Policy Brief on Hospice Palliative Care

Quality End-of-Life Care?
It Depends on Where you Live …
and Where You Die
The Case for Action Now on an Integrated “Systems” Approach to End-of-Life Care

Canadians are living longer. A child born in Canada today can expect to live to be over 80 years old. People who are now 65 can expect to live another 18 to 21 years. But, regardless of how long people live, they will all eventually die. With our aging society, Canadians are now starting to die in much larger numbers.

More than 235,000 Canadians died in 2007 – up from 228,000 in 2006, the largest one-year increase since 1993. The growing number of deaths each year is the beginning of a tidal wave that will radically reshape our society and overwhelm our health care system.

By 2021, there will be more than 300,000 deaths annually; by 2041, more than 432,000 Canadians will die each year. The Canadian Hospice Palliative Care Association estimates that each death in Canada affects the immediate well being of an average of five other people, or almost 1.25 million Canadians each year – disrupting their lives, affecting their income, and causing grief and other psychological issues, including depression and anxiety.

Most Canadians die in old age. When they do die, most are suffering from two or more chronic diseases. Because their end-of-life needs vary, the “right” setting for people to die also varies. With the right supports and care, many are able to die at home. But some need the kind of care that can only be provided in a hospital or hospice. Others will expect to receive care in the settings where they live, whether that is a long-term care home, shelter or prison.

The question we must answer now – and quickly – is will we be able to provide high quality end-of-life care for all Canadians when and where they need it? Can we provide the physical, psychological, social, spiritual and practical care that individuals and families should have at end-of-life? Is the health care system ready?

This brief is intended to encourage discussion and debate on these issues – and a call to action. We must work together to find innovative ways to provide high quality end-of-life care wherever Canadians die.

Dying in Canada Now

To understand where we will be in 10 to 30 years, we must look at where and how Canadians are dying now. What kind of care are they receiving when they face a life-limiting illness and are nearing end of life?

2 Ibid.
We actually know very little about where Canadians die. According to Statistics Canada, most Canadians still die in hospital\(^5\) – but a growing number are now dying at home\(^6\) and in long-term care homes.\(^7\) Some die in other settings, such as hospices, shelters, prisons and group homes. Although most people would prefer to die at home surrounded by their loved ones, recent research shows that the place of care is less important than the care people receive.\(^8\)

Although Canadians die in many settings, we know that the availability of high quality end-of-life care in these settings varies widely. According to a 2009 study of health care use at end-of-life in Western Canada, only 16% to 30% of Canadians who die currently have access to or receive hospice palliative and end-of-life care services\(^9\) -- and even fewer receive grief and bereavement services, which are an integral part of high quality end-of-life care.

The system is currently failing too many people and families. Too many people who are dying end up in emergency departments during the last months and weeks of life, which is an indicator of poor quality end-of-life care.\(^10\) According to an Ontario study, 84% of people who died of cancer between 2002 and 2005 visited the emergency department in the last six months of life and 40% visited emergency in the last two weeks.\(^11\) The main reasons for the emergency visits were symptoms and conditions, such as abdominal pain, dyspnea, pneumonia, malaise and fatigue, and pleural effusion -- symptoms that can be managed in all settings with good end-of-life care. Another recent Ontario study showed that people with life-limiting illnesses who receive care at home earlier and receive more hours of care at home, are less likely to visit emergency in the last weeks of life\(^12\).

The same pattern emerges for people in long-term care. According to a Manitoba study, 41% of long-term care/nursing home residents were hospitalized at least once in the six months before their deaths.\(^13\) They were more likely to be hospitalized and to die in hospital if they were younger, had organ failure, lower care needs and lived in for-profit facilities, which may indicate issues with quality of care in long-term care homes.

\(^6\) Canadian Institute for Health Information. (2007). *Health Care Use at the End of Life in Western Canada*. Ottawa: CIHI.
\(^9\) Canadian Institute for Health Information. (2007). *Health Care Use at the End of Life in Western Canada*. Ottawa: CIHI.
\(^10\) Ibid.
People near end-of-life should receive the care and support they need wherever they are. If they do need hospital care at some point, their transitions should be seamless. They should not have to go through emergency to receive that care.

