



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




SECOND DRAFT FOR  
STAKEHOLDER FEEDBACK  
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Government  
of Canada

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du Canada

A close-up photograph of a hand holding a thin, feathery plant stem. The background is a soft, out-of-focus sunset or sunrise with warm orange and yellow light. The hand is positioned on the right side of the frame, with fingers gently gripping the plant. The overall mood is peaceful and contemplative.

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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**The 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 frailty or chronic 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 a simultaneous or integrated approach to care that can enhance their quality of life throughout the course of their illness or the process of aging.



# 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. As part of this three-year initiative (2012-2015), we will engage health care sectors, professionals and governments in realizing our vision for the integrated palliative approach to care in:



- community settings where care is delivered. This includes primary care practices, home care, long-term care, residential hospices, hospitals and other places where people may live and die, such as shelters and prisons.
- organizations that provide care for people with chronic illnesses, including

Meals on Wheels, day programs and disease-specific support groups like the Alzheimer Society, the Heart and Stroke Foundation and the Canadian Cancer Society.

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 integrated palliative approach to care and ensure that culturally sensitive, supportive hospice palliative care services are available to all those who can benefit, regardless of where they live in Canada.

*The Way Forward National Framework* is a roadmap for implementing the integrated palliative approach to care. Originally developed in the spring of 2013 by *The Way Forward* advisory committee with advice from members of the QELCCC, the framework has been refined and revised. It now reflects ideas and feedback from governments, healthcare professionals and organizations across the country, including First Nations groups. It also captures the experience of Canadians facing care issues associated with aging, frailty and chronic illnesses.

The *National Framework* now reflects ideas and feedback from governments, healthcare professionals and organizations across the country, including First Nations groups.

# Executive Summary

Historically, hospice palliative care was offered only to people who were in the last weeks or months of life, when all curative treatments had been exhausted. At that point, the focus of care shifted 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-threatening illnesses can now live many years with their condition — or they could die suddenly. Their time of death is often difficult to predict, which means

that many are never identified as being at risk of dying or offered the benefits of 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 expert palliative care teams in institutional settings, such as residential hospices and acute care hospitals. However, everyone who is becoming frail or is faced with a chronic illness could benefit from certain key palliative care services. As our population ages, we must ensure that all Canadians have access to 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 integrated with their other care will enable more Canadians to live well with their illness up to the end of life. It will also enable more people to receive care in the setting of their choice and reduce the demand on acute care resources.

## CASE STUDY

**Thérèse 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 Thérèse 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. Thérèse 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.



Everyone who is becoming frail or is faced with a chronic illness could benefit from certain key palliative care services.

# A Roadmap to Guide Change

To do this, we must shift practice. We must move away from thinking that palliative care is only about care at the end of life, once curative treatments have stopped. We must distinguish between the expert hospice palliative care services provided by specialized teams for people with complex needs at end of life and the integrated palliative approach to care that can be delivered by a range of providers

to people throughout their illness trajectory, based on their needs and preferences. We must also identify ways to adapt the integrated palliative approach to Canada's diverse health care environments as well as to the unique needs and jurisdictional realities of all people in Canada, including Canada's First Peoples.



*We must move away from thinking that palliative care is only about care at the end of life...*



## 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.

## Goals of the Integrated Palliative Approach to Care

1. Canadians will talk with their care providers about advance care planning, and discuss their wishes early and often as their illness progresses or as they age.
2. People who are aging, frail and/or have chronic illnesses will receive hospice palliative care services integrated with their other care in the setting of their choice.
3. People who are aging, frail and/or have chronic illnesses will receive consistent, seamless integrated care if/when they must change care settings.



## Impact

- all care settings are able to provide holistic care that respects the person's values and preferences;
- more people in Canada and their families have access to high quality integrated palliative care services that reflect their goals, help them enjoy good quality of life and ensure they have a stronger voice in their care (i.e. more autonomy);
- people can move seamlessly from one care setting to another if their needs change;
- less need for emergency visits and unplanned hospitalizations, with a system able to make more effective use of health resources.

# The Need for a System-wide Shift

Ensuring that all people in Canada have access to the integrated palliative approach to care will require significant shifts throughout the health care system. Based on the practical experience of people and organizations already leading the change to this kind of system-wide shift, we must:

1. Promote and support a **shift in practice culture**;
2. Establish a **common language**;
3. **Educate and support providers**;
4. Engage Canadians in **advance care planning**;
5. Create **caring communities**;
6. Adapt the integrated palliative approach to provide **culturally-safe care**, including with and for Canada's First Peoples;
7. Develop **outcome measures** and monitor the change.

This framework describes concrete steps that could be taken at the federal and provincial/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 – to help the system make the shift.

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.



The integrated palliative approach can start anywhere - and should start everywhere.

# I. A Case for the Integrated Palliative Approach to Care

## Dying is Part of Living

Treatment advances have helped extend our lives, but we will all still die.

Canadians – including those of us who have a chronic illness or are becoming increasingly old and frail – are living longer, but we will all still die.

As we age with these illnesses and frailties, we are both living and dying. To provide the best possible care, our health care system must acknowledge that dying is part of living. The care we receive should help us manage and maintain our health and plan for the kind of care we want as well as help us prepare for death.

Only 10% of people die suddenly. The other 90% of us 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) hospice palliative care services provided by specialists in residential hospices and palliative care units. For the rest of us, our needs can be met by integrating a palliative approach into the care we receive in whatever setting we are in, such as at home, in a long-term care facility, in hospital – even in a shelter or prison. (iPANEL, 2012)

## The Challenge: The Way We Die is Changing

In the past, many Canadians would die suddenly from an infectious disease, a sudden fatal event such as 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, how long they would live. In the last few weeks of life, they may have received organized hospice palliative care services that would help meet their physical, psychosocial and spiritual needs, and enhance their living even at the end of life. However, that predictable decline from illness to death 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, 2014)

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 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 or they can experience periodic crises and complications related to their condition that can lead to death – without ever being identified as being near the end of life. Because “when” they will die is less predictable, most people never receive the palliative care services that could enhance life even in the face of chronic illnesses. For example, three-quarters of British Columbians who die do so without being identified as people who could

benefit from palliative care services. (iPANEL, 2012) This is why the “surprise” question – that is, given this person’s condition, would it be a surprise if he or she were to die? — has become so important. This question puts the emphasis on what could happen – given changing illness trajectories – rather than on a physician’s ability to predict when someone will die.

The surprise question also helps health care providers think more holistically about the person’s physical, emotional and spiritual needs throughout the illness trajectory. These needs, which include pain, loss of mobility and other functions, physical and mental limitations, and loss of roles and relationships (Cochrane et al, 2008), are not being adequately met by current health services. For example:

**John, age 67**, has coronary 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 controlling 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 formal hospice palliative care but, because Mary didn’t fit the usual criteria to receive those 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.



# The Opportunity:

## The Integrated Palliative Approach Can Close the Care Gap

The palliative approach integrates key aspects of hospice palliative care into the regular care that people are already receiving in their primary care provider's office, in their home, in long-term care homes, in hospital or in other community settings.

