



# Improving the Last Stages of Life

**DISCUSSION PAPER**



LAW COMMISSION OF ONTARIO  
COMMISSION DU DROIT DE L'ONTARIO

## ABOUT THE LAW COMMISSION OF ONTARIO

The Law Commission of Ontario (LCO) was created by an Agreement among the Law Foundation of Ontario, the Ontario Ministry of the Attorney General, Osgoode Hall Law School and the Law Society of Upper Canada, all of whom provide funding for the LCO, and the Law Deans of Ontario's law schools. York University also provides funding and in-kind support. The LCO is situated in the Ignat Kaneff Building, the home of Osgoode Hall Law School at York University.

The mandate of the LCO is to recommend law reform measures to enhance the legal system's relevance, effectiveness and accessibility; improve the administration of justice through the clarification and simplification of the law; consider the use of technology to enhance access to justice; stimulate critical legal debate; and support scholarly research. The LCO is independent of government and selects projects that are of interest to and reflective of the diverse communities in Ontario. It has committed to engage in multi-disciplinary research and analysis and make holistic recommendations as well as to collaborate with other bodies and consult with affected groups and the public more generally.

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## LIST OF ACRONYMS

<b>ACE</b>	Advocacy Centre for the Elderly
<b>CCAC</b>	Community Care Access Centre
<b>CCB</b>	Consent and Capacity Board
<b>CHA</b>	<i>Canada Health Act</i>
<b>CPSO</b>	College of Physicians and Surgeons on Ontario
<b>DNR</b>	Do-Not-Resuscitate
<b>HCCA</b>	<i>Health Care Consent Act, 1996</i>
<b>HQO</b>	Health Quality Ontario
<b>HPCO</b>	Hospice Palliative Care Ontario
<b>LCO</b>	Law Commission of Ontario
<b>LHIN</b>	Local Health Integration Network
<b>LSUC</b>	Law Society of Upper Canada
<b>LTCHA</b>	<i>Long-Term Care Homes Act, 2007</i>
<b>MAG</b>	Ministry of the Attorney General
<b>MOHLTC</b>	Ministry of Health and Long-Term Care
<b>OHIP</b>	Ontario Health Insurance Plan
<b>OHRC</b>	Ontario Human Rights Commission
<b>OPCN</b>	Ontario Palliative Care Network
<b>POA</b>	Power of attorney
<b>PSW</b>	Personal support worker
<b>QHPCCO</b>	Quality Hospice Palliative Care Coalition of Ontario
<b>RHPA</b>	<i>Regulated Health Professions Act, 1991</i>
<b>SDA</b>	<i>Substitute Decisions Act, 1992</i>
<b>SDM</b>	Substitute decision-maker



# 1. INTRODUCTION

## A. What is the Law Commission of Ontario's Project about?

The Law Commission of Ontario's (LCO) project, *Improving the Last Stages of Life*, considers how the law shapes the rights, choices, and quality of life for persons who are dying and those who support them. The project seeks to address the experiences of everyone involved in the dying process, including: individuals, caregivers and other family and friends, health care institutions and professionals, government, other professionals, and community organizations. Our goal is to hear from these groups to better identify and recommend law reforms that are concrete, precise, and responsive to the experience of persons in the last stages of life.

The purpose of LCO's discussion paper is to encourage and facilitate public engagement on various issues affecting rights and care in the last stages of life and to invite you to participate in our project. In addition to this paper, the LCO will also be organizing consultation meetings, forums, focus groups and individual interviews across the province throughout the spring and summer of 2017.



For a schedule of public consultations and other information about the LCO's Last Stages of Life Project, please visit our website at <http://www.lco-cdo.org/laststages>

This discussion paper comes at a critical time. Canadian law, policies and values about death and dying are changing, and there is growing demand for compassionate care that supports a wide range of these values and expectations. Death is an immensely significant experience that each person faces as an individual, family member, friend and participant in broader community networks. Many of us value death and the dying process as a uniquely meaningful stage in life and we approach it with mixed sensibilities – from confusion and grief to a sense of celebration and release.

The “last stages of life” is the broad and inclusive term we use in this project to capture this experience of dying as a process or a continuum of events, whether as a result of terminal illness, chronic conditions or serious frailties that could progress until the end of life. Some such persons may have little time left to live, while others may transition through the dying process for an extended period of years. The LCO's definition of “last stages of life” is unique. Our objective in selecting this term is to distinguish the *experience* of persons who are dying – as a particular stage in life – from established *models of care* that may be beneficial during the dying process, most notably palliative and end-of-life care.





Terms such as “last stages of life”, “care” “palliative care”, “end-of-life and “accompaniment” are defined in the Glossary at Appendix A

The importance of these issues cannot be underestimated. The proportion of individuals entering the last stages of life in Ontario is expected to increase appreciably in the coming years as the “baby boom” generation continues to age.<sup>1</sup> Ontarians are also living longer as a result of medical innovations that prolong life; however, we are living longer with chronic illness and complex care needs.<sup>2</sup> Coping with the growing demand for services and supports affects hundreds of thousands of Ontarians; their extended networks of family, friends and caregivers; and countless institutions. Every Ontarian – no matter what their stage of life – has an interest in the dying experience.

The LCO’s project situates these concerns with the last stages of life within Ontario’s legal framework and examines the possibilities for reform. The need for a review of legal frameworks at this time is clear. There are numerous laws and policies that require updating, clarification and simplification, and that currently inhibit access to just outcomes. The LCO’s project asks questions about how to address these challenges, so that the law can facilitate – not hinder – improvements across the health, social and legal sectors.

The LCO has interest and expertise in these issues as Ontario’s leading law reform agency. We provide independent, balanced, and authoritative advice on some of Ontario’s most complex and far-reaching legal policy issues. Our process evaluates laws impartially, transparently and broadly. The LCO’s work is informed by legal analysis; multidisciplinary research; public consultations; social, demographic and economic conditions; and the impact of technology.

As part of this process, the LCO is mindful of rapid and ongoing federal and provincial initiatives actively shaping the legal, regulatory and policy frameworks governing the “last stages of life.” This project has evolved alongside these developments. The key questions asked in this paper have been refined to expand the scope of intersecting issues rather than duplicating governmental initiatives, particularly as they relate to two principal subjects: palliative care and medical assistance in dying (MAID).<sup>8</sup> This paper similarly draws on findings from several completed and ongoing LCO projects, most notably reports regarding capacity and decision-making, older adults, and persons with disabilities. Related ongoing government initiatives and LCO projects are overviewed below, in sections C and D.

**Those in the last stages of life.** A significant number of Ontarians, along with their families, friends, and care givers, face these issues every year. Last year some 103,000 Ontarians died.<sup>3</sup> Most people continue to die in hospital: over 41% of deaths took place at one of 155 public or private hospitals in Ontario.<sup>4</sup> Caregivers are also part of this experience. Estimates are that some 35,000 persons a year acted as end-of-life caregivers in a private home or long-term care facility.<sup>5</sup> Currently there are 78,500 persons who reside in one of Ontario’s 636 long-term care homes, while another 26,000 are on wait lists.<sup>6</sup> Canadians are also accessing medical assistance in dying in greater numbers. Estimates are of some 744 medically assisted deaths across Canada since legislation came into effect in 2016, of which 180 took place in Ontario.<sup>7</sup>



For more information on the LCO's Last Stages of Life Project Scope Statement, and for regular updates on the project, please visit our website at <http://www.lco-cdo.org/en/laststages>



To access reports and other documents from the LCO's past and ongoing projects, please visit our website at <http://www.lco-cdo.org/>

## B. What key questions do these consultations raise?

The paper synthesizes the LCO's considerable research and background consultations to date, and asks both general and specific questions about key issues. The issues and questions identified in this paper are neither final nor exhaustive. Participants are welcome to make submissions on any additional topics they believe are relevant to the project scope.



A comprehensive list of questions the LCO has posed in this discussion paper is listed in Appendix G, "Questions for Discussion".

- **The Importance of Care in the Last Stages of Life (chapter 2):** One consequence of the LCO's inclusive approach to defining care in the last stages of life is that we must account for diversity in Ontario's communities and regulatory frameworks. The project seeks to address the experiences of everyone involved in the dying process, including: individuals, caregivers and other family and friends, health care institutions and professionals, government, other professionals. It also means considering how the quality of care in the last stages of life varies considerably across different communities of need, which may be defined by age, disability, LGBTQ identity, Indigenous identity, income level, place of residence and homelessness, mental health, faith, culture and others. The LCO has made efforts to explore how diversity influences the issues under consideration in the project. This inclusive approach also means keeping up-to-date with dynamic and ongoing legislative developments affecting the last stages of life.

1. *Within the scope of LCO's project, are there any additional affected individuals, communities, and institutions that should be taken into account?*

2. *Are there any additional recent debates or legislative frameworks that LCO should be aware of?*

- **The Law and Care in the Last Stages of Life (chapter 3):** This chapter summarizes existing laws which intersect with the last stages of life. The chapter demonstrates how a wide array of fundamental legal rights and principles affect the delivery of health care. There are also limits on the law, as well as different legal traditions in Canada including Indigenous legal traditions and religious laws. These also impact on professional standards, where there are competing views about the potential conflict between legal

and medical conceptions about rights and care. This is an important question for this project, and illustrates how law reform is relevant to what may be perceived as medical, administrative or public policy issues in the last stages of life.

**3. *What legal rights and principles are important for shaping care and establishing professional standards in the last stages of life?***

- **Ontario's Laws, Policies and Programs (chapter 4):** Laws, policies and programs create a framework defining several core aspects of the last stages of life in Ontario: the approach to and delivery of palliative care services; health-care decision making, planning, and substitute consent; medical assistance in dying; and resolving health care disputes. A considerable amount of discussion is taking place around key controversies in these areas, including a “public health” approach to palliative care, access to palliative care, and access to medical assistance in dying. In addition to these there are other laws which also intersect with medical assistance in dying, raising issues related to capacity assessments, transitions in care, employment concerns, caregiver benefits, insurance coverage, and rights in long-term care and retirement homes.

