

The Senate of Canada



Le Sénat du Canada

Raising the Bar:

**A Roadmap for the Future of
Palliative Care in Canada**

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The Honourable Sharon Carstairs, P.C.

The Senate of Canada

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Dedication

I wish to extend my heartfelt thanks to all who work and volunteer in palliative care, who provide care and nurturing and work to alleviate the suffering – both physical and mental - of those at the end-of-life.

Since 1995, I have travelled across this country from coast to coast to coast meeting with those who work on the front lines. They unanimously tell me that they have been blessed to be able to provide this gift of care to those who are dying because they themselves also receive in return the gift of sharing in this most human of experiences. It is impossible to express enough gratitude for their contribution to the lives of others in this most serious time of need. There are no words, in any language, which can convey the extent of the gift they give of themselves. They define our most human values, and remind us that the most basic and important value in life is to care for each other.

Thank you for all you do.

Table of Contents

TABLE OF CONTENTS	1
EXECUTIVE SUMMARY	3
FOREWORD	5
METHODOLOGY.....	5
TERMINOLOGY	6
INTRODUCTION	7
I. PALLIATIVE CARE IN CANADA.....	9
CONTEXT.....	9
VISION.....	16
II. THE CULTURE OF CARE.....	19
DEATH DENYING SOCIETY	19
DEATH TRAJECTORIES	21
DEFINING PALLIATIVE CARE AND END-OF-LIFE CARE	24
III. CAPACITY BUILDING	27
RESEARCH	27
EDUCATION AND TRAINING.....	28
HEALTH HUMAN RESOURCES	30
IV. CAREGIVERS.....	33
CAREGIVER SUPPORT.....	33
COMPASSIONATE CARE BENEFIT	35
GRIEF AND BEREAVEMENT	36
V. INTEGRATION OF CARE.....	39
VI. LEADERSHIP	43
RECOMMENDATIONS	47
TO THE FEDERAL GOVERNMENT.....	47
TO THE PROVINCIAL AND TERRITORIAL GOVERNMENTS	48
TO THE COMMUNITY	49
CONCLUSION.....	51
APPENDIX: SOURCES.....	53

Executive Summary

Ninety percent of Canadians who die can benefit from palliative care. Palliative care is whole-person health care that is multi-disciplinary in nature, can happen in any care setting, and that aims to relieve suffering and improve the quality of living and dying. It is care which should begin at diagnosis of a life-threatening condition and continues to end of life. It views the patient and the family as recipients of care and continues to include bereavement services for families after the death of their loved one.

Since 1995 there have been some significant improvements in public policy regarding end-of-life and in the delivery of palliative care services. Yet, we need to raise the bar.

Canadians are living longer, but they are living longer with complex conditions. Canadians at end-of-life and their families need the right interdisciplinary health and social services care, at the right time, and in the right setting, based on their needs. Wherever they live in Canada, they also should expect to receive equitable access to the same quality of care. We need to spend smarter.

This report sets out a vision for palliative care in the future with realistic and attainable goals. To realize a society where all Canadians have access to quality palliative care services we need five things: a culture of care, sufficient capacity, support for caregivers, integrated services, and leadership.

We are a death denying society who refuses to accept that we are all going to die, and cling to the hope that our own death will be quick and painless. Yet, that will not be the reality for 90% of us. The evolution of palliative care is being profoundly affected by the increase in chronic diseases. Combined with an aging population, the system is being stretched and tested as never before. There are at least 70% of Canadians who do not have access to palliative care. And even when there is access, it is not equitable. We need a culture of care that recognizes death as a natural part of life, responds to the reality that death trajectories are changing, and that incorporates palliative care services sooner for those who have a life-threatening illness.

There are still Canadians dying in needless pain because health care providers do not know what a good death is. We need to build capacity throughout our health care system with increased research, better knowledge translation, implementation of best practices, better education for our health care providers and a health human resources staffing plan to address future needs.

Caregivers are fundamental in our health care system. We need to provide them with adequate supports to keep the family unit functioning as they experience loss. Paid caregivers could never hope to replace the work of unpaid caregivers. The Compassionate Care Benefit is too narrow in its application and changes are needed to ensure those who can most benefit from this program know about it and can access it.

We cannot afford to overlook the need for follow-up grief and bereavement support to families. We need to adapt systems and programs to facilitate caregiver support, including financial support, education and training, respite care, and bereavement services.

Palliative care programs and services need to be integrated into the health care system and not be an additional program that may or may not be available in the community, and which may come and go with annual budget adjustments. Health and social services must not exist in silos, but in partnership to meet the needs of the population. We need to get serious about integration of services, and we need to overcome incompatibilities that make it difficult for patients and caregivers to transition from one care setting to another.

We are facing a tsunami of aging in the next few years and we are not prepared to handle the increase in numbers of those who will require palliative care. Without leadership there will continue to be a patchwork of services available to Canadians as no single province is equipped to provide the necessary national leadership.

Leadership must emerge from all quarters. Raising the bar in providing quality palliative care to all Canadians will require a multi-jurisdictional approach. It will require leadership from the federal, provincial and territorial governments and from the community as a whole, including professional associations, community organizations and health care providers.

The report identifies the goals for a culture of care, capacity building, caregiver support, integration of services and leadership. To meet these goals, it makes 17 recommendations to serve as a roadmap for the federal government, provincial and territorial governments, and the entire community.

It is the responsibility of every Canadian to work together at all levels - federal, provincial/territorial and community – to ensure quality palliative care for the 90% of Canadians who will need it.

Foreword

In 1994, I was appointed to the Senate of Canada, and I immediately became a member of the Special Senate Committee on Euthanasia and Assisted Suicide. During my work on that Committee, I became convinced of the need for better palliative care services in Canada. Committee members were struck by the fact that many dying individuals most feared becoming a burden to their loved ones and feared they would experience pain, incapacity, and indignities as they were dying. Many were seeing euthanasia and assisted suicide as their only hope of dying with dignity.

However, palliative care offers the opportunity to manage symptoms, and provide physical, emotional, and spiritual support to the dying. Along with many of my Senate colleagues, I became convinced that before we could have a debate about euthanasia and assisted suicide in Canada we should be providing equitable access to quality, integrated palliative care. As a Committee, we were unanimous in our belief that what was needed was better care for the dying - better pain control, better training, and more research.

That Committee tabled its report, titled *Of Life and Death*, in June of 1995. In June of 2000, I tabled in the Senate a Senate Subcommittee report which reviewed progress in implementing the unanimous recommendations from the 1995 report. That report, *Quality End-of-Life Care: The Right of Every Canadian*, included 14 new recommendations for improving end-of-life care in Canada.

In June of 2005, I tabled a third report in the Senate on palliative care in Canada, titled *Still Not There*, which examined progress on implementing the recommendations outlined in the previous reports and included 10 additional recommendations for improving care for those at end-of-life.

It has now been fifteen years since the 1995 report was tabled, and there have been significant improvements in providing quality palliative care to Canadians. However, there are still Canadians needlessly dying in pain and with unnecessary suffering. We can and must do better. This report will examine the current state of palliative care in Canada, why palliative care is important, what progress we have made and what still needs to be done.

Methodology

This report is the culmination of my fifteen years of work in the field of public policy relating to palliative care. The lead researcher who worked with me on this report was Michelle MacDonald, who was also the lead researcher in the 2005 report.

Several methods were used to gather information for this report. We created a survey which was distributed through the Canadian Hospice Palliative Care Association, its provincial associations and several other organizations who distributed it to their

members. It was also made available to interested parties and the general public on my website and through my semi-annual newsletter. We received over 740 responses to the survey, from all parts of Canada.

We held in person roundtables in: Victoria, British Columbia; Edmonton, Alberta; Regina, Saskatchewan; Winnipeg, Manitoba; Toronto, Ontario; Ottawa, Ontario; Montreal, Quebec; Halifax, Nova Scotia; and Charlottetown, Prince Edward Island. We held teleconferences with representatives from New Brunswick and Newfoundland and Labrador. Through these roundtables and teleconferences we were able to hear directly from over 160 experts in the field, such as: physicians, nurses, licensed practical nurses, social workers, pharmacists, music therapists, bereavement counsellors, physical therapists, occupational therapists, researchers, administrators, government representatives, spiritual care advisors, volunteers, hospice staff, aboriginal representatives, home care workers, staff and administrators from long term care homes, and public policy analysts.

We also wrote organizations and individuals who had participated in earlier reports to gather written briefs and submissions. We received many emails, letters, written briefs, and articles. In addition, we did a media scan and a review of recent literature in the field.

Finally, we visited several hospices and palliative care units in various parts of the country. We also held one on one interviews with key individuals in the field.

The information gathered from all these sources forms the basis for the recommendations in this report.

Terminology

In this report, we use the term palliative care in the broadest sense. It is used to refer to whole-person health care that aims to relieve suffering and improve the quality of living and dying. It is multi-disciplinary. It includes all settings of care, such as: the home; the community; the residential hospice; and the hospital. It is care which starts at diagnosis of a life threatening condition, carries through until the death and continues on into bereavement care.

The Honourable Sharon Carstairs, P.C.

Introduction

If each of us was given the opportunity to choose our method of death, we would choose the quick and painless. It could be a massive heart attack or an accident. We would literally not know what felled us. The reality is quite different. Only 10% of people die suddenly.¹ The rest will require terminal medical care. It may take days, months or years, but we will know we are dying. However, we should also have choices as we journey to end-of-life. We should be able to choose to be relatively pain free. We can choose to be or not to be attached to machines. We can choose whether or not to have artificial hydration and nutrition. We can choose to have or not have psycho-social and spiritual supports. Sadly, for many these choices are not offered to them because the vast majority of Canadians will not have palliative care supports in those last days, months or years. They will not have them because governments at all levels have failed to accept their responsibility to make death a natural progression of life itself.

