

# PALLIATIVE CARE

## Canadian Medical Association's National Call to Action

Examples of innovative care delivery models, training opportunities and physician leaders in palliative care

2014–2015



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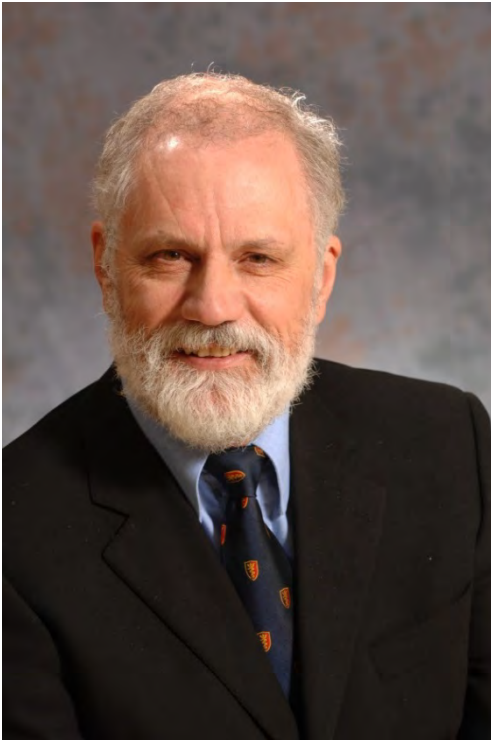
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# Preface

This report is intended as a call to action for Canadian physicians regarding palliative care. It had its genesis during a series of



Canadian Medical Association (CMA) town hall meetings on end-of-life issues held across the country in 2014. What became readily apparent in listening to both the public and to physicians was that Canadian physicians need to become more actively engaged in ensuring that their patients have access to palliative care services.

I have personal experience with this issue. Just before the town hall meetings started, my mother passed away at the West Island Palliative Care Residence in Kirkland, Que. It was such a powerful experience — I learned more about death during her stay there than in my 20-plus years of practice as an emergency medicine physician. Like so many Canadian physicians, I had rarely thought of palliative care.

As a result, I devoted a sabbatical year to finding out what made the West Island Palliative Care Residence so special and to see if this model could be replicated across Canada. It became apparent to

me that we needed a way to spread that story, and the stories of others in the palliative care community, across the country. In this case, the CMA is serving as the amplifier. With the support of the CMA, my focus on one facility has evolved into a cross-Canada review of various palliative care models while at the same time shining a light on Canadian physicians who are directly involved in delivering palliative care in a variety of settings. Thanks to the encouragement of our various partners, we hope that we have provided not only a snapshot of where we are now but also a look at the road we must travel in order to meet Canadians' palliative care needs.

If you are a physician with an interest in palliative care, I hope this report will inspire you. It might encourage you to refer your patients for earlier assessment for palliative care or to obtain more training in the field. It may even challenge you to better serve your own patients' palliative care needs.

Although we could not possibly visit all of the excellent centres delivering palliative care in Canada, just as we could not profile every physician providing palliative care services, we hope the examples we chose will inspire you, not only to deliver exceptional palliative care services but also to ask yourself if your community's palliative care needs are being met.

I welcome you to explore the rich sampling of diversity shown by the practising palliative care physicians we have profiled, and consider how they can serve as role models. There is so much more that remains to be done.



*Professor Louis Hugo Francescutti*  
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*University of Alberta*  
*President of the CMA, 2013–2014*

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## Before embarking on this

**project**, I had limited understanding of palliative care, and the significant benefits it has for people with life-limiting illnesses and not only during the last stages of their lives. I also had no idea what it actually means to practise in palliative medicine. I deferred my admission to the University of Calgary medical school for one-year in order to discover the answers to some of these questions. I wanted to know what it takes to be a palliative care physician and whether this is a field that I would like to specialize in. Through my interactions with various health care leaders while developing this report, I was struck by their commitment and dedication — dedication not only to their current patients, but also to their future patients by engaging in quality improvement initiatives so that more Canadians can

access the physical, psychosocial, existential and spiritual support offered through palliative care. I learned that palliative care is not limited to the end of life; rather, this approach to whole-person care may be integrated into all medical specialties. In my conversation with Dr. Balfour Mount, the father of palliative care in North America, I was surprised to learn that a comprehensive, cost-effective, and high-quality palliative care program is relatively simple in design and needs only the following six components:

1. community consult teams composed of palliative care specialists to support patients in a variety of care settings, including the home, acute care, long-term care and hospices;
2. an inpatient palliative care unit for patients with complex medical needs;
3. a home care program to support patients in the community;
4. a bereavement follow-up program for families and friends;
5. training and education programs; and
6. active palliative care research.

However, despite the vast amount of research and data supporting an integrated palliative care approach, only a few regions in Canada have implemented this concept. The mismatch between theory and application is frustrating, to say the least. Dr. Mount put it this way in 1975: “When we didn’t know the problem was there, we can make an argument for ignoring it. Now that we know the problem is there, there are no moral or ethical legs to stand on to not embrace and support palliative care.”

Excellence in palliative care is not an add-on to the health system. Rather it is central to achieving a balance between the science and art of medicine, as recognized by Sir William Osler well over a century ago. As demonstrated in this report, there are pockets of palliative care innovation around the country, and together they are pushing the boundaries of high quality care and timely access to care. This is an exciting time to be working in this field. I, for one, am enthusiastic about what the future may hold.



*Jennie Ding*  
*MHA, BSc.*  
*Medical Professionalism, CMA*

**“Get involved  
in palliative  
care because  
one day  
chances are  
that you will  
need it  
yourself”**

**– A palliative care  
physician**

# Acknowledgements

We are grateful to all of our partners for their valuable contributions to the report. They are listed below, in no particular order. We are also grateful that 24 palliative care physician leaders have submitted their own stories to this report, and their experiences shed some light on the challenges and opportunities in palliative care. Their names are listed in the table of contents.

## **Featured Palliative Care Delivery Models:**

Bruyère Continuing Care Palliative Care Program (Ontario)

Canuck Place Children’s Hospice (British Columbia)

Capital Health Integrated Palliative Care Program (Nova Scotia)

Colchester East Hants Integrated Palliative Care Program (Nova Scotia)

Edmonton Zone Palliative Care Program (Alberta)

Foothills Country Hospice Society (Alberta)

Ocean View Continuing Care Centre (Nova Scotia)

West Island Palliative Care Residence (Quebec)

## **Organizations:**

Accreditation Canada

Canadian Hospice and Palliative Care Association (CHPCA)

Canadian Society of Palliative Care Physicians (CSPCP)

Covenant Health Palliative Institute

The College of Family Physicians of Canada

The Royal College of Physicians and Surgeons of Canada

Pallium Canada

# Executive Summary

The CMA has already examined the issue of palliative care, and in 2013 General Council adopted resolutions that are now policy. Following the series of CMA town hall meetings on end of life in 2014 that provided a chance to listen to both the public and health care providers, it became apparent that Canadian physicians need to become more actively engaged in palliative care. This report challenges physicians, other health care providers, policy-makers, health care administrators and community leaders to take a more active approach to palliative care, whether via working in this area or advocating for improved access and quality. This report is based on site visits to various palliative care organizations across the country and interviews with physician leaders in this field. The series of 10 recommendations that follows was developed based on the information collected that address physician engagement in palliative care.

In order to overcome the current challenges in palliative care and improve both the quality of care and access to care, the Canadian Medical Association recommends that:

1. All patients should have a primary care provider that can support them with their palliative care needs or else refer these patients earlier to a palliative care team to establish goals of care.
2. Physicians should provide leadership at local, regional, provincial/territorial and federal levels to promote the establishment of integrated models of palliative care.
3. All physicians should obtain essential palliative care skills and knowledge to provide basic palliative care services to their patients.
4. Physicians should advocate for adequate and appropriate home palliative care resources so their patients can stay in their homes as long as possible.
5. Physicians should advocate for an adequate number of palliative and/or hospice care beds to meet their communities' needs.
6. Continuing care facilities and long-term care homes should have in-house palliative care physician support on their palliative care teams.
7. Physicians support the valuable work of hospice volunteers.
8. Medical students are encouraged to look at palliative care as a rewarding career.
9. Practising palliative care physicians are encouraged, if needed, to obtain additional certified training in palliative care from either the Royal College of Physicians and Surgeons of Canada or the College of Family Physicians of Canada.
10. Physicians acknowledge the value of and support the participation of family and friends in caring for their loved ones at the end of life.

# Introduction

*Eric Wasylenko*

*MD, BSc, MHSc*

*Palliative Care Physician and Clinical Ethicist, Okotoks, Alberta*



Palliative and end-of-life care clinicians have long worked for the day that no person will hear these words from a physician “There is nothing more I can do for you.”

We can always care, beyond the potential for cure. We can provide expert and attentive service that addresses pain or physical discomfort arising from serious pathology and declining organ function. Working with colleagues from other disciplines, we can provide relief from emotional and spiritual suffering, from fear and uncertainty, and can help people address important legacy and relationship issues as they approach death. Palliative and end-of-life care works to relieve suffering and to support optimal function so that people are freer to live as well as they can during this challenging time in their lives.

There are currently many thousands of clinicians and volunteers across the country proving their commitment to these fully alive but uniquely vulnerable people and their circle of family and friends. And the number of people who provide service in this way is growing. But much greater organizational and funding support is necessary to assure that more Canadians have access to expert, immediately available palliative care provided by teams.

Every person dies. The experience of that process for the person in our care is primarily what we wish to constantly improve. For those who love them and witness this time of living, and for all the providers who are involved, each particular journey accompanying death lingers for many years and contributes to each person’s understanding, hopes and fears for themselves. We all learn so much from each of these experiences, and what we witness can be seen as one more legacy gift from the person whose life and death we encounter.

Each day we see the enhancement of dignity, the potential for growth and the healing of relationships that can more readily occur when palliative end-of-life care is done well. Yet there is no doubt that death can be a hard road for everyone. Easing those difficult parts is sometimes within the purview of palliative care, but sometimes it is not, and may lie elsewhere. The humility of service and experience teaches us always to be aware of the mystical nature of life and death. Remembering this helps us approach palliative caregiving as a profoundly human interaction. I recall fondly an outstanding few hours in 2003 when I shared lunch with Dame Cicely Saunders — the founder of the modern hospice movement. I return regularly to her often-quoted message to patients: “You matter because you are you, and you matter to the end of



your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

Beginning with the efforts of Dr. Balfour Mount and his colleagues to establish Canada’s first palliative care program some 40 years ago, we have since witnessed emerging clinical skills, scientific advancement and interdisciplinary teamwork that have dramatically improved our delivery of palliative end-of-life services. Teams provide care in people’s homes, within long-term care facilities, hospices, hospitals, on the street, within outpatient clinics and in prisons. Committed colleagues have led the charge in research, education, creation of facilities, program development, advocacy and clinical care provision so that exemplary palliative care can become an assured route for those approaching the end of their life. The stories of people and programs within this report provide terrific examples of both long-term and more recent efforts of colleagues. They also tell of the progression of palliative care from an early focus on people dying from cancer to the recognition of the needs of people living with and dying from any condition.

But not every Canadian will have the opportunity to access well-integrated expert teams — regardless of whether the barriers are due to geography, cultural, or linguistic factors, or other situational issues such as funding and knowledge. It is important to recognize that every day in Canada, exemplary palliative and end-of-life care is being delivered by individual physicians in primary care and other specialty practices, in partnership with non-physician colleagues. Many Canadians receive the benefit of that commitment even if their providers are not part of formally integrated team-based programs. Ideally, those providers will have access to collegial support and consultation when necessary, as well as the opportunity to identify any gaps in their own knowledge and to pursue further skill acquisition.

The stories in this report demonstrate that facilities and services can be developed anywhere and can be uniquely adapted to local circumstances. They serve as exemplars for others to build upon. While this report — as a call to action to physicians — understandably focuses on physicians, it is so important to acknowledge the key contributions of our non-physician health care colleagues, of volunteers, health system leaders, advocates and family caregivers.

The palliative care community is exceptionally generous in sharing knowledge and experience to assist others in their efforts to build capacity. Don’t ever hesitate to engage those you know, including the people and programs highlighted in this report. We have all learned by experience, by dialogue, and mostly we have learned from the deep and meaningful connection that our patients allow us to have with them. They remain our best teachers.

I applaud Dr. Louis Hugo Francescutti, the CMA’s President in 2013–2014, for his grand idea and commitment in engaging with our palliative end-of-life care colleagues to research and write this report. His leadership and that of the Canadian Medical Association is exceedingly welcome in raising both awareness and, indeed, expectation that high quality palliative end-of-life care should be available to all Canadians. Dr. Francescutti was ably assisted by his talented research assistant and co-writer, Jennie Ding (MHA, BSc, Intern, Medical Professionalism, CMA). The CMA’s Dr. Owen Adams (PhD, Chief Policy Adviser, CMA) and Dr. Jeff Blackmer (MD, MHSc, FRCPC, Vice-President, Medical Professionalism, CMA) were instrumental collaborators and contributors in creating this excellent resource. And, of course, special thanks to the physicians, programs and facilities that agreed to have their stories told so that we might all learn and be inspired.

I think that the not-so-subtle message from Louis is that each of you who wish to can do this work, whether by caring well for your individual patients or by developing integrated high-



quality services within your community. Let's make sure that all Canadians have access to the best care that we can offer in their journey of living and dying.

# Section 1

## Care at the End of Life: Ethics & Terminology

*Jeff Blackmer*

*MD, MHSc, FRCPC*

*Vice-President, Medical Professionalism, CMA*



Care at the end of life and palliative care raise complex, and often emotionally charged, ethical and moral considerations. Physicians have a clear ethical obligation to consider first the well-being of their patients, and to put the needs of their patients above their own. What exactly this means will vary from circumstance to circumstance. However, there is a clear ethical imperative to ensure that those who need it will have access to high-quality palliative care in the setting of their choice. This imperative also raises important considerations around resource allocation, justice and equity. Currently, access to palliative care is —

at best — inconsistent across Canada.

We know from studies that where patients and their families have access to high quality palliative care, their perception of the dying process changes significantly. Family members are able to relinquish the caregiver role and focus on spending quality time with their loved one. Patients are able to achieve adequate pain and symptom control, and this allows them to optimize their remaining days and “have a good death”. This is something we heard again and again during our cross-country consultations.

The concept of patient autonomy and control is also an important consideration in care at the end of life. As much as possible, we want to ensure that patients feel that they have control over the process and over their care needs. Palliative care is critical to helping to achieve these goals. We are also becoming increasingly aware that some people feel that no amount of palliative care will help them attain full autonomy, and that the capacity to choose where and when they will die, with medical assistance, may be needed in certain situations. This has led to the recent increase in public discussion about medical aid in dying.

Below are selected paragraphs and terminology from the CMA policy entitled Euthanasia and Assisted Death (Update 2014). (For the full version, visit [cma.ca](http://cma.ca).)

*“Physicians are committed to providing high quality care at the end-of-life. They are also committed to maintaining their patients’ quality of life. There are rare occasions where patients have such a degree of suffering, even with access to palliative and end-of-life care, that they request medical aid in dying. In such a case, and within legal constraints, medical aid in dying may be appropriate. The CMA supports patients’ access to the full spectrum of end-of-life care that is legal in Canada. The CMA supports the right of all physicians, within the bounds of existing legislation, to follow their conscience when deciding whether to provide medical aid in dying as defined in this policy.*

*A physician should not be compelled to participate in medical aid in dying should it become legalized. However, there should be no undue delay in the provision of end-of-life care, including medical aid in dying.*

***Definitions regarding care at the end of life:***

***Palliative care*** is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other symptoms, physical, psychosocial and spiritual.

***Medical aid in dying*** refers to a situation whereby a physician intentionally participates in the death of a patient by directly administering the substance themselves, or by providing the means whereby a patient can self-administer a substance leading to their death.

***Euthanasia*** means knowingly and intentionally performing an act, with or without consent, that is explicitly intended to end another person’s life and that includes the following elements: the subject has an incurable illness; the agent knows about the person’s condition; commits the act with the primary intention of ending the life of that person; and the act is undertaken with empathy and compassion and without personal gain.

***Physician-assisted death (PAD)*** means that a physician knowingly and intentionally provides a person with the knowledge or means or both required to end their own lives, including counseling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs. This is sometimes referred to as physician assisted suicide.

*Euthanasia and physician assisted death are often regarded as morally equivalent, although there is a clear practical distinction, as well as a legal distinction, between them.*

***Palliative sedation*** refers to the use of sedative medications for patients who are terminally ill with the intent of alleviating suffering and the management of symptoms. The intent is not to hasten death although this may be a foreseeable but unintended consequence of the use of such medications. This is NOT euthanasia or physician assisted death.

***Withdrawing or withholding life-sustaining interventions***, such as artificial ventilation or nutrition, that are keeping the patient alive but are no longer wanted or indicated, is NOT euthanasia or physician assisted death.

*“Dying with dignity” indicates a death that occurs within the broad parameters set forth by the patient with respect to how they wish to be cared for at the end-of-life. It is NOT synonymous with euthanasia or physician assisted death.*

*Advance care planning is a process whereby individuals indicate their treatment goals and preferences with respect to care at the end-of-life. This can result in a written directive, or advance care plan, also known as a living will.”*

On Oct. 15, 2014, the Supreme Court of Canada (SCC) heard an appeal in the Carter case, which concerned the legality of physician-assisted death in Canada. On Feb. 6, 2015, the Court rendered a unanimous decision striking down the Criminal Code’s absolute prohibition on providing assisted dying. The Court suspended that decision for 12 months — this means that the current law remains in force for that period — in order to allow legislators and regulators time to respond, should they so choose, with legislation. Justice Minister Peter MacKay indicated that the federal government may require the full year to provide a legislative response.

The SCC’s decision to allow people with a grievous and irremediable medical condition to ask for physician-assisted death has pushed the discussion surrounding palliative care to the forefront in Canada. Seizing this opportunity, the CMA will continue to promote access to high quality palliative care. It is important to ensure that all those needing palliative care can access it when required, and that physician-assisted death is used as one of the last resorts in dealing with impending death.

# Section 2

## Palliative and Hospice Care Delivery Models

The delivery of palliative and hospice care varies greatly across Canada due to differences in regional demographics, societal needs, government involvement and funding structures. Similarly, access to these services can also differ between jurisdictions because funding and legislation of health care services are determined at a provincial and territorial level. Although the number of palliative and hospice care programs has been growing, increases in both quantity and quality will be needed to support our aging population. This section features eight leading organizations in palliative and hospice care, and covers three models of care delivery.

1. Integrated Palliative Care Programs
  - Capital Health (Halifax, NS)
  - Colchester East Hants Health Authority (Colchester East Hants, NS)
  - Edmonton Zone (Edmonton, AB)
2. Continuing Care and Long-Term Care Facilities
  - Bruyère Continuing Care (Ottawa, ON)
  - Ocean View Continuing Care (Eastern Passage, NS)
3. Residential Hospices
  - Canuck Place Children's Hospice Society (Vancouver, BC)
  - Foothills Country Hospice Society (Okotoks, Alta.)
  - West Island Palliative Care Residence (Kirkland, Que.)

These organizations were selected via nominations from within the medical and palliative care community. They were also selected to represent a mix of urban and rural communities, geographical variations across the country, and different population demographics. Unfortunately, we were not able to include the many others that are delivering exceptional palliative care across Canada. Health care providers, administrators and policy-makers can also refer to the experience of these organizations in developing or refining their own palliative and hospice care programs.

# Capital Health Integrated Palliative Care Program

## ***Why is this program unique?***

The Capital District Health Authority (CDHA) Integrated Palliative Care Program in Halifax embodies the philosophy that care is delivered in a seamless manner by various health care providers and services in the community. The care philosophy is person- and family-centred, encouraging active discussions of goals of care and end-of-life needs early in the care process. The goal is to ensure that symptoms are appropriately managed, whether care is provided at home, in the outpatient clinic or in the hospital. The integrated care service merges primary, secondary and tertiary care resources to support patients and families throughout the continuum of care. The program is built on four pillars: integrated service delivery, accountability, family and caregivers, and capacity building and practice change. Overall, palliative care at Capital Health strives to provide integrated, quality palliative care in the care setting of the patient's choice, and to do so seamlessly across these settings based on the patient's needs and conditions. Care should be provided in the context of the patient's location, whether in hospital, at home, or elsewhere in the community.

## ***What does the program offer?***

A referral from a primary care provider is needed for admission into the CDHA program. Patients can be referred to it by a family physician or a nurse practitioner at any point along the dying trajectory, including early stages of illness and when their condition is relatively stable. Once referred, the patient goes through an initial assessment during which the palliative care team may decide the patient does not need ongoing follow-up or even active palliative care services, but the team can be called upon in the future if needs change. One of the key questions that family physicians are asked is: "Do you think your patient will die in the next year?" This question acts as a litmus test and allows the care team to gauge the seriousness of the patient's situation. During patient intake, the team conducts a standardized assessment to capture patient and family demographic, health history, goals of care, advance directives, support infrastructure, and physical and psychosocial needs. The patient is also assessed using the Palliative Performance Scale. Based on the information collected, the program prioritizes those with fast-progressing, life-limiting illnesses and has only three to six months to live because it does not have sufficient resources to care for everyone needing palliative care. The program's involvement is based on the identified needs and generally intensifies as the patient approaches death. If it is not already involved, referral to Continuing Care Nova Scotia for nursing and personal care needs typically occurs as soon as patients are admitted into the CDHA's Integrated Palliative Care Program. All patients are reassessed frequently, and their care plans updated to ensure they are cared for appropriately. Planned death in hospital is initiated if home supports are overwhelmed and every effort has been made for direct transfer to the inpatient palliative care unit without emergency department involvement. Home death is the preferred option for most patients, and it is only possible through increased support from Continuing Care Nova Scotia and guidance from the CDHA Palliative Care Home Consult Team.

The CDHA Integrated Palliative Care Program offers four main services: 1) home-based palliative care consults; 2) outpatient clinics; 3) an inpatient palliative care unit at the Victoria General Hospital; and 4) consultations at other hospitals within the CDHA. These service areas are described in detail below.

To supplement medical care and support patients' psychosocial needs, the program also provides music therapy, group support, bereavement support, and spiritual care. When a patient dies, the family will receive a follow-up call to identify any areas of concern. Bereavement services are available to all families in the program, and they can be enrolled in the services for as long as they wish. As well, memorial services are held three times a year.

### ***Home-based palliative care services***

The Palliative Care Home Consult Team can help house-bound patients plan their care at home. Often, this is done in discussion with the patient and family, the family physician, a continuing care coordinator from Continuing Care Nova Scotia, and a nurse from the Victorian Order of Nurses. In 2013–2014, there were 265 new home-based consults and 625 palliative care physician visits to patient homes. The Palliative Care Home Consult Team documents every home visit and sends the information to the patient's family physician. The team aims to maintain open channels of communication with the family physician to ensure that pain and symptoms are adequately managed and the patient can be supported at home. However, the level of involvement for family physicians varies greatly, from being totally involved and only using the consult team as a backup, to no involvement and leaving the full responsibility for patient care to the team. Although the CDHA Integrated Palliative Care Program has hosted education sessions to explain its role and responsibilities, many primary care providers remain unaware of when they should refer patients to it. Many of the program's patients were referred by their oncologists and other specialists, either because they either don't have a relationship with their family physician or don't have one. Gaining access to palliative care services can be a difficult road to navigate, especially if patients don't have guidance from health care professionals. The CDHA Integrated Palliative Care Program will continue its community outreach efforts to establish relationships with as many primary care providers in the CDHA as possible so patients can get the right care at the right time.

### ***Outpatient clinics***

Before 2015, patients who were mobile were seen in a palliative care clinic in Halifax, Lower Sackville or Windsor. In 2013–2014, the palliative care team in the outpatient clinics conducted 285 new consults.

In January 2015, home services and outpatient clinic services merged to become a single community-based service operating in both care settings. Since patients using home care services often access outpatient clinics for appointments and then transition back home, this change will provide better continuity of care, communication and staff consistency. Clinic patients can transition home more easily and continue to be followed by the same care team at home. Two care teams now operate in this new community service. All staff, including community nurses and palliative care physicians, are trained in both clinic-based and home-based care. Under this new structure, the teams' palliative care physicians will do two to three half-day outpatient clinics per week and spend the rest of the work week providing home services. To prevent service overlap and facilitate community integration, CDHA has been split into two coverage areas. Each community service team is responsible for one region so that they can be familiar with patients, primary care providers and community programs in their respective jurisdiction.

### ***Inpatient palliative care unit at the Victoria General Hospital***

The Victoria General Hospital has a 13-bed palliative care unit for terminally ill patients needing tertiary end-of-life medical care. In 2013-2014 there were 250 admissions to the inpatient unit, with 68% being direct admissions from the community without visits to the emergency department or other units in a hospital. All admitted patients are previously known to the



CDHA Integrated Palliative Care Program via earlier referrals from other units in the hospital, family physicians, outpatient palliative care clinics, or specialty services in the CDHA region.

The unit is able to accommodate patients with physical and mental disabilities as long as they fulfill the criteria for admission. The average length of stay on the unit is 17 days. It is not known how this compares to results from other Canadian hospitals because there is no national benchmark for the average length of stay on inpatient palliative care units. It is also difficult to gather this information because palliative care bed utilization differs among facilities. The size of each unit and criteria for admission also vary across the country.

Approximately 85% of admitted patients die on the unit. Transitions back to home care and long-term care are rare, as most patients on the unit are at the last stage of life. However, if inpatient palliative care is no longer suitable, staff will work to place the patient in a more appropriate setting. Sometimes, certain patients may be transferred to other units in the hospital if the patient's health status requires.

### ***Consultations at CDHA hospitals***

The palliative care team that is based at the Victoria General site can provide consultations to all hospitals in the CDHA, which includes the Queen Elizabeth II Health Sciences Centre, Dartmouth General, and hospitals in the Hants community. It can also provide consults for other medical units located within the Victoria General site. In 2013–2014, the team conducted 730 new inpatient consults and saw approximately 31 new or previously enrolled patients per day.

### ***Resident demographics***

The CDHA Integrated Palliative Care Program is available free to any adult living within the CDHA who is eligible for provincial medical services. Children in the CDHA can access pediatric palliative care services through the IWK Health Centre. The CDHA Integrated Palliative Care Program sees approximately 1,200 new patients per year. About 70% of patients in the program are between 60–90 years old. In 2013, approximately 80% of participating patients had cancer, while the rest had various chronic diseases such as amyotrophic lateral sclerosis. Patients are in the program for an average of 84 days — from first registration until the time of death. Home-based patients spend 94% of their time at home, while patients who come into the inpatient palliative care unit spend 58% of their time at home and 42% in hospital.

## ***Program operations***

### ***Care teams***

The core care team consists of palliative care physicians, nurses, physiotherapists, occupational therapists, a bereavement coordinator, music therapist, volunteer coordinator, social worker and spiritual care provider. There are six palliative care physicians on staff, with three working full-time. These physicians are responsible for both inpatient care and community-based care, and rotate through these two service areas. When the physicians are not covering the inpatient palliative care unit, they work as members of the consultation team and community service teams to provide home- and clinic-based care.

All physicians have received specialized training in palliative care. While the staff nurses may not have received formal palliative care training prior to working in the program, most choose to take additional courses in palliative care and complete a certification exam. Continuing training and education in palliative care is also strongly encouraged and supported by the administration.

### ***Collaboration with community-based services***

The community palliative care service team and the Victorian Order of Nurses (VON) work together to provide the best community-based care possible. The VON is funded by the Nova Scotia Department of Health and Wellness and operates independently from CDHA Integrated Palliative Care Program. The VON is vital in providing home care, nursing care and personal support to patients at home. The community services team also relies on the involvement of Continuing Care Nova Scotia, a branch of the Nova Scotia Department of Health and Wellness, to provide hands-on nursing care and personal care needs at home including respite care, medical equipment rentals and adult protection services. The Department of Health and Wellness has also launched a pharmacare program for patients who have been identified as palliative. It provides 100% coverage for all medications required by these patients, including over-the-counter drugs.

### ***Volunteers***

Program volunteers primarily provide assistance and support on the inpatient palliative care unit. All volunteers receive about eight hours of orientation and training. Patients in the program can also tap into volunteer services offered by other units the Victoria General Hospital. For example, patients can use the hospital's Sunshine Room and receive complementary therapy from volunteers.

### ***Student placements***

The CDHA Integrated Palliative Care Program has student-placement opportunities in medicine, nursing, social work, recreational therapy, music therapy and chaplaincy. The program hosts approximately 60 physicians-in-training every year, and offers two residency slots in palliative medicine. One of the positions is funded by the College of Family Physicians of Canada and the other is self-funded by the Department of Family Medicine at Dalhousie University.

### ***Funding***

The program is funded by CDHA via Cancer Care Nova Scotia, which oversees non-physician staffing and program support, including equipment needs and travel needs.

### ***Service evaluations***

A Quality Committee is responsible for evaluating the program and performing trend analysis. The committee produces quarterly reports that assess a variety of factors, some of which are based on predetermined benchmarks. Currently, this program is not benchmarked to other programs in Canada. Program administrators are in the process of starting a quality improvement initiative similar to morbidity and mortality rounds in the near future.

### ***Key takeaways***

- The CDHA Integrated Palliative Care Program offers four different types of services:
  1. Home-based palliative care is available to patients who are house-bound. The Palliative Care Home Consult Team will work with the family physician, Continuing Care Nova Scotia and the Victorian Order of Nurses to meet the patient's needs in the home environment.
  2. Outpatient clinics in the Capital Health region are available to patients who have relatively stable health status.
  3. The palliative care inpatient unit at the Victoria General Hospital has 13 beds available for patients who require medical intervention in end-of-life care. Due to

limited resources within the unit, all patients admitted for treatment are previously known in the system.

4. The palliative care team that is based out of the Victoria General Hospital can provide consultations to any hospitals in CDHA.
- In January 2015, the home services and outpatient clinic services merged to become two community-based services to improve continuity of care.
  - The program has six palliative care physicians on staff.
  - All palliative care physicians rotate between the inpatient unit, consultation service and the community-based services in outpatient clinics and at patient homes.
  - On average, patients are enrolled in the program for 84 days until their death.
  - For more information, visit <http://www.cdha.nshealth.ca/palliative-care>.

# Colchester East Hants Health Authority Integrated Palliative Care Program

## ***Why is this program unique?***

Colchester East Hants Health Authority (CEHHA) serves a mix of urban and rural communities in central Nova Scotia. The CEHHA Integrated Palliative Care Program was launched in the late 1990s as one of the three demonstration sites for a rural palliative home care project in the Maritimes. The pilot project used interprofessional palliative care teams, education and consultation teams to ensure care integration and coordination. The current program continues to focus on these areas to support and assist terminally ill patients and families.

