

# Death, Dying and Canadian Families



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# Introduction



*Doesn't everything die at last, and too soon?  
Tell me, what is it you plan to do  
with your one wild and precious life?*

MARY OLIVER, "THE SUMMER DAY"

As Mary Oliver so beautifully reminds us, life and death are inextricably linked. Yet, it is a telling fact of contemporary Western society that there are very few public discussions about death or dying. The notion of death as the natural conclusion to life is rarely a topic of conversation, even within families, as if somehow one can avoid its inevitability by refusing to acknowledge its existence.

As a conversation catalyst, this Contemporary Family Trends paper focuses on the *death denying/death defying* culture of the West and its implications for Canadian families. The discussion will be located within the following contexts:

## **1. AGING POPULATION**

First, like most Western countries, Canada is facing a major demographic shift, characterized by a dramatic increase in the number of people over 65 and an even more dramatic increase in people over 80. Often described as the "crisis" of the aging baby boomers, this population shift poses a number of major social and health policy challenges.

## **2. CHRONIC ILLNESS AND THE NEED FOR CARE**

As a result of advances in health care and medical practices, among other things, more Canadians are living (and living much longer) with chronic illnesses, disabilities and complex medical conditions for which they require increasing amounts of care, support and intervention. As a consequence, more Canadians are relying on care provided by family members, including elderly spouses, siblings, adult children and grandchildren.

## **3. LOCATION OF DEATH: GAP BETWEEN DESIRES AND REALITY**

Despite most Canadians' preference to die at home, the vast majority die in intensive care units (ICUs), emergency rooms (ERs), acute care beds, long-term care facilities and nursing homes. This paper will examine the reasons for this outcome and suggest factors that might enable more Canadians to die in the location that best meets their (and their families') needs.

## **4. IMPACT ON FAMILIES**

The silence and denial that surround death and dying in contemporary culture are having a dramatic impact on individuals and families in Canadian society. As this research paper will document, demographic changes (including an aging population and higher life expectancy, the presence of both men and women in the full-time paid labour force, and the later age of child-bearing) put increasing pressure on families as they struggle to care for aging and ill family members.

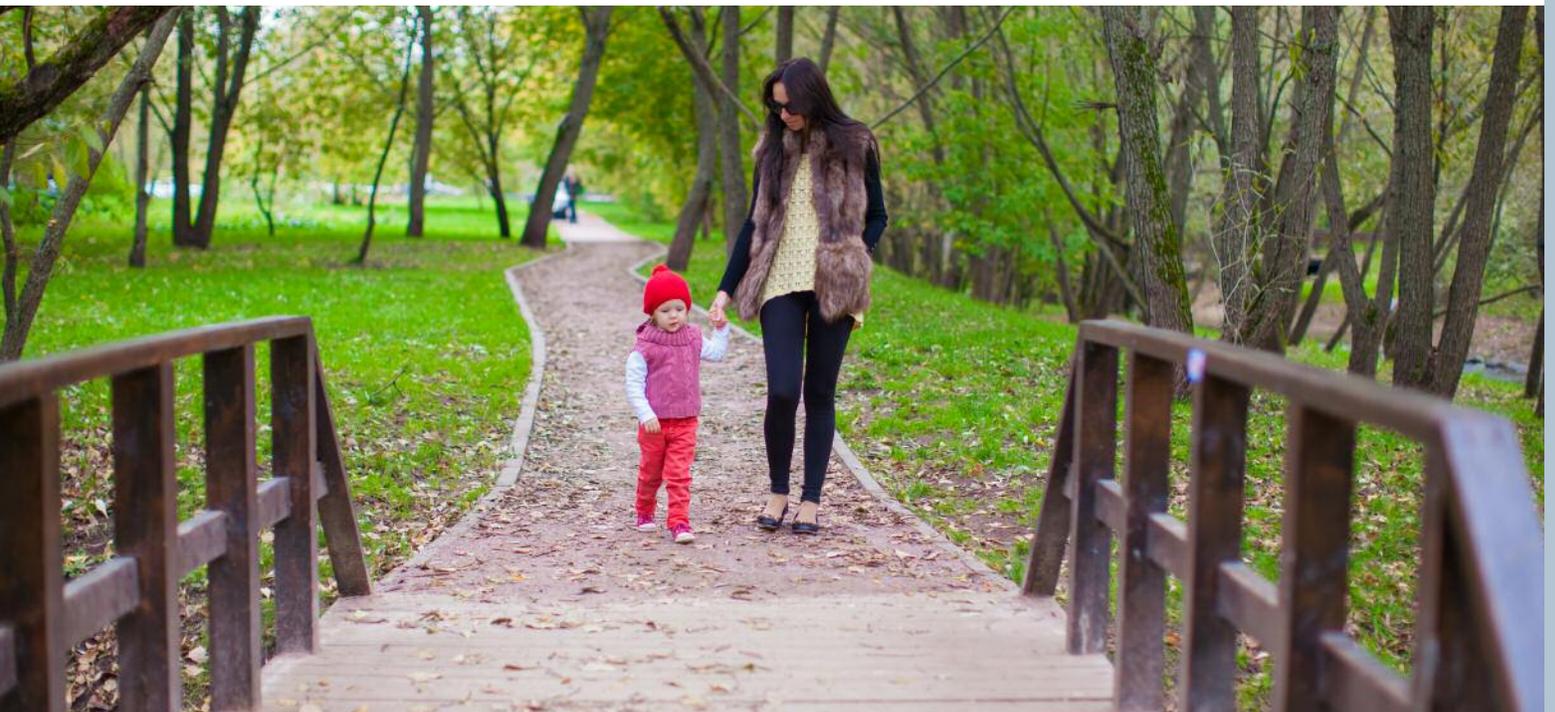
## Introduction

How did we get here? To address this question, this report examines the historical experiences of death and dying, the changing role of families in end-of-life care and the medicalization of death and dying. Such an examination can expand the conversation beyond the polarized debates over the right to die and the use of medical technology at the end of life to a meaningful and comprehensive dialogue about how we want to live our lives and face our deaths.

While the focus of this paper is on death and dying and its impact on Canadian families, it is impossible to separate this topic from the much broader one of aging and the provision of care for the elderly. Dying occurs within that broader context, especially given the continuum of aging, punctuated by crises, visits to the emergency room, doctors, then a return to a lower, steady state (the “new normal”) until the next crisis and, ultimately, death. Given these facts (that the number of elderly people is growing and will continue to do so, and that the elderly inevitably need assistance and care), what does this mean for the health care system and other aspects of the social safety net, and for families?

This report will explore the challenges and opportunities that lie within the demographic realities we face. Our ability to face these challenges will require a significant shift in attitudes toward aging, illness and dying, and in concomitant social, medical and family policies. Facing the reality of death and dying can enable us to treasure our “one wild and precious life.”

*Facing the reality of death and dying can enable us to treasure our “one wild and precious life.”*





# The Historical Context: Death and Dying in Canada over Time

The experiences of death and dying in Canada have changed dramatically over the course of the past 120 years and particularly during the past 70 years. It is important to recognize that the experience of dying and death, like all experiences in life, from pregnancy and birth onward, are affected by gender, race, class, ethnicity, geography, marginalized status, ability, sexual orientation and marital status, and, perhaps more than any, by Indian/Aboriginal/Inuit status. Nonetheless, it is important to document the major changes that have taken place to enable us to place present-day conditions within evolving trends.

## MEDICAL ASPECTS OF DEATH AND DYING: 1900–1950

While we often think of 1900 as the beginning of the modern Canadian nation, in many respects the conditions of life and death remained largely unchanged until well into the 20th century. Death remained a highly visible, ever-present fact of life, as epidemics, war, accidents, infection and childbirth claimed the vast majority of Canadians' lives (see Table 1, "Leading Causes of Death over Time").

**TABLE 1** Leading Causes of Death in Canada over Time

	Rate per 100,000
<b>1921-1925</b>	
All causes	1,030.0
Cardiovascular and renal disease	221.9
Influenza, bronchitis and pneumonia	141.1
Disease of early infancy	111.0
Tuberculosis	85.1
Cancer	75.9
Gastritis, duodenitis, enteritis and colitis	75.2
Accidents	51.5
Communicable diseases	47.1
<b>2009</b>	
All causes	1,144.9
Cancer	160.3
Heart disease	101.4
Stroke	28.4
Chronic lower respiratory diseases	22.9
Accidents	24.5
Diabetes	14.9
Alzheimer's disease	11.8
Influenza and pneumonia	11.7

Note: Disease categories are not identical over time. Rates in 2009 are age-standardized.

Sources: Statistic Canada, Catalogue No. 11-008 and CANSIM Table 102-0563.

## The Historical Context



In contrast to Britain, Europe and the United States, industrialization came rather late to Canada and its arrival in the mid-19th century led to rapid urban population growth. Lacking adequate sanitation, sewage disposal systems and clean water supplies, cities soon became centres of disease. Babies died from contaminated milk supplies, and adults and children alike were victims of epidemics of smallpox, diphtheria, typhoid, tuberculosis and other contagious diseases.

For babies and small children, the picture was particularly bleak. In 1901, Toronto reported that 160 of every 1,000 babies died before reaching the age of one. That number rose to 196 of every 1,000 by 1907. Montreal had the highest infant mortality rate in North America, as one in four babies in Montreal died before his or her first birthday.

A high birth rate and dangers of childbirth led to a high maternal mortality rate as well.<sup>1</sup> In the days before antibiotics, proper hygiene or sterilization, there was almost nothing that could be done about serious illness or infection. Death was usually swift and often extremely painful. There were few hospitals, and most of them provided care for the urban poor and served as training grounds for physicians and nurses. Routinely, neither birth nor death took place in hospital.

Shocked by spiralling infant and maternal mortality rates, the losses from World War I and the Spanish influenza epidemic,<sup>2</sup> Canada joined forces with the burgeoning international infant welfare and public health movements. The post-war period witnessed the growth of hospitals and increased training and specialization of physicians and nurses, but, in the absence of medicare, many could not afford the high cost of care.

By the 1930s, medical advances (such as immunization) and public health efforts had resulted in the reduction of deaths from infectious diseases and a shift from infection to chronic illnesses as the number one cause of death.

### **SOCIAL ASPECTS OF DEATH AND DYING: 1900–1950**

Apart from deaths as a result of war and accidents, most people in this period died at home, cared for by family members and friends. Death was frequently a community event, with extended family, friends and neighbours attending to the dying person and then participating in rituals of visiting the family as the body lay at rest. As historian Philippe Aries notes, “After death, a notice of bereavement was posted on the door.” Windows and doors were closed “except for the front door, which was left ajar to admit everyone who was obliged by friendship or good manners to make a final visit.”<sup>3</sup> The community generally joined the funeral procession to the place of worship and attended the funeral and burial. Aries notes that “the death of each person was a public event that moved, literally and figuratively, society as a whole.”<sup>4</sup> As a result, death had a familiar face for adults and children alike.

While community support no doubt eased the burden of loss for family members, we ought not to romanticize this period, as death was often painful and abrupt. But the approach and attitudes toward dying meant that people were acquainted with death from an early age, as it was not shrouded in silence or mystery.