We can do better. In the last 20 years we have made enormous strides. Yet, we need to raise the bar. We will not have achieved success until we recognize that the passing of life is as important as the birth of that life. The essence of a human being is that life will end. How that life ends will define the kind of society we have chosen to be.

This report sets out a vision for palliative care in the future with realistic and attainable goals. Its recommendations are a roadmap to achieving these goals. Quality palliative care is the right of every Canadian. It is the responsibility of every Canadian to work together at all levels - federal, provincial, territorial and community – to ensure quality care at end-of-life.

¹ William M. Plonk, Robert M. Arnold. Journal of Palliative Medicine. 2005, 8(5): 1042-1054.
doi:10.1089/jpm.2005.8.1042

I. Palliative Care in Canada

Context

Like most countries, Canada is a death-denying society. Canadians rarely discuss death and the end-of-life, let alone accept them as natural stages of life. Yet the inescapable fact remains that the mortality rate for humans is 100%. We may not like to think about it, and we may only talk about it when we can't avoid it, but we will all experience the death of people close to us, and each one of us will someday die.

In a recent study of deaths in Western Canada, five broad causes of death trajectories were identified, as outlined in Table 1.² Of the five categories, only the first category (sudden death) can be identified as a grouping that likely would not benefit from palliative care.

Grouping	Description
Sudden Death	Individuals are likely to be in good health prior to the incident that causes death. This could be an accidental death, fall, or trauma.
Terminal Illness	These include individuals with a terminal diagnosis including cancer, chronic renal failure or HIV-related diseases.
Organ Failure	Typically this grouping includes individuals with long-term limitations due to congestive heart failure or chronic obstructive pulmonary disease (COPD).
Frailty	Individuals of advance age who display a pattern of decline over time including neurological decline. This group also encompasses common causes of death in the elderly.
Other	Causes of death that are not included in the other groupings.

Table 1 – Cause of Death Trajectory Groupings

The number of decedents that fall into each of these categories is shown in Table 2.³ As can be seen, the vast majority of deaths in Western Canada (and by extrapolation, in all of Canada) fall into the categories for which palliative care can play a large role. In

² Table prepared by Library of Parliament using data obtained from CIHI, "Health Care Use at the End of Life in Western Canada," http://secure.cihi.ca/cihiweb/products/end_of_life_report_aug07_e.pdf, accessed 9 April 2010.

³ Table prepared by Library of Parliament using data obtained from CIHI, "Health Care Use at the end of life in Western Canada," http://secure.cihi.ca/cihiweb/products/end_of_life_report_aug07_e.pdf, accessed 9 April 2010.

fact, it has been estimated that only 10% of deaths are sudden, with the rest potentially benefiting from palliative care.⁴

Grouping	Percentage
Sudden Death	2.9
Terminal Illness	28.4
Organ Failure	33.8
Frailty	29.3
Other	5.6

Table 2 – Percentage of Cause of Death

From mid-2008 to mid-2009, there were 242,863 reported deaths in Canada.⁵ Population growth forecasts envision that the number of deaths occurring annually in Canada will nearly double to almost 480,000 annually by the year 2056.⁶

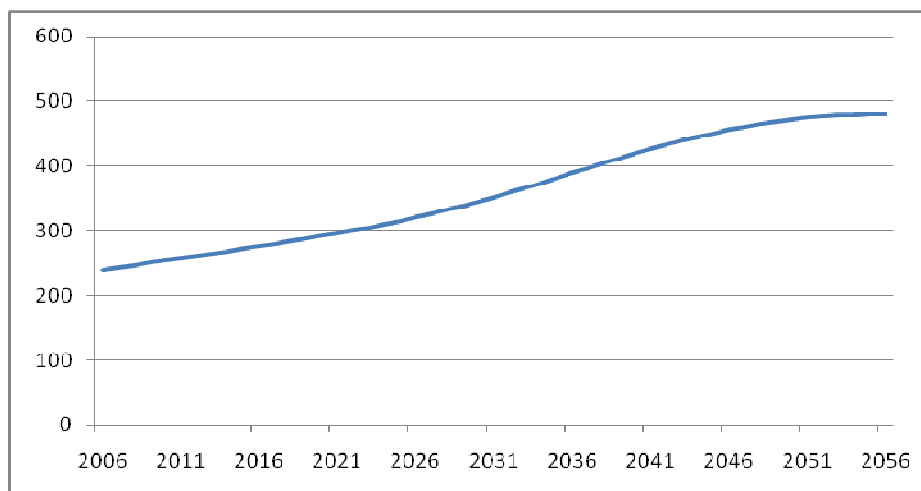


Figure 1 - Number of Deaths in Canada (in hundred thousands)

While the number of deaths is increasing, Canada is also facing an aging population. By 2031 about a quarter of Canadians will be 65 years old or older. That is about double today's proportion, and three times what it was in 1971. The proportion of oldest seniors - those 80 years or over - is also projected to increase sharply. By 2056, an estimated 1 out of 10 Canadians will be 80 years or over, compared with about 1 in 30

⁴ William M. Plonk, Robert M. Arnold. Journal of Palliative Medicine. 2005, 8(5): 1042-1054.
doi:10.1089/jpm.2005.8.1042

⁵ Statistics Canada Table, "Deaths and Death Rate, by province and territory",
<http://www40.statcan.gc.ca/l01/cst01/demo07a-eng.htm>, accessed April 1, 2010.

⁶ Data taken from Statistics Canada Chart, "Projected (2005 to 2056) births and deaths according to three scenarios, Canada", <http://www.statcan.gc.ca/pub/91-520-x/00105/4095109-eng.htm>, accessed April 1, 2010. The forecasted medium growth line is shown.

today. Meanwhile, Canadians are having fewer babies, shifting the historical balance between the young and the old. This has serious implications on the requirement for palliative care, as well as on Canadian society as a whole.

The median age of the population is increasing as baby boomers approach their senior years.⁷ Given the aforementioned number of deaths annually and a current population of 33.3 million, 0.7% Canadians die each year. That is 1 in 143. By 2056, this number is expected to climb above 1.1%, or one out of every 90 Canadians.⁸ Previous studies have documented the loss of productivity and personal income attributable to taking care of family members. It can be expected that as the death rate climbs, the percentage of Canadians who are pressed into taking care of loved ones will also increase.

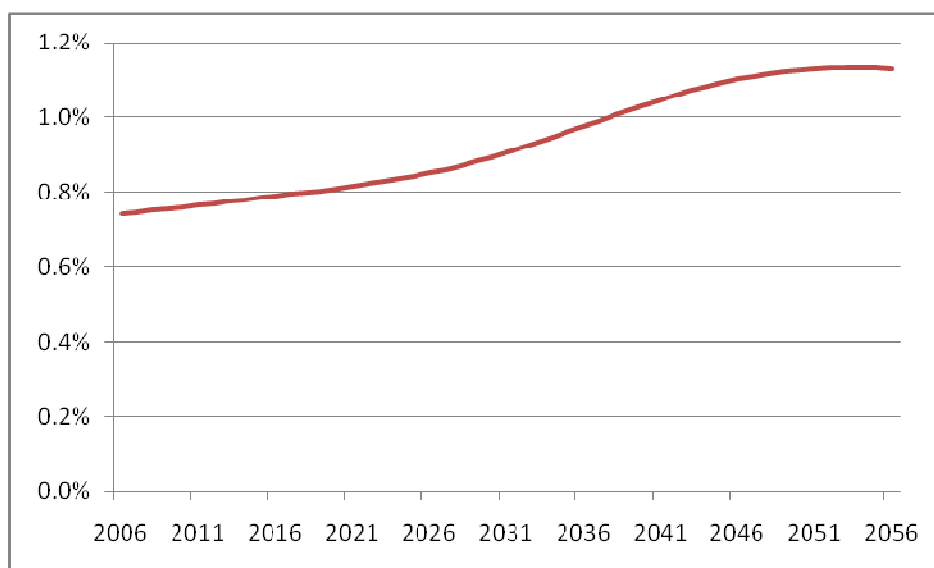


Figure 2 - Death Rate in Canada

In 2007, 23% of Canadians said that they had cared for a loved one with a serious health problem in the last 12 months. Of these people, 22% reported missing one or more months of work.⁹ These numbers represent a significant loss of productivity to the Canadian economy as people take leaves of absence from work, or are forced to temporarily leave the workplace altogether. As the death rate climbs from 0.7% to over 1.1%, this problem can only be expected to increase. Given the predicted reduction of

⁷ Statistics Canada table, "Population by year, by province and territory", <http://www40.statcan.gc.ca/l01/cst01/demo02a-eng.htm>, accessed March 31, 2010.

⁸ Ibid.

⁹ 10th Annual Health Care in Canada Survey: A national survey of health care providers, managers, and the public, 2007, <http://www.hcic-sssc.ca>.

the work force due to an aging population, this loss of productivity due to an increasing death rate is yet one more multiplier effect, reducing economic efficiency.

We know that each death in Canada affects the immediate well-being of, on average, five other people. If projections of a rate of 480,000 deaths per year by 2056 are realized, that means potentially 2.4 million people affected by death in their family or social circle in any given year. The number of caregivers experiencing loss of work for a month or more could rise to 25,000 each year.