The program cares for patients in their home, supports their transition to other care settings, including acute care hospitals, and provides appropriate care in relieving pain and suffering at end of life. The CEHHA Integrated Palliative Care Program relies heavily on nurses, who play an important role on both the community-based and the inpatient interdisciplinary palliative care teams. The program's nurse-centric operation helps to ensure continuity of care as patients move between care settings. The program works closely with primary care physicians in the community to integrate them into the patient's care process. Family physicians work closely with the palliative care consult nurses to achieve optimal pain and symptom management. Family physicians can also consult with palliative care physician consultants when patients require more complex care. The palliative care program also has a close partnership with Continuing Care Nova Scotia (CCNS) in arranging home care and long-term care for patients as their needs change.

## ***What does the program offer?***

The program provides clinical services to all individuals and families within the Colchester East Hants Health District, consistent with the Canadian Hospice Palliative Care Association's National Norms and the Canadian Hospital Accreditations Services Standards of Practice.<sup>1</sup> The CEHHA Integrated Palliative Care Program offers three types of service: 1) community-based palliative care consultation; 2) inpatient palliative care consultation at the Lillian Fraser Memorial Hospital; and 3) inpatient palliative care unit at the Colchester East Hants Health Centre.

### ***Community-based palliative care consult team***

The community-based palliative care consult team is composed of nurses, palliative care physicians and a social worker, and also provides pastoral care. Besides working with the patient's family physician, the team also collaborates with VON, which can provide home care and personal support. Staff from the Colchester East Hants Hospice Society are also involved in patient care by providing grief and bereavement support as well as practical assistance to those needing the service. Nurses on the palliative care consult team have the predominant responsibility in providing patient care. They strive to provide expert level support to family physicians, home care nurses and caregivers, including pain and symptom management and psychosocial assessment and support.

The consult team can conduct visits to long-term care facilities and patient homes. If more intensive medical intervention is needed, the patient will be transferred to a hospital, where the inpatient palliative care team takes over.

The team meets biweekly to discuss care plans and ensure appropriate services are in place. The goal of the integrated service is to provide a combination of physical, psychological, spiritual and social care to dying individuals in their current setting.

A referral, which can be from Cancer Care Nova Scotia, a family physician or self-initiated, is required to become a patient in the community-based palliative care program. The care team assesses all referrals to determine whether the patient is suitable for the program. When a patient is admitted to the program, the referring physician is notified by the team. Certain patients may be discharged from the service and readmitted at a later time if their urgent health issues have been resolved, their health has remained stable for a period of time and they have completed end-of-life care planning.

### ***Inpatient palliative care consult team at the Lillian Fraser Memorial Hospital***

Lillian Fraser Memorial Hospital has a part-time palliative care consult nurse. Additional support comes from the community-based palliative care consult team in the CEHHA Integrated Palliative Care Program.

### ***Inpatient palliative care unit***

The new Colchester East Hants Health Centre opened in November 2012. It has 108 inpatient beds, with six beds allocated to the palliative care unit. Approximately 70–75% of admitted patients are new to the palliative care program and are transferred from the emergency department, other units in the hospital, or other hospitals in Nova Scotia. The remaining patients are referred by family physicians because of pain and symptom management issues or psychosocial issues. Approximately 60% of the patients have cancer, while the rest have other chronic diseases such as chronic obstructive pulmonary disease.

The unit's interdisciplinary care team consists of professionals from nursing, palliative care medicine, social work, pharmacy and spiritual care. A palliative care volunteer coordinator from the Colchester East Hants Hospice Society also works full time to coordinate daily volunteer visits. The team has access to physiotherapy and occupational therapy services provided by the hospital. A case coordinator from Continuing Care Nova Scotia participates on the weekly rounds to help plan for any discharges back home or to long-term care facilities.

Upon admission to the inpatient service, the patient is initially assessed by either a palliative care physician or palliative care nurse. Additional assessments and evaluations then take place in an interdisciplinary manner. The care team will meet with the patient and family to discuss pain and symptom management issues, psychosocial issues and end-of-life care. The patients are assessed daily for changes and to determine whether admission or discharge off the unit is appropriate. Once the care team determines that the patient may be discharged from the hospital, the case coordinator from Continuing Care Nova Scotia will be notified to start the discharge process. Approximately 40% of admitted patients will return home, while the rest either die on the unit or are discharged to long-term care.

## ***Program operations***

### ***Collaboration with community-based resources***

A key component of the CEHHA Integrated Palliative Care Program is its close partnership with the Colchester East Hants Community Hospice Society, a registered charity that is completely funded by donations. The hospice currently has two palliative care social workers who provide end-of-life support to people with life-limiting illnesses, as well as to their families. It works with the palliative care program to enhance the spiritual, psychosocial and practical support at end of

life for patients with life-limiting illnesses. Examples of available services include: anticipatory grief and bereavement support, grief group support, grief education, memorial services, client care financial services, wish fulfillment, and transportation assistance.

### **Volunteers**

Volunteers in the CEHHA Integrated Palliative Care Program are supplied and trained by the Colchester East Hants Community Hospice Society. The palliative care consult teams work closely with the volunteers under the same philosophy of care that values the quality of life until death, patient- and family-centred care, and autonomy in decision-making. Volunteers can visit patients and families in their homes or the hospital. Home visits are scheduled ahead of time whereas hospital visits occur daily.

The Hospice has approximately 50–70 available volunteers each year. All volunteers receive comprehensive training on palliative and end-of-life care before they begin interacting with patients and families in roles such as grief support, advocacy, spiritual care, practical support and companionship. On average, each volunteer receives 25–40 hours of training depending on the role and responsibility. The training modules are based on the Canadian Hospice Palliative Care Association National guidelines, and include topics on active listening, self-care, and the dying process.

### **Student placements**

Student placements are available for medical residents and those studying nursing, social work, recreational therapy, music therapy, chaplaincy and clinical counseling. Medical students in their final year of undergraduate medical education can also do electives with the CEHHA Integrated Palliative Care Program. Approximately five medical students completed electives in 2014.

### **Funding**

The CEHHA Integrated Palliative Care Program is funded by the Nova Scotia Department of Health and Wellness. The program is not funded on a per patient basis — it receives a portion of the total funding provided to the Colchester East Hants Health Centre. With strong community support, the new palliative care unit at CEHHC was created from existing medical beds without any new/additional funding from the Nova Scotia Department of Health and Wellness. As a result, the program does not receive any dedicated palliative care funding for the unit to cover the cost of specialty services. The program holds fundraisers annually to raise money for patient care, and may also receive donations designated for continuing education and service improvement.

### **Service evaluations**

Satisfaction surveys have been used before to assess service quality. Currently, the program is exploring more suitable ways to evaluate both client (family) satisfaction and program performance.

### **Key takeaways**

- CEHHA Integrated Palliative Care Program has three components: 1) community-based palliative care consultation; 2) inpatient palliative care consultation at the Lillian Fraser Memorial Hospital; and 3) inpatient palliative care unit at the Colchester East Hants Health Centre.
- The community-based palliative care consult team can visit long-term care facilities and patient homes.
- Family physicians in the community are integrated into the program to ensure continuity of patient care at home.

- The new Colchester East Hants Health Centre has a six-bed inpatient palliative care unit for patients requiring acute medical intervention.
- Social workers and volunteers from the Colchester East Hants Community Hospice Society provide grief and bereavement support, practical assistance and end-of-life support for patients and families in the CEHHA Integrated Palliative Care Program.
- For more information, visit <http://www.cehha.nshealth.ca/services/palliative.htm>.

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<sup>1</sup> Colchester East Hants Health Authority. Palliative Care Services [Internet]. [cited 2015 March 30]. Available from: <http://www.cehha.nshealth.ca/services/palliative.htm>.



# Edmonton Zone Palliative Care Program

## ***Why is this program unique?***

In Alberta, regional (now called zone) palliative care programs were founded in both Edmonton (October 1995) and Calgary (December 1996) as policy-makers and administrators recognized the growing demand for end-of-life care services. Both programs provide comprehensive, integrated palliative care services that can be accessed in all patient care settings, including the community, continuing care facilities and acute care locations. The Edmonton Zone Palliative Care Program (EZPCP) has a strong focus on clinical care, education and research.

Patients and their families can access palliative care services no matter where they are located. Primary care providers, such as family physicians or nurse practitioners in the community and hospitalists in hospitals, are responsible for providing basic palliative care services. Primary care providers are supported by palliative care consultants — physicians and nurses with specialized training in palliative care. If the primary care provider requires a palliative care consultation for symptom management or assessment for possible hospice palliative care unit (PCU) admission for end-of-life care, a referral for consultation can be made. Consultant palliative care physicians and nurses provide consults at home, in hospice palliative care units and in the Edmonton Zone's nine hospitals.

Residential hospice palliative care units in Edmonton are located in continuing care facilities. If hospice PCU admission is requested, the consult team works with the patient, family, and primary care provider to determine the patient's eligibility. The patient is then placed on a zone-wide triage list. Patients at home are usually admitted in one to two days, and patients in acute care in two to four days. The waitlist is managed by a Hospice PCU Placement Coordinator, who works closely with the hospice PCU site managers.

If patients' symptoms are challenging and complex, palliative care consultants can refer them for transfer to a 20-bed tertiary palliative care unit at the Grey Nuns Hospital, where care will be provided by a specialist interdisciplinary palliative care team.

## ***What does the program offer?***

### ***Palliative home care***

*"Family physicians and home care are recognized as central to the delivery of primary palliative care in the community."<sup>1</sup>*

The EZPCP provides consult services to support the primary care work of the Edmonton Zone Home Care Program to ensure a better experience for palliative patients requiring medical attention at home. Patients enrolled in the palliative home care program have needs that can be met at home, with the additional support of a family physician in the community who has basic knowledge, skills and competencies in palliative care. These family physicians may work on interdisciplinary teams alongside a nurse practitioner to provide direct and ongoing palliative end-of-life care for patients by addressing their physical, emotional, social, practical, cultural and spiritual needs while respecting their autonomy and need for independent living. In the home care program, primary care providers assess care needs, develop care plans, provide medical interventions and emotional support, and manage referrals and care coordination to ensure patients' health needs are met promptly. Patients with complex diseases and symptoms may be referred to the EZPCP.

### ***Palliative care consultation teams***

The EZPCP has a number of consultations teams, all of which can be accessed via a single phone number. Palliative care consultations are delivered by the following specialist interdisciplinary care teams:

- 1) Palliative Community Consult Teams (PCCTs);
- 2) Palliative care programs at the Royal Alexandra Hospital and the University of Alberta Hospital; and
- 3) Symptom Control and Palliative Care Team at the Cross Cancer Institute.

The PCCT is responsible for community consults based on referrals from primary care providers. The PCCT will visit the patient at the site of care, including home, continuing care facilities and the smaller community hospitals that do not have an onsite palliative care team. A triage physician in the program's central office screens all consultation requests, and provides a telephone consultation if appropriate or assigns the consultation to an appropriate team member based on need.

Permanent consultation teams are based at the Royal Alexandra Hospital and the University of Alberta Hospital, and are responsible for consults generated from their respective hospitals. The Symptom Control and Palliative Care Team at the Cross Cancer Institute covers both inpatient and outpatient clinics at the institution, and works as the liaison between oncologists and community-based primary care providers.

All of the palliative care consultation teams are composed of physicians and nurses who have received specialized training in palliative care and are experts in this field. All palliative care consultation teams are available 24/7 to provide information and advice to primary care providers in all care settings, including continuing care facilities.

### ***Hospice PCU beds***

Although a home death is often the preferred option for some patients and families, this may not be possible due to complex medical symptoms, psychosocial circumstances and/or resources available. As a result, there are 70 hospice PCU beds in five continuing care facilities in the Edmonton Zone for end-of-life patients. Patients are admitted to these beds after assessment by a zone palliative care consultation team.

### ***Tertiary PCU***

Grey Nuns Hospital in Edmonton has a 20-bed inpatient palliative care unit to care for patients with the most complex symptoms who require specialized, frequent and skilled assessments and interventions. The unit has a comprehensive interdisciplinary palliative care team dedicated to caring for these patients. Patients are referred to this location after assessment by a zone palliative care consultation team. Referrals are also accepted for out-of- zone patients.

### ***Patient demographics***

The Edmonton Zone Palliative Care Program collects extensive information on patient care to ensure continuous quality improvement. The number of patients enrolled in the program increases by 100 to 150 annually, and the percentage of non-cancer patients has also been increasing.

Reports are published annually on the program website [www.palliative.org](http://www.palliative.org). The most recent report (2013–2014) documents 3,082 consults in acute care, 831 consults at home, 777 hospice PCU admissions and 206 tertiary PCU admissions. The program is continuously evolving to meet the demand from a diverse population.

## **Program operations**

### **Staffing**

Family physicians are expected to participate in a 24-hour on-call coverage service. They also serve as the attending physicians when a patient is admitted to a hospice PCU. In the palliative home care program, nurses play a critical role in patient care by providing a 24-hour response service and working with family physicians in case management.

In the mid-1990s, the provincial funding agency implemented new fee codes specifically for family physicians providing palliative care services at home or on hospice PCUs. The fee codes allowed family physicians to bill for every 15 minutes of direct patient contact and for every 15 minutes of time spent in family or team conferences. The consult palliative physicians have been supported by salary funding through an alternative academic funding model.

*“The palliative care program has been able to continue to develop and grow as a centre of excellence in clinical, education, and research arena in palliative and end-of-life care through the ongoing integration with and support from the regional health authority (Capital Health and Caritas), the University of Alberta, and the Alberta Cancer Board. This has further facilitated:*

- 1. The growth of full-time equivalent palliative care physician positions from 8.5 to 11.*
- 2. The development of the nurse practitioner role within some components of the program,*
- 3. The development of a formal palliative care curriculum for palliative care education at an undergraduate level within the medical school and the establishment of a Palliative Medicine Residency Program jointly accredited by the Royal College of Physician and Surgeons and the College of Family Physicians of Canada, and*
- 4. The incorporation of PhD personnel into the research programs.”<sup>1</sup>*

The number of palliative care physicians has now grown to 15 full-time equivalent positions. Support is provided by the reorganized Alberta Health Services, Covenant Health, Cancer Care Services and the University of Alberta.

### **Training and education**

Although primary care providers are critical in coordinating palliative care services, providing home visits and referring patients for palliative care consultations, many remain unskilled in palliative care because of the low volume of terminally ill patients they see in their practices. As a result, many organizations in Alberta have joined forces to provide more palliative care training and education opportunities for primary care physicians in order to improve the overall service quality. For example, the Alberta Cancer Board created the Alberta Hospice Palliative Care Resource Manual back in 2001 to aid primary care providers to care for their palliative patients and promote similar knowledge and treatment options throughout the province. This has evolved into the nationally used Pallium Pocketbook.

### **Service evaluations**

Common patient assessment tools are used throughout the program to ensure standardization, easy monitoring and evaluation.

*“A number of symptom assessment tools, either developed in Edmonton or elsewhere, were adopted for use by the care teams. These included the Edmonton Symptom Assessment System, the Mini-Mental State Questionnaire, the CAGE Questionnaire, the Palliative Performance Scale, Mean Equivalent Daily Dose of Parenteral Morphine, and the Edmonton Staging System for Cancer Pain (now the Edmonton Classification System for Cancer Pain). These standard assessment tools, as well as a system for recording medical history and medication,*

*were used to ensure a common standard of practice and facilitate communication when transferring patients through the various palliative care settings. A coordinated training program promoted the use of a common approach and protocols for the management of various physical and psychosocial problems. Common guidelines for physicians, nurses, and caregivers are also provided in easily accessible handbooks.”<sup>1</sup>*

Periodic evaluations were carried out to assess program quality.

*“Assessment of outcomes is established through periodic external evaluation, accreditation, and maintenance of a database supporting annual reports and peer-reviewed research. The first external evaluation of the program, completed in May 1996, suggested widespread satisfaction with implementation of the program. Family members, care providers (including family physicians), and nonparticipating physicians said that the program was already well known, that there was strong support for the program’s consultation role, and that recommendations and communication had been appropriate and timely. In 1999, a family physician survey identified overall satisfaction with the program, except with ease of accessing referral. In 2000, a single access number for all types of palliative care services was implemented.*

*A regional database was developed early, managed by a data manager, and maintained with data from all components of the program, including both relevant patient demographics and assessment information. This has been used extensively in developing the program annual report, balanced scorecard, and quality initiatives.”<sup>1</sup>*

Based on the data collected over the years, the following outcomes were noted after the Edmonton Zone Palliative Care Program was implemented:

- There was a significant decline in cancer-related deaths in acute care facilities.
- The number of inpatient days for terminally ill patients at end-of-life decreased significantly.
- The percentage of cancer patients using palliative care services almost doubled.

## **Key takeaways**

- Patients in the Edmonton Zone Palliative Care Program receive continuity of care as they move between different care settings.
- The program consists of home-based palliative care in the community, palliative care consultation teams that can provide expert advice, hospice PCUs in continuing care facilities, and an inpatient palliative care unit for complex medical needs.
- Palliative care consultation teams work with care providers in the community, at the patient’s home, on hospice PCUs and in the Zone’s hospitals.
- The program uses common patient assessment and monitoring tools to facilitate communication between the care teams on different sites.
- The program assesses its impact by collecting and reporting extensive data on quality and outcomes.
- For more information, visit <http://www.palliative.org/>.

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<sup>1</sup> Fainsinger, RL, Brenneis C, Fassbender K. Edmonton, Canada: A regional model of palliative care development. *Journal of Pain and Symptom Management*. 2007;33(5):634 – 639.

# Bruyère Continuing Care Palliative Care Program

## ***Why is this program unique?***

Bruyère's Palliative Care Services (PCS) are founded on the World Health Organization's definition that highlights the need for palliative care to be initiated early in the illness trajectory. Using this approach, Bruyère is able to care for a diverse range of patients who may not necessarily be in the last days or weeks of life. Although the program is hosted in a continuing care institution, PCS provide much more than continuing care; available services include acute inpatient palliative care, community consultation support and capacity building, and palliative care rehabilitation for patients in Ottawa and the Champlain Region.

## ***What does the program offer?***

Three levels of services are provided:

1. An inpatient acute palliative care unit for patients with complex needs across the illness trajectory (not limited to end-of-life);
2. A regional palliative care consultation team that provides support to family physicians and community-based health care professionals, and builds primary care's capacity to provide high quality palliative and end-of-life care in the community;
3. A unique palliative rehabilitation outpatient clinic for patients with progressive incurable illnesses who are still highly functional and who, with the appropriate physical and nutrition rehabilitation, could remain independent and at home for a longer period.

## ***Inpatient Palliative Care Unit***

The unit, along with community consultation team, serves as a hub in the region for palliative care education, research and other important academic activities.

The 31-bed inpatient unit admits patients with complex needs. Admissions are not limited to the terminally ill or those with a do-not-resuscitate order in place. Patients are admitted if they meet the admissions criteria of high complexity or requiring acute palliative care. Although most admissions (75%) are from large acute care hospitals in the region, some patients are admitted directly from home and emergency departments (EDs) if they meet the admission criteria. These direct admissions help to prevent admissions to acute care hospitals and EDs, where care is not focused on meeting these patients' needs. Some patients are admitted temporarily for symptom control, while others are admitted to receive end-of-life care until their death. It is not uncommon for patients referred to the unit for end-of-life care to stabilize and become a long-term patient with a life expectancy greater than only a few weeks. However, the funding formula from the Ontario Ministry of Health and Long Term Care for the unit does not allow for these patients to be cared for on the unit, and the care team must work to make alternate arrangements for them.

A single central referral and triage process is used for admitting patients to both the palliative care unit and the area's residential hospices. This helps to ensure that the right patient is admitted promptly to the right place. After referral, the care team uses a variety of sources, including EMRs from other hospitals, to identify the medical situation, goals of care, advance directives, the values and goals of the patient and family, as well as other important information. The care team develops a personalized care plan with input from the patient and family. Care plans are

constantly updated to reflect the patient's current conditions and wishes. The team meets once a week to review the patient's care plan and identify those who no longer meet the unit's admission criteria. Decisions regarding care plans are largely done collaboratively using an interprofessional approach.

The unit's team consists of palliative care physicians, registered nurses (RN) and registered practical nurses (RPN), a pharmacist and a part-time social worker, chaplain and physiotherapist. Palliative care physicians are required to have advanced specialty training. Consultations with physicians from other service areas at Bruyère and local hospitals are made when procedures such as neuraxial blocks and radiotherapy are required. The staffing ratios on the unit used to be more favourable to the achievement of high quality care. However, in recent years funding cuts by the province have reduced nurse-to-patient ratios on the unit and the availability of allied health professionals.

Approximately 80% of patients admitted to the unit die there, with the remainder discharged home or to long-term care facilities. In 2013–2014, the median length of stay was 13 days, significantly less than a median of 24 days six years ago. The unit has undergone a significant transformation over the last six years, moving from a hospice model to caring for patients with acute and high complexity needs. This change has reduced the length of stay and increased discharge rates. The rate of admission has also increased over time, from approximately 340 patients in 2008 to 540 in 2014. In addition, the wait time for admission onto the unit has dropped from a mean of 9 days in 2009 to 2 days in 2014. These statistics signal a significant turnaround for the program and have helped reduce the program's reliance on acute care hospitals and EDs in patient care.

Bruyère partners with community care access centres and community nursing agencies to ensure a smooth and safe discharge for patients returning home. When a patient is discharged home, the consultation team usually provides a follow-up visit to ensure that the patient is doing well and that there is adequate support for the family physician and home care nurses in caring for the patient and family. If a patient does not have a family physician or his/her family physician refuses to provide home-based end-of-life care, the care team will attempt to transfer the patient's care to a palliative care physician in the community, who will assume the role of attending physician.

While 60–70% of patients on the unit at a given time are acute-level patients with complex needs, other patients fall under different profiles that are not fully remunerated by the current provincial funding formula. This places a considerable financial and moral burden on the unit. Other types of care provided by the unit are:

1. **End-of-life care, high complexity:** This care is provided to patients with complex needs who have a life expectancy of only days or a few weeks. These needs could be physical (symptoms such as pain, dyspnea and delirium), psychological, social and/or spiritual. The complexity of their needs makes it difficult to care for these patients at home or in a residential hospice. The inpatient team provides 24/7 nursing care (RN/RPN) and physician care (palliative care physicians provide daily visits) and assistance from other team members as needed. The complex needs of these patients preclude a hospice admission.
2. **Earlier in illness, high complexity:** These are patients with complex needs with a life expectancy of many months (or longer) who are admitted temporarily for control of



their needs and then discharged to home or other facilities. The complex needs and longer life expectancy of these patients preclude a hospice admission.

3. Chronic palliative care (low or high complexity): These patients are admitted for symptom control or end-of-life care; they have life expectancies of weeks to months, but cannot be cared for at home. There are a limited number of facilities available for these patients, who present a challenge for the unit because the new provincial funding formula that penalizes the unit that cares for them.
4. End-of-life care, low complexity: This care is provided to patients with low complexity needs who are admitted for end-of-life care. Although these patients should be cared for in the area's hospices, they are admitted to the unit due to shortages in the number of hospice beds in the Ottawa region.

Most of patients who are admitted have cancer (85%), but patients with any medical diagnosis can be admitted as long as they meet the criteria. The percentage of patients with non-cancer diagnoses is increasing, and this is expected to rise as palliative care for these patients becomes more accepted. The inpatient unit can accommodate patients with mental and/or physical disabilities.

### ***Regional palliative care consultation team***

The consultation team is composed of one advanced practice nurse, five nurse practitioners (NPs), two nurse consultants and a part-time (0.8 FTE) palliative care physician. Ontario's Ministry of Health and Long-Term Care (MOHLTC) does not provide physician positions in physician alternative funding plans for community consultation teams across the province, and this presents a major challenge to supporting the community and building community capacity. The Division of Palliative Care in the Department of Medicine at the University of Ottawa has therefore allocated its own physician resources to make this team interprofessional. The team provides consultation support and builds primary care capacity by enabling more family physicians to provide primary-level palliative care to their own patients. Once a patient is referred to the team by the family physician, the team first meets with the patient and the family. After the assessment, the team works with the family physician to develop a suitable care plan. Occasionally, the team does joint visits with the family physician and/or the family medicine resident involved in case. The team may also see ambulatory patients in the family medicine clinics with the primary care team. The team does follow-up visits in the home or clinic with the patient until the reasons for the referral have been addressed. At that point the consult team signs off and the family physician continues being the most responsible clinician. The team can be re-engaged if the need arises.

The number of referrals to the consultation program has increased steadily over the last five years. There were approximately 400 new referrals in 2008 and over 700 new referrals from 2013–2014. In addition to face-to-face visits, the team can also provide telephone consults to community-based physicians and nurses. For example, in 2013–2014, the team fielded over 4,000 calls from nurses and family physicians in the community and other facilities such as retirement residences.

Besides consultation support, team members also provide continuing professional education opportunities to physicians and nurses in the community. These training sessions are held in family health teams, long-term care facilities and retirement homes. Through this work, the consultation team is building system capacity and increasing patient access to palliative and end-



of-life care. Recently, the team assisted three of the four family medicine clinics in Ottawa that train family medicine residents to provide palliative care services. A recent study of the Ontario community palliative care teams published in the *British Medical Journal* showed that patients cared for by this team had significantly fewer emergency department visits and acute care hospital admissions and deaths than a control group with no access to a palliative care team.<sup>1</sup>

### ***Palliative rehabilitation outpatient program***

The palliative care rehabilitation clinic is staffed by an interprofessional team composed of a palliative care physician, nurse, social worker, occupational therapist, physiotherapist and dietitian, all working part time. Patients are assessed by the entire team at the initial visit. The team then meets to develop a care plan, which includes a physical exercise plan at the onsite gym, nutritional counseling, and symptom management. Patients visit the clinic once or twice a week for eight weeks. The team recently published results for the first 100 patients to complete the program.<sup>2</sup> They show significant improvements across a number of domains, including physical functioning and quality of life.

## ***Program operations***

### ***Palliative care physicians***

The palliative care physicians working in the Bruyère Palliative Care Services belong to the Division of Palliative Care, Department of Medicine, University of Ottawa Faculty of Medicine. The division has 15.2 FTE positions, of which 7.2 FTE positions are allocated to Bruyère and 8 FTE positions are divided among The Ottawa Hospital's (TOH) General and Civic campuses, the TOH Cancer Centre, the Irving Greenberg Cancer Centre, the Montfort Hospital and the Queensway Carleton Hospital. The 8 FTE positions at these different sites provide clinical coverage mainly through palliative care consultations on inpatient units and in outpatient clinics. In 2014, TOH inpatient units received 2,100 new referrals for palliative care consults, physicians in the outpatient clinics received 610 referrals, and physicians at the Montfort and Queensway Carleton Hospitals received approximately 350 new referrals.

All the division's physicians have advanced, specialist-level training in palliative medicine, mostly in the form of one-year palliative medicine residencies and fellowships, including the conjoint palliative care residency program from the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada. Six physicians are also specialists in other fields, including intensive care, emergency medicine, medical oncology and pediatrics.

The Ontario MOHLTC recently withdrew funding for palliative care physicians to provide on-call services. Thus, unlike other hospital-based consult services, TOH palliative care physicians no longer receive hospital on-call stipends even though they still provide 24/7 coverage. Similarly, palliative care physicians at Bruyère no longer receive on-call stipends for after-hours coverage on both the inpatient palliative care unit and the regional palliative care consultation team. Furthermore, the Ontario MOHLTC has refused to increase the number of FTE positions covering the TOH and other hospitals despite evidence that the work done by its eight physicians is equivalent to that of 12 physicians. The lack of cooperation from the Ontario MOHLTC places considerable strain on the Division of Palliative Care, and makes this work unsustainable in the long-term.

All of the palliative care physicians have academic appointments in the University of Ottawa's Faculty of Medicine. Thus, in addition to their clinical responsibilities, they also participate in

teaching activities, research, quality improvement, health services planning and administration. The demands in all these areas continue to increase.

### ***Undergraduate and postgraduate medical programs***

The Division of Palliative Care at the University of Ottawa's Faculty of Medicine has one of the largest palliative care residency programs in the country with about four to six residents completing a one-year palliative care specialization in any given year. However, only two of these residency spots are funded by the Ontario MOHLTC. The division uses funding from various sources to create the additional residency spots. However, these funding options are never assured. The two funded residency spots are specifically dedicated to family medicine residents who are doing a third year of added competency, and cannot be used by residents from specialist programs in areas such as oncology, critical care or internal medicine. There is high demand from residents to enter these programs — the division recently received 18 applications from residents to fill the two positions. In 2014, more than 60 residents from residency programs such as family medicine, internal medicine, psychiatry, medical oncology and radiation oncology have done palliative care rotations in the program. In addition, more than 70 medical students from the University of Ottawa and other medical schools across the country completed rotations through the program in 2014.

### ***Funding***

Bruyère's Palliative Care Services are funded by the Champlain Local Health Integrated Network and the Ontario MOHLTC.

### ***Performance indicators and service evaluations***

Bruyère Continuing Care and its palliative care services strongly endorse the need for performance indicators related to palliative and end-of-life care. Prior to April 2014, Bruyère used the Discharge Abstract Database (DAD) to report to the Ontario MOHLTC. The DAD is designed to capture administrative, clinical and demographic data from acute care facilities, and is not best suited to capture palliative care indicators. In April 2014, Bruyère switched to the Resident Assessment Instrument–Minimum Data Set, an instrument designed to capture and assess data in long-term care facilities. Unfortunately, neither system is able to capture accurate data on the palliative care unit's patient population and has led to significant funding shortfalls and budget cuts.

The palliative care program also uses regular surveys to monitor patient and family satisfaction with care. Three months after a patient dies or has been cared for on the inpatient palliative care unit, a survey is sent to the family to help evaluate the care provided.

### ***Key takeaways***

- Bruyère's Palliative Care Program offers three type of services for patients requiring palliative care across the illness trajectory and across different settings:
  1. an inpatient palliative care unit for patients with complex needs across the illness trajectory (not limited to end-of-life care);
  2. a region-wide palliative care consultation team to provide clinical and education support to the region's family physicians, community-based nurses, long-term care facilities and retirement homes;
  3. a unique palliative rehabilitation outpatient clinic for patients with life-limiting illnesses who are still functioning well, with the goal of keeping these patients functioning longer and in their homes.

- Bruyère's palliative care physicians are based out of the Division of Palliative Care at the University of Ottawa's Faculty of Medicine. They provide a number of clinical services across different settings, and are also responsible for educating medical students, residents and health professionals.
- The Division of Palliative Care at the University of Ottawa's Faculty of Medicine has one of the country's largest palliative care residency programs.
- Bruyère's Palliative Care Program faces significant challenges stemming from having to report using performance indicators and tools that are inappropriate for the services it provides, resulting in staffing challenges and bed restrictions.
- For more information, visit <http://www.bruyere.org/palliative-care>.

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<sup>1</sup> Seow H, Brazil K, Sussman J, Pereira J, Marshall D, Austin PC, Husain A, Rangrej J, Barbera L. Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis. *BMJ* [Internet]. 2014 Jun [cited 2015 April 15];348. Available from: <http://www.bmj.com/content/348/bmj.g3496.long>.