**4. *Legislation governing health care, housing, employment, professions, and other areas intersects with the last stages of life – what gaps exist that would benefit from greater certainty or clarity?***

**5. *Should a public health approach to palliative care be integrated into Ontario's regulatory framework, and how would it look on the ground?***

**6. *The LCO has identified several areas where medical assistance in dying could be clarified, including transitions in care, conscientious objection, and appeals of capacity determinations. Are there other additional issues to consider?***

- **Access to Justice for Communities with Unmet Needs (chapter 5):** Recent government reviews of palliative care confirm that Ontarians suffer marked disparities in accessing quality care in the last stages of life. LCO has particularly identified unmet needs respecting different communities. These include caregivers and other families and friends; persons living in long-term care and retirement homes; First Nations, Inuit and Métis people; persons experiencing homelessness; persons with disabilities; and faith and culturally diverse communities. There are various strategies, controversies, options, and choices in terms of accommodating these diverse communities.

*7. What are your experiences as a member or supporter of a community of need going through the last stages of life?*

*8. What law reforms do you believe are needed for communities with unmet needs, and how would such reforms be most effectively implemented in law?*

*9. Are there any communities with unmet needs who are not identified in this paper that the LCO should consider?*

- **Specific Challenges to Accessing Care in the Last Stages of Life (chapter 6):** This chapter considers issues related to autonomy, self-determination, beneficence (and maleficence) in care, and safeguards against abuse. These arise in several specific contexts, including the legal framework for, and public understanding of, consent and advance care planning; decision-making authority over life-sustaining practices, including withdrawal and withholding of treatment, CPR, and nutrition; palliative sedation therapy; managing planned deaths at home; the experience of supporting professionals; and accommodation and supports for faith and cultural communities. Unclear legal regulation of these issues leads to uncertainty and conflict, but must also contend with difficult controversies related to who has decision making authority in critical situations.

*10. How can institutions, professionals and the public be better supported to obtain meaningful and legally compliant health care consent?*

*11. How can practice tools achieve the goal of providing accurate, consistent and meaningful information about consent and advance care planning?*

*12. There are connecting laws, principles and policies regarding decision making for life-sustaining practices such as CPR, DN, and nutrition. What are the strengths, weaknesses and gaps in Ontario's current legal framework for decision-making authority over life-sustaining practices?*

*13. Who should have authority to determine whether life-sustaining and lifesaving treatment (e.g., CPR, DNR) is offered to, or withdrawn from, a patient – the patient (or SDM) or a health care provider? Under what circumstances?*

*14. Should Ontario regulate the offering of food and water to persons nearing the end of life, including the authority of SDMs to consent to withholding necessities of life?*

*15. Should Ontario regulate the clarity, consistency and safety of palliative sedation therapy considering the ethical challenges, medical assistance in dying, and the need for safeguards like informed consent?*

*16. Which options are preferred to better plan for and manage expected deaths at home? Would it be beneficial to have a province-wide strategy or formal regulation?*

*17. How can strategies for addressing the needs of health care providers assist with mental and moral stress? How can health care practitioners be better prepared to manage disputes?*

*18. Do legal professionals require specific education and guidance on matters relating to the last stages of life, and what form might this best take?*

*19. What approaches are best suited to address barriers, accommodations and supports to better integrate faith, cultural and spiritual practices into care nearing the end of life?*

- **Assistance with the Law: Navigation, Dispute Resolution and Public Legal Education (chapter 7):** The illness trajectory for each person is unique – it may be long or brief, stable or fluctuating. Care may be provided to persons in their own homes through community-based services; long-term care and retirement homes; hospital departments; and in residential hospices. However, many Ontarians experience problematic transitions and may face barriers to accessing services like medical assistance in dying. It can also be unclear and confusing where to turn when disputes arise.

*20. What are your experiences as a patient or caregiver transitioning between care settings in the last stages of life?*

*21. Are law reform measures needed to improve access, navigational supports, and the coordination of care within the health care system?*

*22. What strategies, processes, or institutions are best suited to resolving disputes in the last stages of life?*

*23. How can legal information or education about the law be made more relevant, timely, and effective in the last stages of life?*

### C. The project scope incorporates ongoing developments

This project was initiated following a request from the Registered Nurses' Association of Ontario (RNAO) that the LCO study medical assistance in dying in Ontario. The LCO Board of Governors approved the project in 2014, prior to the Supreme Court of Canada's decision in *Carter v. Canada (Attorney General)*, which found certain *Criminal Code* provisions prohibiting physician-assisted dying to be unconstitutional.<sup>10</sup> Since the release of the Supreme Court's decision, the federal and provincial governments have taken measures to delineate the availability of medical assistance in dying, the procedural requirements for its delivery, and the respective rights and responsibilities of various parties.

Parliament amended the *Criminal Code* to define eligibility criteria and protect those involved in the practice in specific circumstances.<sup>11</sup> At the provincial level, the Ontario government introduced measures to clarify how medical assistance in dying is to be delivered in practice as well as the process for conscientiously objecting providers to make effective referrals, among other measures. Regulatory health colleges have also published guidance for their members. (More information on the legal framework for medical assistance in dying is found in chapter 4, "Ontario's Laws, Policies and Programs".)

Furthermore, after the LCO's project began, the Ontario Government made a number of public commitments to support a comprehensive strategy on palliative care.<sup>12</sup> One of these commitments included the launch of a provincial network called the Ontario Palliative Care Network (OPCN). The OPCN brings together a broad range of partners, to drive implementation of consistent quality hospice palliative care across the province.<sup>13</sup> The LCO is aware that the OPCN will be addressing systemic barriers relating to Ontario's decentralized institutional framework which may go a long way in bridging disparities in access.

In addition to these non legislative measures, on May 10, 2017, the government of Ontario passed Bill 84, the *Medical Assistance in Dying Statute Law Amendment Act, 2016*.<sup>14</sup> Bill 84 aligns with the federal MAID legislation (Bill C 14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*), to address areas relevant to MAID that fall under provincial jurisdiction.

Throughout our planning for this project, the LCO has sought to be sensitive to government activities in these two areas, which materialized after our own project was approved. The LCO strives to prevent overlap between our work and contemporaneous initiatives in all of our projects. However, avoiding overlap is distinctly important in this instance because the federal and provincial governments' planning is evolving and in a state of development. The LCO will, however, address issues and bridge gaps that complement these initiatives and inform their development from a legal perspective.

For greater clarity, the following determinations have been made regarding LCO's scope for this project:

- **The LCO will not address matters of clinical practice.** During background consultations we asked stakeholders about limitations on the LCO's project. We were advised not to address matters of clinical practice, and we agree. The LCO views the analysis of health care providers' scope of practice as falling outside our mandate as a law reform agency.



The LCO's definition of "last stages of life" is unique; it distinguishes the experience of persons who are dying – as a particular stage in life – from established models of care that may be beneficial during the dying process, most notably palliative and end-of-life care.

Similarly, our definition of "care" is broad; it encompasses various services and supports that could be provided during the last stages of life, including medical treatments (and offering, withdrawing and withholding such treatment); accompaniments (e.g., psychological, social and spiritual counselling); and daily living assistance (e.g., bathing, cooking and dressing). The definition of "care" used in this document recognizes service and supports for caregivers, family and friends, such as respite and bereavement counselling. It is also closely connected to legal assistance and navigational supports that may indirectly affect access to care. It does not include matters of clinical practice.

- **LCO will not address challenges in education for medical and legal professionals.** During background consultations the LCO received many comments from members of the public about several challenges that health care providers face in providing palliative care. The foremost challenges that were identified were the lack of moral supports for psychological distress, lack of clinical education (for primary and specialty care providers), and the desirability of expanding aspects of registered nurses' scope of practice to increase accessibility to a range of services (e.g., medications, death certifications, treatments).

Of these issues, the LCO's project will only address health care providers' employment-related psychological supports for a number of reasons. First, as above, the LCO will not address matters of clinical practice. Second, the LCO does not wish to duplicate ongoing efforts of the Ministry of Health and Long-Term Care and the OPCN to strengthen education for health care providers.

Legal professionals also face a variety of challenges when it comes to advising clients who are dying and those around them. Similar to our approach to health care providers, this project does not consider challenges with education for legal professionals on decision-making issues due to our work on that subject in the *Legal Capacity, Decision-Making and Guardianship* project (see section D, below).



For our discussion about the challenges legal and medical professions face in providing palliative care and services see chapter 6.F, "Understanding the experiences of supporting professionals".

- **The LCO will not duplicate federal and provincial work on medical assistance in dying.** The actions taken, initiatives proposed, and measures introduced by the federal and provincial governments to date were further clarified in December 2016. Ontario's introduction of Bill 84 addressed several amendments to the *Coroner's Act*, *Vital Statistics Act*, *Excellent Care for All Act*, *Municipal / Freedom of Information and Protection of Privacy Act*, and the *Workplace Safety and Insurance Act*. Additionally, the federal government announced that the Council of Canadian Academies will conduct independent reviews of medical assistance in dying requests "relating to requests by mature minors, to advance requests, and to requests where mental illness is the sole underlying medical condition".



These efforts greatly clarify which issues the LCO should address in this project as complementary to or beyond the scope of these government initiatives, and without repeating those initiatives.



For more information on medical assistance in dying and palliative care in Ontario, see chapter 2.B, “Recent Policy Debates about Rights Nearing the End of Life” and chapter 4.E, “Medical assistance in dying”.

- **The LCO will rely on findings from past and ongoing projects.** This discussion paper draws on findings from several of the LCO’s past and ongoing projects, the most notable of which are explained below in section D. Key issues reviewed in these earlier projects include recommendations regarding laws in Ontario on informed consent, advance care planning and substitute decision-making; professional education and rules of professional conduct; and formal dispute resolution mechanisms, particularly the Consent and Capacity Board.

## D. The LCO’s approach to law reform

### 1. Our mandate and values

The LCO is Ontario’s leading law reform agency. The core of our mandate is fostering “access to justice,” which we aim to achieve by undertaking rigorous research and analysis, disseminating reports and engaging in critical debate, among other activities. The LCO recognizes that “[a] more comprehensive understanding of access to justice goes beyond the legal system to encompass efforts to assess and respond to ways in which law impedes or promotes economic or social justice”.<sup>15</sup>

LCO reports include principled, practical, “problem-solving” recommendations informed by broad consultations and tested through a transparent, comprehensive review process that engages a broad range of individuals, experts, and institutions. The LCO gives a voice to marginalized communities and others who should have an important role in law reform debates and discussions.

The LCO has developed a comprehensive project development, research and consultation strategy to organize our work. This strategy ensures that the LCO’s projects are transparent and participatory. LCO projects are delivered in several phases that are typically concentrated around the release of three core documents: a discussion paper, interim report and final report. Below we describe the research and consultations we have conducted to date in preparing this discussion paper.

