



AN INTEGRATED PALLIATIVE APPROACH TO CARE • DES SOINS QUI INTÈGRENT L'APPROCHE PALLIATIVE



THE PALLIATIVE APPROACH: IMPROVING CARE FOR CANADIANS WITH LIFE-LIMITING ILLNESSES

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Quality End-of-Life
Care Coalition of Canada
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Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs



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Prepared for: Canadian Hospice Palliative Care Association
Prepared by: Jean Bacon

Production of this document has been made possible through a financial contribution from the Government of Canada.

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TABLE OF CONTENTS

Executive Summary	2
I. Changing Illness Trajectories	4
Living with Chronic Illness and the Unpredictability of Death	5
Lack of Access to Palliative Care for Canadians with Chronic Illnesses	5
II. The Case for Using a Palliative Care Approach to Expand Access to Palliative Care	6
III. Understanding the Palliative Care Approach	7
What is Palliative Care?.....	7
What is a Palliative Care Approach?.....	7
IV. The Benefits of a Palliative Care Approach	9
Greater Autonomy and Engagement in Decision-Making	9
Better Quality of Life, Greater Longevity, Fewer Hospitalizations	10
V. Challenges to Adopting a Palliative Care Approach	12
Strategies to Overcome Challenges.....	12
VI. Key Questions to Consider in Moving to Community-Integrated Palliative Care	14
VII. Conclusion	15
Bibliography	16



EXECUTIVE SUMMARY

Historically, palliative care was offered only 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.

Illness trajectories are changing, and people diagnosed with life-limiting or life-threatening illnesses can now live many years with their condition. Their time of death is often sudden and difficult to predict, which means that many are never offered the benefits of the palliative approach to care, which includes social support, advance care planning, and effective pain and symptom management throughout the trajectory of the illness.

Although only a small proportion of people will need intensive or tertiary palliative care provided by specialized palliative care teams in hospices, the home or other settings, everyone faced with a life-limiting illness could benefit from other aspects of palliative care. Being diagnosed as “close to death” can no longer be the trigger for initiating palliative care because too many people with life threatening illnesses who die “unexpectedly” will not receive the care that could enhance both their living and dying. Instead, a palliative approach could and should be integrated into care for people with chronic, life-limiting conditions and people who are frail and vulnerable to infections or falls that could hasten death. This integrated palliative care should be provided by primary care, chronic care and long-term care practitioners and available early in the course of a disease (i.e., soon after diagnosis) and throughout the person’s illness trajectory.



After diagnosis and in the early stages of the illness, the palliative care approach should focus primarily on:

- 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 and setting goals of care;
- Psychosocial and spiritual support to help individuals and families struggling with any issues related to the illness;
- Any pain or symptom management that may be required.

In later stages of the illness, a palliative care approach should focus more on:

- Reviewing the person's goals of care and adjusting care strategies to reflect any changes in those goals;
- Ongoing psychosocial support for individuals and families;
- Pain and symptom management;
- If and when to engage specialized palliative care providers (e.g., for people and families with challenging physical, psychosocial or spiritual symptoms, conflicts over goals of care or decision making, family distress).

I. CHANGING ILLNESS TRAJECTORIES

A century ago, death was typically quite sudden, and the leading causes were infections, accidents and childbirth. Today, sudden death is less common. Towards the end of life, most people will acquire a serious progressive illness such as heart disease, cancer or respiratory disorders ... that increasingly interferes with their activities until death. {Murray et al, 2005}

Better lifestyles, public health and medical interventions have given us the opportunity to grow old, accumulate chronic conditions, and die slowly. {Lynn & Forlini, 2001} As a result, people with chronic illnesses are living much longer between diagnosis and death and the burden of chronic disease on individuals, families, and the health care system is growing. {Glare & Virik, 2001}

