations must work together to communicate a consistent message about both the availability of hospice palliative and end-of-life care services and the importance of both advance care planning and advocating on behalf of family members at the end of life.

Messages about the availability of hospice palliative and end-of-life care must be directed to health professionals as well as to the public, because many Canadians rely on their health care providers for advice. Information provided in hospitals, medical clinics and other care settings would be an effective way to reach both providers and the public.

## References

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<sup>i</sup> Population Projections for Canada, Provinces and Territories – 2000 – 2026, Statistics Canada, Catalogue #91-520, p. 110.

<sup>ii</sup> Population Projections for Canada, Provinces and Territories – 2000 – 2026, Statistics Canada, Catalogue #91-520, p. 110.

<sup>iii</sup> Population Projections for Canada, Provinces and Territories – 2000 – 2026, Statistics Canada, Catalogue #91-520, p. 124.

<sup>iv</sup> Population Projections for Canada, Provinces and Territories – 2000 – 2026, Statistics Canada, Catalogue #91-520, p. 110.

<sup>v</sup> Standing Senate Committee on Social Affairs, Science and Technology. (2000). Quality End-of-Life Care: The Right of Every Canadian. Final Report of the Subcommittee to Update “Of Life and Death”.

<sup>vi</sup> Health Canada. (2002).

<sup>vii</sup> Cannuscio C, Jones C, Kawachi I, Colditz G, Berkman L, Rimm E. (2002). Reverberations of Family Illness: A Longitudinal Assessment of Informal Caregiving and Mental Health Status in the Nurses Health Study. *American Journal of Public Health*. Vol. 92 No. 8