Steps Towards More Compassionate End-of-Life Care

CARDUS

Cardus 2016 Pre-Budget Submission
Ontario, January 2016
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BUT

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Introduction

Statistics tell us that a majority of us are highly concerned about the type of end-of-life care we or the ones we love will receive, and that most of us desire to be cared for in a manner that minimizes our suffering while remaining sensitive to our unique psychosocial, cultural, and religious needs. But the current reality is that when it comes to end-of-life care, most of us will not get what we hope for.

Most Canadians—across party lines—want to see improvements in end-of-life care in order that those we care about might die in familiar settings connected to a natural community of caregivers and loved ones. However, this significant consensus has not translated into the frontline change one might expect. Despite years of studies, reports, and recommendations, the way we deliver end-of-life care in Canada still does not match the desire of most Canadians. Ontarians are no exception.

Health and Long-Term Care dominates Ontario's budgetary considerations, constituting 38.5 percent of Ontario's 2015–2016 planned expenses.[1] Not only are these issues of moral and compassionate importance, but they also have a real bottom-line impact on government finances. Many groups have highlighted the need for both the federal and the provincial governments to develop a more coherent "Strategy for Seniors" (or some variation thereof). While some may quibble about the exact numbers, there is a clear consensus that the mix within the current health-care delivery model between institutional and home care needs to be revisited. Systemic reform in this area not only promises to deliver care that will better serve Canadians at the end of their lives but can also realize significant financial savings. Rather than investing approximately $1100 per day for an acute care bed, the system can be reworked to deliver better care that suits the patients' needs at costs closer to $400 per day.

We recognize that change in this area is easier discussed than implemented, and there is no single solution that will accomplish the needed changes. However, some incremental steps can be taken that build on a growing public-opinion consensus, create momentum towards broader, more systemic change, and provide better value for provincial health dollars. This submission focuses on two such steps: building greater capacity for self-directed home care, and developing interoperable electronic health records.

Health Care + Public Opinion

The foundation for this submission is a 2015 Cardus report, "Death Is Natural" (appended to this submission), which called for a reframing of the national conversation regarding end-of-life care. That report built on a 2011 federal report "Not to Be Forgotten: Care of Vulnerable Canadians" produced by an all-party committee and signed by fifty-eight MPs. "Not to be Forgotten" proposed a shift from our current reliance on acute care facilities for end-of-life treatment and highlighted the range of social institutions—from homecare, to hospices, to long-term care facilities—that provide better-quality end-of-life care while being more cost-effective.

A 2013 Harris Decima Survey[2] indicated that among the majority of Canadians who have thought about their own death, the majority (75 percent) would prefer to die at home, while only 52 percent expect this to actually happen. The reality, shown by a Canadian Institute for Health Information (CIHI) report, is that almost 70 percent of Canadians actually die in hospital.[3]

This disconnect between desires and reality is corroborated by the findings from a Nanos Poll,[4] commissioned by Cardus and conducted in February of 2015, which provides an up-to-date snapshot of public opinion regarding end-of-life care in Canada. Two of the indicators in the survey touch especially on empowerment of patients and their families around death.

Considering especially the subset of Ontario data, more than half of Ontarians surveyed (50.3 percent) think that they do not have enough personal control over health decisions when one is nearing death. Further, 83.1 percent of all Ontarians felt that it was important that health-care decisions be made in a manner that respects the wishes of themselves and their family—99.2 percent thought that it was at least somewhat important.

The data from these separate polls reveals that the narrative traced in the "Not to Be Forgotten" report of 2011 remains largely unchanged: when it comes to end-of-life care, there is still a significant disconnect between the hopes of Canadians and frontline realities.

Cardus recommends that the government of Ontario prioritize budgetary resources towards two areas of development in the health-care system: **of capacity in self-directed care for home-care patients,** and **of interoperable electronic health records** (EHRs).

The End-of-Life Care **Landscape**

When Ontarians become patients, they, along with their families, can find themselves in the middle of a new, foreign, and often disjointed landscape. The easy and default response is to think of solutions built around a health-care system, focusing on the appropriate balancing of different components of health care. We support shifting to a paradigm in which the patient and their natural caregiver are the focal point, with the roles of various social institutions (including but not limited to the various components of health care delivered by government) considered in light of how they can best support Ontarians.

HEALTH SYSTEM
FUNDING/RECORDS/WEB SHARING

RELIGIOUS COMMUNITIES

PUBLIC EDUCATION

COORDINATING BODIES

COMMUNITY/
NEIGHBOURHOOD
SUPPORT

INCOME SUPPORT

PATIENTS NATURAL CAREGIVERS

BEREAVEMENT

RESPITE CARE

CLINICAL SUPPORT

ALTERNATIVE LIVING
SUPPORT

ADVANCED CARE
PLANNING

ONGOING
EDUCATION

PALLIATIVE
CREDENTIALS/TRAINING
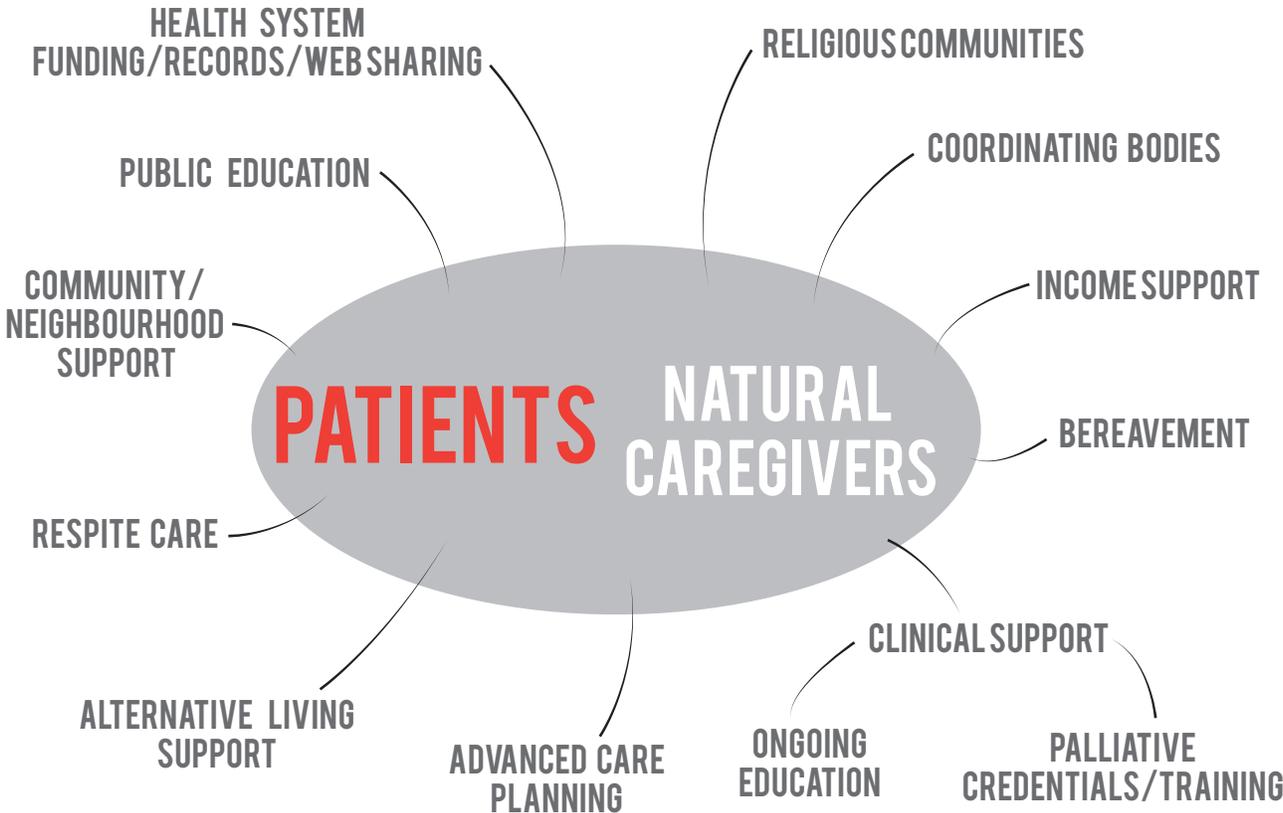
We propose **three lenses**/themes that inform a very different model of delivering end-of-life care. **This model narrows the gap between Ontarians' aspirations for quality end-of-life care and the everyday reality they experience.**

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 an intimate environment surrounded by our natural caregivers.

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.

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.

The Context of Cardus' Recommendations

The perspective of the three lenses allows us to build on the excellent work done by hundreds of good organizations in this field towards a common goal of bringing the best care to some of the most vulnerable among us.

It also fits within the government's published initiatives. The Minister of Health and Long-Term Care's 2015 "Patients First: A Roadmap to Strengthen Home and Community Care"[5] sets out the government of Ontario's goals and steps for 2015–2017 in this area of health care. It pledges that *"over the next two years, we will begin to offer a self-directed-care option, in which clients and their caregivers are given funds to hire their own provider or purchase services from a provider of their choice."* Cardus applauds this initiative. We also support the commitment to develop a capacity plan over the next three years *"to ensure that high quality, timely and appropriate home and community care is available now and in the future."* Cardus offers some specific recommendations that fall within these steps.

Cardus' Recommendations:
Some **Concrete Steps**

Building **Self-Directed** Home-Care Capacity

Using the knowledge Cardus anticipates the Ministry of Health and Long-Term Care will gain from the current Self-Directed Care pilot project and the ongoing Direct-Funding program, we recommend that **the Ontario government afford patients and their families the choice of taking on greater responsibility in directing their own home care.**

Such a development in the availability of self-directed care for home-care patients would increase patients' and families' much-wanted agency in their own care, and save money on case management that could be used to provide better services.

The need for self-directed funding and more patient control over service provision has been noted again and again:

"Stakeholders also told the Expert Group that clients and families need to be actively involved in the development and implementation of their care plan, and that they need flexibility in tailoring the plan to their family's unique and evolving situation. . . . Families want flexibility in determining which of the available services they need most." *(Bringing Care Home: Report of the Expert Group on Home and Community Care)*

"Ontario needs . . . Service planning policies based on individual and patient population needs and choices, including options that support people to direct their own care . . . [and] more flexibility in the way services are delivered based on demonstrated quality in providing better service to patients and better value for public investments." *(OACCAC White Paper: Transforming Home and Community Care for Ontarians)*

"Patients want 'in.' As society becomes less hierarchical, patients want to take charge of their health and healthcare. They increasingly see themselves as partners in their own care and are less willing to accept poor customer service. . . . They expect to interact with a responsive system that is designed around their needs, not around the needs of providers and system managers. While these expectations increase the pressure on providers and systems, they also provide an opportunity to give patients greater responsibility for their own health and healthcare. This, in turn, can be leveraged to improve the quality and potentially reduce the cost of care." *(Unleashing Innovation: Report of the Advisory Panel on Healthcare Innovation)*

"Where patients and families are actively engaged in their health, patient outcomes, experience of care and economic outcomes can be substantially improved." *(Advisory Panel on Healthcare Innovation Commissioned Research: Patient Engagement: Catalyzing Improvement and Innovation in Canadian Healthcare)*

Currently in Ontario, Community Care Access Centre (CCAC) case managers are responsible for the delivery of care to each patient: assessing the eligibility of potential clients for home-care services, developing service plans, authorizing expenditures, and monitoring the adequacy of services provided through site visits and complaint response. This case management accounts for more than 20 percent of CCAC budgets.[6] Yet many patients and families have the capacity and desire to play a greater role in managing their own care.[7]

Research has shown that involving patients in the management of their own case can greatly improve health-care outcomes.[8] Increased self-management respects the ability of patients and families to make decisions about their own care, including the choice of caregivers and environment. It also allows them, in providing for their end-of-life care, to engage the full range of the social architecture unique to their situation.

Across the province, support for self-directed care is clear. The existing small program limited to adults with physical disabilities demonstrates the demand for self-directed care: as of March 2015, the program had 725 beneficiaries but a waiting list of *over 400*, with wait times ranging from two to seven years.[9]

With its 2015 "Patients First: A Roadmap to Strengthen Home and Community Care," the Ontario government has responded to the many prominent panels and organizations, including the 2015 Ontario Expert Group on Home and Community Care and the Ontario Association of CCACs, that have reported on a need for more coordinated access to services and the strong desire of patients and their families for access to self-directed funding and management of their own case.[10]
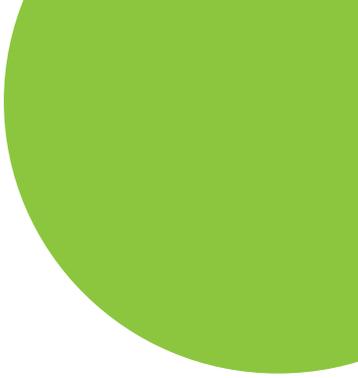
The "Patients First" roadmap's announcement of funding for pilot projects to expand self-directed care to home care more broadly,[11] however, was unclear on the form this pilot project will take. We propose that a successful self-directed-care program will provide *more choice, more personalization,* and *more support:*

MORE CHOICE: Patients and their families are often the best assessors of their service needs. Self-directed care should afford patients the choice of services they value most, when they need them the most.

MORE PERSONALIZATION: Public health-care systems can often feel large and impersonal, with care administered by providers with no connection to the patient. Self-directed care should provide patients and families with the flexibility to take advantage of health-care providers within their own network.