<sup>2</sup> Chasen MR, Feldstain A, Gravelle D, MacDonald N, Pereira J. Cancer rehabilitation and survivorship — An interprofessional palliative care oncology rehabilitation program: effects on function and predictors of program completion. *Current Oncology* [Internet]. 2013 [cited 2015 April 15];20(6). Available from: <http://www.current-oncology.com/index.php/oncology/article/view/1607/1349>.

# Ocean View Continuing Care Centre's Palliative Care Program

## ***Why is this program unique?***

Ocean View Continuing Care Centre (OVCCC) is a community-governed, not-for-profit, long-term care facility located in the Halifax Regional Municipality of Nova Scotia. It is licensed by the Nova Scotia Department of Health and Wellness under the Homes for Special Care Act and it is fully accredited by Accreditation Canada. OVCCC provides a range of services to meet the needs of the residents, ranging from in-house physician, nursing and therapeutic services to recreation activities, spiritual activities, social events and community outings. The organization has placed palliative care as one of its priority areas, as approximately 25–30% of its residents pass away annually. OVCCC is well-equipped to assist people with chronic illnesses and high or low complexity needs, largely due to having a full-time practising nursing home physician.

The organization's philosophy of palliative care is founded on the principles of person- and family-centred care, and enabling the resident to live a life that is meaningful to them until the very end. In short, palliative care at OVCCC aims to allow each resident to live fully until death.

## ***What does the program offer?***

### ***Resident care***

The facility has 176 long-term care beds, one respite bed for the community, and one bed that is specifically designated for palliative care. Anyone who is interested in enrolling in a long-term care residence in Nova Scotia must submit an application through the Single Entry Access System of the Nova Scotia Department of Health and Wellness; the system is managed by Continuing Care Nova Scotia. The applicant must rank his/her top three facility choices in the province. Once matched, the applicant must go to the facility or be placed at the end of the waitlist. On occasion, however, the geographical location of the matched facility is not ideal for the applicant and family. In such cases, residents are able to move to their preferred facility once space becomes available. When a person is matched to OVCCC via the Single Entry Access System, the person's health information is made available to OVCCC, whom will then use it to begin building the care plan. During admission, the resident is assessed by the care team and palliative care services are made available at that time to be integrated into the care plan. After the resident has been at the facility for six-weeks, a resident care conference takes place between the resident, the family and the care team to finalize the initial care plan.

During the course of a resident's stay at OVCCC, the staff not only cares for him/her as part of their job, but also gets to know the resident and family and provides more individualized services to suit their needs. This relationship building enables the staff to have informal discussions with families about their loved ones' health status and mental and physical condition during each visit. In addition, every year, each family has a half-hour Resident Care Conference meeting with the care team during which the team educates the family about the best way to care for their loved one and provide support for the family's emotional and spiritual well-being. Also during these conferences, the physician reviews medical status and prognosis with family members, as well as updates the advance directives to ensure they are appropriate for the resident's current health status.

Palliative care at OVCCC strives to improve the quality of life of the terminally ill by offering professional care, compassion, companionship and counselling for those residents approaching

the end of their lives, as well as offering support for their families. When a resident is in the acute dying phase, the staff aims to make the family feel like this is their home as well. Families receive free meals and are accommodated so they can stay overnight at the facility. OVCCC staff is sensitive to the needs of the families and they work to ensure that the small details are taken care of seamlessly. The care team respects and celebrates the life of the resident.

Following a resident's passing, the staff sends out a sympathy card to the family. The staff also places the resident's name, photo and a brief description of his/her background in a memorial plaque on the floor where he/she resided. The plaque stays for a few weeks before it's taken down. A memorial service takes place every quarter to honour the residents that passed in the previous months. Many of the staff attend both the memorial service at Ocean View and the one held in the community.

### ***Palliative care room***

While OVCCC has one specifically designated palliative care room, all residents can receive palliative care in their respective beds and rooms without needing to move to the palliative care room if they do not wish to do that. Most of the rooms at OVCCC are shared with one other resident. Thus, when a resident is entering the end-of-life stage and wants more privacy in care, the resident can access the palliative care room if they choose. Families and friends can stay with the resident in both the normal resident rooms and the palliative care room.

### ***Respite room***

The respite room at OVCCC is offered to the community and patient caregivers. These individuals can access the respite bed for up to of 30 days per stay, for a maximum of four weeks per calendar year. Access to the respite bed is controlled by the province through a single entry access system similar to the one used to gain admission to long-term care facilities. Since not all long-term care facilities in the Halifax Regional Municipality (HRM) have respite beds, OVCCC's respite bed is available to anyone from the HRM who fulfills the criteria for respite and is matched through the single-entry access system. It is not necessary that the individual live within OVCCC's catchment area. OVCCC's respite bed utilization has been between 50–60% over the past three years, and it is thought this occupancy rate would increase if Ocean View was allowed to control respite bed admissions on its own. Access to the respite beds, not their availability, is the major deterrent for people using the respite service.

### ***Specialty services***

Animal therapy is available at OVCCC, with two resident cats on site. St. John Ambulance also provides pet therapy to OVCCC by bringing dogs to visit residents periodically. Although there's no formal music therapy, music is welcomed in the resident rooms and around the facility. Recreational programmers are also available to keep residents engaged, both mentally and emotionally. This is achieved through one-on-one visits, group events, outings, baking, visiting musicians and many more activities. There is also a dietitian, social worker, occupational therapist, physiotherapist and two physiotherapy assistants on staff at OVCCC. The physiotherapy department organizes walking programs (indoors and out) and exercise programs for the residents. Ocean View also operates an Adult Day Program that is available to seniors in the community.

OVCCC also can provide its residents with specialty medical services such as oxygen therapy — it has an on-site oxygen concentrator. Subcutaneous hydration (hypodermoclysis) is available, as the NS Homes for Special Care Act precludes registered staff at nursing homes from

administering IVs, but there is also a paramedic support program that can be called upon to visit the home to provide onsite IV hydration or IV antibiotics.

### **Resident demographics**

Most of the residents at OVCCC were admitted from home, and few from acute care facilities. The average age of residents is 80 years, and the average length of stay is 18 months. A large number of the residents are frail elderly, while a few have developmental disorders and are relatively young. Over 80% of the residents have dementia, some form of mental illness or a neurodegenerative disease. OVCCC is equipped to adequately care for residents who have mental and/or physical disabilities. The facility has a dementia neighbourhood with designated care staff and nurses to meet the needs of these residents.

## **Program Operations**

### **Care teams**

Residents and families are at the centre of care. Staff work together collaboratively to ensure residents and families are cared for and their needs are met in a timely manner. For example, when staff notice that the husband of a resident is having a bad day during a visit, the staff will recommend the spiritual care coordinator speak with him to ensure he is okay. All staff at OVCCC can refer residents and families for specialty in-house services, such as recreation therapy and spiritual support, when needed.

One aspect of palliative care unique to long-term settings is that most residents are not considered palliative upon admission, but their comorbidities and dementia progress over time, causing them to gradually become more frail and closer to death. As this occurs, an ongoing dialogue between families, residents and staff is needed to ensure that goals of care and advance directives are appropriate. At OVCCC, this occurs annually or upon any acute changes in a resident's health status. This is the key to ensuring that residents are comfortable at the end of their life.

All staff at OVCCC, regardless of department and work function, receives basic palliative care training at orientation. The in-house physician also organizes education seminars for care staff on topics such as narcotics and pain management. Informal coaching during shifts also takes place on a one-on-one basis between the physician and nursing staff.

Having a full-time physician at OVCCC is highly beneficial, not only to the residents and their families in meeting their needs in a timely manner but also to the rest of the care staff, as it increases both their confidence and competency in providing palliative and end-of-life care. The physician is able to provide constant informal education to the nurses during each shift, and these capacity-building exercises increase the nurses' ability to care for residents even when the physician is unavailable during evenings and weekends. There is also 24/7 coverage by physicians in a local call group. As a result, they are less likely to resort to transferring residents to acute care hospitals for treatment. Nurses are able to make different decisions about resident care as a result of their interaction with the in-house physician than they would if a fee-for-service physician based in the community was visiting a few times a week to provide care. All nurses are trained in many areas of end-of-life and palliative care upon hiring. The full-time physician makes daily visits for residents facing acute health care crises and to provide pain management at the end of life.

There are also many continuing education and professional development opportunities for registered staff throughout the course of their career at OVCCC. For example, when a resident

dies, all staff are asked to reflect on the resident's care process — what went well, what may have gone poorly, areas for improvement, etc. OVCCC administrators will then develop specific training and education to meet the identified needs.

OVCCC's staffing ratio of residents to registered nurses (RN), licensed practical nurses (LPN) and continuing care assistants (CCA) is 30:1, 30:1, and 6:1, respectively. These values are above the provincial average. The CCAs are all professionally trained and certified. Additional training for all staff on palliative and end-of-life care are provided during orientation. Other staff involved in resident care include recreation programmers, occupational therapists, physiotherapists, physiotherapy assistants and a dietitian.

Staff also care for each other, and are taught to recognize the signs of compassion fatigue and stress. OVCCC's Employee and Family Assistance Program provides resources specifically dedicated to family and staff wellness. Staff are encouraged to take time to recover mentally after a resident's death.

### **Volunteers**

OVCCC has palliative care volunteers who are specially trained to provide emotional and spiritual care to residents at the end of life, and to their families. They are trained by the Joint Volunteer Group in the HRM. The volunteer manager at OVCCC is a member of the group, along with other volunteer managers from different care facilities in the HRM. The group is not funded by the city or the Nova Scotia Department of Health and Wellness; it is an independent conglomerate formed by volunteer managers who believe that standardized volunteer training can greatly add value to client care at the end of life. The Joint Volunteer Group was formed about two decades ago, and the palliative care volunteer training group is open to any health care facility in the HRM. All palliative care volunteers train together in the HRM through the same program. Thus, if a volunteer moves within the region, he/she can continue to work as a palliative care volunteer with a different organization because of the standardized training, which caters to both acute care and continuing care facilities. The palliative care volunteers are trained on interpersonal and communication skills, compassionate care, and standards of privacy and confidentiality. OVCCC also runs its own palliative care volunteer training program that's more tailored to the organization.

### **Student placements**

Students from various backgrounds often do electives and placements at OVCCC for months at a time. Each semester, OVCCC will have several LPN and RN students working at the facility, and some will come back to work at OVCCC after graduating. OVCCC also has occasional placements involving physiotherapy, dietetic, recreation, CCA, theology and medical students.

### **Funding**

The Nova Scotia Ministry of Health and Wellness provides a portion of the funding for long-term care services. The balance of funding for these services is acquired through resident payments. Residents pay a portion of their income as determined by the province, with fees ranging from \$30–\$110 per day. In Nova Scotia, the ministry covers approximately 55% of the cost of long-term care, while residents co-pay about 45%.

### **Service evaluations**

OVCCC has a high commitment to the science of quality and risk management. This commitment is integrated into the staff's day-to-day work at the facility by educating the staff on its importance from day one.



OVCCC values the thoughts and feedback from families on the services they and their loved ones received while in their care. Families are surveyed on their experience via a bereavement follow-up call conducted by the spiritual care coordinator a few weeks following a resident's death.

At an administrative level, the Balanced Score Card approach is used to track a number of quality indicators in order to monitor and evaluate their services. The indicators, which are not specific to palliative care, include number of falls, number of falls leading to an injury, pressure ulcers, medication errors and infection rates. The data are benchmarked with those from facilities in the HRM that also collect similar data. Currently, OVCCC is expanding its benchmarking provincial-wide. However, the number of organizations to compare to is limited because, unlike OVCCC, many long-term care facilities do not have resources devoted to quality and risk management. OVCCC also faces benchmarking challenges nationally because Nova Scotia does not have a provincial electronic medical record to provide data that can be used by Canadian Institute for Health Information.

### **Key takeaways**

- OVCCC has a full-time in-house physician, and her presence is vital to ensuring the seamless integration of palliative care services into the care of all residents. The presence of a full-time nursing home physician is a leading practice recognized by Accreditation Canada.
- All palliative care volunteers at OVCCC have received formal, standardized training through the Joint Volunteer Group in the HRM.
- OVCCC uses a Balanced Score Card approach to monitor and evaluate its internal operations to ensure high quality care.
- OVCCC's staffing ratios of residents to RNs, residents to LPNs and residents to Continuing Care Assistants are above the provincial average.
- Ongoing communication between staff, family and residents is the key to ensuring the transition from curative to palliative approach as residents gradually decline during their stay in long-term care. This dialogue is key to ensuring advance directives are appropriate.
- Improving palliative care in long-term care can be cost-effective, as OVCCC uses existing health care funding from the Department of Health and Wellness to deliver high quality palliative care. Bringing this approach to other long-term care facilities has the potential to reach large numbers of patients.
- Admission to OVCCC is done through the provincial single entry access system.
- For more information, visit <http://www.ovccc.ca/>.



# Canuck Place Children's Hospice

## ***Why is this program unique?***

Opened in 1995, Canuck Place Children's Hospice (Canuck Place) was the first free-standing children's hospice in North America. As a pediatric palliative care provider located in Vancouver, it delivers clinical care and bereavement services to over 500 children and families facing life-threatening illness across the province. Canuck Place has expanded to a second facility in Abbotsford in 2014. Community service delivery from the Abbotsford location has already begun. The information presented in this section refers to the Vancouver facility, as the Abbotsford facility is still in-development.

The Canuck Place Pediatric Palliative Care Program is specifically tailored to the individual needs of each child and family. The goal is to enhance quality of life for both child and family when the child has a progressive, life-limiting condition. The program includes both inpatient and outpatient consultation services, and provides comprehensive, family-centred care throughout the progression of the child's illness and until the family no longer needs the services. The duration of enrollment is determined solely by the child and family.

Canuck Place supports children and families along the continuum of care across the province regardless of their direct association with the organization. All families, nurses, physicians and other health care professionals in British Columbia can consult with physicians and nurses in Canuck Place throughout all stages of the child's illness via a 24-hour toll-free number.

## ***What does the program offer?***

Referrals to the Canuck Place program can be made by community-based family physicians, medical specialists, community nurses, social workers, and even friends and families. The intake nurse follows up with each referral to gather more information. The intake team then uses several factors to determine acceptance into the program, including the child's diagnosis, prognosis, disease progression, presence of complications, and the family's readiness to be in a palliative care program. If necessary, a determination about urgent referrals can be made by the on-call physician.

The hospice offers the following elements within its inpatient, outpatient and specialized consultation program: 1) respite care and family support; 2) pain and symptom management; 3) end-of-life care; and 4) grief support, bereavement and loss counselling. The facility also provides additional services such as recreational therapy, counselling (to patients, siblings and parents), expressive therapies (music and play), and a full school program. All programs and services are free of charge. The hospice facility has nine beds, and four family suites allow family members to stay in the hospice with their child. Some beds are pre-booked for respite, while the rest are open for urgent admissions related to pain and symptom management and end-of-life care.

### ***Respite care and family support***

Canuck Place Children's Hospice can provide 24/7 nursing care for children for temporary short stays to allow families to rest and recharge. Respite allows children the opportunity to receive clinical care for complex illnesses, pain and symptom management, recreational therapy and counselling, and offers families much-needed rest, renewal and support. While the child stays in the facility, the parents and siblings have the opportunity to stay onsite. The hospice has a full-time teacher who runs a school for children and their siblings to ensure that they can keep up with their schooling.

Families are offered up to 20 days of respite per year and can pre-book stays. Additional requests for respite will be accommodated depending on bed availability. Children requiring respite are assessed on a case-by-case basis according to urgency and need. Upon admission to respite care, the child is assessed in-person by an interdisciplinary care team composed of registered nurses (RN), licensed practical nurses (LPN), and a physician. The team evaluates the child's disease progression and medication history, and performs pain and symptom management. A care plan is developed with input from the child, families and caregivers. Respite care also allows the care team to assess families and caregivers for burnout by reviewing how they are doing physically and psychologically.

### ***Pain and symptom management***

Pain and symptom management services are aimed at managing the adverse physical and emotional symptoms of a child's illness and side effects of treatments. Children can receive these services upon admission to Canuck Place on an urgent basis, or as part of a scheduled respite stay. An admission to Canuck Place for symptom management can be very effective because the team has the ability to monitor the child over the course of a few days or weeks in a homelike environment. Families can also call to discuss symptom management with a nurse, who is available 24/7. The nurse can liaise with a staff physician to determine whether an admission for symptom management is necessary. Outside of Canuck Place, children can receive pain and symptom management in the following ways: 1) at the Madison Clinic, an outpatient clinic located at the BC Children's Hospital; 2) during inpatient consultations at the BC Children's Hospital, Sunny Hill Health Centre for Children, and the BC Women's Hospital and Health Centre (NICU); and 3) home visits for children living in the Lower Mainland region of British Columbia.

### ***End-of-life care***

Canuck Place provides comprehensive services for a child and family when the child's death is considered imminent. For children who require end-of-life care, an in-house admission is facilitated as quickly as possible (within two to 24 hours). The primary focus is to provide pain and symptom management and supportive care. Other important components of end-of-life care include grief support and ongoing bereavement services. The child and family are supported in transitioning home should the child's condition stabilize.

If the family prefers the child to die at home or in the hospital, support for end-of-life care is provided through consultative services from the Canuck Place outreach pediatric palliative care consultation team, either by in-hospital consults, in-home visits, or phone/videoconferencing to families throughout British Columbia.

### ***Specialized pediatric palliative care consultation team***

Canuck Place Children's Hospice's care team also provides pediatric palliative care consultations, primarily in-person, throughout BC's Lower Mainland and by phone and videoconferencing provincially. The team provides specialized consultation services to both families and health care providers. It includes in-person visits with children and families as well as consultations with health care professionals in a variety of care settings, such as a child's home, inpatient regional and community hospitals, and outpatient clinics. Members of the pediatric palliative care consultation team include physicians, advanced practice nurses (nurse practitioner and clinical nurse specialist), and a counsellor. The team members are responsible for conducting patient assessments to evaluate patients' physical, social, emotional and spiritual state. The team is also responsible for developing care plans that contain goals of care and advance care plans,

carrying out symptom management, and coordinating and referring patients, families, and health care professionals to additional services and resources.

### ***Grief support, bereavement and loss counselling***

Grief support, bereavement care, and loss counselling are offered to children and their family members throughout treatment. Loss counselling and consultation are also available to others involved in the child and family's life. Canuck Place uses the Dougy Center model of grief and bereavement support, which focuses on providing group-based support services for siblings and parents. The model emphasizes self-reflection and reflecting the inner emotions, feelings and thoughts outwardly in a constructive manner.

### ***Resident demographics***

Children between the ages of 0–19 are accepted into Canuck Place's pediatric palliative care program if they have a progressive, life-threatening condition. These children often do not live into adulthood. Some children are accepted early in their disease progression, while others are acutely terminal and are at the end-of-life stages when admitted. Roughly 300 children are enrolled in the Canuck Place clinical program every year, and 200 families receive bereavement services through the facility.

## ***Program operations***

### ***Care teams***

The 100 or so staff at Canuck Place comprise palliative care physicians, pediatricians, nurses, recreation therapists, play/music therapists, grief counsellors and a social worker, chaplain, schoolteacher, special education assistant, as well as volunteers and support staff. Staff works in an interdisciplinary manner to provide the best care possible. Nursing care at Canuck Place is led by a nursing coordinator. The nursing staff is composed of clinical nurse specialists, a nurse practitioner, RNs, LPNs, and personal care aids. Together, these individuals provide 24/7 nursing to enhance the comfort and quality of life for both the children and families.

Experienced palliative and pediatric physicians (2.0 FTE) are available to support the in-house staff 24/7, whether in-person or on call. The palliative care physicians have completed either the year of added competency training offered through the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada, or equivalent training. The physicians are cross-appointed to BC Children's Hospital, and are faculty members at the University of British Columbia. All staff members receive continuous training and education throughout the course of their careers at Canuck Place.

The team is committed to providing the best comprehensive care for the children and families by engaging in regular communication and updates. After a child is accepted into the palliative care program, the team arranges a meeting with the family to discuss the situation and develop a care plan. Family-team meetings are held with each family at least annually, and in some cases more often depending on the child's disease progression and health status. All parties involved in the child's care can request family team meetings. At these meetings, the team works together with the family to review concerns about the child's physical health, emotional well-being, family circumstances, and social and spiritual support. Advance care planning is also discussed in these meetings and families may review and update the plan and advance directives. There is no requirement for a child to have a Do Not Attempt Resuscitation (DNAR) order while enrolled in the program.

## **Volunteers**

Volunteers are critical in ensuring patients and families have a comfortable stay at the hospice. At any one time, Canuck Place has more than 325 active volunteers on its roster and a long waitlist of individuals who are interested in becoming volunteers. Before volunteers begin their service, they are screened, interviewed, oriented and trained. Volunteers who work directly with children and families must provide two personal references. Besides performing any activity that requires professional licensing and certification, volunteers take on a variety of roles including family and peer support, bereavement support, facility maintenance, and helping out with cooking, gardening, office reception and transportation.

## **Student placements**

Canuck Place has student placement opportunities available for nursing students and medical residents (R4 and above). Trainees interested in doing an elective in pediatric palliative care can submit an application.

## **Research**

Canuck Place conducts research, both internally and through affiliations with the Child & Family Research Institute, the University of British Columbia and other academic institutions. The program is active in knowledge dissemination and translation.

## **Funding**

Canuck Place receives approximately 80% of its funding from donations and fundraising, and the rest from the provincial government. Certain donations are dedicated to specific services, as dictated by the donors.

## **Service evaluations**

Kimberley Widger from the University of Toronto is currently conducting a study to evaluate the quality of palliative care programs in Canada, and Canuck Place is one of the facilities being evaluated. This report will be released in 2015. Although Canuck Place doesn't conduct exit surveys with families and caregivers, it does conduct biannual family satisfaction surveys to evaluate the general quality of the palliative care program.

## **Key takeaways**

- Canuck Place Children's Hospice offers the following pediatric palliative care services within its inpatient and outreach consultative services:
  1. Respite care and family support;
  2. Pain and symptom management;
  3. End-of-life care;
  4. Grief support, bereavement and loss counselling.
- There are four staff physicians (2.0 FTE) to provide 24 /7 coverage.
- All families, nurses, physicians and other health care professionals in British Columbia can consult with physicians and nurses in Canuck Place throughout all stages of the child's illness via a 24-hour toll-free number.
- Canuck Place uses the Dougy Center model of grief and bereavement support.
- End-of-life care services may be delivered at home by the nursing team on an as-needed basis.
- Canuck Place has more than 325 active volunteers on its roster.
- For more information, visit <http://www.canuckplace.org/our-program/>.

# Foothills Country Hospice Society

## ***Why is this program unique?***

Foothills Country Hospice Society (FCHS) is a grassroots, community-sponsored organization that was founded by residents and, health care and community leaders in Okotoks, a small rural community near Calgary. FCHS is a registered, not-for-profit charitable organization. It owns and operates the Foothills Country Hospice, one of the first rural, free-standing, purpose-built, non-profit adult residential hospice homes in Canada. This facility and its programs demonstrate that rural populations can also have access to specialized, expert residential hospice palliative care. The hospice was conceived, designed, equipped, staffed and funded entirely through the voluntary efforts of the FCHS, and the generosity of the community. It provides palliative, end-of-life care to residents in the rural and metro populations comprising the Calgary Zone of Alberta Health Services. The facility adheres to high quality and safety standards, and received Accreditation with Commendation by Accreditation Canada in 2015.

The Foothills Country Hospice Society is now part of a region-wide network known as the Calgary Zone Palliative End-of-Life Care Service, which provides integrated hospice palliative care services in the Calgary Zone of Alberta Health Services. Calgary has a well-integrated and comprehensive palliative care service network that includes home care, long-term care and continuing-care facilities, secondary and tertiary inpatient palliative care units in hospitals, palliative care consultative services, and residential hospices, of which the Foothills Country Hospice (eight beds) is one of seven local hospices providing a total of 108 hospice beds. The Foothills Country Hospice Society coordinates with these various palliative care services in the Calgary Zone to ensure seamless care integration for all patients in the network.

Palliative care physicians, community-based nurses, family physicians, home care nurses, and specialist physicians can refer patients to hospices and the regional palliative care program. Self-referral to the program is also possible. After patients are assessed by palliative care experts regarding their suitability to particular aspects of the program, they can be admitted to a residential hospice via a central intake system known as Pathways.

Pathways is a system that matches people to suitable residential hospices based on the person's preferences and the capabilities of each hospice. Criteria for placement into Foothills Country Hospice include the presence of a terminal illness with an expected longevity of less than three months, and acknowledgement that the person is no longer seeking treatments to prolong life. People are cared for at the Foothills Country Hospice for an average of approximately 25 days prior to their deaths. However the duration of stay ranges from one day to many months. Occasionally, patients improve or stabilize in their illness trajectory and move back to their homes, or to a long-term care facility in order to better meet their evolving care needs.

## ***What does the program offer?***

The Foothills Country Hospice sits on several acres of farmland, and has a view of the Sheep River Valley, the Rocky Mountains, and the Town of Okotoks. Foothills Country Hospice has eight single-bed resident rooms. Once admitted, residents can bring in items to decorate the space to their liking. The facility also has two family rooms, a spiritual space, a walking path and gardens, a commercial kitchen and common eating areas, meeting and quiet rooms, a play room for children and space for staff. Family and friends can visit at any time and can stay overnight with their loved ones or rest in separate family guest rooms. Visitors can also have meals with the residents in the common meal hall. Pets can visit, and a therapy dog is available for those who

wish. The facility may host other events such as musical activities, spiritual care, family events and culturally important practices, all of which are considered central to the philosophy of care that embodies the notion of living as well as possible, within the limitations of an illness, until death.

There are no charges to residents for room, meals or programs. Families who wish to eat at the facility are charged a small fee per meal. In addition to the commercial kitchen and food services staff, families have areas to heat special food that they may wish to bring in. Funding coverage for oxygen, some equipment and pharmaceuticals occur through the community government programs that exist for patients in Alberta. A contract between the Foothills Country Hospice and a community pharmacy provides the opportunity for specialized drugs, compounding and drug-delivery systems to be ordered at any time.

### ***Resident care***

Care is always provided in an interdisciplinary manner. Upon admission, a comprehensive care plan is developed for each resident. The interdisciplinary care team, which consists of physicians, nurses, social workers, spiritual care providers, counsellors and other health care providers, works with the resident and discusses medical needs, pain and symptom management, hopes and fears, anxiety, preferences, relationship concerns and any other issues related to their loss of independence. The interdisciplinary care teams focus on improving the patients' quality of life by easing the physical, emotional and spiritual suffering that may accompany the end of life.

Advance care planning and goals of care designations, along with advance directives, help guide care planning. The decision-making process considers the resident's expressed wishes, along with medically appropriate services. The focal point of all care plans is to identify what is important to the residents regarding symptom abatement and accomplishment of goals. The care team pays close attention to pain and symptom management in order to reduce suffering and allow patients to have the opportunity to pursue and fulfill their life goals prior to death.

Due to the nature of residential hospices, people admitted to the facility are at the last stage of their lives. While some residents are more mobile than others and can attend outings outside of the facility, most residents are unable to do so because of their health status. Foothills Country Hospice does not currently have a day hospice or outpatient program.

Very complex care needs, medical devices and therapies can be managed at the facility, but there are limitations, by design, regarding certain therapies. For instance, while subcutaneous medication delivery is common, intravenous therapies are very rarely utilized in the area of residential hospice care.

After a resident dies and before a new resident moves into the room, staff will often debrief in the resident's room and gather for a brief ceremony to remember the resident and help the staff to deal with the passing. The staff also lights a candle in the common area to remember the individual. Every six months, the facility hosts a memorial tea for the families and friends of those who have died in the previous months. Bereavement services are available through the hospice staff and also through regional grief and bereavement programs.

### ***Resident demographic***

The hospice serves adult patients. All residents have a terminal illness, whether it is cancer or other chronic illnesses from which they are expected to die soon. The Foothills Country Hospice can accommodate patients with all types of physical disabilities. However, people with severe dementia and who may be prone to wander are not best suited to stay at the facility, which does



not have any locked units. The facility is also unsuited for those with long-standing aggressive behaviours because it does not have the necessary resources to manage their needs. There are designated residential hospices in the Calgary Palliative Care Service network that can care for these patients.

## **Program operations**

### **Care teams**

Foothills Country Hospice, as with all other area hospices, has a palliative care physician consultant from the regional network who is specifically assigned to the hospice. The consultant usually comes to one of the weekly team rounds to interact with the nursing staff and the other family physicians who are the primary attending physicians at the hospice. The care staff also have 24/7, telephone access to palliative care physicians who are on call in the service network. Other than the medical director of the Foothills Country Hospice, all other physicians are based in the community and practise in the hospice on a fee-for-service basis. They have experience in palliative care, and their work at Foothills Country Hospice is built into their own family practices in the community. The attending physicians and the medical director rotate on-call responsibilities among themselves.

The clinical team includes a medical director, a director of care, RNs, LPNs, health care aides, a hospice chaplain, a social worker, a volunteer services coordinator, family physicians from the community, and palliative care physician consultants from the Calgary Regional Palliative Care Service network. Some of these staff members are in part-time roles with the hospice.

The palliative care physicians, nurses, and family physicians at the hospice all have both formal and informal training in palliative care. During their careers at Foothills Country Hospice, staff receive in-service training and continuing education as part of their personal and professional development. This training is centred on particular issues, develops relevant skills and provides updates regarding new developments in the field. As a member of the Calgary Zone Palliative Care Program, Foothills Country Hospice Society can draw on the expertise in the network to provide training and education to its staff. In addition, policies, standards, training and capabilities are generally harmonized throughout the service, utilizing the best practices available while still allowing for some necessary areas of variation.

### **Volunteers**

All staff and volunteers go through a number of training courses on grief and bereavement, communication skills and palliative care. Volunteers are an integral part of the society's operations; at any one time, more than 75 trained volunteers are available to help. Volunteer roles are diverse and varied and can include helping with reception, providing feeding assistance, baking, cooking, fundraising and providing companionship. Additional training in specific areas of work is offered to volunteers depending on their roles. Some volunteers assist with music, pet therapy and landscaping. The Board of Directors is also comprised of community volunteers.

### **Student Placements**

Nursing students at the University of Calgary can do a practicum at the facility, and sometimes these students choose to stay on staff after graduating. Elective opportunities for family medicine residents at the University of Calgary are coordinated through the palliative care service network in the Calgary Zone. Students who are interested in rural palliative care medicine can come to Foothills Country Hospice for a portion of their electives.

## **Funding**

Building and equipping the hospice was accomplished entirely through a multi-year commitment to community fundraising that was supported by local service organizations, individuals, corporations, municipal and government grants. The Foothills Country Hospice Society now receives two-thirds of its operational funding from Alberta Health Services, with the rest provided via fundraising. The volunteer program is funded by the province. The organization also receives specific donations for certain programs and services.

## **Program evaluation**

A suggestion box is available in the common area for thoughts and feedback. A survey is sent to the resident's family a month after the resident dies in order to provide an opportunity for further input into the facility's service. Foothills Country Hospice Society has been accredited by Accreditation Canada and also delivers end-of-life care services in accordance with the national standards of the Canadian Hospice Palliative Care Association.

