THE WAY FORWARD NATIONAL FRAMEWORK:
A ROADMAP FOR THE INTEGRATED PALLIATIVE APPROACH TO CARE

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Quality End-of-Life Care Coalition of Canada
La Coalition pour des soins de fin de vie de qualité du Canada

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

Government of Canada  Gouvernement du Canada
Imagine a new reality, where hospice palliative care is available to Canadians when and where they need it; where living well until death is the goal of care.

Now, imagine a plan to get there. That's *The Way Forward*: an integrated palliative approach to care across settings.
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Building on successful initiatives already underway across Canada, *The Way Forward* will help identify and share best practices to help all care settings implement the palliative approach to care and ensure that integrated, culturally sensitive palliative services are available to all those who can benefit, regardless of where they live in Canada. Effective ways to monitor and measure the impact of the integrated palliative approach to care will also be developed.
Preface

The Way Forward is a collaborative initiative of the Quality End-of-Life Care Coalition of Canada (QELCCC) and the Canadian Hospice Palliative Care Association (CHPCA), supported by one-time funding from the Government of Canada. This three-year initiative (2012-2015) will engage all health care sectors, professionals and governments in integrating a palliative approach to care in the community in all care settings – including primary care, home/community care, long-term care, hospices, hospitals and other places where people may die, such as shelters and prisons.

This document is the first step in developing a national framework: a roadmap for implementing an integrated palliative approach to care in all care settings across the country. This draft framework was developed by The Way Forward advisory committee with the advice of the members of the QELCCC – all of whom are experts in their field and represent national professional organizations, non-governmental groups and patient organizations committed to the integrated palliative approach to care (for a list of members, see Appendix). Over the next year, this draft framework will be revised and refined based on the advice and input of stakeholders across the country to ensure it is practical and actionable. Additionally, the perspectives of Canadians who are experiencing care issues associated with aging, frailty or are managing life-limiting illnesses will be included. The Way Forward will also gather perspectives of First Nations, Inuit and Métis partners on knowledge, tools, and resources that can best address the realities and needs of Canada’s First Peoples.

Over the next year, this draft framework will be revised and refined based on the advice and input of stakeholders across the country to ensure it is practical and actionable.
Historically, hospice palliative care has been offered only to people who are in the last weeks or months of life, when all curative treatments have been exhausted. At that point, the focus of care shifts from cure to comfort. But illness trajectories are changing. Thanks to advances in medical treatment, people who are aging or who are diagnosed with life-limiting or life-threatening illnesses can now live many years with their condition. Their time of death is often sudden and difficult to predict, which means that many are never offered the benefits of hospice palliative care services, such as social support, advance care planning, and effective pain and symptom management throughout their illness.

Only a small proportion of Canadians will need the kind of complex, intensive or tertiary hospice palliative care provided by specialized palliative care teams in residential settings, such as residential hospices and acute care hospitals. However, everyone who is becoming frail or is faced with a life-limiting illness could benefit from certain key hospice palliative care services. As our population ages, we must ensure that all Canadians have access to hospice palliative services integrated with their other care that will help them manage symptoms, enhance their lives, give them a greater sense of control and enable them to make informed decisions about the care they want. More equitable access to palliative care services will enable more Canadians to live well with their illness up to the end of life. It will also enable more people to receive end-of-life care in the setting of their choice and reduce the demand on acute care resources.

Thérése is 86 years old. She is becoming frailer as she ages. Her arthritis bothers her more these days and she has a heart condition that affects her ability to walk for very long. Her doctor would not be surprised if Thérése died in the next three or four months but she could also live for another few years. Her husband died two years ago as did one of her neighbours, who was a close friend. One of her daughters lives in town and drops by every few days. Her other children live several hours away. Thérése is aware that she is nearing the end of life. She would like the opportunity to talk to her doctor and family about what she wants for her care. She is also experiencing more pain and discomfort and would appreciate some psychosocial support to help her deal with all the losses in her life. However, because she is still receiving treatment for her heart disease and she does not have a diagnosis saying that she is likely to die within the next six months, she may not be referred to the hospice palliative care services that could enhance both her living and her dying.
More equitable access to hospice palliative care services will enable more Canadians to live well with their illness up to the end of life.
A Roadmap to Guide Change

To do this, we must change culture. We must move away from thinking that hospice palliative care is only about care at the end of life, once curative treatments have stopped. We must also move away from thinking of hospice palliative care as a service provided only by specialists, to one that can be delivered by a range of providers, depending on people’s needs and preferences.

An integrated palliative approach to care focuses on meeting a person’s and family’s full range of needs – physical, psychosocial and spiritual – at all stages of a life-limiting illness, not just at the end of life. It reinforces the person’s autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees hospice palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging.
Our vision is that:
All people in Canada who are aging and/or have chronic life-limiting conditions will have the opportunity to benefit from the integrated palliative approach to care.

Our objectives are:

1. To change the understanding and approaches to aging among key stakeholders as it relates to chronic and life-limiting illness, dying and advance care planning.

2. To enable stakeholders to move towards community-integration of hospice palliative care across all health care settings.

The framework is a roadmap that will help create the changes required to achieve our common vision and objectives. It describes how a different model of care – one that recognizes that dying is part of living and integrates key hospice palliative services into people’s care – can ensure that:

- all care settings are able to provide culturally sensitive hospice palliative care;
- more people in Canada have access to high quality hospice palliative care services that will help them live and die well and have a stronger voice in their care (i.e. more autonomy);
- individuals and their families have better health outcomes;
- people can move seamlessly from one care setting to another if their needs change;
- there is less need for emergency visits and hospitalizations, and the system is able to make more effective use of health resources.

We must move away from thinking that hospice palliative care is only about care at the end of life.
The Need for System-wide Change

Ensuring that all people in Canada have access to the integrated palliative approach to care requires change throughout the system. The framework describes steps that could be taken at the federal, provincial, and territorial levels, the regional health planning level and in each sector or setting – including long-term care, home care, primary care, acute care and specialized hospice palliative care. Everyone has a role to play. However, organizations and settings do not need to wait for federal, provincial/territorial or regional action. The integrated palliative approach can start anywhere – and should start everywhere – in the system.

The steps and strategies in the framework are based on the practical experience of people and organizations that are already leading the change. They focus primarily on putting in place:

- the education and supports required to engage providers in all settings;
- the relationships that help build shared-care models that support providers in all settings;
- the communication systems and tools that allow different providers and settings to share information quickly and easily;
- culturally sensitive and competent care;
- policy and practice changes;
- indicators to monitor progress in integrating the palliative approach to care and evaluate its impact on the person’s and family’s health, the setting and its providers, and the health care system.

The integrated palliative approach can start anywhere - and should start everywhere - in the system.
I. The Case for an Integrated Palliative Approach to Care

Dying is Part of Living

Treatment advances have helped extend our lives, but they have not been able to defeat death. Canadians – including those of us who have a life-limiting illness or who are becoming increasingly old and frail – are living longer, but we will all still die.

The health care system must acknowledge that, as we age with these illnesses and frailties, we are both living and dying. It should recognize that dying is part of living and therefore help us manage and maintain our health as well as prepare for death.