**How will the integrated palliative approach to care change people's experience?**

**In John's case**, the integrated palliative approach would mean that someone on his cardiac care or primary care team would talk to him frankly about his illness and the uncertainty of his prognosis. His medical treatment would be optimized to control his symptoms. He would be taught a variety of techniques to help him manage his breathing, diet, energy and stress. He would be asked about his preferences for treatment. Based on that discussion, he might choose to be treated for any reversible problems, such as pneumonia or other infections, but not to have CPR or intubation. The team would then help him communicate his wishes to his family.

**In Mary's case**, the integrated palliative approach to care would mean having an in-depth pain assessment and being given treatments and strategies to relieve pain. It would also mean having a meeting with her care team and family to discuss her concerns and wishes for ongoing treatment. Mary would develop an advance care plan that would instruct her physician and her family that, no matter what, she didn't want dialysis again.

**The integrated palliative approach to care recognizes that a health-care system focused on curing or treating specific illnesses sometimes "forgets" to care for the whole person.**



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 acknowledges that most people want to be truly informed about their illness and prognosis, and to have an opportunity to talk openly about their health, their hopes and fears, and about the possibility of dying. The integrated palliative approach to care ensures that people are asked about their care goals and preferences, and encouraged to revisit those goals and discuss how they 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 often 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)

The integrated palliative approach to care also recognizes that, when the care team is focused on treating an illness rather than the whole person, then pain and other symptoms (including those related to treatments) may not be managed as well as they could be, especially as the illness progresses and the person experiences more complications.

The integrated palliative approach gives people the opportunity to discuss their care goals and preferences early and often, and helps them manage symptoms and receive care in the setting of their choice.





## II. About the Integrated Palliative Approach to Care

The World Health Organization defines hospice 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.

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 integrated with their other care, 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.

### 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)



The **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 chronic illness. 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 and in all care settings. For example, when an older person begins to become frail or when someone is diagnosed with a chronic 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 or losses related to the illness;
- **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:

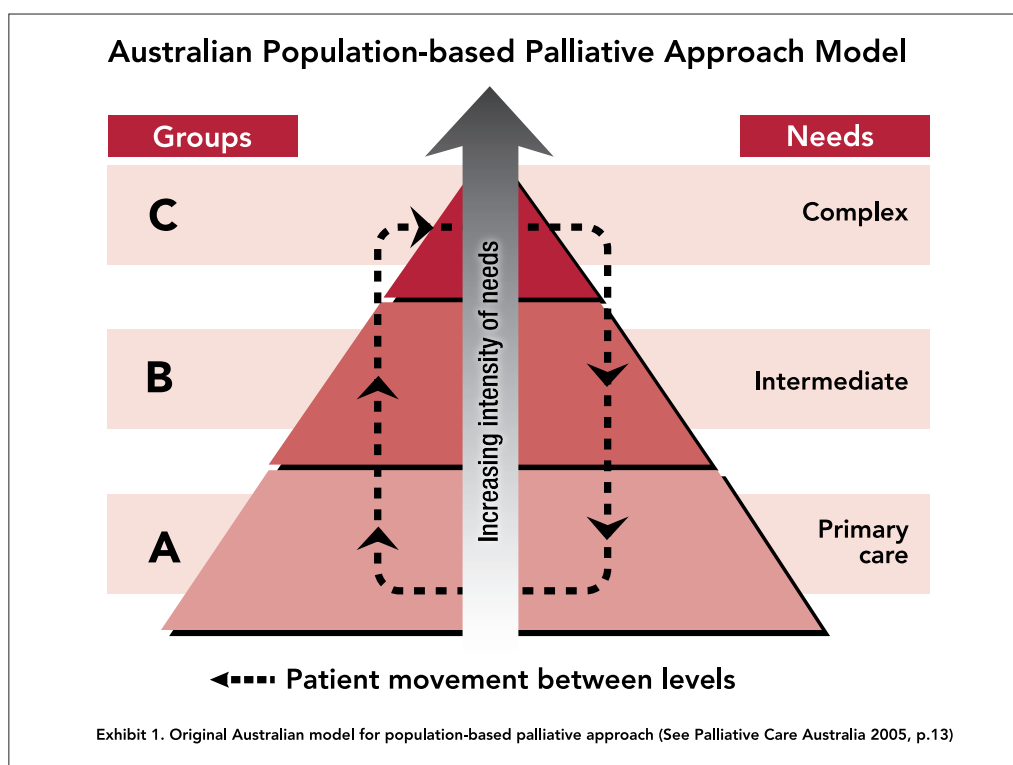
- regular opportunities to **review the person's goals of care** and adjust care strategies to reflect any changes in those goals;
- ongoing **psychosocial support**;
- **pain and symptom management**;
- **referrals to expert hospice palliative care services** if required to help them cope with challenging 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 a way of providing care and not a specialized set of services, it can be provided in all settings in the community where the person lives or is receiving care, including in the primary care provider's office, at home, in long-term care facilities, in hospitals, and in shelters and prisons. The integrated palliative approach can be provided in urban, rural and remote settings, including Aboriginal communities.

By offering this approach 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 lung, kidney and heart diseases, dementia and some cancers.



The integrated palliative approach can be provided in urban, rural and remote settings, including Aboriginal communities.

## 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 to care in their communities. To ensure culturally-responsive services when providing care

with and for Canada's First Peoples, care teams will include community resource people, Elders and cultural advisors as fully recognized members of the care team.

The integrated palliative approach to care is a shared-care model. Expert palliative care teams based in residential hospices, hospital palliative care units or in the community support local care teams and share the care. The role of the expert palliative care team may vary in each jurisdiction depending on the extent to which the palliative approach to care has been integrated into 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 palliative care, even for people who do not have complex needs. As a community

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)

In the integrated palliative approach to palliative care, expert hospice palliative care teams 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.

develops the integrated palliative approach and more primary care providers in different settings have the confidence and skills to integrate palliative services into their patients' care, the expert team will shift to more of a shared-care role, which can include:

- educating providers;
- assessing individuals and referring them to the setting that best meets their needs and preferences;
- being available to consult and provide advice to primary and community 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,

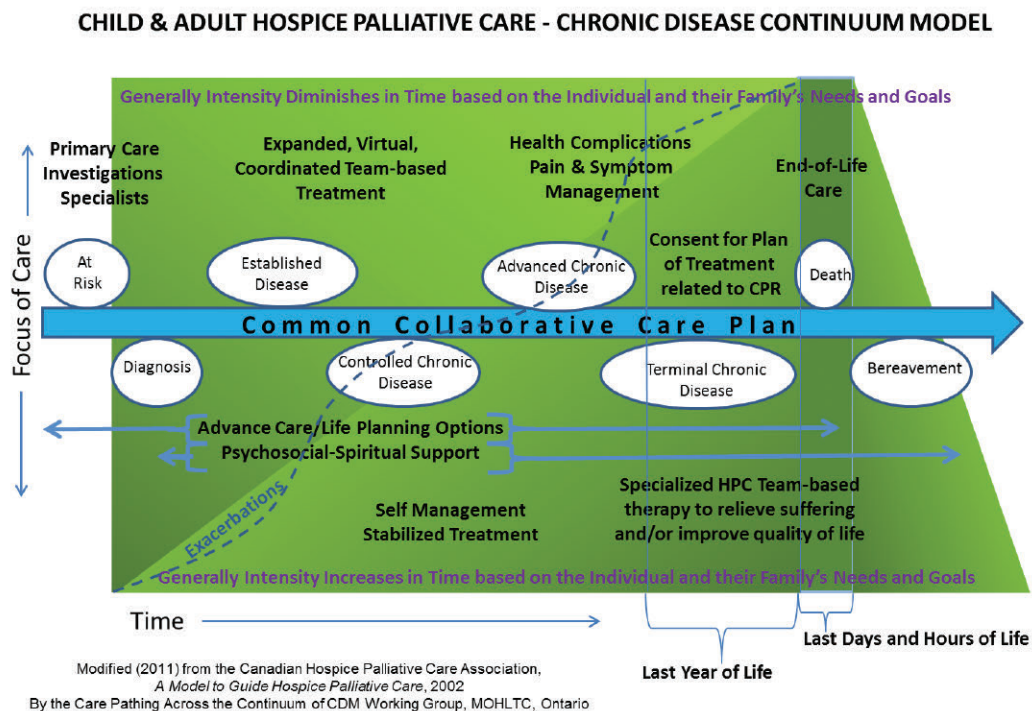
psychosocial or spiritual symptoms, conflicts over goals of care or decision making, or family distress;