Quality improvement is embedded into the staff's daily work. Discussions about current and previous patient cases occur during weekly rounds so the staff can learn from each other and build on their experiences to improve care. Internally, care providers push each other to learn from national standards and benchmarks on palliative and hospice care, and to apply their learning to patient care. Externally, the Foothills Country Hospice Society works with the quality standards and metrics set by both the Calgary Zone Palliative Care Program network and Alberta Health Services. Data are shared with the regional network so the quality of care can be constantly improved. The care staff may also get together with other staff in the region to share knowledge and best practices.

## **Key takeaways**

- As a member of the Calgary Zone Palliative Care Program network, Foothills Country Hospice Society is able to care for its residents in an integrated manner by collaborating and communicating with palliative care services in primary care, tertiary hospitals, home care, and long-term care.
- The facility and programs were conceived and built entirely by residents of rural and small-town Alberta, without formal approval or assistance from the provincial health system.
- The rural focus does not exclude urban patients, but provides access to a home-like end-of-life experience in an environment that might be comfortably familiar for people who have lived and worked as rural Canadians.
- The facility has a strong focus on quality and safety, and is accredited by Accreditation Canada. It delivers care in accordance with regional and provincial standards of care, and applies national quality metrics from organizations such as the Canadian Hospice Palliative Care Association.
- The facility focuses on identifying what is important to residents, and its staff works to ensure that needs are met.
- All staff has formal and informal training in palliative care. The facility provides internal education opportunities for staff and draws on the expertise in the regional palliative care network to provide additional training in certain areas.
- The facility works with the regional palliative care network to share best practices.
- Foothills Country Hospice Society trains all of its volunteers in palliative care.
- For more information, visit <http://www.countryhospice.org/>.



# West Island Palliative Care Residence

## ***Why is this program unique?***

As Canada's largest free-standing palliative care facility, the West Island Palliative Care Residence provides a unique model of palliative care delivery for Montreal residents. The residence is an independent, community-based non-profit organization, accredited by the Quebec government to provide palliative care health services. It was founded by a social worker who saw the need for better end-of-life care, and has grown since it opened in 2002. Today the facility has 23 beds at two sites — the André Brunet site (nine beds) and the Stillview Pavilion site (14 beds). Over the years, the residence has become a model for the provision of free-standing palliative care. All care services are provided free to residents and families.

The residence provides comfort care for every resident. Residents understand that the facility does not aim to either prolong or shorten life. Rather, it focuses on giving people the best quality of life possible — care is provided in a compassionate manner when necessary, and not in excess.

## ***What does the program offer?***

### ***Resident care***

People are admitted based upon need. Often, people who are dying in the emergency department tend to receive top priority for admission. The majority of the residents come either from emergency departments, or from homes where families can no longer manage to provide end-of-life care. People in the community can apply for admission to the West Island Palliative Care Residence by asking their primary care provider, either a family physician or nurse, to complete an intake form. The form is then reviewed by an admission nurse in consultation with the head nurse, the nursing director and a palliative care physician. Suitable patients are admitted as beds become available, with the most urgent cases receiving top priority. For instance, palliative patients in an emergency department may be admitted on the same day, or soon after if a bed becomes available. Although the residence has a waitlist, it tends to move relatively fast because of its 23 beds.

It is well-suited to care for people with psychosocial issues, with social workers and an art therapist on staff to provide comprehensive care for these residents. One of the social workers has training in cognitive therapy, and this has proved to be very beneficial. Staff can also consult a psychiatrist from the Lakeshore General Hospital if additional support is needed.

Upon admission to the facility, residents and families have meetings with a nurse and then a palliative care physician. This group will develop the preliminary care plan, which may be modified during the resident's stay as needs change. Pain and symptom management are typically the first issues to be addressed. Once these issues are under control, the care team may turn its attention to psychological, spiritual and whatever issues the resident may face. Residents and families are also introduced to the rest of the care team at admission, and this can include social workers, spiritual care coordinators, volunteers and an art therapist. After a resident's death, the family can receive bereavement services for up to a year.

### ***Speciality services***

Complementary therapy such as acupuncture or massage therapy is allowed if the family or resident asks for and arranges for it.

## **Resident demographic**

Approximately 3000 people have spent their last days at the residence since it opened, with the youngest resident being 18 years old and the oldest 102 years. People enter the facility for a variety of reasons, including psychosocial issues and pain and symptom management. A majority of residents have co-morbidities — these often involve a combination of diabetes and another condition — and these complicate patient care and service delivery. The residence has been doing a lot of research in this area and is creating education programs for its staff on how to best care for these patients.

The West Island Palliative Care Residence currently serves the CSSS (Quebec Regional Health Services Agency) West Island area, which has approximately 250,000 residents. The residence doesn't normally turn away people based on provincial residential status. It accepts individuals in the CSSS West Island area as long as they live in the area, have family in the area, or use health care services in the area. This is based on the simple philosophy that people want to be near their families in their final days, and the residence does its best to accommodate that fact. Each year, the residence receives approximately 370 individuals, which means it is always operating between 85% to 89% capacity.

Since the residence opened, residents have been served in up to 17 different languages. The average length of stay is 18 days. Approximately 10–15 residents per year return back to the community after their stay. Two of the beds are specifically for respite care for one to two weeks to give families and caregivers some time to recover and rest.

## **Program operations**

### **Care team**

The West Island Palliative Care Residence has over 100 dedicated staff comprising registered nurses, licensed practical nurses, orderlies, housekeeping and kitchen staff, social workers, psychologists, administrative staff, and palliative care physicians. Many of the staff nurses have their palliative care certification. Although the residence does not have a full-time palliative care physician on staff, doctors from the community and Lakeshore General Hospital work there as consultants, and are also available on call, 24/7. Most of the palliative care physicians have completed the year of added competency training in palliative care offered through the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada.

The Residence ensures a minimum ratio of 1:3 (nursing staff to residents) for every shift to ensure that all residents receive high-quality care. Continuing education and training is an important aspect of working at the West Island Palliative Care Residence, which offers many in-house training opportunities for staff and will often send staff members to external conferences. For example, it hosts monthly seminars for staff on topics such as pain management, how to discuss spirituality with residents, self-care and bedside manner. The residence also hosts monthly workshops for its staff nurses, who also participate in palliative and hospice care workshops in the community either as participants or presenters.

### **Volunteers**

Volunteers play a crucial role by taking on roles such as bereavement support caller, gardener, kitchen assistant, providing laundry service, fundraising and providing maintenance assistance, or working to provide pastoral care, patient care and reception.

*“The residence has more than 250 volunteers who provide thousands of hours of help in all aspects of the operation of the residence, except direct medical care which is all provided by dedicated and experienced professionals.”<sup>1</sup>*

Together, the volunteers have contributed over 150,000 hours of service to date. It takes approximately 130 volunteers per week to run both sites. All volunteer applicants are interviewed prior to selection, and once selected must take a mandatory eight-week volunteer course at McGill University. If they choose to take on specific roles that require additional training, such as patient care, they will receive mini-sessions from staff on the respective topic. The residence has a part-time volunteer coordinator, and volunteers receive feedback regularly.

Volunteers are supported in their self-care, and can participate in the case-debriefing process following a resident’s death. The psychosocial team at the residence is also available to provide individual counselling and group therapy if needed.

### **Student placements**

A variety of allied health students complete rotations at the residence in areas ranging from nursing to social work, medicine, and pharmacy. Approximately eight to 10 medical residents from McGill University arrive for short-term placements every year. Students in other disciplines, such as administration, theology, and fundraising, also complete placements. In 2014-2015, the residence hosted six nursing students, two social work students, one theology student and one administration student, in addition to the medical residents.

### **Funding**

The annual operating budget for the Residence is \$4.8 million. One-third of this is funded by the Quebec government and two-thirds — a total of \$3 million a year, or more than \$8,000 per day — is raised in the community through corporate and individual donations and various fundraising events. The cost-of-living adjustment annually is 2.3–2.5%. The residence has 3.9 FTE staff dedicated to fundraising. It does not pay any municipal taxes nor receive any governmental grants beyond the basic Quebec funding.

*“The Residence provides better care for patients and families while saving the government valuable health care resources as the government pays only \$205 a day per bed, compared to about \$1,000 a day for a hospital bed.” – West Island Palliative Care Residence*

### **Program evaluation**

The West Island Palliative Care Residence is accredited by the Quebec Alliance des Maisons de Soins Palliatifs. It is currently not accredited by Accreditation Canada due to the expense. A Board of Directors, to whom the executive director reports, governs the residence. Staff report to the executive director. There is also a Foundation Board, which is responsible for fundraising, and there are some cross appointments between the two boards. The executive director is responsible for evaluating the administrative staff, while the nursing director evaluates the nursing staff and the medical director evaluates physicians.

The residence constantly benchmarks its quality and performance to other facilities across the country. The head nurse participates in biweekly or monthly conference calls across Canada, including discussions with the Canadian Nurses Association, to share knowledge, best practices and compare quality metrics. The executive director works with staff to compare the facility’s results to those of other hospices within Quebec, and the residence has also done recent benchmarking comparisons with hospices in Ontario.

Families whose loved one has left the facility, whether through death or returning home, will receive an exit package that contains information on bereavement and lists the support services that are available through residence. The package also contains an exit survey with a return envelope. A small percentage of families submit the survey. It is hoped that families do not complete the survey immediately after they return home so that they can have time to grieve and then truly reflect on the services provided. The residence does not give satisfaction surveys to residents and families during their stay because there is a high risk of false positives about the services they receive, as they are more than happy to be out of the emergency department.

### **Key takeaways**

- The West Island Palliative Care Residence is Canada's largest free-standing palliative care residence, with 23 beds divided over two sites.
- It offers round-the-clock nursing care, pain and symptom management, counselling and emotional support.
- A variety of students complete rotations at the residence, including those in nursing, social work, medicine, and pharmacy. Approximately eight to 10 medical residents from McGill University come for short-term placements every year.
- The Residence has over 250 volunteers, who contribute more than 20,000 hours of service each year.
- Each year the residence provides care for approximately 370 people, and always operates between 85%–89% capacity.
- Since the residence opened, residents have been served in 17 different languages.
- The residence is accredited by L'Alliance des Maisons de soins palliatifs du Québec.
- For more information, visit <http://residencesoinspalliatifs.com>.

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<sup>1</sup> West Island Palliative Care Residence. Newsletter Spring 2014 [Internet]. [cited 2015 March 30]. Available from [http://residencesoinspalliatifs.com/en/wp-content/uploads/sites/2/2014/12/Newsletter\\_spring-2014\\_en.pdf](http://residencesoinspalliatifs.com/en/wp-content/uploads/sites/2/2014/12/Newsletter_spring-2014_en.pdf).

# Section 3

## Training and Education Opportunities in Palliative Care

The medical community has responded to the societal demand for better palliative care by investing in research, developing more appropriate treatment options, building new facilities and training health care providers. The recent debate on physician assisted death has further challenged physicians and other health care providers to consider whether they have the necessary skills and knowledge to provide the best palliative and end-of-life care to their patients. This section focuses on post-graduate training and continuing medical education opportunities in palliative care. Although we recognize that undergraduate training in palliative care across the country varies greatly and should be standardized in some manner, discussion on this topic is beyond the scope of this report. This section explores the following questions from the post-graduate level and features answers from the College of Family Physicians of Canada, the Royal College of Physicians and Surgeons of Canada and Pallium Canada.

- What training should physicians receive in order to provide basic palliative care?
- How are physicians supported in palliative care training?
- What key competencies and skills do physicians provide specialist-level palliative care?
- How can practising physicians acquire further training in palliative care?

The information should function as a guide into palliative care. We encourage all physicians to speak with the respective regulatory colleges before changing the scope of practice and embarking on further training in palliative care.

# Palliative Care Training as a Family Physician

*The College of Family Physicians of Canada (CFPC)*

## **If I am a family physician who wants training in palliative care, what does the College of Family Physicians of Canada (CFPC) offer?**

Palliative care is provided by family physicians across the country. About 1,170 members of the CFPC have indicated a particular interest in palliative care and are members within this domain in our section of Communities of Practice in Family Medicine.<sup>1</sup> Family physicians provide palliative care within the context of a comprehensive family practice, and some family physicians have attained added competency in palliative care and have a special interest or focused practice in palliative care. The three main routes to practising palliative care within the context of family medicine are described below.

### **Core family medicine training**

Accredited family medicine residency programs exist at 17 medical schools across Canada. Palliative care is a core component of the training of all family medicine residents. There are defined competencies expected of each graduating family medicine resident, with the requirement to have demonstrated those competencies in order to obtain certification in family medicine. Palliative care is one of the core and required clinical domains of care, and thus it is a requirement of programs that residents receive sufficient exposure to palliative care to attain competency to provide foundational levels of palliative care upon graduation. The Accreditation Specific Standards for Family Medicine residency training programs state:

*“Palliative medicine (end-of-life care): Residents must gain the competencies to provide care for patients and their families in the home and in institutions at the end-of-life. Residents should acquire competencies in collaborative models that assist with patient management and there are evaluation objectives specific to palliative care.”*

Individual learner competency in palliative care is ascertained through the evaluation objectives specific to this domain, as per the report from the Working Group on Certification Process:

*“Defining competence for the purposes of certification by the College of Family Physicians of Canada: the evaluation objectives in family medicine”*

*“The evaluation objectives provide an extensive list of competencies in family medicine, in terms of key features and observable behaviours. Each of the competencies is specific to the situation to be dealt with and to the phases of the clinical encounter that are involved; each competence is linked to the six skill dimensions that are essential to overall competence in family medicine. Competence is determined by continuous sampling, observation, and*

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<sup>1</sup> Our Communities of Practice in Family Medicine (CPFM) comprises a number of programs, each of which addresses a particular area of special interest of our members. These programs cover a range of areas that members have asked us to include, be they part of their comprehensive care practices (special interests) or in some cases major or full-time commitments (focused practices). The CFPC remains committed to comprehensive continuing care. As of November, 2013, 19 programs have been approved, including palliative care.

*reflection on an individual's performances with respect to the key features and the observable behaviours until the evaluator(s) is (are) assured and satisfied that the individual is competent in all six of the skill dimensions essential to competence in family medicine.”*

The specific evaluation objectives and key observable behaviours are listed in section six of this report. In addition, the certification examination in family medicine contains elements that specifically assess competency in palliative care.

### **Enhanced skills training in palliative care**

Family physicians have the option of completing an additional year of residency training in palliative care. This is considered a category one training program, with national standards by which programs are accredited. This is available at 13 of 17 departments of family medicine in Canada. Access to this residency year can be gained directly from the two-year family medicine residency program, or through a re-entry route for practising physicians who wish to pursue more training. Since formal recognition in 1999, approximately 175 family physicians have completed this training, and these programs currently graduate about 13 family physicians with enhanced skills each year. At present, this program is conjointly administered with the Royal College of Physicians and Surgeons of Canada, as per the attached accreditation standards. As stated in those standards,

*“The overall goals of the program are:*

- 1. To train physicians with added competency in the area of palliative medicine who will provide primary and consultant palliative care services; and*
- 2. To provide clinical and initial basic academic training for physicians who will be going on to academic careers in palliative medicine.”*

The College of Family Physicians of Canada is presently rolling out a process to acknowledge family physicians who have additional competence in palliative care by awarding a Certificate of Added Competence (CAC) in palliative care. In future, successful completion of the additional residency year (enhanced skills training) in palliative care will allow a graduate to apply for a CAC, provided the core competencies established for the CAC have been achieved and demonstrated. Core competencies for those physicians with added competence are presently being developed, and are going through a robust procedure, including a Delphi process, with practising experts in palliative care.

In addition to the one-year conjoint program, some universities will also offer shorter training programs that may attract individuals looking for a briefer training experience. These programs, although accredited under the auspices of the universities' enhanced skills programs, are not accredited individually and will not automatically lead to a CAC.

### **Practice eligible routes for development of additional competency in palliative care**

Practising physicians who wish to attain additional competence in palliative care may do so through several routes. As noted above, they may choose to complete an additional year of residency training as a re-entry candidate. However, standards and processes for attainment of the CAC in palliative care designation through practice-eligible experience are under development and it is anticipated that this option will be available as a pilot project to family physicians who meet the criteria in 2016. Family physicians may enhance their competencies through a number of continuing professional development opportunities such as Pallium and



LEAP courses.<sup>2</sup> The CFPC and its provincial chapters can provide physicians with information about accredited continuing professional development activities being offered in their area.

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<sup>2</sup> LEAP (Learning Essential Approaches to Palliative and End-of-Life Care). Pallium Canada is a pan-Canadian network of academic health leaders and skilled community-practitioner champions with enhanced skills in palliative care services. Together these champions have collaborated in developing, testing, and refining education materials and palliative care courses for healthcare professionals. Pallium Canada is currently redesigning LEAP and continues its focus on interprofessional learning and collaboration. The updated LEAP products promote palliative care in different settings (i.e. long-term care, oncology, acute care, family medicine clinics, emergency departments, paramedic teams, hospitals, hospices, etc.)

# Palliative Care Training as a Specialist

*The Royal College of Physicians and Surgeons of Canada*

## **If I'm a specialist who wants training palliative care, what does the Royal College of Physicians and Surgeons of Canada (RCPSC) offer?**

### **Training for non-palliative medicine specialists**

All non-palliative medicine specialists receive training in palliative and end-of-life care in order to be able to provide good basic (generalist-level) palliative and end-of-life care, and recognize the need for referral to a palliative medicine specialist. These competencies are requirements of accreditation for each Royal College training program.

### **Training for palliative medicine specialists**

Palliative medicine is currently recognized by the Royal College in two ways: 1) as a one-year conjoint program with the College of Family Physicians of Canada (CFPC) and 2) as a two-year subspecialty. The subspecialty in palliative medicine has been newly recognized and therefore is still in the implementation process.

The entry pathways for the conjoint programs are: 1) completion of the educational requirements for certification by the CFPC, or 2) completion of the educational requirements for certification by the RCPSC. In other words, being certified as a family physician or in any of the Royal College certified specialties allows entry into the conjoint program.

Though the national standards for the subspecialty of palliative medicine are not yet complete, when the subspecialty was approved by Royal College Council, it was approved as having multiple entry routes. Anesthesiology, internal medicine, neurology and pediatrics are the formal entry routes. However, it is being proposed that entry be allowed from other disciplines (including family medicine) providing they include a prerequisite of 12 months of clinical medicine-based rotations (six months of which are at the senior level) designed to allow achievement of competencies in the consultation and care of complex medical patients, interprofessional care, and effective communication skills. These are subject to change as the implementation process continues, but the final standards will be posted to the Royal College website.

## **What are the expected training requirements from the Royal College to be able to competently practice speciality-level palliative care?**

The training requirements for the one-year conjoint palliative medicine program can be viewed on the Royal College website at:

<http://www.royalcollege.ca/cs/groups/public/documents/document/y2vk/mdaw/~edisp/tztest3rcpsced000795.pdf>, particularly sections IV and V.

Since the palliative medicine subspecialty is progressing through the implementation process, the new national standards are currently being developed. Once they are complete and approved by the Royal College, they too will be posted on the Royal College website.

## ***If I'm just starting out in residency, could I enroll in certain training programs to be certified in palliative medicine?***

At this time, any physician starting out in residency who wishes to be certified in palliative medicine will be able to enter the conjoint program providing they meet the entry criteria outlined in the national standards document. A physician wishing to complete training in the palliative medicine subspecialty should either enroll in anesthesiology, internal medicine, neurology or pediatrics, or ensure that their training meets the entry prerequisites stated previously.

## ***Does the training differ depending on the stage of your career?***

Training requirements are standard. To be certified, graduates are expected to demonstrate the same competencies regardless of their entry route or career stage.

## ***How long is the training and can it be done over an extended period of time?***

The palliative medicine conjoint program lasts one year, while the subspecialty training involves a two-year program. Flexible or part-time training must follow Royal College and university policies and procedures.

## ***What is the structure of the training program?***

Both the learning objectives and the structure of the conjoint program are outlined in the Royal College website at:

<http://www.royalcollege.ca/cs/groups/public/documents/document/y2vk/mdaw/~edisp/tztest3rcpsced000795.pdf>. The conjoint program is available at 13 universities across Canada as follows:

- University of British Columbia
- University of Calgary
- University of Alberta
- University of Manitoba
- Queen's University
- University of Ottawa
- McGill University
- Université de Montréal
- University of Toronto
- Western University
- McMaster University
- Université Laval
- Dalhousie University

More information on the programs can be obtained at:

<http://www.royalcollege.ca/portal/page/portal/rc/credentials/accreditation/arps/specialty/palliative>. There is no examination for the conjoint program; successful candidates are granted an attestation that they have completed the training requirements. In terms of the subspecialty program, national standards will also include information about the structure once it is approved. Once those national standards are completed and approved, they will be circulated to a broad range of stakeholders for their information and posted to the Royal College website. At the same time, universities will be invited to submit an application for accreditation. The subspecialty in palliative medicine will have an examination. Successful completion of the subspecialty program and examination will confer certification. Royal College credentials are recognized internationally.

# Continuing Education in Palliative Care

*Pallium Canada*

## **What is Pallium Canada?**

Pallium Canada, which is governed by the Board of the Pallium Canada Foundation, is a national not-for-profit organization that aims to improve the quality of hospice palliative care by developing and disseminating competency-based, peer-reviewed education modules and courses, as well as clinical decision-making tools, to health care providers across different settings and specialty areas. Pallium Courseware and products, including its LEAP modules and courses, have been widely recognized across the country since 2001, and are based on the work of education and content experts from different disciplines. Pallium has partnered with many different partners, including family health teams, regional health authorities and palliative care services, cancer care organizations, the College of Family Physicians of Canada (CFPC), the Royal College of Physicians and Surgeons of Canada, and the Canadian Society of Palliative Care Physicians.

## **Learning Essential Approaches to Palliative and End-of-Life Care (LEAP)**

LEAP courses promote interprofessional care at the primary level, profile local palliative care teams and resources, and address major care variations by standardizing knowledge translation and diffusion. LEAP was originally a two-day course for community-based family physicians, nurses, pharmacists and other health professionals. Over the years, Pallium Canada has significantly updated its modules and courses as a result of increasing demand for additional options. In response, Pallium Canada developed new modules such as a one-day mini LEAPs for busy family medicine clinics, a one-day LEAP Mini Oncology interprofessional course for non-palliative care teams in cancer centres, a two-day LEAP Long-Term Care (LTC) course, and a one-day LEAP for paramedics (LEAP EMS) course. Pallium Canada also continues to offer its very successful interprofessional two-day course, which is now known as LEAP Core. Work is currently underway to develop and test LEAP Surgery, LEAP Emergency Departments, and LEAP Undergraduate courses. Future offerings will include LEAP Hospitals, LEAP Pediatrics, LEAP Chronic Illnesses, and LEAP Hospices courses. These courses target health professionals from different disciplines across different settings. The courses aim to enable these professionals to acquire the skills to provide high quality primary- or generalist-level palliative care.

The LEAP Core and LEAP Mini courses are the only Canada-wide, CFPC-accredited palliative care courses aimed at interprofessional palliative care education. The common modules in LEAP courses may include the following topics:

- Being aware (self-awareness)
- Taking ownership (defining palliative care)
- Decision-making in palliative and end-of-life care
- Essential conversations
- Advance care planning
- Pain management
- Respiratory symptoms
- Psychological distress
- Hydration, nutrition and gastrointestinal symptoms
- Delirium

- Palliative sedation
- Last days and hours
- Grief and bereavement

Other modules under development include palliative care in end-stage heart, renal and lung disease. Pallium Canada is also working with Aboriginal leaders and health professionals to integrate their learning and wisdom into the LEAP products.

LEAP courses are delivered by Pallium trained and certified LEAP facilitators from different disciplines. To become a facilitator, one must have experience and training in palliative care. In addition, facilitators are required to maintain their proficiency with the material and refine their facilitation skills. Pallium Canada is in the process of creating a database of hundreds of trained facilitators across the country to deliver various LEAP courses and workshops.

Participants can register for the courses through an online portal called the Pallium Portal. This also provides facilitators and participant access to other Pallium Products, such as online courselets, Doodles and Snippets, as well as updates on new current and new materials. While Pallium Canada provides the courseware and trains facilitators, local organizations are responsible for hosting individual courses. After an organization registers with Pallium Canada, it can use the provided tool kits to organize courses. As part of Pallium's commitment to ongoing quality assurance, each LEAP course is assessed via a robust evaluation process in which every participant and facilitator can provide feedback.

## **History and Development of LEAP**

In 2001, LEAP was established to develop an education strategy for rural communities in the Prairie provinces. The original LEAP Version 1.0 was developed following a national and international environmental literature scan matched to a learning needs survey conducted in rural Alberta. In 2003, Pallium spread beyond the Prairies to include approximately 72 sub-project areas such as the Pallium Palliative Pocketbook, a children's grief and bereavement camp in Manitoba, and a chaplain training program in Regina. Courseware construction followed the Plan-Do-Check-Act cycle of developing, testing, evaluating, modifying, and piloting. Over 60 content experts and users from across Canada contributed to the content and design, with additional input from hundreds of participants. The original LEAP was finalized in 2004. Pallium Canada continually incorporates new and updated evidence, challenges and technologies into the LEAP courseware to ensure that the information remains current.

## **Pallium Canada Resources**

The Pallium Palliative Pocketbook 1.3 Edition is a peer-reviewed resource guide for clinical practitioners. It can be used as a stand-alone resource to support bedside decision-making. It has gone through extensive peer review and evaluation by over 15 content experts from various disciplines. It is available in print format through the Canadian Hospice Palliative Care Association website. An e-book version is available for tablets and smartphones through iBooks or Amazon.

Other Pallium resources include short online animated education videos called Doodles and Snippets, as well as short online courselets (20 to 30 minutes each). The latter are currently under construction and will be accessible through the Pallium Portal online. Pallium Canada resources can be accessed via [www.pallium.ca](http://www.pallium.ca).

# Section 4

## Palliative Care

### Physician Leaders

*Susan MacDonald*

*MD*

*Associate Professor of Medicine and Family Medicine at Memorial University*

*Medical Director of Palliative Care at Eastern Health*

*President of the Canadian Society of Palliative Care Physicians*

Palliative care doctors are a widely diverse group. While the stereotype might run to the sort of physician who likes nothing better than sitting for ages with seriously ill patients while holding their hands, the truth can be quite different. They come from all sorts of backgrounds including family medicine, internal medicine, pediatrics, surgery, and others. Some hold multiple degrees and have extensive training in the field, while others have varied life experience and have learned “on the job”. Some are at the very beginning of their career and others are trying something new after the bulk of their working life has passed.

Because palliative care doctors are a varied group, so too is the location and the type of work they do. Location can range from the emergency department to the intensive care unit to a home in a rural community. Palliative care interventions range from nerve blocks to family counselling to opioid use.

Primary care clinicians provide the majority of palliative care. Many family doctors include palliative care as a natural part of the continuum of care, seamlessly integrating advance care planning into the conversation, utilizing symptom management techniques and working with their community nursing colleagues to provide end-of-life care. Others provide care within long-term care institutions. A much smaller number of clinicians provide more specialized or tertiary care. These practitioners may have focused their practice to mostly or exclusively palliative care.

Regardless of their backgrounds, whether their route to palliative care was direct or meandering, or where they work — rural clinical practice or the halls of academia — they all have one thing in common: a belief that palliative care is as important as curative care. All palliative care doctors believe that patients who cannot be cured of their illness are as valuable as those who can. They believe that interdisciplinary care adds value to their work as well as benefiting the patient. They meet patients where they are, both physically and emotionally. The patient and family are at the centre of everything the palliative care clinician does.

This section profiles a few palliative care physician leaders who were selected based on nominations from within the medical community. These physicians come from unique backgrounds and bring different skills and perspectives to palliative care. Their work in the field should shed some light on the diversity within palliative medicine and the vast opportunities that exist.

The Canadian Society of Palliative Care Physicians (CSPCP) works on behalf of palliative care physicians to spread the message about this area of care. The society, over 350 members strong, advocates for palliative medicine education at the undergraduate, graduate and continuing education levels, engages its members on issues pertaining to their practice and promotes the highest quality of care for Canadians through work with various partners. Working in human resources and promoting high quality and appropriate education opportunities are the society's priorities. The Annual Learning Conference is likely the most visible work the society does, but its "behind-the-scenes" work with the Canadian Medical Association, Canadian Hospice and Palliative Care Association (CHPCA), Technology Evaluation in the Elderly Network (TVN) and others is just as valuable for increasing interest in palliative care and stressing the importance of the work palliative care physicians do. The CSPCP lobbied and was successful in the development of a two-year palliative care subspecialty in the Royal College and a one-year certificate in palliative care in family medicine.

Yet there is much work to be done. Palliative care physicians are highly diverse and there's little data on the exact number of such physicians in Canada, the scope of their work, or the amount of palliative care that is actually being provided across the country. Combine this with an aging population, a growing number of patients with multiple co-morbidities, and a health care system increasingly unable to cope, and we are poised for a disaster. A palliative care approach could be very helpful in meeting upcoming challenges, and we need to ensure that every person in Canada has access to it. To achieve this, it is essential that every physician in Canada have some basic skills in palliative care. The physicians profiled in this section could serve as role models for health care providers interested in providing palliative care.



# Balfour Mount (Montreal)

MD, OC, OQ

*Father of Palliative Care in North America*

*Emeritus Professor of Palliative Medicine*

## How did you get involved in palliative care?



On completing undergraduate medical studies at Queen's University in 1963, I trained as a urologist at McGill University and as a surgical oncologist at Memorial Sloan Kettering Cancer Center, New York, and at the Jackson Labs, Bar Harbor, Maine, prior to joining the Department of Surgery at McGill's Royal Victoria Hospital (RVH) in 1970. In 1973, I was invited to chair an adult education seminar on dying, hosted by a local United Church. The historical context is relevant. In 1959, Brooklyn-born psychologist Herman Feifel had published *The Meaning of Death*. His work shone a bright light on the endemic denial of death in the Western world. With probing chapters by such authorities as psychiatrist Carl Jung, theologian Paul Tillich, and philosopher Herbert Marcuse, Feifel's book ushered in a new field of inquiry and research, which is known as thanatology. In 1967, Cicely Saunders, initially a nurse, then a lady almoner (medical social worker) and finally a physician, opened St. Christopher's Hospice in

London, a purpose-built centre of excellence for care of the dying, thus giving birth to the modern hospice movement. Two-years later, Elisabeth Kübler-Ross, a Swiss-American psychiatrist, published her best-seller *On Death and Dying*. The CBC then captured her work on the film *To Die Today* and *LIFE Magazine* ran a memorable cover story featuring an attractive young American woman who was dying. Death, a long-standing taboo topic, was coming out of the closet.