Only 10% of people die suddenly. The other 90% will require care and support at the end of life. Only a small proportion of Canadians – about 15% – will need the kind of complex (tertiary) palliative care services provided by specialists in hospices and palliative care units. The needs of the rest can be met by integrating a palliative approach into the care they receive in the settings where they currently reside, such as at home, in a long-term care facility, in hospital – even in a shelter or prison. (iPANEL, 2012)

The Challenge: Our Death Trajectory is Changing

In the past, many Canadians would die suddenly from a heart attack, stroke or organ failure, or they would have a diagnosis, like cancer or AIDS, that had a recognizable terminal phase. Their providers could predict, with relative accuracy, the number of months they had to live. In the last few weeks of life, they would receive organized hospice palliative care services that would help address their physical, psychosocial and spiritual needs, and enhance their living and dying. However, that predictable decline is no longer as common.

Most people with life-limiting and serious illness "dwell in the indistinct zone of chronic illness that has no specific care delivery system". (Lynn, 2004)
By 2025, only 20% of Canadians will die with an illness that has a recognizable terminal phase. Two-thirds of Canadians who die will have two or more chronic diseases and will have lived for months or years in a state of fragile health or “vulnerable frailty.” (CHPCA Fact Sheet, 2012)

Canadians are now more likely to survive a heart attack or a diagnosis of cancer and they are also more likely to be living long-term with two or more chronic, life-limiting conditions. As they age, they become more frail and vulnerable to infections or falls that could lead to death. Because of their complex health needs, they can deteriorate quickly and die suddenly – without ever being identified as “palliative.” Because “when” they will die is less predictable, most people never receive the benefit of hospice palliative care services. For example, three quarters of British Columbians who die, do so without being identified as people who could benefit from the services associated with palliative care. (iPANEL, 2012)

The lack of access to hospice palliative care services is a serious gap in care because all aging Canadians have physical, emotional and spiritual needs – such as pain, loss of mobility and other functions, physical and mental limitations, loss of friends and spouses (Cochrane et al, 2008) – that are not being adequately addressed by current health services.

John, age 67, has cardiac artery disease, hypertension and atrial fibrillation. He has had two heart attacks in the past two years and, each time, he was sick enough to die. Each time he recovered, but with reduced heart function. He is weak and unsteady on his feet, and suffers from shortness of breath. His future is unpredictable: he could live for days or years. He would like help managing his symptoms and improving his quality of life, but the care he receives at the cardiac clinic is mainly focused on managing his cardiac disease and responding to cardiac events.

Mary, age 79, has diabetes, hypertension, chronic renal failure and osteoarthritis. She had been taking NSAIDS for hip and knee pain, which led to her being hospitalized for acute renal failure. Her physician discussed the options with her family and she agreed to a two-week trial of hemodialysis. Her kidneys improved enough for her to stop dialysis but the underlying condition remained. Mary didn’t want to have dialysis again. She hated the experience of being tied to a machine and felt it had a negative impact on her quality of life. However, she did want some kind of treatment for her aching joints and the burning in her hands and feet. She wasn’t sure how to discuss her wishes with her family who wanted her to take advantage of all possible treatments. These discussions are an integral part of hospice palliative care but, because her physician estimated that Mary had one to two years to live, she didn’t fit the criteria to receive hospice palliative care services.

Being diagnosed as “close to death” should no longer be the trigger for Canadians to receive services that can enhance their health and well-being, their living and their dying.
An integrated palliative approach to care focuses on improving quality of life for individuals and their families. It is provided in all health care settings. It involves physical, psychological, social, and spiritual care. The palliative approach is not delayed until the end stages of an illness but is offered early to provide active comfort-focused care and reduce suffering. It also promotes understanding of loss and bereavement. (Adapted from iPANEL, 2012)
The integrated palliative approach to care recognizes that, in a health care system focused on cure and treatment, people may not have the opportunity to talk about dying or be truly informed about their illness and prognosis. They may not be asked about their care goals, or be given an opportunity to talk about how those goals may change over time. For example, early in the disease trajectory, the person’s main goal is usually to prolong life. He or she is willing to give up some function and tolerate some pain for a chance to live longer. As time goes on, maintaining functions such as mobility or cognitive ability may become more important. As the condition progresses, comfort may become the main goal of care and the person may reject treatments that will cause pain or require hospitalization. (Gillick, 2005)

An integrated palliative approach to care also recognizes that, when care is focused on treating an illness, pain and other symptoms (including those related to treatments) are not managed as well as they could be, especially as the illness progresses and the person experiences more complications. The integrated palliative approach focuses on helping people discuss their goals of care early and often, manage symptoms and receive care in the setting of their choice.
II. About the Integrated Palliative Approach to Care

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

What is Hospice Palliative Care?

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- neither hastens nor prolongs death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and throughout their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage distressing clinical complications.” (World Health Organization, 2013)

Hospice palliative care engages individuals and their families in planning for the care they want at different stages in their illness based on their own goals and values and on a clear understanding of their prognosis and treatment options (advance care planning). When people have access to palliative care services, they report fewer symptoms, better quality of life, and greater satisfaction with their care. The health care system reports more appropriate referrals, better use of hospice care, fewer emergency room visits and hospitalizations, and less use of ineffective intensive interventions in the last days of life.
An integrated palliative approach to care focuses on meeting a person’s and family’s full range of needs – physical, psychosocial and spiritual – at all stages of a life-limiting illness, not just at the end of life. It reinforces the person’s autonomy and right to be actively involved in his or her own care, and strives to give individuals and families a greater sense of control. It changes the understanding of hospice palliative care from a service offered to dying persons when treatment is no longer effective to an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging.

What is the Integrated Palliative Approach to Care?

The integrated palliative approach to care makes key aspects of palliative care available to individuals and families at appropriate times in their lives or during an illness in the community setting they choose. For example, when an older person begins to become frail or when someone is diagnosed with a life-limiting condition, the person and family would receive:

- Open and sensitive communication about the person’s prognosis and illness trajectory, including any changes they may have to make in their lives, such as limiting certain activities;
- Advance care planning, including discussing the range of treatments available as well as their benefits and risks, setting goals of care, and establishing a substitute decision maker;
- Psychosocial and spiritual support for both the person and his or her family members/caregivers to help them if they are struggling with any issues related to the illness;
- Any pain or symptom management that may be required.

As the person becomes more frail or the illness progresses (a process that may take years), the person and family would receive:

- Regular opportunities to review the person’s goals of care and adjust care strategies to reflect any changes in his or her goals;
- Ongoing psychosocial support;
- Pain and symptom management;
- Referrals to specialized palliative care services if required to help them cope with challenging physical, psychosocial, or spiritual symptoms, conflicts over goals of care or decision making, or family distress.
Where will the Integrated Palliative Approach be Provided?

Since the integrated palliative approach is not a specialized set of services, it can be integrated into all settings in the community where the person lives or is receiving care. This includes the home, long-term care facilities, hospitals, shelters and prisons. The palliative approach can be provided in urban, rural and remote settings, including Aboriginal communities.

The integrated palliative approach to care recognizes that specialized palliative units and hospices are essential for end of life care, but are not appropriate for all persons facing life-limiting chronic conditions. (Quill & Abernathy, 2013)

As the diagram below illustrates, only a small proportion of Canadians will have the kind of complex end-of-life needs that require the highly specialized tertiary hospice palliative care provided in hospices and dedicated palliative care units. The palliative needs of most Canadians can be met in primary, community and acute care settings.