*Montreal had the highest infant mortality rate in North America, as one in four babies in Montreal died before his or her first birthday.*

*Routinely, neither birth nor death took place in hospital.*

## The Historical Context



*[Increased life expectancy] was largely the result of public health measures, including improved nutrition and the importance of hygiene and sanitation, rather than medical discoveries.*

### THE MEDICALIZATION OF DEATH AND DYING: 1950–2000

While incremental changes did occur following World War I, most did not affect the majority of the population until after World War II. While the period before mid-century witnessed a gradual increase in life expectancy, this was largely the result of public health measures, including improved nutrition and the importance of hygiene and sanitation, rather than medical discoveries.

The period of sustained economic prosperity that followed World War II led to dramatic changes in life and death in Canada. As government coffers grew, so too did public funding for health care. National Health Grants during the 1940s and 1950s supported the growth and improved the quality of care in hospitals. The passage of the *Hospital Insurance and Diagnostic Services Act* in 1957, following on Tommy Douglas's earlier achievements in Saskatchewan, provided publicly funded hospital coverage. By 1961, that coverage was made available to all Canadians. The *Medical Care Act* (1966) extended coverage to include physicians' services. Thus, citizens were able to secure a range of services for themselves and their families, and the use of hospitals for a range of routine procedures increased exponentially.

By mid-century, the location of both birth and death had shifted from home to hospital. By 1950, over half of all deaths took place in hospitals in both the U.S. and Canada, a sharp contrast from the 1930 figure of 30%.<sup>5</sup> The number continued to rise, reaching a peak of 77.3% in 1994.<sup>6</sup> It is important to recognize that there has always been considerable regional variation in the location of death. For example, in 1994, hospital death rates varied widely by province: Quebec, 88.0%; B.C., 70.1%; NWT (including Nunavut), 57.7%, with an even greater disparity for people in the North and on reserves. Since 1994, there has been a decline in the proportion of deaths occurring in hospitals, with 64.7% of deaths occurring in hospitals in 2011.<sup>7</sup>

By the 1950s, both the public and the medical profession were coming to believe in "the limitless powers of science and medicine to control and cure illness."<sup>8</sup> Science became the new source of power and hope in certain respects replacing religion as the source of knowledge and power. This period was characterized by tremendous population growth with the baby boom, as well as large-scale expansion of hospitals, increased use of physicians' services and a host of significant medical breakthroughs (e.g. immunization for diphtheria, tetanus, pertussis and smallpox; widespread use of antibiotics; surgical innovations; growth of specialties offering cures and treatments).

As physicians, bolstered by advances in medical science, focused increasingly on curative measures, death came to be seen as a medical failure. Once all curative measures had failed, the dying person in hospital was often left alone, their care left to nurses who were neither trained nor equipped to care for the dying. Few medications were used and many people died in pain because of physicians' reluctance to prescribe morphine out of fear of addiction. As historians Smith and Nickel note, "Nurses often did a poor job in caring for the dying because they were neither emotionally prepared nor practically trained in what to do. The curriculum taught them how to save lives, not how to care for the dying."<sup>9</sup>

In short, Smith and Nickel say, "modern health care in the affluent postwar years was invested in saving lives, not in improving end-of-life care."<sup>10</sup> Most people, however, died in hospitals (often after receiving "pointless, often stressful, heroic measures to prevent death."<sup>11</sup> Furthermore, with increased life expectancy, people were increasingly living longer with chronic, long-term illnesses, eventually dying in a hospital (perhaps after a stay in a nursing home). Yet little thought was given to dignity, pain relief or quality of care.

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### **SOCIAL IMPACT ON FAMILIES: 1950–2000**

Without minimizing the tremendous gains of medical and scientific developments, it is important to remember that the transition from home to hospital often meant the patient dying alone in a foreign environment, away from friends and family. If one were unlucky enough to be poor, it meant dying in a ward, alone among noise and strangers. Families were by and large not welcome in hospitals, especially in children's hospitals. Strict visiting hours limited parents' access to their sick children to one or two brief slots per week. Children under the age of 12 were not permitted to visit patients in hospital, even if they were dying. As a result, a child might bid farewell to their ill parent, never to see them again.

Thus death, once a social and community event, became a largely individual and family event (and increasingly, family meant the nuclear family, with the decline of the extended family as the majority of the population shifted to urban areas and family members dispersed across the country). As Aries notes, "The burden of care and unpleasantness" of dying "had once been shared by a whole little society of neighbours and friends."<sup>12</sup> With the shift from home to hospital, "this little circle of participation steadily contracted until it was limited to the closest relatives or even to the couple, to the exclusion of children."<sup>13</sup> As a result, people often died alone, with no one (not even hospital staff) in attendance.

The impact of this segregation of death is profound, for society and for families. "Except for the death of statesmen, society has banished death," Aries says. "In the towns, there is no way of knowing that something has happened... Society no longer observes a pause; the disappearance of an individual no longer affects its continuity. Everything in the town goes on as if nobody died anymore."<sup>14</sup>

People were no longer present at the time of death and, as such, death itself became shrouded in mystery and fear. Most people, even today, have not been with someone who is dying or have not seen a dead person until well into middle age. Medical anthropologist Andrea Sankar notes that "fear of the actual death is one of the main reasons people rehospitalize the patient at the point of death or refuse to care for the dying at home."<sup>15</sup>

*Most people, even today, have not been with someone who is dying or have not seen a dead person until well into middle age.*

### **EMERGING TRENDS**

#### *The beginnings of palliative care*

The 1960s and 1970s witnessed dramatic changes in many areas of Canadian society. The prosperity of the post-World War II period enabled greater numbers of people to attend universities and colleges. Increased awareness of the ills and injustices of society, in part a by-product of the growth of higher education, led to the creation of the women's movement, lesbian and gay movement, and civil rights movement, among others. While it is obviously not possible to establish a movement of dying people (with the notable exception of AIDS), those who had first-hand experience of the loss of family members and friends began to question why dying people were being abandoned in hospitals or subjected to extreme and often unnecessary measures when death was inevitable and close. They found their champions in a number of key pioneers of death and dying and what would become the hospice palliative care movement.

## The Historical Context



*The term “hospice” dates back to the Crusades, when monasteries provided refuge not only for the sick and dying, but for weary travellers, labouring women, the poor, orphans and lepers.*

Perhaps the most significant person to bring death into the public eye in North America was Elisabeth Kübler-Ross, a Swiss-born American psychiatrist who pioneered the concept of providing psychological counselling to the dying. In her first book, *On Death and Dying* (published in 1969), she described five stages she believed were experienced by those nearing death: denial, anger, bargaining, depression and acceptance. She also suggested that death be considered a normal stage of life and she offered strategies for treating patients and their families as they negotiate these stages. The topic of death had been avoided by many physicians and the book quickly became a standard text for professionals who work with terminally ill patients.<sup>16</sup> Kübler-Ross’s books became bestsellers among the general public as well, and though her theory of the stages of dying has been subject to critique and modification in recent years, her work remains prominent in any discussions about death, dying and the grieving process.

If Kübler-Ross provided a new theoretical model for understanding the dying process, hospice palliative care became the practice. The term “hospice” dates back to the Crusades, when monasteries provided refuge not only for the sick and dying, but for weary travellers, labouring women, the poor, orphans and lepers. Their goal was real “hospitality”<sup>17</sup>: protection from harm, refreshment, comfort and fellowship. This tradition continued into the late 19th and early 20th centuries as organizations such as the Sisters of Charity opened houses to care for the poor, the sick and the dying.<sup>18</sup>

Modern hospices trace their origins to Dame Cicely Saunders, a pioneering physician and founder of St. Christopher’s House in London, England in 1967. In her book *Living with Dying: The Management of Terminal Disease*, Dame Saunders explained the philosophy behind her work: “A patient, wherever he may be, should expect the same analytical attention to terminal suffering as he received for the original diagnosis and treatment of his condition. The aim is no longer a cure, but the chance of living to his fullest potential in physical ease and activity with the assurance of personal relationships until he dies.”<sup>19</sup>

Inspired by the work of Saunders, Dr. Balfour Mount, a urologist and surgical oncologist, piloted a study of the needs of dying patients at the Royal Victoria Hospital in Montreal. Appalled by the suffering he and his team found, Mount established a hospice-like ward within the hospital to relieve suffering and provide quality end-of-life care. Dr. Mount coined the term “palliative care” (*soins palliatifs* in French), dropping the word “hospice,” which, in Quebec, still carried the stigma as a place of last resort for the poor and derelict.<sup>20</sup> The pilot project also featured “a consultation team to work with other hospital wards, a home-care outreach service and a bereavement follow-up program.”<sup>21</sup> Known as the father of palliative care in North America, Mount has devoted himself to spreading the message of palliative care throughout his life.

### *Deinstitutionalization*

With ever-expanding health care budgets and ballooning deficits threatening all levels of government by the 1990s, communities across Canada experienced the closure of hospital beds and of small community hospitals, and the merger and specialization of urban hospitals (e.g. the Ottawa Hospital, Toronto’s University Health Network). Shorter hospital stays, an increase in the number and range of outpatient procedures, and a move toward pharmaceutical treatments for mental illness, among others, had a dramatic impact on families. In all areas of health care, deinstitutionalization effectively meant that patients were sent home or onto the streets. The home was the place to care for family members, whether they were suffering from a terminal

## The Historical Context



illness, recuperating from surgery or living with mental illness or a severe disability. In the absence of adequate home care services and no longer able to rely upon the support of an extended family or community network, families (and especially women in families) began to experience the crushing demands of caregiving – for children, elderly parents, ill family members – juggled with the demands of full-time employment. This pressure would only increase by the turn of the 21st century.

### Death and Indigenous and Aboriginal Peoples in Canada

The historical conditions of death and dying among Aboriginal peoples in Canada following First Contact were nothing short of appalling, and to a great extent remain so to the present day. Ravaged, decimated and, in some instances, extinguished by disease, Canada's indigenous people continue to suffer higher rates of infectious diseases and alarmingly high infant and maternal mortality and suicide rates. Many are forced to travel great distances from their homes, often alone, in order to receive care in a hospital, be it for birth, treatment or end of life.