MORE SUPPORT: Allowing families to choose self-directed care has the potential to increase the quality of their own care. It also frees up time and resources in the system, indirectly benefiting those patients who lack the capacity or desire to manage their own care, preferring the full support of a case manager.

Following these principles around self-directed home care, Cardus recommends that:

1: Using the knowledge gained from the current Self-Directed Care pilot project and the ongoing Direct-Funding program, the Ontario government allow patients and their families to choose greater responsibility in directing their own care.

1.1: Once a patient has been deemed eligible for home-care services and has been assessed by a case manager, patients or their families can choose a self-directed-care option in which they are responsible for day-to-day management of service provision. Self-directed services include the choosing of service provider and the scheduling of service provision.

1.2: In conjunction with the self-directed-care model, the initial case manager assessments determine an appropriate envelope of funding that gives the patient wide discretion over how funds are used. In consultation with the case manager, patients allocate funding to those services they decide they need most.

1.3: Self-directed patients choose from a wide variety of service providers reflective of the breadth and depth of Ontario's social architecture. Patients can draw on the networks and community that are unique to them, and use funding to support a friend or family member who has taken time off work to provide care, or contract a faith-based group to provide services, or purchase respite services, for example.

Development of **Interoperable Electronic** Health Records

The Ministry of Health's "Patients First: A Roadmap to Strengthen Home and Community Care" includes the following among its five goals:

MODERNIZE DELIVERY
Updated funding models, consistent assessment approaches, flexible contracting, workforce stabilization, and improved technology are used throughout the sector.

Cardus suggests that the development of **interoperable electronic health records** will greatly increase the level of care provided to Ontario patients, and provide special benefit to those patients in home care.

While the majority of health-care providers in Ontario use electronic records, many of these computerized systems operate as silos. For example, a hospital and the local CCAC may both have electronic records for their patients, but when an elderly patient is transferred from a hospital room to a long-term-care facility, the appropriate paperwork is sometimes faxed, and not all of the information on the hospital system is made available to caregivers at the long-term-care facility. Ontario needs to ensure the quick and easy sharing of health information between health-care providers. Such sharing improves and strengthens the continuum of care, ensuring better quality of care and saving money otherwise spent on repeated assessments and testing, and lost time.

The process of building regional electronic heath records in Ontario, already begun, has made a good start. It is not uncommon, for example, for hospitals in a region to share information, and the Ontario Association of CCACs has developed an electronic system for information sharing and treatment of home-care patients.[12] Interoperability, or the ability of a diverse group of electronic health records to share information, is built on standards that regulate the points of contact between systems.[13] Fortunately, Ontario stands ready to benefit from standards developed by international bodies (HL7, DICOM, IHE) and national bodies (the pan-Canadian standards developed by Canada Health Infoway).[14]

The key role for the Ontario government is ensuring that ground-up innovation and integration occurs in an interoperable way, providing the most benefits to Ontarians. This means providing regulation that is *efficient, sustainable, and supportive of innovation:*

Efficiency means supporting ground-up initiatives that increase information-sharing and interoperability. Large-scale, top-down projects have proved to be unwieldy and often out of date by the time they are implemented. Further, numerous private-sector companies with technology solutions and a stable global community of knowledge can help Ontario reach its goals. The government can recognize and utilize the existing work of potential partners.

Sustainability means ensuring that development of EHRs in Ontario meets global standards. Keeping up with these standards allows Ontario to benefit from outside innovation and efficiencies of scale, ensuring the system's long-term effectiveness.

Supportive of innovation means ensuring the system is flexible and open to new developments. The field of EHRs constantly incorporates new innovations, and the Ontario government can ensure that its systems do so as well.

Following these principles regarding electronic health records, Cardus recommends that:

2: The Ontario government regulate electronic health records for implementation and use that is efficient, sustainable, and supportive of innovation.

> **2.1:** Implement regulations on electronic health systems according to global standards. This means requiring data and information-sharing networks to meet standards set by the IHE and other global best practices.

> **2.2:** Rather than attempting to develop a top-down system for sharing electronic health records, foster bottom-up innovation and synchronization. Set minimum standards for interoperability and privacy through regulation, and provide incentives for meeting those standards and for the merging of information-sharing systems.

> **2.3:** Support the continued integration of the CCACs' Client Health & Related Information System (CHRIS) with hospital patient management systems, with the ultimate goal of creating a seamless system of electronic health records and patient referrals.

> **2.4:** Meet the technological health-care innovation challenge that follows the integration of patient electronic health systems: utilize the platform to allow patients a greater role in managing their own care. Gain an edge in promoting such innovation by requiring electronic health systems to provide a platform for patients to directly access their own medical files and informaton.

The need for better regulation of the growing number of EHR systems has been noted again and again:

"There are no legislative and policy provisions to guide electronic health information sharing and address related privacy and security matters. That means health service providers devote time, money, and effort developing one-off data and network sharing agreements that may not reflect leading practices." *(OACCAC White Paper: Transforming Home and Community Care for Ontarians)*

"The comparatively slow roll-out of EHRs has put Canada at a disadvantage compared to better-performing OECD peers. Shortfalls inevitably impede the quality and efficiency of front-line healthcare, leading to wasteful duplication of tests, incompletely informed clinical decisions, and medical errors. Limitations in EHR utilization also impede the development of higher level information systems and databases, with consequences for policy-making, quality management, healthcare research, and data-driven innovation. . . . Point-of-care access to fully interoperable EHR is limited, restricting the ability of healthcare providers to seamlessly share patient heath information with one another." *(Unleashing Innovation: Report of the Advisory Panel on Healthcare Innovation)*

"At the individual level, patients can be supported to engage in their own care by consumer health technologies and better access to information, including their own health records." *(Unleashing Innovation: Report of the Advisory Panel on Healthcare Innovation)*

"[Ontario needs] one electronic health records system that can be accessed or be given to clients and families that can be shared with all home and community care providers. This would decrease the duplication of assessments and the question asking period." *(Bringing Care Home: Report of the Expert Group on Home and Community Care)*

"Not all health information databases are linked, which makes it extremely difficult to find reliable information about utilization across the system, especially for services that are not funded through the LHIN. Common databases across all regions and all sectors must be developed if we are to monitor and evaluate system outcomes in a reliable and responsible manner." *(Bringing Care Home: Report of the Expert Group on Home and Community Care)*

Backing Solutions

The Ministry of Health and Long-Term Care has shown its recognition of the importance of end-of-life care priorities and planning. Further budgetary attention is a necessary next step. Cardus urges the minister of finance to lend his weight to these issues and send an important message at a crucial time—it is doubly urgent in light of the broader social discussions about end-of-life care currently underway.

Conclusion

Cardus reframes the existing work on palliative, hospice, and end-of-life care through the lenses of natural death, social architecture, and the continuum of care. This unique approach not only considers the system by which health care is provided but also places the patients and caregivers at the centre of the discussion, attuning policy to their needs. Along with echoing the many voices calling for greater attention to this ever-growing segment of health care, we make the specific recommendations that the government of Ontario prioritize budgetary resources to the development of capacity in self-directed care for home-care patients, and the development of interoperable electronic health records. Our hope is that these recommendations contribute to our common goal of helping to bring the best care to some of the most vulnerable among us, and to continue making Ontario a province we are proud to live in and also unafraid to die in.

Endnotes

1   *2015 Ontario Budget: Budget Papers,* 2015, table 2.23: "Total Expense."

2   Canadian Hospice Palliative Care Association. *What Canadians Say: The Way Forward Survey Report* (Ottawa: CHPCA, 2013), 22, http://www.hpcintegration.ca/media/51032/ The%20Way%20Forward%20-%20What%20Canadians%20Say%20-%20Survey%20 Report%20Final%20Dec%202013.pdf.

3   Canadian Institute for Health Information, *Report on Seniors and Aging* (Ottawa: CIHI, 2011).

4   Survey data is available on the Cardus website (cardus.ca).

5   Ministry of Health and Long-Term Care, "Patients First: A Roadmap to Strengthen Home and Community Care 2015."

6   Auditor General of Ontario, "2010 Annual Report of the Office of the Auditor General of Ontario." See section 3.04: "Home Care Services."

7   Gail Donner, "Bringing Care Home: Report of the Expert Group on Home and Community Care," March 2015.

8   Canadian Foundation for Healthcare Improvement (CFHI) and Baker GR, Advisory Panel on Healthcare Innovation Commissioned Research: Patient Engagement: Catalyzing Improvement and Innovation in Canadian Healthcare, Ottawa, 2015. See also Karen Spalding et al., "Self Managed Care Programs in Canada: A Report to Heath Canada," June 2006, http:// healthycanadians.gc.ca/publications/health-system-systeme-sante/2006-self-managed- soins-autogeres/index-eng.php#a7.

9   Ibid. See recommendation 12.

10   See OACCAC white paper: "Making Way For Change: Transforming Home and Community Care for Ontarians."

11   Kelly Grant, "Pilot Project to Give Cash to Ontario Patients for 'Self-Directed' Home Care," *Globe and Mail,* May 13, 2015; see also Ministry of Health and Long-Term Care, "Patients First: A Roadmap to Strengthen Home and Community Care 2015."

12   See "CHRIS: CCACs' Client Health and Related Information System," http://oaccac. com/innovation/Pages/chris-ccacs-client-health-related-information-system.aspx.

13   For a beginner's guide to interoperability, see Anita Samarth, "Interoperability for Dummies," https://ic.infoway-inforoute.ca/en/resources/docs/ihe/58-interoperability-for- dummies/file.

14   For more information on pan-Canadian and international standards, see the Canada Health InfoWay: https://ic.infoway-inforoute.ca/en/resources/standards/international- standards.

DEATH IS NATURAL

REFRAMING THE END-OF-LIFE CONVERSATION IN CANADA

APRIL 2015

CARDUS HEΛLTH

DEATH IS NATURAL

REFRAMING THE END-OF-LIFE CONVERSATION IN CANADA

RAY PENNINGS

INTRO DUCTION

Thinking about end-of-life issues is difficult. We don't like to think about the death of our loved ones, let alone ourselves. Yet at some point we all need to start planning for the tough decisions that inevitably come as the body ages and becomes more fragile and dependent.

We know this. Statistics tell us that a majority of us are highly concerned about the type of end-of-life care we or the ones we love will receive; and that most of us desire to be cared for in a manner that minimizes our suffering while remaining sensitive to our unique psycho-social, cultural, and religious needs. But the current reality is that when it comes to end-of-life care, most of us will not get what we hope for. A significant reason for this disconnect is that the end-of-life care system in Canada is fragmented, inaccessible to many, and sporadically supported across the country. In short, end-of-life care in Canada needs renewal.

But we have known this for a while. A 1995 Senate Committee report, "Of Life and Death," high-lighted the importance of making palliative end-of-life care "a top priority in the restructuring of the health care system."[1] Since then, numerous reports and initiatives regarding how we provide such care in Canada have been produced. In part, the motivation for these efforts is simply a natural outgrowth of the value we place upon the dignity of human life. Yet another subtext for this debate has been a growing realization that as the baby-boom generation ages, our end-of-life care systems as presently organized will be stretched beyond capacity. In addition, current debates on the divisive issues of assisted suicide and euthanasia are bringing issues about how we best care for the terminally ill into much sharper focus.

To be sure, there are disagreements about the best allocation of resources, the proper arrangement of our priorities, and more contentious questions over legality and individual autonomy. But there is also a remarkable amount of agreement: most Canadians – across party lines – want to see improvements in end-of-life care in order that those we care about might die in familiar settings connected to a natural community of caregivers and loved ones.

However, this significant consensus has not translated into the front-line change one might expect. A decade after the first studies were articulated, new reports have been issued with recommendations that, save for an updating of statistics and minor modifications, reflect an unchanged narrative: the way we deliver end-of-life care in Canada does not match the desire of most Canadians.

In a sense this report is no different. Most of our recommendations and analysis have their origins in previous reports. Most specifically, this report builds on the 2011 report, "Not to be Forgotten: Care of Vulnerable Canadians," produced by an all-party committee and signed by 58 MPs.

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1   Special Senate Committee on Euthanasia and Suicide, "Of Life and Death: Final Report". (1995). Senate of Canada. Available at: <http://www.parl.gc.ca/content/sen/committee/351/euth/rep/lad-tc-e.htm>.

"Not to be Forgotten" proposed a shift from our current reliance upon acute care facilities for end-of-life treatment and highlighted the range of social institutions—from home care, to hospices, to long term care facilities—that provide better quality end-of-life care while being more cost-effective.

What we seek to do in this document, rather than reinventing the wheel, is to re-evaluate the various recommendations drawn from these sources using 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.

These three lenses are helpful tools to re-frame and broaden the discussion. Much of the discussion to date has been focused on changing the systems that govern our health: reflecting on how the different levels of government ought to do things differently; communicate with each other; synergize their efforts through "national strategies"; and extend the capacity for care to be delivered and supported. All of this remains productive and necessary.

However, if the full potential of our efforts is to be achieved, what is needed is a more innovative ownership of the problem and solutions. A broader recognition needs to be cultivated that preparation for the end of life is part of a well-lived life. And although government has a role, this is as much about creating space for individual Canadians, their natural caregivers, and the many civil society institutions that are well equipped to help.

