

Caring for Canadians at End of Life

*A Strategic Plan for Hospice, Palliative and End-of-Life Care
in Canada to 2015*

*Canadian Hospice Palliative Care Association
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At some time, in some way, we will all face the end of life. And most of us share a common hope: that when death comes to us or to a loved one, it will be peaceful and free of pain. We hope to face death surrounded by those we love, feeling safe, comfortable and cared for.

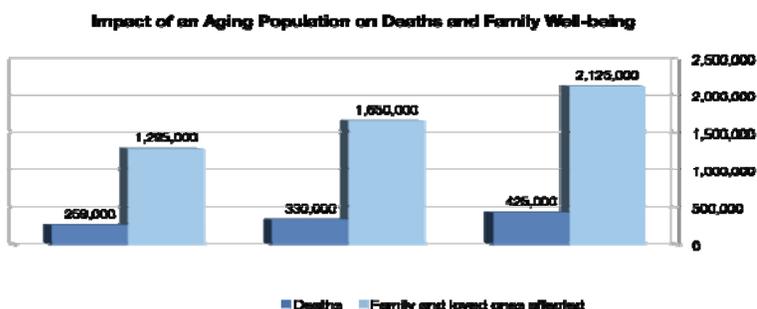
Living Lessons®, The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, 2001.

More Canadians Need End-of-Life Care

More than 259,000 Canadians die each year¹.

Although Canadians can die at any age, the average age of death in Canada is 74. With the aging of our population, the number of Canadians dying each year will increase 40% by 2026 to 330,000 and 65% by 2036 to more than 425,000.²

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.



End-of-life care needs are also becoming more complex.

Canada has become a highly culturally diverse society, and different cultures have different attitudes and beliefs about dying, grief, bereavement and care – physical, mental and spiritual -- at the end of life.

Is Canada Ready?

Canadians who are dying need quality end-of-life care and support, and families need help providing care as well as support in coping with grief and bereavement.

An aging population will mean more demand on the health care system for quality hospice, palliative and end-of-life care. A more culturally diverse population will mean different expectations and needs for care at end of life.

¹ Population Projections for Canada, Provinces and Territories – 2000 – 2026, Statistics Canada, Catalogue #91-520, p. 110.

² Population Projections for Canada, Provinces and Territories – 2000 – 2026, Statistics Canada, Catalogue #91-520, p. 124.

Are our health care systems ready? It is difficult to predict whether an aging, culturally diverse baby boom generation will expect better end-of-life care, more curative care or both -- or how the health care system will respond to their expectations.

What we do know is that, today, only 16% to 30% of Canadians who die currently have access to or receive hospice palliative, and end-of-life care services – depending on where they live in Canada.³ Even fewer receive grief and bereavement services. There is still a great deal of work to be done – at the national, provincial/territorial and regional levels – to ensure that all Canadians “face death surrounded by those [they] love, feeling safe, comfortable and cared for”.

Caring for Canadians at the End of Life sets out a strategy for hospice, palliative and end-of-life care for the next five years: to 2015. It sets out:

- our vision for hospice, palliative and end-of-life care for all Canadians
- the challenges to quality hospice, palliative and end-of-life care in Canada today
- the strengths and opportunities we will build on
- the key strategies we will pursue for the next five years.

The Canadian Hospice Palliative Care Association invites communities, health care providers, health care organizations, policy makers, researchers – everyone -- to work with us to improve the care that all Canadians receive at end of life.

Hospice palliative care is whole-person care that aims to relieve suffering and improve the quality of living and dying. Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement.

The Canadian Hospice Palliative Care Association is a national association of individuals and organizations engaged in hospice palliative and end-of-life care.

³ Canadian Institute for Health Information. (2007). *Health Care use at the End of Life in Western Canada*. Ottawa: CIHI.

I Our Vision

All Canadians have access to quality end-of-life care.

Goals for Our Strategy

By 2015, more Canadians will view dying as part of living and have a plan for the care they expect at the end of life.

Canadians who have a progressive, life-limiting illness and their families will have access to high quality, compassionate, interprofessional, cost-effective care that aims to relieve suffering, improve their quality of living-dying⁴, and help them cope with loss and grief.

Hospice palliative and end-of-life care will be integrated into all settings where people may die, including but not limited to: residential hospices, hospice palliative care units, acute care, long-term care facilities, private homes, prisons, group homes, rehabilitation centres, on the street and in specialized facilities such as mental health facilities, cancer centres, schools, workplaces and day hospice programs. People will be able to move easily between settings as needed.

Care will be provided by interprofessional teams, which include the person, family⁵, other informal caregivers, health care providers, and volunteers, who are supported by specialized palliative care teams. Care teams have the resources as well as the supportive policies and programs to provide the right care in the right place at the right time.

Models of hospice, palliative, end-of-life and bereavement care will be evidence-informed, and meet or exceed accepted standards. All care providers will continually work to develop the knowledge and skills to improve the quality of hospice, palliative and end-of-life care.

Mission

We strive to improve the quality of living and dying for persons with progressive life-limiting illness and their families.

We provide leadership and a common voice for hospice palliative and end-of-life care across Canada, driving, empowering and supporting high quality care at end of life.

⁴ The term *living-dying* is used to honour the belief that persons are simultaneously living and dying. It is also described as a dynamic, constantly changing journey of living while dying/dying while living (McWilliam, 2008)

⁵ The term *family* includes people the dying person has chosen to assist with their care.