- 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 transition does occur, the expert palliative care team ensures the primary providers are kept informed about the person's care and progress and are able to resume responsibility for the person's care if his or her condition stabilizes and the person can be discharged back home or into long-term care.



The same practitioners providing the person's care now will provide the integrated palliative approach to care in their communities.

The following diagram 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.



## Why Adopt the Integrated Palliative Approach to Care?

The integrated palliative approach to care is a cost-effective way to close a gap in care and meet the increasingly complex health and psychosocial needs of Canadians and their families within their communities. It is care that looks at the whole person. It improves health and quality of life for people who are aging, frail or have a chronic illness, gives people a greater sense of control over their lives and care, and makes more effective use of health resources – including the small number of palliative care experts in Canada.

### More Autonomy and Control

The integrated palliative approach works because it gives people the information

and support they need to make informed decisions about their care. Although we have treatments for many progressive illnesses, these illnesses cannot be cured. The integrated palliative approach recognizes that, faced with progressive diseases, people's goals of care may change over time. It gives them the opportunity to discuss their values and wishes earlier and more frequently so they have a greater sense of control.

### Seamless Transitions

When the palliative approach is integrated into all care settings within the community, people will receive consistent seamless care even when they have to



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)

move from one setting to another. Their advance care plan and their goals of care will travel with them, and their wishes will be respected in all care settings. Seamless transitions are particularly important for Canada's First Peoples, who may have to move from one jurisdiction to another in the course of their care (i.e., from the federal health system to a provincial health system). When there is effective communication between jurisdictions – that is, when the person's care plan and goals of care travel with them, and Elders and cultural advisors are recognized members of their care teams – then there will be less fragmentation and more coordinated care.

### **Better Health Outcomes**

A series of studies with people living with a range of chronic illnesses, including amyotrophic lateral sclerosis (ALS), congestive heart failure, chronic obstructive pulmonary disease, multiple sclerosis and some forms of cancer, found that the integrated palliative approach to care led 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 was also associated with positive effects on emotional

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)

wellness, less suffering, and greater longevity. In some cases, people who receive the integrated palliative approach to care lived longer while using fewer services. (Bakitas et al., 2009)

### **Better Use of Resources**

The integrated palliative approach to care is urgently needed for people with chronic conditions and for the health care system. Over the next 20 years, our health care system will face a tidal wave of aging Canadians, many of whom will have chronic conditions. In 2007, 37% of Canadians reported they had been diagnosed with at least one chronic condition, while 41% of seniors had two or more chronic conditions. These illnesses accounted for 70% of all deaths. (Statistics Canada, 2001)

Although Canadians can die at any age, the average age of death in Canada is 74. With the aging of our population, the number of Canadians dying each year will increase 40% by 2026 to 330,000 and 65% by 2036 to more than 425,000. (Statistics Canada, 2001)

Although most Canadians say they would prefer to die at home surrounded by their loved ones, almost seven of 10 die in hospital – many of them in intensive care. (CHPCA, 2012)

The integrated palliative approach to care offers a viable alternative. It has the potential to transform the health care system because it results in:

- less burden on caregivers;
- more appropriate referral to and use of hospice palliative care services;
- more efficient use of the small number of palliative care experts in Canada;
- fewer emergency room visits and hospital stays;
- reduced use of intensive care services. (Lussier et al, 2011)

In a Kaiser Permanente study in the United States, individuals who received 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 (Klinger et al., 2013) – significantly less than \$1,100 cost per day for hospital care in Ontario. (CIHI, 2011)

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. (Fowler, 2013)

# III. The National Framework

The integrated palliative approach to care will vary in different parts of the country, depending on needs, resources, systems and jurisdictions. The models will be driven locally.

**However, to guide implementation of the integrated palliative approach to care across the country, we have developed a national framework that can be adapted to meet local needs.**

## VISION

All people in Canada who are aging and/or have chronic conditions will receive the benefits of the integrated palliative approach to care.

## GOALS OF THE INTEGRATED PALLIATIVE APPROACH TO CARE

1. Canadians will talk with their care providers about advance care planning, and discuss their wishes early and often as their illness progresses or as they age.
2. People who are aging, frail and/or have chronic illnesses will receive palliative care services integrated with their other care in the setting of their choice.
3. People who are aging, frail and/or have chronic illnesses will receive consistent, seamless integrated care if/when they must change care settings.

## PRINCIPLES

**Dying is Part of Living.** Dying is an integral part of living. The health care system acknowledges that people with chronic illnesses are both living and dying with those illnesses. It provides opportunities for them to have good

quality of life throughout the course of their illness and, at the same time, the opportunity to prepare for death by talking about the kind of life and care they want.

**Autonomy and Respect.** People who are aging or who are diagnosed with chronic illnesses have the right to be actively involved in their own care plan and to have a sense of control over their health care decisions. 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<sup>1</sup> Driven Care.** When someone is becoming frail or is diagnosed with a chronic illness, that person's health issues affect at least five other people.

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<sup>1</sup>The 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.

(CHPCA, 2014) 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. To recognize the impact of illness, the integrated palliative approach is both person and family driven. Services are sensitive to the individual's and family's personal, cultural and religious values, beliefs, and practices. The integrated palliative approach also takes into account the burden that different treatment options place on families as well as their capacity to assume that burden.

**Integrated, Holistic Care.** High quality care for people who are frail or who have a chronic 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 expert hospice palliative care teams.

**Equitable Access to Health Services.** All people in Canada who are aging or who have a chronic 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 avoids costly, ineffective measures at the end of life.

## THE BENEFITS OF THE NATIONAL FRAMEWORK

- **Increases awareness** of the integrated palliative approach to care.
- **Reinforces that dying is part of living.**
- **Encourages consistency** across the country, so all Canadians have **equitable access** to the 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 the 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 and reduced hospital stays. The national framework will build on and share the strategies that these programs used to change care.





## Desired Outcomes

People in Canada have care and support that respect their values and preferences, and are able to enjoy optimal health/wellness until the end of life.

As communities and a society, we are more aware and accepting of frailty, disease, and dying as part of life. We are more able to discuss loss and death, and to provide care and support for people who are aging or coping with chronic conditions.

We have a clear common understanding of the integrated palliative approach to care.

Health care providers in all settings are skilled in integrating the palliative approach into people's ongoing regular care.