By offering a palliative approach to care in all settings within the community, we can provide better care for people and their families throughout the many transitions associated with chronic conditions such as dementia, lung, kidney and heart diseases, and cancer.

The palliative needs of most Canadians can be met in primary, community and acute care settings.
Who will Provide the Integrated Palliative Approach to Care?

The same practitioners providing the person’s care now – including primary care physicians and nurses, home care nurses, personal support workers, long-term care staff, hospital staff and the people responsible for health care in shelters and prisons – will provide the integrated palliative approach in their communities. As part of a shared-care model, these practitioners will be supported by specialized hospice palliative care teams based in hospices, hospital palliative care units or in the community. The role of the specialized hospice palliative team may vary in each jurisdiction depending on the extent to which the palliative approach to care has been integrated into different care settings in the community. For example, in communities or regions that are just beginning to implement the integrated palliative approach to care, these teams may continue to provide a significant amount of hospice palliative care, even for people who do not have complex needs. As a community develops the integrated palliative approach and more primary care providers in different settings have the confidence and skills to integrate hospice palliative services into their patients’ care, the specialist team will shift to more of a shared-care role, which can include:

- educating providers;
- assessing and triaging individuals to the setting that best meets their needs and preferences;
- being available to consult and provide advice to primary care providers;
- providing on-call, after-hours, or weekend services to reduce the burden on primary care providers;
- sharing the care for people and families who face challenging physical, psychosocial or spiritual symptoms, conflicts over goals of care or decision making, or family distress;
- in some cases, taking over a person’s care if he or she has to transition to a residential hospice or hospital palliative care unit (particularly if the family physician is not able to continue to provide care in those settings). When this does occur, the specialist team ensures the primary providers are kept informed about the person’s care and progress and are able to resume responsibility for their care if their condition stabilizes and they can be discharged back home or into long-term care.
Some elements of palliative care, such as aligning treatment with a patient’s goals and basic symptom management, should be routine aspects of care delivered by any practitioner. Other skills are more complex and take years of training to learn and apply, such as negotiating a difficult family meeting, addressing veiled existential stress and managing refractory symptoms. (Quill & Abernethy, 2013)

The integrated palliative approach to care is a shared-care model. Hospice palliative care specialists support and share the care. They take the lead only when people have complex, intensive or tertiary end-of-life needs; such as heart failure, respiratory illness, dementia or severe symptom issues, and when normal medical management has not been able to relieve symptoms.

The diagram on the following page, developed by Hospice Palliative Care Ontario illustrates how a palliative approach to care can be integrated into the management of chronic progressive diseases. It shows how different aspects of palliative care can be incorporated at different stages of the illness.

The role of the specialized hospice palliative team may vary in each jurisdiction.
Why Adopt the Integrated Palliative Approach to Care?

The integrated palliative approach to care improves health and quality of life for people who are aging, frail or have a life-limiting illness, gives people a greater sense of control over their lives and care, and makes more effective use of health resources. It is a cost-effective way to fill a gap in care and meet the increasingly complex health and psychosocial needs of older Canadians and their families within their communities. It also makes effective use of the small number of palliative care specialists in Canada.

**Better Health Outcomes**

In a series of studies with people with a range of chronic life-limiting illnesses, including cancer, ALS, congestive heart failure, chronic obstructive pulmonary disease, and multiple sclerosis, findings were greatly in favor of the palliative approach. The integrated palliative approach leads to better outcomes for individuals and their family caregivers, including fewer symptoms, better quality of life, and greater patient satisfaction. (Bakitas et al., 2009; Temel et al., 2010; Meyers et al., 2011; Smith et al., 2012)

The integrated palliative approach to care leads to positive effects on emotional wellness, less suffering, and greater longevity. In some cases, people who receive the integrated palliative approach to care live longer while using fewer services. (Bakitas et al., 2009)
In one study with people with ALS, participants who received an integrated palliative approach to care had a 30% decrease in mortality compared to those who received usual care. They also reported better function and mobility, less deformity and greater comfort and quality of life. (Mayadev et al, 2008)

People with cancer who received integrated palliative care were less likely to die in the year after enrolling in the study. They also reported better quality of life and mood. (Bakitas et al., 2009)
Expensive invasive procedures in the last year of life account for about 18% of Canadians’ lifetime health care costs – and these procedures often do not prolong life or benefit the patient. Sometimes they cause more suffering and hasten death. If we do not find better ways to provide care, the financial, social and human implications will be overwhelming.

In a Kaiser Permanente study in the United States, individuals who received hospice palliative care services integrated with other care had fewer intensive care unit stays and lower health costs: a net cost saving of $4,855 per patient. (Gade et al, 2008) We have seen similar economic impacts in Canada. A study by the Niagara West End-of-Life Shared-Care Project found that providing enhanced palliative care team-based homemaking and nursing services for 95 people in rural Ontario dying at home with illnesses such as cancer, heart disease and chronic obstructive pulmonary disease cost $117.95 a day – significantly less than hospital-based care. (Klinger et al., 2013)
III. The National Framework

This framework describes steps that could be taken at the federal, provincial, and territorial levels, the regional health planning level and at the settings of care level.

However, organizations and settings do not need to wait for federal, provincial/territorial or regional action. The integrated palliative approach can start anywhere – and should start everywhere – in the system.

1. VISION
All people in Canada who are aging and/or have chronic life-limiting conditions will have the opportunity to benefit from the integrated palliative approach to care within their community.

2. OBJECTIVES
1. To change the understanding and approaches to aging among key stakeholders as it relates to chronic and life-limiting illness, dying and advance care planning.
2. To enable stakeholders to move towards community-integration of hospice palliative care across all health care settings.

3. PRINCIPLES
Dying is Part of Living. Dying is an integral part of living. The health care system acknowledges that people with chronic life-limiting illnesses are both living and dying, and provide opportunities for them to live well and, at the same time, prepare for death by talking about the kind of life, care, and death they want.

Autonomy and Respect. People who are aging or who are diagnosed with chronic, life-limiting illnesses have the right to be actively involved in their own care and to have a sense of control over their living and dying. They are treated with respect and given all the information about their health, the expected course of frailty or disease, their treatment options including their likely outcomes and side effects, and the services available to them. They have the opportunity to talk about their health and the possibility of dying, to identify their preferred setting of care and to develop care plans that align with their values. They also have the opportunity to change their plans as their care goals change.

Person and Family Driven Care. When someone is becoming frail or is diagnosed with a life-limiting illness, it is estimated that it affects at least five other people. (CHPCA, 2012) In most cases, family members assume an increasing proportion of the person’s care over time and the need for care can continue for years. The integrated palliative approach to care is

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1The term family includes people the person has chosen to assist with his/her care. It denotes a group of individuals with a continuing legal, genetic and/or emotional relationship to the person.
therefore both person and family driven. Services are sensitive to the individual’s and family’s personal, cultural and religious values, beliefs and practices. They also take into account the burden that different treatment options place on families and their capacity to assume that burden.

**Integrated, Holistic Care.** High quality care for people who are frail or who have a chronic life-limiting illness includes regular holistic assessment of their physical, psychosocial and emotional needs – as well as the integrated palliative services to meet those needs. The integrated palliative approach to care is best provided in the community by an inter-professional team, which includes the person, family caregivers, and health care providers, supported by specialized palliative care teams.