Our Strategy to 2015 at a Glance

Strategy	Activities
1. Integrate hospice palliative and end-of-life care principles and practices into all health settings	1.1 Promote a common/cohesive understanding of hospice palliative care, including bereavement care, and the importance of early access to end-of-life care, among professionals, community organizations and family caregivers 1.2 Continue to review, strengthen and promote the CHPCA Model to Guide Hospice Palliative Care 1.3 Identify and refine best practices and standards for hospice palliative and end-of-life care in all settings and across the lifespan 1.4 Work with accrediting bodies to promote and accredit effective, integrated models of pediatric and adult hospice palliative end-of-life care that reflect national principles and norms of practice 1.5 Develop mechanisms, such as report cards, to hold all governments and settings accountable for meeting accreditation and other standards for hospital palliative, and end-of-life care
2. Educate health care providers in all health settings	2.1 Continue to work with professions and professional associations to increase palliative care content – including practicum placements in palliative care settings -- into the curriculum for all health care providers 2.2 Continue to work with universities, colleges and professional faculty to develop education, curriculum, and training programs to support the integration of hospice palliative and end-of-life care into all care settings 2.3 Explore the potential to develop standardized training programs in hospice palliative and end-of-life care 2.4 Work with the professional associations to develop and promote hospice palliative and end-of-life care competencies for nurses, social workers and personal support workers 2.5 Continue to work with provincial associations to develop core competencies for all team members, including regulated and unregulated providers and volunteers 2.6 Actively promote the interdisciplinary team approach to care, where all members of the team – including family caregivers and volunteers – feel valued and support one another 2.7 Advocate for providers in all settings to have access to specialized palliative care teams -- made up of a minimum of a palliative care physician, a palliative care nurse, a palliative care social worker/bereavement counsellor/ specialist in psychosocial-spiritual care and a personal support worker -- as well as ongoing education and training, and emotional and spiritual support 2.8 Identify innovative ways to educate and support family caregivers, including peer support models.
3. Promote evidence-informed policy	3.1 Develop a research committee to help identify questions that require more research and opportunities for research collaborations, and disseminate findings to the field 3.2 Advocate with the Canadian Institutes of Health Research and other research funders to continue to make interprofessional palliative care research a

Strategy	Activities
	<p>priority, develop new knowledge and actively disseminate findings</p> <p>3.3 Work with academic centres, research funders, palliative care programs and hospice societies to establish Centres of Excellence in hospice palliative and end-of-life care, which will help to monitor and evaluate models of care, and demonstrate cost effectiveness of both care and supportive policies</p> <p>3.4 Advocate, in collaboration with provincial associations, with provincial governments to collect the data required to: understand where Canadians are dying now and the services they receive, support hospice palliative care research; and monitor and evaluate hospice palliative and end-of-life care services</p> <p>3.5 Continue to develop and evaluate effective models of care, providing the evidence to inform practice</p> <p>3.6 Develop a core set of quality indicators relevant for all provinces</p> <p>3.7 Develop policy and/or issues statements on difficult ethical challenges at end-of-life</p> <p>3.8 Advocate with the federal government to play a strong role in developing, promoting and supporting evidence-informed policies and practices – including making the Compassionate Care Benefit easier to access and more generous</p> <p>3.9 Continue to support provincial/territorial associations in their efforts to advocate with provincial/territorial governments to develop, support and promote evidence-informed policy and practice, and other hospice palliative care initiatives, such as staffing levels, patient and caregiver advocates and the education and regulation of personal support workers</p> <p>3.10 Develop new policies to address emerging issues, such as support for family caregivers.</p>
<p>4. Build strong partnerships to improve hospice, palliative and end-of-life care</p>	<p>4.1 Build strong working relationships with provincial and territorial hospice palliative care associations</p> <p>4.2 Build strong working relationships with palliative care programs and hospice societies in each province and territory</p> <p>4.3 Actively seek advice from provincial and territorial associations, palliative care programs and hospice societies</p> <p>4.4 Play a supportive role in helping provincial and territorial associations work with their governments.</p> <p>4.5 Maintain/enhance its partnership with the Quality End of Life Care Coalition of Canada</p> <p>4.6 Collaborate with palliative care organizations internationally to improve end-of-life care, sharing knowledge, expertise and models of care</p> <p>4.7 Identify opportunities to partner with organizations advocating for comprehensive care for people with cancer and progressive, life-limiting conditions, such as heart disease, respiratory diseases, kidney disease, diabetes and dementias.</p> <p>4.8 Explore the potential for more public-private partnerships to enhance hospice, palliative and end-of-life care</p>

Strategy	Activities
5. Raise awareness about hospice palliative end-of-life care	<p>5.1 Use social marketing strategies to educate Canadians about hospice palliative end-of-life care, including the ability to reduce pain and suffering and to cope with grief at end of life</p> <p>5.2 Reinforce that hospice palliative and end-of-life care can benefit everyone who has a life-limiting disease, not just those with diseases that have a more predictable life course</p> <p>5.3 Develop a national approach to advance care planning that takes into account legislative differences among provinces</p> <p>5.4 Inform Canadians about the hospice, palliative, and end-of-life care that is and should be available to them</p> <p>5.5 Give Canadians the information they need to make informed choices about their care at end-of-life</p> <p>5.6 Provide support and education for health care providers to help them feel more confident about talking with patients and families about dying, bereavement and effective end-of-life care, and encourage them to talk to their patients and make earlier referrals to hospice palliative care programs</p> <p>5.7 Provide support and education for family caregivers and volunteers to help them feel more confident about talking with health care providers about dying, bereavement and effective end-of-life care</p> <p>5.8 Encourage Canadians to do advance planning for their care at the end of life (e.g., assessing the potential to adapt the US “National Health Care Decision Day” for use in Canada)</p> <p>5.9 Participate in and enrich the debate about euthanasia and physician-assisted suicide by reinforcing the benefits of hospice palliative care.</p>
6. Build the capacity of the Canadian Hospice Palliative Care Association	<p>6.1 Look for innovative ways to ensure financial sustainability</p> <p>6.2 Strengthen its governance</p> <p>6.3 Recruit and retain people with the skills and commitment to implement the five-year strategy</p> <p>6.4 Work with its partners to plan for the future</p>

II. Challenges to Quality Hospice Palliative and End-of-Life Care

In our efforts to provide high quality hospice, palliative care for all Canadians, we face a number of challenges. Many of these challenges are not new. In our last strategic plan, the CHPCA worked some of the same challenges. (For a summary of the progress that we made, see Appendix 1.)