We have a standard set of relevant measures and tools to assess whether people are receiving the integrated palliative approach to care and its impact on their health and well-being, care experience and use of health services. The same measures are also used to set benchmarks and assess progress in achieving our goals across communities, sectors, regions and provinces and territories.



Providing the integrated palliative approach to care in all settings of care will require a significant change in health care culture and practice – as well as a broader social change in Canadian's attitudes towards dying.

We are more able to discuss loss and death, and to provide care and support for people who are aging or coping with chronic conditions.

# Our Roadmap

Achieving these outcomes will mean a shift in health care practice and culture. Integrating the palliative approach asks practitioners, organizations, communities and health systems to think differently about how we care for people who are aging or have chronic diseases.

The following roadmap was developed by the CHPCA and the QELCCC in consultation with people who are aging or have a chronic illness and with practitioners working in primary care, chronic disease, home care, long-term care and hospitals. When we asked individuals and organizations across the country what would have to happen to shift the system, they identified seven critical steps:

1. **Promote a Culture Shift**
2. **Establish Common Language and Terminology that supports dying as part of living**
3. **Educate and Support Providers**
4. **Engage Canadians in Advance Care Planning**
5. **Create Caring Communities**
6. **Adapt the Integrated Palliative Approach to Provide Culturally-Safe Care, including with and for Canada's First Peoples**
7. **Develop Outcome Measures and Monitor the Change**

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## 1. Promote a Culture Shift

Loss and death are part of life, yet we continue to be a death-denying society. The current single-minded focus on cure and our fear of dying create barriers to holistic, person-centred care. To integrate the palliative approach into routine care for people who are aging or have chronic illnesses, we must shift attitudes – in the health care system and within society at large. In all parts of the health care system and all parts of society, we must **start the conversation about how loss, dying and death are part of life.**

To engage Canadian society in these discussions, we must use all types of media, including social media and story-telling. We must find champions who are already

comfortable talking about death, such as spiritual leaders and funeral directors, and enlist the support of patient advocacy organizations, such as the Alzheimer's Society, Canadian Cancer Society, the ALS Society and the Heart & Stroke Foundation. These conversations should start early. If families are able to talk about loss and death with their children, those young people will grow up understanding that death is part of life. As we start these conversations, we must recognize that different cultures take different approaches to loss and death.

To shift attitudes within the health care system, we must educate and support health care providers to help them overcome their own fear of loss, dying and death. The integrated palliative approach to care should be part of all health care providers' education. In the

**We know these actions are doable because they are already happening in organizations across the country.**

workplace, we must promote best practices in the integrated palliative approach to care and ensure that practitioners have the resources they need to provide that care, and to have

discussions with their patients about advance care planning early and often in a disease trajectory.

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## 2. Establish a Common Language

Words are important. The integrated palliative approach to care is new and not well understood. For many people – including many health care providers – the word “palliative” is associated with the last days or weeks of life. How does the integrated palliative approach differ from palliative care? To ensure a common understanding across the country, we need a common language and clearly defined terms. The words we use must embody dignity, compassion and empathy, as well as respect for different cultural attitudes towards dying.

As part of *The Way Forward* initiative, we have assembled a lexicon of terms but more consultation and discussion is required to develop a common language. A number of provinces and organizations have already started this work, and we can build on their efforts. To have that language adopted and used, we must engage people and organizations across the country in an ongoing process to identify the right words and integrate them into education and practice. We must also be quick to address any misperceptions about what the words mean.

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## 3. Educate and Support Providers

To achieve our goals, practitioners in all care settings – including primary care practices, chronic disease programs, home care, long-term care, hospitals, prisons and shelters – must have the skills and competencies to integrate the palliative approach into routine care. To develop those skills, they must examine their own fears and attitudes about loss, dying and death and come to terms with their own mortality. They must be able to talk easily about death and dying. They must also be able to recognize when a singular focus on treating or curing patients is no longer the best thing for their health and well-being, when they can provide integrated palliative care themselves and when to consult with expert hospice palliative care teams or refer patients and families to more specialized services.

This kind of shift will require changes to health care provider education. It will also require champions in all practice settings and in all health professions, as well as tools and resources. To reach health care providers, we must leverage existing training initiatives, such as the *Educating Future Physicians in Palliative and End-of-Life Care* (EFPPEC) program, the *Learning Essential Approaches to Palliative and End-of-Life Care* (LEAP) program for physicians, as well as national competencies in palliative care for nurses and social workers led by professionals and educators in these fields, and adapt them to focus on the integrated palliative approach to care. We must make innovative use of different tools to reach providers, including social media and story-telling videos. The skills and competencies to provide the integrated palliative approach to care should become a requirement for registration and accreditation.

#### 4. Engage Canadians in Ongoing Advance Care Planning

*The Way Forward* Initiative focuses mainly on integrating the palliative approach into care for people who are aging or who have chronic conditions. However, a truly integrated palliative approach to care should actually start much earlier – before people become frail or ill – with a strong focus on advance care planning.

Advance care planning – the conversations about what people value and the kind of care they want – should begin when they are well, and then continue throughout their lives. It should be grounded in a person-centred, holistic approach and empower people. By talking openly and often about their health and treatment options, people become more involved in their care and better able to make informed decisions.

In 2011, the CHPCA in collaboration with Health Canada released the *Speak Up!* toolkit as part of the larger Advance Care Planning Initiative in Canada. Several provinces, such as BC, currently actively promote advance care planning. However more must be done to engage Canadians in ongoing advance care planning. Once again, we need champions at every level in the health care system, in patient advocacy organizations and in the legal, financial and estate planning world. We can use the *Speak Up!* Toolkit. We can also learn from jurisdictions where a high proportion of people have an advance care plan.

As part of the conversation about the integrated palliative approach to care, we must talk about advance care planning – using all types of communication channels, from social media to public forums. In those conversations, we must reinforce that advance care planning is an ongoing process – not a one-time discussion.

Advance care planning involves thinking about the kind of care you want, talking about it with others and documenting your wishes in an advance care plan.





## Conversation Starters for Health Care Providers

- What do you understand about your illness or what's happening to you?
- Do you have a living will, advance directive, or advance care plan? Do you know what I mean by those terms?
- If we need to make decisions about your care and you were unable to speak for yourself, whom would you want me to speak to about your care?
- Have you talked to anyone about your wishes or preferences for health care decisions that may come up (e.g., resuscitation)? May I ask what you discussed?
- What is important to you as you think about this topic?
- Do you have the information you need to make decisions about the kinds of treatments you do or do not want if you become very sick with a life-threatening illness?

*From Speak Up! Just Ask: Talking to Patients and Families About Advance Care Planning*

### 5. Create Caring Communities

With the integrated palliative approach to care, most people in Canada will receive the palliative services they need - such as open and sensitive **communication about their prognosis, advance care planning, psychosocial and spiritual support, and pain or symptom management** – from their current providers in the settings where they receive care, such as primary care practices, chronic disease management programs, home care and long-term care homes. Only the small proportion of people with complex needs will require expert hospice palliative care services.

While some of the services will be provided by professional health care providers, some will be provided by family caregivers and volunteers. All parts of the community will be involved in creating caring environments that can provide the integrated palliative approach to care. Most communities are ready, willing and able to take on this role, but some may

need some help and support. It will be up to local health care organizations to identify families, populations and/or communities that may struggle to fulfill this role. It is also up to provincial/territorial and regional health system planners to work with local health care providers to provide the support required.