**Equitable Access to Health Services.** All people in Canada who are aging or who have a chronic life-limiting illness have equitable access to the integrated palliative approach to care, regardless of where they live, their care setting, their race or culture, and their economic status.

**Effective Use of Health Resources.** The health care system is accountable for the effective use of its resources. The integrated palliative approach to care helps identify and respond to people’s physical, psychosocial and emotional needs early, and avoid costly, ineffective measures at the end of life.
Laying the Foundation for Change

Integrating the palliative approach to care into the community – offering key hospice palliative care services as people become older or frailer or when they are diagnosed with a chronic life-limiting disease – calls for a significant change in our current culture and practice. It asks practitioners and organizations to think differently about how hospice palliative services can benefit people who are aging or have chronic diseases, and help them develop new skills and care pathways.

Practitioners in primary care practices, chronic disease programs, home care, long-term care, hospitals and other settings – many of whom already feel overwhelmed with care demands – will have to become knowledgeable about the integrated palliative approach to care. They will need to:

- learn to recognize when a singular focus on treating or curing patients is no longer the best thing for their health and well-being;
- develop the skills to communicate with patients and families about death and dying, engage them in their care, give them more control over their decisions, and work with them to develop care plans;
- know when to provide an integrated palliative approach to care, when to consult specialized palliative care teams and when to refer patients and families to more specialized services.

To provide the integrated palliative approach to care, they may also need to examine their own attitudes to living and dying, and come to terms with their own mortality.

Canada is not the only jurisdiction exploring the potential of this approach to care. In its report, **Approaching Death**, the US Institute of Medicine proposed a mixed management model that allows for active, life-prolonging treatment and hospice palliative care to occur in parallel in order to provide comprehensive care throughout the illness and dying experience rather than only at the end. (Glare & Virik, 2001) The World Health Organization has also called for palliative care to be integrated across disease trajectories and settings. (World Health Organization, 2007)

Practitioners may need to examine their own attitudes to living and dying.
Providing a Roadmap

To help the health care system implement an integrated palliative approach, the Canadian Hospice Palliative Care Association (CHPCA) and the Quality End-of-Life Care Coalition of Canada (QELCCC) are developing this National Framework: A Roadmap for the Integrated Palliative Approach to Care. This collaborative iterative framework, developed with primary care, chronic disease, home care, long-term care, hospital teams and practitioners – and with advice from Canadians who are coping with frailty or life-limiting illnesses—reflects the experience of programs here and abroad that are already successfully implementing an integrated palliative approach.

This roadmap will help jurisdictions, organizations and practitioners that aspire to provide the integrated palliative approach to care in all community settings. It consists of a common vision, shared goals and principles as well as a “checklist” of steps and activities. It highlights key tools, structures and supports including: policies and expectations, education and training, remuneration systems, communication and other tools, and monitoring and evaluation.

THE BENEFITS OF THE NATIONAL FRAMEWORK

• Increases awareness of the integrated palliative approach to care.

• Reinforces that the way we live and the way we die matters. Canadians can have much more say and a greater sense of control over their living and dying.

• Encourages consistency across the country, so all Canadians have equitable access to an integrated palliative approach and can benefit from the services.

• Helps ensure seamless transitions of care across all settings.

• Builds on existing strengths. Across Canada, many programs are already using an integrated palliative approach. Driven by a desire to fill gaps in care, these programs have improved training for health professionals, developed models of shared care, increased the number of people who are able to die at home, and reduced hospital stays. The national framework will build on and share the strategies that these programs used to change care.

We know these actions are doable because they are already happening in organizations across the country.
IV. The Framework in Action

Shifting the health care system from its current singular focus on treating illness to an integrated palliative approach to care in the community will require action at all levels and within all sectors and settings.

If people who are frail or have a life-limiting illness and their families are going to receive the care they need in the setting of their choice, then all parts of the health care system must create the conditions that support the shift to the integrated palliative approach to care in the community.

At all levels and in all settings, creating these conditions involves certain key activities, including:

• Establishing a shared vision and goals;
• Developing policies that help shape organizational culture and actively promote the integrated palliative approach to care;
• Setting clear expectations for all providers and staff on their role and how their practice should change;
• Providing ongoing education so staff develop the competencies to integrate the palliative approach with the other care they provide and to provide culturally sensitive care;
• Developing tools and guidelines that help providers integrate the palliative approach to care, including assessment tools that help providers in each setting identify the clients, residents or patients who would benefit from the integrated palliative approach to care;
• Forging strong relationships with other services and settings that can help deliver certain palliative services and/or ensure seamless transitions for individuals and their families if they have to move between settings;
• Being accountable for the quality and impact of this shift in practice by tracking and monitoring that individuals and families have equitable access to the integrated palliative approach to care and assessing the impact of that care on their health and well-being, on their satisfaction with care, on provider satisfaction, on the organization and on the use of other health services.

The following pages describe how these activities would play out, in a practical way, at all levels in the health care system and in different care settings.

The health care system must shift its current singular focus on treating illness only.
Federal, Provincial and Territorial Governments: Develop Policies and Support the System

Leadership for the change in culture can come from the governments that plan, fund and manage health care systems. The federal, provincial, and territorial governments are all critical partners in the framework for action.

Many jurisdictions that have made progress in developing the integrated palliative approach to care have had strong central/government support for the change. The following are the keys actions at this central level:

1. Adapt/adopt the **framework vision, goals and principles**
2. Establish **policy expectations for all care settings and providers**, such as:
   - All patients will have an advance care plan;
   - All patients will have access to an integrated palliative approach in the setting where they are receiving care;
   - All settings will have the capacity to provide high quality hospice palliative services integrated with other care;
   - More care providers will have the skills to provide the integrated palliative approach to care;
   - Specialized palliative care units and hospice residential beds will be available to individuals with complex symptoms and end-of-life care needs that cannot be managed in other settings;
   - More deaths will occur at home or in other settings where people receive care, such as long-term care homes, and fewer will occur in intensive care units.
3. Create **legislation/regulations**, where required, to ensure all settings are accountable for implementing the policy.
4. Establish **guidelines and standards of care** that are consistent with the national norms of practice for hospice palliative care and reflect specific populations’

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2 Provincial and territorial governments are responsible for health services for their citizens. In addition, the federal government is also responsible for providing some health services directly: it manages the fifth largest health care system in the country, providing health care for First Nations communities, the Armed Forces, the RCMP and veterans.
needs for a palliative approach. Governments could make these standards a requirement for accreditation.

5. Develop **remuneration systems and incentives** to support the delivery of an integrated palliative approach. One of the main reasons that primary care physicians often do not stay involved in their patients’ end-of-life care and, instead, refer clients to specialized palliative care services even when they do not require specialized care, is that current remuneration systems do not compensate them for the time required to provide the integrated palliative approach to care (e.g., to take phone calls from home care nurses and long-term care staff, to attend care planning conferences). In many cases, providing incentives may involve reallocating or leveraging existing resources rather than new resources. Some incentives can take the form of supports that reduce the burden on primary care providers, such as, providing an on-call service and after hours or weekend service.

6. **Support communication across settings and seamless care transitions.** When someone has to move care settings (e.g., go from home to a long-term care facility, or from home or long-term care to hospital or hospice), it is essential that their advance care plan, goals of care and other information move with them in a timely way. Effective communication between and across settings is key to seamless care transitions. Jurisdictions need tools and processes to support effective communication and manage any wait times between transitions (e.g., protocols, electronic medical records, collaborative care planning meetings).