1. Dying is not seen as part of living so there is a lack of resources for care at end of life

Canada continues to be a death-denying society. Although people are more aware of hospice palliative and end-of-life care, they still do not see dying as an integral part of life. The focus of the health care system continues to be on keeping people alive, rather than on the quality of their living **and** dying.

As the Institute of Medicine noted in its report, *Approaching Death: Improving Care at the End of Life*: “In some respects, [the 20th] century’s scientific and medical advances have made living easier and dying harder.”⁶ With the strong focus on developing new technologies and medications, treating illness and keeping people alive, care at the end of life – including bereavement services -- is not recognized as part of the continuum of care.

The fact that dying is not seen as part of living affects how health care systems allocate resources, limiting investments in hospice, palliative and end-of-life care. Many jurisdictions are struggling with shortages of home or personal support workers and other workers who provide care at the end of life. As a result, too many Canadians die with their pain and other symptoms poorly controlled, with family members left out of their care and support, and not in the setting of their choice.

To ensure that all Canadians have access to quality care at end of life, the field must work to:

- change attitudes towards death and dying
- make the case for appropriate resources and investment in hospice, palliative, and end-of-life care.

⁶ Institute of Medicine. (1997) *Approaching Death: Improving Care at the End of Life*. Field MJ and Cassel CK (eds). National Academies Press. Washington, DC. P. 14

2. Eligibility criteria and models of care have not kept pace with changing end-of-life needs

Right now in Canada about 75% of people die with or from progressive chronic diseases, such as cardiovascular, circulatory or respiratory diseases, and cancer. Their life course is not predictable. They could die within weeks or months from these conditions, or they could live for many years with one of more these life-limiting conditions.

Models of hospice palliative care and most policies for end-of-life care were originally designed to meet the needs of people with cancer whose journey to death was more predictable.

Joanne Lynn, Director of The Washington Home Center for Palliative Care Studies, Senior Scientist at the RAND Corporation, and President of Americans for Better Care of the Dying, suggests that people who would benefit from hospice palliative and end-of-life care now fall into three categories:⁷

1. People who have an overwhelming illness and go through a rapid, predictable decline to death (e.g., end-stage cancers)
2. People who have a chronic illness who may live for many years but may at any time experience some exacerbation of symptoms that leads to sudden death (e.g., people with congestive heart failure, chronic obstructive pulmonary disease, cirrhosis, kidney failure)
3. People who experience increasing frailty and neurological disorders (e.g., people with Alzheimer's Disease) and dwindle over time.

The current approaches to hospice palliative and end-of-life care – including eligibility criteria (often defined as time from death) and mix of services – do a relatively good job of meeting the needs of people in the first group but they do not necessarily meet the hospice palliative and end-of-life needs of all

Almost four out of five people over age 65 have one chronic disease, and about 70% have two or more progressive, life-limiting conditions. Many could benefit from aspects of end-of-life care including advanced care planning, support and symptom management.

Across Canada, eligibility for hospice palliative care services is often based on arbitrary time limits. For example, some jurisdictions limit access to palliative home care services, prescription drug coverage and hospice programs to the last few months of life. For family members to qualify for Compassionate Care Benefits, people have to be in the last six months of life. For people to access living benefits from their insurance policies, they must have a physician certify that they have only a certain time left to live. Because it is so difficult to determine how long people will live, physicians are often reluctant to give an estimate and, when they do, people often live past that date. As a result, people do not receive the end-of-life care they need. This approach clearly does not meet Canadians' need for end-of-life care.

⁷ Lynn, J. (2004) *Sick to Death and Not Going to Take It Anymore! Reforming Health Care for the Last Years of Life*. University of California Press. Berkeley and Los Angeles, California.

Canadians.

The traditional “no curative or disease modifying treatment” focus of hospice palliative care is not appropriate for many people with progressive, life-threatening illnesses. People with more than one chronic progressive condition will enjoy better quality of living and dying if they receive treatment and symptom management for the conditions that can be treated, and palliative treatment with support and symptom management for those that cannot.

Findings from recent service utilization studies support the need to:

- rethink the practice of defining the need for and the right to end-of-life care in terms of the time the person has to live (e.g., one month, six months)
- focus more on understanding and meeting the hospice, palliative and end-of-life needs of people with progressive, life-limiting illnesses and their families.

3. Canadians need more coordinated, integrated care and the field needs data to develop and support that care

Services for people at end-of-life are fragmented and poorly coordinated except where there are strong regional palliative care programs. It is difficult for people to receive quality, culturally competent hospice palliative and end-of-life care in all settings where they die. It’s difficult for people to move between settings (i.e., from home to hospital or hospital to home) to get care for different conditions/or as their needs change. It’s also difficult for families to receive grief and bereavement services.

In most cases, patients and families still have to go to services – rather than having services come to them -- even when mobility is an issue.