Most communities are ready, willing and able to take on this role, but some may need some help and support.

## 6. Adapt the Integrated Palliative Approach to Care with and for Canada's First Peoples

**Wanda** had been living with diabetes and heart disease for a number of years. Her care was managed mainly by the community health workers in her First Nations community, with some support from fly-in physicians and a hospital that was several hundred miles away. When her condition worsened and could no longer be managed in the community, she was sent to the hospital where she was diagnosed with end-stage heart failure. Far from home and family, Wanda felt anxious and ill at ease. The care team at the hospital provided treatment and tried to have conversations with her about side effects of treatment, quality of life, loss of independence, and the impact of worsening symptoms. However, Wanda felt overwhelmed by the information. She asked for an elder to help her understand, but the hospital did not have one on the care team. When her family did come to visit, they expected to stay the whole day and to have music and a traditional ceremony, but the room in the hospital wasn't large enough to accommodate everyone. The family felt rushed and frustrated, while the hospital staff and other patients complained about the crowd and the noise, especially after visiting hours. In spite of her treatment, Wanda continued to experience a lot of pain and struggled to breathe even when lying in bed. Without the help of a family member or interpreter, she had trouble communicating her needs to the team members who continued to focus on treating the heart failure without giving a lot of attention to her pain and other symptoms or her socio-cultural and spiritual needs. Despite the fact that Wanda was deteriorating, nothing was said to the family about her possible death. When she did die, family members felt that they had been given false hope and not treated with respect. Even after her death, the hospital struggled to provide culturally safe care. In Aboriginal culture, the body is not moved until all the family has come and the body is arranged in a certain way. However, leaving her body in the hospital bed for several hours would have contravened hospital policy.

In implementing the integrated palliative approach to care, we must include approaches that reflect the unique needs, diversity and jurisdictional realities of Canada's First Peoples, particularly in the rural, remote and isolated regions of Canada where most reside. (Kelly L, 2009)

The Constitution of Canada recognizes three groups of Aboriginal Peoples – First Nations, Inuit, and Métis – each with unique heritages, languages, cultural practices, and spiritual beliefs. Both among and within these populations, there is broad diversity as well as shared experiences and challenges that must be considered when adapting the integrated palliative approach to care for Canada's First Peoples.

For example, more than 50 percent of Canada's 1.4 million First Nations, Inuit and Métis live in rural, remote or isolated communities, and studies show that health status declines with distance from urban centers. (Saint Elizabeth Foundation) There is a need, therefore, to develop comprehensive, integrated and affordable ways to deliver the integrated palliative approach that work in rural and remote areas. First Nations, Inuit and Métis in Canada experience a disproportionate burden of ill health (Castleden et al., 2010) and factors such as lower incomes, inadequate housing, and the legacy of the residential school era have a strong influence on their health. (Saint Elizabeth Foundation) At the same time, their populations are growing rapidly, and there is an urgent need to improve their quality of living, including enhancing access to culturally appropriate, integrated palliative care services. (Castleden et al, 2010)

Most First Peoples prefer to pass away in their home community and not in a hospital far from family and friends where there may be language barriers or a lack of cultural safety. However, communities often have limited resources to provide care for people nearing the end of life. The federal government plays a significant role in the delivery of health services and the provision of extended health benefits for some First Peoples of Canada. Under Health Canada's First Nations and Inuit Home and Community Care Program, palliative care is considered "supportive" care so there is no funding specifically allocated for these services. For many of Canada's First Peoples, the fragmentation between federal and provincial health jurisdictions and health services makes it difficult to coordinate health services and follow-up. To adapt the integrated palliative approach to care for Canada's First Peoples and provide seamless services, it will be essential to understand and manage these jurisdictional issues.

In terms of strengths, First Nations, Inuit and Métis in Canada are increasingly involved in health care systems as care providers, in local and regional health care systems, in health authorities and in governments. They are innovators in developing new and effective health care solutions. They are also able to contribute best practices in cultural competence at all levels – as care providers, on care teams, within organizations, in governance and in program and policy related practices. In fact, several programs in Canada and abroad have developed innovative community-driven and nation-based approaches, building on the contributions and ingenuity of First Peoples.

When adapting the integrated palliative approach to care with and for Aboriginal Canadians, health care systems and providers should take several key steps:



- Recognize Canada's First Peoples as partners in their care: ensure that models of care do not see Canada's First Peoples as solely recipients of care, but as true partners in the development and delivery of their care;
- Engage local leaders, including community resource people, Elders and cultural advisors as full recognized members of the health care team at all levels, and build on their knowledge to ensure culturally appropriate models of care and manage potential "professional bias";
- Use a community-based development process to enhance local capacity: start by ensuring all relevant structural elements are in place and coordinated, and then develop local care models, based on needs, using a process that works for each setting and leveraging regional and provincial/territorial capacity as needed;
- Develop culturally-safe, holistic tools and resources (e.g., assessment tools) that include physical, emotional, spiritual and intellectual aspects of health and well-being within a family and community context: ensure flexible and timely access to these tools and resources.

## 7. Develop Outcome Measures and Monitor the Change

To determine whether we are successful in providing the integrated palliative approach to care, we need specific measurable goals to drive the system-wide shift in practice, as well as ways to monitor changes and identify barriers to change. In addition to measuring whether palliative services are being integrated into routine care, we want to measure the impact of those services on people, on providers and on the health care system.

- Are people who are elderly or have a chronic condition more satisfied with their care?
- Do they have a plan of care?
- Do they have a greater sense of control and more support in making their care decisions?
- Are they enjoying better quality of life?
- Are providers more satisfied with the care they provide?
- Did they have ongoing conversations with people about their prognosis and their choices?
- Do providers find it easier to communicate with patients or clients?
- Are people able to receive care in the setting of their choice?
- Is the system seeing less use of hospital and emergency services in the last weeks or months of life?
- Are people receiving fewer unnecessary interventions near end of life?

*The Way Forward* undertook a review of measures (both health and social measures of quality of life) that are being used to monitor progress in palliative care across the country. In many cases, health systems and organizations may already be gathering data on these measures that can be used to assess the impact of the integrated palliative approach to care (e.g., through tools such as InterRAI Community Health (CHA) Assessment Form, the Palliative Performance Scale, and the Palliative Outcomes Scale).

Some of the measures could eventually be used to set standards for the integrated palliative approach to care. Champions in each sector can then work to integrate the standards into practice. With appropriate measures, we could document effective programs and share best practices and lessons learned.



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# IV. The Framework in Action on the Front Lines

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 chronic 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.

Ideally, the shift to the integrated palliative approach to care will happen at all levels in the health care system - the federal, provincial/territorial or regional health planning levels, including regions where First Nation, Inuit and Métis peoples are responsible for directing, managing and delivering a range of health services, and at the local or care setting level.

However, **front-line organizations 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.**

At all levels and in all settings, it is possible to create the conditions that support the shift to the integrated palliative approach to care in the community. Creating these conditions involves certain key activities, including:

- Developing **policies** that help shape organizational culture and actively promote the integrated palliative approach to care;
- Establishing a **shared vision and goals, and a common understanding** (language) of the palliative approach to care;
- Setting **clear expectations for all providers and staff** for 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;
- **Communicating** clearly with health care providers, the public and patients about the palliative approach to care and how it can enhance quality of life as well as both living and dying;
- 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.

