



# End-of-Life Care:

Toward a New Beginning in Ontario

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CARDUS

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**Preface** | In the 2015 report *Death Is Natural: Reframing the End-of-Life Conversation in Canada*, Cardus noted that Canada’s “current healthcare system is under increasing stress as one of the most populous generations on record—the baby-boomers—ages and dies.”<sup>1</sup> Recent estimates suggest that between the years 2005 and 2036 the number of seniors over the age of sixty-five will more than double, increasing from 4.2 million to 9.8 million across Canada.<sup>2</sup> Our report also revealed that despite most Canadians’ desire to die in a natural setting (e.g., their home or a community-based hospice) surrounded by a natural community of caregivers the majority—up to 70 percent in some provinces<sup>3</sup>—spent their last days in a hospital.

Since World War II, increased social disintegration, mobility, and medicalization of death have all combined to drastically change the location of death and dying from community-based settings to hospitals. Yet as many studies predict, current hospital infrastructure across Canada will be ill-equipped to provide the palliative care necessary for the needs of the aging baby-boom generation. Given the built-in limitations of hospitals to best address death and dying, our argument continues to be that something needs to change.

Despite most Canadians’ desire to die in a natural setting surrounded by a natural community of caregivers **the majority spent their last days in a hospital.**

The Canadian Institute for Health Information (CIHI) released a study in 2011 titled *A Focus on Seniors and Aging*, which revealed that “on any given day, more than 5,200 acute care beds across Canada are occupied by ALC [Alternative Level of Care] patients. Nearly 85 percent of ALC patients are age 65 and older; many (35 percent) are older than 85.”<sup>4</sup> Such numbers are indicative of the significant limitations in Canada’s present health infrastructure.

To be sure, there are numerous indicators that these problems *are* being addressed. The previously mentioned CIHI report also notes: “In the decade between 1996 and 2006, the proportion of Canadians dying in a hospital declined steadily from 73 percent to 60 percent. This downward trend of in-hospital death corresponds with growth in community-based end-of-life care.”<sup>5</sup> This is a positive trend worthy of commendation. At a national level, Canadians are making decisions to allow increased reliance on community-based rather than hospital-based palliative care.

1. Ray Pennings, *Death Is Natural: Reframing the End-of-Life Conversation in Canada* (Hamilton, ON: Cardus Policy in Public, 2015), 9.

2. *Population Projections for Canada, Provinces and Territories 2000–2036* (Statistics Canada, 2010), catalogue #91-520, p. 110.

3. Katherine Arnup, “Death, Dying and Canadian Families” (Vanier Institute of the Family, 2013), 8. It should be noted that the regional variation is significant, ranging from 88 percent in Quebec to 57.7 percent in the Northwest Territories.

4. *Health Care in Canada, 2011: A Focus on Seniors and Aging* (Canadian Institute for Health Information, 2011), 115.

5. *Ibid.*

Yet while national statistics have their place, they can be frustrating since they often gloss over regional particularities. Most of us want to know more about how the policies and initiatives are (or are not) taking place in *our* neighbourhoods since these will affect *our* lives. If we are from St. John's or Victoria, Hamilton or Medicine Hat, the national statistics may not say anything of substance to how *we* and our community might experience palliative care at the end of our lives. Therefore, it is helpful to drop down from a thirty-thousand-meter vantage and try to better survey the landscape from ground zero.

The case studies we have developed attempt to do just that. By looking at Hamilton and Ottawa, and their surrounding communities, the studies provide a snapshot of the end-of-life-care landscape in two of Ontario's larger cities and use data, analysis, and interviews with leading stakeholders to show some of the best practices other cities might imitate and obstacles other cities might avoid.

**Compassionate Care in Ontario** | When we talk about needing a change from our current hospital-based paradigm, the change we advocate is *not* simply the abolishment of the hospital's role in palliative care. While hospitals might not be ideally suited for death and dying because of their focus on restoration and health, they still have an integral role to play in the palliative care of Canadians. In fact, our 2015 study provided three ways in which we might “reframe” the current end-of-life care conversations that help us get beyond such either/or stalemates and better think through the role hospitals should have in facilitating more natural deaths.

