L'Institut Vanier de la famille
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FAMILY PERSPECTIVES

Death and Dying in Canada

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NOTE FROM THE AUTHOR

> *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"

When I wrote the first edition of this report in 2013, *Contemporary Family Trends: Death, Dying and Canadian Families*, I could not have imagined how much the circumstances around death and dying would change in a few short years. While I knew that efforts were under way to legalize what I termed "assisted suicide" in the 2013 edition, I did not anticipate the Supreme Court ruling in *Carter v. Canada* in 2015, nor the passage of Quebec's Bill 52 and Bill C-14 that legalized medical assistance in dying (MAID) in June 2016. Although the issues surrounding medically assisted dying are not fully resolved, MAID is legal across Canada (under certain circumstances), and to date more than 2,600 people have obtained medical assistance in dying.

Despite opposition from some organizations and individuals, it appears that most Canadians have come to accept MAID as a fact of life (and, of course, death). There can be little doubt, however, that the silence surrounding death and dying with which I opened my previous report has – to a degree – been broken.

Today, we see countless news articles, television and radio programs, and a vast number of accounts of death and dying experiences every day – and not just about MAID. Whether it's stories about reclaiming death (e.g. death doulas, green burials, living funerals), coverage of the "slow medicine" movement resisting highly medicalized geriatric and end-of-life care, or the debate surrounding legislation such as Bill C-277, *An Act Providing for the Development of a Framework on Palliative Care in Canada*, it's clear that change is in the air.

How have these changes affected Canadians' experiences of death and dying? Certainly nothing so earth-shattering as an end of death *itself* has occurred. What has been the impact of these developments on families across Canada? How do factors of race, indigeneity, income, location, gender and sexual identity, among others, continue to determine people's experiences of death?

Despite the significant evolution in the conversations on death and dying, most Canadians approach death with some measure of fear, ignorance and dread. Thus, major sections from the 2013 edition of this report remain substantially the same, with updated information and statistics. Most people still wish they could avoid death. For the most part, Canadians have not heeded Mary Oliver's sage advice to embrace each day of our "one wild and precious life."

Introduction

This report examines death and dying in Canada in 2018 – a time when many of the demographic trends highlighted in the 2013 report that have shaped family experiences continue, such as an aging population, increased family mobility, more family members in the paid labour force (and remaining there until later ages), the growing number of single people and people living alone, and a lack of adequate and affordable home care and palliative care. Though the numbers have declined, most people are still dying in hospital, especially in emergency rooms and intensive care units, rather than at home. This report examines these facts and points toward some of the possibilities for supporting families as they face the reality of illness and death with greater equanimity, resilience and joy.

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 will require a number of major adaptations to social and health policy.

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 (including Alzheimer's and other forms of dementia) 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. A variety of factors contribute to this gap between desire and reality, and some innovative, emerging approaches to end-of-life care may enable more Canadians to die in the location that best meets their needs (and those of their families).

4. Impact on Families

The silence and denial that surround death and dying in contemporary Canadian culture are having a significant impact on individuals and families in communities across the country. The continuing 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.

Examining the historical experiences of death and dying, the changing role of families in end-of-life care and the medicalization of death and dying can shed light on *how we got here*. 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.

> *Despite the significant evolution in the conversations on death and dying, most Canadians approach death with some measure of fear, ignorance and dread.*

The Historical Context:

Death and Dying in Canada over Time

The experiences of death and dying in Canada have changed dramatically throughout Canada's history 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 and gender identity, marital status and First Nation/Indigenous/Inuit/Métis status. Nonetheless, it is important to document the major changes that have taken place to enable us to situate present-day conditions within evolving trends.

> *The experiences of death and dying in Canada have changed dramatically throughout Canada's history and particularly during the past 70 years.*

MEDICAL ASPECTS OF DEATH AND DYING: 1900 TO 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**[1]

	Rate per 100,000
1921–1925	
All causes	1,030.0
Cardiovascular and renal diseases	221.9
Influenza, bronchitis and pneumonia	141.1
Diseases of early infancy	111.0
Tuberculosis	85.1
Cancer	75.9
Gastritis, duodenitis, enteritis and colitis	72.2
Accidents (unintentional injuries)	51.5
Communicable diseases	47.1
2015	
All causes	737.7
Malignant neoplasms	215.0
Heart diseases	143.8
Cerebrovascular diseases	38.5
Chronic lower respiratory diseases	35.1
Accidents (unintentional injuries)	33.0
Influenza and pneumonia	21.3
Diabetes mellitus	20.0
Alzheimer's disease	18.4

Source: Statistics Canada, *Leading Causes of Death, Total Population, by Age Group and Sex, Canada* (CANSIM Table 102-0561) (page last updated February 23, 2018). **Link:** http://bit.ly/2s9diBF.

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 their first birthday.[2]

A high birth rate and dangers of childbirth led to a high maternal mortality rate as well (see *Maternal and Infant Mortality in Canada* text box).[3] 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 destitute and served as training grounds for physicians and nurses. Routinely, neither birth nor death took place in hospital.

> *In 1901, Toronto reported that 160 of every 1,000 babies died before reaching the age of one.*

Maternal and Infant Mortality in Canada

- Maternal mortality dropped from 508 deaths per 100,000 live births in 1931 to 7 per 100,000 in 2015.[4, 5]
- Infant mortality rates fell from an average of 76 deaths per 1,000 live births in 1931–1935 to 4.5 per 1,000 in 2015.[6, 7]

Shocked by spiralling infant and maternal mortality rates, the losses from the First World War and the Spanish influenza epidemic,[8] 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. Nonetheless, antibiotics such as penicillin and sulfonamides and technologies such as X-ray machines and laboratory testing were not widely available until after the Second World War.

SOCIAL ASPECTS OF DEATH AND DYING: 1900 TO 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. Family members (primarily women) bathed and dressed the body, then laid it out in the parlour for friends and family to pay their respects. The body would then be placed in a wooden coffin, often made by a family member or local cabinetmaker and transported for burial in the local graveyard or on their own property.

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.

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."[9] 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."[10] 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.

With industrialization, urbanization and growing public health concerns about the spread of disease, families were increasingly unable to care for their dead at home. To take their place, funeral parlours began to appear in towns and cities across Canada in late 19th and early 20th centuries. Often a family business passed on through the generations, funeral parlours resembled a family home, complete with sitting rooms for viewings. The funeral director and his family often lived on the upper level of the house, adding a sense of "homeyness" to the building. The funeral director was a highly respected member of the community, someone to whom one could safely entrust their loved ones for their final disposition.[11]

Still, most people could not afford an elaborate funeral and home wakes continued until well into the 20th century in some parts of the country.

> Ryan[12] remembers vividly when his 5-year-old sister died suddenly of rheumatic fever in Summerside, PEI in 1958. "She was waked at home. I think my mother wanted to have her close by." A wreath was placed on the front door to let neighbours know that the family was in mourning.
>
> *– Based on personal interview (March 17, 2018)*

THE MEDICALIZATION OF DEATH AND DYING: 1950 TO 2000

While incremental changes did occur following the First World War, most did not affect the majority of the population until after the Second World War. Although the period before mid-century witnessed a gradual increase in life expectancy (see Table 2, *Life Expectancy in Canada Since 1920/1922*), this was largely the result of public health measures, including improved nutrition and the importance of hygiene and sanitation, rather than medical discoveries.

TABLE 2: Life Expectancy in Canada Since 1920/1922

	Life expectancy *at birth*[13]		Total number of expected years of life *at age 65*[14]	
	Females	**Males**	**Females**	**Males**
1920/1922	60.6	58.8	78.6	78.0
1930/1932	62.1	60.0	78.7	78.0
1940/1942	66.3	63.0	79.1	77.8
1950/1952	70.9	66.4	80.0	78.3
1960/1962	74.3	68.4	81.1	78.6
1970/1972	76.6	69.6	82.7	78.9
1980/1982	79.2	72.0	84.0	79.7
1990/1992	81.0	74.6	85.0	80.8
2000/2002	82.0	76.9	85.5	82.0
2011/2013	83.8	79.6	86.9	84.0

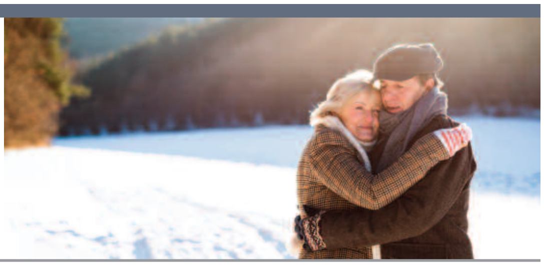
Source: André Lebel and Stacey Hallman, "Mortality: Overview, 2012 and 2013," *Report on the Demographic Situation in Canada*, Statistics Canada catalogue no. 91-209-X (page last updated July 12, 2017). -
Link: http://bit.ly/2IsEu2i. -

The period of sustained economic prosperity that followed the Second World War 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, including access to X-ray technology and laboratory testing. 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 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%.[15] The number continued to rise, reaching a peak of 77.3% in 1994.[16]

It is important to recognize that there has always been considerable regional variation in the location of death. For example, in 2015, the share of deaths occurring in hospitals ranged from a low of 37.5% in Nunavut to a high of 84.2% in Manitoba. Since 1994, there has been a steady decline in the proportion of deaths occurring in hospitals, with 61.5% of deaths occurring in hospitals in 2015.[17]



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."[18] 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 such as open-heart surgery and transplantation; and growth of specialties offering various 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 by many. 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."[19]

> *"Modern health care in the affluent post-war years was invested in saving lives, not in improving end-of-life care."*

In short, Smith and Nickel say, "Modern health care in the affluent post-war years was invested in saving lives, not in improving end-of-life care."[20] Most people died in hospitals (often after receiving what families and dying patients saw as "pointless, often stressful, heroic measures to prevent death").[21] Furthermore, with increased life expectancy, people were 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.

SOCIAL IMPACT ON FAMILIES: 1950 TO 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.

Nigel[22] remembers waiting in the hot car in the hospital parking lot in Belleville, Ontario while his father visited their mother in the hospital. When he was 7, Nigel and his two brothers (aged 3 and 10) would open the window a crack, and their father would admonish them not to talk to anyone or to get out of the car. Though the visits were likely short due to restricted visiting hours, his mother had several surgeries for "female problems," and the family did not have the money for a babysitter.

– Based on personal interview (March 16, 2018)

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."[23] 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."[24] 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."[25]

People were no longer present at the time of death and, as a result, death itself became shrouded in mystery and fear. Most people, even today, have not been with someone who is dying and have not seen a dead person until well into middle age, if at all. 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."[26]

The medicalization of death and the removal of dying from the home created the conditions for the *professionalization of death care* as well. Almost as soon as the person died, family members (if they were present at all) were escorted from the room, and the body moved to the morgue to await the arrival of the funeral home. Funeral homes themselves became increasingly elaborate offering services such as embalming and presentation of the body, the sale of expensive caskets and the provision of burial plots. The family played an increasingly small role in the entire process of after-death care.