Constructive cross-partisan discourse—too rarely achieved and celebrated in Canadian politics today—is what "Not to be Forgotten" achieved in its concern for improving end-of-life care in Canada. Our aim is to build on the good work done by the 2011 Parliamentary Committee and the hundreds of good organizations who are working, in various dimensions, in this difficult and complex field. We want to provide a platform that will contribute to a broader awareness of these issues and increase the momentum to bring about the necessary changes. Our hope is that in some small way, this report will contribute to the common goal of bringing the best care to some of the most vulnerable among us, and continue to make Canada a country we are proud to live in and also unafraid to die in.

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Ray Pennings is a co-founder of Cardus and currently serves as its Executive Vice President, working out of the Calgary office. He has long experience in Canadian industrial relations, as well as public policy, political activism, and political affairs.

ACKNOWLEDGEMENTS:

ABOUT CARDUS

The *cardo* was an ancient north-south road that connected the people of Roman cities to their major public spaces. Cardus's wide-angle periodicals, policies, and punditry come together for a renewed vision of North American social architecture, up and down the *cardo*—the Main street.

CARDUS

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CANADIAN VALUES + PUBLIC OPINION:

Data from two separate polls reveal that the narrative traced in the "Not to be Forgotten" report of 2011 remains largely unchanged: when it comes to end-of-life care there is still a significant disconnect between the hopes of Canadians and front-line realities. What's more, most Canadians have come to expect this disconnect, signalling a certain distrust to the current end-of-life care systems in place throughout Canada.

A 2013 Harris Decima Survey[2] indicated that among the majority of Canadians who have thought about their own death, the majority (75%) would prefer to die at home, while only 52% expect this to actually happen. The reality, shown by a Canadian Institute for Health Information (CIHI) report, is that almost 70% of Canadians actually die in hospital.[3]

This disconnect between desires and reality is corroborated by the findings from a Nanos Poll[4] conducted in February of 2015, which provides an up-to-date snapshot of public opinion regarding end-of-life care in Canada. Again, the clear message is that although Canadians trust their health care providers, 73% are concerned or somewhat concerned that they will not receive the comfort and support they would hope to receive if they or a loved one was facing a life-threatening illness or nearing death. This disconnect is not only a factor of quality of care, but type of care. A majority of Canadians hope that end-of-life care will respect their personal faith and family's culture, yet between 40-45% are unsure as to how faith groups, community groups, and cultural groups—all integral parts of a flourishing social architecture—can contribute to the full continuum of end-of-life care.

There are a variety of reasons for the ongoing disconnect between what we hope for and what we will likely receive in terms of end-of-life care, but this report demonstrates that the key drivers include a lack of advance planning; a default use of acute care facilities for delivering required treatments (with inadequate investment in alternative models of care delivery); and a general lack of awareness of available pain management treatments that can be delivered in a way that mitigates most of the physical pain associated with the physical end-of-life process.

2   Canadian Hospice Palliative Care Association. What Canadians Say: The Way Forward Survey Report, 2013 (CHPCA: Ottawa), p 22. Available at <http://www.hpcintegration.ca/media/51032/The%20Way%20Forward%20-%20What%20Canadians%20Say%20-%20Survey%20Report%20Final%20Dec%202013.pdf>.
3   Canadian Institute for Health Information. Report on Seniors and Aging, 2011 (CIHI: Ottawa).
4   Survey data are available on the Cardus website (cardus.ca).

THE FRONTLINE REALITY

OUR CHANGING EXPERIENCE OF DEATH

Prior to the 1950s, death was a social reality that was more frequently located within the broader community at large.[5] However, since the end of World War II, social disintegration, increased mobility, and the medicalization of death have all worked to relocate death and dying from its natural environment within family and community-based institutions to larger, more impersonal acute care facilities. By the mid-century, over half of all deaths took place in hospitals, contrasted to only 30% in the 1930s. This number peaked in 1994 with 77.3% of all Canadian deaths occurring within a hospital setting.[6] Yet the point to which we want to draw attention here is not so much about *where* we die than it is about *how* we experience death.

The increased medicalization of death has prompted many Canadians to no longer consider death and dying as natural experiences that take place within a familiar social setting under the observation and care of the natural family and local community.[7] As noted in "Not to be Forgotten," the "medical care model," which has largely supplanted the "community care model," emphasizes the central role of professional care teams, and the authoritative role of the doctor. In this model, "doctors, nurses, social workers, psychologists, spiritual counselors, and a range of accredited specialists, become the central actors in the patient's care."[8] This move has required the move to providing end-of-life care at hospitals, which has in turn created a backlash against experiencing life in such a foreign environment. A better approach, we suggest, is not about avoiding the hospital at all costs, but moving toward a more patient-centered approach that would, in turn, have implications for how one might better experience natural death in a hospital setting.

An important consideration that can be easily overlooked in the midst of healthcare statistics is that almost every metric of success in our healthcare system involves the preservation of life. While this is the obvious focus for a healthcare system, it lacks the nuance required for measuring end-of-life care, and may point to an overemphasis on the extension of life. Such an orientation can easily lead to an "over-medicalization" of the dying process. Geoffrey Poitras of Simon Fraser University explains how "medicalization" arose in the 1950s as a way to explain social deviance as a medical problem which could be treated. [9] Since then other social realities—like death—have also been subjected to this "medicalization" process. David Field, in the *European Journal of Cancer Care,* goes on to argue that since this time, "More areas of life are being brought under the scrutiny and control of the medical

5   Arnup, Katherine, "Death, Dying and Canadian Families." (Vanier Institute of the Family, 2013), p 7.
6   Note that the regional variation was significant, ranging from 88% in Quebec to 57.7% in the North West Territories. Drawn from Arnup, Katherine, "Death, Dying and Canadian Families." P 8.
7   Ibid.
8   "Not to Be Forgotten: Care of Vulnerable Canadian" Parliamentary Committee on Palliative and Compassionate Care (Ottawa: 2011). p. 30.
9   See Poitras, Geoffrey. "Medical Ethics and Economic Medicalization." Contemporary Issues in Bioethics. (2012) P. 54.

profession. Thus, experiences which were once seen as a normal part of life, such as pregnancy, child-birth, aging, dying and bereavement, have been deemed matters for medical concern and control."[10]

This increased medicalization is in tension with the dying process. While health care is focused on prolonging life, palliative care takes place after a terminal diagnosis and instead focuses on pain management and symptom control. As a palliative patient grows closer to death, treatment shifts from curative measures to palliative measures, involving both the patient and his or her caregivers. This process is known as the "continuum of care."

PALLIATIVE-CARE CONTINUUM
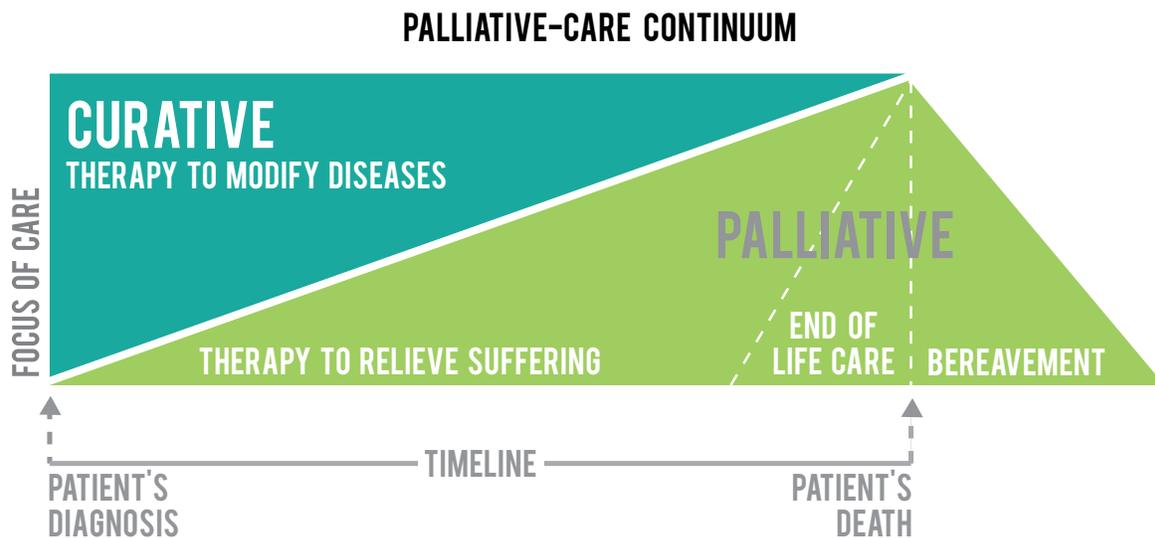
Figure 1 Data Source: Ministry of Health and Long-Term Care. *2014 Annual Report of the Office of the Auditor General.*

Further, while extreme medical measures that separate a person from their natural setting are easily justifiable when the patient can expect to return to a normal life embedded in their community after recovery, a palliative patient cannot expect to recover. This suggests that increased focus should be placed on allowing them to die within their natural environment.

Those on all sides can agree that a humane end-of-life treatment plan would accept the inevitability of death, and that providing support to the patient and their loved ones throughout the natural process of dying need not make use of every life-extending technology and treatment just because they are available.

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10   Field, David, "Palliative Medicine and the Medicalization of Death," European Journal of Cancer Care, (3: 1994) p. 59.

AGING BABY-BOOMERS: NOT GETTING WHAT THEY WANT

As numerous reports in the past fifteen years have shown, our current healthcare system is under increasing stress, as one of the most populous generations on record—the baby-boomers—ages and dies. In Canada, the projections suggest that between 2005 and 2036 the number of seniors 65 years and older will increase from 4.2 million to 9.8 million, which would lead to a doubling of the annual expected deaths.[11] This increase in the number of seniors has led to various efforts to improve efficiencies in Canada's healthcare system, yet hospitals remain the main provider of end-of-life care for about 70% of Canadians.[12]

AGE OF DEATH PREDICTIONS

CANADIANS ARE DYING OLDER
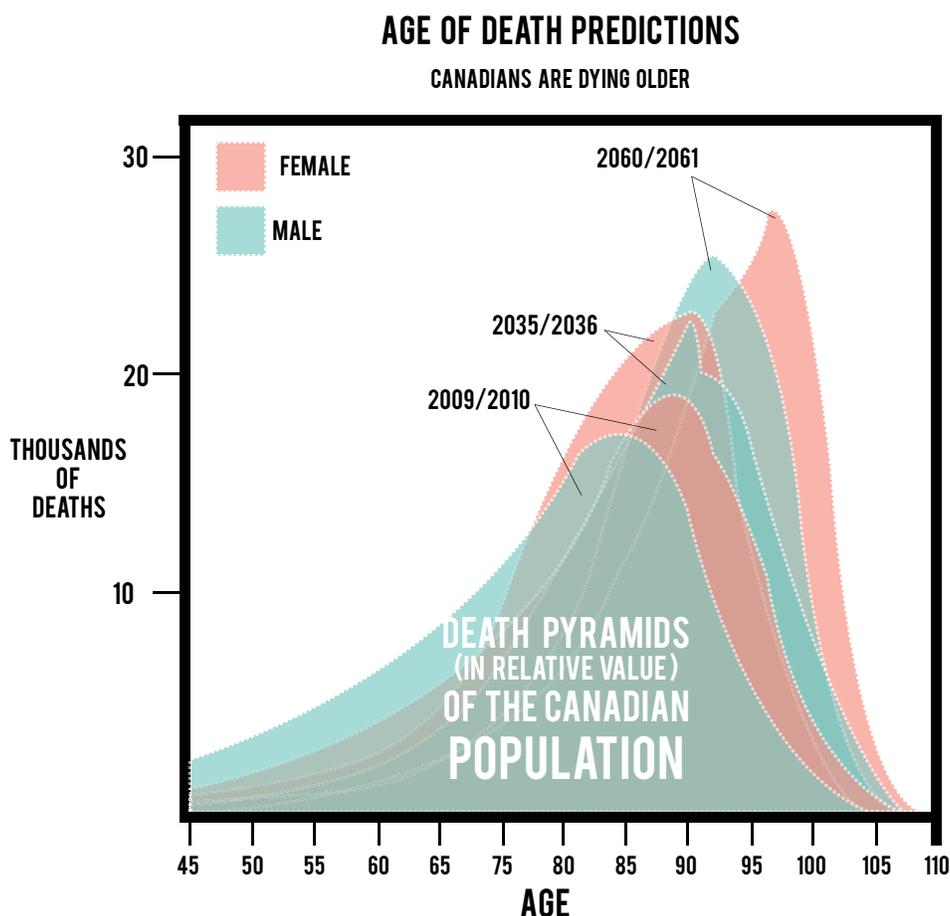
Figure 2 Data Source: *Population Projections for Canada, Provinces and Territories-2000-2036,* (2010). Statistics Canada, catalogue #91-520, p. 46.