Illness trajectories – and people’s health needs during their illnesses – are changing. People diagnosed with a life-limiting illness today will likely live with that condition for many years. Although they will be living longer, they may not be living better. During that time, they will likely experience pain, discomfort, and other symptoms related both to the condition itself and its treatment. They are also likely to have psychosocial and spiritual needs that are part of living with a life-threatening illness. {Cochrane et al, 2008}

Historically, hospice, palliative or end-of-life care was developed to help cancer patients manage symptoms and address psychosocial needs in the last months of life. Someone with cancer typically received treatment (curative care) until there were no other disease-modifying therapies available. At that point in the person’s illness trajectory the focus of care shifted from cure to comfort. Hospice palliative care was the care provided only when treatment had stopped. To be eligible for hospice programs and for palliative care services in the home, individuals had to be close to death (e.g., within six months), and they and their families had to agree to forego active treatment. At that point, the person and family then received services such as pain and symptom management, psychosocial support, spiritual care and bereavement support – designed to enhance the quality of living and dying in the last weeks of life.

Living with Chronic Illness and the Unpredictability of Death

The week in which we die will start like any other, then a pneumonia, pulmonary embolus, stroke, heart attack, arrhythmia or other unpredictable calamity will overwhelm our diminished reserves. {Lynn & Forlini, 2001}

As more people live months and years with life-threatening illnesses, such as cancer, heart disease, renal disease and respiratory illnesses, their care providers have become increasingly aware of the complexity of living longer-term with diseases that will eventually lead to death – not the least of which is the unpredictability of the timing of that death. {Woodruff, 1999} {Higginson et al, 2011}

It has never been easy – even with cancer – to predict when someone is within six months or a year of dying. With other progressive illnesses, predicting death is even more difficult. For example, among most people with heart disease, the median person still had a 50% {Lynn & Forlini, 2001} chance of living for another six months on the day before he or she died. As Lynn & Forlini (2001) note, “Although these patients could not walk across a large room, eat a full meal, or manage their households, the timing of their death was uncertain, right up to the day before their death”.

Lack of Access to Palliative Care for Canadians with Chronic Illnesses

Because of the health care system’s singular focus on prolonging life and the unpredictability of death – even in the face of advances in treatment -- most Canadians with chronic, life-threatening illnesses and their families do not receive the kind of care services that can lead to a “good death”. In fact, most people with non-malignant conditions often reach the terminal phase of their life without having been offered many of the physical and social resources available to people dying of cancer. {Fitzsimmons et al, 2007}

The vast majority of the 220,000 Canadians who die each year do not receive any hospice, palliative or end-of-life care. {Wilson et al, 2008} Only 16 to 30% of Canadians have access to palliative care {CHPCA, 2012} – and most of them receive these services only within the last days or weeks of life.

Although only a small proportion of people who die of chronic diseases, such as heart failure, respiratory illnesses or dementia, will need intensive or tertiary palliative care provided by specialized palliative care teams in hospices, the home or other settings, everyone faced with a life-limiting illness could benefit from other aspects of palliative care.

The lack of access to palliative care is becoming a serious gap in care and a growing public health issue. {Stjernsward et al, 2007} Care providers have begun to realize that people with life-threatening illnesses could and should be able to benefit from receiving many aspects of palliative care much earlier – for example, when they are first diagnosed and during the months and years they are pursuing active treatment. {Gillick, 2005} While their time of death may be uncertain, the issues they will face are not. Patients with chronic, life-threatening conditions may experience physical symptoms, such as pain and loss of function, for a long period of time. They may also experience profound losses and have psychological, social, and spiritual needs that require support, often well before the period close to death. {Higginson et al, 2011} Given the unpredictability of death in people with progressive illnesses, in the case of palliative care, care delayed is definitely care denied.