## 2. Project development, research and consultations

### a. Preliminary Research and Consultations

The discussion paper was drafted following considerable research and consultations beginning in April 2015. Preliminary research involved an environmental scan of literature in disciplines including law, medicine and the social sciences as well as a review of government and other policy documents. Our preliminary consultations consisted of nearly 70 semi-structured interviews with individuals and organizations, representing wide-ranging perspectives. We consulted an additional 35 participants in a large stakeholder event (see below), raising our preliminary consultations to over 100 individuals and organizations. The issues addressed in this paper are grounded in our consultation results as well as our initial research.



A list of individuals and organizations we have consulted is found at Appendix B

This discussion paper also draws on findings from several of the LCO's past and ongoing projects.

Most notably, it relies on LCO reports regarding capacity and decision-making, older adults and persons with disabilities:

**Legal Capacity, Decision-Making and Guardianship:** Since the end of 2012, the LCO has led a law reform project that comprehensively reviews and assesses Ontario's regulatory framework for legal capacity and decision-making. It examines three interlocking statutes: the *Substitute Decisions Act, 1992* (SDA), the *Health Care Consent Act, 1996* (HCCA) and certain provisions in the *Mental Health Act*.<sup>16</sup> In March 2016, we released an Interim Report with draft recommendations.<sup>17</sup>



The final report was released in March 2017, and is available online at <http://www.lco-cdo.org/en/capacity-guardianship>

**A Framework for the Law as it Affects Older Adults:** This project defines a set of principles to guide the evaluation and development of laws, policies and programs in order to take into account the experiences of older adults, and to promote positive outcomes for older adults as full members of society.<sup>18</sup>



The final report was released in April 2012, and is available online at <http://www.lco-cdo.org/en/content/older-adults>

**A Framework for the Law as it Affects Persons with Disabilities:** This project defines a set of principles to guide the evaluation and development of laws, policies and programs in order to take into account the experiences of persons with disabilities, and to promote positive outcomes for persons with disabilities as full members of society.<sup>19</sup>



The final report was released in September 2012, and is available online at <http://www.lco-cdo.org/en/content/persons-disabilities>

These projects are relevant to many of the individuals and communities affected by this current project.

For example, the LCO's "Framework" projects address the communities of older adults and persons with disabilities, both of whom are uniquely affected by care in the last stages of life. The Framework projects also recognize the importance of autonomy, dignity and security as well as the need to balance tensions between these principles. Tensions between these principles underpin current debates on rights to palliative care and medical assistance in dying – to mention but a few issues this discussion paper examines. Additionally, the LCO's Frameworks are consistent with other principles-based frameworks and statements being produced by the courts, government agencies, professional associations and research institutes on rights nearing the end of life.<sup>20</sup>

This project is also related to the LCO's recently completed *Legal Capacity, Decision-Making and Guardianship* project. The capacity and decision-making project has developed recommendations regarding laws in Ontario on informed consent, advance care planning and substitute decision-making, which are all relevant to the last stages of life.

Accordingly, this paper does not repeat our research and analysis in the LCO's capacity and decision-making project; instead, it relies on findings in that project, where appropriate.



To access reports and other documents from the LCO's past and ongoing projects, please visit our website at <http://www.lco-cdo.org/>.

#### ***b. Advisory Group***

In September 2015, the LCO formed an Advisory Group for the project. The purpose of the Advisory Group is to provide the LCO with advice throughout the project. Advisory Group members include representatives of the Ministry of the Attorney General (MAG), MOHLTC, academics, bioethicists, physicians, nurses, personal support workers, psychologists, trusts and estates lawyers, legal clinics, professional associations, residential and visiting hospices, and advocacy organizations. A number of the Advisory Group members are respected specialists in palliative and end-of-life care and in legal frameworks relevant to death and dying.

The Advisory Group gave the LCO helpful input into the structure and content of our documents, beginning with the project scope released in January 2016. It then reviewed this discussion paper and provided the LCO with significant feedback. We are incredibly grateful for the Advisory Group members' invaluable observations and commitment.



A list of Advisory Group members is provided at Appendix C

### ***c. Commissioned Research Papers***

The LCO benefited from seven research papers that we commissioned from multidisciplinary teams especially for this project and from research papers previously completed for our *Legal Capacity, Decision-Making and Guardianship* project. These papers are available publicly at [www.lco-cdo.org](http://www.lco-cdo.org). The authors' findings and suggestions have been taken into account in our analysis to date, although the views expressed in them do not necessarily reflect the views of the LCO. These commissioned papers are as follows.

1. **Judith Wahl (Advocacy Centre for the Elderly), Mary Jane Dykeman (Dykeman Dewhirst O'Brien LLP) & Tara Walton:** Informed consent, advance care planning and substitute decision-making: using practice tools to ensure meaningful decision-making in the last stages of life
2. **Dr. Donna Wilson & Dr. Stephen Birch:** Improved care setting transitions in the last year of life
3. **Dr. Mary Chiu, Dr. Adrian Grek, Sonia Meerai, LJ Nelles, Dr. Joel Sadavoy & Dr. Virginia Wesson:** Understanding the lived experience of individuals, caregivers and families touched by frailty, chronic illness and dementia in Ontario
4. **Omar Ha-Redeye, Ruby Latif & Dr. Kashif Pirzada:** Integrating religious and cultural supports into quality care in the last stages of life in Ontario
5. **Susan Brown, Dr. James Downar, Dr. Jennifer Gibson, Dr. Laura Hawryluck, Dr. Csilla Kaloscai, Dr. Joy Richards, Robert Sibbald & Alexi Wood:** Balancing the interests of patients, substitute decision-makers, family and health care providers in decision-making over the withdrawal and withholding of life-sustaining treatment
6. **Dr. Arne Stinchcombe, Dr. Katherine Kortess-Miller & Dr. Kimberley Wilson:** Perspectives on the final stage of life from LGBT elders living in Ontario
7. **Sandy Buchman, Rosario Cartagena, Rose Geist, Mark Handelman, Kaveh Katebian, Wendy Lawrence, Trudo Lemmens, Harvey Schipper, Gilbert Sharpe & Alison Thompson:** The impact of suffering on decision-making and methods of assessing capacity in the last stages of life



Additional information about research papers commissioned for the LCO's project are listed in Appendix D. The papers are available online at <http://www.lco-cdo.org/en/last-stages-of-life>

### ***d. Roundtable on Legal Ethics and Practice for the Last Stages of Life***

The LCO co-hosted the Roundtable on Legal Ethics and Practice for the Last Stages of Life with our valued partners listed in Appendix E. This consultation brought together about 35 legal experts to discuss common challenges the profession faces and options for reform. Participants included academics, government lawyers, and members of the judiciary, the Law Society of Upper Canada, regulatory health colleges, and the trusts and estates bar. Information from the session was incorporated into this discussion paper.



Further information on the Roundtable on Legal Ethics and Practice for the Last Stages of Life can be accessed through our project webpage at <http://www.lco-cdo.org/en/last-stages-of-life>

## E. How to Participate

The LCO's approach to law reform is driven by public consultation. We take a multidisciplinary approach to research that involves the participation of individuals, communities and institutions across the province. Learning about your experiences and opinions is critical to our analysis of options for law reform.

The full Discussion Paper is the first step in facilitating this engagement. The paper is designed to explain the project's scope, outline the LCO's methodology, identify key issues and provide information on how the public can participate in the project. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders, available on our website.

LCO's formal consultation period runs from May – September 2017. The LCO invites your participation through:

- The project website at <http://www.lco-cdo.org/laststages>
- Written submissions at any time to [lawcommission@lco-cdo.org](mailto:lawcommission@lco-cdo.org)
- Watch live and archived webcast consultation sessions
- Complete the consultation survey on your mobile, tablet, or computer
- Propose an in-person focus group for your community
- Contacting Project Research Lawyer **Ryan Fritsch** through the contact information below

*Send your comments to:*

Law Commission of Ontario	Toronto	(416) 650-8406
Project on Improving the Last Stages of Life	Toll-Free	(866) 950-8406
2032 Ignat Kaneff Building	TTY	(416) 650-8082
Osgoode Hall Law School, York University	Fax	(416) 650-8418
4700 Keele Street, Toronto, ON M3J 1P3	E-mail:	<a href="mailto:lawcommission@lco-cdo.org">lawcommission@lco-cdo.org</a>

Written submissions will be accepted until **September 29, 2017**

## 2. IMPORTANCE OF CARE IN THE LAST STAGES OF LIFE

### A. Demographic Changes and Evolving Values about Death and Dying in Ontario

The way we treat death and dying shifts over time in response to demographic changes (such as life expectancy, ethnic and cultural diversity and aggregate population size) as well as to evolving values (about quality of life and ethics, for instance). In recent years, the provision of care in the last stages of life has garnered considerable attention due to several intersecting social developments that are drastically intensifying the demand for care. These include Ontario's aging population, advances in medical innovation that may prolong life and changing values about the location, timing and general circumstances of our deaths.<sup>21</sup>

The number of individuals transitioning through the last stages of life in Ontario is expected to increase in the coming years. This is due in part to increased life expectancy. The average life expectancy of Canadians has improved since the early 20<sup>th</sup> century by an astounding 24.6 years.<sup>22</sup> By 2011, Canadians lived an average of about 82 years with the most common age at death being 85.<sup>23</sup> Moreover, the proportion of elderly persons is increasing. Although individuals born in the early part of the “baby boom” are still relatively young (they are only entering into their 70<sup>th</sup> year at present), the proportion of elderly Ontarians will grow over the next few decades as this generation continues to age.<sup>24</sup>

Therefore, more Ontarians are living longer; however, we are living longer with chronic illness and complex needs that require dedicated care.<sup>25</sup> Exactly what that care looks like and how it is delivered have also experienced a shift over the past century. Whereas the emergence of new medical innovations in the mid-20<sup>th</sup> century has been correlated with a preference for curative, sometimes aggressive treatment, the LCO was informed that Ontarians are reembracing death as a natural and social phenomenon, not only a medical one. For instance, there is an emerging preference among Ontarians to die at home.<sup>26</sup> Moreover, a large majority of hospitalized Canadian elderly have reported wishes for comfort measures nearing the end of life, rather than traditional life-prolonging treatment.<sup>27</sup>

Meanwhile, palliative care is an established model for comprehensive, person-centred care that aims to relieve suffering and generate “meaningful improvements in quality of life and mood”, and effectively prolong life as well.<sup>28</sup> In fact, less aggressive care that focusses more on comfort does not necessarily adversely affect duration of life. Rather, patients receiving early palliative care have had improved survival compared to those receiving standard care alone.<sup>29</sup> Stakeholders told the LCO about evolving values and experiences that support such data, which speaks to the commonality of preferences that prioritize quality of life over intrusive treatment nearing the end of life.