The cost implications for the health care system are also of grave concern. Although palliative care is for all ages, seniors account for 75% of deaths each year. It is well documented that seniors use more health care than non-seniors. The pressures on palliative care resources and the health care system in general will only increase due to our aging population.

Although most people are uncomfortable talking about their own death, or the death of their loved ones, it is a reality that we all face. Death and grief are a part of the natural cycle of life, and hundreds of thousands, if not millions, of Canadians are faced with those realities every year. A good palliative care system would not only support the dying. It would support their caregivers, mitigate the economic impact of people leaving work to participate in caregiving, and support those left behind through the grief and bereavement process so that their loss does not develop into a long-term impediment to full economic participation and personal fulfilment. The system we have can scarcely acknowledge these needs, let alone address them effectively.

Palliative care is an essential component of the continuum of life-long care that begins even before conception. In 1995 only 5% of Canadians had access to quality palliative care. In 2008, a best estimate suggested that somewhere between 16-30% had some level of access, depending on location. That means upwards of 70% of Canadians still do not have access to even the most minimal form of palliative care. Given the increase in the number of deaths expected over the next generation, the Canadian medical system has a long way to go to catch up to reality, and if we are not careful, we will see a further drop in access as resources are already stretched.

Euthanasia and Assisted Suicide Debate

The lack of access to quality palliative care has contributed to the resurgence in the debate on euthanasia and assisted suicide. According to Margaret Somerville, noted ethicist, the rise of consumerism, secularism and individualism in our society has brought the debate to the forefront. But, for those requesting euthanasia or assisted suicide, it is not just about a loss of dignity or pain and symptom management. It is also about their fear of being a burden on their family and on caregivers.

The terminology is becoming blurred as well. There has been a recent movement to refer to assisted suicide as physician assisted death. There could easily be confusion between this terminology and palliative care services as palliative care physicians

provide patients with pain and symptom management to ease discomfort as they approach death. However, in palliative care, physicians do not take specific measures to hasten death. As one physician said in a written brief, “The antithesis to deliberate ending of life is good palliative care.”

Before we can have an informed discussion on euthanasia and assisted suicide as a society, we need:

- o clear definitions on all the terms;
- o understanding that there is no need for the vast majority to die in pain; and
- o appropriate palliative care services to which all Canadians have adequate access.

Chronic Disease

The success of our health care system has created a situation in which we now manage chronic diseases longer and more effectively than we ever did before. Because of advances in medical technologies, it is not unusual for a person to live long enough to develop multiple chronic, deteriorating conditions. In fact, almost 4 out of 5 people over the age of 65 have one chronic disease and about 70% have two or more progressive, life-limiting conditions.

And chronic disease is on the rise. For example, the number of people living with dementia is expected to double to 1.1 million people by 2038.

Yet, our system is still very much based on a cure model with the solitary goal of cure; questions of quality of life and end-of-life care are secondary and in the background. Many participants in the roundtables expressed disappointment that palliative care is still seen as “boutique” care. Roundtable participants also identified the all too common view of administrators and even some non-palliative care practitioners that resources devoted to dying patients are wasted, as if dying people do not need care. There remains a total disconnect between the model of health care built by politicians, administrators and practitioners, and the real needs of the population.

Barriers to Consistent Care

The prevalence of chronic disease is also putting pressure on the long-term care system. As seniors care needs change, they move into long-term care facilities, which become their homes. More and more, seniors are dying in long-term care facilities. Yet there is no consistency across the country in terminology, facilities, funding models, standards of care, education or training for long-term care facilities. While some long-term care facilities offer excellent palliative care programs, others offer none. But to move patients from a long-term care facility to an acute care facility is not only more costly, it is usually the opposite of what the patient wants.

Canada is a geographically vast and sparsely populated country. Demographics and geography limit the ability to provide consistent services, supplies and equipment. This is compounded by a growing health human resource gap as we suffer from a skilled worker shortage as Canadians, including health care providers, age and demands on the system increase.

We live in a country where the provinces and territories are responsible for delivering health care and they have further devolved it to local health authorities. This leads to a lack of consistency in policy. In many provinces, palliative care is the responsibility of the provincial department responsible for seniors. But palliative care is not a senior's issue. Canadians of all ages die requiring palliative care services, including children. By operating in silos, we impede our ability to provide consistent care.

Palliative Care as an Enforceable Human Right

A recent interesting development has been some preliminary legal analysis on whether palliative care is an enforceable human right under the *Canadian Charter of Rights and Freedoms*. The argument has certainly been made that it is a moral right, but the possibility that it might be an enforceable right under the sections 7 (the right to life and security of the person) and 15 (the equality provision) of the *Charter* is intriguing.

Some Achievements in Palliative Care

- Canadian Institutes for Health Research invested 16.5 M in research on hospice palliative and end-of-life care.
- The Educating Future Physicians in Palliative and End-of-life Care (EFPPEC) project has resulted in all 17 medical schools across Canada now educating new physicians in palliative care.
- Education programs for nurses, social workers, pharmacists and pastoral care providers include some training in end-of-life care.
- Recent \$330,000 federal grant to develop curriculum on palliative care for schools of social work.
- Funding for palliative home care was part of the 2003 and 2004 Health Accords.
- Canadian Virtual Hospice website now gets 1000 hits a day.
- Several new children's hospices have opened across the country.
- The Canadian Strategy on Palliative and End-of-Life Care was supported by the federal government from 2001 to 2006. Its Five Working Groups made important improvements in several areas.
- An Aboriginal Training Manual has been created for home care workers.
- Palliative care is recognized as one of the four pillars of the National Cancer Strategy.
- Palliative care is identified as a priority in the National Heart Health and National HIV/AIDs Strategies.
- Some organizations are developing hospice services for the homeless.
- 12 of 13 jurisdictions cover the cost of at least some medical supplies and equipment for people dying at home.
- 11 of 13 jurisdictions cover the cost of a wide range of pharmaceuticals.
- 11 of 13 jurisdictions promote a team based approach to care.
- The Canadian Nurses Association now offers Hospice Palliative Care Nursing Certification.

Vision

Palliative care is intensely human and caring. It is not synonymous with death—it is about life, about the proper care of someone who is alive, someone who still has days, months, or years remaining in their life. Palliative care strives to provide comfort and dignity for anyone who is facing a life-threatening illness. This implies that we attend not only to their medical needs, but also to their spiritual and emotional needs. The focus of palliative care is on preserving the quality of the recipient's life so that their suffering is minimized but their experience of life is not. Palliative care is not about dying, it is about living well until the very end.

Canadians at end-of-life and their families need the right interdisciplinary health and social services care, at the right time, and in the right setting, based on their needs. Wherever they live in Canada, they also should expect to receive equitable access to the same quality of care.

To realize a society where all Canadians have access to quality palliative care services we need five things: **a culture of care, to build capacity, support for caregivers, integration of services, and leadership.**

We need to develop a **culture of care** that overcomes the limitations imposed by a death-denying society. A culture of care would recognize and respond to the reality that death trajectories are changing, and that Canadians are living longer and longer with chronic and complex diseases. To succeed at developing a culture of care, we need to incorporate palliative care services sooner for those who have a life-threatening illness, confront the challenges of defining palliative care, and achieve a common understanding of what constitutes good care for the dying.

We need to undertake a serious **capacity-building** exercise, comprising the full spectrum, from significantly increased research activities and knowledge translation, to improved and consistent education and training, to modernizing our health human resources plans to meet the emerging needs.

We need to adapt systems and programs to facilitate **caregiver support**, which is a critically important piece of the puzzle. Support includes: providing financial assistance to address lost income due to caregiving; offering training and advice to improve the capacity of caregivers; counselling and support to alleviate the stress of providing care; providing respite; and assisting with the difficult process of bereavement, which begins with diagnosis and carries through well after a death has occurred.

We need to get serious about **integration of services**. This concept is not new, but the reality on the ground is that there is still far too much territoriality and lack of cooperation. We must overcome incompatibilities that make it difficult for patients and caregivers to transition from one care setting to another.

Finally, we need **leadership** on many levels: individual leadership in local settings; champions at various levels of government and within society who help overcome jurisdictional barriers; leadership from community organizations and professional associations; and finally, the restoration of the federal leadership role that is the key to achieving success on a national scale.

II. The Culture of Care

Canadian Virtual Hospice

The Canadian Virtual Hospice is designed to provide support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators. The site, www.virtualhospice.ca, went on-line in February 2004. It now gets over 1000 visits a day.

While issues of death and dying are still not widely discussed in our society, patients at end-of-life and their families are looking for answers. Even if they do not have access to specialized palliative care services, they can turn to this on-line resource for information on managing symptoms, accessing financial benefits and navigating the health care system.

Physicians and other health care providers can seek assistance on complex cases, link to recent research and access tools to provide better care.

Death Denying Society

In Canada, we are a death-denying society. We avoid thinking or talking about death. When speaking about death is unavoidable, we use war-like language. It is somehow viewed as unnatural; something to be fought against at all costs. We talk of beating cancer, the battle, the fight. Our culture is rife with television shows set in hospitals where nurses and doctors cure the most exotic diseases and regularly bring patients back from the brink of death to a state of perfect health and ideal quality of life.