Our Vision for an Integrated Systems Approach to End-of-Life Care

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 all Canadians and their families have the information, resources and support to move from one setting to another based on their needs and preferences. Canadians and their families should have a choice and a say in the services they receive.

In its new strategic plan, *Caring for Canadians at End of Life*, the Canadian Hospice Palliative Care Association has made a systems approach to end-of-life care one of its priorities:

*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, family, 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.*

Fixing End-of-Life Care from the Ground Up

Right now, access to high quality care at the end of life mainly depends on where people live in Canada. Their ability to move easily from home to hospital (if they need that level of care) back to home or to a hospice also depends on where they live.

Some communities in Canada have developed and championed highly effective models of integrated, system-wide hospice, palliative and end-of-life care. There are pockets of excellence in every province. For example:

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

15 Canadian Institute for Health Information. (2007). *Health Care Use at the End of Life in Western Canada.* Ottawa: CIHI.
Victoria Hospice, now in its 30\textsuperscript{th} year of operation, provides care to patients and families in a number of locations in and around the Victoria Area. It has a 17-bed palliative care unit that has tertiary and hospice palliative care beds as well as a respite bed. The staff also consults to other hospitals and health facilities in the region, and help support primary care physicians and home care teams provide care for patients at home. As part of their services, they have a "Palliative Response Team". This 24-hour on-call home visit service, which consists of a nurse and a counsellor (with ready access to a palliative care physician), provides short-term crisis consultation and treatment for people who might otherwise have to go to emergency or be admitted to hospital. Victoria Hospice also has a strong psychosocial and bereavement program. They have an active research department, offer numerous education programs for health care providers and have developed a number of tools to help assess people's needs and symptoms.

Victoria Hospice is fortunate to have over four hundred volunteers and tremendous financial support from the community. Close to half of Victoria Hospice's annual operating costs are paid for by fundraising efforts and community donations. Because of this support and its partnerships -- including with the Vancouver Island Health Authority -- people in the Victoria area have options about where they receive hospice palliative care and can move from one setting to another depending on their needs and preferences. Victoria Hospice helped over 3,000 people last year by providing expert physical care as well as social, emotional, and spiritual support to those facing advancing illness, death and bereavement. About 40\% of the patients under care are able to die at home in familiar surroundings.

The Edmonton Regional Palliative Care Program operates 57 hospice palliative care beds located in three different sites in the city, as well as an intensive palliative care unit in one of the hospitals. The team also consults to all hospitals in the region, and to primary care physicians and home care teams providing end-of-life care at home. A palliative care physician is available 24 hours a day, seven days a week to provide advice and expertise. People and their families have access to palliative care consultants regardless of their setting. Palliative care consultants also use video conferencing to provide advice and guidance to physicians and clinicians working in other settings in the region. The program has played a key role in developing assessment tools that are now widely used in Canada and beyond, and in training palliative care specialists.

Attitudes towards end-of-life care within the health care system have also changed. Before the program, someone with a life-limiting illness, like cancer, would often have been discharged from hospital after treatment without a referral to a family physician or home care. In time, that person would have shown up at the cancer clinic or in the emergency room in a crisis, with their symptoms uncontrolled and no emotional or spiritual support. Now, anyone diagnosed with a life limiting condition is referred and connected to services right away. The impact has been significant. People who are dying have options about where they die, and they can move from one setting to another depending on their needs. They receive better, more consistent end-of-life care, and there is much less pressure on acute care hospitals. Before the program began, 80\% of people with cancer died in hospital. Now only 50\% die in hospital and those who do spend fewer days there: their lengths of stay have been reduced by 75\%. The program is also cost
effective. It costs about eight times as much to receive end-of-life care in an acute care hospital compared to at home or in a hospice.

The Niagara West Palliative Care Team developed a model of shared care that is now being used by Local Health Integration Networks across Ontario. It is a partnership between the hospital and the Community Care Access Centre, which is responsible for coordinating home care and long-term care. The palliative care team works with the family doctors and home care providers to “share the care”. Team members, which include a physician, palliative care nurse clinician, psychospiritual clinician, a bereavement counselor and a dedicated palliative home care manager, see patients in all care settings including the hospital, a residential hospice, long-term care homes, retirement residences and patients’ homes. The palliative care nurse clinician acts as a system navigator, helping individuals and their families connect with a range of care providers and care settings. The team provides 24/7 support for family physicians and community nurses as well as palliative care and bereavement support for individuals and families.