Finally, Ontario's increasing diversity could have a tremendous effect on death and dying in the province. Higher levels of immigration since the end of the 1980s mean that older Canadians are becoming more ethnically and culturally diverse: among the cohort of persons turning 65 in the 2030s, at least 1 in 3 people could be born outside Canada.<sup>30</sup> The recognition of various equality-seeking groups under human rights regimes – including and beyond ethnocultural communities – could also influence the delivery of care in future.

Insofar as beliefs and practices surrounding the dying process can be quite different across faith, cultural, age, gender and other equality-seeking groups, Ontario's system will be called upon to proffer an array of services that enable individuals and communities to exercise nuanced choices. Respecting Ontario's diversity is of the utmost importance to the LCO and is an integral part of this project.



# Social Change and Demographics in Canada



**1921**

life expectancy was ~ 57 years

**until 1951**

gains in life expectancy made largely due to reductions in infant and child mortality

**1946-1965**

"baby boom" occurs with a sharp increase in fertility rates



**late 1980s**

immigration higher since the late 1980s, increasing Canada's population and ethnocultural diversity

**1982**

Charter of Rights and Freedoms established and recognizes many rights-seeking groups

**until 1981**

further gains in life expectancy made largely due to reduced deaths from medical conditions such as heart disease



**2011**

life expectancy reached ~ 82 years

**~ age 80**

more activity limitations occur on average around age 80 along with declines in functional health

**2036**

1 in 4 Ontarians will be over 65 and they will be significantly more diverse

## B. Recent Debates about Rights Nearing the End of Life

Ontario is not alone among jurisdictions grappling with an increasing demand for care in the last stages of life. The Canadian federal government and other provinces and territories are moving to address similar challenges, as are foreign jurisdictions around the world. Therefore, policy debates on related issues are taking place at all levels of governance from the international to the local. In this section, we briefly introduce readers to prominent global debates about rights nearing the end of life before turning to our in-depth review of Ontario's approach to specific issues further in the paper.

The first area that merits discussion is **medical assistance in dying (MAID)** because it has recently attracted an overwhelming amount of public debate. Individuals and organizations have asserted the right to receive medical assistance in dying in various forums for decades and, in 2016, Canada joined a handful of countries that allow the practice in certain circumstances. Medical assistance in dying is premised on principles of human dignity and the rights of individuals to determine their own manner of death when a medical condition causes them to suffer intolerably.<sup>31</sup>

However, the eligibility criteria and procedures for medical assistance in dying differ by jurisdiction. In some countries it is available to persons who suffer intolerably, but who are not dying (such as persons with disability and mental illness);<sup>32</sup> whereas in Canada and elsewhere, the practice is characterized as an avenue of last resort for persons whose death is reasonably foreseeable.<sup>33</sup> Furthermore, in contrast to some countries, in Canada adults must be capable of requesting medical assistance in dying at the time of receipt.<sup>34</sup> The Canadian government has undertaken to study extended eligibility criteria, including for persons with disability and mental illness who are not dying, and for those who wish to make a request in anticipation of future incapacity.<sup>35</sup> (For more information see section 4.E., "medical assistance in dying").

Medical assistance in dying raises a variety of concerns, such as reconciling the interests of objecting service providers and patients seeking access, assessing capacity to request assistance and ensuring safeguards against abuse.

The heightened attention awarded to medical assistance in dying has also raised concerns about the persisting need for improved health care that successfully alleviates suffering for many individuals.<sup>36</sup> Stakeholders have expressed apprehensions about medical assistance in dying detracting from efforts that are in progress to reinforce established forms of care, while others claim it creates an opportunity for frank dialogue to be leveraged. For our part, the LCO agrees with statements made in expert reports that medical assistance in dying must be "part of a continuum of services and supports for Canadians at the end-of-life".<sup>37</sup> In our opinion, medical assistance in dying should not, however, diminish the consideration of issues affecting persons who are dying and their supporters, such as better palliative care.

**Palliative care** has achieved widespread acceptance as the primary model of care for persons who are dying and their caregivers, family and friends.<sup>38</sup> Palliative care has philosophical and clinical dimensions. As a philosophy of care, palliative care strives to help individuals, families and caregivers address physical, psychological, social, spiritual and practical issues from the point of diagnosis of a life limiting illness, through the dying process, and into bereavement. It emphasizes quality of life, "reinforces the person's autonomy and right to be actively involved in his or her own care, and strives to give individuals and families a greater sense of control".<sup>39</sup>

Palliative care includes helping to prepare for and manage choices, cope with loss and grief, treat active issues, prevent new issues from occurring, and experience personal self-actualization.<sup>40</sup> In the health care system, persons who are eligible for palliative care may receive treatments and accompaniments that reflect the philosophy of palliative care. Treatments and accompaniments may be delivered in teams that include specialists, registered nurses and nurse practitioners, social workers, family physicians, psychologists, personal support workers (PSWs) and hospice volunteers.<sup>41</sup>

It is important to understand that palliative care is separate from medical assistance in dying. A request for medical assistance in dying does not, and should not, affect access to palliative (or any other) care, and palliative care may be provided right up until the time of death.

Unfortunately, the LCO has learned that there are significant challenges with “knowledge translation”<sup>42</sup> in the area of palliative care – which is to say that there are difficulties disseminating and applying knowledge about providing palliative care in the health care system.

In addition, closely connected to palliative and other forms of social care are very sensitive debates occurring on the right to decide whether a person will receive **life-saving or life-sustaining treatments**, such as feeding tubes and artificial ventilation. Critical questions being asked in these situations include who has legal authority to decide the withholding or withdrawal of treatment when a patient has lost the capacity to decide – substitute decision-makers or physicians – and on what criteria? Law reform agencies and regulatory colleges around the world have reviewed associated laws in their jurisdictions and the LCO has been asked to do so in this project.<sup>43</sup>

It should be apparent from our discussion so far that capacity and decision-making laws are inseparable from policy debates about rights nearing the end of life. **Informed consent, advance care planning and substitute decision-making** are regulated under standalone legislation (in Ontario, the SDA and HCCA); nevertheless, they are essential aspects of palliative care and the withholding and withdrawal of treatment, among other practices.

Notably, the widespread use of **ad hoc practice tools** to record patients’ wishes, values and beliefs for common end-of-life treatments has faced serious critique.<sup>44</sup> The LCO heard that, in Ontario, “Do-Not-Resuscitate”, “levels of care” and other such forms are inconsistent across care settings, often misstate the law and are disregarded by some health care providers. On the other hand, we were asked to explore whether the design of new practice tools could promote meaningful decision-making consistent with the law, such as template forms to obtain consent to treatment.

A final major subject of debate that each of the above areas must confront is **equitable access to care**.<sup>45</sup> The quality of care in the last stages of life can vary based on factors such as place of residence, ethnic and cultural background, income level, LGBTQ identity and medical diagnosis.<sup>46</sup> In the previous section, we mentioned research showing that many individuals would prefer to **die at home** and jurisdictions have prioritized improvements to home and community care in recent years.<sup>47</sup> However, the majority of Canadians still die in hospital.<sup>48</sup>

Given the immense significance of death and dying for everyone and Ontario’s increasing diversity, promoting equality is a pressing objective for this project.

## C. Affected Individuals, Communities and Institutions

The issues raised in the LCO's project affect all Ontarians because each of us dies and is affected by the deaths of those around us. The LCO recognizes the advantages of a person-centred approach to caring for individuals moving through the last stages of life and their supporters. In addition, we accept that individuals belong to community networks that may share a sense of identity, discourse and experience that the LCO must take into account.

In addition to individuals and communities, the LCO's project concerns those who shape and implement that law as professionals, government and delegated agencies. Our project strives to understand the difficulties they encounter in providing services and supports to persons who are directly affected.

In this section, we provide contextual background information on these interest groups.

### 1. *Persons in the last stages of life*

In the introduction to this paper, we explained the LCO's inclusive approach to defining the experience of persons who are approaching the end of their life as a result of terminal illness, chronic disease or serious frailty. These conditions have different trajectories that vary in terms of their symptoms, predictability and response measures. They could deteriorate quickly or over an extended period of years. Moreover, they may unevenly affect different populations.

From the LCO's perspective, the law must be able to reflect common goals regarding the care that persons who are dying receive, while remaining sufficiently flexible to capture their personal experiences. As a result, any potential measures to change the law must be informed by the full range of conditions that Ontarians experience and how those conditions interact with their livelihoods, care settings and access to adequate care.

Persons with cancer receive the most publicly funded services for palliative care in Ontario.<sup>49</sup> Cancer is the leading cause of death in Canada.<sup>50</sup> Almost half of Canadians will develop cancer in their lifetime and about 1 in 4 persons will die of cancer.<sup>51</sup> The large majority of persons who develop cancer are over age 50 (89%). However, cancer can occur throughout the life course and it has been the leading cause of disease-related death in children under age 15.<sup>52</sup> Despite progress in treating cancer, the Canadian Cancer Society predicts, "there will be an increasing number of cancers related to the growing and aging population".<sup>53</sup> It goes without saying that cancer imposes emotional, financial and other costs on individuals and their supporters, and it also "has major economic ramifications on Canadian society at large".<sup>54</sup>

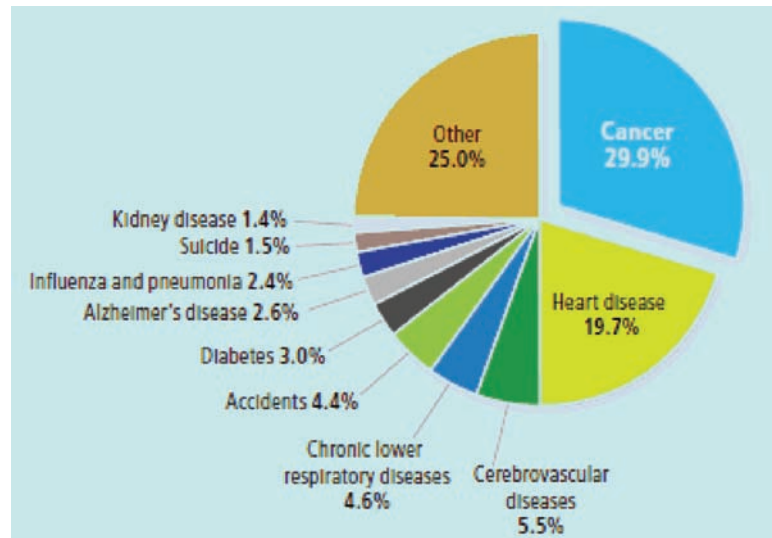
Although cancer is the leading *single* cause of death, at least the same proportion of Canadians die from just a few other chronic conditions, and there has been considerable public acknowledgement of the need to better serve these individuals.<sup>55</sup> For instance, circulatory and respiratory diseases (e.g., heart disease, stroke, and chronic obstructive pulmonary disease) together are the cause of approximately 29.8% of deaths in Canada (see Figure 1).<sup>56</sup>