The United Kingdom has developed the Gold Standards Framework, a systematic evidence-based approach to optimize end-of-life care delivered by generalist providers and coordinate care across settings. The framework is now used to guide education, policies and programs across the country. It focuses on helping providers identify people earlier, talk to them about their wishes (Advance Care Planning), provide care that aligns with their wishes and improve coordination and teamwork.

Federal, provincial, and territorial governments are all critical partners in the framework for action.
7. **Support education of health care providers in all settings.** Education resources developed federally, provincially or territorially can help reduce costly duplication at other levels in the health care system and promote more consistency in how the integrated palliative approach is understood and delivered. Governments should collaborate with the health professions to ensure the integrated palliative approach and hospice palliative care skills are incorporated into professional pre-service and in-service education. There are already strong education programs developed in Canada, such as the Learning Essential Approaches to Palliative and End of Life Care (LEAP) program developed by the Pallium program. Governments could also provide funds to support in-service hospice palliative education for providers in all care settings.

8. **Establish the indicators and monitoring system** to assess progress in providing an integrated palliative approach to care and evaluate its impact. For example, Silver Chain in Australia was able to compare the outcomes of those who received its services with those who did not, and to demonstrate that its program is cost effective. (CHPCA, 2013)

Indicators could include measures of individual satisfaction and outcomes, family satisfaction, provider satisfaction and resource utilization, such as:
- number of individuals who have developed advance care plans, named a substitute decision maker and established goals of care;
- number who have updated those plans within the last six months;
- staff resources required to provide care;
- use of emergency services;
- hospitalizations including length and frequency of hospital stays in the last six months of life;
- location of care at time of death;
- cost of care;
- and costs avoided.

A program in Tasmania was able to demonstrate that it reduced hospital admissions from long-term care facilities by 75%, which more than covered the cost of piloting its Living Well and Dying Well project in a number of homes for the aged. (CHPCA, 2013)
Regional Program Planners: 
Create a Seamless Network of Services

Regional program planners play a pivotal role in developing integrated networks of services that meet individuals’ and families’ needs and ensure seamless transitions between settings, including developing the specialized hospice palliative care teams and programs that will support the integrated palliative approach to care. The following actions will help regional programs promote the integrated palliative approach:

1. **Make palliative care a core service and unique administrative program.** Start by making palliative care a distinct program with the same stature as other programs (e.g., cardiac care, renal programs, cancer care) and with strong support from senior management. All resources, such as hospital-based palliative care units, become part of the specialized regional program rather than being reserved only for patients in each hospital. The specialized regional palliative care program should be a part of the larger discussion about strategic direction in the health care system as well as how to support the integrated palliative approach in all other settings. Specialized palliative care programs can help care teams in a variety of settings integrate a palliative approach to care and provide seamless transitions.

2. **Develop specialized inter-professional palliative care teams.** Winnipeg has developed inter-professional teams made up of a physician, clinical nurse specialists, community nurses, a palliative care coordinator and psychosocial support in each of the four areas in the city. Their role is to support generalist care teams in each setting; however, practitioners in each setting need to become better skilled and more confident as they provide a significant amount of direct care.

3. **Establish a single central number** to call to access the integrated palliative care program and/or team, **staffed 24/7** that provides virtual support for health care

“In Winnipeg, we looked at who was doing more formal or specialized palliative care. We now all work together as a program. We have workshops and other training to enhance our skills, and twice a month we have team conferences to discuss difficult cases. We have also been able to improve flow through the palliative care beds in the region because we are able to decide who gets those beds as opposed to care at home or in another setting based on their needs. We can facilitate transfers back to long-term care and help practitioners provide [the integrated palliative approach] at home and in long-term care facilities.” (Personal communication: Mike Harlos, Canadian Virtual Hospice, 2013)
practitioners. This service will provide consultation and advice for providers in all settings providing the integrated palliative approach. In most of the innovative models of integrated palliative care in place now, this service is provided by the hospice, which is also responsible for developing and maintaining the specialized hospice palliative care teams.

4. **Build relationships** with all sectors and settings where people with chronic, life-limiting conditions receive care: primary care, home care, long-term care, acute care, and hospices. For example, in North Haven, New Zealand, the central specialized hospice program provides consultation, support and education for primary care providers in the community and in hospital. These relationships will help ensure seamless transitions between settings.

5. **Identify core competencies and education programs** to enhance the capacity of practitioners in all settings – primary care, home care, long-term care, acute care and others – to integrate key palliative services with other care. The region can set expectations, such as, all physicians, nurses and pharmacists should have certain core competencies in the palliative approach to care. Some jurisdictions have made training in the integrated palliative approach available to all physicians in family practice, oncology and internal medicine. In BC, for example, family physicians and their office assistants are expected to complete a module on how to manage patients and the resources available and, in some areas of the province, all acute care nurses and home care staff are expected to have basic or enhanced education in providing hospice palliative services. (Personal communication: Carolyn Tayler, Fraser Health Authority, 2013)

6. **Develop guidelines, algorithms and care pathways** for integrated palliative care for each setting. The guidelines should help each sector put into practice any provincial policies and standards, while taking into account regional needs, resources and services. These tools should help staff in each setting to work with individuals to develop advance care plans and be ready to revisit those plans whenever the person’s health deteriorates or the person changes care settings.

7. **Enhance capacity to provide culturally sensitive care across the region.** To provide the integrated palliative approach, health care providers need the capacity to adapt services to meet the needs of both culturally diverse and geographically remote communities. For example, practitioners should know how to
adapt guidelines, algorithms and care pathways to provide culturally sensitive services in Aboriginal communities and in diverse ethnic communities. (Con, 2008) Advance care planning, based on the person’s beliefs and values is key.

Regional planners can also help settings and practitioners develop effective strategies to deliver the integrated palliative approach to individuals in remote communities, such as education and use of technology (e.g., telephone, telehealth), as well as intensive training in cultural competency, with a particular focus on the cultural values of First Nations, Inuit and Métis groups.

8. **Work with chronic disease management programs.** The goal is to improve their ability to deliver some key palliative services, such as advance care planning, goals of care and symptom management, early in the course of a life-limiting illness. For example, Winnipeg’s regional palliative care program works closely

Fraser Health in BC recently introduced a Medical Orders for Scope of Treatment (MOST) that provides tools and supports for physicians to give patients prognostic information and to document/describe their advance care planning discussions with patients. (CHPCA, 2013)

Primary, community and acute care practitioners need information and education as well as the support of specialized palliative care services that can help assess and identify those patients who can be cared for by their own providers in the settings where they are as well as those who need more complex, specialized care. (CHPCA, 2013)
In Central Australia, the program has a strong focus on community outreach to Aboriginal care workers and non-Aboriginal workers who work with Aboriginal communities. Innovations include a one-day workshop facilitated by an Aboriginal Educator on how to work respectfully with Aboriginal clients. (CHPCA, 2013)

with the ALS program and is starting to develop an effective working relationship with cardiac care and COPD. Fraser Health Authority in BC is working alongside renal, cardiac and critical care programs to develop protocols and tools that the teams can use in their everyday practice to talk with people and their families about goals of care and advance care planning. The process is working: the renal program now embeds a palliative approach in the care provided to people with renal disease. (Personal communication: Carolyn Tayler, Fraser Health Authority, 2013)

9. Monitor the impact. Regional planners may establish indicators that could be used across settings to assess both progress in implementing the integrated palliative approach and its impact on quality of life, seamless care transitions, satisfaction, cost of care and use of other health care resources.