As our panel for the February 1973 seminar met to plan the evening program, chest surgeon Dag Munro made the following comment to senior nurse Leah Parks, hospital chaplain Mel McDowell and me:

*"Rather than galloping anecdotes, someone should do a study to find out how patients really die in our hospitals."*

While the seminar was well received, I felt it was important to pursue Dr. Munro's challenge to study our existing standards in end-of-life care. A research proposal, the acquisition of funding and the recruitment of two second-year medical student research assistants followed.

The study involved a survey of RVH staff and patients, complemented by detailed case studies exploring the experiences of dying patients in a wide range of hospital settings. The findings were deeply disturbing. The research documented the patients' desire for complete openness and honesty in discussions relating to diagnosis and prognosis, their physicians' reluctance to be that candid, the residents' lack of concern for their patients' emotional needs and the social workers' tendency to minimize the problem. Staff respondents from all disciplines tended to see their

colleagues' shortcomings more clearly than their own. Published assertions that a physician's personal faith (as a Christian) resulted in increased sensitivity and effectiveness of care were called into question. Indeed, the responses from Christian and agnostic physicians to questions dealing with attitudinal and communications issues were strikingly similar and at complete odds with the patients' responses. The case studies suggested that our care was characterized by inadequate control of pain and other symptoms and by deficient awareness of, and attention to, psychosocial and existential issues. At the same time, family members tended to feel ignored, marginalized and demoralized by staff and felt that their questions and requests were considered bothersome and a burden.<sup>1,2,3</sup>

In search of solutions to these unacceptable deficiencies, I spent a week at St. Christopher's Hospice in September 1973, and at Dr. Saunders' invitation returned for the summer of 1974 as a member of St. Christopher's attending staff. Although I was greatly impressed by the benefits accrued to patients, family members and staff through the attentiveness of the St. Christopher's team, I had concerns about the cost-effectiveness of the free-standing hospice model as a solution to the needs of 80% of Canadians dying in institutions. Thus, I recommended that the RVH develop a hospital-based version of St. Christopher's program. Our initial choice of the name "hospice" for our service was rejected by our francophone colleagues based on the poor reputation of "les hospices" in France. On etymologic grounds I chose the term "palliative" against the advice of Cicely and another hospice pioneer, Oxford's Robert Twycross. On a side note, it was a personal delight when the Royal Colleges of London and Edinburgh created a new specialty in 1987 called Palliative Medicine.

The experimental McGill program became known as The Royal Victoria Hospital Palliative Care Service (RVHPCS). The two-year pilot project (1975–1976) was backed by both the RVH Board and the Quebec government. I would be the director of the RVHPCS while continuing my clinical, teaching and laboratory duties as a surgical oncologist.

The Royal Victoria's ground-breaking experiment featured the following six integrated arms staffed by a robust multidisciplinary team:

1. a home care program staffed through the RVH nursing budget;
2. an in-patient palliative care unit;
3. a palliative care consultation service to the RVH active treatment wards;
4. a bereavement follow-up program staffed by trained volunteers under the supervision of our Psychiatrist;
5. a teaching component that caters to both undergraduate and graduate students in all disciplines, and visiting teams from other domestic and international centres; and
6. palliative care research.

Success depended entirely on the quality of our outstanding team. It was beyond superb.

During the pilot project and thereafter, Dr. Saunders and Dr. Kübler-Ross became hands-on mentors, regular visitors and close friends. The controversial RVHPCS project became a highly scrutinized, closely monitored, pioneering initiative. By the end of the project, it was enthusiastically supported by both the RVH Board and the Quebec government. A special issue of the *Canadian Medical Association Journal* marked the closing months of the project and it contained a cover photograph of volunteer bedside support, two editorial articles, and three academic articles.<sup>4,5,6,7,8</sup> Detailed documentation of the two-year process and its evaluation led to a number of additional publications including the following:

- a chapter for Dr. Kübler-Ross's book *Death the Final Stage of Growth*<sup>9</sup>

- a controversial participant observation study by Sociologist Robert Buckingham<sup>10</sup>
- a discussion of the pilot project's objectives, methods and findings<sup>11</sup>
- a discourse on the impact of the study on Urologic Oncology<sup>12</sup> and an expanded version of the same study<sup>13</sup>
- an examination of the development and administration aspects of the program<sup>14</sup>
- a presentation of our findings at the 1978 Annual Royal College Lecture<sup>15</sup>
- an update in the CMAJ post-project completion<sup>16</sup>
- a documentation of the impact of music therapy in the palliative care setting<sup>17,18</sup>
- a review of current pain management concepts and our studies with Ron Melzack related to cancer pain<sup>19,20,21,22</sup>
- an examination of stress for patient, family and caregiver, in the setting of advanced cancer<sup>23</sup>
- a study on integrating a palliative care service program in a hospital<sup>24</sup>
- editorials comparing end-of-life models of care<sup>25,26</sup>
- the International Work Group proposal for standards of care for the terminally ill<sup>27</sup>
- strategies for successful personnel hiring<sup>28</sup>
- a publication on how to confront staff stress during organizational development<sup>29</sup>
- an award winning National Film Board of Canada film entitled *The Last Days of Living*<sup>30</sup>
- a companion teaching resource guide<sup>31</sup>
- a 555-page reference textbook entitled *RVH Manual on Palliative/Hospice Care*, which would be used for developing palliative care programs in Canada, USA, Australia, New Zealand, Japan, Norway, and other settings<sup>32</sup>

### **When did you switch to practising palliative care full time?**

By the end of the RVHPCS pilot project in 1976 I was both the director of the Palliative Care Service and a full-time surgical oncologist with a busy clinical practice and an active research lab. I was also engaged in undergraduate and graduate medical teaching. Something had to give. While my interest in end-of-life care was all-consuming, switching horses in midstream presented significant challenges. It would involve leaving my close friend, mentor and chief, Dr. Ken MacKinnon, and the plans we had developed over many years of dialogue. It would mean closing my lab and abandoning my indispensable research colleague, Miriam Husk. It would necessitate leaving my chosen specialty with its broad range of clinical and surgical problems and its rapidly developing list of therapeutic options. It would also mean turning to a nascent field whose future was very unclear, while leaving behind a secure academic position in a strong and enjoyable McGill department. I would be leaving academic security for a program that repeatedly found itself under threat of closure by the Department of Medicine hierarchy, which assigned palliative care to be a very low priority in competing for ever-shrinking financial resources. Finally, switching career into palliative care would mean leaving assured financial security for day-to-day work that had no established mechanisms of funding. Despite these uncertainties and barriers, within two-years of the pilot project's completion, I opted for palliative care, a decision that came from the heart, not the head.

### **Given the limited number training and education opportunities, how did you maintain your skills and knowledge in palliative care?**

Fortunately for me, I arrived early in the game. As Dr. Saunders recalled: "In 1973 our document titled 'Drugs most commonly used at St. Christopher's' fit easily on one page." The International Work Group on Death, Dying and Bereavement, the Canadian Society of Palliative Care Physicians and the American Academy of Hospice Physicians nurtured those of us who were

privileged to be involved. These vibrant bodies hosted various local and national meetings — the first McGill Biennial International Congress was held in 1976, the 20th in 2014 — fecund discussions and new journals, and these provided opportunities to form lifelong friendships with many of the visionaries in the field, in my case, particularly with those in the UK, Canada, the USA, Italy, Norway, Australia and New Zealand. Their articles, books and scientific meetings sustained a rapidly expanding knowledge base. Keeping up was a problem, but it always is and it always should be! The challenge is particularly rich in our field since the foundational arenas of concern are broad in scope, including the physical, psychosocial and existential/spiritual components of conscious and unconscious experience that are always operative in “total pain” and suffering. In short, the goal is the balance of the science and the art of medicine advocated by Sir William Osler.

### **Challenges and opportunities in palliative care**

It is 40 years since the RVHPCS opened its doors and proved efficacious, yet to date a depressingly small minority of Canadians have access to competent palliative care! Where is the public outrage? Where is CMA’s outrage? Where is the political outrage?

A national integrated system that incorporates the six arms of the initial RVHPCS, modified according to the specifics of each region, is required for optimal cost-effectiveness across large geographic areas. The evolution of province-wide databases, in-depth training of primary caregivers from all disciplines, and financial support for strong interdisciplinary teams operating at secondary and tertiary-care levels are fundamental to comprehensive, state-of-the-art coverage. Volunteers should be skillfully selected, trained, supervised, enriched with continuing education and subject to recurrent evaluation, thus enabling them to participate, under supervision, in direct patient care. Initiatives such as The Canadian Virtual Hospice and other online resources are critical in reaching rural communities.

### **Tips and advice for physicians who are interested in going into palliative care**

Palliative Care is the most stimulating, challenging, rewarding, personal growth-inducing and life-changing vocation I can imagine. Colleagues transferring into our field from family medicine and all medical and surgical specialties have echoed these sentiments.

Palliative medicine will provide you with unimagined challenges, anguish and satisfaction. It will encourage and push you towards what Carl Jung called the second journey, which is the essential inner journey from ego to deep centre.

As you grow in clinical skill and understanding, practice mindfulness (moment-to-moment non-judgemental awareness) and congruence (full presence to oneself, to the other person and to the context)<sup>33</sup> and remember to attend to your own self-care.<sup>34</sup>

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# Amane Abdul-Razzak (Calgary)

MD, MSc, CCFP

Palliative Care Consultant, Alberta Health Services (Calgary Zone)

Clinical Assistant Professor, Department of Oncology, University of Calgary



## **How did you get involved in palliative care?**

As a family medicine resident, I had the opportunity to spend two weeks on the Intensive Palliative Care Unit, an inpatient unit serving patients with complex palliative care needs, at the Foothills Medical Centre in Calgary. This was an eye-opening experience, as I quickly learned how palliative care principles can be integrated throughout the disease trajectory and for a diverse patient population. There were patients who were only recently diagnosed with cancer and were going through therapy with curative intent, as well as patients who were facing the final days of life. But the common denominator for these patients was their host of complex symptom issues that required careful assessment and management. This experience really drove home to me, for the first time as a resident, that physical and psychological, emotional and spiritual sufferings are intricately linked. I was impressed by the multidisciplinary

team's attentiveness to this fact, as well as their commitment to respecting and honouring personhood and their willingness to respond to all facets of suffering. This philosophy of care was something I had not witnessed on other inpatient rotations, and I was immediately drawn to the unique mixture of acute care medicine and palliative care.

Later on, when I completed my training in family medicine, I began doing locum work at a hospice while also pursuing my acute care interests by working as a hospitalist. The hospice environment allowed me to immerse myself in the spiritual dimensions of palliative care, which was simultaneously enlightening and humbling. I later learned of a plan to open a new hospice within an existing hospital in Calgary, which was eventually named Santuari Hospice, and had the opportunity to become its first medical director. This was a wonderful experience, as I helped to build a multidisciplinary hospice team and develop a hospice culture "from the ground up." Currently I am working as a palliative consultant physician in Calgary, with my time split between outpatient work at the Tom Baker Cancer Centre and the Intensive Palliative Care Unit at Foothills, where my palliative care journey first began.

## **What formal/informal training did you receive in palliative care?**

My informal training has come from work experience as a hospitalist — a significant proportion of the patients have health care needs that warrant a primary palliative approach. In terms of

formal training, this came from rotations during my family medicine residency and the year of added competency program in palliative care, which is conjointly offered by the College of Family Physicians of Canada and the Royal College of Physicians and Surgeons of Canada.

### **Current work in palliative care**

My time is split between work as a palliative care consultant at the Tom Baker Cancer Centre and as an attending palliative care physician on the tertiary inpatient palliative care unit at the Foothills Medical Centre in Calgary.

On the Intensive Palliative Care Unit at Foothills, patients have complex medical conditions as well as pain, symptom and other palliative care issues that often require an intensive tertiary-care and multidisciplinary care approach. The team is composed of a range of health care professionals, including nursing, social work, physiotherapy, occupational therapy, spiritual care, recreational therapy and dietetics. The diverse team allows us to speak holistically about each case and to learn from each other about how to provide the best care possible. The Calgary Zone Palliative Care Network comprises palliative care physicians who provide services in acute care, hospice care and home care, and in outpatient clinics such as the cancer pain clinic. This facilitates the integration of palliative care in a wide variety of settings. In addition, it allows for improved communication with community palliative care providers such as family physicians, who provide care in the residential hospice setting.

Outside of clinical work, I am engaged in some research work focused on end-of-life communication. Most recently, I have completed a mixed methods study on patient preferences for end-of-life communication behaviours, which I had the opportunity to complete as part of my MSc thesis in health research methodology at McMaster University. Lastly, I frequently work with residents and medical students who rotate through the palliative care service and I always derive great satisfaction from teaching eager learners!

### **Challenges and opportunities in palliative care**

The most obvious current challenge relates to the new Supreme Court of Canada ruling on physician-assisted death. I believe it is important for providers to take the time to reflect on how this may affect our work in palliative care and to determine what will be the best ways to address the changes. Palliative care physicians are a diverse group, and certainly there will be differing opinions on how to approach the topic of physician-assisted death, so the challenge will be to operate in a way that respects each physician's professional autonomy while maintaining cohesion as a community. The ruling may also change the dynamic of the conversation between patients and palliative care physicians. Personally, I was inspired to work in this field because I saw how high-quality palliative care promotes dignity at the end of life and helps people achieve the best quality of life possible until they die. I see physician-assisted death as being very much outside of my palliative care paradigm. However, this is the time to showcase the work that we do and educate the public about palliative care in order to alleviate any confusion.

Another challenge is the growing population of patients with chronic palliative care needs—both cancer patients who are living longer because of advances in therapy but suffer from symptoms that impact quality of life, and non-cancer patients, including those with chronic lung disease, heart failure and dementia. Clearly, there is a great deal of opportunity to further expand the scope of palliative care to address these groups of patients, and likely the most feasible and sustainable way is by educating and empowering physicians to provide primary-level palliative care services.



## ***Tips and advice for physicians who are interested in going into palliative care***

Palliative care is a large field with many different potential career paths. If you are interested in pursuing training, it is important to tailor that training to your areas of interest. Opportunities in post-graduate palliative care training will change in the near future to include a two-year program provided by the Royal College of Physicians and Surgeons in addition to the year of added competency training offered conjointly through the College of Family Physicians of Canada and the Royal College. Although the goal of post-graduate training is to produce specialist-level palliative care providers with a possible interest in research and academia, we also need to have a large number of qualified primary care providers to provide home-based and community-based palliative care, and this does not necessitate formal post-graduate training. If you are thinking of entering the field, consider starting out by enrolling in the LEAP courses provided via Pallium Canada or trying out the week-long courses offered by the Victoria Hospice.

## Debra Braithwaite (Victoria)

MD, CCFP, FCFP

Community Hospice Physician, Victoria Hospice



I completed my family medicine residency in 1983, long before palliative medicine became a recognized discipline. My education included exploration of evolving societal attitudes towards death and dying, but little in the way of palliative management. At that time, most people died in hospital and medical care was almost exclusively focused on life prolongation. Awareness of

the unique emotional and physical needs of palliative patients was little recognized or addressed.

Like many others, I felt wholly inadequate when it came to managing severe symptoms in advanced disease, and increasingly frustrated with conventional attitudes that avoided acknowledgement of death at the end of life. When an opportunity arose in 1984 for part-time employment at the newly formed Hospice Victoria, I jumped at the chance to gain experience in palliative care. Within a short time, I became completely captivated by this rapidly growing field, and decided upon a permanent career. Looking back, I can hardly envision a more fortuitous choice.

No formal training existed at that time, but physicians new to the field enjoyed hands-on mentoring from Canadian pioneers such as Balfour Mount in Montreal, Jacky Fraser in Vancouver and Michael Downing in Victoria. Many early materials on symptom management came from the UK hospice movement, and we were soon producing our own. As the number of palliative care organizations grew across Canada in the following decade, clinical care branched to include palliative education and written publications.

My clinical focus has been community based, helping to design and deliver comfort care and the option of death at home for those who wished. From a core population of 30 patients in 1984, we currently support over 400 community patients at all times. Maintaining a large population of seriously ill and symptomatic patients at home requires rapid access to palliative physicians but also the combined talents of family physicians, home care nurses, a palliative response team and other health professionals. As in other palliative settings, successful care at home requires the combined efforts of a well-organized team.

Not surprisingly, palliative care has undergone many important changes over the last three decades, as has medicine in general. Among the most gratifying has been a wider application of palliative management for care beyond cancer populations, including patients with end-stage cardiac, renal, neurologic or respiratory disease, as well as the frail elderly. This clinical expansion has allowed more patients to remain at home but also increased demand for wider access to palliative services in the community and beyond.

In recognition of the growing need for trained palliative care professionals, education opportunities have expanded for both physicians and other care providers. Physicians in pursuit of enhanced palliative skills or seeking specialization in palliative medicine currently undergo a year of added competency training or complete a residency in palliative medicine. However, education of general physicians is also required if we wish to meet the needs of dying patients and their families in the future.

I feel exceedingly fortunate for my 31 years in palliative medicine, both in the opportunities afforded by being part of an evolving discipline and the privilege of providing clinical care in the home. I still find it deeply rewarding to meet and care for people in their own surroundings, to enter as a guest and access the rich information to be gained there, to address patient concerns directly, be they family support, symptom control, or a dignified death at home. The work is often demanding and intense, but always worthwhile.

Palliative care in Canada will undoubtedly face many challenges in the future, but I sincerely hope that community-based practice will remain part of the foundation of end-of-life care, and accessible to all. It has been my consistent experience that most patients and families deeply value uninterrupted time together at the end of life, and the opportunity to die at home, when possible. Our ongoing task is to build systems that provide timely, seamless, effective palliative services across multiple settings — whether acute, residential, hospice or home.

## **Dawn Davies (Edmonton)**

*MD, MA, FRCPC*

*Associate Professor, Department of Pediatrics, University of Alberta*

*Associate Adjunct Professor, John Dossetor Health Ethics Centre*

*Medical Director, ASSIST Palliative Care Program, Stollery Children's Hospital*



### **How did you get involved in palliative care?**

During my last year of pediatric residency I was considering further training in pediatric oncology, but I had some misgivings after an initial interview. Shortly after that, a guest speaker gave pediatric grand rounds on pediatric palliative care, and a light bulb went off for me. I had been a pediatric nurse in oncology in my previous career, and left that role feeling that the system did a poor job of making dying children comfortable. In the 1980s there was virtually no support for children who wished to die at home, so these kids ended up in hospital by default. This still occurs when support at home is inadequate. Pediatric palliative care is the best way to marry all my previous training and experience. I aim to seek ways to make the worst situations even a little bit better for children and their families.

### **What formal/informal training did you receive in palliative care?**

From 1998–1999, I completed a one-year McEachern Fellowship, which was offered through the Canadian Cancer Society at that time. It was divided equally between three areas — the adult palliative care program in Edmonton, the acute and chronic pain management program at Boston Children's Hospital, and the palliative care program at the Westmead Children's Hospital in Sydney, Australia.

### **Current work in palliative care**

I was the only pediatric palliative care physician in our program for the first 10 years. In 2002, I received a community grant to add a nurse coordinator and a grief counsellor to the team, which made a world of difference. Five years ago, another physician joined to cover all my vacations and conferences, and provide some protected time for education and research, which has been a tremendous change. Together, we care for a wide spectrum of children, from those not yet born, by providing information and choices to expectant parents when the baby's prognosis is poor, to dependent children who are young adults living at home. We work with children of any age or diagnosis, as long as they have a life-threatening illness that likely precludes survival into adulthood. Although we see children in the intensive care units, hospital wards and clinics, we focus on providing home care — children wish to stay at home with their families just as much

as dying adults do. Our program depends on our Children's Home Care Services, which provides 24/7 nursing care, so that we can provide high-quality and innovative treatments for children in their homes. As such, support for medical, nursing and psychosocial care is critical. Proper implementation of these services requires a team with different skill sets.

One of my current research projects is to examine pediatric hospitalizations lasting longer than six consecutive months, and the parents' experience during this time. I am also interested in medical ethics and the development of just processes for decision-making for children with chronic serious illness.

### ***Challenges and opportunities in palliative care***

Currently, medical care is delivered mostly in hospitals, outpatient clinics and physician offices. Unfortunately, these settings are inadequate for treating highly symptomatic children and supporting their parents, both of whom want to stay at home. We are completely open to providing care in different care settings, but our priority is to be on call for parents caring for a dying child at home. Often, there are few other physicians able or willing to participate in this type of ongoing care, either because of their time commitment to clinics and wards, or because providing medical care at home is unfamiliar and uncomfortable for those who lack experience. As an on-call pediatric palliative care physician, I have no set schedule because my work is dependent on patients' needs. I hope that in the near future we can recruit more pediatric palliative care physicians into our program who are willing and skilled in providing advanced symptom management at home.

### ***Tips and advice for physicians who are interested in going into palliative care***

Palliative care is often misunderstood, and thought to focus on dying. Fifteen years in this role reaffirms for me daily that palliative care is all about living. My drive for working in this field is to help kids live well and be as comfortable as possible to the end. To work in pediatric palliative care, you need to have passion, compassion, excellent relational and clinical skills, and a clear ability to separate yourself from your work. Taking breaks is essential, whether it is for the evening, weekend or a vacation. You can't constantly bear witness to the suffering of others. When a child is dying, the stakes are high to get it right. Even with the best self-care and professional boundaries, the work is emotionally and sometimes physically tiring. Remember to be gentle with yourself, and ask for help when you need it.

# James Downar (Toronto)

*MDCM, MHSc, FRCPC*

*Divisions of Critical Care and Respiriology and Palliative Care, University Health Network*

*Assistant Professor, Department of Medicine, Faculty of Medicine, University of Toronto*

*Chair, Postgraduate Education Committee, Canadian Society of Palliative Care Physicians*



## **How did you get involved in palliative care?**

By my third year of residency, I knew that I wanted to pursue a career in critical care. However, I felt that my knowledge of pain and symptom management was inadequate, so I did an elective in palliative care. It was a life-changing experience. I felt profound satisfaction when I was able to relieve a patient's suffering, or help the patient come to terms with a terminal diagnosis. I felt that I was better able to help patients who weren't responding to curative or life-prolonging therapies.

I decided to pursue fellowships in critical care and palliative care. I was very fortunate to have support from all the program directors, as well as excellent mentorship and guidance from a host of palliative care physicians.

## **What formal/informal training did you receive in palliative care?**

I have completed the conjoint program in palliative medicine, a one-year training program that is jointly accredited by the College of Family Physicians of Canada (CFPC) and the Royal College of Physicians and Surgeons of Canada (RCPSC). This program has existed for more than a decade, but will soon be phased out with the creation of a subspecialty in palliative care by the RCPSC. The subspecialty will continue to allow trainees from multiple specialty programs, but it will add a second year of training to incorporate more training in research and in palliative care for non-cancer illnesses, such as end-stage heart disease. Meanwhile, the CFPC will begin offering a year of added competency training in palliative medicine. We hope that these changes will help to train the next generation of palliative care physicians to meet the growing need for this care.

## **Current work in palliative care**

Half of my clinical work is in the Intensive Care Unit (ICU), and the other half involves providing consultative palliative care in a teaching hospital. We treat patients with a variety of illnesses, including both cancer and non-cancer illnesses. In particular, our service is frequently involved in caring for patients with end-stage lung disease (including patients waiting for lung transplantation), and renal and heart failure.

The main projects I am working on focus on teaching residents to communicate with patients about goals of care and resuscitation. We are studying the use of simulation training using standardized patients, and finding novel techniques to measure the effects of this training on real patients at the bedside.

I am also involved in studying end-of-life care in the ICU. We are developing guidelines for the withdrawal of life support, and studying bereaved family members in the hope of developing a screening and support program to help those who are experiencing complicated or prolonged grief.

I have also recently completed studies of non-beneficial treatment. One of these studies looked at the causes of and potential solutions to the high incidence of non-beneficial treatment at the end of life. I'm hoping to find new ways of reducing the use of aggressive, non-beneficial therapies that can cause suffering, and ensuring that when patients forgo this aggressive care they receive skilled and comprehensive palliative care.

### ***Challenges and opportunities in palliative care***

We do not have enough palliative care beds in our health care system, and the beds we do have are often inaccessible to the dying. We need to build more specialized palliative care facilities and provide more specialized palliative care beds in every large hospital in the country. Some people may see palliative care as a “boutique” service that costs money and requires other services to be sacrificed, but in reality hospitals are already treating patients at the end of life. When there aren't enough palliative care beds, this care is provided on an acute ward or in the emergency room, where costs are higher and the symptomatic care is worse. We need to treat palliative care the same as every other form of specialized care.

We also need to re-examine the default pathways of care in our system. Even though most people die of a chronic illness with a predictable course, many receive ineffective therapies, hospital admissions, and even cardiopulmonary resuscitation in their final days and weeks. This may be the result of clear communication and planning, but it is usually the result of poor communication and a lack of planning. By questioning the default pathways of care for dying patients, we could probably avoid a lot of unwanted and ineffective treatment.

Physician-assisted death (PAD) will soon be legal in Canada. We need to create a system of safeguards and oversight, so that it will be available and safe, and used only for the purpose intended. We also need to push for substantial new funding and support for palliative care to accompany the legalization of PAD and to follow the example set by many other jurisdictions. All Canadians should have both palliative care and PAD as options, but they should never feel compelled to accept one option because the other is unavailable.

### ***Tips and advice for physicians who are interested in going into palliative care***

We need you! But try to do at least two rotations in palliative care to make sure that this is what you want to do with your life. Also remember that you don't have to be a palliative care physician to provide palliative care. Many specialists from other fields have done extra training in palliative care, and brought this expertise to their own practices. These physicians can positively affect care for a very large number of patients.



## Robin Fainsinger (Edmonton)

*MBChB, LMCC, CCFP*

*Professor, Division of Palliative Care Medicine, Department of Oncology, University of Alberta*

*Section Chief, Edmonton Zone Palliative Care Program*

*Clinical Director, Tertiary Palliative Care Unit, Grey Nuns Hospital*



### **How did you get involved in palliative care? What formal/informal training do you have in palliative care?**

My medical school had no formal training in palliative care. I was working as a family physician in rural Saskatchewan when I had the chance to go to a palliative care meeting in Montebello, Que., in the late 1980s. Many of the speakers are now recognized as formative leading figures in the development of palliative care in North America, and I was inspired by presentations from individuals such as Balfour Mount, Neil MacDonald and Kathy Foley. The experience opened my eyes to a whole new world where there was actually something useful you could do to help patients and families living through an illness that required palliative care. I decided

to seek out formal training and applied for a one-year fellowship position in palliative care at the University of Alberta. As it happened, this was one of two newly created fellowship positions in Canada. The clinical and research experience that I received under the mentorship of Eduardo Bruera proved to be the starting point for my full-time career as a palliative care physician.

### **Current work in palliative care**

I have been working full time in palliative care for 25 years, and currently serve as medical director of the Tertiary Palliative Care Unit at the Grey Nuns Hospital in Edmonton and as medical lead for the Edmonton Zone Palliative Care Program. I have an academic position as a professor in the Division of Palliative Care Medicine at the University of Alberta, and served as the director of that division from 2000 to 2013. During this time palliative care in Edmonton has developed from a few scattered services to a comprehensive integrated service that provides palliative care consultation throughout the Edmonton Zone in every part of the community and in every health care institution. We also have a Tertiary Palliative Care Unit that serves the patients requiring the most complicated palliative care through a comprehensive interprofessional team. We have a number of hospice palliative care units where family physicians are able to continue providing care for patients no longer able to remain in the community. Our program has developed from the original mandate to care for cancer patients. We now cover non-cancer palliative care as well, and this accounts for up to 25% of referred patients in some locations. In addition to our clinical mandate, our palliative care program has promoted and provided palliative care education to medical students and postgraduate medical residents. We were one of the first universities to develop an accredited palliative care residency training program. The comprehensive nature of our palliative care service has allowed us to accommodate growing demand from medical students and residents seeking clinical training. Research has been a core value of our program mandate and has resulted in nationally and internationally recognized palliative care assessment tools such as the Edmonton Symptom Assessment System and the

Edmonton Classification System for Cancer Pain. In addition, research publications validating the benefits of our zone palliative care program have allowed us to advocate and continue to develop and improve our services, while providing valuable information for the development of other similar programs in Canada and in other countries.

### ***Challenges and opportunities in palliative care***

A significant challenge and opportunity is to better understand the often quoted statistic that only 15–30 % of Canadians have access to palliative care services. In a country with universal health care, we should be able to guarantee that everyone has access to primary health care. This means that all health care professionals, especially family physicians and other attending physicians in hospitals, should have the training and ability to provide basic palliative and end-of-life care support. It is not necessary for everyone to see or be seen by a palliative care specialist or specialist palliative care team. However, we do need to be sure we have adequate specialist palliative care services available throughout the country. Given the vast Canadian landscape, this might mean that for some geographic areas specialist palliative care services may have to be provided via telephone or video consultation.

Another challenge and opportunity is to better understand and appreciate the much-quoted statement that “everyone wants to die at home”. While it is certainly true that most people will want to remain at home for as long as possible, this does not mean that every patient and family has the desire to remain in their own home as physical and psychological challenges increase. We need to recognize that preferences for location of care and location of death are not always the same thing, and that preferences can be expected to change over time. This is where comprehensive integrated palliative care service delivery models will be able to offer patients and families choices so that they can be guaranteed to receive both primary and specialist palliative care services in the location they choose and that the health care system will enable them to move seamlessly to whichever option best serves their needs.

In an environment where there is much focus and discussion on physician-assisted death and euthanasia, the challenge and opportunity for palliative care is to ensure that the need to advocate for and develop palliative care services is not lost in the emotion and rhetoric of this debate.

### ***Tips and advice for physicians who are interested in going into palliative care***

For those physicians interested in palliative care training and a career in palliative care there are more opportunities now than ever, as most Canadian medical schools offer accredited residency training programs. These programs continue to evolve and will soon offer different opportunities for family medicine and specialist trainees. Understanding of the difference between basic palliative care training required for physicians interested in providing primary care and training for a full-time career as a palliative care specialist will help physicians determine their educational and experience needs.

## Romayne Gallagher (Vancouver)

*MD, CCFP, FCFP*

*Head, Division of Palliative Care, Department of Family and Community Medicine, Providence Health Care*

*Clinical Professor, Division of Palliative Care, University of British Columbia*



I was introduced to the benefits of palliative care early in my career when my father died of lung cancer in my fourth year of medical school in 1984. He received home visits from the community palliative care physician and that opened my eyes to what palliative care could offer to patients and their families. I learned palliative care by self-study under the tutelage of the many patients who I cared for in my full-service family practice. I went on to do palliative care full time in 1999. I have been working in palliative care locally across the health care spectrum, and provincially and nationally in educational and policy issues. I currently work at Providence Health Care in Vancouver, where I am physician program director of the Palliative Care Program.

Palliative care now has an evidence base to justify its role as an integral part of the care for individuals with serious illness. The challenge is integrating palliative care into the practice of every physician who cares for people with serious illness. Every physician should have essential palliative care skills such as basic symptom management, communicating around prognosis and establishing goals of care with a patient over their illness trajectory and, most of all, being aware of what palliative care can do to enhance the illness journey and when to involve palliative care teams.