There are also illnesses that are admittedly less prevalent, but that also deeply affect a significant number of Ontarians who are deserving of equal treatment under the law. By way of example,

there are an estimated 27,000 Ontarians living with HIV and 1000 new diagnoses each year.<sup>57</sup> HIV disproportionately affects men who have sex with men, African and Caribbean Ontarians, persons who use injection drugs, Indigenous peoples as well as women among or interacting with those groups.<sup>58</sup> Some of these individuals “struggle with low incomes, unemployment, depression, substance use, cognitive impairments, and stigma”.<sup>59</sup> Long-term planning remains a concern. The onset on HIV-associated neurocognitive disorders (HAND) is younger than those with Alzheimer’s disease. The prevalence of milder forms of HAND is high at 50-60%, and 2-3% for more severe forms.<sup>60</sup> Prevalence also does not necessarily equate to awareness; the disorder comes as a surprise for many and can trigger concerns for financial planning, the availability of HIV-designated services, or other ways of addressing vulnerabilities arising from intersecting stigma related to dementia, HIV diagnosis, and LGBTQ status.

Multiple sclerosis, amyotrophic lateral sclerosis (ALS), kidney disease and Alzheimer’s disease are further examples of progressive illnesses that could develop slowly and affect fewer people, but do eventually result in death and do merit access to high quality, personalized care. Alzheimer’s disease is the particular focus of many community organizations as its incidence is rising with Ontario’s shifting demographics toward a higher proportion of older adults.<sup>61</sup> Among deaths due to chronic conditions in Canada, Alzheimer’s underwent the largest growth from 2000 to 2009 (25.4%).<sup>62</sup>

**FIGURE 1: Proportion of deaths by cause, Canada 2011**



*Reproduced from Canadian Cancer Society's Advisory Committee on Cancer Statistics, Canadian Cancer Statistics 2015 (Toronto: 2015)*



Alzheimer's disease is the most common form of dementia. It poses special challenges along the illness trajectory because it is a "progressive and largely irreversible syndrome that is characterized by a loss of cognitive function severe enough to affect social or occupational functioning".<sup>63</sup> Thoughtful and legitimate advance care planning has thus been identified in our project as an important area of the law for this community of Ontarians.

About 90% of persons diagnosed with dementia transition from living in the community to long-term care before their death.<sup>64</sup> The relationship between dementia and long-term care demonstrates the firm connection between medical condition and the location where individuals find themselves placed within Ontario's system. Moreover, the LCO learned that certain care settings are more or less equipped to provide dedicated care for persons who are dying, leading to disparities in access based on medical condition.

Yet individuals' experiences with death and dying are influenced not only by their medical condition, but also factors including their access to information, place of residence and informal supports, which may determine whether they can or cannot access suitable treatments and accompaniments. Therefore, as much as possible, in this paper we try to highlight connections between social factors, access to care and the role of legal frameworks.

We hope to learn more about these connections in our consultations.

## ***2. Caregivers and other family and friends***

Whether the law hinders or nurtures caregivers greatly affects their ability to support persons who are dying and, also, the caregivers' own wellbeing.

At some point in life, most Ontarians act as a caregiver to a family member or friend. Up to 75% of care in Canada is provided voluntarily by unpaid individuals and 97% of patients receiving home care in Ontario get assistance from a caregiver.<sup>66</sup> With Ontario's aging population and a "continuing shift away from institutional, hospital-based forms of care toward more home and community-based care",<sup>67</sup> caregivers occupy an integral role in the health system that is becoming still more vital.<sup>68</sup>

Age-related needs are the single most common problem requiring help in Canada, but an equal proportion of persons receive assistance to manage chronic diseases, and over one quarter (28%) of caregivers have supported a person through terminal illness.<sup>69</sup> In Ontario, specifically, Health Quality Ontario (HQP) estimates that recently 35,000 persons a year acted as end-of-life caregivers in a private home or long-term care facility.<sup>70</sup>

At the end of life, as an individual's condition deteriorates, there is an "increasing need for assistance with daily tasks".<sup>71</sup> As such, persons at the end of life and their caregivers struggle with the implications of advanced medical conditions, which include symptoms as well as practical demands. Caregivers lend their support through a great variety of activities that include emo-

tional comfort, grocery shopping, cleaning, providing transportation, coordinating appointments, managing medications and helping with hygiene.<sup>72</sup>

Caregivers told the LCO that the time and effort required by such daily tasks can be incredibly difficult to manage without supports (such as paid benefits and respite) and that Ontario's existing law and policy framework is wanting in this respect.

Thus, there are positive aspects as well as challenges arising from caregiving in the province. Research on caregivers' perspectives has found that most of them assume the role because they wish to do so.<sup>73</sup> Many find meaning in it and they experience feelings of reciprocity in their relationships with those whom they care for.<sup>74</sup> As the Change Foundation reports, "Caregiving can bring incredible joy, rewarding relationships, personal satisfaction and depth to the human experience; it can be enriching and life defining".<sup>75</sup>

Nevertheless, it is essential to acknowledge that caregivers often function in worrying conditions. In a report on supports for end-of-life caregivers, HQO found that

Providing informal care for people at the end of life can be burdensome, and studies have shown that it can have negative health impacts for the caregivers, such as sleep problems, fatigue, psychological distress (i.e., depression and anxiety), burnout, and an increased risk of mortality. Studies have also shown that informal caregivers tend to suffer from financial strain. Furthermore, it is important to recognize that more people are now working outside the home, which may further add to the burden of informal caregiving.<sup>76</sup>

This discussion paper examines the adequacy of existing supports in Ontario that are intended to relieve difficulties, such as those listed above.

Additionally, we consider the needs of family and friends who may not be caregivers but who are, nonetheless, touched when someone close to them passes away. As with caregivers, family and friends are important stakeholders in the LCO's project because they are bereaved. They may also assume responsibility over practical issues that must be dealt with after a person has died, such as obtaining a death certificate and arranging funeral services. Consequently, part of the LCO's task is to review the current state of benefits that family and friends receive (e.g., leave from work, counselling) and related challenges.



Detailed information on existing services and supports for caregivers, family and friends and on the challenges they face is found in chapter 5.D.1.



### **3. Professionals**

There is a wide range of professionals who provide services and supports in this area including the following:

**Health care providers:** Health care providers in this context include family physicians, medical specialists, registered nurses and nurse practitioners, social workers, personal support workers, pharmacists, psychologists and psychiatrists. Health care providers work in a variety of environments, are regulated separately and may be funded under different arrangements. However, palliative care emphasizes coordinating services in interprofessional teams and capacity building among providers so that not only specialists but also primary level providers can address patients' basic needs. Health care providers are the frontline workers who interact most closely with persons who are dying and their supporters.

**Legal professionals:** Legal professionals with an interest in this project include legal clinics, such as the Advocacy Centre for the Elderly (ACE) and ARCH Disability Law Centre, and members of the health, and trusts and estates bars. Besides legal professionals who have specialized expertise in this area, general practitioners are called upon to assist in related matters, for example, drafting powers of attorney, estates planning and legal representation in disputes.

**Ethicists:** Ethicists develop and apply analytical frameworks to resolve controversial questions that engage medical, legal, philosophical, ethical and other viewpoints. Ethicists practicing in this area work with facilities, government and delegated agencies and research institutions to conduct studies, craft policies and mediate case-based decision-making.

**Facility operators:** Facilities are hospitals, long-term care homes, residential hospices, community clinics and other institutions that oversee service delivery within their authority. For instance, some hospitals have palliative care units and palliative consult teams, and long-term care homes are statutorily required to provide end-of-life care.<sup>77</sup>

**Academics, educators and trainers:** The LCO heard there is a high level of concern about the lack of education and training for professionals who regularly encounter persons in the last stages in life. Furthermore, there is a lack of information for members of the public on relevant topics, such as eligibility for services and consent to treatment. As such, it is essential to include regulatory colleges, professional associations, and academics in law and the health sciences in the LCO's project. Beyond education and training, academics also contribute greatly to the availability of trustworthy research.

#### 4. Government and delegated agencies

Core government and delegated agencies described below are also presented in a flowchart in section 4.B.2, Figure 2, *Ontario's Framework for Publicly Funded Care in the Last Stages of Life*.

**Government:** Overall responsibility for health care in Ontario rests with the MOHLTC. The MOHLTC sets priorities for the sector as a whole and has a stewardship role that focuses on strategic planning, policy development, investment, system-wide performance and accountability.<sup>78</sup> The MOHLTC directly plans, funds and oversees certain services while delegating the majority of funding and administration to external agencies, such as the Local Health Integration Networks (LHINs) and Cancer Care Ontario (CCO). For instance, the MOHLTC funds residential hospices and physicians and is leading the development of a strategy on palliative and end-of-life care.<sup>79</sup> Apart from the MOHLTC, the issues raised in this project cut across government ministries and departments, for instance, MAG, the Ministry of Community and Social Services, Ministry of Children and Youth, Office of the Public Guardian and Trustee, Ontario Seniors' Secretariat and Office of the Chief Coroner.

**Ontario Palliative Care Network:** The OPCN is a partnership of community stakeholders, such as health providers, HQO, the LHINs, CCO, health system planners, patients and their families. The OPCN is mandated to be a principle advisor to the government on hospice palliative care in Ontario. It is accountable for quality improvement initiatives, data and performance measurement and system level coordination along with supportive regional implementation of high-quality, high-value hospice palliative care in Ontario.