“[In an integrated palliative approach] it’s important to recognize everyone’s strengths. Our palliative care consultants are not the renal or critical care experts. Our program is moving toward a model of education that is less didactic and more role playing: working with staff in all [programs] to understand their own attitudes to end of life and the tensions they feel about what’s happening within health care system.

The practitioners themselves are realizing that they need the basic skills to look after their patients, and that not everyone needs specialized services when they are nearing the end of life.” (Personal communication: Carolyn Tayler, Fraser Health Authority, 2013)
Care Settings and Providers: Find Practical Ways to Deliver the Integrated Palliative Approach

Each sector and setting will face different challenges trying to deliver integrated palliative care.

LONG-TERM CARE

Most residents in long-term care homes are highly vulnerable. They are often frail or have at least one chronic, life-limiting disease. Most (57%) will have Alzheimer’s disease and/or another dementia. (Canadian Institute for Health Information, 2010) And 70% of all individuals with dementia will die in a long term care facility. (Mitchell et al., 2005)

Because people in residential facilities are vulnerable, death is common. According to CIHI reports on location of death in western and eastern provinces, between 16% and 27% of deaths occur in long-term care facilities. (Canadian Institute for Health Information, 2007 and 2011) In one long-term care home in Ontario, about 30% of residents die each year. (Personal communication: Deborah Randall-Wood, Lakeland Long-Term Care, 2013) These residents would prefer to die in their “home” – the long-term care residence or facility – rather than be hospitalized, and they would prefer to receive integrated palliative care from their regular care providers. Staff in long-term care have developed good relationships with residents and know them well. They would prefer to provide care at end of life themselves rather than have specialists “parachuted in.”

However, long-term care facilities face a number of challenges delivering integrated palliative care – not least of which are the high rates of dementia among residents. It can be difficult to provide care that reflects the wishes and best interests of a resident when that person may no longer be able to direct his or her care or even communicate that he or she is in pain. Other challenges include: tight budgets; strict staffing ratios; and extensive regulatory requirements and heavy reliance on personal support workers who are only
required to have minimal training and who may have had relatively little education or experience in providing palliative services. Long-term care facilities can take a number of practical steps to overcome these challenges:

1. **Build strong links with specialized hospice palliative care programs and other community agencies.** The services hospice programs provide for people dying at home, such as volunteer visiting, should also be available for people in long-term care facilities. Trained volunteer visitors can take pressure off staff and enhance quality of life for dying residents. The long-term care facility can also take advantage of education available through specialized hospice palliative care programs and arrange for it to be delivered in a way that makes it accessible to staff without taking too many away from front-line responsibilities (e.g., 15-minute lunch and learns).

A strong relationship with specialized hospice palliative services also means the long-term care facility can access consultation services if required; the goal is to be able to care for the person in the long-term facility with support from the specialists.

The facility could also develop strong links with community organizations, such as the Alzheimer Society, which may be able to provide training and support in providing the integrated palliative approach for residents with dementia.

2. **Modify staffing strategies when a resident is nearing end of life.** On average, a personal support worker in a long-term care facility is responsible for providing care for 10 residents at any given time. To meet the needs of residents nearing end of life who may require more staff-intensive care, long-term care facilities should modify their staffing strategies; for example, by reducing the daily caseload from 10 to 8 residents for a personal support worker who is caring for someone who is dying and asking other staff to cover 11 or 12 residents for that period of time.

"Lakeland Long-Term Care Home maintains palliative care carts that contain all the supplies care providers will need. Staff then spend less time getting supplies and more time with residents. The facility also provides specific basic instructions on how to provide care - for example, what to do to lessen pain, how to reposition people, how to clear the airway, how to set the fan to blow on someone’s cheek, how to prevent bed sores – on laminated cards in a “recipe” box on the cart. It takes only a few seconds for staff to check a card and then know what to do.” (Personal communication: Deborah Randall-Wood, Lakeland Long-Term Care, 2013)
3. **Ensure tools and guidelines are practical, accessible and easy to use.** Long-term care facilities are very busy places. Staff face extensive time pressure. Every effort should be made to put the supplies and information staff need to provide integrated palliative services at hand, in a form and language that is accessible to staff who have a range of education backgrounds and literacy skills.

4. **Integrate hospice palliative care education into mandated education programs.** Long-term facilities are highly regulated environments. Staff are already required to complete extensive training on many care issues. All staff are required to have basic education about care at the end of life: what happens when people are dying, what the person will look like, and how to talk to families. However, they may not be knowledgeable about all the aspects of the integrated palliative approach to care. It may be burdensome for facilities and staff to find the time for this education. Instead, some facilities use a combination of palliative-care specific and integrated education. Staff also need education on how to provide culturally safe and appropriate integrated palliative care for people of different cultures in their facility and/or community. Long-term care homes providing care for First Nations, Inuit and/or Métis individuals should link with Aboriginal services in the community to ensure their services are culturally sensitive and safe.

To change the culture within a long-term care home, it is essential that education go beyond the people who provide direct care to include housekeeping staff, gardeners – everyone. Integrating the palliative approach and

“Lakeland Long-Term Care ensures all staff have received basic education about care at the end of life and then incorporates integrated palliative care into other training. For example, training on nutrition and diet includes the nutrition needs of residents who are frail or dying as does training on mouth care. In each type of training staff are asked to consider ‘how would this be different for someone who could die at any time or is nearing end of life?’ “ (Personal communication: Deborah Randall-Wood, Lakeland Long-Term Care, 2013)
providing the hospice palliative care services in the long-term care setting requires a significant culture change. It involves listening to residents – including those with dementia – and respecting their wishes.

5. Collect data and enhance capacity to “code” palliative residents and monitor impact of the integrated palliative approach. Funding for long-term care facilities is often calculated using a complex formula based on the acuity of residents. In Ontario, that involves collecting 350 data points on each resident every three months. The data collection and coding must be thorough to capture the heavy care needs of people with life-limiting conditions, particularly those in the last weeks or months of life. Collecting this information could help facilities make a strong case for more funding.

Data collection can also help long-term facilities monitor and assess the impact of the integrated palliative approach to care. To measure the extent to which the facility is providing high quality integrated palliative services, it could track indicators such as:

- the number of residents who have up-to-date advance care plans;
- resident satisfaction with care and location of care;
- use of emergency services;
- hospitalizations;
- use of staff resources;
- and the proportion of residents who die in the home rather than being hospitalized at time of death.

6. Share best practices within the long-term care sector. The long-term care sector is a close community. People are connected and already meet in chat rooms to discuss common challenges and issues. The sector should routinely collect and share information on best practices in hospice palliative care in long-term care – perhaps through regular workshops. This venue would provide an opportunity to discuss the challenges of integrating a palliative approach in long-term care settings.