Yet as shown in the Harris Decima and Nanos polls quoted above, this is hardly what most Canadians want. And other reports validate this. D.M. Wilson, in *The Journal of Palliative Medicine* reports that 70.8% of Albertans prefer to die at home and 14.7% prefer a hospice. Only 7% prefer to die in the hospital.[13] Another study found that of the 76% of Canadians who had planned for end-of-life care

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11   Population Projections for Canada, Provinces and Territories-2000-2036, (2010). Statistics Canada, catalogue #91-520, p. 110.
12   CIHI, 2011
13   Wilson, D.M. Et AL, "The Preferred Place of Last Days: Results of a Representative Population-based Public Survey." Journal of Palliative Medicine, 2013. 16(5), 502-508. p 1.

in 2013, only 15% preferred aggressive medical management, including resuscitation.[14] It is important to reiterate that deaths within hospitals are not necessarily deaths without palliative care; in fact, in the Atlantic provinces it was shown that 59% of those who died in hospitals received some form of palliative care.[15] The problem is that most hospitals are settings that disconnect individuals from their communities, and do not provide for the fulfillment of religious, cultural, and psycho-social needs of patients and caregivers as well as alternative institutions like long-term care facilities, hospices, or one's home.

ALBERTA: PREFERRED V. ACTUAL PLACE OF DEATH

PREFERRED PLACE OF DYING
WILSON ET AL 20B

HOSPITAL
UNSURE
HOME OR PALLIATIVE NURSERY

ACTUAL PLACE OF DYING
STATS CANADA 2007

HOSPITAL
HOME OR PALLIATIVE NURSERY
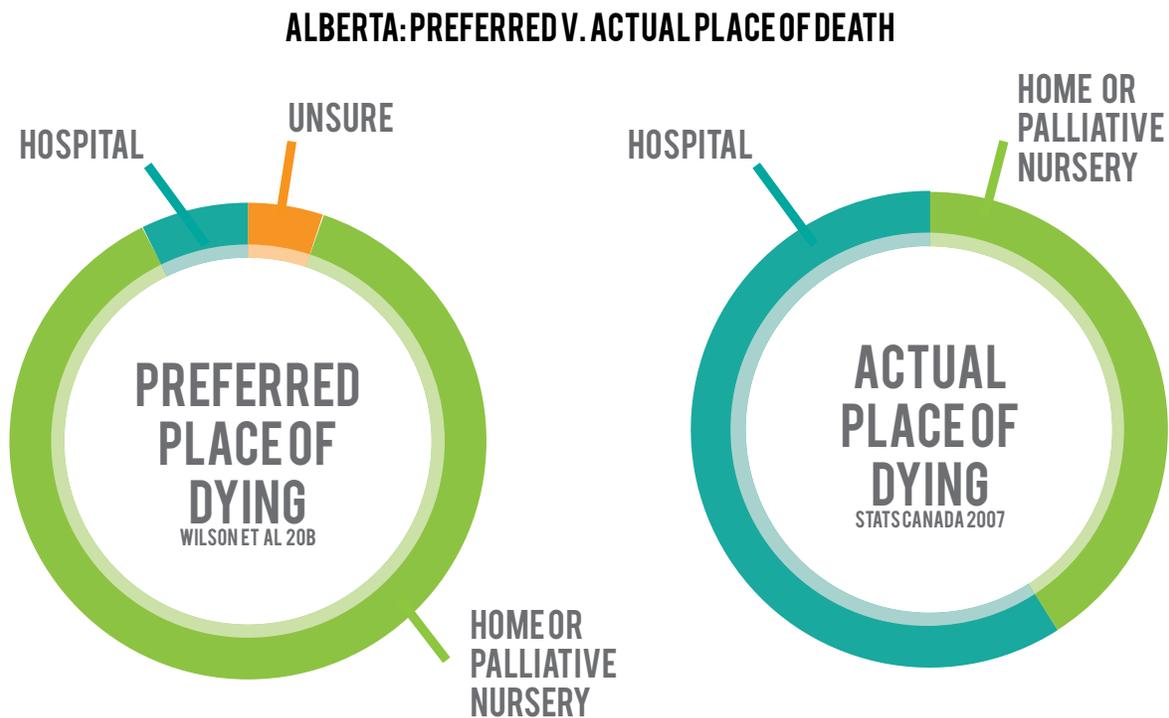
Figure 3 Data Source: Wilson, D.M. et al, "The Preferred Place of Last Days: Results of a Representative Population-based Public Survey." *Journal of Palliative Medicine,* 2013. 16(5), 502-508.

While many are not dying in their place of highest preference, it is again important to note that there remains a significant amount of regional variation in the location of death throughout Canada. In 2007, CIHI reported that 58% of Western Canadians died in a hospital, of which 62% were hospitalized at least once during the last year of their life for an average of 30 days.[16] Hospital-based palliative care, however, was only received by a small minority (13% to 16%). And especially for those in rural settings, access to hospital-based palliative care was severely limited.

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14   Heyland, DK, et al. "Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning." JAMA Intern Med, 2013. p. 5.
15   Canadian Institute for Health Information, Health Care Use at the End of Life in Atlantic Canada, (Ottawa: CIHI, 2011).
16   Canadian Institute for Health Information. Health Care Use at the End of Life in Western Canada (Ottawa: CIHI, 2007). p 35.

In 2011, CIHI published another report[17] on death in the Atlantic provinces from 2007 to 2008. The findings showed that 63% of individuals died in hospitals overall, but 59% of those dying in a hospital received some form of palliative end-of-life care. Still, 71% of those who died spent an average of 26 days in the hospital in their last year of life.

It should also be noted here that variation in palliative care is not only due to regional capacity, but can also be due to diverse traditions of minority people-groups with different understandings of death. One example of this is the resistance that many aboriginal people have towards hospital-based end-of-life care. Such resistance is based in an understanding that hospitals often disconnect them from their communities at the most vulnerable moments in life. In the journal *Health and Social Care in the Community,* researchers interviewed aboriginals from the interior of British Columbia to find out why such resistance existed. One participant remarked: "A person [who] is getting sick […] doesn't really want to go to [the hospital], because they don't have any connections, they don't know anyone. They don't really want to go there to die, but they'd like a connection."[18] In the report, other participants indicated that death, ideally, should occur in a place determined by the individual, and this is necessary for providing the best care possible.

While it should be noted that these statistics do not cover decedents who received palliative care and moved to a hospital for the last days or hours of life, the consistent finding of this research is that Canadians in various regions and of various ethnic backgrounds desire to die at home or in a palliative care setting.

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17   CIHI, Atlantic Canada, 2011.
18   Castleden, H., Crooks, V.A., Hanlon, N., & Schuurman, N. (2010). Providers' perceptions of Aboriginal palliative care in British Columbia's rural interior. Health and Social Care in the Community, 18(5), 483-491.

PERCENTAGE OF DECEDENTS IN HOSPITAL WITHIN THE LAST SIX MONTHS OF LIFE.
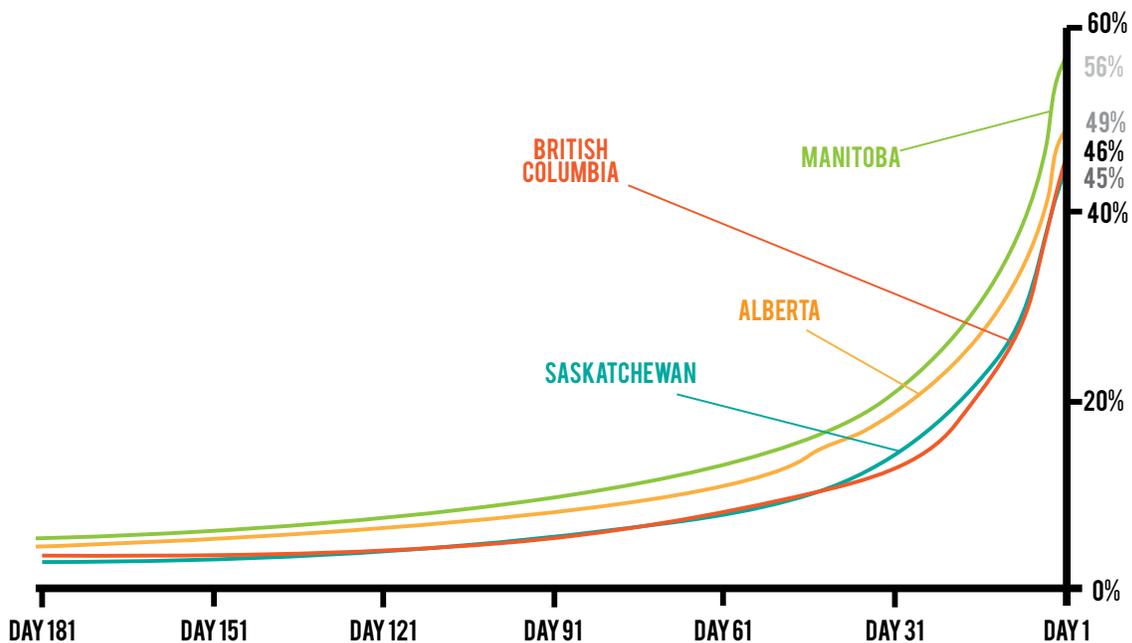
Figure 4 Data Source: Canadian Institute for Health Information. *Health Care Use at the End of Life in Western Canada* (Ottawa: CIHI, 2007).

COUNTING THE COSTS

While the number of Canadians dying in hospitals has been slowly decreasing since a peak in 1994—a positive sign that changes are slowly starting to take place—there are still far too many Canadians not receiving the end-of-life care they desire. One commonly advocated solution is to create an integrated model of care where access to end-of-life care is more readily available (both geographically and economically) to all Canadians. Such an integrated model would see hospitals without any palliative care strategies as a "last resort" for dying Canadians, and multiple smaller organizations— ranging from home care and hospices to long term care facilities and hospital-based palliative pro-grams— would step in to provide services up until the end of life.

The move to an integrated model of care would not only give more Canadians the death they desire and drastically improve comfort at the end of life, but would also significantly reduce government spending. Currently Canada spends 12% of its gross domestic product on healthcare.[19] A growing proportion of this amount is spent on seniors: it has been estimated that more than 40% of total healthcare spending is accounted for by those 65 and older in Canada, a group that comprises only 20% of the population.[20] The cost of dying in Canada ranges from as low as $10,000 dollars for a sudden death to between $30,000 and $40,000 for someone with a terminal disease like cancer or

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19   2009 Statistic. Source: Constant, Alexandra, et al. "Research Synthesis on Cost Drivers in the Health Sector and Proposed Policy Options" Canadian Health Services Research Foundation, Paper 1. (Ottawa, 2011). p. 3.
20   Canadian Institute for Health Information, Western Canada, 2007. p 5.

chronic obstructive pulmonary disease. However, introduction of hospital-based palliative care is estimated to save between $7,000 to $8,000 dollars per patient.[21] In total, hospital-based palliative care could reduce the cost of end-of-life care by 50% or more simply by reducing the number of ICU admissions, diagnostic tests, interventional procedures and overall length of hospital stays.[22]

THE COST OF DYING: 2001–02
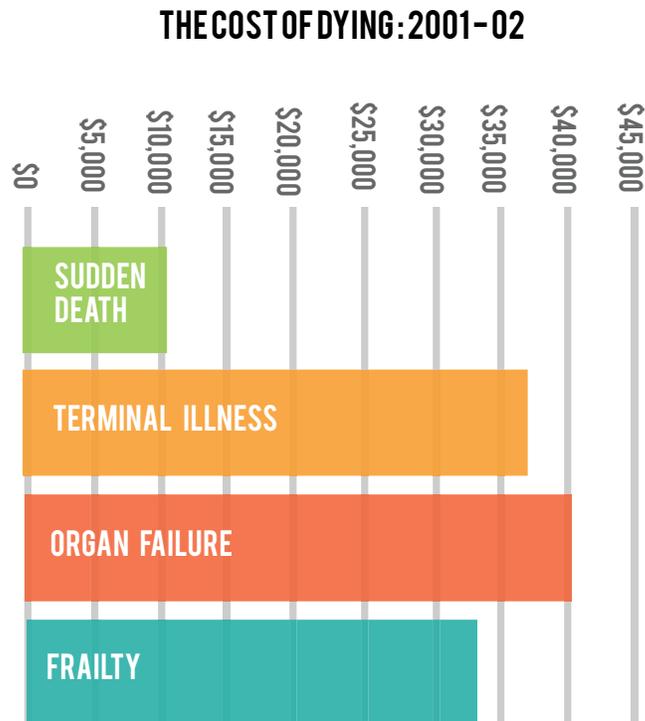
Figure 5 Data Source: Fassbender et al., "Cost Trajectories at the End of Life: The Canadian Experience." *Journal of Pain and Symptom Management,* Vol 38 No 1 (2009).

The expansion of non-hospital palliative care also provides an economic benefit. CIHI noted that per capita healthcare costs rise from $9,264 for a person younger than one year old, to $12,050 for those aged 75 to 79 and upwards, to $20,0113 for those 80 and older.[23] Depending on these numbers, expanding access to quality non-hospital palliative care would have saved between $40 and $345.5 million between 2003 and 2011 in Ontario alone. Projected savings from 2012 to 2036 range from just under $247 million to just over $2.1 billion.[24]

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21   Hodgson, Corinne. "Cost-effectiveness of Palliative Care: A Review of the Literature". CHPCA, (Ottawa: 2012). p 12.
22   Ibid, p 12.
23   Canadian Institute for Health Information. National Health Expenditure Trends, 1975 to 2012. (2012). p. xiv.
24   Institute of Marriage and Family Canada. (2013). Why Canada needs more palliative care. p.1.

But not all the costs of palliative care are borne by government healthcare systems. As of 2010, residential hospice palliative care programs were 50% funded by charitable donations.[25] This means that even though moving to higher levels of hospice use would cut healthcare costs, it is also financially out of reach for many Canadians.