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

EMERGING TRENDS: 1970s TO PRESENT

Health Promotion and the Decline in "Preventable Deaths"

In the early 20th century, public health measures focused on cleanliness, sanitation, pasteurization of milk, clean drinking water and the treatment of sewage. In an effort to improve maternal and infant health, public health nurses provided classes and home visits for new mothers – especially to immigrant women whose ideas about infant and child care might differ from the "Canadian norm."[27]

Renewed public health measures in the 1970s and 1980s (and continuing today) have contributed to a decline in "preventable deaths." One factor has been an increasing focus on health promotion during this period, which was facilitated by a growing body of research connecting smoking with cancer and other diseases.[28]

Since then, the death rate among Canadian men resulting from respiratory system diseases fell from a peak of 144.3 per 100,000 in 1988 to 81.3 by 2012. The death rate for men resulting from cancer also peaked in 1988 at 349.4 per 100,000, and has since fallen to 258.8 per 100,000 in 2012 – a decline that "mainly reflects changes in mortality due to the decline in lung cancer," according to Statistics Canada.[29]

Changes in auto/driving safety in Canada since the early 1970s, such as the mandatory introduction of seat belts in all new cars, the introduction and proliferation of car seats for children, the introduction of the breathalyser test and campaigns against drinking and driving – contributed to a decline in preventable deaths due to external causes (e.g. accidents), which fell from a peak of 127.1 per 100,000 in 1973 to 64.7 in 2012.[30, 31]

In 1971, the federal government established ParticipACTION, which sought to promote exercise, physical fitness and health through a series of television public service announcements called *Body Break* and through information and incentives designed to get Canadians moving. Cancelled in 2001, the program was reinstated in 2007 and continues to encourage Canadians of all ages to be active.[32]

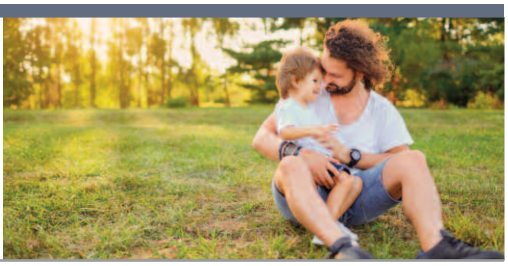
The Beginnings of Palliative Care

The 1960s and 1970s witnessed dramatic changes in many areas of Canadian society. The prosperity of the period following the Second World War 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 rise of the women's movement, lesbian and gay movement[33] and civil rights movement, among others. While it is obviously not possible to establish a movement of dying people (with the notable exception of people with AIDS in the 1990s), 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.

Elisabeth Kübler-Ross 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.

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."[34] Kübler-Ross's books became best-sellers 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.

The Historical Context



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"[35]: 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.[36]

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."[37]

Inspired by the work of Dame 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 in 1975 to relieve suffering and provide quality end-of-life care.[38] 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.[39] 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."[40] Known as the father of palliative care in North America, Dr. Mount has devoted himself to spreading the message of palliative care throughout his life.[41]

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 major impact on families.

In all areas of health care, deinstitutionalization effectively meant that patients were sent home or onto the streets, particularly if they were suffering from mental illness and/or addictions. The home was deemed to be the place to care for family members, whether they were suffering from a terminal 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.

> *The home was deemed to be the place to care for family members, whether they were suffering from a terminal illness, recuperating from surgery or living with mental illness or a severe disability.*

Photo (top): Sisters from the Soeurs du Sacré-Coeur d'Ottawa posing with students from Pukatawagan Residential School, Manitoba, circa 1960. Source: Library and Archives Canada.

Ravaged, decimated and, in some instances, extinguished by disease, Indigenous people in Canada continue to experience higher rates of infectious diseases and alarmingly high infant and maternal mortality and suicide rates.

Death and Indigenous Peoples in Canada

The historical conditions of death and dying among Indigenous 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, Indigenous people in Canada continue to experience 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 Indigenous 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 Indigenous 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.[42]

Epidemic TB among the Indigenous peoples spread with the growth of the railway and the move of settlers westward. Their forced relocation to crowded, often isolated reserves, coupled with poverty, malnutrition and a destruction of their way of life, facilitated the rapid spread of the disease. 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[43] were far higher, reaching 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."[44] In fact, the estimated odds for children of dying in residential schools (1 in 25) was even higher than the odds for a Canadian soldier dying in the Second World War (1 in 26).[45]

When TB epidemics spread among northern Inuit communities in the 1950s and 1960s, thousands were transported to southern hospitals and sanatoria for treatment, many of them segregated Indian TB hospitals where conditions were appalling and abuse not uncommon.[46] 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 2.5 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.[47]

Today, Indigenous 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, they 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).[48] "Youth suicide is an urgent issue for First Nations and Inuit youth in Canada," says Health Canada's suicide prevention webpage. "While there is much variation among communities, overall rates are high."[49]

- According to the Chief Public Health Officer, TB rates in 2016 were nearly 300 times higher among Inuit people compared with the non-Indigenous population in Canada.[50]
- In 2012, 27% of Inuit youth, 17% of off-reserve First Nations youth and 16% of Métis youth aged 18 to 25 reported that they had suicidal thoughts at some point in their lives (compared with 15% among non-Indigenous youth).[51]
- First Nations youth with a personal/familial history of residential school attendance are nearly twice as likely to report having suicidal thoughts as those who did not.[52]
- Suicide rates among Inuit youth are among the highest in the world, at 11 times the national average.[53]

For decades (if not longer), Indigenous women and girls in Canada have been disproportionately subject to violence, abduction and murder. According to the most recent data from Statistics Canada, in 2014, Indigenous women and girls had an overall rate of violent victimization (220 violent incidents per 1,000 women) that was *double* that of Indigenous males (110 per 1,000), nearly *triple* the rate among non-Indigenous women (81 per 1,000) and *more than triple* that of non-Indigenous males (66 per 1,000).[54]

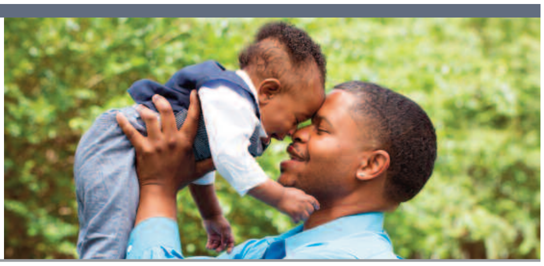
For decades (if not longer), Indigenous women and girls in Canada have been disproportionately subject to violence, abduction and murder.

Frustrated with the lack of attention paid by police and other legal authorities and suspecting that violence against Indigenous women was higher than publicly available data suggested, the Native Women's Association of Canada (NWAC) created a database of missing and murdered Indigenous women and girls, which gathered information on about 582 cases (covering up to March 31, 2010).[55] Their suspicions turned out to be well-founded, as the RCMP released a report in 2014 (mentioned below) revealing more than *twice as many cases* as NWAC had gathered information about.[56]

Established in 2016, the National Inquiry into Missing and Murdered Indigenous Women and Girls (MMIWG) is currently documenting the stories of these women and girls.[57] The most comprehensive numbers[58] are from the 2014 RCMP report, *Missing and Murdered Aboriginal Women: A National Operational Overview*, which counted 1,181 *police-reported* incidents of Indigenous women and girls *missing and murdered* between 1980 and 2012, and the April 2015 update, which provided updated data on the number of *missing* Indigenous women (174 police-reported incidents at time of publication) and unsolved cases (204) in which the homicide was unsolved or the Indigenous woman or girl was still missing.[59, 60] However, these estimates are incomplete, as Statistics Canada and some major police forces in Canada do not track missing Indigenous women.[61]

Indigenous families' experiences with death and dying are diverse, complex and evolving. However, health and well-being data, as well as the oral testimonies of Indigenous families themselves, *clearly indicate* that the impact of colonialism, including colonial policies and practices identified by the Truth and Reconciliation Commission as physical, biological and cultural genocide,[62] continues to this day.

Desires and Realities of Death and Dying in Canada



While we might all hope to live forever, the fact remains that we will all die.

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 the 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 significant 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.

DESIRE 1: WE WANT TO LIVE FOREVER

> "Everybody has got to die, but I always believed an exception would be made in my case."
> WILLIAM SAROYAN

> "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 rumour."
> ALDOUS HUXLEY

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 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 skydivers.

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. It brings to mind the Struldbrugs, a tiny minority of the Luggnaggians, in Jonathan Swift's *Gulliver's Travels*.[63] 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.

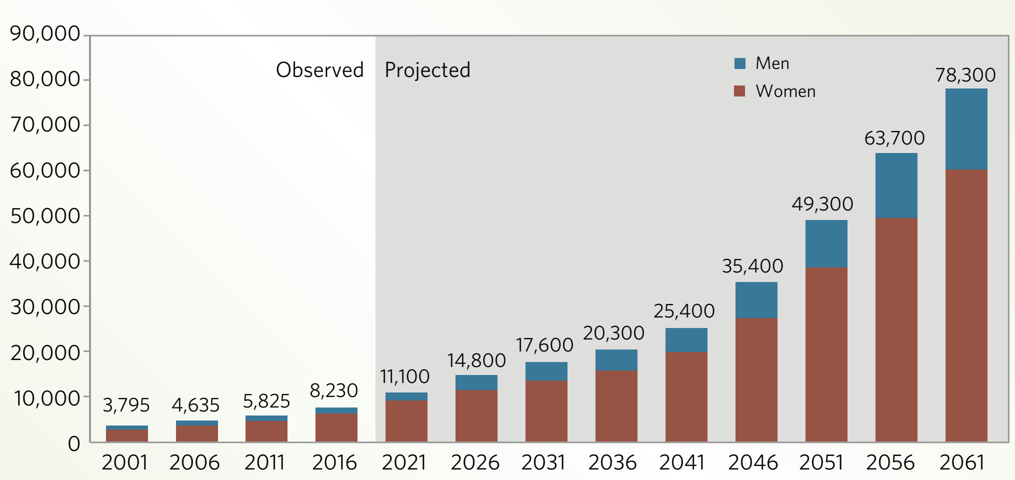
TABLE 3: Population Growth, by Age, 2001 to 2016

Age	Population Growth, 2001 to 2016
Total	+17.1%
0 to 14	+2.0%
15 to 64	+14.6%
65 and older	+52.6%
85 and older	+85.3%

Source: Statistics Canada, *"Age and Sex Highlight Tables, 2016 Census," 2016 Census Data Products* (page last updated May 5, 2017). **Link:** http://bit.ly/2pgq2Re.

Like most Western countries, Canada is facing a major demographic shift. Data from the 2016 Census show a significant increase in the number and proportion of people over 65, over 85 and over 100 years of age (see Table 3, *Population Growth, by Age, 2001 to 2016*, and Figure 1, *Projections for Centenarians, Canada, 2001 to 2061*).[64] With this seemingly never-ending increase in life expectancy, living forever can seem like a possibility. A walk through any long-term care facility might shatter anyone's illusions about the wisdom of this.

FIGURE 1: Projections for Centenarians, Canada, 2001 to 2061



Sources: Statistics Canada, "Number of Centenarians by Sex, Canada, 2001 to 2061," *Centenarians in Canada*, Statistics Canada Catalogue No. 98-311-XWE2011003 (December 21, 2015). **Link:** http://bit.ly/N6mvfi.

Statistics Canada, "Census in Brief: A Portrait of the Population Aged 85 and Older in 2016 in Canada," *2016 Census Analytical Products* (May 3, 2017). **Link:** http://bit.ly/2qt2WdZ.

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.

DESIRE 2: WE WANT TO BE FULLY ABLE AND THEN 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 a small minority of Canadians experience sudden death.[65] 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 help 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 having a 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."* [66]
>
> *– Katherine Arnup, 2005*

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."[67] For these people, the period of dying is on a continuum of aging rather than the result of a single ailment or event. As Herbert Northcott and Donna Wilson from the University of Alberta note, "Most diseases, once correctly diagnosed, can be managed or stabilized through medication, surgery, or a change of living habits … It is not surprising, then, that terminal illnesses can last for many years."[68] It's a far cry from our desire to live well and die suddenly.

DESIRE 3: WE WANT TO DIE AT HOME

According to the 2016 Census, 92.3% of seniors live in private households, and nearly nine in 10 surveyed Canadians aged 55 and older (87%) say they want to live at home as long as possible.[69] The reality, however, is that despite an overall decline over the past 20 years, most Canadians die in hospital (see Figure 2, *Percentage of Deaths Occurring in Hospital*), further adding to the mystery shrouding our knowledge of death.