This fantasy world in which there is no death spills over into everyday life. Doctors treating patients at end-of-life feel they must try the newest experimental treatments and latest drugs, regardless of cost, else patients and family members accuse them of not caring or not wanting to spend the money on their loved one. Health care providers may even pursue redundant or futile measures to avoid confronting the inevitable. So we see bizarre and even harmful decisions near the end-of-life. Consider these scenarios as examples:

- o administering insulin to diabetics who have not eaten because they are hours from death;
- o recommending highly experimental treatments to avoid discussing the possibility of death to a cancer patient whose chemotherapy has not been successful; and
- o administering cholesterol medications to dementia patients in the last few days of life.

Many doctors have not learned to accept that some patients in their care are dying and need

help with that process. Most have not learned how to have the discussion about death with patients, and to be fair, most patients don't want to accept it as a possibility. So we witness the all too common situation where a patient has had surgery, radiotherapy, and even seen an oncologist, often more than once, without anyone mentioning the word cancer at any stage. Yet, the diagnosis is obvious. That is a startling measure of the reluctance even of health care professionals to discuss death and dying. Advance care planning can help ease the conversation for physicians, patients and families.

Technology has pushed the boundaries. Better treatments and medications for conditions like cancer, HIV/AIDS, heart disease, diabetes, and lung disease mean that patients are now not dying quickly of any of these conditions, but are living longer and longer with chronic conditions. Yet, most will eventually die of these diseases. Although we should celebrate the successes of new technologies which prolong life and provide a better quality of life, the fact remains that all these illnesses have a terminal phase. Death is inevitable and it is as natural as birth. We are all going to die, and most of us will spend many months, even years, living through the process.

One survey participant noted that “patients are living longer due to more treatment options that prolong life. However, their physical condition is that they require help but no supports are available for patients who are living longer but not capable enough to care for themselves.”

Palliative care is about living well every hour of every day. Despite the best efforts of the palliative care community, there are still many politicians, administrators, practitioners, caregivers and patients that equate palliative care with giving up. The perception is that somehow it is substandard care and that curative treatment and palliative care are mutually exclusive. This is not true, and this attitude is a significant barrier to progress. We need a paradigm shift to overcome it.

Within acute care settings palliative care can sometimes be seen as “boutique” care. Administrators, tasked with meeting impossible demands and too small budgets, naturally look for savings. Sadly, and all too often, they look first to the dying. Participants in the roundtables commonly reported examples of administrators saying, “Well, why do your patients need these services? They are dying anyway.” But the point is, these patients are living, often suffering from pain, anxiety, isolation and depression. These patients are in need of help, yet they are prematurely pronounced dead by a system under pressure to save money. These patients are living people; they need and deserve care, including appropriate pain and symptom management, nursing care, and emotional and psychosocial care to ensure good quality of life for every day they go on living.

Goals

- Philosophical and societal change to accept death as a natural part of living, just as birth.
- Increased expectations for palliative care within the community so Canadians understand what palliative care is and what they should expect from it.
- Additional educational resources for physicians to facilitate culturally sensitive discussions about death and dying with patients and families.

Death Trajectories

There is no question that the timing of death is variable and unique to each individual. It is also true that personal needs vary greatly at end-of-life. Some patients can suffer severe symptoms or have multiple conditions that require complex care. Others have simpler care needs. Modern palliative care services have been developed in response to the needs of cancer patients and the course of the disease, especially for certain cancers, is fairly predictable. The course of illnesses such as chronic obstructive pulmonary disease (COPD) and heart disease is not nearly so predictable.

Almost 90% of survey respondents stated that they perceived an increase in demand for palliative care services.

Recent research has confirmed the following four death trajectories, three of which involve living with a fatal illness.¹⁰ The fourth trajectory represents sudden death. The sudden death trajectory occurs in only about 10 % of deaths.

¹⁰ Canadian Institute for Health Information, *Health Care Use at the End of Life in Western Canada* (Ottawa: CIHI, 2007).

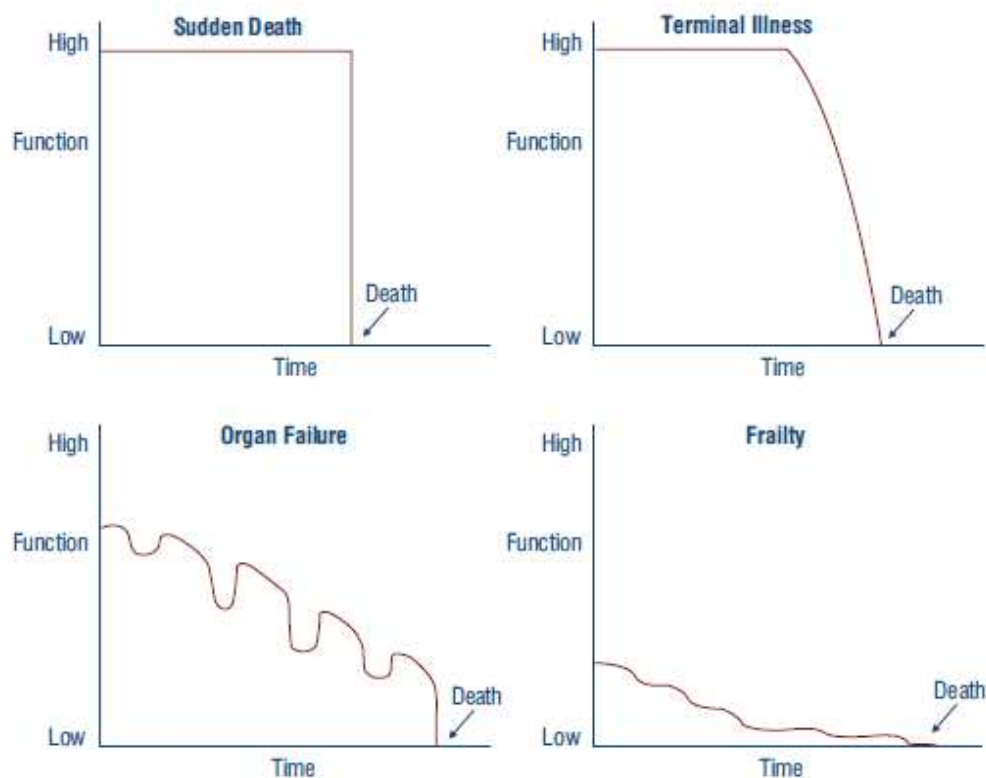


Figure 3 – Trajectories of Death

The Terminal Illness trajectory is defined as one with a short course of rapidly progressive disability in the last two months of life. This would be typical of many cancer deaths.

The Organ Failure trajectory is defined as one with a longer course of slow decline with intermittent life threatening exacerbations and then a sudden death. Often this would occur over a period of 2 to 5 years. This would be common with lung or heart failure.

The Frailty trajectory is defined as one with a very long course of slow decline with the ability to self care decreasing over time, maybe even over as much as 8 to 10 years. This would be consistent with the onset of dementia. Recent reports seem to indicate this trajectory is becoming increasingly prevalent in the patient population.

One survey respondent emphasized that “the common needs of caregivers and patients span all diseases, and are not only specific to cancer.”

Keeping Palliative Patients in the Home in Winnipeg

In the Winnipeg Regional Health Authority in Manitoba the palliative care program provides 24/7 coverage to palliative care patients in the home. The palliative care teams keeps 15 medicine kits for use in home deaths.

These medicine kits are kept in locked boxes which are left in the home with the palliative patient and contain medications such as pain killers, sedatives, and anti-nausea medications. The kits have enough medications to last 24 hours.

A palliative nurse can do a home visit, call the palliative care physician with an assessment and, if necessary, get approval to open the kit and use the medications. This innovative idea has reduced emergency room visits, is proving to keep patients at home longer, and assists patients in their wish to die at home.

The challenge for palliative care is that services have been very well developed to serve those who have a relatively short time of decline leading to death. The current approach to palliative care, including eligibility criteria and mix of services, has been based largely on serving the people who follow the Terminal Illness trajectory. Current programs often do not do such a good job in serving the needs of those who follow the Organ Failure or Frailty trajectory at end-of-life. Yet, it is clear that individuals in all three trajectories can benefit from a palliative care approach.

In many parts of Canada, eligibility for palliative care services is based on arbitrary time limits. For example, some jurisdictions limit access to palliative homecare services, drug coverage and hospice programs to the last few months of life. Yet those in Organ Failure trajectory or Frailty trajectory need these services for much longer periods of time. Moreover, this approach puts doctors between the proverbial rock and hard place. They are put in the role of gatekeeper, yet they can only allow access to services if they predict that someone will die within a very specific, and very short, amount of time. Such a prediction is fraught with ethical, medical and scientific problems. It is no wonder they are reluctant to make it, yet this reluctance effectively denies services to untold numbers of patients in need.

Goals

- For all non-sudden death trajectories, introduce palliative care services at the point of diagnosis and revisit the care provided as needs change.
- Expand the definitions of when patients become eligible for palliative care services ensuring flexibility of services to reflect individual needs at end-of-life.
- Develop educational resources for all physicians and specialists to inform them of

availability of palliative care services for their patients who are facing a potentially life-threatening illness.

- Develop a capacity to care for all patients throughout the system who have a life-limiting illness.
- Integrate palliative care services with chronic disease management in recognition that all chronic conditions have a terminal phase.
- Achieve recognition that palliative care services are required for people at all stages of life, including children.