Right now, we do not know what proportion of Canadians who die in acute care and long-term care facilities actually receive quality, culturally competent hospice palliative, end-of-life care. Under the national strategy led by the federal government, a surveillance group was established but little progress was made before the federal Secretariat on Palliative and End-of-Life Care was dissolved in 2006.

To improve access to hospice, palliative, and end-of-life care, we need:

- better, more consistent data on where Canadians die and the services they receive at end-of-life
- strategies, processes and systems to improve transitions between settings
- continue to develop and promote evidence-based models of integrated care.

4. Models of hospice palliative, and end-of-life care must be adapted to different settings

Despite the growing number of Canadians who are now dying at home or in hospices, many will continue to die in acute care and long-term care facilities, and some will die in shelters – and, for some people, these may be appropriate settings.

Canada, like many other jurisdictions, is working to adapt models and practices developed in settings dedicated to end-of-life care, such as hospices, to other settings and to marginalized populations. For example:

- There are now hospices for the homeless, units located in shelters that allow people who are homeless to die in an environment where they feel at home. Shelter staff, receive extensive training and provide round-the-clock support, supported by medical and nursing students who serve internships at the hospice. In one hospice for the homeless, to meet the dying person's needs, staff developed a safety protocol that allows the smoke detectors to be shut off temporarily for Aboriginal sweetgrass ceremonies and still maintain a safe environment.
- Hospice organizations now offer one-day intensive workshops on palliative care for persons with end-stage dementia for staff working in long-term care homes and retirement residences. The course provides information on: the characteristics of advanced dementia, how to assess and manage discomfort in people with dementia, and how to provide holistic care for the resident and family members.
- Jurisdictions like the United Kingdom have engaged family physicians in activities to improve end-of-life care, including keeping a registry of people who are sick enough to die, ensuring that these patients and families have adequate support at home after office hours, documenting where each person wants to be when near death, and trying to enable each person to have his or her choice.⁸
- Some hospital-based programs have created special units with specially trained staff while others deliver palliative care to people wherever they are in the hospital. The hospitals see the value of palliative care expertise which addresses the dying person's and family's needs in a way that was not otherwise possible.⁹

To ensure the quality of hospice palliative and end-of-life care, the Canadian hospice palliative care field has developed a Model to Guide Hospice Palliative Care (based on National Principles and Norms of Practice). Accreditation Canada has also established accreditation standards to help improve the quality and consistency of end-of-life care in all settings – although these standards do not exactly align with the CHPCA Model to Guide Hospice Palliative Care.

Based on the literature and practice experience, Canada needs to:

- continue to identify and promote effective ways to adapt models of hospice palliative, and end-of-life care for all care settings
- actively promote the national principles and norms of practice as well as accreditation standards in all settings
- work with all care settings to reinforce the importance of early access to hospice palliative and end-of-life care.

5. Family caregivers need more support

Regardless of the setting where people choose to die, a significant portion of their hospice, palliative and end-of-life care will be provided by family and other informal caregivers.

⁸ Lynn, J. (2004) *Sick to Death and Not Going to Take It Anymore! Reforming Health Care for the Last Years of Life*. University of California Press. Berkeley and Los Angeles, California.

⁹ Lynn, J. (2004) *Sick to Death and Not Going to Take It Anymore! Reforming Health Care for the Last Years of Life*. University of California Press. Berkeley and Los Angeles, California.

In the past, family caregivers used to focus primarily on providing emotional and practical support for the family member through the process of the person's living and dying. Because of trends in the health care system – including the under-resourced shift to provide more care at home and in the community, and the global shortage of health care providers -- the role of family caregivers in hospice, palliative and end-of-life care has changed.

Now, family caregivers are often expected to provide a significant amount of personal care – such as feeding and bathing -- even for those family members who are dying in a health care facility. For people who choose to die at home, family caregivers may be asked to administer medications and provide more complex physical and medical care that involves equipment, complex drug regimens and intrusive procedures, such as giving injections. This level of involvement in care can give some families greater sense of control over the situation and/or it can cause families greater distress. Many family caregivers do not feel confident about their ability to provide complex care.

A 2004 Ipsos-Reid survey reported that, on average, Canadians estimate that it takes 54 hours a week to care for a dying loved one at home -- as much or more time than people spend at a full-time job. Based on that estimate, 64% of the people surveyed said that, because of other work and home responsibilities, they could not devote that amount of time.

These shifts in the health care system are occurring at a time when, with smaller families spread over larger geographical areas, people have fewer family members close by to care for them. As a result, more informal caregiving is falling on older, frail spouses and partners, and on one or two older children, who often have other work and caregiving responsibilities -- usually a daughter or daughter-in-law, although men are becoming much more involved in providing end-of-life care.¹⁰

Family members often provide care at great cost to their own health. According to research done in the United States, family caregivers who provide care 36 or more hours a week are more likely than non-caregivers to experience depression or anxiety: for partners, the rate is six times higher; for those caring for a parent, the rate is twice as high¹¹. When family members are intensely involved in providing care, particularly at home, they may not have the time or support to anticipate and prepare for the acute grief and loss that will come with the person's death.

Family caregivers may also pay a price in terms of their social lives, incomes and out-of-pocket costs. According to Statistics Canada, a significant proportion of informal caregivers providing personal care for someone over age 65 report a loss in social activities, a drop in income, and an increase in costs. The cost of extra help, such as

¹⁰ Canadian Hospice Palliative Care Association. *The Role of Informal Caregivers in Hospice Palliative and End-of-Life Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges*. Voices in Health Policy, 2005.