II. THE CASE FOR USING A PALLIATIVE CARE APPROACH TO EXPAND ACCESS TO PALLIATIVE CARE

Palliative care should be the gold standard for all patients with progressive, life-threatening illness. We should advocate for an interdisciplinary approach that attends to psychosocial issues, advance care planning, and symptom management – the essence of palliative care – for all suitable patients. {Gillick, 2005}

Being diagnosed as several weeks or months from death can no longer be the trigger for providing palliative care because it will mean that too many people with life threatening illnesses who die “unexpectedly” will not have access to care that could enhance both their living and dying. Instead, people diagnosed with illnesses that could shorten their lives – as well as people who because of age or frailty are vulnerable to infections or falls that could put them on a trajectory towards death – should have access to a palliative care approach that helps them manage their illness and allows them a greater sense of control over both their living and their dying. A palliative approach could and should be integrated into care for all people with chronic, life-limiting conditions (including cancer). {Smith et al, 2012} It should be provided by primary care, chronic care and long-term care practitioners and available much earlier in the course of a disease to address each patient's needs.

There is growing consensus that a palliative care approach early in the course of disease – integrated with chronic disease management -- offers significant advantages to people with a range of life-threatening illnesses. In its report, *Approaching Death*, the US Institute of Medicine proposed a mixed management model that allows for active, life-prolonging treatment and death preparation to occur in parallel, thus providing comprehensive care throughout the illness and dying experience rather than only at the end. {Glare & Virik, 2001} Special Senate Committees and the Commission on the Future of Health Care {Romanow, 2002} recommended increased access to publicly funded end-of-life care. The Quality End of Life Care Coalition of Canada (QELCCC), which represents a range of life-threatening illnesses, is actively lobbying for advanced care planning/directives and access to high quality end-of-life care.

III. UNDERSTANDING THE PALLIATIVE CARE APPROACH

What is Palliative Care?

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

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone 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 in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of 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.”

In the United States, the National Consensus Project for Quality Palliative Care (2004) notes that palliative care “goes beyond the traditional medical model to focus on psychosocial issues, spiritual matters, medical decision-making, and on the relief of suffering in all its dimensions throughout a person’s illness. {Smith et al, 2012} Care in the last days and weeks of life is just one component of palliative care.

What is a Palliative Care Approach?

A palliative care approach would make certain aspects of palliative care available to patients and families at appropriate times throughout the illness trajectory. After diagnosis and in the early stages of the illness, the palliative care approach focuses primarily on:

- 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 and setting goals of care;
- Psychosocial and spiritual support to help individuals and families struggling with any issues related to the illness;
- Any pain or symptom management that may be required.

At later stages of the illness, a palliative care approach focuses more on:

- Reviewing the person’s goals of care and adjusting care strategies to reflect any changes in those goals;
- Ongoing psychosocial support for individuals and families ;
- Pain and symptom management; *(cont’d on next page)*