The New Brunswick Extra Mural Program has been providing home care for the palliative patient and family throughout the entire province since 1993. Since its inception, care has included: case management; availability of an interdisciplinary team; a nurse available 24 hours a day to provide assessment or intervention; funding for palliative medications; and access to home support services, supplies and hospital equipment. In 2009, one of the largest health zones in Horizon Health Network, Zone 3, launched a palliative care program designed to strengthen the ties between the hospital and the Extra-Mural Program. The Zone 3 Palliative Care Program was developed to encompass palliative care services within the hospital and in the community, and to promote the use of best practice evidence and consistent standards of care at all care sites (i.e., four hospital sites and four extra-mural units). One of the program’s fundamental premises is that palliative care should be consistent and seamless between the hospital palliative service and the home setting.

The Zone 3 Palliative Care Program has developed program standards, admission criteria, a symptom assessment tool, some medical policies, guidelines and order-sets that can be used to provide consistent, evidence-based care regardless of the setting. Five part-time palliative care physicians – who were trained through the Edmonton Regional Palliative Care Program – provide a consultative and gate-keeper role in all of the hospital services. A Clinical Nurse Specialist is active in the program and assumes the roles of program development, education of nurses, and consultation to patients.

Hospital protocols were changed so people receiving palliative home care do not have to be re-referred by their physician to be admitted to the palliative care unit. Once they are part of the palliative care service, they can move easily from home to hospital and back home again based on their needs. Whenever a patient is re-admitted – for any reason – the service is notified immediately. Some of the greatest gains have been made in the hospital. Patients in the palliative care unit always received high quality care, but those who were dying in surgical and medical units (because beds in the palliative unit were full) did not necessarily receive the same services or attention. The program has worked with nurses on all floors, investing heavily in training to bring up the standard of end-of-life care in all parts of the hospital.
Most of these “gold standard” integrated hospice, palliative and end-of-life services are the result of individual champions who worked from the ground up to create them. They were not driven by overarching policy initiatives, but by the desire of committed people to fill gaps in the system and provide the best possible care.

**Integrated Hospice, Palliative End-of-Life Services Increase Satisfaction and Reduce Costs**

All the programs described above – and others like them across Canada – reflect best practices. They incorporate components like common assessment tools, collaborative care plans, interdisciplinary teams, consistent care across settings, and support for family caregivers that have been proven through research to improve patient and family satisfaction and reduce health care costs.161718

There is no doubt that integrated hospice palliative and end-of-life care services are cost effective. They reduce the number of emergency visits as well as the number and length of hospital stays.19 Less use of acute hospital services means that the system can provide end-of-life care for more people at the same or less cost.20 However, cost should not be the primary driver of the shift to integrated care. The change should, instead, be driven by the imperative need to ensure that all Canadians have access to high quality care at end-of-life.

**Quality of Care Depends on Where You Live**

Individuals with life-threatening illnesses who are lucky enough to live in areas served by best practice programs benefit and receive a higher standard of care than those in regions without an integrated approach to end-of-life care. Access to high quality care should not depend on luck.

Even within regions that have integrated end-of-life programs, some people continue to die a bad death – simply because they are not referred to the program or they are referred too late. Many remain in acute care hospital beds past the time when they can benefit from that type of care. Some are moved to alternate level of care units where they do not receive the spiritual or emotional support or symptom management that would add quality to their lives. Some suffer at home and make emergency room visits that could be avoided.

It is not enough to simply provide an integrated end-of-life care system: everyone working in the system must know that care is available and refer people as early as possible to the services. The low rate of referrals is due, in part, to the health care

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system’s focus on curative care. It is also due to the lack of understanding that – for people with a number of chronic conditions -- palliative, end-of-life care can be integrated with curative care.

Many people with life-limiting illnesses could benefit from high quality end-of-life care – particularly advanced care planning and emotional/spiritual support – even though they may still live many years. Anyone who is sick enough or has a condition where it would be “no surprise” if he or she died within the next few months, should have the opportunity to benefit from hospice palliative and end-of-life care. In fact, access to palliative care combined with treatment can significantly improve the ability of people with severe chronic illnesses to function in the last years of their life.