Another key component of an integrated model of care is providing support for those who wish to die at home, which could actually result in further reduces healthcare spending. While caring for a terminally ill patient in an acute care setting is estimated to cost over 40% more ($1100/patient/day) than providing the care in a hospital based palliative care unit ($630-$770/patient/day), providing at-home care ($100/patient/day) is by far the most cost-effective for government.[26] A 2010 study estimated a savings of $35 million for every 10% of patients who are shifted from receiving palliative care in an acute care setting to receiving care at home.[27]

But for many families, dying at home is also not financially feasible. Currently, Canadian families shoulder 26% of the total cost of palliative care with home-based services, such as nursing and personal care services.[28] In addition to financial cost, the time commitments in caring for a loved one who is dying are strenuous for the family members providing care. Family members have been called the "unsung heroes" of our end-of-life care system, performing an estimated $25 billion worth of care.[29] It is estimated that providing care for a dying family member requires an average of 54 hours per week, but 64% of care providers polled by the CHPCA indicated they do not have enough time.[30]

The costs of poor alternatives to hospital care are also more than economic. "Alternative level of care" (ALC) patients in acute care beds waiting to be moved to another setting like residential care or rehabilitation—are increasingly composed of seniors. The 2011 CIHI report on Canadian seniors and aging states:

> Some of the time spent in emergency departments is the result of beds not being available for those already assessed and requiring inpatient acute care. This may be driven in part by challenges in discharging acute care inpatients experiencing ALC waits. On any given day, more than 5,200 acute care beds across Canada are occupied by ALC patients. *Nearly 85% of ALC patients are age 65 or older; many (35%) are older than 85.*[31]

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25   Quality End-of-Life Care Coalition of Canada. Blueprint for Action 2010 to 2020. (Ottawa: 2010). p 10.
26   Ministry of Health and Long Term Care, 2014, p. 264-5.
27   OHA, OFCMHAP, OACCAC, "Ideas and Opportunities for Bending the Health Care Cost Curve" (2010). p. 12.
28   Dumont et al., "Costs associated with resource utilization during the palliative phase of care: A Canadian Perspective". Palliative Medicine, 23(8),Dec 2009. p. 712.
29   Hollander, Marcus, Liu, Guiping, and Chappell, Neena. "Who Cares and How Much?" Healthcare Quarterly. 12(2): 2009. p.46.
30   Ipsos-Reid Survey. Hospice Palliative Care Study: Final Report. The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association. Jan. 2004. 31.
31   CIHI, Health Care in Canada. "A Focus on Seniors and Aging." 2011. p 115.

This statistic is crucial because the increased duration of wait times of ALC patients has proven to have adverse effects upon the health of those already dying, and while about 15% of all ALC stays are only a few days, one in five (20%) lasts more than a month.[32] Research shows that prolonged hospitalizations are associated with serious adverse outcomes of particular concern to seniors: accelerated functional decline, pressure ulcers, and infections.[33]

END-OF-LIFE CARE AND HIGHLY VULNERABLE POPULATIONS

With regards to provision of government services, two especially vulnerable minority groups are first-generation immigrants and aboriginal peoples. Addressing the needs of these groups is increasingly necessary, given our aging population and the unique vulnerability of our aboriginal peoples and immigrant communities. Increasing support for palliative care and home care may also increase options for culturally sensitive end-of-life care for these groups.

The needs of immigrant communities are growing. The 2011 National Household Survey reported that 6.8 million (20.6%) of the Canadian population were first-generation immigrants. Statistics Canada projected that the first-generation population will continue to rise, reaching between 25% and 28% of the Canadian population.[34] Aboriginal groups comprised 1.4 million people.[35]

Cultural norms need to be taken into account in providing end-of-life care to diverse ethnic communities. Currently aboriginal communities are not provided end-of-life care that accords with their cultural beliefs and stated desires. Rather than receiving home care, often the dying members of these communities are transferred to regional and urban hospitals; separated from family, friends, and community members; and die in an environment which conflicts with deeply held cultural, familial, and spiritual values.[36] Providing end-of-life care to individual aboriginal and immigrant populations will require an understanding and sensitivity to cultural beliefs, as well as a high degree of responsiveness to their expressed needs.

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32   Canadian Institute for Health Information, Alternate Level of Care in Canada (Ottawa, Ont.: CIHI, 2009).
33   K. E. Covinsky et al., "Loss of Independence in Activities of Daily Living in Older Adults Hospitalized With Medical Illnesses: Increased Vulnerability With Age," Journal of the American Geriatrics Society 51, 4 (2003): pp. 451–458.C. Graf, "Functional Decline in Hospitalized Older Adults," American Journal of Nursing 106, 1 (2004): pp. 58–67.M. Lindgren et al., "Immobility a Major Risk Factor for Development of Pressure Ulcers Among Adult Hospitalized Patients: A Prospective Study," Scandinavian Journal of Caring Sciences 18, 1 (2004): pp. 57–64.S. Ackroyd-Stolarz et al., "Impact of Adverse Events on Hospital Disposition in Community-Dwelling Seniors," Healthcare Quarterly 12 (2009): pp. 34–39.
34   Statistics Canada. National Household Survey, 2011. (Catalogue number: 99-011-X2011001). Retrieved January 27, 2015.
35   Ibid.
36   Parliamentary Committee on Palliative and Compassionate Care, "Not to Be Forgotten: Care of Vulnerable Canadians" (2011), p 39.

OUR END-OF-LIFE CARE LANDSCAPE

The 2011 CIHI Seniors Report concludes with the following statement:

> As age advances, the inevitability of the end of life becomes more salient, and the focus of care may therefore shift from treatment to palliation. As Canada's population ages, taking a patient-centered approach to planning end-of-life care will be increasingly important. The literature suggests that seniors prefer to die in their own homes. Despite this, palliative care was among the top ten conditions for which seniors were hospitalized in Canada in 2009–2010. Eight out of every ten adults who died in hospital, and who had been receiving palliative care, were seniors. Most deaths in Canada occur in one of four settings: at home, in long-term care, in hospice or in an acute care hospital. In the decade between 1996 and 2006, the proportion of Canadians dying in hospital declined steadily, from 73% to 60%. This downward trend of in-hospital death corresponds with growth in community-based end-of-life care.[37]

As the report goes on to indicate, Canadians are united in their belief that health care needs to become more patient-centered if it is to improve; however, the only health care that "offers such care consistently, effectively, and across all jurisdictions is palliative care."[38] It must be noted that palliative care is designed to treat those who are dying at any age and is not about prolonging life but about reducing pain and suffering. As such, it is a "patient-centered, family-focused, and community-based care of the whole person."[39] Currently, palliative care strategies are employed in some but not all of our acute care facilities. Yet what many Canadians are unaware of is the fact that hospital-based acute care is only part of a larger continuum of the health care delivery system.

In order to better understand the current situation, it will be helpful to look at the current palliative care landscape through its FOUR main sectors:

- Palliative Care in the Home

- Community Care Hospices

- Long-Term Care Facilities (LTCs)

- Palliative Care in an Intensive Setting[40]

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37   CIHI, Health Care in Canada. "A Focus on Seniors and Aging." 2011.
38   Not to be Forgotten. P.23
39   Ibid.
40   See Hierarchy of Care Environments, "Not to Be Forgotten," p.28, for a finer breakdown of these areas into eight more distinctive levels. Our work is a continuation of this categorization, but due to limited data on the finer stratifications, we have kept our breakdown into these four main sectors.

SECTOR ONE: PALLIATIVE CARE IN THE HOME

This form of palliative care is delivered primarily by family, but is often accompanied by regular home-care staff and supported by palliative care specialist teams. The person who is ill lives at home and enjoys the natural supports of family, friends, neighbours, spiritual communities, plus their own family physician and local health care providers.[41]

As reported earlier, at least 75% of Canadians would prefer to die in their home.[42] Data are limited on rates of home care use throughout the country, which has resulted in multiple calls for a renewed research strategy. This would allow us to better understand where home care is being utilized, which communities do it best, and the precise costs, among other things. Based on several reports (most specifically, the 2011 CIHI "Report on Seniors and Aging"), we present a limited small glimpse at some aspects of home care in Canada today.

It has been projected that about 1 million Canadians are receiving home care at any moment in Canada and the majority (82%) are aged 65 or older.[43] A variety of professionals—such as nurses, physiotherapists and social workers—provide home care, but the majority of home care providers are support workers—home health aides, personal support workers, personal care workers and home health attendants.[44] In addition to these supports, family caregivers also provide significant levels of care: some 70%-80% of care given in Canadian homes and communities, worth an estimated $25 billion per year.[45] Just over 3.1 million Canadians were estimated to have provided informal care to home care recipients in 2007, totaling over 1.5 billion hours.[46]

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41 "Not to be Forgotten" p.28.
42 Arnup, Katherine, "Death, Dying and Canadian Families." p 14.
43 Canadian Institute for Health Information, Quick Stats: Home Care Reporting System, 2009–2010 (Ottawa, Ont.: CIHI, 2011).
44 CIHI, Seniors Report 2011. 2011. p. 74
45 M. J. Hollander et al., "Who Cares and How Much?," Health Care Quarterly 12, 2 (2009): pp. 42–49.
46 Hermus Greg, Carole Stonebridge, Louis Theriault, and Fares Bounajm. Home and Community Care in Canada: An economic footprint. (Ottawa: The Conference Board of Canada) 2012. p. ii.

ESTIMATED CONTRIBUTION OF UNPAID CAREGIVERS IN CANADA

2.4 BN HOME MAINTENANCE / OUTDOOR WORK

3.6BN SHOPPING (GROCERIES ETC), TRANSPORT, BANKING, BILL PAYMENT

11BN MEAL PREP, HOUSE CLEANING, LAUNDRY, SEWING

3.5BN BATHING, TOILETING, HYGIENE, DRESSING
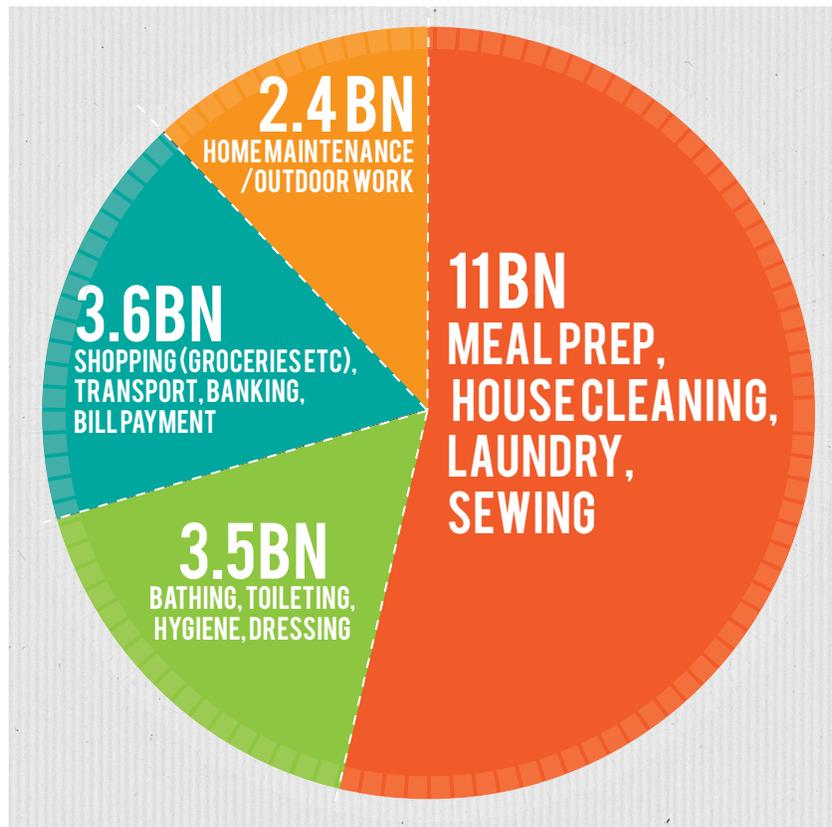
Figure 6 Data Source: M. J. Hollander et al., "Who Cares and How Much?," Health Care Quarterly 12, 2 (2009)

The care of "informal caregivers" helps seniors attain a more natural death where they are able to receive the right care from the ones most intimately connected to them. Yet home care must be coordinated with other healthcare providers and services, particularly as seniors become more dependent or obtain a serious illness or condition. It's for this reason that the "Not to be Forgotten" report differentiates between several levels of home care. As they note, "home support services include assistance with activities such as homemaking and personal care (for example, bathing, dressing, and eating)... home care may also include provision of adult day programs, meal services, home maintenance and repair, transportation, and respite services."[47]

It is also important that home care is embedded into larger social structures—or social architecture—since seniors still long to be connected to their communities. "Not to be Forgotten" provided a helpful list of other social institutions which partner with home care recipients to allow them continued participation in local, community life. The list included seniors' centers, outreach services, respite care, adult day programs, internet-based support groups, Meals on Wheels, home and yard maintenance, and escorted transportation to essential appointments. [48]

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47   CIHI, Seniors Report 2011.
48   Ibid.