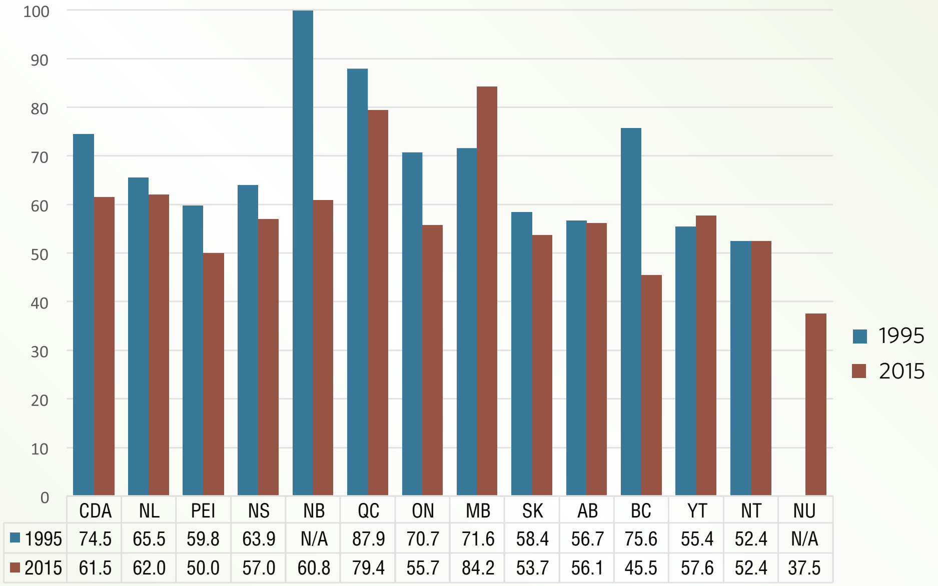
Desires and Realities of Death and Dying in Canada

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 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.

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." A 2018 study demonstrated that home visits by either a family doctor or a palliative specialist dramatically affected patients' ability to die at home. Tanuseputro et al. found that "receiving at least one physician home visit from a non-palliative care physician was associated with a 47% decrease in the odds of dying in a hospital. When a palliative care physician specialist was involved, the overall odds declined by 59%. Location of death is strongly associated with end-of-life health care in the home. Less than one-third of the population, however, received end-of-life home care or a physician visit in their last year of life, revealing large room for improvement."[70]

> *A 2018 study demonstrated that home visits by either a family doctor or a palliative specialist dramatically affected patients' ability to die at home.*

FIGURE 2: Percentage of Deaths Occurring in Hospital, Canada, Provinces and Territories, 1995 and 2015



	CDA	NL	PEI	NS	NB	QC	ON	MB	SK	AB	BC	YT	NT	NU
🟦 1995	74.5	65.5	59.8	63.9	N/A	87.9	70.7	71.6	58.4	56.7	75.6	55.4	52.4	N/A
🟥 2015	61.5	62.0	50.0	57.0	60.8	79.4	55.7	84.2	53.7	56.1	45.5	57.6	52.4	37.5

Note: Data for the Northwest Territories in 1995 *includes* Nunavut, which was not established as a separate territory until 1999 (as a result, no data is available for Nunavut in 1995). Data for the Northwest Territories in 2015 *excludes* Nunavut.

Data from New Brunswick before 1997 do not break down location of death, and have therefore been excluded for 1995 in this chart.

Rate is higher in Quebec in part because deaths in residential and long-term care centres are included in "hospital" category in that province.

Source: Statistics Canada, *Deaths in Hospital and Elsewhere, Canada, Provinces and Territories* (CANSIM Table 102-0509) (page last updated February 22, 2018). **Link:** http://bit.ly/2s67lFw.

DESIRE 4: WE WANT TO DIE PAIN-FREE

Most people fear dying in excruciating pain. Indeed, many 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, many people are able to manage their pain with medication (e.g. liquid morphine), under the supervision of care providers – thus alleviating one of people's greatest fears about dying. Many patients are able to have their pain alleviated once they receive palliative medical care.

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 the past 25 years, 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 or through a needle, pain pump or patch, these medications are generally begun at a low dose and increased very slowly 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 locations, a pain and symptom management team is available for consultation with physicians to assist them in providing the best care possible for their patient.

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 (e.g. eating, eliminating waste, bathing) is inherently demeaning.

It is likely that few people would choose to spend their final days, weeks or months bedbound, incontinent, having to depend on others (whether family members or paid staff) to perform personal care. Yet, 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, hospice staff and volunteers ensure that the patient has had adequate pain relief prior to being moved. They explain to the patient what they are doing at each step of the process, even if they appear to be asleep or in a coma. They do not talk "over" a patient about their own personal interests (e.g. movies, weekend plans) as if they weren't there. Rather, they talk to the patient, as they proceed slowly and calmly with each task.

Desires and Realities of Death and Dying in Canada

> 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.[71]
>
> 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.
>
> *– Katherine Arnup, 2005*

Impact on Families

Family members face a maze of services and jurisdictions with which they are unlikely to be familiar.

Dying and death do not only affect 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, nieces and nephews, siblings or friends. Here we are talking not just about the "burden of care," but the painful 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 the growing share of Canadians living alone (see *Growing Share of Canadians Living Alone in 2016* text box), who is their advocate? This question can begin to be addressed by looking at some of the assumptions people make about end-of-life care.

Growing Share of Canadians Living Alone in 2016

Data from the 2016 Census shows a growing share of Canadians are living alone – people who may not have immediate support around them.

- Nearly three in 10 (28.2%) households were one-person households – up from 7.4% in 1951 and the *highest share in Canadian history*.
- For the first time, one-person households were the *most common type of household*, now greater than couples with children (26.5%).
- Approximately one in seven Canadians (13.9%) lived alone, up from only 1.8% in 1951.
- Nearly one-third of senior women (33%) lived alone, up from 31% in 2006.
- Approximately one in six senior men (18%) lived alone, up from 11% in 2006.[72, 73]

ASSUMPTION 1: OUR FAMILY CAN TAKE CARE OF US

Health care and eldercare systems in North America increasingly 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 boomer population) means there are fewer adult children to share the caregiving responsibilities.

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 may still be at home or returning home after college, divorce or becoming unemployed, 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.

Impact on Families

Families Providing End-of-Life Care in 2012

- 3.7 million Canadians (13%) reported having provided end-of-life care to a family member or friend *at some point in their lives*.
- 621,000 Canadians (2%) reported having provided end-of-life care to a family member or friend *in the past year*.
- 35% of Canadians who report having provided end-of-life care did so in their own home.
- The average amount of time per week that surveyed Canadians expect for caring for a dying family member is 54.4 hours, and when asked whether they feel they could devote that much time, the majority of Canadians (65%) say that they would not be able to.

Sources: 2012 General Social Survey, Canadian Hospice Palliative Care Association

Effects of being part of the "sandwich generation" include lost time from work, increased stress levels, illness, burnout and caregiver fatigue (see *Impact of Family Caregiving in 2012* text box on page 25).[74] When adult children are unable to help, the primary caregiver is increasingly an elderly spouse who may be facing their 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 reasons people consider ending their own life.[75]

ASSUMPTION 2: ONE BIG, HAPPY FAMILY

Media representations of dying 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.[76]

In stepfamilies, 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. Hospice volunteers and staff witness all kinds of situations. Sometimes, there are scenes of open conflict between feuding family members as grief and fear unleash existing family tensions. In contrast, people from the dying person's past such as ex-spouses (particularly wives) sometimes step 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* on page 37).

> *When adult children are unable to help, the primary caregiver is increasingly an elderly spouse who may be facing their own health challenges.*

Unequal sharing of the caregiving role may be another source of tension within families. While factors such as proximity, family status and employment 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.[77]

Young Caregivers in Canada

Young carers play an important role in providing family care in Canada. In 2012, there were 1.9 million youth aged 15 to 29 (27% of the population in this age group) who reported providing care in the past year. While most experience some benefits from providing care (e.g. 85% say their relationship with the care recipient strengthened during the caregiving period), the time and energy involved can have an impact on their well-being, since many are also working and/or attending school. According to Statistics Canada, one in five young carer students say their studies have been affected, and 12% of employed young carers say they had to reduce their weekly work hours due to their caregiving duties.[78]

ASSUMPTION 3: 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.

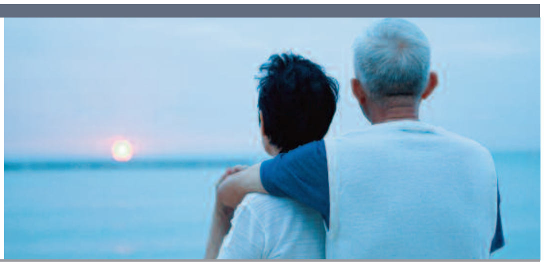
The services that are provided and the number of hours per week vary widely between provinces and territories and even between regions within provinces.

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 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 local regional health authorities and/or by private non-profit or for-profit agencies.

Unmet Home Care Needs in 2012

- 461,000 Canadians aged 15+ needed but did not receive home care.
- Two-thirds (290,000) had *asked for help* but did not receive it.
- The remaining 170,000 were people who *didn't have family members available* to help or provide care, as well as those who *did not want to request help* for whatever reason.
- One-quarter (24%) of those with unmet home care need were *seniors*.
- Baby boomers (aged 45 to 64) were the *most represented* among those who had unmet needs, accounting for 40% of those who needed help or care but did not receive it.[79]

Impact on Families



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 Globe and Mail health columnist André Picard documented a particularly shocking gap in the provision of end-of-life home care services. In 2016, Dan Duma, a former autoworker from Windsor, living in Alberta, was dying of liver cancer. He and his wife decided to move back to Windsor to be close to their two daughters. As Picard writes, "It was clear that, with untreatable liver cancer, he was going home to die." Duma correctly assumed that his Alberta medical coverage would travel with him. While that is the case for hospital and physician services, Ontario provincial legislation imposes a three-month waiting period for prescription drugs, home care and palliative care services. Duma died in July 2016 at the age of 48, before his eligibility waiting period had run out.[80]

The patchwork nature of home care, and its often limited provisions, affects not 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.

Dr. Jack Kitts, Chair of the Health Council of Canada, summarized the Council's April 2012 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."[81] Data from the 2012 General Social Survey on Caregiving and Receiving shows that while most family caregivers are effectively coping with their responsibilities, many experiences some negative impacts at home and at work (see *Impact of Family Caregiving in 2012* text box).

> *"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."*

Impact of Family Caregiving in 2012

- In 2012, there were 8.1 million family caregivers in Canada (28% of the total population aged 15 and older), including 966,000 senior carers (12% of all caregivers), 4.2 million aged 25 to 54 (53%) and 1.3 million young carers aged 15 to 24 (15%).
- Most surveyed caregivers in Canada (95%) say they are effectively coping with their caregiving responsibilities.
- Caregivers can incur direct and indirect *financial/career costs* due to lost time in paid employment, out-of-pocket expenses and/or career development.
  - 10% of employed caregivers say they've turned down or did not pursue a new job or promotion because of their caregiving responsibilities.
  - 15% of employed caregivers reported cutting down on their regular weekly hours of work to accommodate the caregiving needs of family and friends.
- Caregiving can also have an impact on individual and family *well-being*.
  - 28% of caregivers in Canada who provided care in the past year reported that they found it "somewhat or very" stressful.
  - One in five caregivers (19%) said that their "physical and emotional health suffered" in the last 12 months as a result of their caregiving responsibilities.

Source: 2012 General Social Survey

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 their 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?

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."[82]

Palliative care improves the quality of life of dying people and their families, and research has shown that palliative care can increase the quantity of a patient's life.

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. Wherever it is delivered, palliative care improves the quality of life of dying people and their families, and research has shown that palliative care can increase the quantity of a patient's life.[83]

> A recent article in *The Economist* reports:
>
> *Since 2009 several randomised controlled trials have looked at what happens when patients with advanced cancer are given palliative care alongside standard treatment, such as chemotherapy. In each, the group receiving palliative care had lower rates of depression; and in all but one study, patients in that group were less likely to report pain.*
>
> *[I]n three trials the patients receiving palliative care lived longer, even though the quantity of conventional treatment they opted to receive was lower. (The other two trials showed no difference.) In one study their median survival was a year, compared with nine months for the group receiving only ordinary treatment. A review in 2016 of cases where palliative care was used instead of standard treatment found that even when it was the only care given, it did not seem to shorten life.*
>
> *The reason for the results is unclear, and the research has mostly been on cancer patients. Those receiving palliative care spend less time in hospital, so may contract fewer infections. But some researchers think that the explanation is psychological: that through counselling they reduce depression, which is linked to earlier death. "A conversation can be more powerful than technology," says Dr. Sleeman.*[84]

Options for End-of-Life Care

Regardless of where it is delivered, evidence shows that palliative care can have a significant impact on the well-being of dying people and their families, and it is being increasingly incorporated into the health care system and some facilities for seniors. Today, many hospitals have a palliative care unit and steps have been taken to provide palliative care in long-term care facilities and nursing homes, where large numbers of Canadians spend their final days.