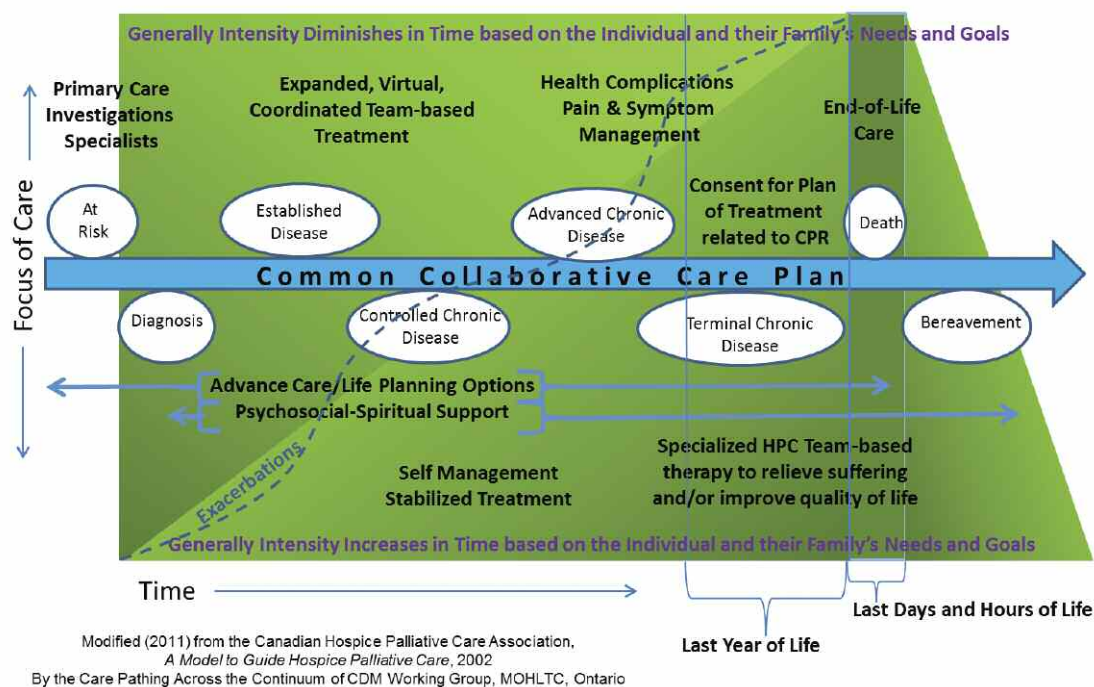
III. UNDERSTANDING THE APPROACH

- If and when to engage specialized palliative care providers, such as for people and families with challenging physical, psychosocial, or spiritual symptoms, conflicts over goals of care or decision making, family distress).

The palliative care approach focuses on person and family, and on their quality of life throughout the 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 patients 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 quality of life throughout their illness. The palliative care approach recognizes that, in a health care system focused on cure and treatment, people may not be given the opportunity to talk about dying or be truly informed about their illness and prognosis. They may not be asked about their care goals. The palliative care approach also recognizes that, when care is focused on treating an illness, pain and other symptoms – including those related to the treatments – are not as well managed as they could be, especially as the illness progresses and more complications occur.

The following diagram developed by Hospice Palliative Care Ontario illustrates how a palliative care approach 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.

CHILD & ADULT HOSPICE PALLIATIVE CARE - CHRONIC DISEASE CONTINUUM MODEL



For example, when the illness is diagnosed, the person would be offered psychosocial and spiritual support and the opportunity to discuss advance care planning. These services, which would be provided by primary care practitioners or other members of the chronic care management team, would continue throughout the illness. As the disease advances and the person experiences more complications, he or she may need more intensive or more specialized palliative care services, such as pain and symptom management – which may be provided by the person’s primary care practitioner, by providers in the settings where the person is (e.g., at home, in hospital, in long-term care) or by specialized palliative care teams, depending on the severity of the person’s needs.

IV. THE BENEFITS OF A PALLIATIVE CARE APPROACH

Greater Autonomy and Engagement in Decision-Making

Progressive deterioration and death are inevitable. ... A realistic dialogue about the illness trajectory between patient, family and professionals can allow the option of supportive care, focusing on quality of life and symptom control, to be used earlier and more frequently. Palliative care should be offered alongside curative treatment to support people with chronic progressive illness over many years. {Murray et al, 2005}

A palliative care approach gives individuals and their families information and opportunities to be more engaged in care and decision-making throughout the illness trajectory. The open conversations that are part of a palliative care approach can help people address emotional or spiritual concerns. They can also help with goal setting and advance care planning so, as the illness progresses, individuals and families can make care decisions that reflect their personal desires and goals.

Palliative management focuses on the care of patients with advanced illness or a significant symptom burden by emphasizing medically appropriate goal setting, honest and open communication with patients and families, and meticulous symptom assessment and control. {Smith et al, 2012}