SECTOR TWO: COMMUNITY CARE HOSPICES

These institutions are outside of the home, but work at a community level and allow the dying person to stay close to home, while offering a full range of palliative care supports. The patient cannot be taken care of at home and moves into a free-standing hospice program where elements of home care are still possible. Aspects of care are provided by the program's own staff and volunteers. The greater the extent to which one can use one's own community, family, friends, and volunteers (and thus less professional staff) the better.[49]

According to the Canadian Hospice Palliative Care Association,

> "Hospice palliative care strives to help patients and families address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears; prepare for and manage self-determined life closure and the dying process; and cope with loss and grief during the illness and bereavement. Hospice palliative care also aims to treat all active issues, prevent new issues from occurring, promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization." [50]

What is important in this definition is that hospice care seeks to meet the diverse needs of individuals and their care community beyond the death of the loved one. It provides care to the dying and to those who mourn and are affected by the loss.

In many ways, hospices are uniquely situated to administer the end-of-life palliative care most want, but are still drastically in short supply. In the "Not to be Forgotten" report, it was noted that "there should be no expectation that all families will care for their loved ones [since it] would not be reasonable, given levels of family dysfunction, geographic distances, internal family problems, career and financial considerations, abilities, etc."[51] For this reason, the researchers suggest that "small community hospices are essential for improved end-of-life care in Canada. In Vancouver, for example, the model chosen was to build small five or six bed hospices throughout the metropolitan area. Small, local hospices keep people closer to their communities, closer to the life they knew before they got sick. They are more responsive to people's desire for a homey family atmosphere, in a way a large institution can never be."[52]

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49   "Not to be Forgotten" p. 29
50   CHPCA. Hospice Palliative Care in Canada: A Brief to the Special Senate Committee on Aging. 2007.
51   "Not to be Forgotten" p. 30.
52   Ibid.

Over 60% of deaths are caused by cancer and chronic illnesses, which should allow planning that would let many of these patients die comfortably at home or in a hospice. Caring for terminally ill patients in an acute-care hospital is estimated to be more than double the cost of providing care in a hospice bed. According to a Hospice Palliative Care Ontario, "The total average cost of a palliative-care hospice bed is $460 a day (excluding drug costs)," which is "much less than the $1,100 provincial average daily cost of providing palliative care to a patient in an acute-care hospital bed."[53]

PER-DAY COST OF PROVIDING PALLIATIVE CARE IN ONTARIO

COST PER DAY

$460 HOSPICE BED

$1100 ACUTE-CARE HOSPITAL BED

$630-770 HOSPITAL PALLIATIVE CARE UNIT

LESS THAN $100 HOME CARE
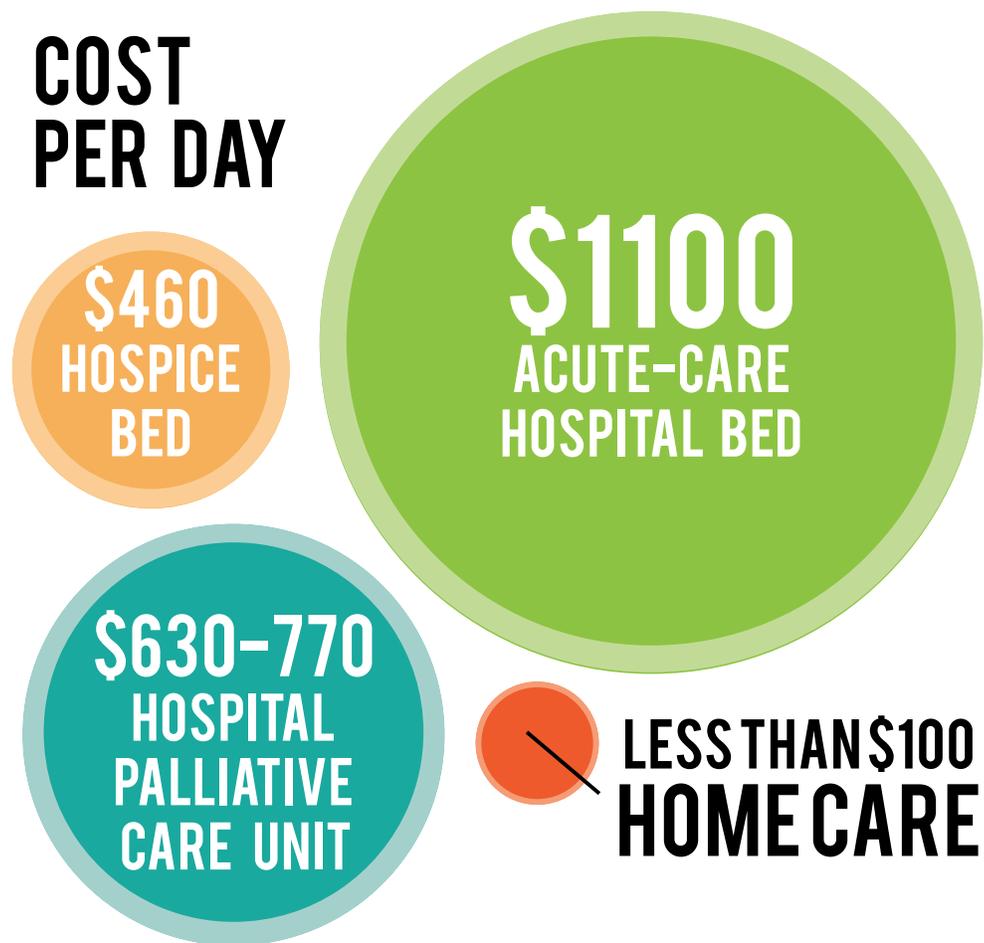
Figure 7 Data Source: Ministry of Health and Long-Term Care. 2014 *Annual Report of the Office of the Auditor General*

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53   *Palliative Care Report*. 2014. P. 265

Again, a current barrier to improving the hospice program across Canada is a lack of reliable data. As noted in the previously mentioned 2014 Ontario Ministry of Health and Long-Term Care Report on palliative care, it was not even aware of 10 hospices with a total of 59 beds, even though six of the hospices received Ministry funding through other programs.[54]

Rather than thinking in terms of "beds" and trying to pre-determine the demand for various types of beds, be they acute care, long-term care, or hospice care, it would be helpful for health officials to think in terms of patients that are likely to need care and to provide support for funding for these patients, regardless of the setting where care is delivered. We recognize that this is a complex matter with broad health system implications that cannot be simply implemented. However, the Ministry could facilitate flexibility in program delivery for a variety of organic community-developed programs and institutions which, by their very character, respond to the needs of local communities. Viewing seniors as "beds" and "dollar amounts" is necessary at times, but also part of a deeper, more systemic problem that becomes a barrier to improving long-term care as a natural place for people to die.

SECTOR THREE: LONG-TERM CARE FACILITIES

Also provided outside of the home, long-term care facilities deliver palliative care through a range of in-house and visiting specialist staff.[55]

Long-term care facilities are designed for individuals who are no longer able to live at home due to an inability to receive appropriate care without additional help or facilities. Long-term care homes provide assistance for almost all of the daily activities of residents. 24-hour nursing and personal care is available and individuals have access to different types of rooms featuring more or less privacy depending on their state of health. Staff in such homes are responsible for providing services, including dinner planning, cooking, laundry, and cleaning, in order to alleviate the otherwise difficult tasks that would cause discomfort and potentially create a risk of injury.

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54   Ibid.
55   "Not to be Forgotten" p. 29

Using 2011 data from Statistics Canada, researchers of the 2011 CIHI report noted that "In 2008–2009, […] there were 4,845 residential care facilities in Canada, comprising nearly 270,000 beds."[56] The report goes on to show that:

> Almost half (46%) of these facilities were homes for the aged, delivering services specifically to seniors. Among residents in all facilities (excluding those in Quebec), 42% of those in homes for the aged were older than age 85, of which 78% were female. Across jurisdictions, there was variation in the services and number of beds in homes for the aged per senior population. On average in Canada in 2008–2009, there were 46 beds staffed and in operation per 1,000 seniors age 65 and older, ranging from 35 in Quebec to 89 in Prince Edward Island.[57]

In Ontario, close to 50% of residents who are in a long-term care facility die each year,[58] which makes these facilities a frequent place of death. But there are already signs that positive change is happening. In Ontario, this information has led to a significant shift towards the provision of end-of-life palliative care in long-term care facilities that began with a new long-term care act in 2007. The act mandated that palliative care education be taught to every staff member at long-term care facilities.[59]

These signs of positive change go beyond Ontario. Rates of institutionalization among seniors have declined across the country. Again, the 2011 CIHI report took note that "in 2006, only 1.4% of those between age 65 and 74 and 12% of those 75 and older lived in a special care facility as defined by the census. In 1981, rates were 3% and 17%, respectively."[60]

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56   Includes all types of care, ranging from room and board with custodial care, with a maximum of 30 minutes of care per day, to 24-hour monitoring outside of an acute care setting. Statistics Canada, Residential Care Facilities 2008/2009 (Ottawa, Ont.: Statistics Canada, 2011).

57   CIHI. Report on Seniors and Aging. 2011. p. 100

58   "Long-Term Care Homes: Hospice of the Future." Quality Palliative Care in Long Term Care.

59   http://www.e-laws.gov.on.ca/html/source/regs/english/2010/elaws_src_regs_r10079_e.htm

60   Statistics Canada, *Selected Collective Dwelling and Population Characteristics and Type of Collective Dwelling for the Population in Collective Dwellings of Canada, Provinces and Territories, 2006 Census* (Ottawa, Ont.: Statistics Canada, 2011), catalogue no. 97-554-XCB2006054.

SECTOR FOUR: PALLIATIVE CARE IN A HOSPITAL SETTING

The person moves to a hospital with a specialized team and/or palliative care unit. The quality and compassion of palliative care supports may be similar in many cases to what one would receive at home, but the providers are mostly new people who share little common history with the person who is ill and, therefore, the naturalness of one's own community is somewhat lost. The caregiver roles that are played by family and friends are often reduced to "visitor" roles.[61]

While it might be easy to disparage the hospital setting, particularly as a place where it is unlikely that Canadians could receive a natural death, hospital-based palliative care should be located on the continuum of care. While the hospital might not be the preferred place for most to spend their last days, this is no reason to ignore the very good and necessary role that hospital-based palliative care plays for many.

One key note is that the cost of palliative care in a hospital setting is often less than providing palliative care in an acute-care bed.[62] The Ontario "Palliative Care Report" found that "at two hospitals visited that tracked comparable information, the cost of a bed in a palliative-care unit ranged from $630 to $770 per day, compared to the provincial average of over $1,100 per day for a regular acute-care hospital bed."[63] The breakdown of hospital beds versus other end-of-life care beds varies in different regions; for example, the Edmonton Zone of Alberta Health Services and British Columbia's Fraser Health Authority proposed that about 80% of beds should be in hospices and 20% in hospitals.[64]

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61   "Not to be Forgotten," p. 29
62   *Palliative Care Report.* 2014. P. 265
63   Ibid.
64   Ibid.

DID YOU KNOW?
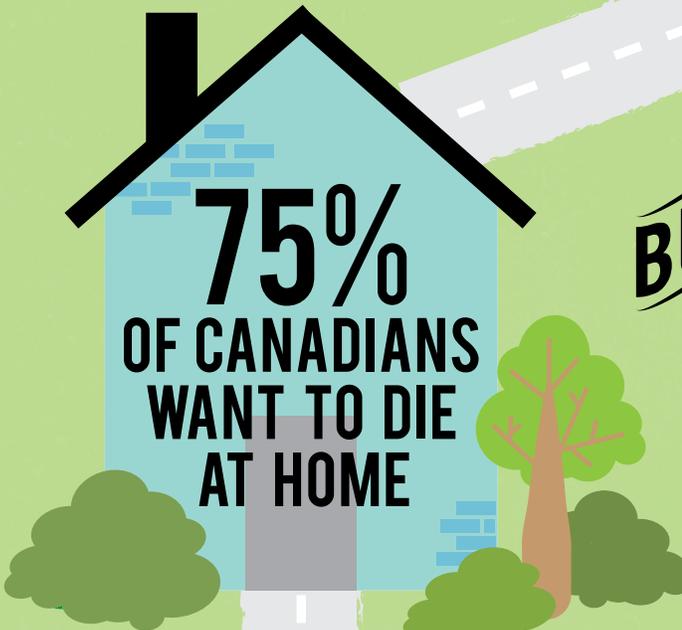
75%
OF CANADIANS
WANT TO DIE
AT HOME
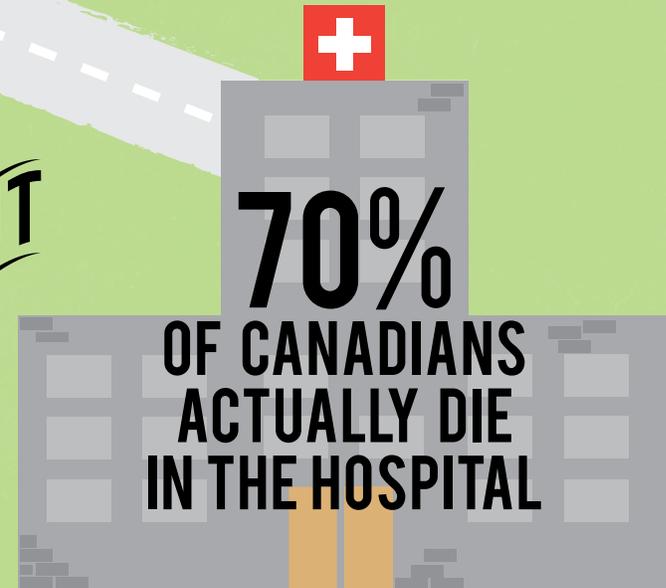
BUT

70%
OF CANADIANS
ACTUALLY DIE
IN THE HOSPITAL

WHY?