Most of the existing integrated end-of-life care programs focus on meeting the needs of people in traditional health settings. They do not extend to other places where people live and die, such as shelters, prisons and on the street. There are now a small number of hospices for the homeless in Canada: 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 care, supported by medical and nursing students who serve internships at the hospice.

The current disparities mean that Canada’s health system does not achieve the ethical concept of distributive justice. Patients are likely to receive very different palliative services, or none at all depending on where they live, or receive care and as a result some will suffer more than others.

Challenges to Providing an Integrated Systems Approach to End-of-Life Care

If we know how to provide integrated end-of-life care and we know it increases patient satisfaction and reduces costs, why are the practices not more widespread? If some hospitals, some long-term care homes, some home care services, some shelters and some regions can do it, why is this standard of care not available everywhere?

The reasons are many and varied.

Geography. Integrated end-of-life care is easier to provide in urban settings where there is a critical mass of palliative care expertise, health services and people needing end-of-life care. It is much more difficult to provide in rural and remote areas, where people may live many miles from the nearest hospital, hospice or palliative care specialist. As a result, people in some rural areas are more likely to be hospitalized at end-of-life, depending on the other health care services available to them. Researchers and care providers are identifying effective ways to close this gap in care, such as helping rural

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and remote communities develop their own capacity to meet needs,\textsuperscript{25} using factors such as population size and distance from specialized palliative care services as criteria to establish secondary palliative care hubs,\textsuperscript{26} and making more effective use of video conferencing and other technologies. More must be done to implement these options.

**Lack of Patient-Centred Care.** In many parts of Canada, services are still organized for the convenience of the system rather than around the needs of patients. That is why so few end-of-life services are offered outside health care settings and in other places where people die, such as prisons, shelters, mental health facilities and on the street.

**Attitudes/Lack of Knowledge.** The professionals providing care for people with life-limiting illnesses often have misperceptions about end-of-life care, including symptom control and eligibility for palliative care services. Aggressive care until death is still the norm in many settings – despite the advances that have been made in palliative care\textsuperscript{27} or institutional policies related to end-of-life care.\textsuperscript{28} As a result, many people do not receive end-of-life care at all or only receive it late in the course of their illness. Family physicians continue to be the primary caregivers for most people at the end of life, but may not have the knowledge or support to provide high quality care. Shared care models can help by modeling best practice, helping providers identify people who could benefit from palliative care early, and provide ongoing advice and support.\textsuperscript{29}

**Lack of Understanding of High Quality End-of-Life Care.** There are also misunderstandings on the part of funders and policy makers about what is involved in high quality end-of-life care. For example, as a cost saving measure, some jurisdictions have cut essential components of end-of-life care, such as spiritual counselors.

**Lack of Policy Leadership.** In many Canadian jurisdictions, policies have not kept pace with knowledge about best practices. Health authorities and health system planners have not developed the policy framework required to support integrated end-of-life care. This includes policies that ensure access to palliative care expertise or remove barriers to people moving easily from home to hospital and back again or provide adequate supports for family caregivers, who bear a large burden of end-of-life care particularly when family members die at home.

**Cultural Diversity.** Programs and services are struggling to meet the needs of an increasingly diverse population. People of different cultures have different attitudes towards death and dying, and they require services that are culturally sensitive. It can be challenging to develop palliative care teams and adapt palliative care models to meet these diverse needs.


**Funding.** Canadians will not receive high quality end-of-life care in all settings where they die until services in all these settings are funded equitably. Canada’s health care systems continue to fully fund only hospital and physician services. Long-term care services are only partially funded, and there are limits on the amount of home care services that people receive. Hospice programs continue to rely on fund raised dollars. Even the Victoria Hospice program, which is an integral part of its regional health authority, depends on fund raising to deliver what most would argue are essential end-of-life services. According to a recent study, the health care system pays about 70% of the cost of end-of-life care – mainly related to hospital stays, while families pay 27% and non-for-profit organizations about 2%.³⁰

Although there has been a conscious effort on the part of health systems to shift end-of-life care from acute care to other settings, funding has not followed services. The lack of full funding for care in other settings mean that many people cannot afford to leave hospital or are forced into hospital to relieve the financial burden on their families, who face average costs of more than $24,000 per month in terms of travel, out-of-pocket expenses and time devoted to caregiving.³¹ Lack of funding also means that even high functioning integrated programs do not have the resources they require to meet the growing demand for end-of-life care. They are currently not able to meet the needs of everyone in their catchment area who could benefit from their services. What will they do over the next 10 years as the number of people dying and the demand for care increase?