Smallpox, tuberculosis (TB) and other life-threatening diseases unknown to Aboriginal peoples came to Canada with the European settlers beginning as early as the 1700s. Lacking exposure and therefore immunity to smallpox and TB, indigenous populations quickly succumbed to disease, with as much as half of the Aboriginal population in certain regions dying from the outbreaks. In some instances, death came via blankets infected with smallpox, a gift from the military troops seeking to extinguish their enemy through this early form of biological warfare.<sup>22</sup>

Epidemic TB among the indigenous peoples spread with the growth of the railway and the move of settlers westward. The forced relocation of First Nations people to crowded reserves coupled with poverty, malnutrition and a destruction of their way of life allowed the disease to spread rapidly. Death rates in the 1930s and 1940s were in excess of 700 deaths per 100,000 persons, among the highest ever reported in a human population. TB death rates among children in residential schools were even worse – as high as 8,000 deaths per 100,000 children, with residential schools reporting that as much as 75% “of students discharged from residential schools died shortly after returning home.”<sup>23</sup>

When TB epidemics spread among northern Inuit communities in the 1950s and 1960s, thousands were transported to southern hospitals and sanatoria for treatment. At least one-third of Inuit were infected with TB in the 1950s. In 1956, one-seventh of the entire Inuit population was being treated in southern Canada. The average length of stay was two-and-a-half years, and some patients stayed much longer. Many families were not notified when a TB patient died in the south. The dead were buried in paupers' graves in a southern cemetery, paid for by the Department of Northern Affairs.<sup>24</sup>

Today, Aboriginal people continue to experience much higher rates of morbidity and mortality and a much lower life expectancy than any other group in Canada. In particular, Aboriginal peoples have higher rates of infectious diseases, including TB, meningitis and HIV; higher infant mortality rates; and higher death rates from renal failure (consistent with higher rates of diabetes and obesity), suicide, homicide and other forms of violence, and accidents (including fires and motor vehicle accidents).<sup>25</sup>

# Desires and Realities of Death and Dying in Canada



The historical trends and cultural changes outlined above have resulted in the experience of death being very foreign and frightening for many contemporary Canadians. The public (and often private) avoidance and denial of and silence around death – and our fear of death resulting from our lack of experiences with dying – have allowed a range of myths and misconceptions to flourish. These factors, combined with baby boomers' reluctance to come to terms with aging and the dramatic changes in life expectancy, have led to a schism between Canadians' desires and assumptions about death and the realities faced by dying Canadians, their families and their communities.

While we might all hope to live forever, the fact remains that we will all die. No matter how active, healthy and vibrant we may be, death will still come. Only if we face the realities – as opposed to our desires and assumptions – can we prepare for the demographic challenges that lie ahead. Only then can we prepare for our own deaths and those of the people we love.

*“Everybody has got to die, but I always believed an exception would be made in my case.”*

WILLIAM SAROYAN

## **DESIRE 1: WE WANT TO LIVE FOREVER**

As if to keep death as far away as possible, contemporary culture focuses almost exclusively on youth and physical vitality. Pick up a copy of any women's magazine on the newsstand and you will see countless ads for anti-aging products, promoted by models and movie stars who appear to be in their late 20s or early 30s at best. Pop culture tells us that 60 is the new 40! And magazines such as *Zoomer*, aimed at the “over 40” population, present stories of 80-year-old marathoners and sky jumpers.

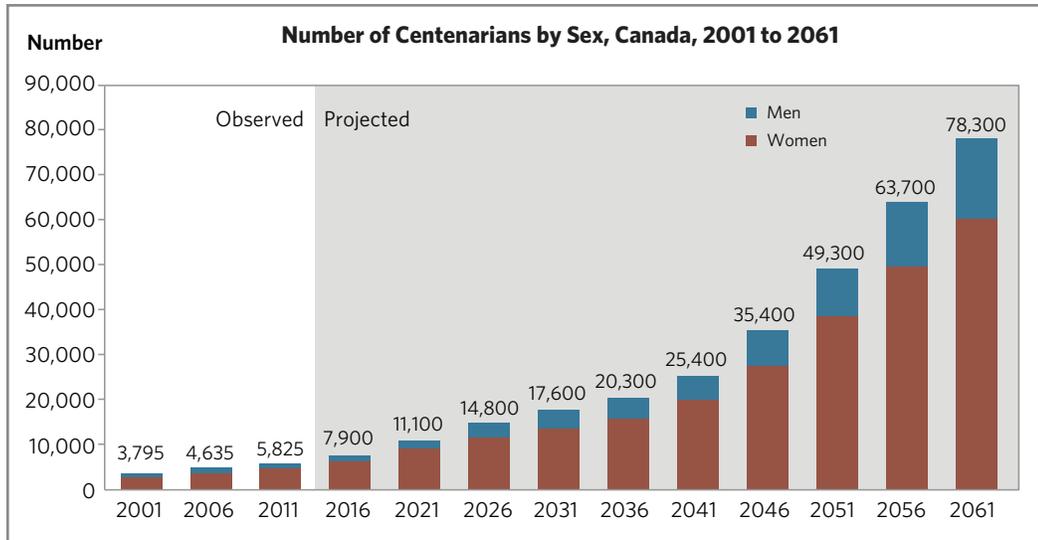
*“A belief in hell and the knowledge that every ambition is doomed to frustration at the hands of a skeleton have never prevented the majority of human beings from behaving as though death were no more than an unfounded rumor.”*

ALDOUS HUXLEY

People are living far longer than at any time in history. While that might seem like a dream come true for those who seek a contemporary version of the Fountain of Youth, the reality is that with aging comes the inevitable deterioration of the body and, frequently, the mind. I am often reminded of the Struldbrugs, a tiny minority of the Luggnaggians, in Jonathan Swift's *Gulliver's Travels* (part 3, chapter 10). People marked at birth with a red spot over their left eyebrow never died, but they did suffer the vagaries of illness and old age and spent eternity begging to be put out of their misery. In witnessing their fate, Swift quickly became less enamoured of the notion of immortality.

Like most Western countries, Canada is facing a major demographic shift. Data from the 2011 Census show a dramatic increase in the number and proportion of people over 65, over 85 and over 100 years of age.

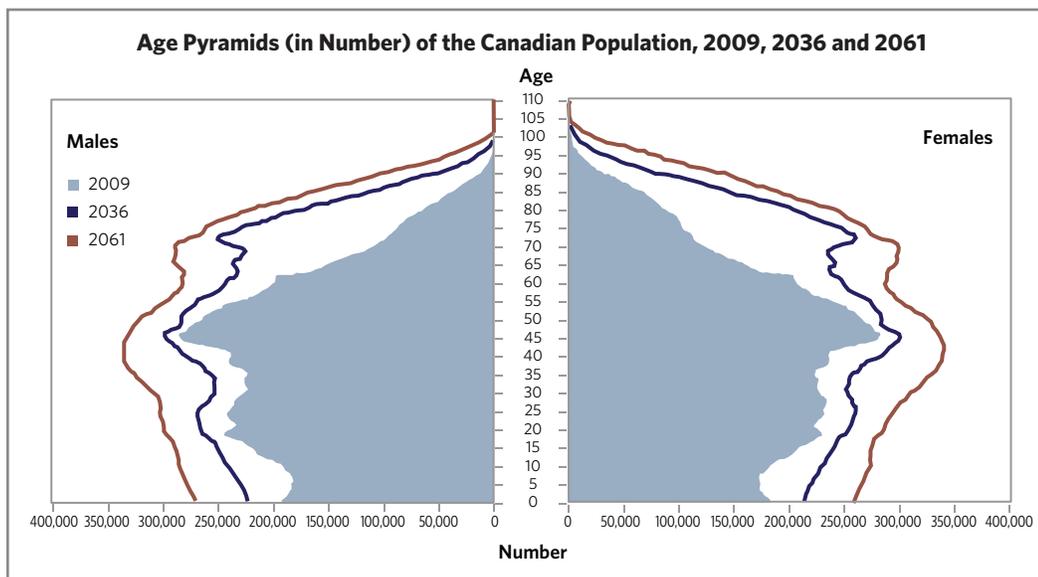
# Desires and Realities of Death and Dying in Canada



**Figure 1.** Projections for centenarians, 2001 to 2061

Source: Statistics Canada (2013). "Number of Centenarians by Sex, Canada, 2001 to 2061," (Figure 1) in *Centenarians in Canada*. Statistics Canada Catalogue No. 98-311-XWE2011003. Accessed September 27, 2013. <http://bit.ly/N6mvfi>

Statistics Canada projections for 2036 and 2061 show a dramatic change in the shape of the age pyramid that describes the Canadian population.



**Figure 2.** Statistics Canada projections for 2036 and 2061

Source: Statistics Canada (2012). "Age Pyramids (in Number) of the Canadian Population, 2009, 2036 and 2061 (Scenario M1)," in *Population Projections for Canada, Provinces and Territories*. Statistics Canada Catalogue No. 91-520-X. <http://bit.ly/16FqYN6>

The statistics show that there will be both larger numbers and larger proportions of the population experiencing the process of senescence. And while "old age" is virtually never listed as the cause of death, it is increasingly a fact of life's end, as the body and its organs simply wear out.

## Desires and Realities of Death and Dying in Canada



### **DESIRE 2: WE WANT TO BE FULLY ABLE AND THEN TO DIE SUDDENLY IN OUR SLEEP**

Despite all the changes that have taken place in the past century, our image of death is still very much of the final moment – one that is often associated with sudden death (e.g. heart attacks, accidents). However, only about 10% of Canadians experience sudden death. The reality of dying in the 21st century is that death frequently occurs after long, lingering dying processes that require ongoing and often intensive care and support.

We are accustomed to thinking about dying as a sudden or at least relatively quick and predictable event. This is, however, far from the current 21st-century reality. I learned this first-hand during my father's two-year dying process.

*As I wrote: For almost two years, I've been telling people that my father is dying. I spent last summer on high alert, cellphone on day and night. "He won't live 'til Labour Day," his doctor predicted, a year ago. I took the summer off to care for him. When he didn't die, I went back to work, warning the students in my university classes that I would have to leave suddenly when my father died. Not a single missed class all year. In April, he nearly died – fell in his apartment, stopped breathing, revived despite the DNR order. We cancelled appointments, plans, meetings. Gathered around. Prepared an obituary. Made arrangements at the funeral home. My younger daughter told her teachers, "My grandfather is dying." They made allowances. Extended deadlines. After two weeks, the teachers began to wonder. "They think I'm making it up," she tells me.*

*My father is dying in tiny increments. The pace of this dying is so different from the cancer deaths I have witnessed.*

*Tiny increments punctuated by dramatic leaps. A heart attack. A bleed. Then interventions. Mega doses of drugs. Transfusions. Then home again to the "new normal."*

*For many seniors, "old age" is accompanied by a progressively increasing number of ailments and chronic conditions.*

For many seniors, "old age" is accompanied by a progressively increasing number of ailments and chronic conditions. For people with "conditions such as cardiovascular disease, dementia and Alzheimer's disease, arthritis and diabetes," the pathway is "far less predictable. These chronic illnesses bring about a slow decline, with a number of incidents, most of which are managed but any one of which might result in death."<sup>26</sup> For these people, the period of dying is on a continuum of aging rather than the result of a single ailment or event. Thus home care and other alternatives to hospital become an essential aspect of life.