BECAUSE OF BARRIERS TO
CANADIANS NATURAL DEATH:

INTEGRATED DELIVERY MODELS

CAPACITY

ADVANCE CARE PLANNING

PUBLIC EDUCATION

SYSTEMIC SUPPORT FOR NON-HEALTH COMMUNITIES

HEALTH PROFESSIONAL EDUCATION
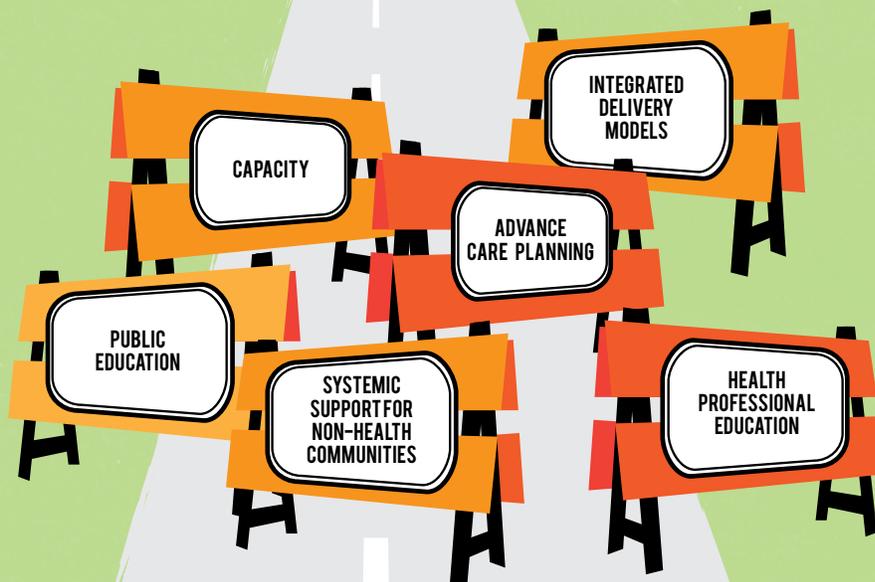
BARRIERS TO AN IMPROVED END-OF-LIFE CARE LANDSCAPE

The above snapshots of home care, hospices, long-term care facilities, and hospital-based palliative care present the options available, in varying degrees of consistency depending on region, across Canada. While our argument suggests that all of these options might be good places to have a natural death, there are six identifiable barriers to creating an integrated system where all options on this continuum of care are both available and allow for more easy transition between them. These barriers include:

- *Limited Capacity of Hospital-based Palliative Care*

- *Professional Education*

- *Advance Care Planning*

- *A Fragmented System*

- *Lack of Community Support*

- *Public Education*

LIMITED CAPACITY OF HOSPITAL-BASED PALLIATIVE CARE

On an average day in Canada, 4,400 seniors are in acute care beds waiting for alternative care placements.[65] In addition to increasing healthcare costs, prolonged hospitalization is associated with increased health risks and does not respect the wishes of most patients. Since acute care beds are the most expensive option for palliative care, they should only be used for patients with complex conditions requiring that level of care.[66] This highlights the need to have a sufficient number of palliative care beds available for those who cannot be cared for in the home setting and do not need all the supports that an acute care facility provides.

In the Canadian Hospice Palliative Care Association's report "The Way Forward," Jean Bacon argues that "[a]lthough only a small proportion of people who die of chronic diseases, such as heart failure, respiratory illnesses or dementia will need intensive palliative care provided by specialized palliative

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65   CIHI, 2011, p 118.
66   Ministry of Health and Long Term Care, 2014, p. 265.

care teams in hospices, the home or other settings, everyone faced with a life-limiting illness can benefit from other aspects of palliative care."[67] This is to say that not all dying people need to be placed within a hospital; in fact, many that are not chronically ill could likely be better served in an alternative care facility such as a hospice.

That same report goes on to indicate that the lack of access to palliative care is "a growing public health issue"[68] since it places undue pressure upon the acute-care facilities. This pressure might be relieved by having more individuals better served in alternative locations.

NEED FOR PALLIATIVE CARE FOCUS IN PROFESSIONAL EDUCATION

Another challenge to improving end-of-life care is the need for palliative care education among our healthcare professionals. While the rates of education have improved in the past ten years, there is still much more to be done. In Ontario, there are currently no minimum education requirements for physicians or nurses providing palliative care.[69] While medical students must receive some education on end-of-life care, any physician in Ontario can refer to him or herself as a palliative care physician.[70]

With the current palliative care gaps in healthcare education, it is not surprising that knowledge on advance care planning, palliative options, and the process of making end-of-life decisions varies from region to region. Yet as Jean Bacon puts it, "the goal of [health] education should be to de-mystify end-of-life planning and help primary care practitioners be mindful of the bigger picture."[71]


PERCENTAGE OF CANADIANS WHO HAVE PLANNED FOR END-OF-LIFE

76.3% THOUGHT ABOUT FUTURE CARE BEFORE HOSPITALIZATION

30.3% DISCUSSED WITH PHYSICIAN

47.9% ADVANCE CARE PLAN COMPLETE

73.3% NOMINATED SURROGATE DECISION MAKER

11.9% PREFER LIFE-PROLONGING CARE, INCLUDING RESUSCITATION
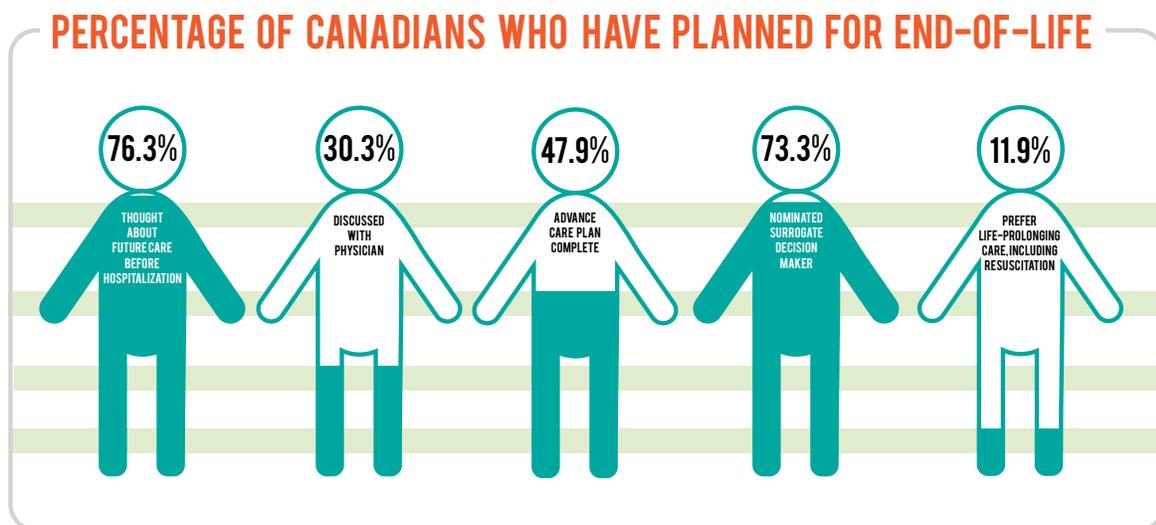
Figure 8 Data Source: Heyland et al., "Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Health Care Planning". *JamaInternalMed* (2013).

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67   Bacon, Jean, "The Way Forward: An Integrated Approach to Palliative Care," Canadian Hospice Palliative Care Association, (2012), p. 5.
68   Ibid.
69   Ministry of Health and Long Term Care, 2014, p. 261.
70   Ibid, p 267.
71   Bacon, Jean, "The Way Forward: An Integrated Approach to Palliative Care," Canadian Hospice Palliative Care Association, (2012), p. 11,12

LACK OF ADVANCE CARE PLANNING

One significant barrier to improved healthcare that is connected to professional education is the need for improved advance care planning. As Fowler and Hammer note in their report on end-of-life care in Canada,

> Advance care planning occurs very uncommonly. […] Most patients (76%) had thought about end-of-life care, and only 12% preferred life-prolonging care; [but only] 48% of patients had completed an advance care […]. Of patients who had discussed their wishes, only 30% had done so with the family physician and 55% with any member of a healthcare team.[72]

Challenges and Issues in 2010: The Quality End-of-Life Care Coalition of Canada states that "one of the key challenges over the next ten years will be persuading Canadians that end-of- life care planning is important for everyone, not just those diagnosed with a life-limiting illness, such as cancer."[73]

A FRAGMENTED SYSTEM

Another large barrier to a more integrated care model is the currently fragmented nature of the end-of-life care institutions across the landscape. Whether in terms of availability, accessibility, funding, ease of movement between institutions, or incentive programs, the current landscape contains many inconsistencies. For example, the Quality End-of-Life Care Coalition of Canada (QELCCC) found that "in Ontario the Ministry currently funds the full cost of palliative care services in the hospital setting, while it only pays a per-bed amount in the hospice setting, which covers the costs of nursing and personal support services. It is estimated that this only covers 50% of the cost of hospices."[74] This means that hospices are expected to generate their own revenues to cover the remainder of the costs through fundraising and donations and, because of this, most depend upon volunteers in order to operate.[75]

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72   Heyland, DK, et al., 2013, p 5.
73   Quality End-of-Life Care Coalition of Canada, 2010. p.18.
74   Ibid, p 9.
75   Ministry of Health and Long Term Care, 2014, p. 267.

HOW DO WE PREPARE
FOR NATURAL DEATH?

WE NEED MORE
THAN HEALTH CARE,
RIGHT?

WHO WILL
HELP ME?

WHEN DO WE START
PLANNING?

CAN THE HOME CARE
NURSE COME WITH US?

WHERE DO WE
TURN FIRST?

PATIENT'S NEEDS:

- PAIN AND SYMPTOM MANAGEMENT
- EMOTIONAL AND SPIRITUAL SUPPORT
- APPROPRIATE PHYSICAL SPACE
- THE GOALS OF CARE

CAREGIVER'S NEEDS:

- EMOTIONAL AND SPIRITUAL SUPPORT
- INCOME SUPPORT
- RESPITE CARE
- BEREAVEMENT CARE

LACK OF SUPPORT FOR RURAL COMMUNITIES

"Not to be Forgotten" reported on the fact that access to a variety of end-of-life care options was not always equally available to rural populations. The report noted:

> If there is a form of "two-tiered" health care in Canada it would be the distinction between urban and rural areas in terms of health care delivery. Canada's health policy has emphasized urban centres, attempting to adopt urban models of health care to rural health care delivery. Certainly as vast an area as Canada, with a widely dispersed population, makes it extremely challenging to deliver health care to rural and remote areas. [76]

A real barrier to improved end-of-life care in Canada is the lack of support for local communities of care. Physician availability to do house calls varies greatly by location, particularly in rural and remote areas. In Canada, it is estimated that "there are close to seven million people who live in rural areas and communities that are made up of only a few thousand people."[77] This makes it difficult for specialized physicians and medical services to be offered to every community, therefore, rural people must often travel to an urban center in order to receive the care they need.

There are signs that work is being done to improve this. Many provinces recognize the need to invest in home and community care in order that proper palliative care can be provided to individuals in their communities. For example, the government of Newfoundland and Labrador has been investing steadily in home and community care, with investments valued at $480 million from 2006-2012.[78]

A NEED FOR PUBLIC AWARENESS

A final barrier to improving quality end-of-life care is that Canadians are often unaware of their end-of-life care options and are therefore ill-equipped to take the necessary steps in advance care planning. This lack of knowledge about the availability of pain-relief programs and alternative palliative care models has meant that many will find themselves in an unfavourable situation at the end of their lives that they might not have been in otherwise.

Rather than focusing on "more care and resources," solutions focused on "right care"—defined by CIHI as care "in the right, place, at the right time, to the right person, in the most efficacious way possible"[79]—needs to be prioritized. Many Canadians are still not aware of all the available palliative care services or how they can best access them, which leads to an inappropriate use of services, increased health care costs, and possibly unnecessary patient suffering.

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76   "Not to be Forgotten," p. 40.
77   Statistics Canada, Selected Collective Dwelling and Population Characteristics and Type of Collective Dwelling for the Population in Collective Dwellings of Canada, Provinces and Territories, 2006 Census (Ottawa, Ont.: Statistics Canada, 2011), catalogue no. 97-554-XCB2006054.
78   Sullivan, S.) "Close to Home: A Strategy for Long-Term Care and Community Support Services. Government of Newfoundland and Labrador, (2012). p 3.
79   CIHI. Health Care in Canada, (Ottawa: 2010), P.42

REFRAMING THE CONVERSATION

The current challenges regarding the delivery of end-of-life care cut through jurisdictions, partisan affiliations, and institutional spheres. Whether at the federal, provincial, or regional level; and whether designed for politicians, educators, healthcare professionals, community workers, or the individual Canadians who must plan care for themselves or for their loved ones, the following recommendations reflect an attempt to bring us together with the common goal of improving end-of-life care in Canada. They seek to reframe the current conversation, and to amplify those voices in the conversation that have been calling for such change. The following recommendations are organized according to three lenses through which we can see end-of-life care in a new light: [80]

- Natural Death

- Social Architecture

- Continuum of Care

By examining end-of-life care through each of these lenses, our hope is that care in Canada will recover the central role of the patient and natural care communities. In order to die naturally, which is what most Canadians want, we do not need to abandon the hospital in favour of our homes; rather, the best end-of-life care environment is where the full continuum of institutions are available to all, sustained by a range of community and federal supports, and are not obstructed by the barriers discussed earlier in this report. Such a thriving, patient-centered, end-of-life care strategy would form an integral part of a healthy social architecture and lead to an improved end-of-life care strategy for more Canadians.