In 2011, the death of Jack Layton, the late NDP leader, 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.[85]

> *Today, many hospitals have a palliative care unit and steps have been taken to provide palliative care in long-term care facilities and nursing homes.*

RESIDENTIAL CARE HOSPICES

Modelled on Dame Cicely Saunders's work at St. Christopher's House in London, residential care 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.[86]

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, patients' doctors follows 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.

The focus of residential hospice programs is on the entire family, rather than on the patient alone.

The focus of residential hospice programs is on the entire family, rather than on the patient alone. 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.

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. Increasingly, a "home" may be a retirement residence, a senior's residence or a long-term care facility.

Many hospice programs offer services such as day hospice programs that provide a "day away" for people with a life-limiting disease who are living at home. 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.

Home support volunteers make weekly visits, providing companionship and performing whatever tasks the person might need. These might range from writing letters, making lunch and reading aloud, to providing transportation to appointments, shopping and other outings.

In a talk for Hub Hospice in Almonte, Ontario, a month before his death, Alan Mirabelli, Co-Executive Director of the Vanier Institute of the Family for 30 years, described the enormous benefit he derived from his relationship with his two home support volunteers:

> *Just because I've been diagnosed with terminal cancer doesn't mean that I choose to stop living! I wanted to find volunteers who, if asked, would help me live – fully – not watch me die and hold my hand while I do it. That time will come, but that is not what I want right now. As some of you know, art and photography is a lifeline for me. It is a meditation. It is everything that feeds my soul. I wanted two people who, if I said, "Could you drive me somewhere," would say, "What time?" And they both have.*
>
> *If I need to go downtown because I want to get something from the store, even though I'm weakening, they ask "What time and when?" You know, just getting that opportunity to nourish that little piece of me has done more to enliven me. These days are getting harder and harder, but both of the volunteers are interested in what I'm doing, so the conversations become real and not sort of passing time.*
>
> *When I was clear in asking for what I wanted, they were able to respond in a manner that works for them and works for me, and I tell you, it is what keeps me going every day. Every day is a surprise and they're part of it somehow. Whether it is anticipating the next visit, arranging the next visit or outlining what we might do – and it might have to change on that day because I'm not up to it – that possibility is so vital to me.*
>
> – Alan Mirabelli, *Hub Hospice and the Palliative Care Experience* (2017 speech)

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 the hospital. Being at home enables both the family and the dying person to have more control over the conditions and circumstances of their 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 stressful and frightening time.

Being at home enables both the family and the dying person to have more control over the conditions and circumstances of their care.

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, hallucinations, bleeding and seizures) can lead to a family feeling 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 who 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 to 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[87] (see *The Diane Morrison Hospice* text box on page 30). Toronto is scheduled to open a new hospice for homeless people in 2018.[88]

> *The Diane Morrison Hospice has strengthened the community and brought meaning and dignity to the end of life for a group of people who are otherwise forgotten.*

THE DIANE MORRISON HOSPICE

The Diane Morrison Hospice (formerly Ottawa Mission Hospice) provides palliative care to 21 terminally ill people who are homeless or street-involved. Founded in 2001 with a capacity of 14 beds, the hospice expanded to include 21 beds in 2015. The program serves men and women and is committed to welcoming everyone who is homeless and in need of end-of-life care.

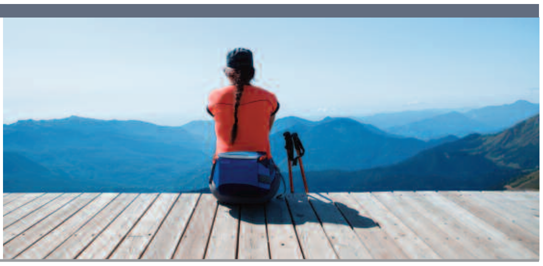
Eligibility:

- People who are homeless or street-involved and living with a rapidly progressing terminal illness
- People who need assistance in managing pain or symptoms associated with a terminal illness
- People with a terminal illness who are unable to access “mainstream” palliative care 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 provides an alternative to hospital care, thereby saving the health care system an estimated $50,000 per person.

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 as well as Indigenous communities.

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 are otherwise forgotten.[89]



MEDICAL ASSISTANCE IN DYING (MAID)

Prior to 2015, the *Criminal Code of Canada* prohibited both euthanasia and assisted suicide.[90] However, a mentally competent dying person had the right to refuse treatment, which includes the cessation of eating and drinking, a practice known as VSED (Voluntarily Stopping Eating and Drinking). Furthermore, attempting to commit suicide was decriminalized in 1972.[91]

The *Criminal Code* prohibition of assisted suicide was challenged by Sue Rodriguez, a BC mother with a young son, who was diagnosed with ALS in 1991. Wanting to spend as long as possible with her son, yet hoping to protect him from witnessing her 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 BC 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. Few who watched the news coverage of the case can forget the determination and courage of Rodriguez and the power of her questions: "If I cannot give consent to my own death, whose body is this? Who owns my life?" A few months later, on February 4, 1994, Rodriguez ended her life, with the assistance of an unnamed physician. No charges were ever laid in her death.

Despite the ongoing efforts of proponents of assisted suicide, no further judicial decisions or legislative action were taken until 2011. In that year, Gloria Taylor, another BC woman living with ALS, joined an existing case (*Carter v. Canada*) brought forward by the BC Civil Liberties Association that sought the repeal of the prohibition of assisted suicide. Taylor's lawyers argued that the prohibition violated Section 15 of the Canadian Charter of Rights and Freedoms because it discriminated 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. Her ruling explicitly exempted Taylor from that suspension. Taylor died of an infection in October 2012, before she could exercise her right to assisted dying.

The federal government appealed Justice Smith's ruling to the BC Court of Appeal, which in turn overturned the lower court's ruling. The BC Civil Liberties Association appealed that ruling and the case reached the Supreme Court of Canada in October 2014. In a unanimous decision released on February 6, 2015,[92] the Court struck down the relevant provisions of the *Criminal Code*, finding that they contravened the Charter of Rights and Freedoms. The Court gave the federal government one year to bring forth legislation governing medical assistance in dying (adding an additional four months upon the request of the government). That legislation, Bill C-14, received Royal Assent on June 17, 2016.

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 their 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.

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.

> *"If I cannot give consent to my own death, whose body is this? Who owns my life?"*
> – Sue Rodriguez

In its decision, the Court granted the right to receive MAID to all competent adults with a "grievous and irremediable condition." Bill C-14 established more restrictive grounds for eligibility, requiring that the applicant:

a) be eligible for publicly funded health services

b) be at least 18 years of age, and capable of making decisions about their health

c) have a "grievous and irremediable medical condition"

d) have made a "voluntary request for medical assistance in dying" in the absence of external pressure

e) give "informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care"

Section 241.2 (2) of Bill C-14 provides further guidance on the meaning of "grievous and irremediable medical condition." To qualify, a person must:

- have a "serious and incurable illness, disease or disability";
- be in an "advanced state of irreversible decline in capability";
- be "enduring physical or psychological suffering" as a result of the illness, disease or disability or state of decline "that is intolerable to them and that cannot be relieved under conditions that they consider acceptable"; and
- furthermore, "their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining."[93]

> *In its decision, the Court granted the right to receive MAID to all competent adults with a "grievous and irremediable condition."*

Since the passage of Bill C-14 on June 17, 2016, debate on the legislation has continued and more than 2,600 Canadians have died with medical assistance.* On the one hand, individuals and organizations – especially hospices and faith-based hospitals and long-term care facilities – have argued that they should be exempt from participating in MAID.[94] Although the Act exempts individuals on religious and ethical grounds, it is silent on the question of institutions. Further, it does not require that conscientious objectors refer patients to other physicians who might provide MAID. The College of Physicians and Surgeons of Ontario established a policy requiring that physicians must make an "effective referral" in such cases.[95] On January 31, 2018, the Ontario Superior Court rejected a challenge to the policy brought forward by a group of doctors led by the Christian Medical and Dental Society of Canada.[96] Both of these issues have been taken up by Dying With Dignity Canada[97] and other proponents of a wider interpretation of the law.

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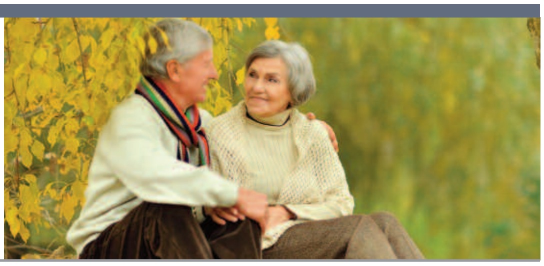
*As of May 4, 2018, Health Canada has yet to release the third update on medical assistance in dying in Canada report with data beyond June 30, 2017. While more recent data is available through some provincial health and statistics agencies (due to privacy concerns resulting from their small population, data remains unavailable for the Yukon, Northwest Territories and Nunavut), additional updates beyond June 2017 were available only for British Columbia, Alberta, Saskatchewan, New Brunswick and Nova Scotia. This estimate is derived from numbers in the *Second Interim Report on Medical Assistance in Dying in Canada* (link: https://bit.ly/2gh1PHW), which have been updated when possible with new data from reporting provinces.



The legislation on MAID is already being challenged in a number of court cases.[98] The main issues concern the eligibility of mature minors and people suffering from a mental illness, the meaning of the term "reasonably foreseeable death" and the use of advance directives.[99]

Many proponents of palliative care argue that MAID effectively puts the cart before the horse. People have a right to live with dignity first and foremost (and the Charter guarantees that). Yet, they do not have a right to quality end-of-life care including but not limited to palliative care, access to home care and medical professional services, and medications. In the absence of this type of end-of-life care, some argue that MAID may become the only option.

In an op-ed piece in *The Globe and Mail*, Tom Koch argues, "That means having palliative physicians and nurses who can attend to pain, psychological support for those struggling with limiting conditions, rehabilitative specialists who can assure maximum engagement and social services that guarantee a person's care is not an impossible burden on their family. Until and unless those things are in place the choice to die prematurely isn't balanced and fair, it's just a choice made when other, better alternatives are not available. And for many, they are not."[100]

MEDICAL ASSISTANCE IN DYING (MAID) IN QUEBEC

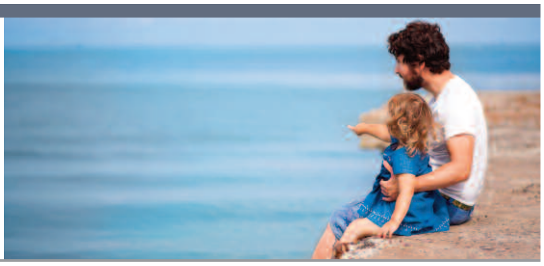
Legislators in Quebec began work on assisted dying well in advance of the federal government. By the time the National Assembly of Quebec had passed Bill 52, an *Act respecting end-of-life care*, on June 5, 2014 and the Act came into force 18 months later, on December 10, 2015, the province had already conducted a significant amount of study, consultation and deliberation under the jurisdiction of the Select Committee on Dying with Dignity, which was formed in late 2009.[101]

To be eligible for medical assistance in dying, Bill 52 requires that the patient be "in an advanced state of weakening capacities, with no chance of improvement" and suffering unbearably. While Quebec requires that the patient be "at the end of life," the federal legislation requires that "death has become reasonably foreseeable," without the need for a specific prognosis regarding the length of time that the person has left to live.

Legislators in Quebec began work on assisted dying well in advance of the federal government.

On the other hand, the Quebec legislation does not expressly require that suffering be caused by the person's medical condition, whereas the federal law does. Finally, in Quebec, only physicians can administer the medication and they must remain with the patient until death occurs. In the rest of Canada, MAID is extended to include nurse practitioners as well as patients themselves.