**Local Health Integration Networks:** Ontario's 14 LHINs are Crown agencies that plan, fund and oversee the accountability of far-reaching health services in the province, including hospitals, long-term care homes and community support services. Under Bill 41, Patients First Act, 2016, which received royal assent December 8, 2016,<sup>80</sup> the LHINs are proposed to assume greater responsibility for primary care, long-term care placement coordination, and home and community care (the latter two have otherwise been the responsibility of the Community Care Access Centres (CCACs)). Home care is intended for those who can live independently when they receive nursing, homemaking and personal support services.<sup>81</sup> The LHINs are mandated to promote the integration of health services within their regions. In furtherance of that mandate, all LHINs have a Regional Palliative Care Network that brings stakeholders together to strengthen quality, integrated services. Planning and implementation at the local level will be through the governance structure of these 14 Regional Palliative Care Networks, which will aim to ensure a system-wide approach to palliative care that is patient focused. The networks are connected through the Provincial-End-of-Life Network, which fosters strategic guidance, collaboration and the dissemination of best practices.<sup>82</sup> The LHINs are core participants in the OPCN.

**Cancer Care Ontario:** Cancer Care Ontario is mandated by the MOHLTC to improve cancer and kidney disease services, and access to care for key health services, through strategic guidance and funding arrangements with facilities and service providers. CCO creates and maintains information systems, establishes guidelines and standards, tracks system-wide performance, and delivers care at the local level through 14 regional cancer programs

that correspond to the LHIN regions. CCO devotes considerable resources to improvements in palliative care, for example, by developing evidence-based standards and piloting early identification tools.<sup>83</sup>

**Health Quality Ontario:** HQO is a Crown agency that collects and analyses information on the quality of health care in Ontario, in part, through the review of annual performance reports that health care organizations are required to submit (called quality improvement plans). HQO publicly disseminates its reports and advises government and health care providers on evidence to support improvements.<sup>84</sup> HQO has conducted research to generate an evidentiary framework for end-of-life care.<sup>85</sup> HQO is a core participant in the OPCN.

**Regulatory colleges and professional associations:** Regulatory colleges oversee health care professionals' responsibilities by drafting practice guidelines, standards and policies, and by undertaking enforcement. Professional associations advocate on behalf of their members in consultation with the government and regulatory colleges. Ontario regulatory colleges and professional associations have released documents relating to palliative and end-of-life care, decision-making and physician-assisted dying.<sup>86</sup>

**Administrative tribunals:** Three administrative tribunals adjudicate disputes relevant to care in the last stages of life. The Consent and Capacity Board (CCB) adjudicates disputes about capacity and decision-making, including issues surrounding the suitability of a substitute decision-maker's (SDM) provision of consent for end-of-life treatments. The Health Professions Appeal and Review Board (HPARB) considers the reasonableness of regulatory college complaints committees' findings about matters of professional conduct, for example, whether a health care provider has met practice standards in delivering palliative care. Finally, the Health Services Appeal and Review Board (HSARB) adjudicates complaints about eligibility for home and community services that have been dismissed by prior designed complaints committees.

**Office of the Patient Ombudsman:** The Patient Ombudsman is a recent addition to Ontario's health care system with the first appointment to the role in December 2015.<sup>87</sup> The Patient Ombudsman's responsibilities include responding to unresolved complaints from patients and caregivers about the patient's health care experience at a health sector organization, which includes hospitals, long-term care homes and centres for coordinating home care.<sup>88</sup> Because the operationalization of the office is relatively new, there is little information currently available to understand its role and effectiveness. The Patient Ombudsman's mandate does, however, include responding to complaints from patients and caregivers, investigating a health sector organization in response to the complaint or on her own initiative, making recommendations to a health sector organization, making reports to the MOHLTC and annual recommendations, and providing reports to LHINs as appropriate.<sup>89</sup>

## 5. Community organizations

Some community organizations overlap and collaborate with professionals working in this area of the law. Nonetheless, they have separate interests as communities advocating for the rights of their constituencies.

**Advocacy organizations:** Community organizations with an interest in this project include those advocating for patients, older adults, persons with disabilities and caregivers. Often advocacy organizations have conducted research, carried out law reform endeavors and published materials for public education. Hospice Palliative Care Ontario (HPCO) is a prominent voice for advocacy in this area. HPCO is also the Secretariat for the Quality Hospice Palliative Care Coalition of Ontario whose membership includes provincial associations and organizations, such as universities, community organizations and professional associations, among others.

**Faith and cultural communities:** Religion and culture strongly influence beliefs and practices surrounding death for individuals, families, health care providers and communities. Faith and cultural leaders have begun to address ethical approaches to the last stages of life in recent years with some having delivered positions on the appropriateness of different courses of treatment. They may also be involved in supporting persons as they move through the dying process by providing counsel, leading prayer, mediating disputes and performing rituals after death.

### D. Questions for Discussion

1. *Within the scope of LCO's project, are there any additional affected individuals, communities, and institutions that should be taken into account?*
2. *Are there any additional recent debates or legislative frameworks that LCO should be aware of?*

### 3. IMPORTANCE OF CARE IN THE LAST STAGES OF LIFE

#### A. Introduction

This project addresses complex systems for planning and delivering health care in Ontario. During the LCO's consultations several stakeholders, especially in the medical field, asked the LCO to explain how law reform is relevant to what they perceive to be medical, administrative or public policy issues.

In this chapter, we explain the law's contributions to governing the health care sector. We begin by exploring nuanced definitions of what the law is. Then, we discuss fundamental legal rights and principles that must be adhered to in delivering health care and the law's interaction with professional standards of care.

The purpose of this chapter is to clarify the law's expansive reach, but also its limits, and the LCO's approach to law reform.

In contrast, the next chapter of this paper provides detailed information on Ontario's existing law, policy and institutional framework specific to care in the last stages of life (including key government agencies and health care benefits).

#### B. Defining "Law"

##### 1. *The LCO's expansive understanding of the law*

The LCO has an expansive definition of the "law", which includes legislation and case law as well as the policies, institutions and everyday practices necessary to implement the law on the ground. Understood in this way, the law can assume various forms and it can be enforced and shaped by many actors.

To begin, the law includes the decisions of governmental and non-state actors whose authority derives from statute, such as regulatory college standards, tribunal guidelines, and government policies and programs. These types of delegated authority do not require the same rigorous procedures as enacting legislation. However, they are a significant part of the legal system and must conform to fundamental legal frameworks, such as administrative and constitutional law.

Take the College of Physician and Surgeons (CPSO), which is one of the colleges regulated under the *Regulated Health Professions Act, 1991* (RHPA).<sup>90</sup> The CPSO's policies must fit within its mandate under that statute, and they must maintain consistency with the *Human Rights Code*,<sup>91</sup> SDA, HCCA, common law standards of care for physicians and so on. Should these laws change, the CPSO's policies would change. In turn, the CPSO itself might influence the advancement of the common law when its standards are considered by the judiciary.<sup>92</sup>

There are also different legal traditions in Canada, including Indigenous legal traditions and religious laws.<sup>93</sup> These legal traditions are grounded in protected rights that individuals and com-

munities enjoy under the Constitution and human rights statutes.<sup>94</sup> Other rights under these two sources of law include rights to life, liberty and security of the person; language rights; and the right to be free of discrimination based on grounds such as race, national or ethnic origin, sex, age and disability.<sup>95</sup>

Laws can infringe these guaranteed rights on their face or in practice, and one of the roles that law reform agencies assume is to identify areas of concern that may not be readily apparent. Although the LCO cannot declare a law invalid, we may nevertheless recommend measures that would ensure consistency with foundational rights and principles.

Moreover, where we find that a law is valid or appropriate but there are barriers to proper implementation, we may make recommendations about practical tools for implementation, such as pilot programs, education and training, and advocacy supports in the community.

Given the LCO's expansive definition of the law, our analysis and recommendations may thus concern a range of instruments and, also, actors from government ministries to regulatory colleges and community organizations.

## **2. *The limits of the law***

Laws relating to care in the last stages of life can only be a partial answer to the complex medical, administrative, ethical and social issues that run throughout this project. Stakeholders informed the LCO about various constraints that exceed the law's reach and, therefore, limit the project scope. Clinical best practices are an obvious example.

Economic pressures in Ontario must also be taken into account as we formulate our recommendations. In our consultations, we heard about the shortage and inequitable distribution of resources available for care in the community, long-term care homes, hospices and elsewhere. Often facilities lack the resources to provide adequate supports to persons who are ill or frail. And caregivers may be stretched to the limits when they use their own finances to help another. As a general rule, the LCO does not make direct recommendations about policies for specific government expenditures. Our suggestions could nonetheless have an indirect impact on resource allocation insofar as changes to legislation, policies, programs and institutions may require funding.

Additionally, while the law can foster change, it cannot transform society by itself. Perspectives on the value of life and death, prejudices against certain groups and opinions on a patient's best interests illustrate the types of issues that the law can address as a matter of rights and principles, such as safety, equity and dignity. However, the law also exists within the larger context of attitudes and structures that naturally enhance or diminish its effectiveness.

## C. Legal Rights and Principles Affecting Health Care

### 1. *Constitutional rights and principles*

The Constitution Act, 1867 and Constitution Act, 1982, including the Canadian Charter of Rights and Freedoms, lay the foundation for government powers and duties respecting health care and corresponding rights for individuals.

Under the Canada Health Act (CHA), the federal government participates in regulating health care through its constitutional spending powers.<sup>96</sup> The federal government transfers funds to provinces that provide health care services through insurance plans, such as the Ontario Health Insurance Plan (OHIP). Service delivery rests largely with the provinces due to their exclusive authority over hospitals (and other health institutions) and “property and civil rights”, which “has been interpreted broadly by the courts to encompass most professional services”, including health care providers.<sup>97</sup>

There is no constitutional right to health in Canada and the Supreme Court has explained that medicare “is, by its very terms a partial health plan”.<sup>98</sup> The CHA grants conditional funding for the provinces to insure “medically necessary” services provided by hospitals and physicians.<sup>99</sup> Medically necessary services are not defined in standardized criteria and they vary across jurisdictions.<sup>100</sup> But the Act does distinguish them from “extended health care services”, which the provinces are not obliged to fund or administer.<sup>101</sup> Extended services relevant to this project include palliative care in private and long-term care homes not administered by physicians, and medications outside hospital.<sup>102</sup>

The provinces can and do supplement the CHA baseline of core services at their discretion.<sup>103</sup> For instance, the Ontario Drug Benefit Program covers the costs of some prescriptions for persons age 65 and older, living in long-term care or receiving home care.<sup>104</sup> Across the country publicly funded non-core services are inconsistent, there may be limits on eligibility and private co-payments may be charged.<sup>105</sup>

While rights to care arising from the CHA and provincial plans are circumscribed, the Supreme Court has nonetheless found that “where the government puts in place a scheme to provide health care, that scheme must comply with the *Charter*”.<sup>106</sup> In several cases, the Court has also identified what types of government activities violate the *Charter*. Below, we briefly summarize notable findings on the grounds of equality and life, liberty and security of the person:

**Equality (*Charter*, s.15):** Publicly funded health care services must be provided in a non-discriminatory manner. In *Eldridge v. British Columbia (Attorney General)*, the Supreme Court held that requiring deaf persons to pay for communication assistance services they needed to access the same basket of health services as the general public violated s.15 of the *Charter*.<sup>107</sup> As a result, the government was ordered to take positive steps to accommodate deaf persons up to the point of “undue hardship” by providing sign language interpretation necessary for effective communication.<sup>108</sup> Section 15 equality protection does not, however, extend to discrimination claims relating to services that governments have chosen not to include in the basket of medicare services.<sup>109</sup>



**Life, liberty and security (*Charter*, s.7):** The *Charter* protects individuals from criminal sanctions against medical practices that deprive them of fundamental rights and s.7 cases have expressly supported rights for persons with terminal illness and chronic disease.<sup>110</sup> In explaining the invalidity of prohibitions against physician-assisted suicide in *Carter*, the Supreme Court held that s.7 engages principles of autonomy, dignity, quality of life and the right to make decisions about one’s bodily integrity and medical care.<sup>111</sup> Particularly relevant to this project, the Court stated that the Constitution “recognizes the value of life, but it also honours the role that autonomy and dignity play at the end of that life”.<sup>112</sup>

The application of s.7 to health care outside the criminal context is ambiguous.<sup>113</sup> In *Chaoulli v. Quebec (Attorney General)*, the Court split on whether restrictions on private insurance for otherwise publicly funded services infringe s.7 when the public system fails to provide timely, quality care.<sup>114</sup> The case was ultimately decided in the claimant’s favour under Quebec’s provincial rights framework.<sup>115</sup> But “even the justices who read section 7 more liberally emphasize[d] that the Charter does not constitutionalize a positive right to health care”.<sup>116</sup>

As mentioned above, specific constitutional rights have been recognized by the courts regarding health, such as non-discrimination in publicly funded care. Furthermore, the Supreme Court’s decision in *Carter* established a right to physician-assisted dying in Canada. This constitutional right has since been interpreted and incorporated into federal and provincial measures for the planning and delivery of medical assistance in dying. We discuss these developments more in-depth in chapter 4.

However, a positive right to palliative care has not yet been adjudicated in Canada. Quebec’s *An Act Respecting End-of-Life Care* establishes a “right to receive end-of-life care” in facilities, residential hospices and homes in that province.<sup>117</sup> The LCO is aware of legal professionals and community advocates who argue for a national right to palliative care under ss.7 and 15 of the Charter and we will keep abreast of related developments in this project.<sup>118</sup>

Constitutional rights to other forms of health care have also already been asserted on Indigenous and religious grounds.<sup>119</sup> The cases addressing those rights involve complex issues about the interaction of the Constitution with provincial decision-making laws, and we have reserved our analysis of them to more suitable parts of the paper. Only a few observations are notable here.

The first is that the federal government’s power to make laws respecting Indigenous peoples under the *Constitution Act, 1867* complicates governance over health care for Indigenous peoples, both in terms of planning and administration, and individuals’ access to palliative care.<sup>120</sup> Second, faith and cultural communities’ legal advocacy on constitutional grounds attests to concerns that the LCO heard regarding the need to integrate differing values about life, death and treatment into medical perspectives and systems.



For more information on care in the last stages of life for Indigenous peoples, see chapter 5.D.3, and for faith and cultural communities, see chapter 6.G.

## 2. Fundamental provincial rights and principles

Ontario's institutional framework for delivering health care is embedded in statutes that are fragmented across sectors, such as the *Home Care and Community Services Act, 1994* and *Long-Term Care Homes Act, 2007*.<sup>121</sup> Unlike Quebec, British Columbia, Alberta and other jurisdictions with strategies to incorporate palliative care across the system, Ontario is currently formulating its provincial strategy.<sup>122</sup> We present how Ontario's existing regime is developing later in this discussion paper, including specific laws, policies and programs (see chapter 4).

Here, the focus is narrower. This section briefly canvasses three areas of provincial law that (similar to constitutional law) integrate fundamental rights and principles across sectors: health quality, human rights and decision-making.

The ***Excellent Care for All Act, 2010*** articulates an overarching vision for publicly funded “high quality health care” in Ontario.<sup>123</sup> The preamble describes a high quality health care system as

one that is accessible, appropriate, effective, efficient, equitable, integrated, patient centred, population health focused, and safe...<sup>124</sup>

Furthermore, the preamble expresses the belief that supports for patients and caregivers and patients' lived-experience are “a critical element of ensuring the future of our health care system”.<sup>125</sup> These acknowledgments directly underpin Ontario's performance measurement and improvement laws, and they could be interpreted as principles that guide separate laws relating to care in the last stages of life (e.g., accessibility, integration and equity).

The Ontario ***Human Rights Code*** (Code) applies more directly to a range of actors in the province as legislation with quasi-constitutional status. The *Code* resembles s.15 of the Charter because its purpose is to uphold and mainstream equality rights.<sup>126</sup> Similarly, it prevails over statutes and regulations, and applies to government activity. However, the *Code* has a wider scope – it also applies to private businesses and organizations, including care settings.<sup>127</sup>

The *Code* requires that services, goods and facilities treat every person equally without discrimination based on race, place of origin, creed, sexual orientation, gender identity, age and disability, among other grounds.<sup>128</sup> Compliance may demand accommodations that meet the needs of disadvantaged persons up to the point of undue hardship.<sup>129</sup>

The *Code* is inspired by principles of inherent dignity, the worth of every person and participation in community life.<sup>130</sup> The ***Accessibility for Ontarians with Disabilities Act*** (AODA) and ***Ontario's Action Plan for Seniors*** have comparable goals with respect to these specific communities, which have an interest in the LCO's project. These two frameworks supplement to *Code* with methods for implementing tailored standards, policies or programs.<sup>131</sup>

Decision-making laws are not the final instance of cross-cutting provincial laws in this context, but they are our last example here.<sup>132</sup> Together, the ***Health Care Consent Act, 1996*** and ***Substitute Decisions Act, 1992*** govern informed consent, advance care planning and substitute decision-making. The HCCA empowers individuals to make decisions for themselves when capable.<sup>133</sup> It

also enables them to express wishes, values and beliefs that SDMs must take into account when making decisions on their behalf, should they become incapable.<sup>134</sup> Health care providers must obtain informed consent from a patient or SDM prior to administering every treatment with very few exceptions stipulated in the HCCA.<sup>135</sup>

The HCCA and SDA codify common law rights to bodily integrity and personal autonomy in decision-making, which the courts have described as “co-extensive” with the constitutional right to security.<sup>136</sup>

### **3. Interactions with professional standards of care**

Professional standards of care are intimately tied to the law. Professional standards of care have several sources: the common law, statute and regulatory college guidance, which may include policies, codes of ethics and guidelines.<sup>137</sup>

In the course of this project, the LCO learned that health care providers sometimes refer to the “standard of care” as a *clinical* determination about beneficial treatment options for a patient. As a legal concept, however, standards of care are much more – they determine what can be reasonably expected of a prudent professional in the circumstances.<sup>138</sup> They encompass clinical judgment about treatment options and non-clinical rights and principles under the law. For instance, standards of care include duties of disclosure and obtaining informed consent.<sup>139</sup>

Standards of care may be defined through case law when individuals allege that providers negligently executed their duties. Negligence law helps to define standards of care insofar as it provides information about what would be expected of a prudent professional faced with the facts at hand. In determining the standard of care, the courts may take into account statute as well as regulatory college guidance. Regulatory college guidance may be informative, though not determinative of the standard of care. In turn, regulatory college guidance and general clinical standards of practice must be updated to be consistent with the law.<sup>140</sup>

Aside from health care professionals, lawyers also provide services to persons who are dying, caregivers and family members. Their respective regulatory colleges are mandated under statute to oversee issues relating to licensing, practice standards, competence, complaints and discipline.<sup>141</sup> For lawyers, the *Law Society Act* applies to the Law Society of Upper Canada, while for health professionals the *Regulated Health Professions Act, 1991* applies broadly to a number of self-governing health professions.<sup>142</sup>

Members of the public who have complaints about the care they receive have several avenues of recourse within and outside regulatory colleges. Many health facilities, such as hospitals, have informal dispute resolution processes. The *Law Society Act* and RHPA also require regulatory colleges to administer complaints resolution procedures.<sup>143</sup> Furthermore, appeals of regulatory college complaints determinations may be available through administrative processes (e.g., HPARB),<sup>144</sup> and the courts may lend an added degree of supervision as a last resort.

Throughout this paper, we consider matters relating to professional ethics and practice. We also review mechanisms that could prevent or resolve disputes prior to making a formal claim.

## D. Questions for Discussion

3. *What legal rights and principles are important for shaping care and establishing professional standards in the last stages of life?*

## 4. ONTARIO'S LAWS, POLICIES AND PROGRAMS

### A. Introduction

This chapter summarizes Ontario's laws, policies and programs. After this chapter, the remainder of the discussion paper analyzes issues that might benefit from reform.

The chapter begins with an overview of Ontario's regulatory framework for health care funding, planning and delivery. Then, it situates palliative care, health care decision-making, medical assistance in dying and dispute resolution within that framework. Finally, the chapter briefly reviews a number of specific laws that are separate from but intersect with these areas.

As Ontario's health care system is presently in a state of change, the chapter focuses on providing summary information about the existing regulatory landscape.

### B. Framework for Health Care Funding, Planning and Delivery

#### 1. Overview of the Ontario's Regulatory Framework

In chapter 3 we introduced the constitutional foundation for health care in Ontario, which is grounded in the division of powers between the provincial and federal governments. The federal government uses its constitutional spending powers to transfer funds to provinces that provide health care services through insurance plans – OHIP is Ontario's health insurance plan. Service planning and delivery then rests largely with the provinces.

The legislation governing this arrangement, the *Canada Health Act*, only covers medically necessary services provided by hospitals and physicians. There is a range of so-called extended health services that are not funded by the federal government and that are significant for the last stages of life, including medications outside hospital and most palliative care provided in private and long-term care homes. As a result, in addition to overseeing the planning and delivery of medically necessary care, Ontario supplements the CHA with provincial funding.