¹¹ 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*. Vo. 92 No. 8.

private nurses, to assist with hospice palliative care at home, in a long-term care facility or in hospital can create a severe financial burden for family caregivers, particularly if the dying person does not have private insurance. In research conducted by Health Canada in 2002, 70% of family caregivers reported that providing end-of-life care is stressful and that they require breaks and time away from the responsibility.¹² While the Compassionate Care Benefit administered through the Employment Insurance program provides some job security and income support, it is a short-term benefit (maximum of eight weeks, six weeks with pay) that is only available to people who contribute to employment insurance.

To provide more support for family caregivers, there is a need to:

- continue to monitor and document the impact of caregiving on families
- focus more attention on the information, education and services required to support family caregivers
- explore more innovative use of caregiver teams that would allow family caregivers to continue to work and not lose their employment status
- explore the potential for tax credits for families who make changes to the home environment to make it more suitable for end-of-life care.

6. Care providers need ongoing education and support

People with progressive, life-limiting conditions will encounter many different health care providers and volunteers during the course of their care. Because Canadians may die in all settings, all health care providers need skills in hospice palliative and end-of-life care, based on core competencies for hospice palliative, end-of-life care. All health care providers should also recognize the value of patient and family-centred, team-based care.

We have made progress integrating the core competencies for hospice palliative and end-of-life care into the initial training curriculum for educating future physicians. Through the Spiritual Care Development Initiative (part of the Pallium Project), the field has also developed an occupational analysis profile for hospice palliative care spiritual care providers and a peer-reviewed core curriculum for accredited clinical pastoral education. But we must do more to develop initial, continuing and ongoing education for physicians, nurses, personal support workers, social workers, spiritual care providers, pharmacists and volunteers.

Better informed providers and volunteers can provide support and advocate for more integrated hospice, palliative and end-of-life care services for adults and children,

Core Competencies for Palliative and End-of-Life Care

1. Able to address and manage pain and symptoms.
2. Able to address psychosocial and spiritual needs.
3. Able to address end-of-life decision-making and planning using basic bioethical and legal framework.
4. Able to communicate effectively with patients, families and other caregivers.
5. Able to collaborate as a member of an interdisciplinary team.
6. Able to attend to suffering.

¹² Website: http://www.hc-sc.gc.ca/hcs-sss/pubs/care-soins/2002-caregiv-interven/sum-som_e.html

including pain and symptom management and bereavement support. To improve quality of care, there is a need to:

- identify and capitalize on learning opportunities for all care providers
- educate all providers about pain and symptom management
- integrate the hospice palliative, and end-of-life care competencies into all health professional training
- develop working environments that value and support formal interprofessional team-based care.

In addition to education and skills, health care providers need to know how to: manage their own fear of or attitudes towards death; talk about death; manage pain and symptoms; and refer people and families to services in their community. They also need ongoing emotional and spiritual support to be able to provide high quality care for people at the end of life and their families.

Given the growing number of Canadians who will die over the next few decades, there will likely be a dramatic increase in demand for volunteers to provide the emotional, social and practical support that dying people – particularly those without family members close by – will need. The field must value and nurture its volunteers; it must also assess whether the potential volunteer workforce will be large enough and have enough support to meet growing needs.

7. We need political leadership and political will

Health care – including hospice palliative and end-of-life care – is a provincial responsibility and provincial and territorial governments are responsible for providing high quality care in all settings. Over the past five years, all provinces and territories have received federal funding for end-of-life care – at least in home care settings. However, we have no common indicators to be able to assess how the funding has been used or its impact.

Between 2001 and 2006, the federal government funded the Secretariat on Palliative and End-of-Life Care to develop and implemented a National Strategy for Palliative and End-of-Life Care in Canada. Over that period, the country saw some a move toward greater consistency in hospice palliative and end-of-life care. Unfortunately, the federal Secretariat disbanded its working groups and coordinating committee in March 2007 before the strategy had been fully implemented. There is, once again, no national strategy for hospice palliative and end-of-life care, and there appears to be a lack of political will to provide federal leadership and support on these issues.

8. Canada needs evidence on the impact and cost effectiveness of hospice palliative and end-of-life care.

We need more concrete data to be able to measure the impact, outcomes and cost-effectiveness of hospice palliative and end-of-life care – including bereavement services - - in all settings. When making decisions about allocating resources, health systems are looking for information on cost effectiveness and outcomes as well as a commitment to continuous quality improvement. Without more data on the impact of services and the

outcomes for individuals and their families, it will continue to be difficult for the field to make the case for more investment in hospice palliative and end-of-life care, or to develop the comprehensive information that programs need to improve the quality and consistency of end-of-life care wherever Canadians die.

The recent Canadian Institute for Health Information (CIHI) reports on Health Care Use at the End of Life (Western Canada, Manitoba, Saskatchewan and BC) provide valuable data, analysis and recommendations to inform end-of-life care service planning, and these types of initiatives must continue and be expanded to other parts of the country.

Over the next five years, there is an urgent need to:

- know where Canadians are dying (i.e., in what settings) and the type and quality of services they receive at end of life
- develop the capacity to monitor and measure the cost effectiveness, impact and outcomes of hospice palliative and end-of-life care models and services.

9. The field needs to speak with a strong consistent voice

With a growing number of national, provincial/territorial and regional organizations involved in palliative and end of life care policies and planning, the field is often challenged to speak with one voice. There will always be some policy and service delivery differences among jurisdictions, but it should be possible for the field to articulate consistent clear messages to guide government and the health care system.

Individuals and organizations involved in hospice palliative and end-of-life care across Canada need to work together to reach agreement on definitions and different models of care, develop common messages, and communicate them clearly to provincial and federal governments.

The ability to have a strong, consistent voice is being affected by, among other factors, current economic conditions, which are making it more difficult for the CHPCA and the provincial/ territorial associations to raise funds and advocate for sustainable hospice palliative and end-of-life care programs and services.