Perhaps the most significant difference between the two pieces of legislation is that the federal legislation is specific to *medical assistance in dying*, whereas in Quebec, *medical assistance* is part of the *much broader continuum of care*. Indeed, the Act can be read as a primer on the needs and rights of people at the end of their lives. It includes specific recommendations regarding the training of physicians in end-of-life care, the availability of home care and the requirements of people at the end of their lives. One small but significant requirement is that "an institution must offer every patient receiving end-of-life care a private room for the final few days preceding the patient's death."[102] Those who have witnessed a death in hospital will appreciate the significance of that requirement for dying people and their families.



Significance of MAID and Its Impact on Families

In Canada, a qualified person can receive assistance in dying from a nurse practitioner trained in palliative care or from a physician. While an individual may administer the medication themselves[103] (with or without a physician present, depending on the province), the more common procedure is to receive the medications intravenously from a physician or nurse. The procedure can be performed at the individual's home (however that is defined), in a hospital or in a physician's office or medical facility.[104]

Regardless of where the person receives MAID, they are entitled to receive palliative care throughout their illness and up to the time of their death. This may include pain and symptom management, and home visits from a physician, palliative nurse, personal support worker and/or hospice volunteers. Many hospices (and some hospitals) have chosen not to allow MAID on their premises: a patient who wishes to receive medical assistance in dying must be transferred to a hospital or other facility, but they can remain in the hospice or hospital receiving care until that point.

> *Regardless of where the person receives MAID, they are entitled to receive palliative care throughout their illness and up to the time of their death.*

Despite the enormous media attention that MAID has garnered, it is important to recognize that it will likely be the choice of a small minority of dying people, while palliative care could benefit up to 85% of people at the end of their lives.[105] Nonetheless, the mere fact of the availability of medical assistance in dying changes the broader conversation about death and dying, because in Canada people now have greater agency when it comes to death (in certain contexts).

Questions Remain and the Conversation Continues

Will the availability of MAID influence people's willingness to seek an end to their lives to relieve the burden they fear they are placing on family and friends?

Will vulnerable people, including people with disabilities and debilitating chronic illnesses, seek MAID because they are not getting the social services and supports they need?[106]

Will it reduce people's fear of death, or merely contribute to their denial and avoidance?

Finally, what is the impact of medical assistance in death on family members and friends?

The simple answer to all of these questions is that we don't know – the legislation is new, the number of cases is relatively small and research is necessarily limited. Thus we have only anecdotal evidence and oral testimony to guide us. Furthermore, the impact will be based on many factors, most importantly perhaps on the conversations that have taken place among family members prior to the death, the degree of suffering of the dying person, their personal perspectives and their views of MAID.

For many Canadians, medical assistance in dying violates deeply held religious beliefs or philosophical views; the prospect of MAID can be deeply upsetting, especially if they fear that their family member might be judged for the act and have a different afterlife as a result. Family conflict could be increased if family members and other loved ones disagree among themselves about the person's decision to pursue MAID.

Some family members may feel guilty, thinking that they haven't done enough and that the dying person might have lived longer if they had only offered more help or support. They may feel that the person died prematurely (in order to be able to give the consent required to be eligible for MAID) and thus they face greater grief and sadness.

Alternatively, MAID can have a *positive* impact on family members. Some people have expressed relief that the suffering of their loved one has come to an end. They may be relieved that the dying person was able to be in control of the circumstances of their death (especially since disease can rob them of virtually all their control).[107]

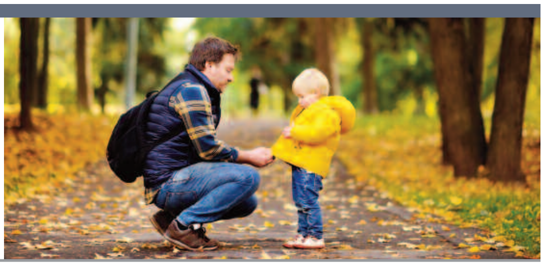
In the end, the decision to pursue MAID is the patient's choice alone. Under ideal circumstances, family members will spend time talking with the person regarding their decision, perhaps with the assistance of a social worker, physician or other health care person.

Further research into MAID with an in-depth examination of the reasons people seek MAID is essential for us to fully understand the impact of medical assistance in dying on those seeking it and on their families.[108,109]

Again, it is important to recognize that MAID is likely to be the choice of a small percentage of dying people. For example, from June 17, 2016 to December 31, 2017, medically assisted deaths accounted for only 78 out of approximately 14,000 deaths that occurred in Saskatchewan (0.6% of all deaths). During the same period in Nova Scotia, 74 of approximately 13,500 people received medical assistance in dying (0.5% of all deaths).[110] Figures for all provinces and territories were not available at the time of publication.[111]

> *For many Canadians, medical assistance in dying violates deeply held religious beliefs or philosophical views.*

Demystifying Death



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 in the lives 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?

Stories from family members who have had positive end-of-life experiences can challenge some of the misconceptions Canadians have about dying.

In recent years, the concept of death with dignity has been largely appropriated by advocates of medical assistance in dying. 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 herein, we live in a culture that largely denies the reality of death. As the Economist Intelligence Unit's 2010 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."[112] Thus, while Canada scored 9th out of 40 countries in the overall ranking on quality of death in the 2010 report, the nation scored poorly (3 out of 5) when the public awareness of end-of-life care was measured.[113] In the 2015 Quality of Death Index, Canada had dropped to an overall ranking of 11th (from 9th), a change that ought to ignite concern.[114]

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 positive end-of-life experiences can challenge some of the misconceptions Canadians have about dying.

Start the Conversation

In Canada, even though there is general public support for advance care planning, only a small minority engage in it. According to a 2013 survey conducted by Harris/Decima on behalf of the Canadian Hospice and Palliative Care Association,

- 74% of Canadians report having thought about end-of-life care
- 34% of Canadians have actually had a conversation with a family member
- 13% of Canadians have completed an advance care plan to communicate their wishes[115]

The results of this survey demonstrate the huge gap between people's belief in the importance of talking about end-of-life wishes and their actions. To close that gap will require concerted efforts on the part of non-profit organizations and governments at all levels to encourage people to "start the conversation on end-of-life care" for themselves, their aging parents and their families. Initiatives such as the SPEAK UP! Campaign and Advance Care Planning Day (April 16) provide free resources, including videos and advance care booklets.

More important than the legal documents are the conversations that accompany them, when family members begin to talk about how they might want to be cared for at the end of their lives. While few 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).

> *Discussions about end-of-life wishes can provide an additional benefit for families, bringing them closer together as they plan for what lies ahead.*

Equally important are the conversations between physicians and their patients. And while three-quarters of the Canadians surveyed indicated that they would turn to their physician for information about hospice palliative care services, few have actually raised these issues with their doctor.[116]

The importance of these conversations is underscored by the circumstances that are repeated day after day in ERs and ICUs. An elderly parent experiences a severe health event (stroke, heart attack, bowel obstruction or breathing difficulties) that threatens to end their life. Family members are called and those close by gather at 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. 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.[117]

Start the Conversation

Discussions about end-of-life wishes can provide an additional benefit for families, bringing them closer together as they plan for what lies ahead. 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.[118]

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.[119] It might well be useful for family physicians, who 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) were reflected on their medical record only 30.2% of the time. Daren K. Heyland, MD, MSc, FRCPC, and colleagues at the Kingston General Hospital in Ontario examined elderly patients' advance care planning activities before hospitalization and preferences for care from the perspectives of patients and family members.[120]

The results of a 2017 by the Canadian Institute for Health Information (CIHI) (see *Seniors and End-of-Life Care Planning* text box) suggest that more seniors may be talking about and documenting their end-of-life wishes.

Seniors and End-of-Life Care Planning

A 2017 survey of Canadian seniors by CIHI suggested that many are having conversations with family and medical professionals about end-of-life care:

- 66% say they've discussed their end-of-life care wishes with someone, while 44% have a written plan or document describing their end-of-life care wishes.
- 63% say they've documented a substitute decision-maker.
- 12% say they or a family member have talked to a health care provider about access to MAID.[121]

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.

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.[122]

DEATH CAFÉS

One of the most popular manifestations of an emerging desire to talk about death are *death cafés*. A death café is a gathering of people (generally strangers) who come together over tea and cake to talk about death. The idea originated with Swiss anthropologist Bernard Crettaz, who organized the first *café mortel* in 2004. The concept was picked up by Londoner Jon Underwood, who organized the first death café at his home in East Hackney in 2011. Since then, an astounding 6,012 (and counting!) death cafés in 55 countries have been held, all of them loosely based around the idea of talking about all aspects of death and dying while sharing a cup of tea and cake.[123] Tragically, Underwood died at the age of 44 in June 2017 of a brain hemorrhage caused by undiagnosed leukemia.[124] But the movement he started continues to grow exponentially around the world.

Start the Conversation

Though gatherings have appeared under many different names, and people meet in diverse settings,[125] those that go by the name "Death Café" are organized by people who have affiliated with the organization that Underwood founded. There are few rules that govern the meetings, beyond that there can be no promotion of any services or merchandise and there is to be no orthodoxy. The organizers provide a list of conversation starters for each table; often, little prompting is required besides the initial question: "What brought you here tonight?"

Why would so many people choose to give up an afternoon or evening to talk about death? While the reasons people attend are as individual as the people themselves, it appears that everyone is drawn to the café as a safe place to talk about death – something that, despite its inevitability, is all too often a taboo subject in much of the Western world.

Death cafés were founded on the belief that if we talk about death, we can take away some of the fear and mystery that surrounds it.

One of the surprising things about the death cafés is the wide variation in the ages of the participants. While one would expect to see many people in their 60s or 70s, there are a surprising number of people in their 20s and 30s at death cafés around the world.

Generally people at a death café are seated at a table of four or five for the duration of the event, and thus don't have the chance to get to know everyone in attendance. Most people have experienced death first-hand (a grandmother, mother, sibling, close friend) or have had a serious illness themselves, and longed for a place to talk about the experience.

> At my first death café, I sat with a young mother of three who had lost both her parents at a very young age; an 84-year-old woman who, though quite fit and hardy, was exploring the options for medical assistance in dying (for when the time comes); and a man in his 40s who seemed more driven by curiosity than direct experience. And, of course, I had lost both my parents and my sister, and was very involved in hospice work.
>
> We talked about our fears of death (whether we had them, how we had gotten over them, *how we dealt with others'* fears), our hopes for the end of our lives and how we felt about how society deals with death.
>
> Sometimes we could barely hear each other, as the conversations at the other tables broke into gales of raucous laughter or heated discussions. I could hardly believe it when the organizer announced that it was 8 p.m. and time for us to go. We had been talking about death non-stop for an hour and a half. And I suspect we could have gone on much longer!
>
> What I love about death cafés is how refreshing it is to be able to talk about death - without having to whisper or worry about someone telling us we are being morbid. -
>
> – *Katherine Arnup, 2017*

Death cafés were founded on the belief that if we talk about death, we can take away some of the fear and mystery that surrounds it. In so doing, we can become more aware of the finite nature of our lives, something that might help us to appreciate and value what we have in the here and now, in our daily lives.

Reclaiming Death

Over the past 15 years, a movement has grown to reclaim and embrace death and the end of life. From Buddhists to birth midwives, funeral practitioners to "new age" spiritualists, people across Canada and around the world are working to change how we think about death and the very way we die.

Over the past 15 years, a movement has grown to reclaim and embrace death and the end of life.

Although people of all ages are involved, at the core of much of the pressure are baby boomers (members of the generation born between 1946 and 1965). During this period of significant population growth, there were approximately 412,000 births per year, compared with an estimated 390,000 in 2016–2017, when Canada's population was more than twice as large.[126, 127]

Because of their sheer numbers, their relative prosperity and the optimism of the period in which they were born, baby boomers have fuelled tremendous change in Western (and especially North American) society: from teenage rebellion in the late 1960s to challenging the norms of hospitalized, medicalized childbirth, to changing attitudes toward and expectations of aging (*Zoomer*, "60 is the new 40") and, now, the way we die.

As documented in this report, over the course of the last 100 years, families became more and more removed from caring for their family members during and after death. The movement to reclaim death – through home deaths, celebrations of life, green burials, among others – seeks to return death care to the family and the community, and to find meaning in death itself.