Care goals often change over time. As Gillick (2005) notes, given that there is no cure for progressive life-threatening illnesses such as congestive heart failure, severe chronic obstructive pulmonary disease, and progressive neurological conditions such as dementia, amyotrophic lateral sclerosis and Parkinson's disease, individuals are often choosing potential life-prolonging therapies based on their goals of care, which can change as the illness progresses. Early in the disease trajectory, the person's main goal is usually to prolong life. He or she is willing to give up some function and tolerate some pain for a chance to live longer. As time progresses, maintaining functions such as mobility or cognitive ability may become more important so the person may choose treatments that prolong life but not at the expense of the ability to function. As their condition deteriorates, comfort may become their main goal of care and the person may reject treatments that will cause pain or mean he or she has to be hospitalized. {Gillick, 2005} When persons and families have access to a palliative care approach throughout their illness, they have the information and support to make the decisions that are right for them. This process of making choices that reflect personal goals was highlighted in a recent newspaper article. {Globe and Mail, March 19, 2012}

Her kidneys and lungs are failing, her mobility is limited, but Emma Marie Eddy's end-of-life wishes remain simple: she wants to stay out of hospital as long as possible and not be kept alive on machines. ... Ms. Eddy is one of about 200 Canadians who went through a unique program in Nova Scotia that helps frail, elderly patients decide whether to go through with medical procedures that could do more harm than good. At this stage of life, complications such as cognitive decline and loss of function could land them in a nursing home; an infection or lung problems could land them in intensive care. After undergoing a personalized assessment ... many opt for less aggressive measures ... Since the program began ... scheduled tests, operations and procedures among participants have declined by 76 per cent.

There is growing evidence that these kinds of conversations are most helpful when they occur early. {Bruera & Hui, 2012} Decision making around advance care planning is less threatening when a person is feeling well than during a crisis or when death is imminent. It is easier to explore psycho-emotional issues when physical symptoms are controlled. {Bakitas et al, 2010} Early incorporation of a palliative care approach can improve quality of life while minimizing caregiver distress and aggressive measures at the end-of-life. {Bruera & Hui, 2012} It is also cost effective: holistic assessment of a person earlier in their course of their chronic disease could identify physical, emotional, and social needs that can be met at relatively little cost. {Fitzsimmons et al, 2007}

Better Quality of Life, Greater Longevity, Fewer Hospitalizations

International oncology and palliative care panels have recommended early introduction of concurrent oncology palliative care to improve patients' quality of life and end-of-life care ... to ensure that patient values, preferences, and treatment goals guide care throughout the illness, from diagnosis through death. {Bakitas et al, 2010}

There is strong and growing evidence that a palliative care approach – when combined with treatment – leads to better outcomes for persons and their family caregivers, including: improvement in symptoms, quality of life and patient satisfaction; less burden on caregivers; more appropriate referral to and use of hospice; and less use of futile intensive care. {Smith et al, 2012} {Temel et al, 2010} {Bakitas et al, 2009} {Meyers et al, 2011} Advance care planning also promotes choice and improves quality of care. {Sanders et al, 2008} In some cases, it also increases longevity.

The evidence for a palliative care approach is growing. For example:

- People with metastatic non-small-cell lung cancer who received access to palliative care early reported better quality of life, fewer depressive symptoms, and longer survival compared to those who received more aggressive end-of-life care. {Temel et al, 2010} According to an ad hoc panel who reviewed that study, understanding the prognosis and goals of treatment had the strongest impact on the person's subsequent choices of therapy and survival: people who understood the amount of time they had left to live and the benefits and risks of treatment received less aggressive end-of-life care but they lived longer. {Smith et al, 2012}
- Housebound terminally ill people with cancer who received in-home palliative care (e.g., coordinating and managing care and discussing goals of care, expected course of the disease, expected outcomes, and success of treatment options) as well as usual care reported greater satisfaction with care, had fewer emergency room visits and hospital days, and had lower costs of care. They were also more likely to die at home. {Brumley et al, 2007}
- In a Kaiser Permanente study, individuals who had a palliative care approach 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}
- Cancer patients who received usual care plus a palliative care approach had higher quality of life and mood. They were also less likely to die in the year after enrolling in the intervention. {Bakitas et al, 2009}
- Caregivers of people with cancer who have access to a palliative care approach early in their loved one's treatment reported significantly less decline in their psychological, social, and spiritual quality of life scores. {Meyers et al, 2011}