To have a greater impact on health care and social policy, the field must:

- recognize when there are strategic advantages to working closely and advocating together
- develop effective mechanisms to reach consensus on key issues, while continuing to respect one another's unique interests and autonomy.

III. Strengths and Opportunities

While the field faces many challenges – including the current economic climate -- it also has many strengths and opportunities to build on, including:

- committed passionate people
- strong networks of services in some provinces
- strong national partnerships
- more knowledgeable providers who have experience working in interprofessional teams and who are actively mentoring and training others within their professions
- a forum for national dialogue through the CHPCA
- a strong record in advocating for services
- an openness to new models of care
- access to research funding through CIHR
- opportunities to use information/communication technologies to advance and deliver care.

Another strength and potential opportunity is the growing shift in the health care system to the chronic disease management model, which espouses a comprehensive, integrated patient-centred approach to care across the lifespan. This trend should create more opportunities for hospice palliative and end-of-life care to be integrated with other services for people with progressive, chronic, life-limiting diseases.

IV. The Next Five Years

Over the next five years, the members of the Canadian Hospice Palliative Care association will continue to work together to advance and advocate for quality hospice palliative and end-of-life care for all Canadians. We will focus on six key strategies:

Strategy #1: Integrate hospice palliative and end-of-life care principles and practices into all health settings

All settings where Canadians are living with and dying from a progressive life-limiting illness should have the knowledge and capacity to provide high quality hospice palliative end-of-life care. All community-based organizations that work with or advocate for people with specific illnesses should be aware of the principles and benefits of hospice palliative and end-of-life care. Canadians should be able to feel confident that they will receive quality end-of-life care delivered with compassion wherever they are. The CHPCA will work with its partners to:

- Promote a common/cohesive understanding of hospice palliative care, including bereavement care and the importance of early access to end-of-life care, among professionals, community organizations and family caregivers
- Continue to review, strengthen and promote the CHPCA Model to Guide Hospice Palliative Care
- Identify and refine best practices and standards for hospice palliative and end-of-life care in all settings and across the lifespan
- Work with accrediting bodies to promote and accredit effective, integrated models of pediatric and adult hospice palliative end-of-life care that reflect national principles and norms of practice
- Develop mechanisms, such as report cards, to hold all governments and settings accountable for meeting accreditation and other standards for hospice palliative, and end-of-life care.

Strategy #2: Educate health care providers in all health settings

Providers in all settings – including physicians, nurses, social workers, nursing aides, personal support workers and pharmacists -- must have the knowledge and skills to provide quality hospice palliative and end-of-life care, as well as the emotional and spiritual support to provide this care. Family caregivers also need education and support to be full members of the palliative care team. The CHPCA will:

- Continue to work with professions and professional associations to increase palliative care content – including practicum placements in palliative care settings -- into the curriculum for all health care providers
- Continue to work with universities, colleges and professional faculty to develop education, curriculum, and training programs to support the integration of hospice palliative and end-of-life care into all care settings
- Explore the potential to develop standardized training programs in hospice palliative and end-of-life care

- Work with the professional associations to develop and promote hospice palliative and end-of-life care competencies for nurses, social workers and personal support workers
- Continue to work with provincial associations to develop core competencies for all team members, including regulated and unregulated providers and volunteers
- Actively promote the interdisciplinary team approach to care, where all members of the team – including family caregivers and volunteers – feel valued and support one another
- Advocate for providers in all settings to have access to specialized palliative care teams -- made up of a minimum of a palliative care physician, a palliative care nurse, a palliative care social worker/bereavement counsellor/ specialist in psychosocial-spiritual care and a personal support worker -- as well as ongoing education and training, and emotional and spiritual support
- Identify innovative ways to educate and support family caregivers, including peer support models.

Strategy #3: Promote evidence-informed policy

Hospice palliative end-of-life care is a relatively young field. More research is required to inform our work. More monitoring and evaluation is required to refine our practice, and to ensure consistent, quality care in all settings. To promote evidence-informed policy and practice, the CHPCA will work with its partners to:

- Develop a research committee to help identify questions that require more research and opportunities for research collaborations, and disseminate findings to the field
- Advocate with the Canadian Institutes of Health Research and other research funders to continue to make interprofessional palliative care research a priority, develop new knowledge and actively disseminate findings
- Work with academic centres, research funders, palliative care programs and hospice societies to establish Centres of Excellence in hospice palliative and end-of-life care, which will help to monitor and evaluate models of care, and demonstrate cost effectiveness of both care and supportive policies
- Advocate, in collaboration with provincial associations, with provincial governments to collect the data required to: understand where Canadians are dying now and the services they receive, support hospice palliative care research; and monitor and evaluate hospice palliative and end-of-life care services
- Continue to develop and evaluate effective models of care, providing the evidence to inform practice
- Develop a core set of quality indicators relevant for all provinces
- Develop policy and/or issues statements on difficult ethical challenges at end-of-life
- Advocate with the federal government to play a strong role in developing, promoting and supporting evidence-informed policies and practices –

including making the Compassionate Care Benefit easier to access and more generous

- Continue to support provincial/territorial associations in their efforts to advocate with provincial/territorial governments to develop, support and promote evidence-informed policy and practice, and other hospice palliative care initiatives, such as staffing levels, patient and caregiver advocates and the education and regulation of personal support workers
- Develop new policies to address emerging issues, such as support for family caregivers.