Defining Palliative Care and End-of-Life Care

Creating a commonly understood definition can be difficult. Yet, in order to move forward, we need to share a common language and common understanding of the issues. This confusion exists in the public, as in the case of the patient who did not want to be hooked up to machines, but wanted to be resuscitated. But it also exists among health care providers as there is no common understanding of palliative care and end-of-life care and where each begins. A common understanding is lacking even within the palliative care community itself. This makes it difficult to advocate effectively with lawmakers, with administrators and with the public. Unless we can be clear on what the community is advocating for, it is hard to gain traction on any of the goals we identify.

When asked about new challenges to palliative care in the past five years, one survey respondent noted “increasing demand but no equal increase in funding for health care professionals, leading to burn out for these professionals.”

In the past, when patients were designated “palliative”, they did not receive any treatment whatsoever. As a result, physicians were reluctant to refer their patients to palliative care until the very last, as they were not willing to give up. Patients and families were reluctant to accept palliative care, as this meant accepting that death was imminent. This has meant that patients have refused palliative services as they have pursued treatment, resulting in poor pain and symptom management and a lack of access to needed palliative care services. Although those beliefs are changing, it is taking time for that mindset evolution to percolate through the system. With our aging population and with the rise in chronic disease over the past four decades, it has been recognized that palliative care can and should be introduced earlier in the disease trajectory and can co-exist with treatments. The side effect of this reluctance to refer patients to palliative care services are that physicians operate in silos and those patients do not get adequate care.

Palliative care should not be limited to measures taken in the last hours or days of life. It should be viewed as the requirement for care and services that form part of the continuum from the point of diagnosis. This can and should overlap with active treatment. It must also continue after death to include bereavement support to family members.

Even when referrals to palliative care have increased, resources have not increased. In many cases, physicians are reluctant to refer patients to palliative care for fear that the demand will outstrip resources.

Often, physicians think they are providing “end-of-life care” just because their patients are dying. There is not always a good understanding of what is a good death. It is not unusual to see people actively dying in acute care wards in a room with three others, with no support for their unique needs or the needs of their family. This failure on the part of administrators and practitioners to meet the real needs of patients illustrates the expression so often resorted to by participants in the roundtables that, “they don’t know what they don’t know.”

Dr. Michael Downing of Victoria Hospice recently identified five key indicators to good care for the dying. They are:

1. Safety
2. Comfort
3. Respect
4. Support
5. Ability to tell their story

Is the patient in a safe environment, where their physical and emotional needs can be met? Are they comfortable with pain and symptoms being well managed? Are they being treated with respect? Are they and their families receiving support, psycho-social, spiritual and emotional? Is the dying person able to tell their story and have someone listen? If we can answer “yes” to all these questions, then we know they are receiving good palliative care.

Goals

- Consistency in the use of terminology so that the public, caregivers, health care providers, policy makers and administrators have a common understanding of the terms and what they mean.
- Earlier referral of patients to palliative care, so that services can overlap with treatment, and can continue after death to include bereavement services.

- Access for those at end-of-life to trained staff and volunteers who understand their needs, regardless of the setting of care.
- Initiation of palliative care from when a life threatening illness is recognized and someone is prepared to accept care.

III. Capacity Building

Research

Research is one step to building capacity within the system to improve care for those at end-of-life. In 2005 the federal government recognized the importance of increased research into palliative care by investing \$16.5 Million of research dollars over five years through the Canadian Institutes of Health Research. Those research funds went a long way towards building the capacity for research in palliative care. Canada almost doubled its world share of palliative and end of life care publications between 2004 and 2009. Unfortunately, research dollars are drying up, though much more is needed. What research has been done has not yet been translated into practice and resources are needed to help establish these best practices in all places of care.

Despite some progress with the CIHR funding, research is needed in every aspect of the palliative care field, including:

- o the socio-economic benefits of palliative care;
- o common definitions;
- o quality indicators;
- o common data collection methods;
- o models of care;
- o how to best meet the needs of caregivers; and
- o use of technology in providing care.

Research findings also help determine educational needs and research priorities.

Most research measures outcomes. In research relating to medications, for example, researchers measure the medication's outcomes in terms of the improved health of the patient. In palliative care an outcome measure on the improved health of the patient would not be helpful, as the patients are dying. Instead, the research must measure improvements in the quality of life of the patient. In this way, the focus for palliative care needs to be on qualitative research. Qualitative research is harder to get funded and is less accepted in peer reviewed journals. Many in the research community recount anecdotes about proposals being rejected by granting organizations on the grounds that it is unethical to include dying people in the group of patients to be studied. These barriers to funding have held back the advancement of palliative care for too long. There remains a need for more evidence based, best practice research to improve care for those at end-of-life.

Much of the research to date has been urban-based and we lack models for sparse populations. The ability of rural settings to participate in research related to direct clinical care and to translate research findings into practice remains challenging.

Yet, there is unique work being done in rural areas which is not being collected and shared more broadly across the country. Research into improving palliative care needs to consider the geographic realities of Canada. And the research results need to be widely disseminated.

Much knowledge is not translated into practice because research funds are so scarce, they are barely sufficient to sustain a few basic studies, let alone fund knowledge translation. Knowledge translation must be an integral part of research to make the most of the dollars invested. Identifying new ways to communicate best practices across care settings is essential to improving palliative care and creating sustainable systemic changes and cultural shifts. These new models of knowledge translation need to be adapted to the workplace realities of today.

Innovative solutions will be required to meet the increasing demands on our systems as the population ages. Adequate research capacity is one of the best ways to determine how best to meet the growing needs within the fiscal realities of governments.

Goals

- Robust research capacity that would identify opportunities to improve care and ensure efficiencies that will maintain palliative care as a cost-effective alternative.
- Evidence-based quantitative and qualitative research that identifies best practices, both in the sense of improved care and in the sense of cost-effective delivery.
- Dissemination and widespread adoption of best practices through effective knowledge translation activities.

Education and Training

In addition to research, another important element is education and training for the intra-professional health care team.

There have been a number of important developments in education and training since 2005. There has been some recognition of the need for additional education and training programs in palliative care. The Royal College of Physicians and Surgeons of Canada and the College of Family Physicians of Canada have a one year conjointly accredited program in Palliative Medicine. This program provides advanced training at a post-certification level for those physicians who wish to develop added competence in this area. It is a one-year combined special program entitled Palliative Care that follows formal training in family medicine or a discipline of specialty medicine. There are also

Pallium's LEAP

LEAP (Learning Essential Approaches to Palliative Care) was designed specifically for family physicians, registered nurses, licensed practical nurses and pharmacists, and focuses on improved management of advanced, end-stage illness in the community by inter-professional teams.

The course's multi-professional format mirrors the way that health care professionals are increasingly expected to work together, complementing each other's unique clinical skill sets. This resource is available on a licensed basis for education in Canada by appropriately qualified instructors.

The LEAP course is part of the Pallium Project's outreach education efforts to make palliative care learning accessible. The Pallium Project was founded as a Health Canada supported education and professional development project.

12 medical schools with accredited residency training programs in palliative medicine programs. There were 11 trainees in 2007, 10 in 2008 and currently 24 are enrolled. There is also a proposal before the Royal College to consider a 2 year program.

In another important development, all 17 medical schools across Canada now educate medical students in palliative care. This progress was made possible by the work done in the Educating Future Physicians in Palliative and End-of-life Care (EFPPEC) project funded by Health Canada.

Similar work is being done in education programs for nurses, social workers, pharmacists and pastoral care providers to ensure that training in palliative care is included in their course work.

Despite progress in many areas, there is certainly no room for complacency. Education and training of new health care providers is only one part of building capacity within the system. Education and training opportunities need to be ongoing and need to reach out to those already in the field on a continuous basis. Programs such as LEAP (Learning Essential Approaches to Palliative Care) by Pallium are helpful in this manner.

Palliative care is by its very nature, interdisciplinary. Therefore, it is essential that there be a coordinated, integrated and sustained approach to making education and training available for all disciplines, including home care workers, volunteers and family caregivers.

It is also clear that any education and training programs need to recognize the multi-cultural reality of Canada. We need more education on how different cultures perceive death and how palliative care programs can support patients, caregivers and families appropriately. Different cultures have different constructs on how they view death and dying. Challenges such as language and cultural differences can lead to a lack of understanding of needs. This can further lead to under-referral to

programs and a lack of access. Cross-cultural awareness training for health care providers and policies and resources aimed at directly facilitating culturally appropriate end-of-life care can promote understanding and an increased ability to meet the unique care needs of every individual.

There are still Canadians dying in needless pain because health care providers do not know what a good death is. Many physicians do not know how to have a helpful conversation about death and dying. As one of the roundtable participants said, in medical school he had been trained in cardiopulmonary resuscitation but was never trained in Do Not Resuscitate Orders.

Goals

- Basic skills in end-of-life care are core competencies in all health care professions.
- Volunteers consistently trained with basic, core skills.
- Integrated, intra-professional training and education opportunities which are culturally appropriate and provide innovative solutions to overcome the barriers of continuing education.
- Provide education and support for disease-specific medical specialists to communicate effectively with palliative medicine specialists and primary care providers in order to ensure integration of curative treatment and palliative care and continuity of care between disease treatment and palliative care.

Health Human Resources

Canada is a geographically vast, sparsely populated country with skilled health human resource gaps and a growing prevalence of complex chronic conditions as a leading cause of death.

The health care field has several occupations facing human resource shortages. The best known of these is a real lack of primary care physicians in Canada. There is also a serious shortage of nurses in Canada. Our aging population is placing a greater demand for these resources on the systems. Yet, our health care professionals are also ageing and retiring, faster than we can replace them with newly trained professionals. This shortage is making working conditions even more challenging for health and social care staff currently in the workforce.