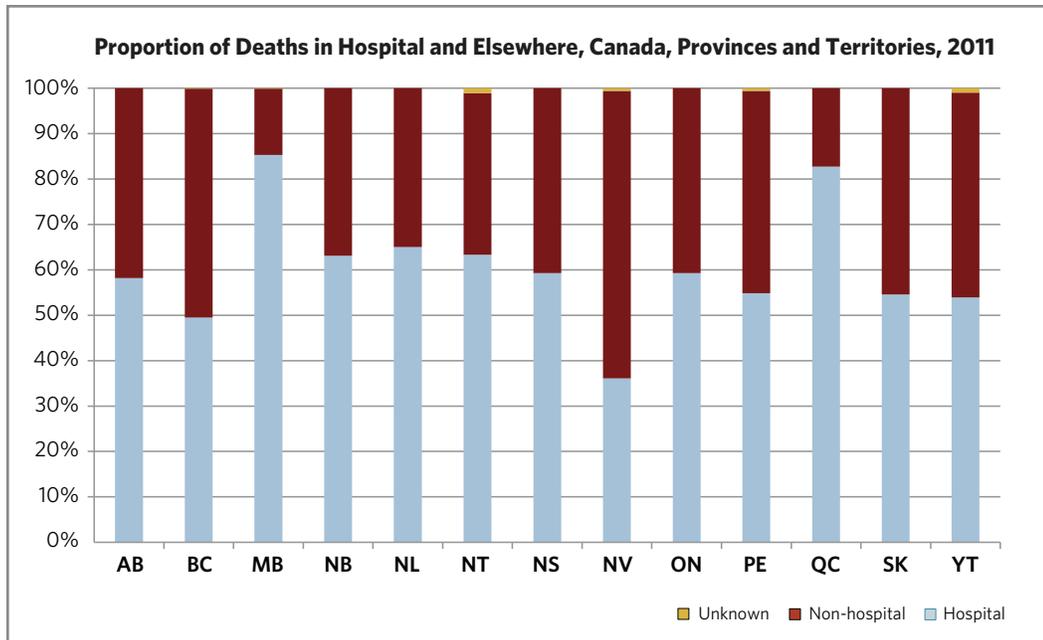
### **DESIRE 3: WE WANT TO DIE AT HOME**

According to the Canadian Institute for Health Information, "most seniors (93%) in Canada live at home and want to stay there as long as possible."<sup>27</sup> The reality, however, is that most Canadians die in hospital, further adding to the mystery shrouding our knowledge of death.

Many factors contribute to these high rates of hospitalization. The historical transition from home to hospital as the location for death – the result of the medicalization of aging and dying that was detailed in the first section of this report – can account at least in part for the ongoing reliance upon hospitals at end of life. The shortage of family physicians in many regions and their reluctance to make home visits can also account for hospital visits that some critics might term "unnecessary." The widespread fear of dying and the reluctance to talk about end of life can also lead to the use of an acute care hospital at end of life.

Arguably the largest factor, however, is the inadequacy of home care and other forms of support for families caring for a dying person. These issues will be addressed later in this paper.

## Desires and Realities of Death and Dying in Canada



**Figure 3.** Place of death by province, 2011

Source: Statistics Canada (2013). *Deaths in Hospital and Elsewhere, Canada, Provinces and Territories*. CANSIM Table 102-0509. Accessed September 27, 2013. <http://bit.ly/15Zgj4v>

### DESIRE 4: WE WANT TO DIE PAIN-FREE

Most people fear dying in excruciating pain. Indeed, most people assume that dying is inherently painful. As my father said, shortly before his death, "I don't want to be alone. And I don't want to die in screaming pain." Those were things he had witnessed in his lifetime and he did not want that for himself. With the assistance of a palliative care physician, who came to my father's apartment and provided us with liquid morphine that we could administer to deal with the pain, and the constant presence of privately paid home care providers, my father was able to have his wishes granted. In my volunteer work at a residential hospice, I have witnessed countless patients whose pain was alleviated once they were able to receive palliative medical care.

In the past two decades, significant strides have been made in the management of pain and other symptoms at end of life. The development of new drugs and the increasing willingness to prescribe opioids for pain relief have vastly improved the quality of life for dying people. Whether administered orally, through a needle, a pain pump or a patch, these medications are generally begun at a low dose and increased slowly (titrated) until pain relief is achieved. While side effects such as constipation, nausea and sleepiness are common, there are a number of remedies, including medications, that can generally help the patient to manage these symptoms. In many places, a pain and symptom management team is available for consultation with physicians to assist them in providing the best care possible for their patient.

*"I don't mind dying. I just don't want to be there when it happens."*

WOODY ALLEN

## Desires and Realities of Death and Dying in Canada

### **DESIRE 5: WE WANT TO DIE WITH DIGNITY**

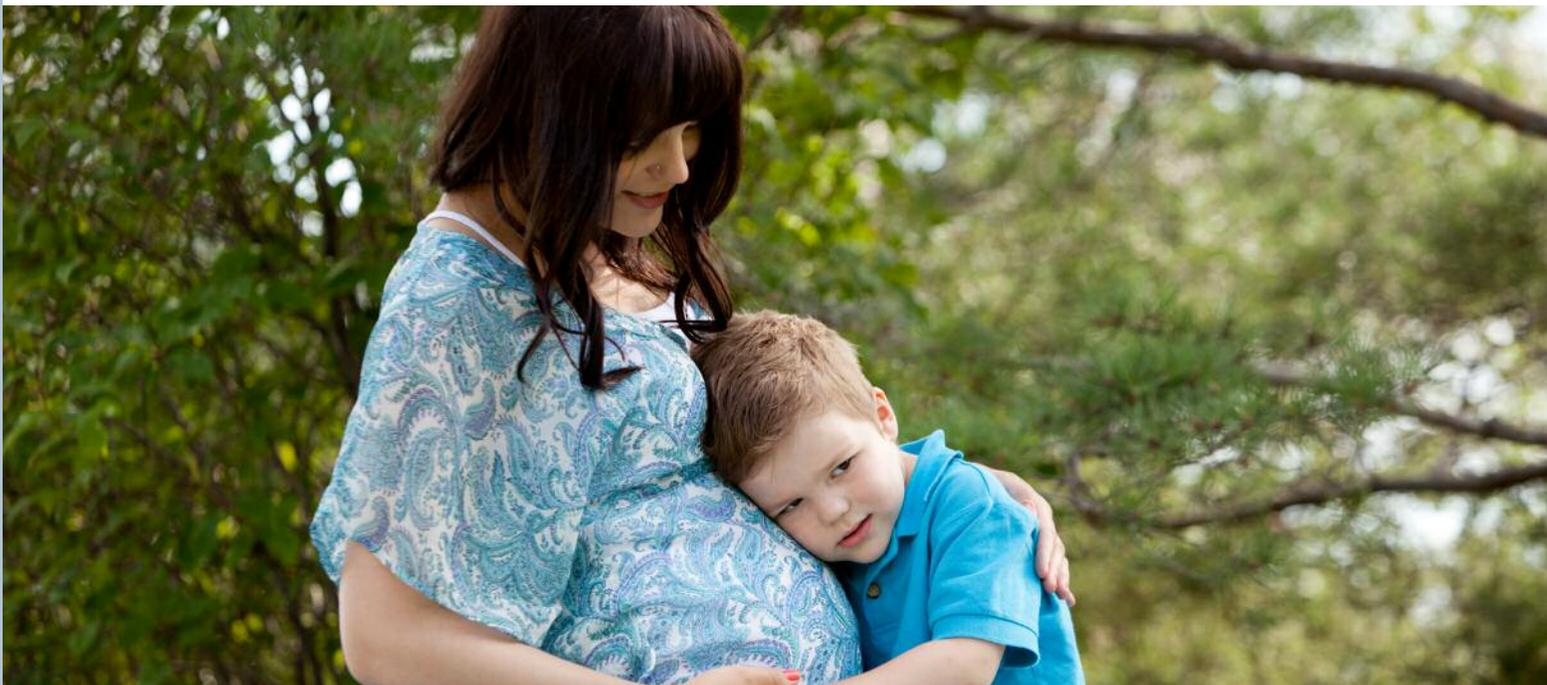
Most people believe that dying is inherently undignified. Underlying this belief is the assumption that having to depend upon others to meet our personal care needs (eating, eliminating waste, bathing, etc.) is inherently demeaning.

*Dignity resides in the quality and nature of the care provided and in the attitudes of both the caregiver and the recipient of care.*

I doubt that anyone would choose to spend their final days, weeks or months bedbound, incontinent, having to depend on others (whether family members or paid staff) to change their diaper and bathe them. Yet, after nearly a dozen years as a volunteer in a residential care hospice, assisting staff in the provision of personal care, I would suggest that there is nothing inherently undignified in the care that is required at end of life. Rather, dignity resides in the quality and nature of the care provided and in the attitudes of both the caregiver and the recipient of care. In giving a bed bath or changing a patient, for example, staff ensure that the patient has had adequate pain relief prior to being moved. We explain to the patient what we are doing at each step of the process, even if they appear to be asleep or in a coma. We never talk “over” them about our own personal interests (movies, weekend plans, etc.) as if they weren’t there. Rather, we proceed slowly and calmly with each task.

When people hear about my hospice volunteering, they often remark, “Shoot me if I get like that!” After several years of hearing such remarks from my university-level students during our discussions of death and dying, I asked them what they meant by “that.” Their answers ranged from being unable to drive a car any more (they were 18 after all!) to not being able to care for themselves (feeding, getting dressed, etc.) to being bedridden. I doubt I convinced many of them that there could be dignity in diapers, but several of them did recount stories of feeding and caring for their grandparents in ways that affirmed the possibility for dignity.<sup>28</sup>

When my father was ill, he and I used to joke that getting assistance with the activities of daily living “beats the alternative.” As a strong, independent man, he certainly did not like having a strange woman give him a bath or provide his medication, but he preferred suffering those indignities (which they were, to him) to not being alive.



# Impact on Families



Dying and death affect not only the person who is dying. Rather, death impacts everyone in the dying person's circle of life and caring, be they spouse, parents, grandparents, children, grandchildren, siblings or friends. Here we are talking not just about the "burden of care," but the experience of witnessing the suffering and eventual loss of someone they love. At the same time, family members face a maze of services and jurisdictions with which they are unlikely to be familiar. Who helps families navigate this terrain? And for someone without a family, who is their advocate? This question can begin to be addressed by looking at the assumptions people make about end-of-life care.

## **ASSUMPTION 1: YOUR FAMILY CAN TAKE CARE OF YOU**

Health care and eldercare systems in North America still operate on the assumption that family members (in particular women – wives, mothers, sisters, daughters, nieces, granddaughters) will be able to care for ill, injured, aging and elderly family members once they are discharged from hospital or for disabled family members in need of care and support.

However, the reality of geographic and employment mobility of the late 20th and 21st centuries has meant that adult children often live vast distances from their parents when they are in need of care and support. Furthermore, a relatively low birth rate (in contrast particularly with the baby boom population) means there are fewer adult children to share the caregiving responsibilities. As well, the vast majority of both men and women are now working in the paid labour force, meaning that the assumption that there will be a woman at home able to absorb the additional care their parents may require is false (see data from the Vanier Institute's Caregiving & Work Project). In addition, the pattern of sequential care responsibilities (children, then parents, spouse, siblings, self) familiar prior to the 1960s has largely been replaced by concurrent care responsibilities for multiple generations, especially because women often delay childbearing until they are established in their careers. The result is that children are still at home or returning home after college, divorce and unemployment, at the same time as spouses may be experiencing early onset of illness or recovering from serious injury and elderly parents are in need of increasing assistance and direct care and support.