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80   Many of the following recommendations are derived from: Quality End-of-Life Care Coalition of Canada. Blueprint for Action 2010 to 2010. Ottawa, ON. Other worthwhile recommendations can be found in the following reports: Ministry of Health and Long-Term Care. 2014 Annual Report of the Office of the Auditor General. for the Province of Ontario; and: "Not to Be Forgotten: Care of Vulnerable Canadian" Parliamentary Committee on Palliative and Compassionate Care. Ottawa: 2011; and Ministry of Health and Long-Term Care. 2014 Annual Report of the Office of the Auditor General. For the Province of Ontario; however, we believe these recommendations are useful across the provinces and territories. Our purpose here is not to reinvent the good recommendations already brought forward in the past decade; rather, we are seeking to re frame these recommendations through our three lenses and, where possible, to encourage a grassroots type of revival over-and-against top-down directives.

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.

While most Canadians desire a "natural death," few plan for it. One strategy to overcome this hurdle is a public awareness campaign that informs Canadians about what natural death is and what the available options are, and urges them to develop care plans for themselves and their loved ones. Given the current lack of awareness about available options, there is little reason to be surprised that hospitals are often a default location for end-of-life care.

In connection to increasing public awareness, doctors might also be encouraged to provide more information about advance care planning and palliative care options during routine check-ups. A parallel example might help to illustrate this policy. Doctors in Ontario are already incentivized to promote smoking cessation; in fact, the 2009 *Guide to Physician Compensation* states: "Physicians are entitled to receive an annual incentive of $15.40 added on the normal visit fee for dialogue with enrolled patients who smoke."[81] This has caused cessation rates to rise by 12%, making such programs very effective.[82] If such incentives can work for smoking cessation, they might also work to improve the rate of advance care planning for many Canadians.

Since one of the largest barriers to home care access is the financial demands it places upon natural caregivers, a more comprehensive set of caregiver programs that coordinates financial and social supports would be helpful. This would help local caregivers better provide home care in every region of the country, according to the specific needs they have in their unique communities. Such changes are not only more compassionate and humane, but also in society's economic self-interest. To economically support the natural caregivers of those with a terminal diagnosis can help keep dying patients out of the most expensive acute care beds and into less-costly ones where their end-of-life needs are much better met.

One way to relieve the financial demands on natural caregivers is to rethink the Compassionate Care Benefit. Presently Canada provides a Compassionate Care Benefit through the Employment Insurance system, which until very recently was only six weeks. The recent federal budget has increased Compassionate Care leave from six weeks to six months,[83] which is a very good step in the right direction. However, there are other ways in which the Compassionate Care Benefit might be re-imagined in order to further assist natural caregivers at the end of their loved one's life. Various proposals, including reducing the waiting period to receive financial assistance, increasing the amount of

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81   Government of Ontario. Guide to Physician Compensation, (2009), Accessed April 2015.http://www.health.gov.on.ca/en/pro/programs/fht/docs/fht_compensation.pdf

82   "Effectiveness Matters: What Smoking Cessation can Do" NHS Centre for Reviews and Dissemination, (3(1):1998). Accessed April 2015. <https://www.york.ac.uk/media/crd/em31.pdf>.

83   "Making Ends Meet," Economic Action Plan, 2015. Government of Canada. (2015). Accessed April 2015, http://www.budget.gc.ca/2015/docs/plan/ch1-eng.html#_Toc417204087

assistance that is provided, or further increasing the length of those benefits have been discussed. In addition, providing more flexibility so that such assistance can be taken in partial, rather than full-week, blocks would also greatly assist natural caregivers. Whatever the case, such supports like the Compassionate Care Benefit given to natural caregivers are one way to encourage end-of-life care options at the most local and intimate levels while simultaneously relieving hospitals of providing this care in a more costly manner.

In Canada, we have made great strides in supporting parents during the first year of a child's life with maternal and paternal leave options. Yet respect for life's dignity needs to ensure that our citizens are provided support not only when they need it at the beginning of their lives, but similarly during the last year of their lives.

Rethinking support for natural caregivers means thinking about how individuals or communities might also invest into better end-of-life care. For instance, if the Compassionate Care Benefit had a companion program, like the Registered Retirement Savings Plan (RRSP) or the Registered Disabilities Saving Plan (RDSP), individuals could pay into such a plan on a regular basis and the government could encourage such saving plans by matching them to a certain percentage. Natural caregivers might draw from this when the time came for them to care for a dying loved one. Such policies would help to relieve the financial burdens that affect natural caregivers.

Apart from funding, another significant barrier to having a "natural death," is a lack of current data for end-of-life care in Canada. Particularly since home care has several subtypes, we do not yet have the information needed to pinpoint where weaknesses in the landscape are and which options are available in various regions throughout Canada. For this reason, we recommend a coordination of data collection on the full range of end-of-life care institutions so that it will be possible to better understand the current state of affairs.

Such research can then be used to convene discussions where best practices could be shared across regions and between the various stakeholders of end-of-life care. The list of such stakeholders is diverse: doctors, nurses, hospice care providers, natural caregivers, long-term care facility workers, support staff, government officials, urban planners, religious leaders, social workers, counsellors, and psychologists.

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.

The full range of end-of-life care institutions involves home care and hospices, long-term care facilities and hospitals. Yet a social architecture approach realizes that all of these end-of-life care options must also be embedded into a wider range of social institutions which make up our shared lives together. Therefore, our argument is that a flourishing end-of-life care landscape coincides with a flourishing social architecture in which the full range of end-of-life care options are connected.

It is easy to see social architecture as an urban phenomenon, since the city is the place where so many institutions—community centres, libraries, schools, banks, and churches—intersect on a daily basis. However, even within cities, breakdown of social cohesion exists and individuals can be isolated and alienated while surrounded by many people. From a social architecture perspective, then, one of the largest challenges concerns the many Canadians who do not have access to close community. Finding ways to support palliative options outside of dense urban populations or within populations with high degrees of social disintegration must be a key priority. We need to work on finding ways to bring the full range of palliative care options to these locations and make access to quality end-of-life care less dependent upon where one lives.

In the emerging landscape of palliative care, new organizations are forming. Pallium Canada encourages collaboration between stakeholders in order to promote education about, and standardization of, palliative care in Canada,[84] while the Canadian Virtual Hospice works to provide up-to-date information on palliative options and support programs across Canada.[85] It is likely that other organizations like these will emerge, but in order to encourage them and better equip them for their work, they will need a stable source of funding. In addition, finding ways to seek out, foster, and support more ground-level innovators already doing good work in this area is essential for building a robust social architecture. Convening round tables between regional leaders might be one of the best ways to share best practices across regions and encourage innovation at the local level.

A social architecture approach also means aligning our perceptions so that we see dying seniors as full humans, not just as "beds" and "cost-benefit" analyses. It is often easy to look at the baby-boom generation and their end-of-life care needs as only a portion of our GDP to be quibbled over, but that's often an unhelpful starting point that does not put individuals and their natural caregivers at the center. This is not to say that costs don't matter—and a portion of this report looked at the costs for

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84   See: http://pallium.ca/
85   See: http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

this reason—but it is to caution against reductive language rather than placing humans in all their complexity at the center of our end-of-life care discussions. Doing this allows us to re-imagine the full range and variety of institutions on the end-of-life care continuum as not merely where people go to eat and sleep, but also where they want to worship, play games with friends and family, tell stories, and have the kind of full life most of us want.

As mentioned earlier, creative ways of improving end-of-life care are developing throughout the world. In the Netherlands, for instance, long-term care facilities have been connected with universities in a program that gives free rent to university students willing to live in long-term care senior homes. While benefiting students with affordable housing options, such intergenerational housing intentionally seeks to connect seniors with the broader community. Similar innovations exist in Lyons, France; Cleveland, Ohio; and several cities throughout Spain.[86]

Successful innovations in end-of-life care demonstrate that embedding the individual within his or her natural community puts the desire of the patient first. Yet such innovation doesn't happen in a vacuum. Discussions need to be coordinated on the ground level between health care providers, palliative care specialists, and local residents, and other stakeholders to better understand the cultural, psycho-social, and religious needs of decedents. From these discussions, we can begin to imagine more creative solutions that better enable a natural death for more Canadians.

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 we our fellow citizens and their loved ones travel the journey through to the end of their natural lives.

The continuum of care presupposes a robust social architecture and is primarily concerned about the ease with which individuals might move from home care to a hospice or a long-term care facility to a hospital without ever losing the ability to have a natural death. As care moves from life-prolonging treatment to pain management and ensuring comfort, having better education on diagnostics and better plans in place will help to ensure that patients no longer needing life-prolonging treatment are either put into the appropriate care setting, or that the care setting can better provide a natural death.

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86   Reed, Carey. "Dutch Nursing Home offers rent-free housing to students." PBS Newswire. April 5, 2015. Available at <http://www.pbs.org/newshour/rundown/dutch-retirement-home-offers-rent-free-housing-students-one-condition/>

One of the first ways to move towards such a continuum is to better coordinate data around patients. Ministries of Health, working together with Local Health Integration Networks (as they are called in Ontario—variations exist in other jurisdictions), might find better ways to give all healthcare providers in the continuum easy and timely access to a person's medical records and end-of-life care plan. In addition to this information, such a system could track and report the extent of time that patients spend waiting in more expensive acute care facilities when they might move to more suitable accommodations and open up beds and other resources to individuals who might require life-prolonging measures rather than palliative care.

But more than data is needed, and for this reason both within the Local Health Integration Networks and across the provinces, governments should work to implement a coordinated system for the delivery of palliative care that enables patients to move easily among health care providers and receive needed palliative-care services on a timely basis.

Another barrier to improving the continuum of care is perception. Often moving into a hospice is seen as the "end" of home care, which means that many natural caregivers stop providing care at this point. However, this does not have to be the case. We need to find ways to encourage natural care providers—family members, religious leaders, and friends—to continue their involvement with care in the hospice setting. In order to do this, some of the caregiver relief mentioned above should remain in place for caregivers who continue to help in the hospice setting.

Again, in addition to top-down change, we might also convene conversations that cross health and social service institutional lines (health, education, finance, human resources, First Nations, veterans, and non-governmental organizations, such as unions and insurance associations). The role of these organizations would be to consult with communities and make recommendations to advance palliative end-of-life care. Such conversations might help us gather the following:

- The determination of available palliative-care resources and the total cost of currently providing palliative care services;

- An analysis of the cost of providing palliative care through different service providers (for example, hospital versus hospice versus home care);

- A projection of the best mix of services (for example, hospital versus hospice versus home care) to meet current and future patient needs;

- An assessment of current and potential future funding structures; and

- A position on educational requirements for health-care providers who provide palliative care.[87]

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87   This list has been taken from a report published by the Auditor General of Ontario. See Ministry of Health and Long-Term Care. (2014) Annual Report of the Office of the Auditor General.

Finally, the continuum of care suggests that the hospital may be the best place for end-of-life care in some cases. There are some patients for whom the supports available in a hospital-based palliative wing are best suited for their condition, just as for others the best place of care might be their home. And despite our wishes and hopes, circumstances at the end of life are often unpredictable and could mean that the care we want might not be best option. However, for too many Canadians today, hospital-based palliative care is the only option available when dying becomes too difficult for the home environment and natural caregivers. Advance care planning can provide an earlier consideration of options, so that the full range of palliative options are utilized.

CONCLUSION

Social change is a mysterious phenomenon. It occurs when there is a mix of increased public awareness, changed behaviours, new government programs, and the creation of civil society organizations that can deal with issues often rarely even considered years before.

For example, in the '70s and '80s, the need to prepare for retirement became a large part of our social consciousness, which led to the creation of an RRSP program and private and government pension plans. Such changes combined to create not only a consciousness, but also the practical means of meeting the recognized need. Today, retirement planning is widespread and an entire industry of financial planners and mutual funds have developed.

Similarly, an awareness of the negative health impacts from smoking became mainstream in the '70s. Through a combination of government programs and regulations, as well as the development of civil society organizations meant to help educate the public, the cultural practices around smoking today are very different than they were just a few decades ago.

We are in the midst of a similar social change when it comes to end-of-life care.

Recognizing this, our report tries to articulate the shape of a movement already underway more than it attempts to break any new ground. It seeks to highlight that while there are many good developments in research, data collection, and collaboration, and while there is a slow-yet-increasing awareness of the importance of palliative care, there is still much more to be done.

Our hope is to reframe these good discussions through the lenses of natural death, social architecture, and the continuum of care. This unique approach not only considers the system by which healthcare is provided, but places the patients and caregivers at the centre of the discussion, attuning policy to their needs. Our hope is that in some small way this will contribute to our common goal of helping to bring the best care to some of the most vulnerable among us, and to continue making Canada a country we are proud to live in and also unafraid to die in.

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