Strategy #4: Build strong partnerships to improve hospice, palliative and end-of-life care

The CHPCA cannot address all the issues facing the field on its own. It must collaborate effectively with its member organizations and with other organizations with an interest in the field, and develop equitable partnerships that recognize the skills and strengths of all members. To create and maintain strong partnerships, the CHPCA will continue to:

- Build strong working relationships with provincial and territorial hospice palliative care associations
- Build strong working relationships with palliative care programs and hospice societies in each province and territory
- Actively seek advice from provincial and territorial associations, palliative care programs and hospice societies
- Play a supportive role in helping provincial and territorial associations work with their governments
- Maintain/enhance its partnership with the Quality End of Life Care Coalition of Canada
- Collaborate with palliative care organizations internationally to improve end-of-life care, sharing knowledge, expertise and models of care
- Identify opportunities to partner with organizations advocating for comprehensive care for people with cancer and progressive, life-limiting conditions, such as heart disease, respiratory diseases, kidney disease, diabetes and dementias
- Explore the potential for more public-private partnerships to enhance hospice, palliative and end-of-life care

Strategy #5: Raise awareness about hospice palliative end-of-life care

One of the greatest barriers to high quality end-of-life care continues to be society's failure to see death, dying and bereavement as part of life, to plan for care at end of life, and to demand that their health care systems have the resources to provide high quality hospice palliative and end-of-life care.

To overcome that barrier, the CHPCA will continue to work with its partners to:

- Use social marketing strategies to educate Canadians about hospice palliative end-of-life care, including the ability to reduce pain and suffering and to cope with grief at end of life
- Reinforce that hospice palliative and end-of-life care can benefit everyone who has a life-limiting disease, not just those with diseases that have a more predictable life course
- Develop a national approach to advance care planning that takes into account legislative differences among provinces
- Inform Canadians about the hospice, palliative, and end-of-life care that is and should be available to them
- Give Canadians the information they need to make informed choices about their care at end-of-life
- Provide support and education for health care providers to help them feel more confident about talking with patients and families about dying, bereavement and effective end-of-life care, and encourage them to talk to their patients and make earlier referrals to hospice palliative care programs
- Provide support and education for family caregivers and volunteers to help them feel more confident about talking with health care providers about dying, bereavement and effective end-of-life care
- Encourage Canadians to do advance planning for their care at the end of life (e.g., assessing the potential to adapt the US “National Health Care Decision Day” for use in Canada)
- Participate in and enrich the debate about euthanasia and physician-assisted suicide by reinforcing the benefits of hospice palliative care.

Strategy #6: Build the capacity of the Canadian Hospice Palliative Care Association

To achieve its goals, the CHPCA must be a strong, well-resourced, vibrant organization that is able to work closely with its provincial partners to advance the field. Over the next five years, the CHPCA will continue to:

- Look for innovative ways to ensure financial sustainability
- Strengthen its governance
- Recruit and retain people with the skills and commitment to implement the five-year strategy
- Work with its partners to plan for the future.

Appendix I: Our Progress Over the Past Five Years: Where are We Now?

In its last strategic plan, the CHPCA established five goals designed to address many of the same challenges. The following describes our progress over the past five years in achieving each goal.

1. Improve Access to Hospice Palliative Care Programs and Services

Over the past five years, the Canadian Hospice Palliative Care Association and our members focused on making hospice, palliative and end-of-life care accessible to more people and on improving the quality and consistency of that care. We have made some progress. For example:

- End-of-life care is now part of national cancer, heart health and HIV strategies – which should support better integration of services
- In the 2003 First Ministers Accord on Health Care Renewal, the federal, provincial and territorial governments recognized the importance of hospice, palliative and end-of-life care by including it in the basket of services to be provided by home care services.
- In the 2004 Health Accord, the federal government made a commitment to fund case management, personal care, nursing care and palliative-specific pharmaceuticals provided through home care programs.
- In 2006, to help guide the provinces and territories and ensure consistency across the country, the CHPCA issued the Pan-Canadian Gold Standards for home care in case management, nursing, personal care and pharmaceuticals.
- In 2008, CHPCA in partnership with the Quality End of Life Care Coalition of Canada (QELCCC) surveyed all provincial and territorial governments, compared their practice to the Gold Standards and issued a report card. The CHPCA project was not designed to assess the impact of services on people at end-of-life. The changes reported came from provincial and territorial governments and may not reflect the experience in all parts of their jurisdictions. However, some of their responses were encouraging. For example:
 - 12 of 13 provinces and territories provided equipment and supplies for people dying at home
 - 11 covered pharmaceuticals for people receiving palliative home care
 - 11 reported that they promoted team-based care
 - 4 had policies on access to case management
 - 6 had policies on 24-hour access to nursing and personal care.

Although Canadians would prefer to die at home, in 2009, most (60 – 75%) still die in hospital. Because of lack of data, we don't know where people are dying or the quality of care they are receiving at end of life.

In 2007, between 13 and 16% of people who died in BC, Alberta, Saskatchewan and Manitoba received hospice palliative care. Although that proportion seems small, it represents a 300% increase since 2000.

For a full copy of the report card, see: <http://www.chpca.net/qelccc.htm>.

The CHPCA has also had an impact on professional education, which, in turn, should improve access to care. For example:

- Educating Future Physicians in Palliative and End-of-Life Care – which started as a pilot project -- is now part of professional health curriculum.
- The Canadian Nurses Association began to offer certification in hospice palliative care nursing to Canadian nurses.
- The CHPCA developed a training program for personal support workers.
- PALLIUM and Learning Essential Approaches to Palliative and End of Life Care (LEAP) is being presented in provinces and territories as part of educational and facilitator training workshops. LEAP resources and the 2008 PALLIUM Palliative Pocketbook are offered in the CHPCA marketplace.