First, we argued that our policies and practices should increase the likelihood that Canadians get the natural death. This is death by natural causes in a natural setting surrounded by natural caregivers. Of course, there are numerous reasons such a death might not work or even be in a given person's best interests. Indeed, several of the interviewees reiterate this point: for many, the most “natural” death may very well be in a hospital bed! Our argument, however, concerns those deaths in hospitals that could be avoided. To achieve this will require public-awareness campaigns, better advance care planning, more efficient and effective gathering and disseminating of data on end-of-life care, and the introduction of new benefits and programs that provide financial and other resources in order to better support communities of natural caregivers.<sup>6</sup>



**When we become completely reliant on professional services for our care, we do not recognize or use the resources and abilities that exist in our natural communities.**

Second, we need to think better about how the full range of social institutions can be equipped and enlisted so that natural deaths are more available in Canada. End-of-life care, then, needs to be embedded within the institutions of our civic life—banks, schools, libraries, art galleries, churches and places of worship, and so much more.<sup>7</sup> This is not simply a health-care-system issue; it's one facing all of us.

Third, and finally, we need to think of the various institutions on offer for end-of-life care not as competitors, but as differing options on a continuum of care. Again, the hospital has a valuable place within

6. Pennings, *Death Is Natural*, 3–32.

7. Pennings, *Death Is Natural*, 33–34.

this continuum, but we must recognize that end-of-life care involves numerous institutions across our civil society. It involves families, schools, art galleries, churches, community centres, family practices, and so much more. Since death is something that faces all of us, we are all to some degree “stakeholders” in how we think about and plan for dying.

As sociologist and professor of palliative care Allan Kellehear argues, when we become completely reliant on professional services for our care, we do not recognize or use the resources and abilities that exist in our natural communities. Rather, we encourage others to define our needs in terms of their inability to meet them, and we do not develop relationships between professional services and communities.<sup>8</sup> Kellehear’s work is pertinent for Canadians, especially today, and we would do well to heed his warnings that “the social and economic costs in permitting this ‘professionalization’ of death to continue are unimaginable.”<sup>9</sup>

In lieu of this “professionalization,” Kellehear advocates for the creation of compassionate cities, an idea “derived from a global public health approach to the promotion of community-wide strategies for health.”<sup>10</sup> In fact, the World Health Organization (WHO) created the Healthy Cities projects in an attempt to fulfill the Ottawa Charter for Health Promotion (1986).<sup>11</sup> Yet absent from these discussions of healthy cities was any discussion about the proper place of death and dying. The working assumption that health is the absence of disease, and the corollary that death is a failure, are not, Kellehear suggests, the solutions our cities need.<sup>12</sup> In fact, such mindsets are indicative of the problems that beset us as death becomes highly medicalized and health is increasingly professionalized.

In distinction from the healthy city, then, the *compassionate* city is one in which people quite literally “suffer with” their neighbours.<sup>13</sup> Yet what does this look like? In addition, if cities are only as compassionate as their populace, how do we track this over time as people come and go? The following reports are interested in these and other questions as they relate to Hamilton and Ottawa.

**Signs of Hope: Compassionate Care Act** | Perhaps one of the most positive “signs of life” that the concerns raised in our 2015 national report are being addressed provincially in Ontario is the introduction and passing of Bill 182: the Compassionate Care Act.<sup>14</sup> As was the case with the federal “Not to Be Forgotten” report, the issues addressed in this act are of concern across party lines. The collaboration of MPPs Sam Oosterhoff (PC), John Fraser (Liberal), and France Gélinas (NDP) including many others from these parties is a strong indication that there is collective will in Queen’s Park and in the various regions of Ontario to address the growing concerns about end-of-life care in the province be adequately addressed. The Compassionate Care Act, which passed Second Reading unanimously as of December 14, 2017, is designed to ensure that the provincial government develops a framework that will lead to improved access to and education about hospice and palliative care in Ontario.

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8. Allan Kellehear, *Compassionate Cities: Public Health and End-of-Life Care* (New York: Routledge, 2005), 1.