Building capacity among all health care practitioners is the one of the biggest challenges for palliative care. Our team at Providence Health Care has worked to develop relationships with other programs to foster awareness and integration that have resulted in earlier referrals, more rational use of health care resources, and improved care of patients and families. We have also developed educational resources such as a palliative care app to put essential information at the fingertips of care providers. The app not only provides drug doses but also communication tips and opening lines because palliative care research has highlighted the therapeutic value of communication about serious illness.

Over my career I have seen the development of multi-morbidity as the new norm in medicine. This is a huge challenge to all of medicine as patients grapple with multiple chronic diseases and often report poor quality of life as their illness progresses. Medicine, with its focus on organs and systems, is in danger of providing care to a collection of organs rather than an individual with multiple medical conditions. A palliative approach to caring for patients with multiple morbidities focuses on symptoms and quality of life as opposed to disease indices, and offers a method to assess, treat and assist patients in coping with advanced illness.

The development of a subspecialty in palliative medicine is both a benefit and challenge to the practice of palliative care. The benefits of expanding the research and academic reach of palliative care in medicine are many, and expansion undoubtedly will result in more physicians acquiring palliative care knowledge and skills. However, the generalist method of palliative care up to this point must not be lost because this holds the key to managing patients with multi-morbidities with a holistic approach.

The practice of palliative care has provided me with much professional satisfaction. I have been honoured to be involved in key moments in people's lives as they deal not only with change and loss but also with personal growth. Yes, I have seen a lot of death, but mostly I have learned about life from the many patients and families I have met.

# Gordon Giddings (Ottawa/New Zealand)

*MD, CCFP*

*Associate Physician, Regional Palliative Consultation Team, Bruyère Continuing Care, University of Ottawa*

*Senior Medical Officer, Hospice Waikato, New Zealand*

*Associate Editor, CMAJ Research and Practice*

*Clinical Editor, Pallium Canada*



My initial involvement in palliative care came through my work as a clinical associate physician in the Blood and Marrow Transplant Program at the Ottawa Hospital. Through that work, I had the opportunity to participate in some cutting-edge approaches to numerous hematologic malignancies as well as other life-altering diagnoses, such as multiple sclerosis and aplastic anemia. The team did some incredible work involving very difficult diseases, but there were always cases in which even the most advanced treatments were not able to offer a cure, or even a short-term remission. It was in relating to the humanity of these patients with progressive disease that I first began to truly develop as a physician. I was in my late twenties when I first started working with the team, and was uncomfortable with the concept of death and dying. I often used the Patch Adams approach to suffering (humour) as my default in an attempt to make the patients smile or laugh on “bad days.” I soon realized, however, that they needed something more than that from me.

One patient, a man with lymphoma who was not much older than me, was able to cut through my facade by asking some very in-depth questions about his cancer and prognosis, which led to deeper discussions about life and what gives it meaning. I realized that by resisting this deeper level of understanding and processing, I was doing my patients a disservice by not fully witnessing and allowing them to express the true extent of their suffering. I also realized that there was tremendous therapeutic value for patients in getting to share their stories and in being heard.

Several similar experiences led me to apply for the Palliative Medicine Residency Program at the University of Ottawa, where I cultivated a particular interest in pediatric palliative care. I rotated through Children’s Hospital of Eastern Ontario and Rogers House (pediatric hospice), and culminated the year with the Pediatric Pain Master Class at Children’s Hospitals of Minnesota. After completing my training, I had the opportunity to help create and serve as program director for the Palliative Medicine Residency Program at Western University, which represented a

collaborative effort between clinicians and administrators from multiple sites around southwestern Ontario, and with a tremendous amount of cumulative experience.

I then joined the Regional Palliative Consultation Team with Bruyère Continuing Care at the University of Ottawa. In 2013, I was selected for the *Canadian Medical Association Journal's* Medical Editorial Fellowship, and was subsequently hired as an associate editor for the Research and Practice sections. This has been an invaluable experience that has given me the opportunity to meet, engage with and exchange ideas with some of the most respected researchers, thinkers and policy-makers in the Canadian and international palliative medicine community, and the general medicine community. It has also allowed me to play a role in the ever-increasing base of palliative care research and to remain on the forefront of developments in the field. I also serve as clinical editor for Pallium Canada, a national education community-of-practice that develops interprofessional educational resources and clinical decision support tools to help build capacity for those providing palliative and end-of-life care.

In 2014, I accepted an invitation for an assignment as the senior medical officer at Hospice Waikato, in the second largest region of New Zealand. Similar to Canada, New Zealand is very advanced in its recognition and development of palliative services, and maintains very high standards for the certification of physicians in palliative care. Unfortunately, the other similarity is that New Zealand faces a severe shortage of palliative care physicians, and has had to rely on overseas recruitment to fill some of its service gaps. This opportunity has allowed me to expand my skill set in a centre with international expertise. I continue to work in both inpatient and outpatient settings, as well as at Rainbow Place, New Zealand's only pediatric hospice. I have also had the privilege of learning about the rich Maori culture and the Maori approach to and beliefs around death and dying, which are in some ways similar to those found in some First Nations' traditions in Canada. This position has helped me to develop greater cultural competency in the delivery of palliative care, and to put the experiences of my Canadian training and practice into a larger context.

I realize that some of the best palliative care providers I have met may not even realize they are doing palliative care. I recall a family physician driving two hours to see a patient in a small coastal Newfoundland town because the patient's pain pump had stopped working on a Saturday night. I also remember an oncology nurse who was able to advocate successfully for a patient whose family did not want her to be told that she was dying. These experiences have taught me that palliative care is not so much a field that practitioners choose but a field that chooses practitioners. It requires us to step outside of our comfort zone and to be present with people at some of the most vulnerable times of their lives. All health care providers have a role to play, and the most important tenet is treating the person, not just the disease.



## Neil Hilliard (Abbotsford)

*MD, MCFP*

*Program Medical Director, End-of-Life Care Program, Fraser Health Authority*

*Clinical Assistant Professor, University of British Columbia*



At my 25th medical reunion we were offered some good advice from a previous class mentor: “Consider focusing and doing one thing well at this stage in your career, for past the age of 50 you will find it harder and harder to continue to do all things well”. I was already interested in palliative care, picking up orphan patients who, approaching the end of life, did not have a family doctor. Realizing I lacked knowledge in the field, I sought continuing medical education in palliative care and related fields such as chronic disease management, cancer care and ethics. When I was given the opportunity to work several hours a week in hospice, I found it to be a refreshing diversion from the daily pressure and demands of a busy general practice.

When I began to become more involved in palliative care in 2000, there was no year of added competency training available in British Columbia. My training was a one-week course with the Victoria Hospice, followed by a two-month University of British Columbia Family Practice Enhanced Skill Residency Program to become a general practitioner in oncology. Further training was provided on the job, and also by being mentored by and consulting with colleagues. In 2007, I accepted a full-time palliative care position in an urban community providing consultation for patients in hospital and at home. This involved working with an interdisciplinary team composed of a certified nurse specialist, nurse clinician, social worker and pharmacist. One day per week I provided pain and symptom management (PSM) consultations with the BC Cancer Agency.

The average age of all patients on the End-of-Life Care Program is 73 years, while on the tertiary palliative care unit it is 66 years, and in the PSM clinic it is 55 years. Of End-of-Life Care Program patients, 75% are cancer patients, and the remainder mostly have end-stage chronic disease. Many of the patients we see earlier in their patient journey at the PSM clinic we see again later as they transition to the End-of-Life Care Program. It was rewarding to follow these patients through their end-of-life journey and provide care regardless of whether they were at home or in the hospital, tertiary palliative care unit, or hospice.

Recently, I was given the opportunity to become program medical director for the End-of-Life-Care Program in our health authority. My work is now 30% clinical, 10% research and 60% administration. The challenge I am faced with is having a limited budget while having to provide enough support to patients and families, especially as the over-65 age group continues to grow. We have a population model of palliative care which aims to provide a palliative approach to care to all who will benefit. Since there are not enough palliative care physicians, part of our challenge is to provide support and education in the palliative approach to care to all health care providers.



There are many and exciting opportunities in palliative medicine. It has been rewarding to mentor family practice residents and those in the year of added competency in palliative medicine program. By virtue of being a council member with the BC Cancer Agency Family Practice Oncology Network, I had the chance to co-chair the working group that authored BC's provincial palliative care guidelines, which were adopted for use in the BC Practice Support Program End-of-Life (EOL) Module. The guidelines and support program algorithm have now been incorporated into the family physician workflow for point-of-care access within the clinic electronic medical record (EMR). This is the outcome of a partnership with and a research project of the University of Victoria. Rather than the usual 5–10% uptake of guidelines, there has been over a 50% uptake with the practice support program, and further uptake with adoption of the EOL module into physician EMRs.

I have been privileged through our health authority and the BC Cancer Agency to have been provided research opportunities. Recently, two colleagues and I completed a pilot clinical drug trial for treatment of intractable symptoms that produced encouraging, groundbreaking results.

Those who decide to become involved in palliative medicine will find it rewarding, with much satisfaction in providing guidance, support and opportunity to provide impeccable symptom control to those who are suffering. In many ways, the rewards for caring for a patient and family at the end-of-life are similar to those experienced when ushering a newborn into this life. Interested family physicians could participate by making palliative medicine an additional focus to their family practice. If you are looking for a career in palliative medicine, it is recommended to enroll in the year of added competency training in palliative care offered conjointly through the College of Family Physicians of Canada and the Royal College of Canada. For those who qualify, there will soon be a two-year Royal College subspecialty training program in palliative medicine. Residency positions are expected to be available starting in July 2016.

# Gil Kimel (Vancouver)

MD, MSc, FRCPC

Intensivist and Palliative Care Physician, St. Paul's Hospital

Clinical Assistant Professor, Department of Medicine, University of British Columbia



## How did you get involved in palliative care?

I started my training in internal medicine with a specialization in oncology. While in oncology one of my mentors noticed that I seemed to be most interested in patients who had incurable disease. After some time, I realized that I was most interested in helping relieve suffering in those patients who were no longer candidates for oncologic treatments because of the progressive nature of their disease. My mentor encouraged me to continue to study palliative care in oncology by connecting me with Dr. Nathan Cherny, an expert in oncology and palliative care. I worked with Dr. Cherny in Israel, focusing on clinical and communication skills in palliative care. This experience changed the course of my career. After returning I continued my studies and completed the palliative care

fellowship program at the University of British Columbia (UBC).

Another experience that helped shape my career came when I read a paper by Dr. Jennifer Temel, who found that patients who had metastatic lung cancer and had received palliative care in conjunction with the standard oncological treatment had fewer symptoms and lived longer than those who only received standard oncologic treatment. I thought that it would be useful to apply this approach to patients with heart failure and to test if we could improve quality of life by focusing on symptoms in patients with advanced heart failure.

## What formal/informal training in palliative care did you receive in palliative care?

Formally, I have completed UBC's one-year fellowship in palliative care.

Professionals in any skilled profession, whether it is in athletics, theater or medicine, need coaches or mentors to guide them along the way. It is important to find a mentor that you trust and that has the experience to provide you with valuable and careful feedback that allows you to grow, mature and improve. Every staff physician in our division can be paired with a mentor of their choice through an optional mentorship program. The mentor will observe as you work with trainees and provide feedback to help you improve. This is a great opportunity for both professional and personal development as the amount of career development may decrease after

you become a staff physician. As I have gone through this program, I found it to be very valuable to furthering my skills as a palliative care physician.

I keep up with advances in medicine by reading journals, participating in rounds and lecture series, and attending rounds in pain management or other related areas.

### **Current work in palliative care**

I work at St. Paul's Hospital in downtown Vancouver. Patients at St. Paul's can be very sick, and many live in unstable housing, have addictions or have end-stage disease. Approximately 70–80% of palliative care patients at St. Paul's have malignancy, while 10–20% have heart failure, chronic obstructive pulmonary disease or renal failure.

Although I trained in internal medicine, I now dedicate approximately 95% of my practice to palliative care. My main clinical and research project in palliative care is with our Heart Failure Supportive Care Clinic, which was launched in 2011 and is located at both St. Paul's Hospital and the Vancouver Hospital (VGH). We see patients who are not candidates for heart transplants or left ventricle assist devices, but have advanced heart failure. We focus on improving patient symptoms and aim to support them so that they can remain at home. The vast majority of patients do not want to be in a hospital — they want to be at home with their loved ones. In the clinic, physicians work closely with nurses to provide the care that's needed. Most clinic appointments take one hour because of the amount of information we need to collect. We also spend a significant amount of time educating and preparing patients for what might happen as their disease progresses.

### **Challenges and opportunities in palliative care**

We ought to expand outpatient access to palliative care. Not only is it preferred by most patients, but it is also much more cost-effective for the health care system. In our view, patients who want to be at home and can be at home should be at home. We need to develop new ways to support this in the community and to increase funding in this area.

Another challenge in palliative care in Vancouver is the lack of hospices. Many palliative care patients who can't manage on their own at home will be admitted as an inpatient on a palliative care or medicine unit but would probably be more comfortable at a hospice. A large part of government funding for palliative care is spent on providing inpatient palliative care, which provides help for most patients in the short-term, but helping patients transition safely to the community is the key to the highest quality palliative care.

### **Tips and advice for physicians who are interested in going into palliative care**

Medical students and residents who have an interest in chronic disease management should consider rotating through a palliative care elective. This will allow the trainee to focus on complex medical patients and to treat their symptoms in a holistic manner. Students should choose a medical discipline that they are most interested in and that they are enthusiastic about, and then consider completing the palliative care fellowship. It is important for students to find a great mentor who can guide and challenge them along the way. I probably would not have ended up in palliative care if I didn't have mentors who showed interest in me and suggested that I consider studying palliative medicine. You have to love what you do and the people that you work with, and I'm very fortunate to have had mentors who pointed me in this direction.

## Martin LaBrie (Calgary)

*MD, CCFP, FCFP*

*Palliative Care Consultant, Alberta Health Services (Calgary Zone)*

*Clinic Physician, Southern Alberta (HIV) Clinic, Calgary*

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My involvement with palliative care developed early in my career. Coincidentally, from 1980 to 1982, my clinical experiences in internal medicine and pediatrics during my medical clerkship and family medicine residency program were in cancer care settings. At the time, it was common to see patients admitted to care with a diagnosis of cancer remain in hospital to undergo treatment, become increasingly symptomatic from illness progression and treatment, and die within days or weeks. Patients and their families often have a poor understanding of

their illness, prognosis and goals of treatment. I was extremely distressed by our inability to address the physical, emotional and existential suffering that individuals and their loved ones faced when confronted with life-limiting illnesses. Palliative care was still a very new concept at the time, developing as a counter-culture response to the medicalization at the end of life, but there were already a few clinicians who were involved in developing capacity for palliative care in my community. I sought out these mentors and spent much of my elective time during my residency in palliative care. When I opened my family medicine practice in 1983, I continued to develop a focus on palliative care.

At that time, palliative care was mostly community based and low acuity, and involved providing end-of-life care almost exclusively for patients living with cancer after there was “nothing left to offer” in terms of active treatment. There was little research to guide treatment decisions. Most medical interventions involved the use of opioid analgesics and sedation, or were based on anecdotes and opinions from more experienced physicians. It was not long after this that two developments directed my involvement in palliative care. The first was the increasing quantity and improving quality of research in palliative medicine thanks to pioneers such as Balfour Mount, Neil MacDonald and Eduardo Bruera. The second was the emergence of HIV/AIDS. I encountered my first patient living with AIDS in 1985. At that time, persons living with HIV/AIDS were almost exclusively gay men, often disengaged from their families and marginalized in the community, factors that further limited the supports available to them. They suffered from multiple concurrent medical problems that were very poorly understood and endured a heavy burden of symptoms and unpredictable illness courses. They were also highly stigmatized. The options available to them focused heavily on survivorship as well as political and

social activism. As I cared for these patients by providing palliative symptom management and prescribing antiretroviral therapies as they became available, I learned the importance of maximizing the quality of living throughout the trajectory of the illness, and not just at the end of life. I also learned the importance of using disease-modifying and palliative interventions concurrently rather than on a mutually exclusive basis, as was the standard for cancer care. I also became more aware of the critical need to normalize the living situation as much as possible for people and families confronted with progressive, life-limiting illnesses. Palliative care is a community's response to the suffering that results from illness. The suffering is not limited to the individual — it also affects families and the entire community. Although palliative medicine is an important aspect of this, it is only a subset of palliative care.

In 1997, I took on a part-time role as a palliative care consultant with what was then the Calgary Regional Health Authority. By the end of 1999, I left family practice and restricted my medical activities to palliative medicine and HIV care. I currently practice as a palliative medicine consultant in the acute care sites in Calgary, primarily at the Foothills Medical Centre. I am very active in teaching in the faculties of Medicine and Nursing at the University of Calgary, at the undergraduate and post-graduate levels. My academic interests are in the areas of palliative care development for homeless and marginalized individuals, as well as the development of community palliative care capacity. I am very concerned by the professionalization of palliative care that has occurred over the last several decades, which is likely unsustainable and may not meet the needs of smaller and isolated communities. Through a project sponsored by the Canadian Medical Foundation, I had the opportunity to work on developing palliative care capacity for individuals living with HIV in resource poor settings in Burkina Faso, Western Africa. I think that the lessons we can learn from these settings can dramatically improve our capacity to manage suffering in our own communities.

I encourage all of my students to incorporate the management of suffering into their medical practice, regardless of which speciality they pursue, and I'm always open to helping my students find innovative ways to do so. Faculties of medicine have a critical role to play in further expanding this area.



# Stephen Liben (Montreal)

MD

*Director, Pediatric Palliative Care Program, The Montreal Children's Hospital*

*Associate Professor of Pediatrics, Faculty of Medicine, McGill University*



## **How did you get involved in palliative care?**

I had been working as a pediatric intensive care specialist for eight years when I began to recognize that what was most challenging and rewarding for me was being involved in the possibility of making a positive difference for children who had a high chance of dying, and for their parents. They often referred to “small things” that I could offer as a physician

that made a huge difference to the lives of these children and their parents. Such interventions as reducing pain, minimizing intrusive and ultimately useless medical interventions, and making things better in the immediate present were anything but “small things”. Children and parents told me over and over again how much it meant to them to have pain reduced, interventions carefully planned, and to have someone who could be present with them when cure was no longer likely possible.

In 1995, the director of pediatric palliative care position opened up in the same hospital where I was already working as an intensivist. I applied, despite knowing very little about what the work might entail. I ended up getting the position, probably because the field was so new at the time but, most importantly, because no one else had applied!

## **What formal/informal training in palliative care did you receive in palliative care?**

I realized that I needed more training before I could take on the role at Montreal Children’s Hospital in 1995. However, in the 1990s there were no formal training programs in pediatric palliative care, so I set out to create my own program. I spent a month with Dr. Balfour Mount, a world-renowned adult palliative care expert based at the Royal Victoria Hospital in Montreal, and another month with Dr. Ann Goldman at the Great Ormond Street Hospital for Children in the United Kingdom. These two extraordinary early mentors have had an impact on my life and career to this day. With two whole months of informal observer training under my belt, I took on my new role. I felt a little more prepared than when I started my journey, but I was still incredibly ill-prepared to face the challenges of clinical pediatric palliative care. I’m very relieved to see that there are now comprehensive formal training programs to properly prepare clinicians for work in this area.

### ***Current work in palliative care***

As director of a pediatric palliative care program in an academic medical centre, I spend my time in clinical practice, teaching and research. I am also a pediatric hospitalist on inpatient medical units for approximately two months per year, which helps me maintain my skills in general pediatrics. In addition, I'm currently engaged in a teaching project to help educate undergraduate medical students at McGill University about mindfulness in medical practice. While not directly connected to palliative care, mindfulness-based practice allows practitioners to respond more effectively to stress, foster personal well-being and improve patient care. I cannot overstate how helpful mindfulness training and practice continues to be in my work and outside-work life.

### ***Challenges and opportunities in palliative care***

One of the most critical issues in this field is the need for pediatric palliative care to be recognized as a core component of pediatric medicine. Positive steps in this direction include the recent recognition of speciality status for the field by the Royal College of Physicians and Surgeons of Canada.

### ***Tips and advice for physicians who are interested in going into palliative care***

In this job nothing matters more than the quality of relationships: relationships with yourself, with colleagues, and with patients and families. Essential ingredients for a happy and successful career are the skills of paying attention to your own need to make space for yourself in your life, coupled with being open to the possibilities that this work offers to be creatively engaged in meaningful work that helps both self and others.



# Susan MacDonald (St. John's)

MD

*Associate Professor of Medicine and Family Medicine, Memorial University*

*Medical Director of Palliative Care, Eastern Health*

*President, Canadian Society of Palliative Care Physicians*



My interest in palliative care began over 30 years ago as a Public Health nurse, but it became a passion as a family medicine intern on my first medicine rotation. Faced with a patient who had a second devastating stroke on top of end-stage Parkinson's disease, I found the attending physician's orders, which were to use enemas to reduce the patient's potassium, unconscionable. Being told "no one dies on my service with elevated potassium level" was the equivalent of a red flag to a bull. It was at that moment I decided to ensure no other patient suffered in the same manner.

I began my career as a full-time palliative care consultant in Newfoundland after completing two fellowships in palliative medicine, one at the University of Alberta under Dr. Eduardo Bruera and Dr. Neil MacDonald, and the other at Harvard University with Dr. Andy Billings.

I'm currently the medical director of palliative care for Eastern Region. This is a half-time position. The rest of my time is split between clinical work and academia. My main research project is developing an app to track patient's symptom scores (using the Edmonton Symptom Assessment System). The scores are remotely monitored, and any changes will lead to an immediate clinical evaluation followed by an intervention. There are plans to expand this project from palliative care into chronic care.

My real passion is teaching. Several years ago I redeveloped the undergraduate palliative care course at Memorial University by using a combination of movies, simulated family meetings, case-based instruction and didactic lectures. The course has been the highest evaluated course for several years, and I have won three teaching awards because of it. One thing I've learned from over 17 years of teaching is that a collegial approach works best for me. All of my students are colleagues and deserve to be treated as equals.

Currently, I'm the president of the Canadian Society of Palliative Care Physicians (CSPCP). This position has been a challenge, particularly in light of the current issues related to euthanasia, physician-assisted suicide, advance care planning, and the pressure on health care workers to do more with less. However, I'm glad to have the opportunity to speak out on a subject I feel very strongly about. The board and staff of the CSPCP are an amazing group of individuals and a joy to work with, and have made being in this position much easier.

My personal philosophy of palliative care could be summarized as follows: it is not something to be afraid of; instead, it should be embraced. It is an approach to care that allows the patient to make the best decisions possible and to live as well as they possibly can. It should be started early

on, along with active treatment. All clinicians should provide basic palliative care and receive training in this field as the skills and knowledge are attainable by everyone. Primary care clinicians, such as family doctors, nurse practitioners and nurses, provide most palliative care, and it is paramount that this continues. As a former nurse, I embrace the interdisciplinary approach that palliative care offers. It is a model of care that any other field could, and likely should, emulate. Palliative care people tend to be highly creative, used to hard work, can deal with seemingly impossible odds, and are able to come together as a team. These are some of the reasons why they are great to work with. That and their distinct sense of humour!

In my spare time, I dabble in the arts. I've tried my hand at acting and screenwriting, and produced a short film for film school. I'm an award-winning author of a young adult science fiction novel. (How cool is it to say that?) My second novel came out last year, and the third novel is (I hope) on the last edit. I'm married to an endocrinologist/researcher who paints for a hobby. I have two moderately well-behaved young adult children, and two dogs who are not so much.

# Erin O'Connor (Toronto)

MD, MSc, FRCPC

Physician, Division of Emergency Medicine and Palliative Care, University Health Network



## **How did you get involved in palliative care?**

Before being accepted to medical school I worked at a nursing home and saw how physicians can improve the quality of life of the elderly. Although I decided to pursue specialty training in emergency medicine, I gave serious thought to training in geriatrics or oncology while in medical school. Then, while completing my five-year residency in emergency medicine at the University of Ottawa, a friend and colleague, Dr. Lisa Fischer, presented grand rounds on the application of palliative medicine in the emergency department. This seemed the perfect way to combine my previous interests with my chosen residency training.

## **What formal/informal training do you have in palliative care?**

My first exposure to palliative care was in medical school, where I was a member of both a palliative medicine and an ethics interest group. These groups

were a forum for discussion of research articles, and also provided the opportunity to observe palliative physicians during patient home visits. My formal training occurred in my fourth year of residency when I completed a fellowship program in palliative medicine. While subspecialty training for emergency physicians in palliative medicine is a very new concept for Canada, in the United States, palliative and hospice medicine has been a recognized subspecialty of emergency medicine since 2008.

## **Current work in palliative care**

I completed residency training in 2014 and I currently work at the University Health Network in Toronto. Two-thirds of my time is spent as an emergency physician and one-third is spent working with the inpatient palliative consult team at the Toronto General Hospital. Research studies based in the United States and Australia indicate that Emergency Physicians would like more training in managing patients with palliative needs, and so I am working with Pallium Canada to develop LEAP – Emergency (Learning Essential Approaches to Palliative and End-of-Life Care), which is a course to teach the essentials of palliative medicine to emergency clinicians. In the past I have also worked with Pallium Canada in a smaller role on a similar course teaching palliative medicine skills to paramedics. My research interest is in quality improvement projects that will enhance emergency department care of patients with palliative needs or those who are near the end of life.

## ***Challenges and opportunities in palliative care***

Many people may think that palliative medicine is only for those at the end of life or those with metastatic cancer, but in reality, patients facing a large burden of symptoms but are not near the end of life and patients with chronic non-cancer illnesses can benefit greatly from palliative medicine. With an aging population, I believe pain and symptom management skills will become more important across the entire spectrum of medicine and I would encourage all physicians to gain a greater understanding of the issues. In terms of patients in the emergency department, major challenges that we face involve the lack of end-of-life planning by the majority of patients with end-stage disease.

## ***Tips and advice for physicians who are interested in going into palliative care***

Although the environments are very different, I enjoy working in both the emergency department and with the palliative care team. Palliative care allows for the development of bonds with patients and their families, which is not possible very often in the busy emergency department.

The approach to patient-centred care that is the foundation of palliative medicine can enhance the ability of physicians to care for their patients. I encourage physicians or trainees with an interest in palliative medicine to pursue further training, either in the form of skill-based courses or more formal subspecialty training.

# Patrick O'Shea (St. John's)

MD, CCFP, FCFP

Family Physician



## **How did you get involved in palliative care?**

When I was completing my family medicine residency at Memorial University from 1980 to 1982, I included a placement in the then new palliative care unit. This was followed by a three-month elective rotation in geriatrics in Plymouth, England. When I started my practice, I accepted a lot of referrals for older patients, and palliation was just a natural part of the comprehensive family practice we were all striving for at that time. I always considered end-of-life care as just the logical conclusion of caring for a patient over the years. For about 10 years, I was medical consultant for the St. John's Home Care Program and worked closely with the community nurses, who continue to refer palliative patients to me to this day.

## **What formal/informal training did you receive in palliative care?**

Along with my exposure in my residency program, in 1995, I completed a month-long fellowship in geriatrics and palliative care in London, Ont., which was sponsored by the Royal Canadian Legion. I have been lucky to have a close collegial relationship with the palliative care consultants in our city, including two partners in my practice who work part time for the palliative care consultation service. One never stops learning!

## **Current work in palliative care**

I still have an old-fashioned comprehensive family practice (I gave up doing deliveries five years ago after 27 years) with daily office clinics. I do rounds with patients in two nursing homes and an assisted living facility, and spend two half-days a week doing other house calls in the city. As a result, I spend half-time in the office and half-time in the community. I have about one to three palliative patients at any one time. For them I make regular home visits, and give the families my cell number. I palliate all my own patients, and accept referrals from other doctors and home care nurses, and from the palliative care consultants. I do not have a formal program. I have been doing things this way for 32 years, and hope to continue to do so for many more years.

## **Challenges and opportunities in palliative care**

There has been a growing acceptance of palliation by patients, as society becomes more aware of and grapples with the issues around end-of-life care. There are many more patients looking for assistance and guidance in caring for themselves and loved ones. The media find end-of-life stories irresistible for their emotional hooks, and the medical profession is starting to react and

respond. As a result the opportunities are great for more awareness, education, and training. This particular initiative by the Canadian Medical Association is an example. There are more opportunities for people to choose the option to stay at home to die.

However, there are also significant challenges. I am not sure the ongoing fragmentation of family medicine into “special interest groups” is a good thing. Although I acknowledge the need for interested physicians to do further training and become local experts, letting only “palliative care specialists” deliver services is fraught with danger. Family doctors have to provide the great bulk of palliative services. The experts should be aiding and consulting. Their challenge is to give family doctors the knowledge and support to look after their own patients until they die. This may not be easy. If family physicians continue to abdicate these responsibilities, the profession and our patients will not benefit.

### ***Tips and advice for physicians who are interested in going into palliative care***

If you are a family doctor interested in palliative care, you have to accept support – from palliative care specialists, from community nurses, from colleagues, and from your spouse. You have to be willing to give patients your cell number. You have to make the commitment to be there at all times for your patient and their family. You have to resist the urge to do something, when there is nothing to do but listen and provide support. You have to go to wakes, and allow yourself to grieve. You have to be aware of your own emotions and beliefs, and respect those of your patient.

Palliative care is one area in family medicine where you can most clearly appreciate the reason you entered medicine: to help your fellow human journey through life, comforting always, even to the end.



## José Pereira (Ottawa)

*MBChB, DA, CCFP, MSc(MEd)*

*Head and Professor, Division of Palliative Care, Department of Medicine, The Ottawa Hospital and University of Ottawa*

*Chief, Department of Palliative Medicine, Bruyère Continuing Care, Ottawa  
Scientific Officer, Pallium Canada*



In 1994 a patient named “George” walked into my office in rural southwestern Manitoba and changed my career. The patient told me that he had advanced metastatic cancer; it was progressing despite chemotherapy and radiotherapy. He said that he had come to terms with his mortality but was experiencing severe pain. He was terrified that he would spend whatever time that remained of his life in excruciating pain. He had seen several physicians but none were helpful.

I remembered feeling uncomfortable. I, like many physicians, had never had any palliative care training. I informed him that I could not increase the small dose of morphine he was on because it had serious side effects, including addiction. He looked disheartened. He got up to leave and said “I hope that one day doctors like you will be able to look after people like me.” This prompted me to attend a five-day palliative care course in Hamilton a few weeks later. It was an eye-opener! When I returned to

Treherne I called George and asked him to give me a second chance. I cared for him until his death several months later. I learned that with a little bit of education doctors can make a big difference for patients like George.

In 1995 I made the decision to become a palliative care physician and successfully applied to do a one-year palliative care clinical research fellowship at the University of Alberta in Edmonton, where I was mentored by Dr. Eduardo Bruera, Dr. Robin Fainsinger, Dr. Mel Miller and Dr. Sharon Watanabe. I worked in different settings and learned that a fully functioning palliative care system requires several key components, including palliative care consultation teams in hospitals and the community, a palliative care unit, hospices, home care and family physicians.