# Federal, Provincial and Territorial Governments: Develop Policies and Support the System

Leadership can come from the governments that plan, fund and manage health care systems. The federal, provincial and territorial governments<sup>2</sup> are all critical partners in the framework for action. Strong leadership can also come from Canada's First Peoples, who are increasingly taking greater control over health care services in their communities, as illustrated most recently by the historic transfer of all Health Canada programs and services to B.C. First Nations (via the new First Nations Health Authority).

Many jurisdictions that have made progress in developing the integrated palliative approach to care have had strong government support for the change. In regions with large indigenous populations, such as New Zealand and Central Australia, local (community-driven) leadership and engagement have been fundamental to their success.

The following are the keys actions at this central level:

1. Adapt/adopt the **framework's 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;
  - All communities and settings will develop approaches to integrating palliative care that are culturally sensitive and

<sup>2</sup> 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 and Inuit communities, the Armed Forces, the RCMP, inmates in federal prisons, and veterans.

The End-of-Life Care Strategy for England (2008) guides care and mandates the use of programs such as the Gold Standards Framework and the Liverpool Care Pathway for the Dying Patient.

Australia has developed a national palliative care strategy (2010) as well as national guidelines for a palliative approach for aged care in the community setting (2011), while the Northern Territory Government in Australia—where about 34% of the population is indigenous—has adapted the national strategy for its region in close partnership with aboriginal health workers and social service organizations.

meet local needs, including the needs of Canada's First Peoples;

- 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. Develop the **tools** that communities need to assess their current capacity to provide the integrated palliative approach to care, to identify any gaps (e.g., knowledge, skills, workforce, training) and to build capacity such as: patient assessment tools, advance care planning tools, care plans, information and resources for family caregivers and volunteers).
  4. Create **legislation/regulations**, where required, to ensure all settings are accountable for implementing the policy.
  5. Establish **guidelines and standards of care** that are consistent with the national norms of practice for hospice palliative care (CHPCA, updated 2013) and reflect specific populations' needs for the integrated palliative approach to care. Governments could make these standards a requirement for accreditation.
  6. Consider developing **remuneration systems and incentives** to support the delivery of the 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 expert 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 providing new resources. Some

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.

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. Federal and provincial/territorial governments may also consider funding pilots of the integrated palliative approach to care with patients with a particular chronic disease in order to demonstrate its impact and outcomes.

- 7. 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 residential 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).

- 8. 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 palliative care skills are incorporated into professional 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 Pallium Canada. Governments could also provide funds to support ongoing palliative education for providers in all care settings.
- 9. Develop a communications strategy.** Different techniques and forums should be



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)





used to ensure the public and patients understand the integrated palliative approach to care. Effective communication will help create and reinforce a common understanding of the integrated palliative approach to care. As part of the communications strategy, we can share success stories from communities that have worked across settings and sectors to support people who are aging or have a chronic illness to receive integrated palliative care in the setting of their choice.

10. Establish the **indicators and monitoring system** to assess progress and evaluate 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.

# 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 expert 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 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.

Expert hospice 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 the integrated palliative approach to 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, 2013)

The central hub and spoke approach used in North Haven, New Zealand, encourages standardization of care, equal access across the district and economical use of resources. A specialist nurse educator and advisor works to increase the capacity of primary care providers and break down silos between services. The model aims to have most end-of-life care provided by primary care providers, with specialist palliative care services taking on complex cases. (CHPCA, 2013)

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 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 or hospital-based palliative care unit, which is also responsible for developing and maintaining the expert palliative care teams.
4. **Build relationships** with all sectors and settings where people with chronic conditions receive care: primary care, home care, long-term care and acute care. 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 integrated palliative approach to care. Some jurisdictions have made training in the integrated palliative approach available to all physicians in family



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. Most physicians agree that these discussions should happen; however, most do not feel that they should be the ones to have that conversation. (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 increasing reliance on specialized palliative care teams, there has been a general “deskilling” of primary, community and acute care practitioners. As a result, many lack confidence in their ability to provide care at end of life. They 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)

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 palliative services. (Personal communication: Carolyn Tayler, 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, regional planners could work with diverse Aboriginal and diverse ethnic communities to adapt guidelines, algorithms and care pathways to provide culturally sensitive services. (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 safety and competency, with a particular focus on the cultural values of First Nations, Inuit and Métis groups. Fundamental to successful cultural competency is the



[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, 2013)

meaningful engagement of Canada's First Peoples in designing and implementing programs at all levels — as care providers, members of care teams, part of organizations and providing governance.

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 chronic illness. For example, Winnipeg's regional palliative care program works closely 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, 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.

Two hospice-based programs in New Zealand—Arohanui Hospice and Otago Community Hospice—have been particularly effective in engaging and “reskilling” family physicians in palliative care. They have also developed culturally sensitive services that meet the needs of the aboriginal individuals and their families. (*Innovative Models of Integrated Hospice Palliative Care*, page 32)

# 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 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, 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 the 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 residents who may no longer be able to direct their care or even communicate that they are 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 palliative 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 expert 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-learn sessions).

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

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)



“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, 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 required 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, dining room staff, gardeners, volunteers – everyone. Integrating the palliative approach to care 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 chronic 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;
- 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 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, rather than being moved to a hospital or residential hospice.



In the UK, care homes are organized into learning clusters where they can discuss any issues they face providing hospice palliative care services for residents. (CHPCA, 2013)

## HOME CARE

Many home care programs provide 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 lessen 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 illness are not benefiting from the integrated palliative approach to care. To ensure all clients have access to palliative services integrated with their other care 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

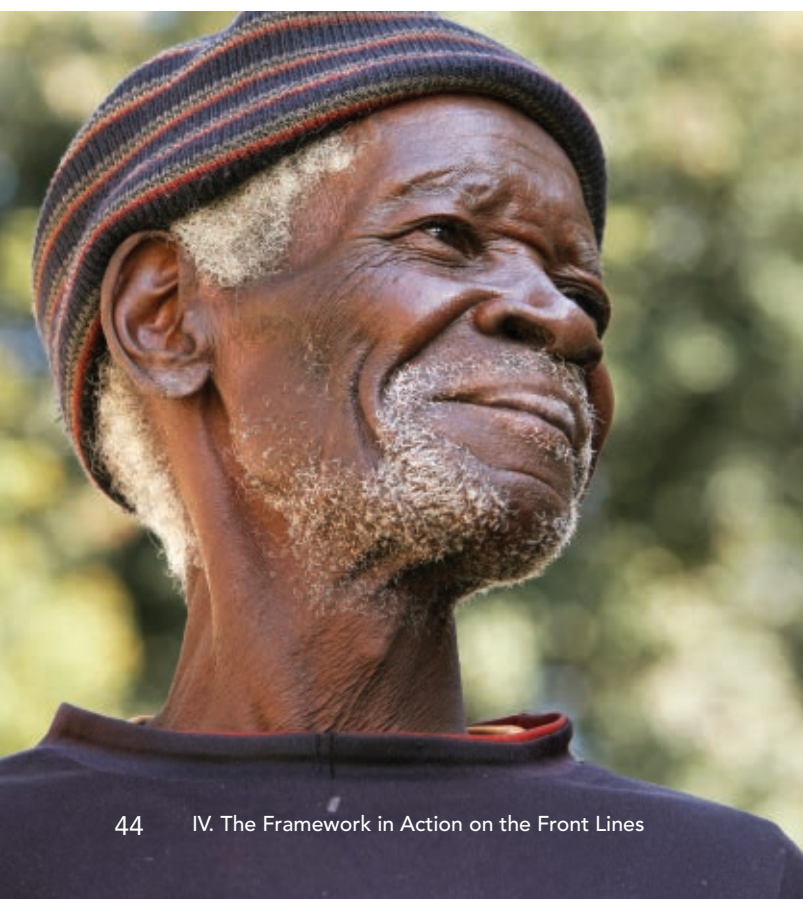
**palliative services.** Many home care programs only designate clients as eligible for palliative services when they have been assessed as being in the last six months of life. The sector should revisit those criteria, adapting it to reflect the changing ways that Canadians now die and ensuring the 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.