When asked about new challenges over the past five years, the most common survey responses concerned lack of resources, with many emphasizing health human resources.

Montreal's Jewish General Hospital

The palliative care program at the Jewish General Hospital in Montreal follows 500 patients at home. With only 17 beds in their inpatient unit, they enter a moral contract with patients and their families, guaranteeing that if the patient needs to be admitted to the hospital, they will do everything they can to bypass the emergency room and admit them directly to the palliative care ward.

Over the past year, 20% of all admissions to the unit were facilitated this way. With a physician on call 24/7 to handle calls from patients at home, they can admit directly when a bed is available. If no bed is immediately available, they organize increased home care or admit to another ward. e. This moral guarantee of access to the unit if needed provides patients and families with the confidence that enables them to keep the patient at home.

On a regular basis, communities are struggling to attract primary care physicians. In some parts of the country almost 2/3 of the physicians are foreign trained. In some cases with foreign-trained physicians, they may not have basic skills in palliative care. Furthermore, language can be a barrier to effective communication between the physician and the patient. Increasingly, there is a need to rely on nurses and nurse practitioners.

But as we are placing more and more stresses on already overworked health care providers, it is also important to remember the need for self-care for health care providers. Health care providers need the tools and resources to support each other, especially in dealing with the loss of their patients.

There is a need for increased mentoring and succession planning. There is also a need for increased workforce planning processes to identify the needs for the delivery of integrated palliative care services and to ensure the capacity exists to meet these needs.

Geography and isolated populations will impact the workforce planning process. The needs and capacity of rural and urban settings differ. In rural areas there is not just an absence of trained people: often remote communities lack a sufficient labour pool to do the work, even if training were not an issue. Innovation and technology will have to play a part in building capacity for consistent and equitable access to services across the country.

Volunteers are a huge untapped resource and should be considered part of workforce planning processes. There has been a lack of national leadership in volunteerism in recent years, but building capacity in volunteers is one way to help meet the emerging needs of our aging population, particularly in rural areas. But volunteers need adequate training and support.

One of the barriers to incorporating palliative care services more effectively into the system is the lack of education and training in palliative care. There

needs to be a continuum of services available, based on geographical and demographic realities. Palliative care must exist as an integrated, comprehensive and coordinated service within a home and community-based health care system which can provide care in a wide variety of settings.

All health care providers, including physicians, nurses, LPNs, personal care workers, home care workers and volunteers need basic training and education in palliative care. Although primary care physicians must be able to provide palliative care, specialized intra-professional consult teams should be available in areas where the population warrants and supports it. These consult teams could be called upon for more complex cases and act as a resource to primary care physicians. In addition, palliative care should be recognized as a medical specialty. This would help in improving the overall quality of care and increase research capacity.

Goals

- A strong health human resource sector, including volunteers, which can support the provision of quality palliative care services to all Canadians regardless of their location, financial, cultural or linguistic situation.
- A basic level of training and education in palliative care for all health care providers, regardless of their professions.
- Intra-professional consult teams exist to provide support and consultation services for more difficult cases.
- Palliative care to become a recognized specialty.

IV. Caregivers

Caregiver Support

The increasing reliance on deinstitutionalized care has had a great impact on Canada's 1.5 to 2 million family caregivers, who provide \$25-26 billion worth of care annually while incurring \$80 million annually in out of pocket expenses.¹¹ The increasing emphasis on health care delivery in the home setting and in the community has meant the family caregiver will continue to shoulder a greater burden of care.

Family caregivers come from all walks of life and all age groups. Although caregivers can be found across all income strata, generally they have household incomes below the national average. Only 35% of households with caregivers report income over \$45 000. Twenty five percent of caregivers report their employment situation has been affected by their caregiving responsibilities. Caregivers can be young or old, but most are women (77%).

Family caregiving can help the patient remain in their home longer. For example, the Alzheimer Society of Canada has data showing that providing structured support to family members caring for a person with dementia has been found to delay the need for a person with dementia moving to a care facility by as much as 15 months. Family care giving can be a rewarding experience for many people. Yet, for others it can be a horrific experience. For some, it can even cause serious harm to their psychological, economic and physical well-being.

When asked about the most needed supports for caregivers, the most common survey responses suggested respite, access to a palliative care coordinator, and financial assistance.

Care giving comes with a price. Most family members who provide chronic care are in the labour force. As noted above, in 65% of the cases with family caregivers, the household income is less than \$45,000 a year. Sometimes it is the main income earner who is ill and can no longer work. Family caregivers are often forced to give up their paid work. While often unavoidable, this sacrifice represents more than loss of wages. It has long-term effect such as reducing eligibility for the Canada Pension Plan and other retirement plans. While making it possible for the health care system to save money through home care, caregivers also shoulder extra out of pocket expenses such as the costs of transportation, medication and supplies in caring for their dying loved

¹¹ Hollander, M.J, Liu, G., Chappeell, N.L. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2), 42-59.

NS Caregiver Allowance

The Government of Nova Scotia provides a caregiver allowance of \$400/ month to regular caregivers providing more than 20 hours/week of care.

There are eligibility criteria both for the recipient of care and for the caregiver. The recipient of care must be low income, must undergo a needs assessment by a Continuing Care Coordinator, and must require significant care over time due to a very high level of impairment or disability. The caregiver must be in an ongoing and regular care giving situation with their family member or friend, live nearby, and provide care for a minimum of 20 hours/week.

The program does not affect a care recipients' eligibility for other Continuing Care services.

This program innovates by breaking through a barrier that was once unassailable: family members can receive payment, albeit a small amount, as compensation for their extraordinary efforts.

one. These financial demands are all the more difficult because they are incurred precisely when their financial resources are already stretched to the breaking point.

It is no wonder that the provision of caregiving often results in compromised mental, emotional, physical, social and financial health due to the demands of giving family care and the demanding nature of end-of-life care. The home setting also complicates caregiving. One roundtable participant even remarked that family caregivers are sometimes giving care in the home that physicians would hesitate to ask nurses to perform in hospital or other institutional setting.

There is a fine line for family caregivers between their role as caregiver and their role as spouse, child or parent. Especially at end-of-life we need to preserve their ability to still be a child, parent or spouse to their dying loved one and not solely a caregiver. Palliative care has always regarded the whole family as the recipients of care, not solely the patient. It is critically important that we never lose sight of the fact that family caregivers are in need of care themselves.

Although the health care system continues to increase the burden on caregivers, we have failed to recognize that trend from a public policy perspective and put in place measures to ease the financial, emotional and psychosocial effects.

Well beyond the field of palliative care, family caregivers are part of the solution in dealing with the tsunami of an aging population and increased demands for care. We must invest the resources necessary to support caregivers. Family caregivers need better information at the time of diagnosis. They also need access to respite services, training, counselling and resources that can provide information and advice any time of the day or night.

We need additional research into how best to support family caregivers. It costs the whole

economy a lot more when a family is non-functional because of one person dying. And sometimes the problem is that caregivers do not have enough knowledge about what might be available to them to even ask the right questions to access any support which is available.

The Government of Nova Scotia now provides a caregiver allowance of \$400 per month to regular caregivers providing more than 20 hours per week of assistance. This program innovates by breaking through a barrier that was once unassailable: family members can receive payment, albeit a small amount, as compensation for their extraordinary efforts.¹²

Goals

- Provide financial support to family caregivers who stay home to provide care.
- Well resourced home support programs to provide needed support to family caregivers in the home.
- Information and resources provided to all family caregivers to support them.

Compassionate Care Benefit

The Compassionate Care Benefit was introduced in 2004 by the federal government as a benefit under the Employment Insurance Act with an aim to providing financial support for those who took a leave of absence from paid work to care for a terminally ill family member. The program has never had as much uptake as anticipated and, despite several efforts to improve the program, it still does not meet its original objectives.

Recent research has identified the following as the largest barriers to accessing the benefit:

- o the complex application process;
- o the short time frame for taking the benefit;
- o the eligibility requirements;
- o the low compensation level;
- o the definitions; and
- o the lack of flexibility of when the benefit can be taken.

Most people who are eligible for assistance under the program do not even know it exists. Because the time frame is too short, 6 weeks of benefit, people often delay

¹² http://www.gov.ns.ca/health/ccs/caregiver_allowance.asp

Greystone Bereavement Centre

The Greystone Bereavement Centre in Regina, SK is unique in Canada in its capacity and in its programs. Since March 1, 2008 the Centre has been offering counselling expertise and education around the grieving process to ensure that each client receives the appropriate care at the appropriate time.

The Centre's goal is to contribute proactively to the health and well-being of those grieving. It seeks to compliment the natural support systems already in place to help individuals reinvest themselves in living and find a new normal following the death of someone special.

Two grief counsellors offer individual counselling services and group counselling. The services are also extended to those who lost a loved one through violent or sudden means, not just to families whose loved one received palliative care.

applying and then their loved one dies before they complete the application or before the benefit starts.

Currently, the benefit ends on the Sunday after the death of the family member. If a death occurs on a Saturday, the recipient is left to his or her own devices on 24 hours notice. There is no recognition of a need for time for grief and bereavement.

Compassionate care benefits may be paid to a person who has to be absent from work to provide care or support to a gravely ill family member at risk of dying within 26 weeks. This definition poses difficulties for physicians who are unwilling to predict that someone will die within 26 weeks and to parents of children who resist strongly the notion that their child is at risk of dying.