In 2001 I moved to Calgary and opened a palliative care unit at the Foothills Hospital. I became involved in education and co-founded the Pallium Project of Canada, a national project to build primary-level palliative care capacity through education ([www.pallium.ca](http://www.pallium.ca)). Pallium has grown in size and scope over the years and I am currently its scientific officer. Later, to do a better job teaching, I completed a master’s degree in Medical Education in Calgary.

In 2002, as co-chair of the Education Committee of Health Canada’s Palliative Care Strategy, I co-founded, with the late Dr. Larry Librach, the Educating Future Physicians in Palliative Care and End-of-Life Care (EFPPEC) Project, a project to implement palliative care in Canadian



medical schools. In 2008 I took up my current position as head and professor of the Division of Palliative Care at the University of Ottawa and medical chief of palliative care at Bruyère Continuing Care. In Ottawa, I co-led the implementation of the first regional Palliative Care Program in Ontario (2010) and a more equitable funding model for hospices.

My time is currently divided between clinical work (mainly on a palliative care unit), administration, education, research and advocacy. It is becoming increasingly difficult to do all of these things because the Ontario Ministry of Health and Long Term Care is not providing new positions to meet growing needs. At the end of 2013, I completed a three-year stint as the provincial lead of Cancer Care Ontario's Palliative Care Program. During that time we worked to integrate palliative care earlier in the trajectory of illness and to undertake standardized symptom assessment in everyday practice.

One of the biggest challenges facing palliative care currently is the notion that such care is limited only to the last days or weeks of life. In Ontario, the health ministry's Health Services Funding Reform, while much needed, is undermining some key palliative care services such as palliative care units, consultation teams and specialist academic physician positions. Another challenge, prompted by the euthanasia debate, is reducing complex concepts such as suffering, dignity and pain to oversimplified statements, leaving the misperception that dying is invariably accompanied by suffering and indignity.

I encourage all clinicians to take the time to get a little bit of training in palliative care – a day or two will make a big difference to your patients, themselves and the health care system. For those wanting to become palliative care specialists, particularly if taking on the role of consultants, researchers, educators and managers, obtain the required advanced training. If setting up shop as a specialist without the required training is not acceptable in other fields, why should palliative care be any different?

## Geneviève Richer (Montreal)

MD

*Medical Director, West Island Palliative Care Residence*

*Chief of Palliative Care Service, Lakeshore General Hospital*

*President of Counsel of Physicians, Dentists and Pharmacists CSSS-ODI*

*Vice-President, Association des conseils des médecins, dentistes et pharmaciens du Québec*



I am a general practitioner who works as a hospitalist. In the last 15 years I developed an interest in palliative care and became the medical director of the West Island Palliative Care Residence in Montreal in 2005. I obtained my medical degree in 1990. I was originally trained in emergency medicine, so I was working as an emergency physician when I first started my practice. I highly enjoyed that segment of my career, mostly because medical interventions can have immediate impact on the patients.

After ten years in practice and two babies, I needed to reorient my career towards a practice with more stable schedules, but I couldn't give up the gratification of the immediate impact I was referring to earlier. All this coincided with the period that saw palliative care become an emerging field in North America at the end of the 1990s. Some hospitals offered a palliative care service, others barely had a palliative care consultant, and some had nothing at all.

I started to contemplate the idea of steering my practice towards end-of-life care. I was still convinced that I would be able to make a significant difference to these dying patients for whom there was “nothing else we could do.” And yet, as I learned during the following years, there is so much that we could still do in palliative care to improve patients' quality of life and peace of mind.

In order to familiarize myself with the medical guidelines and pharmacologic aspects of palliative care, I started reading everything I could find on the subject and attended palliative care conferences. I also joined a group of doctors in a teaching hospital where a palliative care unit was being developed. The more I learned, the more I noticed that patients were still being treated in a very “medicalized” environment. From that point on, I began secretly dreaming of a better setup for them.

Then I met Teresa Dellar, one of the most inspiring people I know. Teresa is a social worker who used to work in the oncology department at the Lakeshore General Hospital and witnessed many of her patients dying on a random medical floor or, worse, dying on a stretcher in the emergency room, which is the ultimate undignified death. Teresa had the vision and the initiative to kick-start the creation of a hospice for terminally-ill patients. I was working at the Lakeshore General Hospital at that time and this facility was being built almost in my backyard. A year after the

facility opened in 2002, I joined the medical team. When I started working at the West Island Palliative Care Residence, it was a nine-bed facility built in a house, with a living room and a kitchen where there was always something baking in the oven. The residence is able to offer a homey feeling to the families and visitors while also meeting their physical, spiritual and existential needs in an interdisciplinary manner.

I became medical director two years after joining the residence. Soon after I began this new role, I worked with my team to develop a consultation service at the nearby Lakeshore General Hospital, a 200-bed facility with an oncology department but no palliative care consultation service. The first problem we faced is that I had only a team of two doctors — myself and my dear colleague, Dr. Pierre Cholette, who will be retiring in mid-2015.

Ten years have passed since then. The facility continues to improve under Teresa's leadership. In 2012, West Island Palliative Care Residence opened up a second location that added 14 new beds. The new location admits patients who have a little longer life expectancy. This facility upgrade resulted in our 23-bed facility becoming the largest free-standing palliative care hospice in Canada. I look back on these last 10 years with satisfaction. We are now a group of nine doctors split between the two sites. Some of the physicians also work at the Lakeshore General Hospital, where we now offer palliative care consultative services and an outpatient clinic in the oncology department. Others do home visits with a palliative care nurse in the community. Recently, we were accredited by McGill University and Université de Montréal for undergraduate and post-graduate medical training, and became a designated teaching facility. What a journey!

Today, I may have some wrinkles and grey hair (don't worry, I dye it!) but I still remain amazed by the lessons of grace and courage a deathbed can provide. I was privileged enough to capture the last moments, and sometimes, the last words, of so many people. Every interaction with patients remains a unique and emotionally charged experience.

What follows is some advice for young doctors who are considering palliative care as a career path:

1. Remain humble: In the face of an unavoidable death, remember that you don't have a lot of control over the situation. Patients still want to maintain their autonomy until the very end. Thus, it's important to provide them with what they need to be comfortable during the process. That's your mandate. The rest belongs to them.
2. Remain serene, despite all the sadness, the emotional pain, the losses and the tragedies that you will witness. Keep in mind that death is a natural and inescapable outcome of life. You won't be able to alter that, so don't even try. Just accept it. But make the silent promise to your dying patients that you'll "have their back" as their doctor, no matter what.
3. Remain human, in the most imperfect sense of the word. Despite your professionalism, you will sometimes cry. And despite your great empathy, sometimes you will not cry. Forgive yourself when you do as well as when you don't. Be warm and compassionate, then take a step back in order to preserve your own emotional sanity.

You are a mortal too, after all. This daily display of finality will bring you to face your own human condition, with all its wonders and its precariousness. So enjoy your career as a palliative care doctor, but most of all, enjoy your life, in its full essence, and make the most of it.

# Marli Robertson (Calgary)

*MBCbB, FRACP*

*Clinical Associate Professor, Section Chief, Palliative Medicine Department of Pediatrics, Faculty of Medicine, University of Calgary*

*Medical Director, Children's Hospice and Palliative Care Service (Rotary Flames House), Alberta Children's Hospital*



Rachel Naomi Remen<sup>1</sup> speaks of physicians' long lineage of healers, the meaning that comes from providing service, and the concept of healing when things cannot be fixed. These concepts of the "art of healing" including bringing one's whole self to be a "companion" to those who are suffering has long been a framework that has underpinned my pediatric practice.

My whole career I have been drawn to care for children with medical complexity and their families. In particular, my practice has involved caring for a high proportion of children with neurodevelopmental disabilities. My research and clinical practice as a pediatric gastroenterologist and nutrition physician focused on nutrition in children with cerebral palsy (CP), gastrointestinal function in children with autism and CP, care of children with short bowel syndrome and leadership of the Southern Alberta Home Nutrition program.

This clinical background, coupled with my personal philosophy about medicine and my interest in clinical ethics and health care communication, meant that the opportunity to be medical director of a yet-to-be built pediatric hospice "called" to me. I made a shift to full-time pediatric palliative medicine late in my career, enjoying the opportunity to increase skills and knowledge in new areas and to be able to be innovative in developing new models of service for this patient population.

Opening the seven-bed pediatric hospice, Rotary Flames House, required the integration of the Palliative Care and Grief Support Team services at the Alberta Children's Hospital with Rotary Flames House staff to form a new program called the Children's Hospice and Palliative Care Service (CHaPS). This provided an integrated model of palliative care with services in a variety of care settings ranging from the hospital, home, community, and hospice. Palliative care services are often combined with care towards a cure or prolongation of life. The team works in close collaboration with the child's specialist and primary health care providers.

At Rotary Flames House, infants, children and youth with serious illnesses are offered pre-planned respite care for up to 30 nights per year as well as emergency respite and some transition stays if needed. Children with complex medical, life-limiting or life-threatening conditions and are followed by our palliative care service could also receive specialized recreational day programming from a certified child life specialist and volunteers.

The hospice is also home to our grief support service. Grief support is offered to all parents whose child has died — this includes sudden unexpected death and death from a serious illness or from a chronic condition. This support may involve individual counselling with our grief counsellor or facilitated bereavement groups for parents, as well as an invitation to attend the annual memorial service at the hospital and other special workshops and events to mark occasions.

The hospice was built with two family apartments, allowing the entire family to live there when a children are being cared for by an inter-professional team at the end of their life and when this is the best choice for the family. The close proximity and the organizational links to Alberta Children's Hospital means that not only can intensive symptom management be provided by the palliative care team in a home-like setting, but the child's other health care providers remain part of the supportive team for the family.

Working in pediatric palliative care is a privilege. It is a specialty that requires first and foremost medical expertise, but also a sense of humour, being comfortable with the uncertain and the unknown, and the humanity and compassion to be truly present to great suffering.

One of the challenges in pediatric palliative care locally, nationally and internationally relates to lack of understanding of the integrated model of palliative care where referral will ideally be at the onset of the potentially life limiting condition, not at the end of the trajectory of illness. Early referral for blended care provides families with another layer of support while living with a child with a serious complex condition and facilitates the relationships which allow for care planning as the child's illness progresses.

Currently, as co-chair of the executive of the Canadian Network of Palliative Care for Children, the pediatric representative on the Quality End-of-Life Care Coalition of Canada (QELCCC) and a member of the Board of Trustees of the International Network of Palliative Care for Children, I have the opportunity to advocate for these vulnerable children living in Canada and around the world, as well as advocating for more support for the community of pediatric palliative care providers.

In Canada a major challenge is a growing gap between the resources allocated to pediatric palliative care and the increasing numbers of children who will benefit from specialized palliative care. Advocacy to effect change at provincial and federal policy level is important and any initiatives and innovations designed to improve palliative care need to consider the needs of all Canadians, inclusive of infants, children and youth and their families.

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<sup>1</sup> Remen, RN. Practicing a Medicine of the Whole Person: An Opportunity for Healing. *Hematology/Oncology Clinics of North America*. 2008 Aug; 22(4): 767–773.



## Rajeev Sharma (Calgary)

*MBBS, CCFP*

*Medical Director, Santuari and Agapé Hospices, Calgary*

*Hospitalist Physician, Peter Lougheed Centre of the Calgary General Hospital*



I first became exposed to palliative care during medical school, but only in a superficial sense. It wasn't until family medicine residency that I learned more about what palliative care means, and the challenges that come with it. However, my hands-on experience came as a hospitalist physician in Calgary, where I work with a broad spectrum of adult patients and medical conditions. Some of these include individuals with multiple chronic illnesses, including those with cancer and non-cancer terminal illnesses.

It was my encounters with palliative patients in this setting that challenged my understanding and comfort level with end-of-life care. I have been fortunate to have had great palliative care consultant mentors such as Dr. Martin LaBrie and Dr. Hubert Marr, who have helped me expand my horizons. Over time with their encouragement, I became increasingly keen on enhancing my skills and knowledge of palliative care.

I was looking to explore this avenue with hospice palliative work, and serendipitously I was invited to work at Santuari Hospice, a 20-bed hospice located within the hospital where I work, The Peter Lougheed Centre in Calgary. This hospice is unique in that it is located within an acute care facility, but endeavours to follow a community focused model similar to other hospices in our region.

Over the past four years, it has been humbling and a true privilege to be involved in the lives of our hospice patients and families. We are also fortunate to have a cohesive and high-functioning interdisciplinary team, which has been crucial for success. Prior to working here, hospice palliative work was a fearful and an uncharted journey fraught with anxiety and uncertainty. This work frequently challenges me intellectually, emotionally and spiritually. There have been very unique and interesting situations that have brought our team to tears, both from joy and pain. I have expanded my clinical time in palliative care, now also working at the Salvation Army Agapé Hospice in Calgary. I am fortunate to also participate in administrative roles at these hospices.

Santuari Hospice at the Peter Lougheed Centre has been an amazing oasis of peace, comfort and hope nestled within an often chaotic acute care world. Although the Santuari Hospice will close at the end of May 2015, a new community hospice in Calgary, the Covenant Care Dulcina Hospice, will be opening soon. I am eager to help the team at this new facility to provide high quality hospice palliative care.

When explaining to friends and family the nature of hospice work, the most common remark is, “Oh, that work must be so hard.” Indeed, there are some raw and challenging moments, but we are also equally privileged to witness moments of beauty, hope and inspiration. In fact, as my colleagues and team members can attest, this work can be quite draining but simultaneously soul-energizing. Supporting patients and families through these experiences provides us with an acute sense of reward and fulfillment. Palliative care is not all doom and gloom! As much as we try and lessen any grievous turmoil that might burden our patients and their families, we also achieve indescribable personal buoyancy when sharing moments of humour, remarkable life stories and truly unique encounters. So yes, I reply to my friends, this work can be hard but then again it is outweighed by far-reaching personal and professional fulfillment.

One key lesson I have learned is that our patients reflect our community — they are our friends, families, and neighbors. Despite facing the end of their journey, they still need us to recognize and respect their relevant and significant existence during their final days, weeks and months. Furthermore, a dignified and well-supported death is as important as a well-supported birth and other celebrated moments we experience in our lives. Hospice care is not just about the final moments of life. The hospice philosophy gives patients and families the opportunity to be united, to reflect, honour, and cherish their loved one. People are different in how they progress in this journey, but every patient reminds us that they are individuals worthy of dignity, respect and support during their most vulnerable time.

Over time, I have come to realize that some of the most important skills physicians need to work in palliative care are communication, patience, cooperation, trust, and flexibility. Although clinical knowledge forms the foundation for our work, these other pillars truly shape the direction of the care we provide. Also, somewhat surprisingly for this type of work, a well-timed and appropriate sense of humor can be remarkably effective at breaking tension and developing both rapport and trust. One also needs to rely on well-honed clinical skills, as invasive tests and treatments are not readily available or appropriate in a hospice setting. This can be challenging, but it forces us to be creative in managing the options available.

My personal belief is that hospice palliative care is one of the best examples of patient and team-based care. Prior to hospice work, I believed that I understood what a multidisciplinary team meant. However, I am frequently impressed by the significant impact that a well-supported and cohesive team can make in hospice care. It also highlights the importance of continuity and communication. My training in family medicine certainly has helped me develop a balanced approach, however palliative work has truly taught me the critical importance of being patient, being present, and keeping the goals and wishes of the patient in sharp focus. Our current learners in medicine will be very well served by being exposed to the educational opportunities in hospice palliative care.

In terms of training, the Victoria Hospice provides an excellent resource for extra training, in addition to our program’s regular Palliative Grand Rounds, and other regional and national continuing medical education opportunities, some of which are available online.

Although additional training is clearly invaluable to enhancing care, I encourage both newer physicians and those interested in expanding their palliative skills to first sit and listen to your patients and families. Be present for them and for the staff whom you work with. Your team members will invariably reflect and bear some of the burden your patients and families experience and will look to you for support, as you will to them.



Also, do not rush to remove hope from your patients' journeys, for you will find that hope is an indomitable force and a central anchor for patients at the end of life. You may be anxious, upset, frustrated, challenged and occasionally humoured by your experiences, but don't be afraid to let your patients know that despite contrary evidence, you are human, and can sympathize with their difficulties on some level.

The future of palliative care will include the challenges of how to provide optimal palliative care for our increasingly complex patients with non-cancer diagnoses, and how to support individuals who are unable to access hospice care. Palliative care is a remarkable and somewhat under-recognized field, but it has been the most rewarding aspect of my career to date, and it will absolutely continue to challenge my knowledge and perspectives in the future. I cannot predict where this journey will take me, but I am certain that I will continue to be challenged and humbled. I remain optimistic this journey will remain greatly rewarding.

## Harold (Hal) Siden (Vancouver)

*MD, MHSc, FRCPC*

*Medical Director, Canuck Place Children's Hospice*

*Physician, General Pediatrics and Palliative Care, British Columbia Children's Hospital*

*Senior Associate Clinician Scientist, Child and Family Research Institute*

*Clinical Professor, Division of General Pediatrics, Department of Pediatrics, University of British Columbia*



I was trained in pediatrics, biochemical diseases and developmental pediatrics, but pain management and holistic medicine were constant interests of mine. As a member of the BC Children's Hospital Pain Service, I was asked to consult at Canuck Place Children's Hospice, and in 1999 became one of the three staff physicians at the facility. In 2001, I became medical director. At the time, there was no formal training in pediatric palliative medicine. Instead, I undertook education in Canada and the US wherever I could. I also partook in longer training opportunities in palliative medicine in the United Kingdom to cement my skills.

The Canuck Place Children's Hospice provides pediatric palliative care consultative services to the BC Children's Hospital/Sunny Hill Health Centre, the BC Women's Hospital, and at various care settings around the province. Pediatric palliative care is the focus of my clinical work. I have an active research group, which is multidisciplinary and cross-Canada; we study all aspects of pediatric palliative care, ranging from clinical issues to family support to health systems. My personal focus is in symptom

management, epidemiology, and longitudinal study of metabolic, neurologic and chromosomal conditions. Canuck Place has an active education program for pediatrics or palliative medicine residents and a subspecialty fellow every month.

Palliative care faces many challenges, and some, such as funding support, are obvious. A more fundamental challenge is developing a solid research base and focusing on measurable outcomes to inform research, clinical practice, funding and program development. Our work is becoming more necessary as we reach the margins of cure for many children in industrialized countries and while still facing unacceptable childhood mortality in the developing world. As I sometimes say, "smarter doctors than me still have to come up with the cures, and in the meantime my job is to focus on the child's symptoms and quality of life."

My advice to physicians interested in pediatric palliative care are:

1. Giving morphine to a dying child does not make you a palliative expert. There is a fundamental corpus of knowledge and skill set that must be acquired first.
2. You must be highly tolerant of uncertainty and ambiguity. Children, even dying ones, can always surprise you.

3. Pediatric palliative care training should begin only after one has acquired and demonstrated all the skills of the general pediatrician, including knowledge of oncology, neurology, respiratory, genetics, gastroenterology, critical care, and newborn care. We apply skills in these areas daily.
4. It really helps to always have the big picture in mind.
5. Know how to take care of yourself and of your team.

## Cortney Smith (Truro)

MD, BSc.H, CCFP

Colchester East Hants Health Centre, Truro, Nova Scotia

Associate Professor, Family Medicine, Dalhousie University



### **How did you get involved in palliative care?**

I was fortunate enough to have a lot of exposure in palliative care as an undergraduate medical student at Western University and also as a family medicine resident at Dalhousie during my training. A lot of my elective experiences were geared towards geriatrics and chronic disease, so when I had the option to spend some time with the palliative care team I leapt at the chance. The interactions with patients and their families were such a rewarding, fulfilling part of my training; afterwards I sought to spend as much time with the team as possible, learning and being more involved.

### **What formal/informal training did you receive in palliative care?**

I completed my certificate of added competence from Dalhousie University in 2009. Since then, I've actively participated in LEAP (Learning Essential Approaches to Palliative and End-of-Life Care) sessions within our facility and facilitator training on a regular basis.

### **Current work in palliative care**

My entire practice is devoted to palliative care. I am lucky to work with a dynamic team that provides both inpatient consultation and home/community-based visits in rural Nova Scotia within the Colchester East Hants area, serving a geographically large district with a population of 75,000.

Our patient demographic is approximately 60% oncologic diagnoses and 40% end-stage chronic disease/neurologic diagnoses. Individuals can be referred by their physician, specialist or can self-refer to our program.

Some of my current interests within my work include tissue and organ donation at end of life, parental grief, delirium screening across all hospital settings, and art therapy.

### **Challenges and opportunities in palliative care**

I think one of the biggest challenges for palliative medicine involves advocacy and awareness. The words "palliative care" are still thought to be quite synonymous with the last hours of life. Now we use a palliative approach for illness that is most effective when initiated earlier in the disease trajectory. Patients and families are often quite surprised at our team's involvement. We live in a death-denying society in which the dying process is something most individuals have no knowledge of and find frightening. Engaging in discussion about planning, advance directives

and speaking openly about the emotions associated with illness and the end of life make this less daunting and intimidating for families, especially when done with an honest, compassionate approach. Many people, including health care professionals, are aware of our role in pain and symptom relief, but the other role, which is just as important, is getting to know our patients' values and goals and synthesizing this into a supportive plan that enables good decision-making. We see our job as coaches helping patients and families understand the normal experiences of dying, death and grief. Core palliative care skills should exist across all specialties and be available to all Canadians, but unfortunately is still limited to areas with the staff, expertise and resources to provide it. This challenge, though, is an opportunity in the making. By raising awareness, even locally, one family at a time, we can help to support and develop hospice and palliative care services within our communities and build upwards on a provincial and national level.

### ***Tips and advice for physicians who are interested in going into palliative care***

Find a mentor who can inspire you within the field and be engaged in some of the national discussions within the specialty. The Canadian Society of Palliative Care Physicians is an excellent resource for information, education and advocacy from a national perspective. Hospice and volunteer organizations are a foundation and voice for the values, needs and concerns for those living with a palliative illness locally. Volunteering your time with these groups can help you better understand your community's needs. Lastly, know your own limits of comfort, self-awareness and when to ask for help from your colleagues. Palliative care can be emotionally rewarding, but sometimes the journey we take with our patients can be difficult. Working with a team that shares their compassion and resiliency always lightens the spirit.

## Sharron Spicer (Calgary)

*MD, FRCPC*

*Pediatric Palliative Care Physician, Rotary Flames House Children's Hospice*

*Physician Lead for Safety and Chair of the Quality Assurance Committee, Alberta Children's Hospital*

*President, Alberta Children's Hospital Medical Staff Association*

*President Elect, Calgary and Area Medical Staff Association*



I am a pediatrician who has found a calling in pediatric palliative care. I completed medical school in 1995 and my pediatrics residency in 1999, both at the University of Calgary. After five years working in community and inpatient settings, I was drawn to providing a longitudinal approach of care for children and families with life-limiting conditions, from recognition and diagnosis, through the illness trajectory, at the time of death and into bereavement. In 2003, I entered a palliative care training program in Calgary and subsequently returned to Alberta Children's Hospital as a palliative care physician, leading the creation of the Division of Palliative Care within the Department of Pediatrics. Over the past 10 years, it has been exciting to see the growth of the division from one physician and a part-time nurse and social worker to five physicians and an entire interdisciplinary team! Over this time, we have also seen the opening of Rotary Flames House, Alberta's only pediatric

hospice. With the team and a specialized facility, we are truly able to meet the needs of families during the illness journey.

Pediatric palliative care has always been about living life to its fullest, no matter how long or how short that life may be. While many of our patients have childhood malignancies, a larger number of families face degenerative neurologic conditions, genetic syndromes or conditions related to birth events. The palliative care needs of children with cancer tend to escalate sharply as the time of death approaches, while those with other conditions may face years or decades of progressively decreasing functioning with life-threatening crises between periods of relative stability. Having a palliative care team work alongside the other care providers ensures that the family is supported with a team that understands their goals and can help with decision-making, symptom control and transition planning as their needs and conditions change.

In addition to providing clinical care, I have been part of regional and provincial initiatives in advance care planning, care (of the deceased) after death, and child advocacy. I am involved in quality and safety, and since 2013 I have been the physician lead for safety and chair of the Quality Assurance Committee at Alberta Children's Hospital. I have strong interests in ethics and family-centred care. I find that palliative care offers a rich blend of opportunities to mix clinical care in a patient- and family-centred approach, with a view of best practice and quality. I have enjoyed a rich career in this field.



## Lynn Straatman (Vancouver)

MD, FRCPC

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*Clinical Cardiologist, Heart Failure and Cardio-oncology, Vancouver General Hospital*

*Palliative Care Consultant, British Columbia Children's Hospital*

*Cardiology Lead, Specialist Services Committee Doctor of BC Project on Adolescent Transitions*



I initially became interested in palliative care during my fellowship in pediatric cardiology at the University of Michigan, and then continued this interest as I further specialized in adult heart failure, cardiac transplantation and adult congenital heart disease. Patients who were not considered to be acceptable candidates for transplantation often had a very palliative course after the decision not to transplant was made and the referral to palliative care for these individuals was not well established or even considered. As heart failure cardiologists we were often caring for these patients until their death. This experience led me to become a pediatric palliative care consultant at Canuck Place Children's Hospice in 2001, and I have worked their part time as a physician ever since.

Currently I am a clinical cardiologist at the Cardiac Function Clinic and Cardio-oncology

Clinic at Vancouver General Hospital. At this institution I follow adults with chronic heart failure and, if appropriate, refer them to our pain and symptom management/palliative care clinic which is staffed by an adult palliative care physician and nurses from the heart function clinic. This provides the patients with continuity of care throughout the course of their disease and allows for early referral for symptom management, advance care planning and counselling. This has increased the comfort of the nursing staff in making advance care planning part of the discussion at each visit where appropriate.

Through my work in pediatrics I became very aware of the challenges facing adolescents with chronic health care conditions who were transitioning from pediatric to adult care. Guidelines for acceptance to a pediatric hospice program are very different than for an adult palliative care program. Pediatric patients can be accepted to a palliative care program at the time of diagnosis and receive respite and symptom management care for many years. Some may receive care for over 10 years and then be transitioned off the program when they reach adulthood, and many may survive well into their 20s and 30s. They therefore do not fit the requirement for adult palliative care, which is usually expected survival of less than six months. The adolescent patient's ongoing medical issues therefore need to be addressed by family physicians and specialists delivering care to adults. This work is currently one of the focuses of a Doctors of BC grant examining methods to improve the care coordination of all youth with chronic health care issues through better communication between specialists and primary care providers.



## Irene Ying (Toronto)

MD, MHSc, BAsC, CCFP

Palliative Care Consultant, Sunnybrook Health Sciences Centre and St. Michael's Hospital Academic Family Health Team

Assistant Professor, Division of Palliative Care, University of Toronto



### **How did you get involved in palliative care?**

Palliative care was my final rotation during my family medicine residency. I left it until the end, not because I felt it unimportant, but because I felt that other rotations took priority. I was very fortunate to meet my preceptor for that rotation, Dr. Jacqueline Hui, who dispelled many of my misconceptions about palliative care and taught me that there is always “something” we can do to help our patients — even if it means just sitting quietly with them.

### **What formal/informal training did you receive in palliative care?**

By the time I discovered my passion for palliative care, it was too late to apply for a fellowship for the next academic year. I started working as a family physician and requested a home palliative care observership at the Temmy Latner Centre for

Palliative Care. Since I was a recipient of the C. Robert Kemp Palliative Care Grant, I received financial support for this endeavour through the College of Family Physicians of Canada. After some time splitting my practice between family practice and home palliative care, I realized that I wanted to practise full-time academic palliative medicine. I applied for and was accepted into the one-year conjoint palliative care fellowship at the University of Toronto.

### **Your current work in palliative care**

I currently work full time in palliative care in Toronto. The majority of my time is spent working at Sunnybrook Health Sciences Centre, a large hospital with a well-established inpatient consult team and an ambulatory outpatient clinic in the cancer centre. I also initiated a palliative care clinic embedded within the St. Michael's Hospital Academic Family Health Team. This idea emerged from my frustration with the lack of access to early palliative care services for patients not receiving care at large cancer centres or for those with diagnoses involving non-malignant disease. I consider myself an extra layer of support and a resource for family physicians in the family health team who wish to care for their patients at high risk of dying. Often I simply field family physicians' questions via e-mail or over the phone. Another one of my favourite projects involves the Integrated Long-Term Care Program run by physicians at Toronto East General Hospital, where I provide monthly telemedicine consults to a long-term care home. Using the Ontario Telemedicine Network, I discuss symptom management and end-of-life concerns with

the physicians, nurses and personal support workers who are on site and who regularly experience emotional distress caring for some of society's frailest members.

### ***Challenges and opportunities in palliative care***

Awareness and understanding of palliative care is truly growing at an exponential rate. Many experts will agree that there will never be enough palliative care clinicians to care for every person at the end of life, and neither should there be. The vast majority of patients at the end of life can be cared for by primary care clinicians and generalists. However, I also believe that every physician, from those based in the largest urban centres to the smallest rural outposts, deserves access to palliative care support. I believe the use of telemedicine and technology is one means of achieving this goal.

There are patients suffering and burdened by their illnesses who are not necessarily at the end of life. Their symptom management needs may be complex, but because of the misconception that palliative care is only relevant at the end of life or when disease-targeting therapies have been exhausted, they are not referred to the correct services. This may affect their ability to achieve good symptom control, which in turn has an impact on their quality of life. However, an encouraging culture shift is slowly getting underway. I estimate that in my outpatient practice, approximately 5-10% of my patients are undergoing or have undergone treatments with curative intent.

### ***Tips and advice for physicians who are interested in going into palliative care***

In Canada, palliative care was recently approved to receive a subspecialty designation from the Royal College of Physicians and Surgeons of Canada, and the palliative care landscape in this country is likely to change substantially in the future. For now, physicians interested in palliative care must first enter a separate residency program, either through the Royal College or the College of Family Physicians. I think palliative care is a field that benefits immensely from a variety of perspectives and experiences. I will advise individuals in medical school to choose a residency that they feel passionate about, and during their post-graduate years, seek out palliative care experiences in a variety of settings: inpatient consultations, ambulatory clinics, palliative care units or residential hospices, or home palliative care, to gain a greater understanding of patients' illness experiences. Ultimately, palliative care demands a strong patient-centred approach.

# Section 5

## How Do We Ensure High Quality Palliative Care?

With the call to action to provide better access to palliative care across Canada, we will need to be assured that the quality of this care will be high regardless of whether it is delivered in the home, in a long-term care setting or acute care setting, or in an independent hospice.

We will need to make sure that our regulatory colleges have standards specifying who can deliver this care and what level of training and continuing education is required to protect the public. We need to ensure that the programs or facilities delivering this care meet or exceed some recognized standards.