7. Talk to families. In many cases, families are not aware of the capacity of long-term care facilities to provide the integrated palliative approach. Long-term care facilities should let families know the range of services they provide, including symptom management and psychological support and that the person can safely stay in the home to die, rather than being moved to a hospital or hospice.
HOME CARE

All home care programs provide hospice palliative care services, and many have formal palliative programs or teams. They are making a concerted effort to provide more care at home and reduce the pressure on acute care hospitals and thus lessening the cost to health care systems. In most cases, formal palliative home care teams will not be assigned until a person has been deemed palliative, with no more than six months to live. However, this criterion means that many home care clients who could die suddenly because of frailty or a chronic, life-limiting illness are not benefiting from the integrated palliative approach to care. To ensure all clients have access to hospice palliative services as they age, the home care sector may consider the following actions:

1. Implement policy and services guidelines to support integrated palliative approach
   • Increase access to integrated palliative care by reassessing the eligibility criteria for palliative services. Many home care programs only designate clients as eligible for palliative services when they have been assessed as being in the last six months of life. The sector should revisit those criteria, adapting it to reflect the changing ways that Canadians now die and ensuring the integrated palliative approach is available to clients whose health could deteriorate quickly and who might die suddenly.
   • Respond to changing client needs by implementing flexible service provision guidelines. As clients age and their health deteriorates, they may need more intensive services. Home care programs could consider strategies to make services more flexible such as, allowing for more hours of service and providing access to a broader health care team that can address clients’ and families’ increasing complex needs.

2. Develop assessment tools to proactively identify clients who could benefit from the integrated palliative approach. A significant number of people referred to home care have recently been discharged from the hospital. Some, such as those who have had cardiac procedures, are at high risk of being readmitted or of dying suddenly. An assessment tool would help home care programs identify these individuals. The program could then assign these clients to nurses who are skilled in both the integrated palliative approach and the person’s disease or condition. The nurses could assist with advance care planning and ongoing assessment to ensure clients continue to receive the hospice palliative care services – including symptom management – they want and need integrated with their other care.

Another approach is to ensure all home care providers are trained in the components of the integrated palliative approach so that they can apply these skills in the care of all clients.

In Kenora, high risk cardiac patients are followed by a cardiac nurse who monitors them closely. As a result, their readmission rates are only 9% compared to 37% in other parts of the province. The same approach could support other clients who would benefit from the integrated palliative approach.
3. Develop program expectations to change front-line service provider behaviour, such as all clients will have an advance care plan, providers will engage clients in discussions about their prognosis, treatment options and the benefits and risks associated with these options.

4. Provide targeted education on the integrated palliative care approach and culturally sensitive care.
   • Dedicated palliative home care teams already receive extensive education in end-of-life care. However, other home care staff will need appropriate training in the integrated palliative approach to care, particularly given the fact that it is now possible to care for people with much more complex illnesses at home. Education should take into account the roles and responsibilities of primary care physicians who continue to manage clients’ overall care. While physicians will lead a client’s care, home care coordinators may be responsible for some of the advance care planning conversations with clients as they work with them to develop their home care plans. Personal support workers could also benefit from education that allows them to provide emotional support for clients and for family members.
   • Attitudes towards death and care at the end of life are often strongly rooted in culture. Home care staff that are caring for Aboriginal peoples, or people of diverse cultures and their families, will need education to be able to provide culturally safe and appropriate palliative services integrated with usual care.

5. Develop practical tools and guidelines. Professional home care staff (nurses, case managers) will benefit from access to easy-to-use tools and algorithms to help them deliver integrated palliative care, such as tools to assist in advance care planning, communication cues, descriptions of both the
benefits and risks of different treatments for life-limiting conditions, and criteria and reminder systems that trigger teams to revisit care plans and goals of care. Non-regulated staff (e.g. personal support workers), many of whom have varying education backgrounds and literacy skills; will need easy-to-use tools and resources to help them incorporate the integrated palliative approach into everyday practice.

6. **Build strong links with primary care teams, chronic care teams, specialized palliative care teams and hospice programs.** Home care programs will be providing the integrated palliative approach collaboratively with the clients’ primary care or chronic care teams, so it will be important to develop strong links and effective ways to communicate within those teams, particularly with the leading care physicians. Home care programs will also need strong relationships with specialized palliative care teams so they can seek their advice in the care of clients with complex needs and make appropriate referrals if the person’s care can no longer be managed effectively at home.

Home care services can also help clients and families connect with volunteer visiting as well as other services provided by the hospice program.

7. **Support quality and accountability by identifying and tracking indicators of the integrated palliative approach.** Home care programs can play an active role in helping the health care system assess the impact of the integrated palliative approach on client outcomes, provider satisfaction and use of health care resources. Indicators could include:
   - client satisfaction;
   - management of pain and symptoms;
   - provider satisfaction;
   - use of emergency services;
   - hospital readmissions – including frequency and length of stay;
   - cost of care;
   - and cost savings.

It will be important to develop strong links and effective ways to communicate within care teams, particularly with the leading physicians.
PRIMARY CARE

In the first half of the 20th century most deaths occurred at home and were managed by family physicians. Since that time we have experienced intense specialization within medicine. People who would once have died at home are now being admitted to the hospital for intensive interventions and this is often where they die. When aggressive interventions are no longer indicated, people who are dying are often referred to specialized palliative care teams. As a result, primary care physicians have lost skills related to hospice palliative care interventions.

However, this trend is beginning to change. Primary care providers now take more responsibility for chronic disease management. As part of the broader shift to a shared care model, primary care practitioners are expected to be more actively involved in their patients’ care throughout their illness, including at end of life. The challenges the primary care sector faces in providing an integrated palliative approach to care include: a lack of skills in applying the integrated palliative approach in primary care; compensation models that do not remunerate primary care practices for the time required to provide end-of-life care; and the varied models of primary care. For example, it can be extremely difficult for an individual practitioner to provide the integrated palliative approach, while it may be easier for primary care practices/teams, particularly those with nurses and nurse practitioners, to take on a significant amount of both advance care planning and end-of-life care.

The following actions can help integrate palliative services into primary care:

1. Identify the members of the primary care team who will champion the integrated palliative approach and seamless transitions. There is a growing trend among primary care practices for members of the team to “specialize” in specific areas of care, keep up-to-date on current research and trends, and provide training and be the “consultant” for others on the team. Within the team, there will likely be some members who have strengths in palliative care and who will choose to take on more responsibility in this role. However, all members of the team should be familiar with hospice palliative care practice policies and be able to provide care in key areas of the integrated palliative approach. Primary care practices may choose to identify a nurse to work with patients who are frail or have a chronic life-limiting illness, whose role will be to coordinate with home care and other services and ensure seamless transitions between care settings.

2. Ensure appropriate, ongoing education. Members of the primary care team will need education in the integrated palliative approach to care. Teams can connect with specialized palliative care services to access this training. Education should include: advance care planning, plans of care, communicating with individuals and families, pain and symptom management, and other services available in the community. Primary care practitioners

Primary care practitioners should also be educated in such a way that they are able to provide culturally safe and appropriate palliative care for Aboriginal peoples, and people of diverse cultures.
should also be educated in such a way that they are able to provide culturally safe and appropriate palliative care for Aboriginal peoples, and people of diverse cultures.