**3. Develop program expectations to change front-line service provider behaviour.** For example, 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 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. This education must recognize the broad diversity that exists among individual First Nation communities across Canada, and reflect each community's identified needs and priorities.

**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 chronic 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 to develop strong relationships with expert hospice 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 a local hospice or regional palliative care program or other community programs.

- 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;
- access to psychosocial and spiritual support;
- 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.



## HOME CARE IN FIRST NATIONS AND INUIT COMMUNITIES

Health Canada's First Nations and Inuit Home and Community Care Program provides funding for basic home and community care services to First Nations communities and Inuit settlements. Under this program, palliative care is considered "supportive" and no funding is specifically allocated to provide these services. Although the common Aboriginal preference is to die in the home community, limitations in community resources hinder this option in remote areas. (Saint Elizabeth Foundation)

A number of innovative programs are underway in Canada and abroad, focused on building palliative care capacity within communities and among both Aboriginal and non-Aboriginal

workers. These leading and promising practices all share one critical success factor—they are community-built and driven, with indigenous peoples leading the design, planning and implementation of curriculum and materials to ensure inclusion of appropriate cultural traditions, content and competencies. These models are founded in the needs and processes that work for their particular settings, pulling in regional and governmental capacity as needed.

For example, with funding from the Canadian Institutes of Health Research, four First Nations communities in Ontario and Manitoba, along with Aboriginal health organizations and a team of researchers from Lakehead University, are working to improve end-of-life care by developing palliative care services and knowledge within their communities. First Nations health care providers will be empowered

and supported to be catalysts for community change in developing local palliative care programs. Lessons learned from this project have the potential to be applied to other First Nations communities also in need of developing local palliative care services.



## 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. As a result, primary care physicians have lost skills related to caring for their patients until the end of their lives.

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 the end of life. The challenges the primary care sector faces in providing an integrated palliative approach to care include: a lack of knowledge or 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 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 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 expert hospice 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 should also be educated in such a way that they are able to provide culturally-safe and appropriate palliative care for diverse Aboriginal and ethnic communities.

Primary care practitioners should also be educated in such a way that they are able to provide culturally-safe and appropriate palliative care for diverse Aboriginal and ethnic communities.



**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. Primary care providers would routinely ask themselves the “surprise” question: would it be a surprise if this person were to die? When the answer is “no”, they would provide more intense integrated palliative services, which would lead to end-of-

life care based on the person’s needs. Advance care plans should be initiated and revisited with all patients as the illness progresses.

- 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 chronic 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**



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.

**integrated palliative approach in primary care.** Primary care practices should routinely collect data on key indicators of the integrated palliative approach to care including:

- 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 of care.

## **CHRONIC DISEASE MANAGEMENT TEAMS/ 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.

A sizable proportion of Canadians with chronic illnesses such as cancer, progressive neurological diseases, or organ failure will be hospitalized or will visit hospital-based chronic disease 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, such as:**

- 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. Chronic disease management/acute care programs that see a large number of patients who are frail or who have conditions can work with expert hospice palliative care program in their community to develop the skills and protocols 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 chronic disease management/acute care staff about services available in other settings.** Chronic disease management/acute care programs may be reluctant to discharge patients either to their homes or to a long-term care facility because staff may be unaware of the level of complex care that can be provided safely in settings in the community. Chronic disease management/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 chronic disease management/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 chronic disease management/acute care. To assess progress implementing the integrated palliative approach and its impact, chronic disease management/acute care programs should routinely collect data on key indicators of the integrated palliative approach to care including:



- patient satisfaction;
- pain and symptom management;
- 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.



## V. Next Steps

This document, *The Way Forward National Framework*, is part of a pan-Canadian effort to ensure that all people in Canada who are aging or living with a chronic illness have access to the benefits of the integrated palliative approach to care when they need them.

It proposes a fairly radical change in the way people access these services. It acknowledges that, for most Canadians, their time of death will be unpredictable. Instead of having to be diagnosed as “close to death” to receive palliative care services, people will now be able to access these services much earlier in their disease trajectory. The trigger for these services could be a diagnosis with a progressive or chronic illness. For people who are aging and becoming frail, it could be the “surprise” question. In fact, some aspects of the integrated palliative approach to care, such as advance care planning, will be available and promoted to people – particularly seniors – before they even become ill.

With this framework, health care providers will be encouraged to talk much more openly with patients and their families about their prognosis, treatment options, and the benefits and risks associated with these options. People

who are aging or have a chronic illness will have care plans that they develop with their providers and can update as their needs change. They will also have access to other aspects of palliative care, including pain and symptom management and psychosocial support, as they need them. These services will be provided by their own health care providers, with the support of palliative care experts, and integrated with their other care.

This framework is an evergreen document. As sites across Canada begin to implement the integrated palliative approach to care, we will learn more about how to do it well. The framework will be continually updated to reflect best practices, lessons learned, and feedback from the many people and organizations involved in providing or receiving palliative services integrated into their care and in the setting of their choosing.



# Appendix

## Quality End-of-life Care Coalition of Canada

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### Coalition Members

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

### Associate Members

Canadian Arthritis Patients Alliance
Canadian Caregiver Coalition
Canadian Network of Palliative Care for Children
Canadian Virtual Hospice
Long Term Care Planning Network

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# Lexicon of Terms Related to the Integrated Palliative Approach to Care

Like all health care practices, hospice palliative care has its own language and terminology. This lexicon of terms is designed to help those interested in implementing the integrated palliative approach to care develop a common language and understanding.

**Advance Care Planning** - A process people can use to: think about their values and what is important to them with regard to their health care choices; explore medical information that is relevant to their health; communicate their wishes and values to their loved ones, substitute decision-maker and health care team; and record their health care choices and decisions in the event they can no longer speak for themselves. The process may involve discussions with their health care providers and people who are significant in their lives. Advance care planning may result in the creation of an advance directive or "living will", which is a person's formal or informal instructions about their future care and choice of treatment options.

**Aging** - Aging is a natural process that happens to all living things. In people, the process of aging has an effect on the body and mind, and can affect health and quality of life. For example, as people age, their hearts become slower, their blood vessels and arteries become stiffer, their bones shrink in size and are more likely to break, their muscles lose strength, they may become less coordinated or have trouble balancing, and their memory becomes less efficient. The changes that occur with aging affect quality of life and increase the risk of dying. See "Frailty".