**Critical Success Factors for an Integrated Systems Approach to End-of-Life Care**

Canada must act now to develop an integrated systems approach that will ensure that all Canadians – regardless of where they live or die – have access to timely, high quality hospice palliative end-of-life care. It is time for policy to catch up with practice and to actively promote consistent high quality care in all settings as well as seamless transitions from one setting to another.

At a time when different parts of the health care system are trying to clearly define their distinct roles and ensure that people receive the right care in the right place from the right provider, they must recognize that all settings need the knowledge and capacity to provide high quality end-of-life care.

The four essential components for a best-practice integrated end-of-life care model are:³²

1. **Universality:** Everyone nearing end-of-life will need psychosocial, spiritual, and physical support.

2. **Care coordination:** A care coordinator or case manager is essential to ensure the dying person and his/her family have access to care across sectors and settings.

3. **Assured access to a broad range of basic and advanced end-of-life service.**
   People who are dying must have access to a full range of accessible basic services to specialized hospice/palliative care services at all times.

4. **End-of-life care regardless of care setting.** End-of-life care must be available in any setting where someone is dying.

Effective end-of-life care policy should reinforce best practices, including:

- Services based on the assessed needs of people and families, not solely on prognosis and predetermined funding allocations
- Public awareness of the benefits of end-of-life care, and the services available
- Active promotion of advanced care planning
- Strong reinforcement of the role of primary care providers in end-of-life care in a shared care model (i.e., easy access to support from specialists)
- Ongoing education in end-of-life care and support for all health care providers, including communication, patient-centred care, decision support, and effective pain and symptom management
- A clear mission and vision, and common language for end-of-life care across the health system and settings
- Consistent use of common assessment tools, processes, and care guidelines – based on the national principles and norms of practice for palliative care
- The development of collaborative care plans
- The establishment of regional databases that track and monitor patient demographics, assessment information, services provided, outcomes and other information that can be used to assess the quality and impact of end-of-life services
- A single access number for all types of palliative care services
- Information about care options, and support in making decisions about end-of-life care
- 24/7 access to specialized interdisciplinary palliative care teams
- Routine, common assessments offered to everyone with a life limiting illness to identify those who would benefit from end-of-life care early
- Policies that allow patients to move easily between settings
- System navigation services for people who are dying and their families
- Effective symptom control and pain management in all settings
- Psychosocial and spiritual support in all settings
- Services and support for family caregivers
- Strategies to meet end-of-life needs in rural and remote communities, as well as in non-health settings such as shelters and prisons
- Full and equal funding of end-of-life care services in all settings
- Advocacy for hospice palliative care services for people who are dying and their families.

The problems – and the solutions – are bigger than the health care system. A good death depends on more than just access to comprehensive, integrated health care services. For many Canadians, it is linked to larger socio-economic issues, such as poverty, housing, social support and wellness. The same factors that affect people’s health also affect their deaths.
To ensure that all Canadians have the opportunity to have a good death, we must be willing to work across all our service systems, looking beyond the typical four-year political planning cycle, and working together to create caring communities that support people and their families at the end of life.

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About the Canadian Hospice Palliative Care Association
The Canadian Hospice Palliative Care Association (CHPCA) is the national voice for hospice palliative care in Canada. It is a bilingual, national charitable non-profit association whose mission is the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened.

CHPCA strives to achieve its mission through:
- collaboration and representation;
- increased awareness, knowledge and skills related to hospice palliative care of the public, health care providers and volunteers;
- development of national norms of practice for hospice palliative care in Canada;
- support of research on hospice palliative care;
- advocacy for improved hospice palliative care policy, resource allocation and supports for caregivers.

CHPCA works in close partnership with other national organizations and will continue to move forward with the goal of ensuring that all Canadians, regardless of where they may live, have equal access to quality hospice palliative care services for themselves and their family.

*All Canadians have the right to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice.*