Effects of being part of the "sandwich generation" include lost time from work, increased stress levels, illness, burnout and caregiver fatigue. When adult children are unable to help, the primary caregiver is increasingly an elderly spouse who may be facing his or her own health challenges. People who are dying are all too aware of the impact their need for care may be having. Fear of being a burden to their family is one of the principal reasons that people consider ending their own life.<sup>29</sup>

*Fear of being a burden to their family is one of the principal reasons that people consider ending their own life.*



*Many Canadians assume that they will have access to sufficient home care when they or a member of their family becomes disabled or terminally ill.*

### **ASSUMPTION 2: HOME CARE WILL BE AVAILABLE WHEN WE NEED IT**

Many Canadians assume that they will have access to sufficient home care when they or a member of their family becomes disabled or terminally ill. Unfortunately, they are sadly mistaken when reality hits. In fact, home care is not an essential service guaranteed by the *Canada Health Act*; rather, it is provided on a regional and local level, with funding from provincial and territorial levels of government.

Since health care falls primarily under provincial jurisdiction, the services that are provided and the number of hours per week vary widely between provinces and territories and even between regions within provinces. The term “home care” refers to a range of services, such as professional services including physical and occupational therapy, nursing care, personal care with activities of daily living (such as bathing, toileting, assisting with eating), homemaking and housekeeping. These services may be provided by the government through Community Care Access Centres (CCAC) and/or by private non-profit or for-profit agencies.

While some jurisdictions will provide 24-hour care for patients at the end of life, others offer much more limited support. As needs escalate beyond available services, many patients are forced to go to an acute care hospital, despite their wishes to die at home.

The patchwork nature of home care, and its often limited provisions, does not affect only the direct recipient of care (e.g. a person with a disability, an elderly person, recipient of rehabilitation treatment or a dying person), but it also dramatically affects the health, well-being, longevity and ability to provide care of the caregiver and the entire extended family, often for years after the death has occurred. In an April 2012 report, Dr. Jack Kitts, Chair of the Health Council of Canada, summarized the report’s finding that “seniors with complex health needs receive, at home, a few more hours of home care a week than what is offered to seniors with moderate needs.” As a consequence, he noted, “many family caregivers of these high-needs seniors are stretched beyond their capacity, reporting high levels of stress, depression and difficulties in continuing to provide care.”<sup>30</sup>

Consider the following results from recent research on family caregivers in Canada:

- “The increasing reliance on deinstitutionalized care has had a great impact on Canada’s 1.5 to 2 million family caregivers, a group that provides hands-on care, spiritual and emotional care, and care coordination worth \$25-\$26 billion annually while incurring \$80 million annually in out-of-pocket costs.”<sup>31</sup>
- Prevalence rates for depression and anxiety among family caregivers are reported to be as high as 39% and 46% respectively.<sup>32</sup>
- Risk of mortality in bereavement for family caregivers experiencing emotional and mental strain is increased by 63% compared with bereaved who were not caregivers.<sup>33</sup>

## Impact on Families

### ASSUMPTION 3: ONE BIG, HAPPY FAMILY

Media representations of dying (*Love Story*, *Terms of Endearment*) present images of intact multi-generational families arriving in time for the final exchanges of meaningful messages at the bedside before the dying person slips peacefully away. These images suggest that everyone will get along, share the work and worry, and be compassionate toward one another when someone in the family is dying. The reality of the family in 21st-century Canada is frequently quite different.

In the face of a parent's terminal diagnosis or illness, family members who might not have seen one another in years are thrown together in what is arguably the most emotionally taxing experience of their lives. Not surprisingly, family dynamics, differing perspectives and past experiences may come to the fore.

In blended families, an increasingly common family form in Canada, conflict may arise between biological children and stepchildren as to who is responsible for caregiving or for taking a lead role at end of life and after the death. Former husbands or wives may wish to visit a dying ex-spouse or ex-in-law to support their children at this difficult time. Concerns over the cost of care may intensify existing tensions between family members. As a hospice volunteer, I have witnessed scenes of open conflict between feuding family members as grief and fear unleash existing family tensions. I have also seen countless examples of ex-spouses (particularly wives) stepping forth to care for their former partners at the end of their lives, visiting frequently, bringing food and comfort, without a hint of tension. Family tensions may be greatly exacerbated by the family's failure to discuss matters of life, death and finances prior to the "crisis" of end of life (see later section, "Start the Conversation").

Unequal sharing of the caregiving role may be another source of tension within families. While factors such as proximity, family status and employment status may dictate who is able to care for an elderly or dying parent, resentment can nonetheless build as the period of infirmity and dependence extends for a long period of time. Similarly, young carers – an increasingly large group of unpaid family caregivers – may feel resentment at having to postpone their social, educational or employment opportunities as they care for a grandparent while the adult children attend to their careers and family needs.<sup>34</sup>

*Family tensions may be greatly exacerbated by the family's failure to discuss matters of life, death and finances prior to the "crisis" of end of life.*



# Policy Measures to Support Dying People and Their Families

If it takes a village to raise a child, surely it takes as many people to care for and support a person at the end of his or her life. Yet, in the 21st century, while we retain rituals and celebrations for welcoming new babies into our communities (baby showers, pink or blue balloons outside the home of a new baby, etc.), dying is largely hidden and certainly not celebrated. Today, in contrast to the community response to death described at the beginning of this paper, death is recognized in a small obituary in the newspaper, often with the notice: “There will be no funeral. No flowers please.”

Fiscal and government policies of deinstitutionalization in the 1990s resulted in moving the care of the dying and terminally ill from acute care hospitals to the community (whether in homes, long-term care facilities or nursing homes). While this move may have been motivated in large measure by fiscal concerns, it also coincided with the increasing expression of a desire to die at home, rather than in hospital. The challenge, however, is the lack of community and family capacity to provide this often complex and always demanding care. In modern society, communities are often fragmented, lacking a centre where they can gather to support one another when someone is dying. While religion traditionally provided a focal point and a means through which people could support one another (e.g. pastoral care teams, ministers visiting, praying for members of the congregation who were ill, church ladies making the lunch after a funeral), declining religiosity has meant that fewer people can draw upon that support. Thus, community-based services, including expanded home care, fill an important gap in families’ lives.

## EXPANDED HOME CARE

One of the earliest and strongest cases for universally accessible home care services was made by Roy Romanow in his landmark report *Building Values: The Future of Health Care in Canada*.<sup>35</sup> Anticipating the tremendous impact of the aging population on health services, Romanow recommended that home care be deemed an essential service under the *Canada Health Act*. However, these recommendations were never implemented.

Numerous reports have reached similar conclusions in the decade since the Romanow Report was released. In 2011, the Parliamentary Committee on Palliative and Compassionate Care recommended that “the federal government in collaboration with the provinces and territories implement a right to home care, long-term care and palliative care” equivalent to other insured health services in the *Canada Health Act*. To help families meet the high costs of caregiving, the Committee recommended that the Compassionate Care Benefit be expanded to at least 26 weeks coverage and be made more flexible to align with people’s caregiving needs, and that a refundable tax credit and a Canada Pension credit be established for family caregivers.<sup>36</sup>

In addition, families caring for someone who is dying may need respite care, whether in a hospice or nursing home, or provided in the home by live-in caregivers. Through this service, family care providers can get a much needed break from full-time care, whether to take a holiday with children or simply to rejuvenate. Home care services could also be expanded to include counselling and support before, during and after the dying process.

## COMPASSIONATE CARE BENEFIT

As documented in this paper, one of the many challenges for family caregivers facing the death of a loved one is financial. Losing the income of the dying person is worsened by the loss of some or all of the caregiver’s income as the demands of caregiving increase.

*One of the many challenges for family caregivers facing the death of a loved one is financial.*

## Policy Measures to Support Dying People and Their Families



On January 4, 2004, the federal government implemented the Compassionate Care Benefit (CCB). “The primary goal of the CCB is to provide income assistance and job security to family members and friends who take temporary leave from regular employment to care for a terminally ill person at risk of dying within 26 weeks.”<sup>37</sup>

“Compassionate care benefits are Employment Insurance (EI) benefits paid to people who have to be away from work temporarily to provide care or support to a family member who is gravely ill and who has a significant risk of death within 26 weeks (six months). A maximum of six weeks of compassionate care benefits may be paid to eligible people.”<sup>38</sup>

As with EI, the program under which the CCB falls, the CCB is based on the income on which the person pays into the EI plan. While the maximum payable is \$501 per week for six weeks, many people would earn considerably less. As with EI, applicants must experience a two-week waiting period before benefits begin. For low-income people, the loss of income for two weeks while awaiting benefits and the low amount of the benefit received may mean that the benefit does not in fact provide sufficient relief to merit leaving their work.

In a recent study on the CCB, researchers conducted interviews with various constituencies with a focus on family caregivers.<sup>39</sup> They found that the most significant positive aspect of the program is the assurance it provides that applicants are entitled to return to their jobs after the leave. The study concluded that six weeks is too short to cover the demands of caregiving at end of life. Furthermore, the benefit is complicated to apply for and has many requirements, including a doctor’s note stating that death will occur within six months. The study found that many people waited too long before applying (in hopes that the benefit would be in place for the final six weeks, when they would want and need time off from work the most). As a result, many people found themselves ineligible for the benefit, as their family member died during the application process or shortly after. The benefit applies only to end-of-life care and does not extend into the period of bereavement.

In addition to the CCB, family caregivers can also access tax credits available through the Family Caregiver Amount,<sup>40</sup> claiming a reduction on income tax for providing care for an ill or dying family member.

### LEGISLATIVE AND COMMUNITY INITIATIVES

Some provinces have already begun to implement policies and legislation to support family care providers. Manitoba, for example, implemented the Primary Caregiver Tax Credit, which provides a refundable tax credit for caregivers. The province also passed the *Caregiver Recognition Act*. Nova Scotia has implemented the Caregiver Benefit Program, which provides caregivers with an allowance of \$400 per month. While the benefit does not cover the cost of caregiving and lost wages, it does recognize the labour and the financial burden of caregiving.

A number of American states, including Rhode Island, Maryland, Connecticut and New Hampshire, have passed legislation designed to improve palliative care training for physicians and nurses, to encourage the use of advanced care directives and to establish a permanent government committee to oversee the provision of end-of-life services.<sup>41</sup>

*The primary goal of the CCB is to provide income assistance and job security to family members and friends who take temporary leave from regular employment to care for a terminally ill person.*

# Options for End-of-Life Care



There is no “one size fits all” answer to the needs of dying people and their families. Dying people, like any other group of people, are heterogeneous, varying in age, income, family status, sexual orientation, race, ability and a host of other ways. Each death is as unique as the person who is dying, and his or her needs may change from day to day or moment to moment. As a result, over the course of the dying process, a patient may receive care in a number of different locations.

Nonetheless, regardless of these differences, many people end up in the emergency room or intensive care unit at end of life, in most cases arguably the least desirable option and definitely not what most people indicate that they want. Hospitals are designed for acute care needs, where the focus is on treatment and cure, and death itself is not an acute care event. What alternatives to acute care hospitals are available for dying people and their families?