**Autonomy** - The capacity for self-determination, and one of the rights associated with liberty. Respect for autonomy means acknowledging the person's right to make choices and take actions based on their own values and belief system and not interfering with the person when he or she exercises that right.

**Care** - All interventions, treatments and assistance provided to the person and family to treat disease and enhance health and well-being.

**Care plan** - See "Plan of Care"

**Caregiver** - Anyone who provides care. Formal caregivers are members of an organization and accountable to defined norms and professional standards of practice. They may be professionals, support workers, or volunteers. They are sometimes called "providers." Family caregivers are not members of an organization. They are family members and other significant people (as identified by the care recipient) who provide unpaid care and assistance to individuals living with a debilitating physical, mental or cognitive condition. Family caregivers usually have no formal training. While they are expected to follow certain ethical norms, they are not accountable to professional standards or practice.

**Chronic Disease** - A chronic disease is one that may develop slowly, last a long time, be incurable, and be progressive and/or life-limiting. Examples of life-limiting chronic diseases include cardiovascular disease, chronic kidney disease, congestive heart failure, diabetes, dementia, emphysema, multiple sclerosis, amyotrophic lateral sclerosis and some forms of cancer. The

disease and its treatment may cause symptoms such as fatigue, pain and sleep problems; they can also limit people's activities, cause them psychological distress and have a negative effect on their quality of life. A chronic disease can't be cured but its symptoms can be managed.

**Expectations** - Issues, hopes and fears identified by the person and/or family that require attention in the plan of care.

**Family** - Those closest to the patient in knowledge, care and affection. The person defines his or her "family" and who will be involved in his/her care and/or present at the bedside. May include:

- the biological family
- the family of acquisition (related by marriage/contract)
- the family of choice and friends (including pets).

**Frailty** - Frailty is a nonspecific state of vulnerability caused by changes to a number of physiological systems (see Aging), which may be related to a variety of physical, psychological, cognitive and social factors. Together, these changes lead to reduced function and strength, and affect the person's resilience and ability to cope with any stress, such as an infection or disease or personal loss. Frailty is most commonly seen in the elderly but can also occur in adults and children who are seriously or chronically ill. Someone who is frail is at high risk of physical and cognitive decline, disability and death. Frailty can cause pain and discomfort. It can also limit people's activities, cause them psychological distress and have a negative effect on their quality of life.

**Goals of care** - Describes people's goals for their care and should include treatment of the disease and/or symptom management. In some cases, it includes limits on the interventions that people want, such as "do not resuscitate" orders.

**Home Care** - Home care includes an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for family caregivers.

**Hospice palliative care** - Care that aims to relieve suffering and improve the quality of life

**Illness** - Absence of wellness due to disease, other conditions, or aging.

- An acute illness is one that is recent in onset and likely to be time-limited. If severe, it could be life threatening.
- A chronic illness is likely to persist for months to years. If it progresses, it may become life threatening. (continued)

- An advanced illness is likely to be progressive and life threatening.
- A life-limiting illness is one that affects health and quality of life, and can lead to death in the near future.
- A life-threatening illness is one that is likely to cause death in the immediate future.

### **Integrated palliative approach to care/community-integrated palliative care**

- Care that focuses on meeting a person's and family's full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness. 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 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. It provides key aspects of palliative care at appropriate times during the person's illness, focusing particularly on open and sensitive communication about the person's prognosis and illness, advance care planning, psychosocial and spiritual support and pain/symptom management. As the person's illness progresses, it includes regular opportunities to review the person's goals and plan of care and referrals, if required, to expert palliative care services.

### **Interdisciplinary, multidisciplinary or interprofessional team**

- Caregivers with different training and skills who work together to develop a team and implement a person's plan of care. Membership varies depending on the services required to address the person's and family's identified issues, expectations, needs and opportunities. An interdisciplinary team typically includes one or more physicians, nurses, social workers, psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may be part of the team if resources permit.

**Outcome** - A measurable end result or consequence of a specific action, usually related to the person's health or overall well-being.

**Palliative approach to care** - See "Integrated palliative approach to care"

**Pain and symptom management** - Pain and other symptoms that cause discomfort (e.g., shortness of breath, fatigue, changes in mood or functional ability, psychosocial or spiritual distress) can be caused by underlying diseases. They can also be caused by the treatments for those diseases, the side effects of treatments and the process of aging. The integrated palliative approach to care focuses on helping people manage pain and other symptoms as a way to reduce discomfort and improve quality of life. Many different techniques can be used to manage symptoms, including medication, exercise (physiotherapy), breathing, meditation, the use of heat and cold, biofeedback processes, diet, repositioning, counselling and psychosocial and spiritual support.

**Person** - Someone living with a chronic progressive illness. Based on the person's preferences and wishes, the person directs and guides his or her own care plan as far as possible, and is a contributing member of the interdisciplinary team.

**Plan of care** - The written plan that describes the person's assessed health needs and goals, and the care that will be provided to meet those needs and goals.

**Performance Indicators** - A statistical compilation of standardized measures/metrics used to evaluate specific parameters of a health service, such as access and quality.

**Provider** - A formal caregiver who is a member of an organization and accountable to norms of conduct and standards of practice. They may be professionals, support workers or volunteers.

**Quality care** - The continuous striving by an interdisciplinary team/organization to meet the expectations and needs of the people and families it serves and the standards established by the organization, health authority, profession and accreditation bodies.

**Quality of life** - Well-being as defined by each individual. Quality of life relates both to experiences that are meaningful and valuable to the person, and his/her capacity to have such experiences.

**Regional health programs or authorities** - Health planning organizations responsibilities for setting policies, allocating resources to support care and approving organizational plans to deliver services.

**Regional team** - Regional teams are functional units designed to provide oversight and expert support for formal caregivers and multiple care teams within a given population/region/setting of care.

**Setting of care** - The location where care is provided. Settings of care may include the person's home, primary care settings (e.g., a doctor's office, nursing station, community clinic), an acute, chronic, or long-term care facility, a hospice or palliative care unit, a jail or prison or in the case of homeless individuals, the street.

**Spirituality** - An existential construct inclusive of all the ways in which a person makes meaning and organizes his/her sense of self around a personal set of beliefs, values and relationships. Spirituality is sometimes understood in terms of transcendence or inspiration. Involvement in a community of faith and practice may or may not be a part of an individual's spirituality.

**Substitute decision-maker** - A person or agency chosen by the person or appointed by the state to act on his or her behalf. Substitute decision-makers are normally held to substituted judgment or best interest standards.

**Suffering** - A state of distress associated with events that threaten the intactness of a person. It may be accompanied by a perceived lack of options for coping.

**Value** - Something that is morally desirable and/or a fundamental belief on which spirituality and/or a practice is based. A value can be intrinsic — perceived as worthy or treasured in and for itself (e.g., liberty) — or a value can be instrumental perceived as worthwhile for pragmatic purposes (e.g., money to obtain goods or services).

## NOTES



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## THE WAY FORWARD INTEGRATION INITIATIVE

Annex D - Saint Vincent Hospital  
60 Cambridge St. North, Ottawa, Ontario  
K1R 7A5

email: [info@hpcintegration.ca](mailto:info@hpcintegration.ca)  
tel: 1-800-668-2785 ext. 228  
fax: 613-241-3986

[www.hpcintegration.ca](http://www.hpcintegration.ca)



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