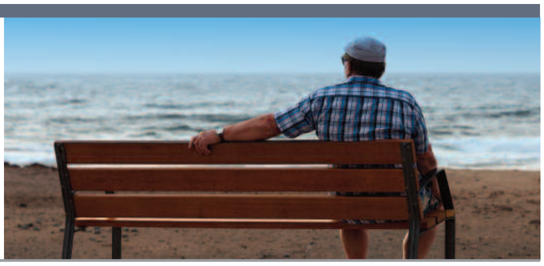
DEATH DOULAS

As the data show, home deaths have become increasingly common, with as many as 75% of Canadians expressing a desire to die at home,[128] where they can be in a familiar setting, surrounded by the people they love. Home deaths are reminiscent of the way death occurred in earlier times – at home with the assistance of family, friends or the local midwife.

Much like birth midwives, *death doulas* (also called *death midwives* or *soul midwives* in some locations)[129] support the dying person and their family throughout the dying process and often beyond. Many doulas were birth attendants who found themselves naturally drawn to end-of-life care, sometimes as the result of a death in their own lives. Like birth doulas, death doulas are available before, during and after the death occurs. Their services are delivered along a continuum of care, and may include facilitating advance care planning and discussions about end-of-life care, coordinating care, sitting with the family at the vigil and tending to, bathing and dressing the body after death, to offering home funeral services, celebrations of life, burial rituals and grief support for the family throughout the process. Some doulas have been trained as nurses and can provide medical assistance.[130]

Though death doulas were initially informally trained (often by other practitioners), certification programs have recently developed. To date, however, no formal, government-approved certification program exists in Canada.[131] Many death doulas prefer to retain a more informal, community-based approach.

Reclaiming Death



Rayne Johnson, an Edmonton, Alberta woman, felt a calling to provide end-of-life care in the 1990s. She explains that the purpose of a death doula is "to empower and teach families to do the work themselves." Rayne believes that being connected with the dying person and the body can help family members with their grieving process after the death.[132]

Sarah Kerr, a Calgary practitioner and teacher, explains, "As the baby boomers get older, we are yearning for creative ways to reclaim death. We are also watching our parents die, and we want to regain control of the process. And that's where I come in." As with most death educators and doulas, Kerr sees her job "as supporting people, physically and spiritually, throughout the process of dying" and hopes to help "get people back in touch with death in a way that our society has lost."[133]

Death doulas represent one segment of a much broader movement that is working to change the way we die, a movement that includes hospice volunteers and staff, palliative care nurses and physicians, community death care activists and, sometimes, more traditional funeral homes.

Death doulas represent one segment of a much broader movement that is working to change the way we die.

Cassandra Yonder, founder of the BEyond Yonder Virtual School for Community Deathcaring in Canada, explains, "[Community deathcaring] is a social movement about reclaiming community-centred care for the dying, dead and bereaved. I compare it to the slow food movement, which is about reclaiming the production of our own food. The movement can be served in many ways: some practitioners are actively assisting/educating/empowering their own families as well as the public to care for their own dying, dead and bereaved without professional assistance if they so choose."[134]

Other community and national organizations, including the Canadian Integrative Network for Death Education and Alternatives,[135] Community Deathcare Canada[136] and Deathcaring,[137] a Facebook group with more than 4,000 members, are powerful examples of the movement to change our approach to dying.

In these times, people who have experience with death can be of tremendous value. A palliative physician, a hospice nurse or volunteer, end-of-life coach or doula can help the dying person and their family to navigate the unfamiliar waters of their final passage.

CELEBRATIONS AND RITUALS

With the increasing secularization of society and a decline in the share of Canadians identifying with and practising a religion (24% of Canadians reported "no religious affiliation" in 2011, up from 17% a decade earlier[138, 139]), a growing number of end-of-life events have shifted from funerals held in churches and other religious settings to celebrations of life held in community centres, secular sacred spaces, restaurants and even hockey rinks.[140] As well, families, often with the help of death doulas and other celebrants, are choosing to hold a home funeral, with friends and family in attendance in the company of the body. On occasion, people have turned the traditional funeral service on its head, holding a living wake or live funeral with the dying person as the guest of honour! Such events enable a community to celebrate the person's life with them before they die.[141]

Lest we think that celebrations of life are necessarily cheaper than traditional funerals, a recent interview with an event planner, whose business has expanded to include celebrations of life, notes that such events can cost upwards of $10,000–$20,000, approaching the cost of a wedding![142]

> Members of the deathcare movement have helped people to make their own coffins – generally a simple pine box reminiscent of an earlier era, and sometimes decorated by family and friends. People who choose cremation have fashioned their own urns out of pottery or wood. One man, whose wife was dying at a residential hospice, decided he would fashion a box to hold his wife's ashes and, when the time came, his own. His wife insisted that he create a barrier between the two sections so their ashes wouldn't get mixed up. He promised her that he would. However, he confessed to me later that he intended to leave a small opening in the barrier "so that I can visit her."

While environmental concerns have led to a growing interest in "green burials" (laying the body directly in the ground, wrapped in a shroud or placed in a simple pine box), cremation continues nonetheless to stand as the favoured choice of most Canadian families.[143]

It remains to be seen what impact the deathcare movement will have on traditional funeral homes. Trends such as video recording or live streaming of funeral services, so that family members and friends can "attend" the service from anywhere in the world, suggest that funeral homes are aware of the need to modernize their practices to continue to attract patrons.[144]

Why Celebrations?

While people might view "celebrations of life" as a symptom of the crassness of modern culture, they represent a genuine search for meaning in life and death. People want something that's meaningful to them, that they feel they have some control over, that they can fashion in a way that's true to who the person was and that can help people deal with the loss of someone they love. After a more traditional service, led by a person who might not have even known the deceased, one can feel empty – not comforted by the bromides delivered from the altar that may hold no meaning for the family and may bear no resemblance to the person who died.

"… grief is not a disease. Instead, it's the normal, healthy process of embracing the mystery of the death of someone loved."

A celebration of life after a death can serve to support the family and friends left behind – a chance to gather with friends and members of their community, to feel that they are not alone in their grief.

In a speech in Ottawa a few years ago, grief expert and Founder and Director of the Center for Loss and Life Transition, Dr. Alan Wolfelt expressed his concerns about the growing trend of not holding funerals at all. Wolfelt believes that funerals and memorials are an important part of the healing process and provide a chance for the community to offer support for the grieving family:

> Instead of encouraging mourners to express themselves, our culture's unstated rules would have them avoid their hurt and "be strong." But grief is not a disease. Instead, it's the normal, healthy process of embracing the mystery of the death of someone loved. If mourners see themselves as active participants in their healing, they will experience a renewed sense of meaning and purpose in life.[145]

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 their 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 a notice such as "At Mom's wishes, 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.

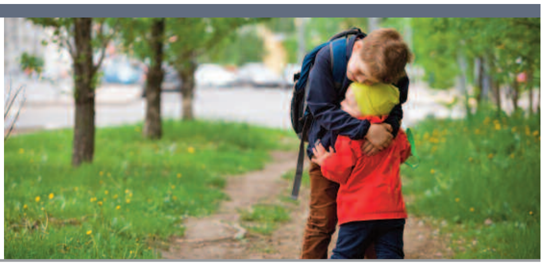
While religion traditionally provided a focal point and a means through which people could support one another (e.g. pastoral care teams, priest or minister visiting the sick and dying, praying for members of the congregation who were ill, church ladies making the lunch after a funeral), declining religiosity 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.

> *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 their life.*

ENHANCED PALLIATIVE CARE

Despite the efforts of the hospice palliative care pioneers discussed earlier, 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. The release of the Economist Intelligence Unit's 2015 Quality of Death Index highlighted the continued shortage of palliative care services, when Canada scored 18th out of 80 nations on the provision of palliative care. Critics were quick to decry the result: ER doctor and CBC commentator Brian Goldman expressed his anger at Canada's "D" on the health care report card.[146] Respirologist Dr. Graeme Rocker chastised the government, "We ought to be doing better and can be doing better."[147]

A report based on data from Ontario, and collected and analyzed by CIHI, 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."[148] 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.



According to the Office of the Auditor General of Ontario's 2014 Annual Report (newer figures were not provided in more recent Annual Reports), the cost of providing palliative care in the last month of a patient's life averages approximately:

- $1,100 per day in an acute-care hospital bed
- $630 to $770 per day in a bed in a palliative-care unit
- $460 per day in a hospice bed (excluding drug costs)
- Less than $100 per day where at-home care is provided
- The daily cost of an ICU stay is as high as three times that of stays in general hospital wards across Canada in 2013–2014 ($3,592 versus $1,135).[149]

Estimates show that the average stay in a residential hospice in Ontario lasts 18 days and costs a total of $8,280,[150] and that implementing palliative-care teams to provide in-home care could result in cost savings of at least $191 million a year.[151]

EXPANDED HOME CARE

One of the earliest and strongest cases for universally accessible home care services was made by Roy J. Romanow in his landmark report *Building Values: The Future of Health Care in Canada*.[152] Anticipating the tremendous impact of the aging population on health services, Romanow recommended in 2002 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.[153]

> *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.*

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.

Policy Measures to Support Dying People and Their Families

On January 4, 2004, the federal government implemented the Compassionate Care Benefit (CCB). According to Service Canada,"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."

"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."[154]

On January 3, 2016, the period of eligibility was extended to 26 weeks and the period during which benefits can be taken was expanded to 52 weeks (up from 26 weeks). In addition, the program was amended to enable benefits to be shared between family members and to reduce the waiting period from two weeks to one. If the benefits are shared among family members, only the first claimant is subject to the one-week waiting period.[155] These changes address a number of key issues that critics raised with the original program.

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 $547 per week for 26 weeks, many people would earn considerably less. As with EI, applicants must experience a one-week waiting period before benefits begin. For low-income people, the loss of income for even one week 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 study on the initial version of the CCB, researchers conducted interviews with various constituencies with a focus on family caregivers.[156] 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. It is hoped that the extended period of benefits and the ability to share the benefits among family members will alleviate many of these concerns.

> *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.*

Caregivers can also apply for and receive the Family Caregiver Benefit for Adults. This benefit "allows eligible caregivers to receive up to 15 weeks of financial assistance to provide care or support to a critically ill or injured adult. Caregivers must be family members or someone who is considered to be like family by the person needing care or support."[157] This benefit can be received over and above the CCB.

In addition to the above benefits, family caregivers can also access income tax deductions available through the Canada Caregiver Credit, claiming a deduction on income tax for providing care for an ill or dying family member.[158]

Policy Measures to Support Dying People and Their Families

LEGISLATIVE AND COMMUNITY INITIATIVES

Some provinces have already begun to implement policies and legislation to support family care providers.

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.[159] The province also passed the *Caregiver Recognition Act*. Nova Scotia implemented the Caregiver Benefit Program, which provides caregivers of low-income individuals with a severe impairment or disability with a monthly allowance of $400. While the benefit does not cover the actual cost of caregiving and lost wages, it does recognize the labour and the financial burden of caregiving.[160] In 2015, Ontario announced its three-year Patients First funding commitment of $750 million to strengthen home and community support.[161]

In December 2017, Bill C-277, *An Act providing for the development of a framework on palliative care in Canada*, received Royal Assent.[162] While the Act represents a significant symbolic statement on the importance of palliative care, it contains no financial or legal *commitments* to the provision of end-of-life services, and only tasks the government with providing a *framework* on palliative care within six years. Moving beyond such a framework to the actual development, coordination and provision of palliative care could (and likely would) take years beyond that.[163]

Conclusion

"The way we care for people at end of life reflects our values and compassion as a society."

– DAME CICELY SAUNDERS

There is a smartphone app available called WeCroak.[164] For 99 cents (US), the app will remind you at five randomized times per day that you are going to die. That's all it does. The designer's premise is that contemplating death five times a day will help you to more fully appreciate your life.[165]

For some people, WeCroak is a sign that death is trending. For others, it is yet another indication of how removed we are from the ultimate reality of life: we are all going to die. Many people – Indigenous women whose daughters are missing and murdered, Black mothers in the U.S. whose sons are shot to death in the streets as they walk to the corner store, people with disabilities who have to fight for the basic health and social services essential to their very existence, refugees who have experienced untold dangers and witnessed horrific acts of violence – experience death in "real life" on a daily basis. They don't need an app to remind them of the fragility of their lives.