Goals

- A revised Compassionate Care Benefit that addresses the barriers to accessing the benefit.
- A Caregiver Financial Support Program that covers all Canadians, not just those eligible under Employment Insurance.

Grief and Bereavement

By 2036 Canada will see approximately 400 000 deaths per year. Given that each death affects, on average, five other people, potentially more than 2 million Canadians per year could be facing grief and bereavement.

Grieving is a normal and healthy process. That process begins as early as diagnosis, a phenomenon known as "anticipatory grief". Efforts to assist people with grief and bereavement need to take this reality into account, rather than focus exclusively on the period following death.

Support and counselling does not always need to be done by professionals. In most communities that

have good programs, the majority of the work is done by volunteers and in informal groups with support from professionals.

Currently, where well established palliative programs exist, grief and bereavement support and follow-up are sometimes included. However, because palliative care is part of the health care system, when the patient dies, the family is no longer connected to the system. Without early referral (before death occurs), and without a specific grief and bereavement program to refer the family to, those grieving are easily lost to follow-up.

It is essential that we include bereavement services as part of the basket of palliative care services. These services need to be offered through the trajectory of the illness to the patient and the family.

Goal

- To establish formal bereavement and grief services available for everyone in need.

V. Integration of Care

Hospice Greater Saint John

Hospice Greater Saint John in New Brunswick has opened the first residential hospice in Atlantic Canada.

Renovations to the residence are currently underway and the new 10 bed residential hospice is set to start accepting residents in the Fall of 2010. It is expected that the hospice will serve 150 residents each year. This will free up hospital beds and help shorten wait times in the Greater Saint John area.

Bobby's Hope House was made possible with a generous donation in 2005 from Bobby Lawson, a long time hospice volunteer facing her own end-of-life illness. Hospice and the provincial government will cover the daily costs of care for the residents.

Donations from the community and businesses have helped bring about the necessary renovations to the residence.

Our health care system is designed to deal mainly with brief periods of episodic illness. It is not well positioned to cope with the rise of chronic illness and the longer term needs associated with these death trajectories. In addition, the various health and social service systems are not sufficiently integrated to allow caring professionals and family members to pull together the right basket of services to meet the individual needs of patients nearing the end-of-life.

Canadians are still struggling to navigate the system and access services that are dispersed across many different settings, and even across various levels of government. There is no consistency in what is available in different settings of care, or continuity of care from one setting to another. There is no help for patients and families in navigating a system that is difficult for practitioners to understand, let alone a lay person. And transitions between settings of care (home, hospice, acute care, etc.) can be very challenging.

There are significant differences in what services are available between rural and urban settings. There are significant differences in what is available not only from province to province, but also within different health care regions within a province. Some locations have 24/7 consultation services available, but this is the exception rather than the rule. Some locations have access to interdisciplinary consult teams, but the overwhelming majority of Canadians live in health jurisdictions where no such service is available. Even within a health region, the question whether medication and equipment costs are covered varies from one setting to the next.

In many communities, not-for-profit groups can, and do, play an important role in end-of-life care. They support the publically funded services and

try and bridge gaps. Yet the capacity of these organizations is also limited.

For a person at end-of-life and for family members struggling to provide care, it is difficult if not impossible to navigate this mix of publicly and privately funded services that vary depending upon location. Choices are often made when a crisis occurs, and the family has reached a breaking point. This means people are choosing the path of least resistance, whatever stop-gap measure is available in the moment, rather than making a coherent plan for care. We need a system where there is a patient navigator to help get the appropriate services in the right place at the right time, and to line up services to swing into action when needed. This would be a key member of the interdisciplinary team that would be a specific individual who assists patients and families to navigate through the health and social services system.

One survey respondent noted that “rural areas have a very difficult time getting the support they need. Everything seems to be based on city needs.” Another noted the “growing diverse minority populations with palliative care needs and inadequate supports to address the specific cultural needs.”

According to a recent study by the Canadian Homecare Association, first dollar coverage for palliative care and end-of-life support has been implemented in every jurisdiction in Canada, with the exception of Health Canada's First Nation and Inuit Health Branch. However, there is still a need for portability across provincial boundaries. Saskatchewan for instance, will cover home care for those out of province, but other provinces will not. Furthermore home care services are still often not sufficient to provide the needed support for patients to be at home. Even in areas where these services exist, demand often exceeds the capacity of the system to provide care. There is also a real lack of consistency in staff going into the homes. A patient seeing a dozen or more different care workers in a week in the home is not unusual. This means the caregiver is not getting any true respite as they are constantly training new home care workers on the specific needs of the patient. There is a need for accountability on the part of provincial and territorial governments to make sure there is progress on the commitment to support people in receiving the necessary case management, nursing, palliative specific pharmaceuticals and personal care at end-of-life.

Canadians are still being presented with the hospital as their best or only choice for palliative care in many parts of Canada. That option is often the most expensive and the least appropriate for meeting the actual needs of the patient. The silos of our medical model and the artificial barriers, which have been constructed around eligibility for services at end-of-life, result in bad care decisions, poor economics within the system and poor care for the person at end-of-life. Providing integrated, coordinated care to persons at end-of-life allows health and social services to mobilize a range of

resources quickly to meet needs as they arise, delivering the best care possible while avoiding using resources inappropriately.

Goals

- Ease of access to the right services at the right time for patients and families.
- Seamless transitions across care settings.
- Improved portability of services between provinces.

VI. Leadership

Canada's political organization has profoundly affected the evolution of palliative care as healthcare in this country crosses the jurisdictional boundaries between the provincial governments and the federal government.

The federal government, through Health Canada, provides funding for our national health insurance system, develops health policy, enforces regulations, and has direct service responsibility for the delivery of healthcare to certain population groups – notably veterans, the RCMP and military, First Nations on reserve and Inuit, federal inmates, and refugees.

The ten provincial and three territorial governments implement national health policies and oversee direct health care delivery for the population as a whole. Most provinces and territories have further decentralized health care responsibility to regional health authorities. These jurisdictions have integrated palliative care into their health care programs to varying degrees. The four western provinces have designated palliative care as a core service of the provincial health care program with a separate budget line. Other provinces and territories offer palliative care services, but often as a sub-section of services to seniors, homecare or cancer care. Palliative care is still largely funded by charitable donations.

Of the respondents in the survey, 93% identified a role for the federal government in palliative care, 97% identified a role for the provincial government, and 96% indicated a role for regional authorities.

Of the 14 governments that deliver health care directly in Canada, the federal government is the 5th largest, behind Alberta and ahead of Manitoba. But its importance as a direct provider of care and insurance is surpassed by its substantial fiscal support to the other governments in the form of transfers. This year the transfers amount to \$53.7 billion, or 21% of federal expenditures¹³. Of this, the Canada Health Transfer alone is \$25.4 billion¹⁴. The Equalization program designed to enable citizens in provinces with lower fiscal capacity to have comparable services, including health care, is another \$14.4 billion.

Despite the enormity of the federal government's roles both as a direct provider and as a key partner enabling the provinces and territories to maintain their health delivery systems, there is no national strategy for palliative care. It is important to note that a

¹³ Main Estimates 2010-2011, page 8.

¹⁴ Ibid. page 9.

few of the existing federal strategies, such as the cancer strategy, have made palliative care a priority. But there is no overarching national strategy for palliative care. There is also a lack of coordinated provincial or territorial approaches or strategies. The result is a lack of consistency even within a province or territory on whether or how palliative care services are offered. For instance in Ontario, there are 14 Local Integrated Health Networks; however, only 2 have listed palliative care as a priority within their region.

Palliative care programs and services need to be integrated into the health care system and not be an additional program that may or may not be available in the community, and which come and go with annual budget adjustments. There also needs to be the political will to remove the systemic barriers which impede the provision of quality palliative care to Canadians.

We are seeing an increase in the incidence of chronic disease, longer death trajectories, an aging population, health human resource shortages, funding deficiencies and a lack of investment in research and inadequate education and training. To meet these challenges, we need a coordinated approach to public policy and planning. We need to drive systemic change to respond to current and future needs through adequate data collection, human resource planning, education, research, and funding.

Roundtable and survey participants indicated palliative care was too important, with too much work still needing to be accomplished, for us to remain parcelled in so many silos. Participants were convinced that without coordinated, national leadership there will continue to be a patchwork of services available to Canadians as no single province is equipped to provide the necessary national leadership.

Too often in many organizations, not just palliative care, successes and progress are the result of the efforts, the vision, and the dedication of individuals in particular settings or particular regions. Where pockets of excellence exist, it is almost always based on individual leadership on a local level. What we need is not a change within one institution. We need a systemic change. Just as change does not happen locally without leadership, systemic change on a national scale cannot happen without sustained leadership.

Systemic change takes time. Too often governments look to make changes in chronically underfunded systems in piecemeal fashion. Even when governments invest strategically, they do not always sustain the funding long enough for the systemic change to occur and become the new way of work. Focussed, sustained, strategic funding, taking a whole system view, is necessary to bring about a cultural change.

Leadership must emerge from all quarters. Raising the bar in providing quality palliative care to all Canadians will require a multi-jurisdictional approach. It will require leadership from the federal, provincial and territorial governments and from the community as a whole, including professional associations and community organizations. Any national strategy on palliative care must include the community as

a key partner. In partnership with professional organizations and government, the Canadian Hospice Palliative Care Association can play a key coordinating role.

A few years ago, Canada was on the forefront internationally in developing public policy to support palliative care and in the provision of care. Now, other countries have once again surpassed us. We can look to countries like Australia and the UK for best practices. We can examine their national strategies and practices and determine what best practices we can implement here in Canada.