3. Identify individuals who could benefit from the integrated palliative approach. A significant number of patients who receive primary care will likely have health conditions, such as frailty or a chronic illness that put them at risk of being hospitalized or dying suddenly. With an effective assessment tool, primary care practices can identify these individuals and develop a mechanism to manage their care and monitor their well-being. People at risk would be a priority for advance care planning, physicians or other members of the team would: talk with them about their health, their prognosis, treatment options and their potential benefits and risks. Each of these individuals would then have an advance care plan and goals of care that reflect his or her values.

4. Provide practical tools, algorithms and guidelines. Primary care practitioners will benefit from having easy-to-use tools and algorithms to help them deliver integrated palliative care, such as tools to assist in advance care planning, communication cues, descriptions of both the benefits and risks of different treatments for life-limiting conditions, and criteria and reminder systems that trigger teams to revisit care plans and goals of care.

5. Build strong links with other settings and services, including specialized palliative care teams and hospices. Strong relationships with other settings and services will help primary care practices ensure their patients and families can benefit from the services available in their community. They also help ensure seamless transitions between care settings.

6. Identify and track indicators of the integrated palliative approach in primary care. Primary care practices should routinely collect data on key indicators of the integrated
Many practitioners working in acute care settings are frustrated by the current challenges in practice. They recognize that there are limited health care resources and that these resources should be used where they will do the most good. At the same time, they work in a system that is singularly focused on curing patients and with patients and families who may feel entitled to use all the health care system has to offer. Acute care staff need protocols and skills to help them talk to patients and family members early and throughout the course of an illness so that when intensive measures are no longer appropriate or effective, the transition to palliative care will be easier.

A sizable proportion of Canadians with chronic illnesses such as cardiac disease, renal failure and COPD will be hospitalized or will visit hospital-based clinics. This gives chronic disease management teams in the acute care sector a unique opportunity to ensure better access to an integrated palliative approach earlier in the course of an illness, thereby enhancing patients’ quality of life and engaging them in their own care.

Actions to help acute care settings implement the integrated palliative approach include:

1. **Develop policies/expectations to guide the integrated palliative approach in the program.**
   - All patients will have an advance care plan;
   - Providers will engage patients in discussions about their prognosis, treatment options and the benefits and risks associated with these options;
   - Non-aggressive measures are always presented as an option.

2. **Develop the skills and protocols** to provide the integrated palliative approach to care. Acute care programs that see a large number of patients who are frail or who have life-limiting conditions can work with the specialized palliative care program in their community to develop the skills and protocols.

**ACUTE CARE**

Between 60% and 70% of Canadians still die in the hospital, and only a small proportion of those die in dedicated palliative care units. The challenge facing the acute care sector is ensuring that patients die in their preferred setting and ensuring that those who do die in the hospital have access to the integrated palliative approach.

The palliative approach to care includes:
- the number of patients who have up-to-date advanced care plans;
- the number of patients who are frail or have a chronic life-limiting condition who are being well managed at home or in a long-term care facility;
- the extent to which care pathways and algorithms are followed routinely;
- patient satisfaction;
- the avoidance of emergency room visits and hospitalizations;
- and the number of deaths that occur in the patient’s preferred setting.

Many practitioners working in acute care settings are frustrated by the current challenges in practice. They recognize that there are limited health care resources and that these resources should be used where they will do the most good. At the same time, they work in a system that is singularly focused on curing patients and with patients and families who may feel entitled to use all the health care system has to offer. Acute care staff need protocols and skills to help them talk to patients and family members early and throughout the course of an illness so that when intensive measures are no longer appropriate or effective, the transition to palliative care will be easier.
to incorporate the integrated palliative approach in their everyday practice. These acute care programs may consider identifying individuals on their teams who demonstrate particular skills in the integrated palliative approach to champion these practices and mentor/educate others.

3. **Educate acute care staff about services available in other settings.** Acute care programs may be reluctant to discharge patients either to their homes or to a long-term care facility because acute care staff may be unaware of the level of complex care that can be provided safely in the above settings. Acute care staff should receive education about the services available and, where possible, visit these other settings in order to identify more effective ways to collaborate to improve patient care – both throughout a long-term illness and at end of life. This education should help acute care staff know when someone can be discharged from the hospital to their preferred setting for care.

4. **Identify and track indicators** of the integrated palliative approach in acute care. To assess progress implementing the integrated palliative approach and its impact, acute care programs should routinely collect data on key indicators of the integrated palliative approach to care including:

- the number of patients who have up-to-date advance care plans;
- the proportion of patients who die in intensive care;
- the proportion of patients who are discharged to, and die in, their preferred setting (e.g., home, long-term facility or hospice) rather than in the hospital;
- the satisfaction of family members of people who do die in hospital;
- cost of care;
- care costs avoided.

Between 60% and 70% of Canadians still die in the hospital, and only a small proportion of those die in dedicated palliative care units.
V. Next Steps

This version of The Way Forward National Framework: A Roadmap for the Integrated Palliative Approach to Care is the first step in reaching out to stakeholders from across the country to seek their advice and gather their feedback.

Developed with the guidance of The Way Forward Advisory Committee and members of the QELCCC, the framework will be shared widely with organizations and individuals across Canada, including First Nations, Inuit and Métis groups, who are intensely interested in the health needs of the growing number of aging people in Canada, the future of hospice palliative care, and the sustainability of our health care system.

The Way Forward Initiative will be seeking advice and gathering constructive feedback.

Questions to be considered will include:

Will the framework help progress the field of hospice palliative care?

How can we make hospice palliative care services stronger and more useful?

What else is required to enable people throughout the health system – from funders to people delivering services on the front lines – to provide the integrated approach to palliative care and realize its potential to:

• improve health outcomes;
• give people in Canada more say in their care;
• ensure seamless transitions between care settings for people near end of life;
• make better use of skills and resources;
• contribute to the sustainability of our valued publicly funded health care system?

Be part of the conversation. Visit www.hpcintegration.ca
Appendix

Quality End-of-life Care Coalition of Canada

Coalition Members

ALS Society of Canada
Alzheimer Society of Canada
Canadian AIDS Society
Canadian Association of the Deaf
Canadian Association of Occupational Therapists
Canadian Association for Spiritual Care
Canadian Association of Social Workers
Canadian Breast Cancer Network
Canadian Cancer Society
Canadian Cancer Action Network
The College of Family Physicians of Canada
Canadian Healthcare Association
Canadian Home Care Association
Canadian Hospice Palliative Care Association
Canadian Lung Association
Canadian Medical Association
Canadian Nurses Association
Canadian Pharmacists Association
Canadian Society of Palliative Care Physicians
Canadian Society of Respiratory Therapist
Canadian Working Group on HIV and Rehabilitation
Catholic Health Alliance of Canada
The GlaxoSmithKline Foundation
Heart and Stroke Foundation of Canada
Huntington Society of Canada
Kidney Foundation of Canada
Mental Health Commission of Canada
National Initiative for Care of the Elderly
Ovarian Cancer Canada
Saint Elizabeth Health Care
VON Canada
The Pallium Foundation
Women’s Inter-Church Council of Canada

Associate Members

Canadian Arthritis Patients Alliance
Canadian Caregiver Coalition
Canadian Virtual Hospice
Long Term Care Planning Network
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Personal communication: Deborah Randall-Wood, Administrator, Lakeland Long Term Care. Dec 2012

Personal communication: Carolyn Tayler, Director, Clinical Programs, End of Life Care, Fraser Health, BC. Dec 2012