2. Develop public policy to support quality hospice palliative care

Nationally

The CHPCA actively promotes a number of public policies designed to improve the quality and consistency of hospice palliative care across the country. For example:

- Each year, the CHPCA hosts the National Palliative Care Conference, providing a forum to present, discuss and collaborate on national policy issues.
- More providers are endorsing and using the National Principles and Norms of Practice, and the CHPCA has developed a toolkit to help organizations implement the Norms of Practice in their setting.
- The CHPCA led a process to develop an issues paper on the ethically challenging issues of euthanasia and physician-assisted suicide.
- The CHPCA and its members are working to develop a discussion document on the definition of end-of-life care.
- The Gold Standards for Home Hospice Palliative Care, developed collaboratively with Quality End-of-Life Care Coalition of Canada, established clear expectations for certain components of home hospice palliative care and provided a way for provinces and territories to report whether they were meeting expectations.
- Thanks to ongoing lobbying by the national and provincial associations, the Government of Canada now offers the Compassionate Care Benefit. Through the Employment Insurance Program, eligible family members can receive up to six weeks of benefits while caring for a dying loved one. While we still have a long way to go to support family members caring for someone who is dying, this is a beginning.
- Working with its partners, the CHPCA developed a policy issues paper, and has been directly involved in targeted efforts to influence federal and provincial government policies on access to hospice palliative and end-of-life care in all settings.

Over the past 10 years, the CHPCA has taken a leadership role in managing the Quality End of Life Care Coalition of Canada (QELCCC): a group of 30 national organizations concerned about quality end-of-life care. The QELCCC provides a forum to discuss policy issues, and advocate for a national strategy for hospice palliative and end-of-life care.

Across the country, some provinces and territories report that there has been more interest and investment in hospice palliative care – particularly home hospice palliative care – however details about spending are difficult to obtain.

Internationally

The CHPCA has also played an active role in international efforts to promote high quality hospice, palliative and end-of-life care. Our organization is a member of the Worldwide Palliative Care Alliance Steering Committee, and our Executive Director served as Chair of the Advocacy Committee for the Worldwide Palliative Care Alliance. The CHPCA's international involvement allows the association to learn from other countries, and to contribute its expertise. For example:

- In 2006, the CHPCA helped the African Palliative Care Association obtain a \$100,000 grant from the Canadian International Development Agency, the Canadian Society for International Health, and the Interagency Coalition on AIDS and Development to support a collaborative palliative care project in five sub-Saharan African countries.
- In a project recently funded by Health Canada, the CHPCA provided policy and technical expertise to the global response to HIV/AIDS.

3. Support Provincial/Territorial Associations

As a national association, part of the CHPCA's mission is to support and collaborate with the provincial/territorial hospice palliative care and end-of-life care associations. To improve quality of end-of-life care and influence policy, we must work together. Because health care is a provincial responsibility, the provincial and territorial perspectives are key to influencing policy and improving the availability of services.

To build and maintain collaborative relationships, the CHPCA and the provincial associations:

- ensure that representatives of provincial associations are active members of the CHPCA Board
- are in the process of developing a memorandum of understanding, clarifying national and provincial/territorial roles and responsibilities
- created a policy on common messaging and communications, which has led to a more unified advocacy strategy and the highly successful, country-wide Hospice Palliative Care Week
- developed a list of experts across the country who can provide advice on policy issues or handle media enquiries. This list is reviewed and up-dated yearly, and is available from CHPCA.

In addition to having representatives of provincial/territorial associations on our board, the CHPCA also actively seeks input from and establishes collaborative communications with the associations through teleconferences, surveys, listservs and other mechanisms.

4. Create a sustainable organization

With the dissolution of the federal government's secretariat on hospice, palliative and end-of-life care, the CHPCA no longer receives as much federal funding or support. Our

organization is now mainly dependent on fees, fundraising and project grants for its operations. Over the past few years, the CHPCA has taken a number of steps to improve its financial sustainability, including:

- introducing a new membership fee structure
- establishing the Marketplace, where it sells tools and publications
- developing partnerships with the private sector
- applying for and receiving project funding.

To remain a relevant, well-managed and efficient organization, the CHPCA has established an annual priority setting process. Board members have received training, and the organization is committed to an ongoing process of strategic planning and consulting with its members.

5. Develop a strategy to increase awareness of hospice palliative care

Part of the CHPCA's role is to raise public awareness of the importance of hospice palliative and end-of-life care – including bereavement services. As part of our awareness strategy, we hired a communications officer, redesigned our web site, and developed fact sheets and information brochures. The organization issues press releases and is quick to seek media opportunities and respond to media enquiries. Over the past five years, there has been an increase in the number of feature articles and media segments on issues related to hospice palliative and end-of-life care. As a result, people are more aware of the importance of end-of-life care planning and of the need for more hospice palliative and end-of-life care services.

By December 2003, 75% of Canadians knew about palliative care – up from 30% in 1997.
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One of the most effective recent initiatives has been the innovative Living Lessons® program developed by The GlaxoSmithKline Foundation in partnership with the CHPCA. Living Lessons® provides tools and information for people with a progressive, life-limiting illness and their family caregivers. The program addresses significant issues in Canadian society, including our death denying medical system and culture, by encouraging open dialogue on death and dying. Using the compelling experiences of people with life-threatening illnesses, Living Lessons® hopes to move hospice palliative care from the periphery of the medical system into the mainstream where it belongs. It is designed to educate patients, caregivers, medical professionals, volunteers, policy makers and the public-at-large about the resources and expertise that are -- or should be -- available in their communities.

In addition to these initiatives, the CHPCA is starting to identify patrons or champions across the country who will become the recognized “faces” of hospice palliative and end-of-life care.