9. Kellehear, *Compassionate Cities*, ix.

10. Kellehear, *Compassionate Cities*, 37

11. Kellehear, *Compassionate Cities*.

12. Kellehear, *Compassionate Cities*, 39

13. Kellehear, *Compassionate Cities*, 41.

14. To learn more about The Compassionate Care Act, visit “What We Are Doing,” Ontario Palliative Care, <http://ontariopalliativecare.ca/what-we-are-doing/>.

The bill calls on the minister of health and long-term care to develop a “provincial framework designed to support improved access to hospice palliative care, provided through hospitals, home care, long-term care homes, and hospices, among other things.” This framework requires a definition of what hospice palliative care is and the training and education needed to equip both health-care providers and other caregivers (particularly family members). Throughout the bill, it is noted that the minister will work in collaboration and consultation with health-care professionals, and also other community care providers in order to publish a report that sets out the provincial framework. Again, as in regard to the hospital, we would also note in regard to the provincial legislature: improving our health care is not their sole responsibility.

At the federal level, Bill C-277 (also known as the Framework on Palliative Care in Canada Act) already became a law in late 2017. This bill is meant to improve the end-of-life care for all Canadians and asks for a united national framework. Conservative MP Marilyn Gladu (Sarnia-Lambton), who lead the way with this bill, has stated that she would like to see as many Canadians “live as well as they can for as long as they can.”<sup>15</sup> Now that this law is

in effect, the federal government has six months to work with provincial governments and palliative care providers to develop a national plan outlining how the wide range of care providers in the social landscape can be better equipped and enabled in carrying out their work for more people. The hope is that this national framework will address some of the gaps between what Canadians need and what is currently available, what Canadians know about end-of-life care and what they should know, what training and education caregivers have and what they need.

In the case studies for Hamilton and Ottawa and the surrounding LHIN region, we provide a more granular look at the larger trends we reported on in 2015. Throughout these case studies, composed of interviews with some of the key stakeholders in end-of-life care, the refrain you will hear throughout is that a new beginning for end-of-life care in Ontario requires that all the institutions of our social architecture, all the political parties, all the citizens no matter their age or ethnicity or social background, have a role to play. But as indicated by these two Bills at the federal and provincial legislatures, we now have the opportunity to bring Queen’s Park, healthcare, and our civil society leaders together to bring about real and needed improvements to end-of-life care in our province, our city, and our community.

A new beginning for end-of-life care in Ontario requires that all the **institutions** of our social architecture, all the **political parties**, all the **citizens** no matter their age or ethnicity or social background, have a role to play.

15. Marilyn Gladu website, <http://www.marilyngladu.com/news/mp-marilyn-gladu-introduces-bill-c-277--an-act-providing-for-the-development-of-a-framework-on-palliative-care-in-canada>.



## CASE STUDIES:

**Hamilton** [go.cardus.ca/endoflifeHamilton](http://go.cardus.ca/endoflifeHamilton) | **Ottawa** [go.cardus.ca/endoflifeOttawa](http://go.cardus.ca/endoflifeOttawa)

**ABOUT CARDUS HEALTH** | Cardus Health is an emerging program advancing research on Canadian end-of-life care through three lenses:

1. **Natural Death:** We need to build a social system that supports the desire of Canadians for a natural death, which we understand to mean dying of natural causes in our natural environment surrounded by our natural caregivers.
2. **Social Architecture:** We need to think of this system in terms of more than health, recognizing that not only the patient but also the natural caregivers need to be the focus of support, and thus the full range of social institutions best equipped for natural deaths need to be made more available to more Canadians.
3. **Continuum of Care:** We need to think of the delivery of care not as a series of alternatives to be chosen between, but rather as a continuum of care in which there is a seamless continuity of end-of-life care supports and settings as our fellow Canadians and their loved ones travel the journey through to the end of their natural lives.

Cardus aims to build on the good work done by the 2011 Parliamentary Committee and the hundreds of good organizations in this field, toward the common goal of bringing the best care to some of the most vulnerable among us.

**ABOUT CARDUS** | Cardus is a think tank dedicated to the renewal of North American social architecture. Headquartered in Hamilton, ON, Cardus has a track record of delivering original research, quality events, and thoughtful publications which explore the complex and complementary relationships between virtues, social structures, education, markets, and a strong society. Cardus is a registered charity.

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