The acceptance of common indicators, outcome measures, definitions and language would be an important first step in setting national benchmarks and national goals.

Goals

- Coordinated strategy involving the federal/provincial/territorial governments and the community to set a national vision, national benchmarks and accountability measures.
- Adequately funded palliative care services.
- Equitable access to palliative care services across the country.

Recommendations

Achieving a society where all Canadians have access to quality palliative care services will require five things: a culture of care, building capacity, support for caregivers, integration of services, and leadership.

Realizing the goals of this vision requires a multijurisdictional approach. Responsibility for raising the bar lies with governments at the federal level and at the provincial and territorial levels. It also lies with the community as a whole, including community organizations, health care providers and professional organizations. In particular, the Canadian Hospice Palliative Care Association can play a key coordinating role.

To the Federal Government

1. Re-establish a Canadian Strategy on Palliative Care as a partnership between the federal, provincial and territorial governments and the community. With federal leadership, financial support and coordination, this Strategy would:
 - o Pave the way for consistent minimum standards and benchmarks of nationally available palliative care services;
 - o Support the integration of comprehensive palliative care services into the system; and
 - o Provide the leadership, vision, best practices, coordination and awareness necessary to ensure the provision of quality palliative care services for all Canadians.
2. Recognize and accept the federal government role as a direct provider of health care to certain populations under federal responsibility and ensure appropriate programs and funding for these populations, most especially for our First Nations and Inuit peoples.
3. Establish a Canada Pension Plan drop-out provision for caregivers, similar to that for parents who stay home with new babies.
4. Revamp the Compassionate Care Benefit Program under Employment Insurance to include the following elements:
 - o Implement a CCB awareness campaign that targets all stakeholder groups and the public simultaneously through a range of formats;
 - o Improve the application process to be quicker, simpler, and more sensitive to the stressful and emotional realities of CCB applicants;

- o Lengthen the period of support from 6 to 26 weeks to allow for flexibility because of the challenges in prognosticating death, a more reflective and not rushed process, and to allow caregivers to extend the paid leave after death to include time for bereavement;
 - o Increase the financial assistance to more adequately reflect the real costs endured by family caregivers when taking time off to work to provide end-of-life care; and
 - o Change the eligibility criteria from “significant risk of death” to “high need of care giving due to a life threatening illness”.
- 5. Establish a Caregiver Benefit, similar to the Child Tax Benefit, to cover expenses such as nursing, bookkeeping help and transportation.
- 6. Establish a National Strategy for Family Caregivers which safeguards health and wellbeing with respite care; recognizes the importance of grief and bereavement services; minimizes excessive financial burden; provides information and education for caregivers; provides adequate home care services; ensures flexible work options; and supports caregiving research.
- 7. Establish a Health and Social Care Transition Fund to assist provinces and territories in continuing to realign the health care system to meet the needs of the aging population and increase in incidences of chronic disease. This would include support for communities to transition to alternative settings of care, such as a residential hospice and home care services.
- 8. Establish a Canadian Palliative Care Capacity Building Fund of at least \$20 Million annually for 5 years to undertake priority health care provider and public engagement and capacity building activities, including:
 - o The establishment of a health human resources workforce plan to address workforce needs;
 - o Creation and implementation of nationally standardized volunteer training package;
 - o Research and knowledge translation;
 - o Dissemination of best practices; and
 - o Development and implementation of culturally sensitive, interdisciplinary education and training materials and programs for all health care providers.

To the Provincial and Territorial Governments

- 9. Using the Canadian Association of Provincial Cancer Agencies as a model, foster interprovincial/territorial cooperation to establish common data definitions,

technologies, and policies within health care regions to facilitate smoother transitions between care settings.

10. Using models such as those used in some of the provinces or the one used by the Canadian Partnership Against Cancer, establish system navigators to assist caregivers and patients in accessing services they need. These navigators would be assigned to them at the time they are diagnosed with a life-threatening illness and would be able to help them navigate through the health and social services systems.
11. Work in partnership with the federal government and the community to establish a national public awareness campaign on advance care planning and palliative care to raise awareness on end-of-life issues and start the dialogue among Canadians. This campaign could include a public schools component where discussions could begin among younger Canadians.
12. Using the Nova Scotia Caregiver Allowance as a starting point, collaborate with the federal government to establish a national program for those who lose income by engaging in care giving but are not covered by Employment Insurance.
13. Ensure palliative care services are covered under all provincial and territorial health insurance plans.
14. Create reciprocal agreements among the provincial and territorial governments to eliminate waiting periods and create a national standard of care for palliative care services for all Canadians to improve the portability of services between provinces.

To the Community

15. Professional organizations such as the Royal College of Physicians and Surgeons, the Canadian Medical Association and the Canadian Society of Palliative Care Physicians, in partnership with the Canadian Hospice Palliative Care Association, must promote an early referral system designed to educate and support physicians in referring patients to palliative care services at the time of diagnosis of a life-threatening illness.
16. The Royal College of Physicians and Surgeons, the College of Family Physicians of Canada and the Canadian Society of Palliative Care Physicians work together to recognize palliative care as a speciality.
17. Professional organizations work together to adopt nationally standardized core competencies in palliative care for all disciplines.

Conclusion

We are a death denying society who refuses to accept that we are all going to die and we should endeavour to make that dying process as comfortable as possible. The evolution of palliative care is being profoundly affected by the increase in chronic diseases. Combined with an aging population, the system is being stretched and tested as never before. There are still at best 70% of Canadians who do not have access to palliative care. And even when there is access, it is not equitable. There are still those who do not understand palliative care and see it as boutique care, rather than as a natural and equally important part of health care as is maternity care. We need a culture of care that recognizes death as a natural part of life and rises to meet the challenges of the new realities of caring for those at end-of-life.

There are still Canadians dying in needless pain because health care providers do not know what a good death is. We need to build capacity throughout our health care system with increased research, better knowledge translation, implementation of best practices, better education for our health care providers and a health human resources staffing plan to address future needs.

Caregivers are fundamental in our health care system. Paid caregivers could never hope to replace the work of unpaid caregivers. We need to provide them with adequate supports to keep the family unit functioning as they experience loss.

The Compassionate Care Benefit is too narrow in its application and changes are needed to ensure those who can most benefit from this program know about it and can access it.

We cannot afford to overlook the need for follow up grief and bereavement support to families.

Palliative care programs and services need to be integrated into the health care system and not be an additional program that may or may not be available in the community, and which come and go with annual budget adjustments. Health and social services must not exist in silos, but in partnership to meet the needs of the population.

We are facing a tsunami of aging in the next few years and we are not prepared to handle the increase in the numbers of those who will require palliative care. Without federal leadership there will continue to be a patchwork of services available to Canadians as no single province is equipped to provide the necessary national leadership.

When asked about the key strengths of the palliative care system, the most common survey response was the quality of the doctors, nurses, volunteers, and staff that actually deliver palliative care to those in need.

Conclusion

Since 1995 there have been some significant improvements in public policy regarding end-of-life and in the delivery of palliative care services. Yet, we need to raise the bar.

This report sets out a vision for palliative care in the future with realistic and attainable goals. Its recommendations are a roadmap to achieving these goals. Quality palliative care is the right of every Canadian. It is the responsibility of every Canadian to work together at all levels - federal, provincial, territorial and community – to ensure quality care at end-of-life.

Appendix: Sources

Roundtables and Conference Calls¹⁵

February 2, 2010 - Montreal, Quebec

February 4, 2010 - Winnipeg, Manitoba

February 8, 2010 - Victoria, British Columbia

February 9, 2010 - Edmonton, Alberta

February 10, 2010 - Regina, Saskatchewan

February 16, 2010 - Charlottetown, Prince Edward Island

February 22, 2010 - Halifax, Nova Scotia

February 23, 2010 - Toronto, Ontario¹⁶

February 24, 2010 – Ottawa, Ontario

March 10, 2010 - New Brunswick Conference Call

March 10, 2010 - Newfoundland and Labrador Conference Call

Written Submissions

Northern Health, Hospice Palliative Care Consult Team, British Columbia

Michael Aherne, Edmonton, Alberta

Mary Hampton, Ed.D, University of Regina

Alzheimer Society of Canada

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¹⁵ Conference calls included representation from across the province.

¹⁶ There were two separate roundtables held in this location on this date.

Margaret Somerville AM, FRSC, DCL, McGill Centre for Medicine, Ethics and Law

Canadian Home Care Association

Canadian Cancer Society

Royal College of Physicians and Surgeons of Canada

Alberta Hospice Palliative Care Association

Dr. Michelle Chaban, HABITAT, University of Toronto

Hospice Renfrew

Health Council of Canada

Norman Brown, Hospice Palliative Care Manitoba Member and Volunteer

Anne Ledger, Hospice Palliative Care Manitoba Volunteer

Donna Wilson, RN, PhD, University of Alberta

Canadian Hospice Palliative Care Association

Quality End of Life Care Coalition of Canada

Canadian Association of Occupational Therapists

One on One Interviews

Canadian Hospice Palliative Care Association

Alberta Hospice Palliative Care Association

Winnipeg Regional Health Authority, Winnipeg Manitoba

Regina Wascana Grace Hospice, Regina

Grey Nuns Community Hospital, Edmonton

Palliative Care Unit- Jewish General Hospital in Montreal

Regina Qu'appelle Health Region Palliative Care Unit

Canadian Home Care Association/Canadian Caregivers Coalition