The evidence showing the benefit of integrating a palliative approach into the care of people with chronic illnesses now extends far beyond cancer. For example:

- Individuals enrolled in a multidisciplinary ALS clinic who received a palliative care approach had a 30% decrease in one-year mortality compared with those who received usual care. Their care included a comprehensive rehabilitative and palliative care plan that aimed to maximize functional capacities, prolong or maintain independent mobility, prevent and minimize physical deformity, enhance comfort, and improve quality of life. {Mayadev et al, 2008}
- Comprehensive curative and palliative care of people with congestive heart failure reduced hospitalizations by at least a half – reducing utilization of health services and avoiding suffering. {Lynn & Forlini, 2001}

- People who were seriously chronically ill who received a palliative care approach exhibited better outcomes on self management of illness, awareness of resources, and legal preparation for end-of-life. They reported lower symptom distress, greater vitality, better physical function, and high self-rated health than randomized controls. The impact was particularly strong for people with COPD who were more likely to have returned to an activity they enjoyed, less likely to have experienced a health event for which they were unprepared, and more likely to have a living will. {Aiken et al, 2006}
- A pilot project in an emergency department identified chronically ill older adults in need of palliative care, home care, and hospital services. Providing a palliative care approach and case management services was associated with increased person and family satisfaction with symptom relief and increased uptake of hospital-based palliative care services and hospice. {O'Mahony et al, 2008}
- For people severely affected by multiple sclerosis (i.e., unresolved issues with symptom control, psychosocial needs, advanced planning needs, nutrition and/or hydration issues), a palliative care approach reduced symptoms and caregiver burden. {Higginson et al, 2011}
- A palliative care approach is also extremely useful for caregivers and substitute decision makers. In a Montreal study, nursing home residents with advanced dementia were less likely to undergo a burdensome intervention such as hospitalization, an emergency room visit, parenteral therapy, or tube feeding when their substitute decision makers had a better understanding of the poor prognosis from these interventions. {Lussier et al, 2011}

There is a ground swell of support to improve access to aspects of palliative care early in the illness trajectory. For example, the Department of Veterans Affairs in the US has made "advance planning" a quality measure for all conditions and requires pain to be measured as a fifth vital sign. {Lynn & Forlini, 2001}. Practitioners in long-term care are actively promoting a palliative care approach to symptom control and chronic disease management to ensure the comfort, dignity and quality of life of the frail elderly. {Winn & Dentino, 2004} The National Association of Orthopaedic Nurses is advocating for providers to be prepared to recognize how fractures and other orthopaedic conditions adversely affect function and quality of life, and create health care environments that foster dignified care for patients by integrating the palliative care approach. {NAON, 2005}

V. CHALLENGES TO ADOPTING A PALLIATIVE CARE APPROACH

The palliative care approach offers clearly measurable benefits for patients, families and the health care system yet there are challenges to adopting it widely, including:

THE CAPACITY OF PRIMARY CARE PRACTITIONERS. The palliative care approach – particularly those aspects provided early in the course of an illness – is best provided by the primary care practitioners responsible for helping people manage chronic, progressive diseases. However, many primary care practitioners have not been trained in the palliative care approach. A key challenge will be providing training and support in the palliative care approach.

CLINICIAN ATTITUDES. Clinicians who are highly focused on treating or “rescuing” patients may resist incorporating a palliative care approach or referring patients to palliative care providers. Clinicians who have developed a relationship with their chronically ill patient and who believe in the power of “hope” can find it challenging to tell the person when he or she has exhausted the therapeutic options – although people are usually aware of their terminal state even when the clinical team is unwilling to discuss it. {Fitzsimmons et al, 2007} Despite the fact that providers know their patients are extremely ill, they report that they are often surprised by their patients’ death: “At the time, there seemed to be hope that he would improve”. {Kramer & Auer, 2005} Clinicians are also often unaware of what palliative care has to offer. {Fitzsimmons et al, 2007} Because of these attitudes, people are often referred too late for end-of-life care – an average of 30 to 60 days before death {Bruera & Hui, 2012} – when they have multiple problems and are experiencing significant distress and are less able to benefit from the timely treatment of symptoms, psychosocial support, and counseling. These “too little too late” referrals occur even though most families reported that they would have preferred an earlier consultation. {Bruera & Hui, 2012} {Teno et al, 2007}