While death may be a medical fact of life, death is also a human issue, a social issue, an issue that impacts each and every one of us.

Those who suggest that "death is trending" point to the outpouring of grief on social media that follows the death of another celebrity. Surely death has "come out of the closet," as some observers have suggested.[166]

Death and dying in Canada, and our thoughts, beliefs, expectations and aspirations regarding the end of our lives, have evolved significantly over the past 120 years. While certain changes, such as the legalization of medical assistance in dying, might suggest that Canada has moved beyond its death denying/defying ways, others argue that MAID may be but one more means to avoid being present for our *own* deaths. Today, many needs of families facing illness and the death of a loved one remain unmet. Home care and palliative care services are unavailable or woefully inadequate for the vast majority of Canadian families. Bereavement leave and supports are rare and insufficient in a culture that urges us to get back to work following the death of a loved one within a day or two.

While death may be a medical fact of life, death is also a human issue, a social issue, an issue that impacts each and every one of us. When we can embrace our deaths – with or without the aid of an app – perhaps we can begin to create a culture that truly values living and dying.

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 health care 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 their 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.

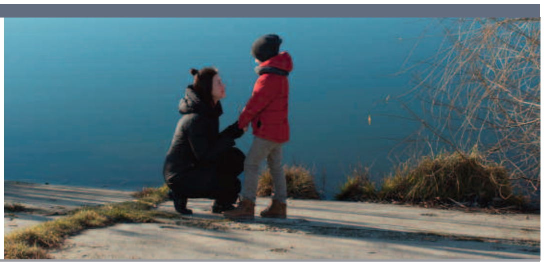
Medical assistance in dying (MAID)

In June 2016, Canadian legislation (Bill C-14) established criteria and procedures for the provision of medical assistance in dying under certain specified conditions. Similar legislation was enacted in the province of Quebec in December 2015. Canada joined Switzerland, the Netherlands, Belgium, Luxembourg and Colombia in allowing medical assistance in dying. In addition, Oregon, California, Colorado, Montana, Vermont, Washington and the District of Columbia allow some forms of medical assistance in dying.

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.

Voluntarily stopping eating and drinking (VSED)

The conscious and deliberate choice made by a person with capacity to voluntarily refrain from eating and drinking all food and fluids with the intention of hastening death. There are many reasons for a person to choose VSED, including unbearable suffering, having a debilitating disease, terminal illness or neurological disorder. On average, a person who chooses VSED will die within seven to 10 days of dehydration, but the length of time until death varies according to many factors. A person seeking death via VSED is advised to seek support and care from palliative specialists, who can help to relieve pain and other symptoms associated with dehydration.

About the author

Dr. Katherine Arnup is a writer, speaker and life coach specializing in transitions, and a retired Carleton University professor. Author of the award-winning book *Education for Motherhood*, a history of advice for mothers, she has pioneered studies on the diversity and complexity of family life. In her latest book, *"I Don't Have Time for This!" A Compassionate Guide to Caring for Your Parents and Yourself*, she tackles the last taboo – death itself. Katherine is also the author of the 2013 edition of this report, *Contemporary Family Trends: Death, Dying and Canadian Families* (now archived but available upon request).

Endnotes

[1] Note: Disease categories are not identical over time.

[2] See Katherine Arnup, *Education for Motherhood: Advice for Mothers in Twentieth-Century Canada* (Toronto: University of Toronto Press, 1994), pp. 15–16. -

[3] Ibid. -

[4] Jill Strachan and Surinder Wadhera, "Selected Mortality Statistics, Canada, 1921–1990," *Health Reports*, - Statistics Canada catalogue no. 82-003-X (November 9, 1993). **Link:** http://bit.ly/2oRnqLu. -

[5] World Health Organization, *Trends in Maternal Mortality: 1990 to 2015: Estimates by WHO, UNICEF, UNFPA, The World Bank and the United Nations Population Division* (November 2015). **Link:** http://bit.ly/2oYxNvA. -

[6] Jill Strachan and Surinder Wadhera, "Selected Mortality Statistics, Canada, 1921–1990." -

[7] Statistics Canada, *Deaths and Mortality Rates, by Age Group and Sex, Canada, Provinces and Territories* (CANSIM Table 102-0504) (page last updated February 23, 2018). **Link:** http://bit.ly/2oxlOTO. -

[8] In the First World War, 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. -

[9] Philippe Aries, *The Hour of Our Death* (New York: Vintage Books, 1981, 2008), pp. 559–60. -

[10] Aries, p. 559. -

[11] The first funeral home in Canada opened in 1826 in what is now Niagara Falls. Primarily the funeral - director's home and woodworking studio where he made coffins, the business grew to include a carriage and horses to carry the coffin. "In the 1800s, funeral services and practices were far different from those known and accepted today. Marsena [Morse]'s era was characterized by embalming at bedside, funeral services in the parlour of the family home and the horse-drawn hearse." **Link:** https://bit.ly/2ILe3oP.

[12] Name changed for this publication. -

[13] Learn more with *A Snapshot of Population Aging and Intergenerational Relationships in Canada*. -

[14] Total number of expected years of life is the sum of the age reached and life expectancy for that age. -

[15] 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. -

[16] Statistics Canada, *Deaths in Hospital and Elsewhere, Canada, Provinces and Territories* (CANSIM Table - 102-0509) (page last updated February 23, 2018). **Link:** http://bit.ly/2s67lFw. -

[17] Ibid.

[18] Smith and Nickel, "Nursing the Dying" (2003), p. 330, citing Jeanne C. Quint, *The Nurse and the Dying Patient* (New York: Macmillan, 1967). -

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[20] Ibid., p. 333. -

[21] Ibid., p. 334. -

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[22] Name changed for this publication. -

[23] Aries, p. 570. -

[24] Ibid. -

[25] Ibid., p. 560. -

[26] Andrea Sankar, *Dying at Home: A Family Guide for Caregiving* (Baltimore: Johns Hopkins University Press, - 1991), p. 134, cited in Smith and Nickel, "Nursing the Dying" (2003). -

[27] See Katherine Arnup, *Education for Motherhood: Advice for Mothers in Twentieth-Century Canada* (Toronto: University of Toronto Press, 1994). -

[28] "After his success with the first cohort study, Hammond and the American Cancer Society in 1959 started - a larger and more robust long-term follow-up study, called Cancer Prevention Study I (CPS-I). This time, - 68,000 volunteers, across 25 states, recruited more than 1 million men and women" (from the American - Cancer Society website). -
"The data Hammond collected through this study provided further conclusive evidence about the harmful - effects of smoking and were a major contributor to the landmark 1964 Surgeon General's Report on Smoking - and Health. That report led to sweeping tobacco policy changes in the United States and played a significant - role in curbing smoking throughout the nation" (from the American Cancer Society website). -
Link: https://bit.ly/2DMOobC. -

[29] Statistics Canada, "Changes in Causes of Death, 1950 to 2012," *Canadian Megatrends*, Statistics Canada - catalogue no. 11-630-X (page last updated March 3, 2017). **Link:** http://bit.ly/22A5vEZ. -

[30] Ibid. -

[31] Seat-belt legislation was first implemented in Ontario and Quebec in 1976; Alberta finally passed - legislation in 1987. Seat belts are now required in all provinces. -

[32] ParticipACTION, *About* (n.d.). **Link:** https://bit.ly/2ILVvVs.

[33] While bisexual and transgender people were also involved in this movement, it was commonly known as - the "lesbian and gay movement" during this time. -

[34] Changing the Face of Medicine, *Dr. Elisabeth Kübler-Ross* (biography) (page last updated June 3, 2015). - **Link:** http://1.usa.gov/16CCatY. -

[35] The root word for "hospice" is *hospes*, meaning "host," the same root as hospitality and hospital. -

[36] 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. -

[37] 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. -

[38] Saint Boniface Hospital in Winnipeg also opened a unit for terminally ill patients in 1975. -

[39] 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. -

[40] Andrew Duffy, "A Moral Force: The Story of Dr. Balfour Mount," *The Ottawa Citizen* (April 25, 2005). - **Link:** https://bit.ly/2ILeS0T. -

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[41] For an inspirational article on Dame Cicely Saunders' influence on Balfour Mount's work, see https://bit.ly/2lPLvlc.

[42] 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," *Canadian Journal of Infectious Disease*, *11*(2) (March-April 2000). **Link:** https://bit.ly/2EUyPns.

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[44] John S. Milloy, *A National Crime: The Canadian Government and the Residential School System, 1879 to 1986* (Winnipeg: University of Manitoba Press, 1999), p. 91; Fournier and Crey, *Stolen from Our Embrace* (Vancouver: Douglas & McIntyre, 1997), p. 49.

[45] Daniel Schwartz, "Truth and Reconciliation Commission: By the Numbers," *CBC News* (page last updated June 3, 2015). **Link:** https://bit.ly/2wnTzi7.

[46] See Maureen Lux, *Separate Beds: A History of Indian Hospitals in Canada, 1920s–1980s* (Toronto: University of Toronto Press, 2016).

[47] Canadian Public Health Association, *TB and Aboriginal People* (n.d.). **Link:** https://bit.ly/2pCMaX4.

[48] Canadian Institute for Health Information, *Improving the Health of Canadians* (February 5, 2003; revised September 2004). **Link:** https://bit.ly/2ExYkaX.

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[50] Public Health Agency of Canada, *The Time Is Now – Chief Public Health Officer Spotlight on Eliminating Tuberculosis in Canada* (March 22, 2018). **Link:** https://bit.ly/2DPGCh0.

[51] Mohan B. Kumar and Amy Nahwegahbow, "PastYear Suicidal Thoughts Among Off-Reserve First Nations, Métis and Inuit Adults Aged 18 to 25: Prevalence and Associated Characteristics," *Aboriginal Peoples Survey*, 2012, Statistics Canada catalogue no. 89653X2016011 (October 13, 2016). **Link:** http://bit.ly/2x3nR8l.

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[56] Native Women's Association of Canada, "Understanding MMIWG," *National Inquiry into MMIWG* (n.d.). **Link:** https://bit.ly/2E06uXA.

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[64] Learn more with *A Snapshot of Population Aging and Intergenerational Relationships in Canada*.

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[84] *The Economist*, A Better Way to Care for the Dying (April 29, 2017). **Link:** https://econ.st/2uiGgvS.

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[87] For an excellent review of the challenges of providing services for homeless and street-involved people, see "Palliative Care as a Public Health Issue: Understanding Disparities in Access to Palliative Care for the Homeless Population Living in Toronto, Based on a Policy Analysis," *Current Oncology, 24*(3) (June 2017). **Link:** https://bit.ly/2pAb0XR.

[88] Rachel Levy-McLaughlin, "Ontario to Open End-of-Life Care Facility for Toronto's Vulnerable and Homeless," *The Globe and Mail* (December 18, 2017). **Link:** https://tgam.ca/2Ed9WhS.

[89] Adapted from http://ottawamission.com/hospice/.

[90] According the *Criminal Code of Canada*, Section 14, euthanasia is illegal: "No person is entitled to consent to have death inflicted on them, and such consent does not affect the criminal responsibility of any person who inflicts death on the person who gave consent." **Link:** https://bit.ly/2uefYPj.

[91] Attempting suicide was decriminalized in 1972. Assisting a person in their suicide was prohibited by Section 14 of the *Criminal Code* until 2015.

[92] Supreme Court of Canada, *Carter v. Canada* (February 6, 2016). **Link:** https://bit.ly/1zXx3I7.

[93] Justice Laws Website, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying), S.C. 2016, c. 3.* Assented to June 17, 2016. **Link:** https://bit.ly/2uixZfB.

[94] Some physicians have indicated that they will cease practising palliative care if they are forced to make referrals or if the institution with which they are affiliated is required to perform MAID. Personal conversations with the author.