## **HOSPITAL-BASED HOSPICE PALLIATIVE CARE**

The term “hospice” is defined as “a caregiving facility that provides coordinated, multidisciplinary care for people living with terminal illnesses and for their families and caregivers.” In Canada, the term “‘hospice care’ is used interchangeably with ‘palliative care’ to describe an approach to care or a community program providing services with such an approach.”<sup>42</sup>

Hospice care can be provided within a specialized palliative care unit in a hospital; in a patient’s home through visits by community nurses, palliative care physicians and hospice volunteers; and in free-standing residential care facilities. Today, many hospitals have a palliative care unit and steps are being taken to provide palliative care in long-term care facilities and nursing homes, where large numbers of Canadians spend their final days.

Despite the efforts of the hospice palliative care pioneers discussed earlier in this paper, the need for palliative care far outstrips the resources that are available. The Canadian Hospice Palliative Care Association estimates that only 16% to 30% of Canadians receive *any* form of palliative care, depending upon where they live.

A recent report based on data from Ontario and collected and analyzed by the Canadian Institute for Health Information, showed that “From 2003 and 2011, 7,525 individuals died in a palliative care bed, compared to 32,217 in ICU beds, and 84,754 in acute care beds.”<sup>43</sup> The report did not include deaths in hospices or at home due to the challenges of data collection. Increasingly, however, both government efforts toward deinstitutionalization and individuals’ expressed desires have looked toward home and home-like services.

## **FREE-STANDING RESIDENTIAL CARE HOSPICES**

Modelled on Dame Cicely Saunders’s work at St. Christopher’s House in London, free-standing hospices began to appear in Canada in the 1980s with the establishment of Casey House (a Toronto hospice for AIDS patients, established in 1983). Although relatively few in number, free-standing hospices have become an important model for the delivery of palliative care services, providing an alternative to home – when medical needs or personal circumstances may make a home death unrealistic – or hospital – the most costly and perhaps least desirable alternative.

According to a recent article in the *Globe and Mail*, “There are at least 63 residential hospices across Canada, ranging from a few beds in a home stitched together with volunteers and visiting doctors to 10-bed institutions. Because the model is not fully established and integrated into the health care system, only some hospices receive provincial funding. Those, such as Kensington [in downtown

*Despite the efforts of the hospice palliative care pioneers discussed earlier in this paper, the need for palliative care far outstrips the resources that are available.*

## Options for End-of-Life Care



Toronto], which run mostly on charity, are arguing that it is time for that to change.”<sup>44</sup> Even those hospices that receive government funding still rely on donations for a substantial portion of their operating budget.

The philosophy of residential hospices mirrors the goals of palliative care – to alleviate pain and suffering to allow the dying person to live their final days in comfort and ease amid the people they love. Both the patient and the family receive support and care from the interdisciplinary hospice team, which includes nurses, personal service workers, physicians (at many hospices, the patients’ doctors follow them to the hospice to provide continued care), social workers, chefs and other administrative and cleaning staff. Residential hospices are also supported by large numbers of volunteers who may assist staff with feeding and repositioning patients, cooking meals, reading to and sitting quietly with a patient, as well as non-direct client care roles, such as building maintenance, tending the gardens, organizing fundraising events and serving as receptionists. Typically, hospices are led by nurse-run teams.

Many hospice programs offer services such as day hospice programs that provide a “day away” for patients with a life-limiting disease. In a typical day hospice program, participants are dropped off by volunteer drivers for a program that includes a morning snack with tea or coffee, happy hour with wine or juice and a gourmet lunch. Activities include drawing and painting, Scrabble and jigsaw puzzles, massage and guided relaxation. In home support programs, patients receive a weekly visit from a volunteer, who often provides respite for the regular caregiver. Volunteers might cook a meal, play cribbage, read aloud, drive them to appointments or shopping, engage in conversation or sit quietly while the patient sleeps. Many hospice programs also provide counselling for family members and bereavement support.

The focus of stand-alone hospice programs is on the entire family, rather than only on the patient. In the residence, family members can visit 24 hours a day and cots are often provided for them to stay overnight as the end nears. Family members often describe the feeling of a burden being lifted, as they are able to rely upon the professional care of nurses and personal support workers, and the care of volunteers.

*Globe and Mail* reporter Lisa Priest states, “Hospices provide a more home-like experience, while costing only about \$439 per patient a day, compared to \$850 to \$1,000 in a hospital bed.”<sup>45</sup> Although the bed-care cost of a residential care hospice is between one-half and one-third of the cost of a hospital bed, governments have been relatively slow to get on board to support hospices, perhaps mistakenly fearing that these facilities would add to the mushrooming health care costs. The Daval Hospice website addresses the cost of a hospital bed vs. a hospice bed per day: “\$2,908 intensive care bed, \$800–\$1,000 acute care bed vs. \$300–\$486 hospice bed.”<sup>46</sup>

### DYING AT HOME

Families and patients seeking an alternative to a medicalized, hospital-based death have increasingly turned to dying at home as a way to provide comfort, familiar surroundings and support to their loved ones. In many respects, this shift resembles the home birth and midwifery movements that began in North America in the late 1960s and 1970s. Indeed, programs have been established to train doulas (midwives) for the dying.

With adequate support (including nursing support, a palliative care team visiting on a regular basis to attend to medical needs, home health and home support volunteers), the home can provide an alternative to a hospital death. Being at home enables both the family and the patient

*The philosophy of residential hospices mirrors the goals of palliative care – to alleviate pain and suffering to allow the dying person to live their final days in comfort and ease amid the people they love.*

## Options for End-of-Life Care



to have more control over the conditions and circumstances of the patient's care. As well, there is far more space, enabling family and friends to come and go, taking turns sitting with the patient, rather than crowding into the patient's room. Most importantly, the home can feel safe and familiar at a potentially frightening and painful time.

As indicated above, caring for a terminally ill person at home can be very taxing, as both the physical and emotional demands are enormous and potentially overwhelming. Both the duration of the dying process and its circumstances are unpredictable: medical events (such as uncontrollable pain, vomiting, bowel obstruction, hallucinations, bleeding, seizures) can lead to a family being unable to continue at home, unless they can receive emergency medical assistance. Some patients do end up at a residential hospice or acute care hospital when the care at home is no longer adequate. Families that undertake a home death need to be aware that the demands may outstrip their abilities and resources and are advised to prepare for the fact that they might be unable to satisfy a person's wish to die at home.

In any discussion of the merits of home deaths, it is crucial that we bear in mind that not everyone has a home that would be a suitable place for them to die, nor a loving family to care for them. Homeless and marginally housed people may end up dying on the street, in a shelter or an emergency room, with little or no say over how they might have wanted to die (see sidebar on the Diane Morrison Hospice).

Wherever it is delivered – in a palliative care unit in a hospital, in a residential care hospice in the community or in the patient's home – palliative care improves the quality of life of dying people and their families. Furthermore, recent research has shown that palliative care can increase the quantity of a patient's life.<sup>47</sup>

*Caring for a terminally ill person at home can be very taxing, as both the physical and emotional demands are enormous and potentially overwhelming.*

### The Diane Morrison Hospice

The Diane Morrison Hospice (formerly Ottawa Mission Hospice) provides palliative care to 14 terminally ill people who are homeless or street-involved. The program serves men and women and is committed to welcoming everyone who is homeless and in need of end-of-life care.

Eligibility:

- Those who are homeless or street-involved can be accepted for admission if they are living with a terminal illness that is progressing rapidly
- Those who need assistance in managing pain or other symptoms
- Those unable to access or benefit from "mainstream" care services due to behaviour or lifestyle

The intent of the hospice program is to provide a safe home where people can live well for their remaining days and die pain-free and with dignity. The hospice provides clients with the equivalent of a home and a family so they can access palliative care services as others do in the community. The hospice seeks to provide the best quality of life possible for its clients for the days that remain for them. This means providing an atmosphere that is safe, secure and respectful. The program also provides an alternate to hospital care and saves the health care system an estimated \$50,000 per person.

## Options for End-of-Life Care



### ASSISTED SUICIDE AND THE RIGHT TO DIE

It is not the purpose of this report to engage in an extended discussion about assisted suicide. Given the prominence of this issue in the media and the political arena, however, it cannot be ignored. The Criminal Code of Canada prohibits both euthanasia and assisted suicide.<sup>48</sup> However, a mentally competent dying person has the right to refuse treatment and attempting to commit suicide is no longer illegal in Canada.

In 1991, this provision was challenged by Sue Rodriguez, a B.C. mother with a young son, who was diagnosed with ALS in 1991. Knowing that she wanted to spend as long as possible with her son, yet hoping to protect him from witnessing her inevitable suffering at the end of her life, she fought for the right to have assistance with dying at the time of her choosing. Rodriguez took her case for the right to die to the British Columbia Supreme Court; when they ruled against her, and the B.C. Court of Appeal followed suit, she took her case to the Supreme Court of Canada. On September 30, 1993, in a 5–4 decision, the court ruled against her, upholding the prohibition of assisted suicide contained within the Criminal Code. Few who watched the news coverage of the case can forget the determination and courage of Rodriguez and the power of her questions: “Whose body is this? Who owns my life?” A few months later, on February 4, 1994, Sue Rodriguez ended her life, with the assistance of an unnamed physician. No charges were ever laid in her death.

Despite the efforts of proponents of assisted suicide, no further judicial decisions or legislative action was taken until 2011. In that year, Gloria Taylor, another B.C. woman living with ALS, joined an existing case brought forward by the B.C. Civil Liberties Association that sought the

In addition to a palliative care nurse specialist, physicians and nurse practitioners, volunteers contribute to the program by reading to individuals, playing games or cards, helping with meal service and taking someone for a walk or to a medical appointment. Clients’ biological and street families and friends are welcome to help with care. The hospice also has access to spiritual caregivers from all religious denominations and the Aboriginal community.

The hospice encourages their clients to continue to live well and spend time with friends and family. Some describe their time in the hospice as the happiest and most comfortable time in their lives. The Diane Morrison Hospice also provides support in end-of-life planning when clients feel ready to address these issues. Clients who wish to die at the hospice can do so surrounded by those who care about them. A service is held for each individual to provide a chance for their community to mourn and comfort each other. The program does more than simply take care of the dying. It has strengthened the community and brought meaning and dignity to the end of life for a group of people who desperately need and deserve it.

Adapted from <http://ottawamission.com/hospice/>

## Options for End-of-Life Care



repeal of the prohibition of assisted suicide. Taylor's lawyers argued that the prohibition violates Section 15 of the Canadian Charter of Rights and Freedoms because it discriminates against people with degenerative diseases who are unable to end their lives without assistance. They also argued the ban violates their Section 7 "right to life and the security of person" because, if they want to end their suffering, they would have to do so earlier than they might otherwise want, before they lost the capacity to act. Justice Lynn Smith found in the plaintiffs' favour, but suspended her decision for one year to allow the federal government to change the law to exempt physicians from criminal prosecution. Her ruling explicitly exempted Taylor from that suspension. Taylor died of an infection in October 2012, before she could exercise her right to assisted suicide. The federal government appealed Justice Smith's ruling and the case was heard in March 2013. Court observers believe the case will advance to the Supreme Court of Canada, where the justices will consider this issue for the first time since Sue Rodriguez's case in 1993.