PATIENT RELUCTANCE. Patients themselves sometimes resist or reject the offer of a palliative care approach; however, they still need access to palliative services when they are ready to face end-of-life issues.

FAMILY DISAGREEMENTS. In some cases, family members may disagree with a person’s care plan or refuse to honour the person’s preferences.

MAINTAINING THE PALLIATIVE CARE APPROACH ACROSS CARE SETTINGS. When people move between providers or care settings, the palliative approach may not move with them. During care transitions, the patient’s goals of care may not be clearly communicated. Some settings have little concept of comfort care. For example, emergency care providers may focus only on life-saving interventions rather than symptom control – and they may not take the time to discuss the person’s goals and preferences. {Bakitas et al, 2010} Primary care practitioners who incorporate a palliative approach into chronic disease management report that they have few resources or supports, and they often have to fight to ensure the person’s comfort needs continue to be met or to prevent other settings from initiating invasive diagnostic procedures that the person has indicated in their plan of care that they do not want. {Kramer & Auer, 2005}

Strategies to Overcome Challenges

DEVELOP POLICIES THAT REFLECT THE NEEDS OF PEOPLE WITH CHRONIC, LIFE-LIMITING ILLNESSES. Primary care practices and other care settings, such as long-term care, should develop policies that create the type of responsive palliative care approach required by people who live for many years with chronic, life-threatening diseases. {Wilson et al, 2008}

EDUCATE HEALTH PROFESSIONALS. Clinicians – especially primary care practitioners – need to know more about the palliative care approach emphasizing in particular its focus on communication, goals of care, advance care planning, comfort, quality of life, symptom management, and assisting the person and family with complex decision making. {Fitzsimmons et al, 2007} It’s important for them to realize that “the absence

of any plans to help someone with a progressive advanced illness manage physical and psychosocial distress and to prepare for the possibilities should be considered unreasonable denial of service rather than hopefulness". {Bruera & Hui, 2012}

The goal of education should be to de-mystify end-of-life planning and help primary care practitioners be mindful of the bigger picture. {Kramer & Auer, 2005} It is important they recognize that integrating a palliative care approach does not mean that the patient is going to die imminently, but that the approach to their care should be different. Acute medical crises are opportunities to educate the person and his or her family about future scenarios and deepen their awareness of end-of-life needs. {Kramer & Auer, 2005} Placing material on the sensitive subject of death and dying within the context of a positive chronic disease self-management program can draw attention to ambiguities of cultural ideas related to health, illness, and death that both care providers and families may need to explore. {Sanders et al, 2008} Primary care practitioners must also be able to identify triggers and initiate palliative care treatments or referrals early and appropriately. {Higginson et al, 2011}

In collaboration with the Association of Faculties of Medicine, the Canadian Hospice Palliative Care Association has developed curricular palliative care core-competencies for undergraduate medical students, and postgraduate residents attending Canadian universities. This, combined with other professional education initiatives, should help overcome some of the resistance to a more integrated approach to a palliative care approach – at least among younger practitioners. {CHPCA}

ESTABLISH PROTOCOLS, ALGORITHMS AND CARE PATHWAYS. Standard processes – protocols, algorithms, and pathways – can help ensure that everyone with a life-threatening illness receives a palliative care consultation – as part of usual care rather than at the discretion of individual clinicians. {Bakitas et al, 2010} Primary care providers/chronic disease management teams would use established protocols, algorithms and pathways to provide the palliative care consultation, referring the person to a palliative care specialist only when he or she had more complex or intense palliative care needs.