[95] College of Physicians and Surgeons of Ontario, *FACT SHEET: Ensuring Access to Care: Effective Referral* (June 2016). **Link:** https://bit.ly/2G2T0MC.

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[96] College of Physicians and Surgeons of Ontario, *CPSO's Effective Referral Requirement Affirmed by Superior Court* (January 31, 2018). **Link:** https://bit.ly/2pvdgAn.

[97] Dying With Dignity Canada is a "national not-for-profit organization committed to improving quality of dying, protecting end-of-life rights, and helping Canadians avoid unwanted suffering." Learn more at www.dyingwithdignity.ca/about.

[98] See Dying with Dignity Canada for a discussion of these issues. **Link:** http://www.dyingwithdignity.ca.

[99] See "Interpreting Canada's Medical Assistance in Dying Legislation" by Jocelyn Downie and Jennifer A. Chandler (Institute for Research on Public Policy, March 2018). **Link:** https://bit.ly/2tnnbwc.

[100] Tom Koch, "Assisted death should be the final option," *The Globe and Mail* (January 4, 2018). He continues: "We have spent so much time focused on 'dying with dignity' that we've ignored the right to life with dignity despite restrictions. While 96 per cent of Canadians support hospice care for patients with end-stage illnesses, fewer than 30 per cent of all Canadian patients have access to them."
Link: https://tgam.ca/2pBxQOD.

[101] The Committee's work, which lasted for two years, involved extensive collaboration:

- hearings with 32 experts (February/March 2010);
- the release of a public consultation paper in May 2010 (6,558 responses and 273 briefs were received between May 2010 and July 2011);
- public hearings (239 individuals and groups over 29 days in 8 cities from September 2010 to March 2011);
- 21 meetings with experts in Europe (in June 2011); and
- committee deliberations over 51 meetings (from June 2011 to March 2012).

Quebec National Assembly, Select Committee on Dying with Dignity, Dying with Dignity Report (March 2012).

[102] Bill 52, *An Act Respecting End-of-Life Care*, 1st Session, 14th Leg., Quebec, 2013 (assented to June 10, 2014), - RSQ c S- 32.0001, s 26. Chapter 3, Division 1, (1), item 12 (page last updated October 10, 2012). -
Link: https://bit.ly/Kn9aTa. -

[103] In November 2017, secobarbital – the drug most commonly used for assisted death in other countries – - was approved for use in Canada. Experts predict that given the availability of this drug, which is much more - fast-acting and effective, the number of people who will administer the medication themselves will increase. - See https://bit.ly/2GwYNKv. -

[104] In Toronto, a group of physicians and assisted-dying advocates are working "to establish a home - dedicated to medical assistance in dying (MAID), a project they are calling MAIDHouse." Kelly Grant, - "Toronto Group Hopes to Open Space for Physician-Assisted Dying," *The Globe and Mail* (March 17, 2018) - (A15). **Link:** https://tgam.ca/2q12Ac8. -

[105] See André Picard, "Palliative Care Should Be Embraced as a Priority and a Philosophy," *The Globe and Mail* (June 26, 2013) (Politics Insider). **Link:** https://tgam.ca/2DOEvu3. See CHPCA on who could benefit from - palliative care. -

[106] See the work of the Vulnerable Persons Standard, and, in particular, Catherine Frazee (see - https://bit.ly/2Hr6aDq). Frazee argues that close monitoring of the application of MAID is necessary to - ensure that vulnerable people are provided with adequate social, medical and financial supports; in their - absence, people may feel they have no choice but to resort to MAID. See also Charlie Fidelman, "Life in - Long-Term Hospital 'Unbearable': Montreal Man with ALS," Montreal *Gazette* (June 27, 2016). -
Link: https://bit.ly/2JZJiNj. -

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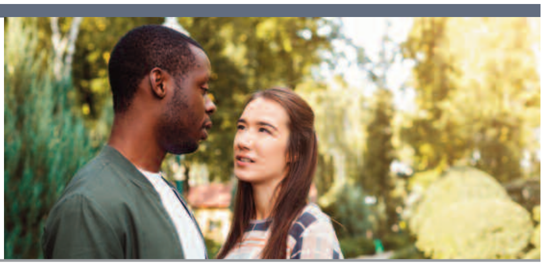

[107] For one such example, see Nicole Ireland, "1,300 Canadians Have Died with Medical Assistance Since Legalization – Here's One Man's Story," *CBC News* (April 20, 2017). **Link:** https://bit.ly/2pluawQ.

[108] A 2017 review of research commissioned by the Ontario HIV Treatment Network discusses research conducted in Switzerland, Holland, and Oregon, places that have a much longer history with assisted dying. See Ontario HIV Treatment Network, "Impact of Medical Assistance in Dying on Family and Friends," *Rapid Response Service* (June 2017). **Link:** https://bit.ly/2pA2pVK.

[109] For ongoing discussions and news about the potential impact of MAID for vulnerable people, see *The Vulnerable Persons Standard* (2017). **Link:** https://bit.ly/2GjrCx6.

[110] TOTAL DEATHS: eHealth Saskatchewan, *Saskatchewan Vital Statistics Reports* (n.d.). **Link:** http://bit.ly/2FRFL4G; MEDICALLY ASSISTED DEATHS: Saskatchewan Ministry of Health (March 21, 2018). Note that data for medically assisted deaths in Saskatchewan also includes January 2018.

[111] TOTAL DEATHS: Nova Scotia Government's Open Data Portal, *NS Births and Deaths with Rates and Natural Increase* (page last updated February 5, 2018). **Link:** https://bit.ly/2DQzC3D; MEDICALLY ASSISTED DEATHS: Nova Scotia Health Authority, "NSHA Medical Assistance in Dying (MAID) Information 2016–2017," *NHSA Medical Affairs – MAID Information* (February 1, 2018). **Link:** https://bit.ly/2G4oVjQ.

[112] 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). **Link:** https://bit.ly/2FZg7f7.

[113] Ibid.

[114] On the measure of "overall palliative and healthcare environment," Canada stood 18th (with a score of 57.5/100); on "affordability of care," Canada ranked 22nd. See Economist Intelligence Unit, *2015 Quality of Death Index* (October 6, 2015). **Link:** https://bit.ly/1KYEDGB.

[115] Harris/Decima conducted a quantitative online research survey of 2,976 Canadian adults for The Way Forward, with data collected between July 5 and August 7, 2013. Survey data were weighted using the 2011 Census to reflect the general population (gender, age and region). See Canadian Hospice Palliative Care Association, *What Canadians Say: The Way Forward Survey Report*, for The Way Forward initiative, Harris/Decima: 2013. **Link:** https://bit.ly/2o4SnM2.

[116] Ibid.

[117] For a discussion of these issues, see Chapter 9, "How to Start the Conversation (and Keep on Talking)," in Katherine Arnup, *"I Don't Have Time for This!" A Compassionate Guide to Caring for Your Parents and Yourself*.

[118] The Conversation Project, started by journalist Ellen Goodman, provides start-up kits for talking with your family and your doctor. See https://theconversationproject.org/.

[119] Amber Daugherty, "New 'Conversation Guide' Helps Doctors Discuss End-of-Life Care with Patients," *The Globe and Mail* (July 15, 2013). **Link:** https://tgam.ca/2ukPImE.

[120] 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. **Link:** https://bit.ly/2INHp5L.

[121] Canadian Institute for Health Information, *How Canada Compares: Results from the Commonwealth Fund's 2017 International Health Policy Survey of Seniors* (February 8, 2018). **Link:** https://bit.ly/2INhtYi.

[122] For an excellent article on the importance of talking with children about death, see Dave McGinn, - "What Is the Best Way to Explain Death to a Child?," *The Globe and Mail* (March 11, 2018). - **Link:** https://tgam.ca/2FJ57SM. McGinn interviewed Kathy Kortes-Miller, author of *Talking About Death Won't Kill You: The Essential Guide to End-of-Life Conversations* (Toronto: ECW Press, 2018). -

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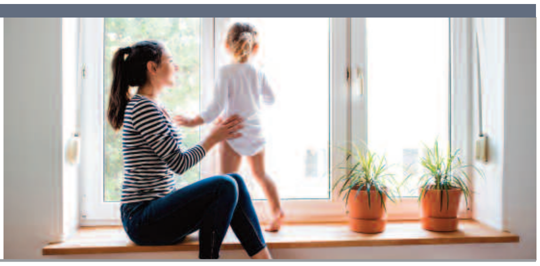

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[124] Iliana Magra, "Jon Underwood, Founder of Death Cafe Movement, Dies at 44," *New York Times* (July 11, 2017). **Link:** https://nyti.ms/2ucQYqf.

[125] People also meet to discuss death over lattes, beer, wine, at picnics and more.

[126] Statistics Canada, "Generations in Canada," *2011 Analytical Products*, Statistics Canada catalogue no. 98-311-X-982011003 (page last updated December 21, 2015). **Link:** https://bit.ly/2DH6ey5.

[127] Statistics Canada, *Components of Population Growth, Canada, Provinces and Territories* (CANSIM Table 051-0004) (page last updated September 27, 2017). **Link:** https://bit.ly/2nE6lT9.

[128] "According to a 2014 Harris/Decima survey, those Canadians that have a preference of where they die, the majority would prefer to die in their home (75%)." CHPCA Fact Sheet Summer 2016, citing the quantitative online research survey of 2,976 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7, 2013. Survey data were weighted using the 2011 Census to reflect general population (gender, age and region).

[129] *Doula*: (original meaning) a woman who serves. *Thanadoula*: a woman who serves the dying. In Britain, a group of death doulas are known as *soul midwives* (see http://www.soulmidwives.co.uk).

[130] For example, in 2018, Ontario announced that it would allow nurse practitioners to prescribe painkilling drugs for their dying patients, as long as they had received training in palliative care.

[131] Douglas College now offers a continuing education course leading to an End-of-Life Doula Certificate. The Institute of Traditional Medicine in Toronto (**Link:** http://itmworld.org); BEyond Yonder Virtual School for Community Deathcaring in Canada (**Link:** http://www.deathcaring.ca).

[132] Interview with Loraine (Rayne) Johnson, *Doing Deathcare Differently*, Skype interview and Facebook Messenger conversation, April 3, 2017.

[133] Rachel Brown's words, not Kerr's.

[134] Cassandra Yonder, email to the author, February 18, 2018. Cassandra is the founder of BEyond Yonder Virtual School for Community Deathcaring in Canada, http://www.deathcaring.ca/. I am grateful to Cassandra for her assistance with this section of the report.

[135] See http://www.cindea.ca/midwifery.html.

[136] See https://www.communitydeathcare.ca.

[137] *DEATHCARING, Community Based Deathcare, Death Midwifery, Death Doula* (Facebook Group). **Link:** https://bit.ly/2umYrEC.

[138] Statistics Canada, "2011 National Household Survey: Immigration, Place of Birth, Citizenship, Ethnic Origin, Visible Minorities, Language and Religion," *The Daily* (May 8, 2013). **Link:** http://bit.ly/13hGjpq.

[139] Furthermore, General Social Survey data shows that fewer Canadians attend church on a regular basis and a growing share report *never* attending church. In 2008, approximately 31% of women and 26% of men reported attending a religious service monthly, down from 48% and 37%, respectively, since 1985. The share of Canadians who said they *didn't attend any religious services* in 2008 stood at 39% for women and 45% for men, up from 26% and 34% in 1985 (newer data not available at this time). See Statistics Canada, "Religious Attendance Rates, by Sex, 1985 to 2008," *Social Fact Sheet* (page last updated March 8, 2010). **Link:** http://bit.ly/16AsArD.

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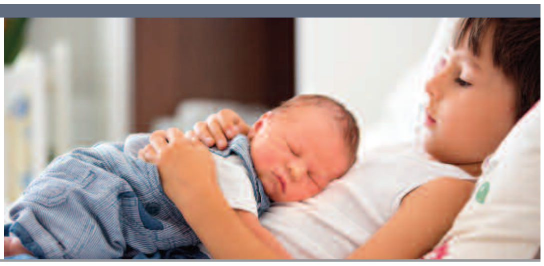

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