*Two major reports have recommended the revision of the Criminal Code to allow physician-assisted suicide under very limited conditions.*

In addition to the B.C. legal challenge, two major reports have recommended the revision of the Criminal Code to allow physician-assisted suicide under very limited conditions.<sup>49</sup> Seldom noted in the debates is the fact that both reports devote considerable attention to the importance of palliative care, underpinning the importance of universal access to adequate pain management, supportive and dignified care and support, and both home care and hospice services. Hospice palliative care advocates and practitioners express the fear that funding for hospice and palliative care services will be cut (or at the very least a commitment to expanding hospice and home care will not be met) should assisted suicide be decriminalized.

Quebec's legislation received first reading on June 12, 2013. The legislation could become law as early as the end of the year. Organizations such as the Canadian Medical Association, Canadian Society of Palliative Care Physicians, Canadian Hospice Palliative Care Association, Ontario HPCO have joined in calling for broader discussions about hospice palliative care and improved access to hospice palliative care for all Canadians. According to a survey of 1,600 Canadian doctors released in July 2013, only one-quarter of respondents said they would participate in doctor-assisted suicide if it were legal: 26% of doctors said they would be "very or somewhat likely" to participate in doctor-assisted dying, while 54% said they were "very or somewhat unlikely" to do so.<sup>50</sup>

Despite the attention that this issue has garnered, it is important to recognize that assisted suicide is likely to be the choice of a tiny minority of dying people, while palliative care could benefit up to 85% of dying people.<sup>51</sup>

# Conclusion



Despite our efforts to deny and defy death, it does in fact come to us all (and its coming is largely out of our control in terms of where, when, how, with whom and even why).

We can learn to accept that death is a fact of life and engage in conversations about:

How do we want to live as we age? What kind of legacy do we want to leave?

How do we want to approach death and how do we want to die?

How do we want to be cared for and how do we want care for one another?

How do we want to show up in this last stage of our own lives and of the people we love?

What individual, family and community resources and supports do we need to be able to manage end of life with dignity, respect and comfort?

In recent years, the concept of death with dignity has been largely appropriated by advocates of physician-assisted suicide. As the research presented in this paper documents, dying with dignity has a lengthy history and meaning far beyond the provision of the means to die at a chosen time and place. Rather, it means supports and services provided within people's own homes and home-like environments in communities when they are dying. It means palliative care units in hospitals and long-term care facilities, providing pain and symptom management services with a focus on quality of life rather than quantity. It means hospice outreach services to support dying people and their families throughout the dying process and beyond.

Ensuring that these services are available to all Canadians, whatever their circumstances, will require broad-based family and community conversations and national discussions about how we live our lives, how we care for one another and how we want to die. It will require cross-generational family dialogues about caregiving needs and provision throughout the life cycle. These conversations can serve to bring death out of the shadows and enable us to shape the end of our lives.

As documented in this report, we live in a culture that largely denies the reality of death. As *The Economist's* report on "The Quality of Death" notes, the "medicalization of death in Canada has engendered a culture where many people are afraid to raise the topic of death." Thus, while Canada scored 9th out of 40 countries in the overall ranking on quality of death, we scored poorly (3 out of 5) when the public awareness of end-of-life care was measured.<sup>52</sup>

Public awareness and information campaigns about the importance of advance directives can serve as a starting point for these important conversations about end-of-life care. As well, stories from family members who have had good end-of-life experiences can challenge some of the misconceptions Canadians have about dying.

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## Conclusion



### START THE CONVERSATION

In Canada, even though there is general public support for advance care planning, only a minority engage in it. According to a 2004 poll conducted by Ipsos-Reid on behalf of the Canadian Hospice and Palliative Care Association and GlaxoSmithKline:<sup>53</sup>

- 8 in 10 Canadians agreed that people should start planning for end of life when they are healthy.
- 70% of Canadians had not prepared a living will or advance directive.
- 47% of Canadians have not designated a substitute decision maker to make health care decisions for them if they are unable.
- Fewer than 44% Canadians have discussed end-of-life care with a family member.
- Although Canadians felt that end-of life care was an important discussion to have with a physician, only 9% had done so.<sup>54</sup>

*One of the most significant developments in changing attitudes toward dying has been initiatives to encourage people to “start the conversation on end-of-life care.”*

One of the most significant developments in changing attitudes toward dying has been initiatives to encourage people to “start the conversation on end-of-life care.” Organizations by this name and others encourage people to talk about end-of-life care, for themselves, their aging parents and their families. Groups such as the Quality End-of-Life Care Coalition of Canada provide kits that outline key terms (e.g. Power of Attorney, DNR, etc.).<sup>55</sup> More important, perhaps, than the legal documents are the conversations that accompany them, when family members begin to talk about how they might want to die. While few if any people know exactly how they will die (what disease, the duration of their illness, etc.), these initiatives can help people tease out the nuances of their inchoate desires and hopes (e.g. whether they want to be kept alive by a feeding tube or respirator; who they might want to have with them when they die; where they might wish to spend their final days).

Equally important are the conversations between physicians and their patients.

The importance of these conversations is underscored by the circumstances that are being repeated day after day in ERs and ICUs. An elderly parent experiences a severe health event (stroke, heart attack, bowel obstruction, breathing difficulties) that threatens to end his or her life. Family members are called and those close by gather by the bedside. When the doctor asks if the patient has any advance care directives, the family members shake their heads. “Not that I know of,” one responds. “We never really talked about that sort of thing.”

“What do you think your mother would like us to do right now?” the doctor continues, since the patient herself is unconscious and unable to make her wishes known. In the absence of any documented wishes, the beliefs of individual family members take over. While there may be basic agreement about fundamentals (as in the case of my family when my mother suffered a massive brain aneurysm and we all knew with certainty that “Mom wouldn’t want to live like a vegetable”). Matters get more complicated, however, when one or more family members hold strict religious beliefs that dictate that life must be saved at all costs. Another family member may believe that their mother would not want to be kept alive by heroic means and that the best thing would be to let her die in peace with only pain relief provided. If one or more family members have been designated Power of Attorney for Personal Care, the matter may be resolved, though that resolution may not in fact reflect the patient’s wishes and may cause a serious rift between the remaining family members.

Discussions about end-of-life wishes can provide an additional benefit for families, bringing them closer together as they plan for what lies ahead of them. Decisions about life support, medical interventions, CPR and so on can be made much more easily when the wishes of family members are clearly stated.

## Conclusion



It's not only families that have difficulty talking about end of life. A recent article in the *Canadian Medical Association Journal* provides guidelines for physicians to help them initiate discussions about advance care planning with their patients and their families. The end-of-life "conversation guide" is geared toward hospital physicians who have the opportunity to talk with patients and families about priorities, hopes, fears and wishes, yet currently rarely raise these issues.<sup>56</sup> It might well be useful for family physicians, whom researchers suggest seldom talk to their patients about end-of-life care. A recent study of Canadian patients, published in the *Journal of the American Medical Association*, found that only 30.3% of the 278 patients and 225 family members surveyed had discussed end-of-life issues with their family physicians, and the preferences that they had (e.g. DNR, etc.) were reflected on their medical record only 30.2% of the time. Daren K. Heyland, M.D., M.Sc., of Kingston General Hospital, Ontario, Canada and colleagues examined elderly patients' advance care planning activities before hospitalization and preferences for care from the perspectives of patients and family members.<sup>57</sup>

Beginning and expanding our conversations about our wishes for care at end of life is an important step in bringing the subject of death out into the open. By talking openly about dying, we can break the silence, mystery and misconceptions that surround death.

In the end, how we care for dying people and their families is a measure of our capacity to be a caring society.

In 2011, the death of the late NDP leader Jack Layton brought the message of palliative care into the public eye. His widow, Olivia Chow, has become a spirited advocate of the importance of what she calls celebrating life in the face of death. In a speech to the Saskatchewan Hospice Palliative Care Association in June 2013, Chow offered the following observations:

Jack was blessed with excellent palliative care and support. We had nurses to provide personal care and support at our home. We had doctors to help control pain, to provide last-minute instruction and let us know what to expect when the final hours arrive. We had listening ears to help comfort us and the rest of the family.

Jack's death was without pain, without trepidation and without fear. His family experienced no guilt and regret, and made decisions in full accordance with Jack's will.

We were very lucky - financially, and professionally, I was able to take time off from work in the last month to be with Jack and help with his care. We live just a stone's throw from the hospital in Toronto. We have a house where we were able to take care of Jack in comfort - and a front garden where we could have flowers planted to bloom in his view. The children live nearby, and many of the family.

And we were very lucky to have palliative support from the medical community, caregivers, volunteers.

Because of the palliative support, in death, we were able to celebrate Jack Layton's life. To rejoice in his spirit.<sup>58</sup>

The emotional, financial, physical, psychological and spiritual costs of caring for elderly parents (often while holding down a full-time job and caring for school-aged children) are enormous and will only escalate with the aging of the Canadian population. Without changes in social and health policies, such as the ones discussed in this paper, these costs will be borne by families and by women in particular. The hidden costs of this caregiving work will continue to take a toll not only on caregivers, but on the Canadian economy (in terms of lost days of work, decreased productivity) and on the spirit of the nation as a whole. 🏠

*The emotional, financial, physical, psychological and spiritual costs of caring for elderly parents (often while holding down a full-time job and caring for school-aged children) are enormous and will only escalate with the aging of the Canadian population.*

# Glossary



## **Advance (care) directive**

Advance directive for health or personal care consists of instructions given by a capable person, often in written form, about their wishes for health care (treatment) and/or personal care in the event that they become incapable of giving informed consent. The advance directive may appoint a proxy who will assume responsibility for ensuring that the person's wishes are respected. The term "advance directive" has replaced the notion of a "living will," a term that had no legal meaning in Canada.

## **Assisted suicide**

Assisted suicide occurs when a person assists an individual, usually someone who is terminally ill or experiencing intractable pain and suffering, to end their own life. Physician-assisted suicide refers to the practice whereby a doctor provides the patient with the means to end his or her own life. The assistance may take the form of providing a lethal dosage of a drug that the patient can take themselves or of providing a lethal injection.

## **Do not resuscitate order** (commonly DNR)

An order placed by a physician on a patient's chart that instructs health care personnel not to attempt resuscitation in the event of cardiac or respiratory arrest. In some jurisdictions, the term "allow natural death" is used to direct health care providers not to attempt medical interventions to prolong life when death is imminent.

## **Euthanasia**

Euthanasia is the deliberate act undertaken by one person with the intention of ending the life of another person in order to relieve that person's suffering. Voluntary euthanasia is an act performed with the patient's consent. Involuntary euthanasia is the act of ending the life of another person without their consent.

Both euthanasia and assisted suicide are hotly contested issues in contemporary society; as a result, even the definitions of these terms are subject to debate.

## **Medicalization**

Medicalization is the process by which certain conditions and problems come to be defined and treated as medical conditions, and thus become the subject of medical study, diagnosis, prevention or treatment. In the context of death and dying, medicalization refers to the increasing reliance upon physicians, medical technology and pharmaceutical products in an effort to stave off the death process.