MAKE COLLABORATIVE CARE PLANS A STANDARD OF PRACTICE. One of the most effective ways to ensure a more integrated approach to palliative and active care is the use of a care plan. Care plans are the basis for partnership between the individual and his or her primary care/chronic disease management teams. Care plans developed collaboratively with individuals and families make for informed and enabled patients, and they contribute to better coordination of care. {McCorkle et al, 2011} Each person should have a written care plan that is continuously reviewed that recognizes the person's medical and care status, as well as their social, emotional, cultural, and spiritual needs. {Lokk, 2011}

IMPROVE COMMUNICATION BETWEEN CARE SETTINGS. Every effort should be made to reduce unnecessary transitions and to ensure continuity of care. However, when a person does have to move, policies and communication protocols should be in place to ensure quality and consistency of care, and support a palliative care approach in all settings. {Kramer & Auer, 2005}

ENGAGE THE FAMILY IN CARE PLANNING. Primary/chronic care teams should routinely engage family members early in discussions about the person's current and future needs. There should be at least one family planning meeting, regardless of the person's health, to discuss health maintenance and treatment options, end-of-life scenarios, preferred outcomes and preferences, and advance directives.

MEASURE OUTCOMES. Primary care practices and chronic disease management programs that establish and measure outcomes (e.g., patient and family satisfaction, quality of life, anxiety, stress, care consistent with individual preferences, utilization of services) will be able to demonstrate the benefits of a palliative care approach. {Bakitas et al, 2010}

VI. KEY QUESTIONS TO CONSIDER IN MOVING TO COMMUNITY-INTEGRATED PALLIATIVE CARE

According to the readers of the *British Medical Journal*, providing palliative care to a larger group of people is the project that would make the greatest difference to health care. {Cochrane et al, 2008}

Over the past 15 years, Canada has made progress in providing high quality palliative care – particularly in the last months of life – to more of its citizens, but palliative care is still not a mainstream service available to everyone with a life-limiting illness. While a growing number of people inside and outside the health care system see the benefits of improving access to a palliative care approach to all people with chronic, life-threatening illnesses, the key challenge remains “how”. *How do we ensure that primary care providers and providers in the community have the knowledge, skills and competencies to provide this care?*

How can transitions in care become more seamless and better integrated across settings so that patients and families have access to the care they need throughout the trajectory of their illness?

Are there some patients – such as the dementia patient who has few physical health problems and no issues with pain management – whose palliative care needs can be managed primarily by primary care providers throughout their lives? *Are there others who, because of their illness trajectory, will benefit from referral to specialized palliative care services at a key point in their disease?*

How will we ensure access to a consistent palliative care approach across Canada?

VII. CONCLUSION

The growing support for integrating the palliative care approach into the management of chronic disease across all settings of care is being driven by a number of factors including:

- advances in treatment that are changing illness trajectories, allowing people with chronic, life-threatening illnesses to live many years – although often with pain, loss of function or other symptoms;
- the growing realization that palliative care is a highly holistic, person-centred approach that has something of value to offer all people with serious illness;
- the strong evidence that a palliative care approach can enhance health and quality of life, and reduce the utilization of more costly health services;
- the evidence that this care can be provided effectively by primary care practitioners and other health practitioners who have developed the required competencies.

A palliative care approach – particularly its focus on open communication, advance care planning, autonomy, pain and symptom management and quality of life – has a great deal to offer individuals and families faced with chronic, life-threatening illnesses. Medical advances mean that many people will live many years with these illnesses; however, most will eventually die of these diseases and should have the right support to make informed decisions about their care. Rather than dimming people’s hope, frank discussions about the prognosis and trajectory of these illnesses can help increase access to effective pain and symptom management, give individuals a greater sense of autonomy and control, and enhance their quality of both living and dying with these diseases.



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

email: info@hpcintegration.ca
tel: 1-800-668-2785 ext. 228
fax: 613-241-3986

www.hpcintegration.ca