Patients and their families will be assuming that someone is looking after their best interests. They will be assuming that research will be driving the decisions made as to what palliative care model best suits their needs. At the time of their greatest need they are expecting quality care to be delivered, and they deserve to have that expectation met.

Palliative care is a rapidly evolving area in medicine, but in our haste to try and meet the growing demand quality of care may not always be foremost on our minds.

What follows in this section are proposed standards of palliative care and the rationale behind them. The goal is to assure that during every Canadian's final days, his or her best interests are being protected by standards we can all be proud of.

# Hospice Palliative Care and Accreditation

## *Accreditation Canada*

The Accreditation Canada Qmentum program provides organizations with a quality framework to design and monitor their services. Qmentum equips organizations with tools for self-evaluation and includes a periodic external review by peer surveyors. Hospice palliative care is addressed in the Qmentum program via dedicated standards of excellence for organizations offering these services, and through more general criteria for organizations that need to facilitate access to these services for their clients.

### **Hospice, Palliative, End-of-Life Services Standards**

At Accreditation Canada, we work with a number of hospice palliative care organizations across the country. They vary in size and design, and include organizations that specialize in such care delivery, large organizations that offer these services along with many others, and regions or health authorities.

The Hospice, Palliative, End-of-Life Services Standards have been part of Qmentum since the program's introduction in 2008. Like all Accreditation Canada standards, this set was developed using a rigorous process that includes a comprehensive literature review, consultation with a standards working group (or advisory committee) comprised of experts in the field, and evaluation by client organizations and other stakeholders.

The Hospice, Palliative, End-of-Life Services Standards are built around a quality framework that looks at ongoing quality improvement from service design to its delivery. The standards help organizations design and provide services that are embedded in client- and family-centred care, incorporate the crucial role played by volunteers, and emphasize the unique needs of clients and team members working in a hospice palliative care setting.

The Hospice, Palliative, End-of-Life Services Standards contain five sections:

1. Investing in quality services: This section focuses on co-designing services with clients and families to ensure their needs are met and that the organization is providing an effective and comfortable environment for clients.
2. Building a prepared and competent team: This section addresses the core elements of having an effective team to deliver services. It also emphasizes two unique elements of hospice palliative care: the volunteers' role and ensuring that they are appropriately screened, supervised, and supported; and the need to have supports available to team members who provide palliative care.
3. Providing safe and effective services: This section is the most detailed, as it addresses the provision of hospice palliative care. It begins by looking at how clients access services, including enabling clients and families to become familiar with the setting prior to receiving services. It also supports clients and families in receiving a comprehensive assessment of their symptoms and needs, which includes the need for volunteers as well as emotional, cultural, spiritual, and bereavement support. The standards in this section are intended to ensure that clients and families are comfortable, cared for, and supported

while receiving services and following the client's death. They also address specific topics like client independence and the unique needs of children and youths.

4. Maintaining accessible and efficient information systems: This section addresses how the organization keeps client information up to date, protects their privacy, and uses their information.
5. Monitoring quality and achieving positive outcomes: This section focuses on the organization's quality improvement initiatives, how it sets targets, and how it evaluates itself for continuous quality improvement.

## **Hospice palliative care (HPC) across the Qmentum Program**

The Hospice, Palliative, End-of-Life Services Standards provide a framework for quality HPC services. However, two significant challenges remain: facilitating access to services, and helping other teams and organizations understand what services are available.

In January 2015, Accreditation Canada introduced content into the service-based standards to support organizations that do not provide hospice palliative care, but that might care for clients requiring these services. It provides organizations with tools to identify when a client or family may need to access hospice palliative care, and guidance on how to connect with those services. The content throughout the Qmentum program focuses on the following areas:

- giving team members access to information about what hospice palliative care resources are available in their community and how to access these services;
- knowing how to make relevant hospice palliative care information available to clients and families;
- making education and training available to team members to help them identify clients' and families' hospice palliative care needs, including what steps to take to initiate services;
- incorporating hospice palliative care needs into the overall client assessment of physical and psychosocial health, when applicable;
- completing a comprehensive assessment of hospice palliative care needs once a desire or need for services has been identified; when this is out of scope, team members initiate contact with the appropriate service to complete a needs assessment; and
- ensuring there is a process to initiate hospice palliative care for client and families once a need has been identified.

Although offering specialized hospice palliative care may not fall within an organization's mandate, a client- and family-centred approach to care means the organization and its team members need to be aware of what is available to clients and families, and how to enable access to those services.

### **Summary**

Hospice palliative care is an important part of health care across Canada, and will continue to gain focus as the population ages. The Qmentum program provides a quality framework for building an effective client- and family-centred program, and also addresses the role that other services and organizations must play in providing effective care to clients and families.

# The Importance of Palliative Care Research

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*PhD*

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Ensuring that Canadians have access to comprehensive, coordinated, integrated and high-quality care at end-of-life requires a commitment to conduct research, evaluation and employ quality-improvement initiatives. Capacity to conduct these activities requires investment, predominantly in education and training, and in producing high-quality data. Human capacity can be enhanced by enticing researchers — both new and existing — and educators to enter the field of palliative and end-of-life care. Electronic capture and consistent use of screening, assessment and evaluation tools is required in order to capture high-quality data. Coordinated administrative and ethical approval processes are further required to make these data available. Dissemination, knowledge transfer and knowledge translation are also required.

Research, evaluation and quality improvement play important roles in establishing innovative and evidence-based palliative and end-of-life care services. High-quality research involves collaboration among academic researchers, clinicians and decision-makers. With few exceptions, innovation requires a carefully orchestrated program of research that encompasses four pillars: basic sciences, clinical research, health services research, and population health. These pillars embrace input from all scientific disciplines, and converge to provide a rigorously defensible evidence base serving societal needs. Patients, caregivers, health care providers and decision-makers all benefit from high quality research designed to optimize outcomes.

Caring for patients and their families at end-of-life fundamentally differs from care in other contexts in several important ways. First, dying is inevitable for all disease trajectories, differing only in timing, predictability and symptomatology. As a result, palliative care is aimed at the relief of resulting suffering in order to improve the quality of life. Although palliative care may alter the quantity of life, survival is itself not the primary goal of treatment. Secondly, death and the process of dying are intimately associated with the provision of care by caregivers, typically family members. Caregiving requires a considerable investment of time and resources. Providing care for caregivers therefore becomes imperative at several points: anticipatory grief, support during the active phase of caregiving, and during bereavement. In fact, the unpredictable timing of dying and the fact that caregiver support is necessary beyond the time of the patient's death is



a third way in which palliative care is different. Fourthly, care for the dying is not associated with a single setting. People die at home, in nursing homes, in hospices, in hospitals and in specialized tertiary care units. Finally, suffering is not confined to physical dimensions. Psychological, social, spiritual and existential sufferings are all prevalent at end-of-life.

Because palliative care is a relatively new medical discipline, a comprehensive evidence base does not exist for most topics. For example, symptoms such as pain, shortness of breath, fatigue, appetite, anxiety and depression each constitutes a major focus for research and evaluation. Quality of life encompasses all of these symptoms, and is already a research topic on its own. Caregiving constitutes substantial societal resources provided to dying patients. Both the intensity and duration of caregiving results in adverse consequences for caregivers and is responsible for much research. Bereavement signals a time for care after death of the patient. Health services research and health care delivery evaluations are needed to improve the conceptual, operational and policy domains for coordinated and integrated services across diverse health care settings. Addressing psychosocial, spiritual and existential concerns is a major topic for research and evaluation. Finally, advance care planning, goals and preferences for care at the end of life likewise describe a significant portion of the research agenda.

### **Infrastructure needs in palliative care research**

Paucity of quality palliative care research emerged as a theme when the Canadian Institute of Health Research (CIHR) and other organizations sought direction regarding palliative care during the early 2000s. In May 2002, the CIHR's Institute for Cancer Research Advisory Board decided to form the Priority Working Group on Palliative Care, which led to a request for application for a strategic initiative in July 2003; \$16.5 million in funding was secured a year later. Numerous career transition awards, pilot projects and new emerging teams were formed as a result. Most significant, though, was the formation of a dedicated palliative and end-of-life care peer review panel, which guaranteed ongoing operational support for research projects.

The Canadian Cancer Research Alliance (CCRA) conducted a special study into palliative care research entitled *Investment in Research on Survivorship and Palliative and End-of-Life Care 2005–2008*. The report identified that investment in palliative care research during this time period amounted to \$6.4 million, with 36% of the money involving research into physiological effects and care delivery, and 31% directed towards researching access and quality issues. The remainder of the funding was spent researching quality of life, thanatologic issues, psychological effects, social support needs and economic support. The federal government contributed 80.5% of the funding, of which three-quarters came from CIHR. The remaining 19.5% came from the volunteer sector, of which three-quarters came from the Canadian Cancer Society. On a per-capita basis, this funding represented less than 37 cents per person in Alberta and 29 cents in Manitoba.

The CCRA report identified 96 principal investigators across Canada, many of whom are affiliated with research centres providing additional infrastructure to conduct and integrate research into clinical and administrative practice. From west to east, some of the major centres include:

- British Columbia Centre for Palliative Care to support its Provincial End-of-Life Action Plan;
- Victoria Hospice's Research and Development Office;
- Covenant Health Palliative Institute, Edmonton;
- Manitoba Palliative Care Research Unit, CancerCare Manitoba;

- Bruyère Research Institute, Ottawa;
- University of Ottawa Nursing Palliative Research and Education Unit;
- Global Institute for Psychosocial, Palliative and End-of-Life Care, established by University Health Network and the University of Toronto; and
- Network for End-of-Life Studies at Dalhousie University.

# Top 10 Signs that Palliative Care is Fully Integrated into a Health Care System

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## Introduction

The presence and access to palliative care services across Canada is patchy.<sup>1</sup> There is excellence in some jurisdictions and many significant gaps in others. With a few exceptions, such as the Edmonton and Calgary zones in Alberta and Fraser Health in British Columbia, most regions lack the full scope of hospice palliative care services that is required. An Ontario study of four regions, for example, showed that core components such as community- and hospital-based palliative care consultation teams, palliative care units and residential hospices were often missing.<sup>2</sup> As jurisdictions across Canada work towards better integration of palliative care within their health care systems, one is compelled to ask: “What are the signs that full integration has taken place?” Here are 10 key signs of effective integration, which will help ensure that people who will benefit from palliative care will receive it promptly and in the right setting, and that the care will be provided by competent and caring health care professionals.

## The ten signs

### 1. Health care professionals have initiated a palliative care approach earlier in treatment, not only in the last days or weeks of life.

The current culture equates palliative care with dying and the last days or weeks of life. In addition to missing the opportunity to improve symptoms and quality of life at an earlier stage in treatment, this means that discussions concerning goals of care and advance care planning are held too late, if at all. Palliative care should be considered much earlier in the illness, preferably at the time of diagnosis but at the very least when the illness is deemed life limiting. To highlight this, the World Health Organization has since 2002 defined palliative care as being applicable for patients with “life-threatening illnesses”. A recent randomized study showed that patients with metastatic lung cancer in whom palliative care was initiated earlier experienced significantly less psychological distress and symptom burden and lived almost three months longer than patients who received palliative care only at the end of life (EOL).<sup>3</sup> Similar benefits have been shown in other cancer populations<sup>4</sup> and in end-stage heart disease.<sup>5</sup>

A culture change is therefore required. The model of early integration of a palliative care approach, whether it is provided by the attending physician or a specialist palliative care service, should replace the current “late” model. The “early” model avoids the often abrupt and traumatic transitions of care from curative or control to palliative or hospice at the EOL. In the earlier phases of a disease, when the main focus of care may be on controlling the disease, palliation can optimize symptom control, quality of life and goal-of-care discussions. Palliation becomes the main focus as the disease advances and EOL approaches.

The language we use is an indicator of culture. It is not uncommon to hear phrases such as:

- “The patient is not palliative yet.”
- “Do you want active care or palliative care?”

- “Discontinue ventilation and start palliative care.”

Such phrases propagate the misperception that palliative care is limited to the terminal phase, is passive care and implies giving up. On the contrary, palliative care is about improving living throughout the illness. It is active care. It is more appropriate to ask: “Will this patient benefit from a supportive and palliative care approach at this time?”

Some have suggested changing the name “palliative” to help overcome the stigma associated with the word. While this may be apt for patients who are at an early stage in the course of their illness, changing the name will likely encourage avoidance behaviour by clinicians and patients and mean that important and honest goals-of-care discussions are sidestepped, even in the face of obvious disease progression.<sup>6</sup> The issue is not the term, but rather a culture of fear surrounding end-of-life care.

## **2. The “Surprise Question” is used by Health Professionals in Daily Practice.**

Lynn and colleagues introduced a simple question to identify patients who could benefit from a palliative care approach at an earlier stage.<sup>7</sup> The question is simple — “Would I be surprised if this patient died in the next year?” — has become known as the “Surprise Question” and has been shown to be a useful screening tool across different settings and disease groups, including cancer and end-stage renal, heart and lung diseases.<sup>8,9,10</sup> It has, for example, been successfully adopted by the Gold Standards Framework in the United Kingdom, which is an initiative to improve palliative care in primary care settings.<sup>11</sup> If the answer to the question is “No”, then a palliative care approach should be activated. It should not be used simply as a referral tool for specialist palliative care.<sup>12</sup> Rather it is a screening question to alert the most responsible clinician and team to initiate, if this has not been done already, a review of the patient’s situation and goals of care, assessment and management of symptoms and other needs, and engagement in planning and setting appropriate care goals. The question does not suggest that palliative care is limited to the last year of life, but it does prompt earlier action. It recognizes that prognostication is not an exact science<sup>13</sup> and that in some cases, patients identified by the question may live longer or shorter than predicted. The Surprise Question should not be used in isolation, but does require a broader clinical assessment. It can be supplemented with clinical criteria that help with prognostication.<sup>14,15</sup>

## **3. Goals of care discussions and advance care planning are part of everyday life and daily clinical practice.**

Advance care planning (ACP) has been shown to improve end-of-life decision-making. However it is often done poorly, if at all, and this leads to poor care choices.<sup>16</sup> In Ontario approximately 42% of cancer patients visit an emergency room in the last two weeks of life.<sup>17</sup> While some of the visits are inevitable and appropriate, many others could be avoided by honest goals of care and ACP discussions.<sup>18</sup> A large Canadian study found that only 14% of patients with end-stage heart disease and 9% of patients with advanced chronic obstructive airway disease recalled discussing their prognosis with physicians.<sup>19</sup> Only 27% of cancer patients recalled such discussions. These discussions are also often avoided when patients with advanced heart failure are being treated with implantable cardioverter defibrillators and left ventricular assist devices, even though the one-year mortality rates even with these interventions remain high (up to 50%).<sup>20,21</sup>

All health professionals should become acquainted with and refer regularly to the Canadian *Speak Up Campaign*. Its website has excellent videos, useful discussion prompts and practical handout material for the public, patients and health care professionals ([www.advancecareplanning.ca](http://www.advancecareplanning.ca)). Cancer Care Ontario has developed a tool kit to guide ACP quality improvement in family

health clinics, but it can easily be used in others clinics as well. The kit can be accessed at <https://www.cancercare.on.ca/pcs/primcare/qitoolkit/>.

**4. The system has a strong primary-level palliative care base, with family physicians and non-palliative care specialists providing good generalist-level palliative care.**

There is a need for both generalist and specialist level palliative care. Patients with basic palliative care needs do not necessarily require specialist-level palliative care services. Their needs can be addressed by a palliative care approach provided by family physicians and other non-palliative care specialists such as oncologists, internists, cardiologists and geriatricians. It does require education for these clinicians to acquire these basic competencies. Only a smaller number of patients with complex needs require specialist level palliative care. Quill and Abernethy have recently underscored this: “As in any medical discipline, some core 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”.<sup>22</sup> Relying on a small number of specialist palliative care clinicians to provide all palliative care is neither sustainable nor appropriate.

Health care funders should provide the resources, remuneration systems and performance indicators that support primary level capacity building by specialist palliative care teams rather than relying on these teams to take on all palliative care, primary and specialized. There should be incentives and accountability mechanisms that promote primary level palliative care by family physicians and other non-palliative care specialist teams.<sup>23</sup>

**5. Specialist-level interprofessional palliative care consultation and support teams are available in all hospitals and the community, and adequate home care nursing resources are in place.**

A growing body of evidence supports the need for specialist level palliative care consultation and support teams in acute care hospitals and in the community.<sup>24,25</sup> Overall, specialist palliative care teams that practise in hospitals, patient homes, and inpatient palliative care units improve patient outcomes related to pain and symptom control and psychosocial distress.<sup>26</sup> They also reduce hospital admissions, inappropriate health care resource utilization and overall care costs.<sup>27,28</sup> A recent Ontario study of community-based palliative care specialist teams found that nine of the 11 teams significantly reduced hospital admissions and emergency department use.<sup>29</sup>

**6. There are enough acute palliative care unit beds and residential hospice beds in each region.**

Specialized palliative care units (PCUs) with interprofessional teams are needed to care for patients with complex needs who require short-term inpatient care during their illness, and not only at the end of life. Without such units, patients with the most challenging needs are hospitalized in medical and surgical units where palliative care is generally neither the focus of care nor part of the teams' expertise. Residential hospices, with fewer resources than PCUs, are required for patients with relatively lower complexity requiring inpatient EOL care in the last days or weeks of life.

Gomez-Batiste *et al.* have recommended that a jurisdiction requires at least 10 palliative care beds for every 100,000 inhabitants.<sup>30</sup> Of these, one-third should be acute PCU beds and two-thirds hospice or complex continuing care beds. Investments in the right number and combination of beds, alongside the other key elements such as hospital and community-based consultation

teams, home care and family physicians, have produced better care and significant reductions in hospital admissions and deaths, emergency department utilization and health care costs in jurisdictions such as Catalonia in Spain and the Edmonton and Calgary zones.<sup>31,32,33</sup>

**7. *There are palliative and end-of-life care strategies in place in long-term care (LTC) facilities, retirement homes, complex continuing care facilities, rural regions and in Aboriginal communities.***

Special end-of-life care needs exist across these different settings and populations, but regrettably there are still many gaps in addressing such needs.<sup>34,35,36,37</sup> A number of successful strategies have been used to begin to address these gaps. They include the use of telemedicine, rural teams and education for health professionals in rural communities, in-house teams and education of staff in LTC facilities, and resources such as adequate home care and access to medications in Aboriginal communities, along with cultural sensitization and education for health care professionals.<sup>38</sup>

**8. *Specialist palliative care teams are adequately staffed, and new positions and training positions are made available when staff shortages exist.***

There are significant variations within and between provinces with respect to staffing ratios and staffing mixes on specialist palliative care units, teams and hospices. The Edmonton Zone, for example, has five palliative care physicians and five palliative care nurses to provide consultation support in that region. In contrast, the Champlain region of southeastern Ontario (Ottawa), a region that is larger in area but with a similar population, has been provided with only 2.5 palliative care nurse positions and 1.4 physician positions by the Ontario Ministry of Health and Long Term Care. In some jurisdictions, PCUs and hospital-based consultation teams are inadequately staffed to meet current and future needs. A 2012 Ontario-based study, for example, identified significant staffing and resource challenges in PCUs and hospices.<sup>39</sup> There is an urgent need to establish country-wide standards for the size and makeup of palliative care teams, including hospice, PCU and hospital and community consultation teams.

**9. *There is adequate palliative care education in undergraduate and post-graduate medical, nursing and allied health training programs, as well as ample opportunities for continuing professional development for health professionals.***

Despite some improvements in the last decade, many shortcomings remain in palliative care education in medical and nursing schools, and in residency programs. Many medical students and residents are still graduating from medical schools and residency programs without the appropriate palliative care competencies. Change and improvements in the health care system should be starting here but this opportunity is being missed. Minimal hours and optional rotations are no longer acceptable. Organizations tasked with accrediting these programs ought to apply closer scrutiny when reviewing palliative care education during the accreditation process. Token inclusion and the failure of staff to act as role models should not be accepted. There is a need for faculty and other professionals already in practice to identify their own shortcomings in this area and to participate in courses and workshops to improve their palliative care approach and ACP skills.

**10. *The right performance indicators and funding formulae are in place to monitor health care system performance related to palliative care.***

Setting and monitoring system-performance indicators drives quality improvement. Jurisdictions should have the processes and resources in place for real-time monitoring of palliative care-related performance indicators. However, it is imperative that the right indicators are identified.<sup>40</sup> For



example, there has been a lot of interest in the indicator related to preferred place of death. However, this indicator is difficult to assess and preferences change over time and according to needs. A more appropriate indicator could be the percentage of time patients spend at home in the last month of life. In Ontario, health system funding reforms are resulting in new procedure-based funding formulae for hospitals. Unless the formulae and their associated performance indicators are tweaked to better reflect the roles of acute palliative care units, these units face significant cuts and closures.

### Conclusion

A systems-thinking approach is required to improve the integration of palliative care in health care systems.<sup>41</sup> Various components are required, and these need to be supported adequately to ensure seamless and timely access. Regionalization promotes systems thinking and better integration of services.<sup>42</sup> Palliative care, whether provided by a primary-level provider or a palliative care specialist, is a unique vehicle that enhances the integration of compassion, communication, self-care and interprofessional collaboration within the health care system.

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# Section 6

# Appendix

This section contains the following:

- Overview of the Canadian Hospice and Palliative Care Association
- The College of Family Physicians of Canada (CFPC) Evaluation Objectives: the Key Features for Palliative Care and for Chronic Disease
- Victoria Hospice Palliative Care Medical Intensive Course
- Pallium Canada Educational Resources

# Canadian Hospice Palliative Care Association

## *Canadian Hospice Palliative Care Association*

The Canadian Hospice Palliative Care Association (CHPCA) is the national association representing hospice palliative care. It currently has about 3,000 members, who represent all provincial hospice palliative care associations as well as the various professional, volunteer, and specialty groups involved in providing end-of-life care across the country. This includes those who are involved in shaping and implementing clinical practice and policy. Its work includes public and health policy, education and awareness. Established in 1991, its volunteer Board of Directors is composed of hospice palliative care workers, volunteers from different provinces and members-at-large.

The CHPCA is engaged on multiple fronts in order to encourage the pursuit of excellence in hospice palliative care:

1. It was at the forefront of implementing an integrated palliative approach to care across settings in Canada with the launch of The Way Forward (TWF) project in 2012. The goal is to develop a national framework so that the palliative approach to care can become a reality throughout the country. The project was made possible thanks to the federal government, which provided one-time funding of \$3 million to the CHPCA and its partners to develop TWF from 2012-2015. During this period the project developed a national framework to guide professionals, health system leaders and program planners as they adopt an integrated palliative approach to care. It includes a tool kit of resources, offers suggestions for removing the barriers to integrated hospice palliative care, and encourages groups to build opportunities for their own communities. TWF will help Canadians with life-limiting illnesses understand the importance of advance care planning and the hospice palliative care services that are available to them. More information can be found at [www.hpcintegration.ca](http://www.hpcintegration.ca).
2. CHPCA leads the Advance Care Planning in Canada initiative that has launched the Speak Up: Start the conversation about end-of-life care campaign to encourage Canadians to engage in and promote advance care planning through the development of programs, the education of professionals, and working with the media to spread awareness. The project has developed multiple tools and resources, including workbooks, tool kits and other resources to help Canadians develop a sense of comfort for both patients and physicians when it comes to discussing advance care plans. More information can be found at [www.advancereplanning.ca](http://www.advancereplanning.ca).
3. The CHPCA manages the Canadian editions of eHospice.com, a globally run news and information resource committed to providing the latest news, commentary and analysis from the world of hospice, palliative and end-of-life care. The website offers a single point of access to information and good practices from around the world, with the aim of helping improve patient care globally. More information can be found at [www.ehospice.com/Canadaenglish](http://www.ehospice.com/Canadaenglish).
4. The CHPCA runs accredited and non-accredited webinars throughout the year as part of its mandate to increase knowledge and skills related to hospice palliative care among the public, health care providers and volunteers. These webinars are presented by experts in hospice palliative care and aligned health fields, and are open to the public. Topics

range from challenges associated with palliative care, pain and symptom management and best practices. More information can be found at [www.chpca.net](http://www.chpca.net).

5. CHPCA is the secretariat of the Quality End-of-Life Coalition of Canada (QELCCC), which believes all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice. Formed in 2000, it is comprised of 34 national member organizations and four associate member organizations. Within the QELCCC are four working groups, as well as an Executive Committee composed of the chairs of each of the four working groups (Advocacy, Caregiver, Research and Knowledge Translation and Education). The Canadian Hospice Palliative Care Association serves as the secretariat for the QELCCC and provides administrative support for working group tasks. The coalition believes that to achieve quality end-of-life care for all Canadians there must be a well-funded, sustainable national strategy for hospice palliative and end-of-life care. The QELCCC mission is to work together in partnership to achieve this goal. Its work includes a Blueprint for Action 2010 to 2020, which outlines priorities to improve end-of-life care for all Canadians over the next 10 years, and leading The Way Forward initiative, aimed at creating a roadmap for an integrated palliative approach to care.
6. Lastly, the CHPCA organizes and hosts the Canadian Hospice Palliative Care Conference every two years. It is the foremost national conference in Canada focusing on hospice palliative care. The conference provides doctors, nurses, pharmacists, hospice palliative care and other allied health care professionals, as well as caregivers, volunteers, spiritual advisers and social workers the opportunity to share their experience and expertise on a national platform. The event continues to attract 600-800 participants each year, and it provides many cutting-edge presentations and research outcomes. More information can be found at [www.conference.chpca.net](http://www.conference.chpca.net).

# College of Family Physicians of Canada Evaluation Objectives: the Key Features for Palliative Care and for Chronic Disease

## Chronic Disease

<i>Key Feature</i>	<i>Skill</i>	<i>Phase</i>
1 In a patient with a diagnosed chronic disease who presents with acute symptoms, diagnose: - acute complications of the chronic disease (e.g., diabetic ketoacidosis). - acute exacerbations of the disease (e.g., asthma exacerbation, acute arthritis). - a new, unrelated condition.	Clinical Reasoning	Diagnosis
2 Regularly reassess adherence (compliance) to the treatment plan (including medications).	Clinical Reasoning	History Follow-up
3 In patients with chronic disease: a) Actively inquire about pain.	Clinical Reasoning	History
b) Treat appropriately by: - titrating medication to the patient's pain. - taking into account other treatments and conditions (e.g., watching for interactions). - considering non-pharmacologic treatment and adjuvant therapies.	Clinical Reasoning	Treatment Hypothesis Generation
4 In patients with chronic disease, actively inquire about: - the psychological impact of diagnosis and treatment. - functional impairment. - underlying depression or risk of suicide. - underlying substance abuse.	Patient Centred Clinical Reasoning	History
5 Given a non-compliant patient, explore the reasons why, with a view to improving future adherence to the treatment plan.	Patient Centred	History



## Palliative Care

<i>Key Feature</i>	<i>Skill</i>	<i>Phase</i>
1 In all patients with terminal illnesses (e.g., end-stage congestive heart failure or renal disease), use the principles of palliative care to address symptoms (i.e., do not limit the use of palliative care to cancer patients).	Patient Centred Clinical Reasoning	Treatment
2 In patients requiring palliative care, provide support through self, other related disciplines, or community agencies, depending on patient needs (i.e., use a team approach when necessary).	Patient Centred	Treatment
3 In patients approaching the end-of-life: a) Identify the individual issues important to the patient, including physical issues (e.g., dyspnea, pain, constipation, nausea), emotional issues, social issues (e.g., guardianship, wills, finances), and spiritual issues.	Patient Centred Clinical Reasoning	History
b) Attempt to address the issues identified as important to the patient.	Patient Centred Clinical Reasoning	Treatment
4 In patients with pain, manage it (e.g., adjust dosages, change analgesics) proactively through: - frequent reassessments. - monitoring of drug side effects (e.g., nausea, constipation, cognitive impairment).	Clinical Reasoning	Treatment Follow-up
5 In patients diagnosed with a terminal illness, identify and repeatedly clarify wishes about end-of-life issues (e.g., wishes for treatment of infections, intubation, dying at home)	Patient Centred Clinical Reasoning	History Hypothesis Generation

# Victoria Hospice Palliative Care Medical Intensive Course

## **About Victoria Hospice**

Victoria Hospice is a registered charity located in Victoria. Since its opening in 1980, the hospice has provided end-of-life care focused on palliative treatment. The nurses, counsellors, spiritual caregivers, physicians and trained volunteers provide comfort for the patient and support for the family, rather than a cure for progressive and life-limiting illness. Care can be provided in patients' homes, within our 17-bed in-patient unit, and as specific medical consultation to patients in other health care facilities. Over 300 trained volunteers provide companionship and support. Victoria Hospice offers bereavement support to families for up to one year following a death.

## **The Palliative Care: Medical Intensive Five-Day Course**

The Palliative Care: Medical Intensive Course provides an excellent interdisciplinary foundation in palliative care for physicians, family practice residents, pharmacists and nurses from a variety of health care settings. The objectives of the biannual course are:

1. to increase understanding, skills and knowledge in order to apply a palliative approach to both cancer and non-cancer illness;
2. to increase awareness of and sensitivity to issues of death and dying, including ethical considerations;
3. to increase specific medical and nursing skills in assessment and management of distressing symptoms associated with advanced disease;
4. to increase understanding of psychosocial and spiritual needs of patients and families including grief and bereavement;
5. to enhance understanding of the role of the interdisciplinary team in palliative care.

The course utilizes many learning strategies, from lectures, topic reviews, role play and panel discussions to group discussions and small-group, case-based problem-solving sessions. At the completion of the course all participants will receive a certificate of attendance noting that this course has been accredited for 31.5 Mainpro-M1 continuing medical education credits through the College of Family Physicians of Canada and its BC Chapter. For more information, contact Education and Research at 250-370-8283 or visit [victoriahospice.org](http://victoriahospice.org).

# Pallium Canada Educational Resources

The following list offers a sample of some of the education resources available through Pallium Canada:

1. Learning Essential Approaches to Palliative and End-of-Life Care (LEAP) Courseware
2. The Pallium Palliative Pocketbook: This is a practical, peer-reviewed and fully-referenced manual that is intended to support safe, ethical, effective and accountable palliative clinical service interventions in various care settings.
3. Pallium Canada Doodles on topics such as advance care planning, palliative care early better than late, and the words we use.
4. Conversations on Caring — Volume 1: This instructional DVD presents 11 case scenarios. It also includes a teaching companion designed to promote critically-reflective dialogue about many common communication challenges associated with providing quality palliative and hospice care in a primary health care settings.
5. Developing Spiritual Care Capacity for Hospice Palliative Care — A Canadian Curricular Resource: This is the first integrated palliative and hospice care educational resource developed in Canada. It aligns with the Canadian Hospice Palliative Care Association's (CHPCA) Model to Guide Hospice Palliative Care.
6. In Our Own Voices: Aboriginal Perspectives in Hospice Palliative Care: This instructional DVD presents 11 case scenarios. It also includes a teaching companion designed to promote critically reflective dialogue about many common communication challenges associated with building and keeping relationships with Aboriginal patients and families in a variety of primary care settings.