## Glossary

### **Palliative care; hospice care; hospice palliative care**

An approach to care that focuses on comfort and quality of life for those affected by progressive, life-threatening illness, including both patients and their families. The goal of palliative care is to control pain and other symptoms; to support emotional, spiritual and cultural needs; and to maximize functioning.

In Canada, the term “hospice care” is used interchangeably with “palliative care,” and hospice palliative care is in widespread use to refer to services provided within the home, in a residential care hospice, in long-term care facilities and in palliative care units within hospitals. Hospice palliative care relies upon an interdisciplinary team of nurses, physicians, social workers, personal support workers, pharmacists and volunteers.

In the U.S., a distinction is made between palliative care and hospice, the former being available to patients earlier in the disease process. Patients may be deemed eligible for hospice care if they are medically certified to have less than six months to live and have agreed to forgo further treatment. The distinction rests primarily with the practices of Medicare and other health insurance providers.

In Canada, no such distinction is made.



# Endnotes



<sup>1</sup> See Katherine Arnup, *Education for Motherhood: Advice for Mothers in Twentieth Century Canada* (Toronto: UTP, 1994), Chapter 1, for a discussion of infant and maternal mortality.

<sup>2</sup> In the carnage of WWI, more than 60,000 Canadians died, while an estimated 250,000 returned home with serious injuries. An estimated 50,000 Canadians, many of them healthy young adults, died from the Spanish influenza epidemic, brought home by veterans returning from the front.

<sup>3</sup> Philippe Aries, *The Hour of Our Death* (New York: Vintage Books, 1981, 2008), 559–60.

<sup>4</sup> Aries, 559.

<sup>5</sup> Susan L. Smith and Dawn Dorothy Nickel, “Nursing the Dying in Post-Second World War Canada and the United States,” in *Women, Health, and Nation: Canada and the United States Since 1945*, ed. Georgina Feldberg (McGill-Queen’s University Press, 2003), p. 333.

<sup>6</sup> Statistics Canada (2013). *Deaths in Hospital and Elsewhere, Canada, Provinces and Territories*. CANSIM Table 102-0509. Accessed September 27, 2013. <http://bit.ly/15Zgj4v>.

<sup>7</sup> *Ibid.*

<sup>8</sup> Smith and Nickel, “Nursing the Dying” (2003), 330, citing Jeanne C. Quint, *The Nurse and the Dying Patient* (New York: Macmillan, 1967).

<sup>9</sup> Smith and Nickel, “Nursing the Dying” (2003), 336.

<sup>10</sup> Smith and Nickel, “Nursing the Dying” (2003), 333.

<sup>11</sup> *Ibid.*, 334.

<sup>12</sup> Aries, 570.

<sup>13</sup> *Ibid.*, 570.

<sup>14</sup> *Ibid.*, 560.

<sup>15</sup> Andrea Sankar, *Dying at Home: A Family Guide for Caregiving* (Baltimore: Johns Hopkins University Press, 1991), 134, cited in Smith and Nickel, “Nursing the Dying” (2003).

<sup>16</sup> Changing the Face of Medicine: Biography. <http://1.usa.gov/16CCatY>.

<sup>17</sup> The root word for hospice is *hospes*, meaning host, the same root as hospitality and hospital.

<sup>18</sup> In 1900, five of the Irish Sisters of Charity founded St. Joseph’s Convent in the East End of London and started visiting the sick in their homes. In 1902, they opened St. Joseph’s Hospice with 30 beds for the dying poor.

<sup>19</sup> Dame Cicely Saunders, “Living with Dying: The Management of Terminal Disease,” cited in Heather Robertson, *Meeting Death: In Hospital, Hospice, and at Home* (Toronto: McClelland and Stewart, 2000), p. 69.

<sup>20</sup> The word “palliative” comes from the Latin word *palliare* meaning “to cover or cloak.” Today, the term “palliative care” is often used interchangeably with “hospice” in Canada.

## Endnotes



- <sup>21</sup> "A Moral Force: The Story of Dr. Balfour Mount," *The Ottawa Citizen*, April 25, 2005.
- <sup>22</sup> C. Stuart Houston, OC, SOM, DLitt, MD, FRCPC, and Stan Houston, MD, FRCPC, "The first smallpox epidemic on the Canadian Plains: In the fur-traders' words," *Can J Infect Dis*. 2000 Mar-Apr; 11(2): 112-115.
- <sup>23</sup> John S. Milloy, *A National Crime: The Canadian Government and the Residential School System, 1879 to 1986*. University of Manitoba Press (1999), 91; Fournier and Crey, *Stolen from Our Embrace*. Vancouver: Douglas & McIntyre (1997), 49. <http://bit.ly/10wOdqp>
- <sup>24</sup> Canada's Public Health Leader, "TB and Aboriginal People." <http://bit.ly/1b9Q7ES>
- <sup>25</sup> Canadian Institute for Health Information, *Improving the Health of Canadians*, Ottawa, ON: CIHI (2004).
- <sup>26</sup> Economist Intelligence Unit, "The Quality of Death: Ranking End-of-Life Care Across the World," a report by the Economist Intelligence Unit commissioned by LIEN foundation (2010), 9.
- <sup>27</sup> Canadian Institute for Health Information, *Health Care in Canada, 2011: A Focus on Seniors and Aging*. Ottawa, ON: CIHI (2011).
- <sup>28</sup> Katherine Arnup, "Lessons in Death and Dying," *Journal of Palliative Care* (June 2009).
- <sup>29</sup> Christine McPherson, Keith G. Wilson and Mary Ann Murray, "Feeling Like a Burden to Others: A Systematic Review Focusing on the End of Life," *Palliative Medicine*, 21 (2007) 115-28; Keith G. Wilson, Harvey Max Chochinov, C.J. McPherson et al., "Desire for Euthanasia or Physician-Assisted Suicide in Palliative Cancer Care," *Health Psychology* 26, 3 (2007), 314-23.
- <sup>30</sup> Dr. Jack Kitt, foreword to Health Council of Canada Report, "Seniors in Need, Caregivers in Distress: What Are the Homecare Priorities for Seniors in Canada?" (April 2012).
- <sup>31</sup> M.J. Hollander, G. Liu and N.L. Chappell, "Who Cares and How Much? The Imputed Economic Contribution to the Canadian Health Care System of Middle Aged and Older Unpaid Caregivers Providing Care to the Elderly," *Healthcare Quarterly* 12(2) (2009) 42-59.
- <sup>32</sup> Ramirez, Amanda, Julia Addington-Hall and Michael Richards. "The Carers." *Boston Medical Journal* 324 (1998): 1291-2. Accessed September 27, 2013. <http://bit.ly/1h8WRUk>
- <sup>33</sup> Richard Schulz and Scott R. Beach. "Caregiving as a Risk Factor for Mortality." *Journal of the American Medical Association* 282.23 (1999): 2215-2219. Accessed September 27, 2013. <http://1.usa.gov/1fvd8au>
- <sup>34</sup> Grant Charles, Tim Stainton and Sheila Marshall, "Young Carers in Canada: The Hidden Costs and Benefits of Caregiving." <http://bit.ly/19JObQf>
- <sup>35</sup> Roy Romanow, *Building Values: The Future of Health Care in Canada* (Final Report), November 2002.
- <sup>36</sup> Parliamentary Committee on Palliative and Compassionate Care, "Not to Be Forgotten: Care of Vulnerable Canadians," November 2011.



<sup>37</sup> Valerie A. Crooks, Melissa Giesbrecht and Sarah Dykeman, "Evaluating Canada's Compassionate Care Benefit: From the Perspective of Family Caregivers," Executive Summary, p. 1. <http://bit.ly/16CDeOr>

<sup>38</sup> Service Canada, Employment Insurance Compassionate Care Benefits. <http://bit.ly/cRLwOY>

<sup>39</sup> Allison Williams, Valerie A. Crooks, Melissa Giesbrecht and Sarah Dykeman, "Evaluating Canada's Compassionate Care Benefit: From the Perspective of Family Caregivers." <http://bit.ly/16CDeOr>

<sup>40</sup> See Canada Revenue Agency. *Family Caregiver Amount (FCA)*. Accessed September 27, 2013. <http://bit.ly/1bhpX6F>

<sup>41</sup> Emily Warner, "Rhode Island Passes Palliative Care Legislation," *Palliative in Practice (Center to Advance Palliative Care blog)*, July 3, 2013.

<sup>42</sup> Canadian Virtual Hospice website: [http://www.virtualhospice.ca/en\\_US/Main+Site+Navigation/Home.aspx](http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx)

<sup>43</sup> Derek Miedema, "Why Canada Needs More Palliative Care," *Institute of Marriage and the Family Canada*, June 2013.

<sup>44</sup> Lisa Priest, "To Go Gently into That Good Night: When Quality of Death Can Enhance Quality of Life," *The Globe and Mail*, March 1, 2012.

<sup>45</sup> *Ibid.*

<sup>46</sup> Daval Hospice, "What's All This Talk About Death & Dying... Frequently Asked Questions and Need for Advocacy." <http://bit.ly/18sAoym>

<sup>47</sup> Jennifer S. Temel, MD, Joseph A. Greer, PhD, Alona Muzikansky, MA et al. "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer," *N Engl J Med* 363 (2010) 733-742.

<sup>48</sup> According to the Criminal Code of Canada, Section 14, euthanasia is illegal: No person is entitled to consent to have death inflicted on him, and such consent does not affect the criminal responsibility of any person by whom death may be inflicted on the person by whom consent is given. See more at <http://bit.ly/19MdCRi>

<sup>49</sup> "End-of-Life Decision-Making in Canada," report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making (November 2011); "Dying with Dignity," report of the Quebec National Assembly (March 2012) and Bill 52, Introduced on June 12, 2013.

<sup>50</sup> Sharon Kirkey, "Most Canadian Doctors Oppose Physician-Assisted Suicide, Survey Suggests," *Canada.com*, August 5, 2013. Accessed September 30, 2013. <http://bit.ly/1c74UUn>

<sup>51</sup> André Picard, "Palliative Care Should Be Embraced as a Priority and a Philosophy," *The Globe and Mail (Politics Insider)*, June 26, 2013.

<sup>52</sup> Economist Intelligence Unit, "The Quality of Death: Ranking End-of-Life Care Across the World," a report by the Economist Intelligence Unit commissioned by LIEN foundation (2010).

## Endnotes

<sup>53</sup> Ipsos-Reid, "Hospice Palliative Care Study," study commissioned by GlaxoSmithKline and the Canadian Hospice Palliative Care Association. 2004.

<sup>54</sup> Canadian Hospice Palliative Care Association, *Advance Care Planning: A National Framework* (2012).

<sup>55</sup> For more information, visit: <http://www.qelccc.ca>

<sup>56</sup> Amber Daugherty, "New 'Conversation Guide' Helps Doctors Discuss End-of-Life Care with Patients," *The Globe and Mail*, July 15, 2013.

<sup>57</sup> Daren K. Heyland, MD, MSc, FRCPC, Doris Barwich, MD, CCFP, Deb Pichora, RN, MSc et al., "Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning," *JAMA Internal Medicine*, published online April 1, 2013.

<sup>58</sup> Olivia Chow, speaking at the Saskatchewan Hospice Palliative Care Conference, Regina, June 14, 2013.





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