However, there may be limits to eligibility for provincially funded services and some services may receive partial or no funding. For instance, patients who are receiving complex continuing care in hospitals while waiting for admission to long-term care may be required to pay a **co-payment** for the cost of their meals and accommodation.<sup>145</sup> Once in a long-term care home, residents must also make co-payments for food and accommodation. If a resident is in standard/basic accommodation and is unable to afford the co-payment rate, they may be eligible for financial assistance and have their co-payment amount reduced based on their income.<sup>146</sup>

**Retirement homes** are an example of an entirely private arrangement. Retirement homes are regulated under the *Retirement Homes Act, 2010*, but residents are legally tenants who also have rights under the *Residential Tenancies Act, 2006*.<sup>147</sup> Retirement homes may, but are not required to, offer care services that meet the needs of persons nearing the end of life.<sup>148</sup> In this

project, we review concerns that stakeholders raised about palliative care in retirement homes (see chapter 5, “Access to Justice for Communities with Unmet Needs”).

In the following section, we set out Ontario’s existing framework for publicly funded care in the last stages of life. It should be recalled that some of these services may still require co-payments.

## **2. Framework for Publicly Funded Care in the Last Stages of Life**

Ontario’s framework for publicly funded health care is decentralized. The MOHLTC has overall responsibility for the sector; however, significant planning, funding and accountability functions are delegated to agencies that operate within 14 separate regions across the province.

Despite this distribution of authority, the MOHLTC maintains control over certain matters. It provides partial funding for **residential hospices**.<sup>149</sup> It funds primary care, physician fees, medications covered in hospital, and other drug programs.<sup>150</sup> It also plays a role in funding and regulating public health initiatives.<sup>151</sup> Moreover, the MOHLTC has a stewardship role that focuses on regulation, strategic planning, policy development and rule-making, investment, performance and accountability for the whole system.<sup>152</sup>

Beneath the MOHLTC sit the **Local Health Integration Networks**. LHINs are Crown agencies charged with promoting the integration of local health systems within their respective regions under the *Local Health System Integration Act, 2006*.<sup>153</sup> LHINs plan, fund and ensure the accountability of wide-ranging health services delivered in hospitals, long-term care homes and community support services, as follows:

**Hospitals** provide many essential services to persons with life-limiting illness in departments, including emergency, intensive care, complex continuing care and palliative care units. Some hospitals also have palliative care consultation teams that visit patients in other wards.<sup>154</sup> Hospital-based palliative care programs and consultation teams may also offer day programs and make house calls.<sup>155</sup> Public hospitals operate under the *Public Hospitals Act*.<sup>156</sup>

*Long-term care homes* are “home” for thousands of individuals, many of whom may experience serious frailties, including chronic conditions and dementia.<sup>157</sup> Almost one third of the residents in long-term care pass away each year.<sup>158</sup> The *Long-Term Care Homes Act, 2007* requires licensees to train all staff who provide direct care to residents on palliative care.<sup>159</sup> Licensees also have a statutory duty to “ensure that every resident receives end-of-life care when required in a manner that meets their needs”.<sup>160</sup>

*Community support services* include a mix of initiatives run by community agencies.<sup>161</sup> Visiting hospice programs stand out as an example in this area: their volunteers serve thousands of Ontarians with daily living support, respite for caregivers, counselling, and recreational activities, among other services.<sup>162</sup>



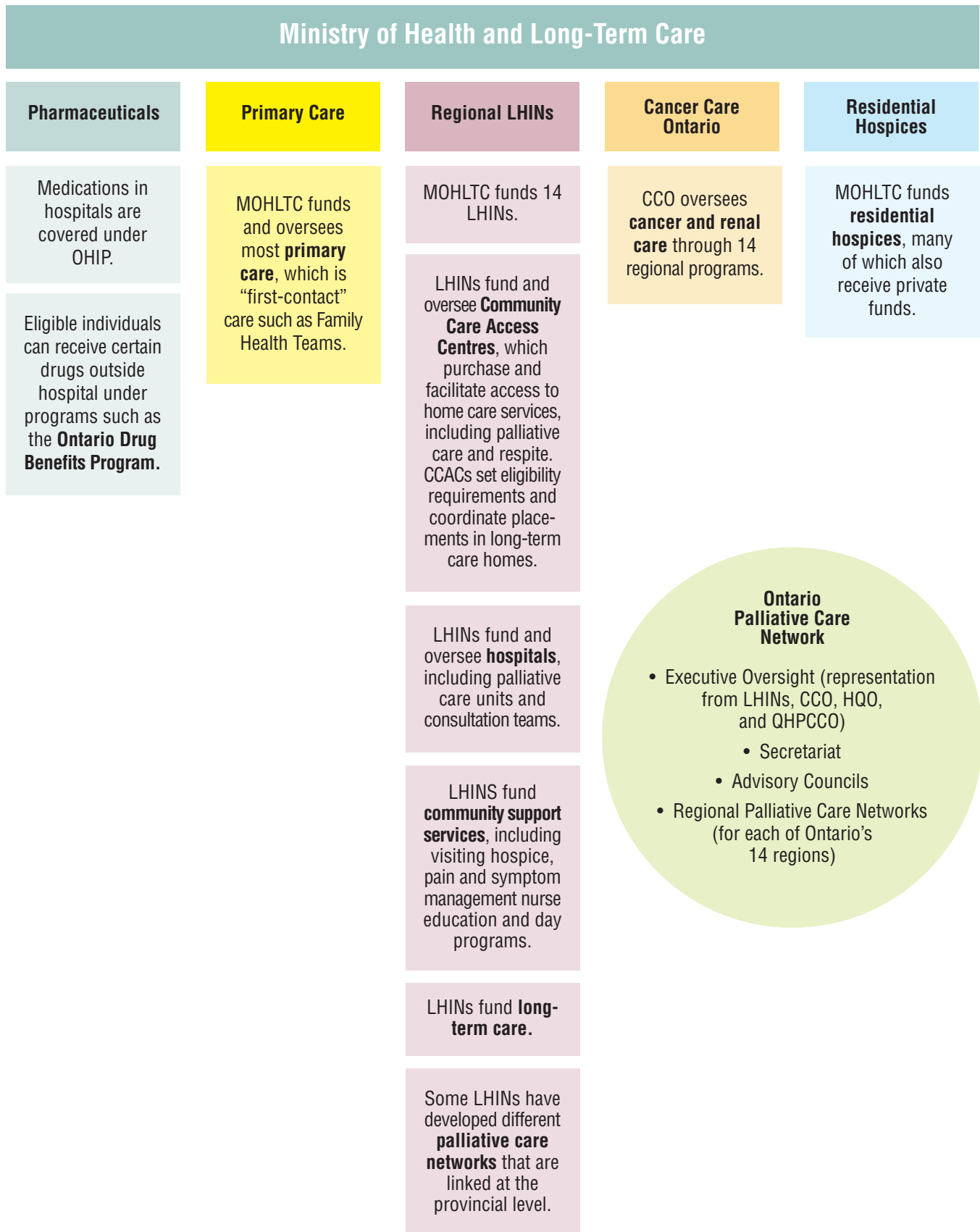
LHINs also fund and oversee CCACs, which are independent agencies that facilitate access to **home and community care** under the *Home Care and Community Services Act, 1994*.<sup>163</sup> CCACs coordinate admissions to long-term care and assess eligibility for a range of services provided in the home.<sup>164</sup> The Act stipulates a maximum number of hours that individuals can receive for homemaking and personal support services.<sup>165</sup> In practice, however, CCACs determine eligibility for services.<sup>166</sup> Persons eligible for palliative care may be able to receive added services to help them die at home and their caregivers may also receive supports.<sup>167</sup>

**Cancer Care Ontario** operates beneath the MOHLTC in parallel with LHINs. Under the *Cancer Act*, CCO plans, funds and ensures the accountability of services for persons with (or at risk of developing) cancer and kidney disease.<sup>168</sup> CCO manages regional cancer programs in each of Ontario's 14 regions and works with LHINs and providers to deliver care in different settings.<sup>169</sup>

Finally, the **Ontario Palliative Care Network** is a recent addition to Ontario's provincial approach. As discussed below, Ontario has experienced immense difficulties achieving equitable access to palliative care due to a lack of coordination across our decentralized institutional framework and care settings, and a lack of unifying policy. The OPCN was introduced to improve the quality of and equitable access to palliative care for all Ontarians. We discuss the OPCN's history and mandate in more detail in section C.2, below.

Readers should be aware that this description of Ontario's framework (and Figure 2) will be changing in the near future as a result of a legislated restructuring of the system through the recently enacted Bill 41, *Patients First Act, 2016*.<sup>170</sup> Bill 41 gives the LHINs enhanced responsibility over home and community, primary care and public health care. Most importantly for this project, the LHINs will assume the current responsibilities of the CCACs and sub-regions would be created to deliver care across the 14 LHIN regions.

FIGURE 2: Ontario's Framework for Publicly Funded Care in the Last Stages of Life



## C. Palliative Care

### 1. *What is palliative care*

The term “palliative care” describes both a philosophy of care and a wide-range of services that are provided to realize the philosophy for individuals and society at large.

Referring to palliative care as a “philosophy” captures its nature as a general approach to providing care that is rooted in assumptions, values and principles.

For example, the World Health Organization describes palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness...”, among other characteristics.<sup>171</sup> In Ontario, the MOHLTC, LHINs and Quality Hospice Palliative Care Coalition of Ontario define palliative care as,

**[A] philosophy of care that aims to relieve suffering and improve the quality of living and dying. It aims to help individuals and families to:**

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined end-of-life choices and the dying process
- cope with loss and grief during illness and bereavement
- treat all active issues and prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Individuals with palliative care needs are those where much (but not necessarily all) of the focus of care is the relief and prevention of suffering and improving quality of life and comfort.<sup>172</sup>

This philosophy is also translated into practice. The “service” dimension of palliative care refers to the actual medical, social and legal services and supports that individuals receive on day-to-day basis, such as treatment, facilitating health care consent and advance care planning conversations, social activities and counselling. These services may be offered by a number of providers alone or in teams across the different care settings mentioned above, which include

- private homes
- long-term care homes
- retirement homes
- hospitals
- residential hospices
- day programs

A person's actual care setting, services and supports will depend on her unique needs but, ideally, the approach to caring for each individual will be consistent with the goals that palliative care seeks to achieve.

## **2. Origins and evolution of palliative care**

### **i. Early years of advocacy and government involvement**

In Ontario, the provision of palliative care as a publicly funded service has resulted from the advocacy efforts of committed health care providers and grassroots organizations.<sup>173</sup> Since the 1960s, palliative care has progressively gained increased attention, publicly and within government, and it has become an integral part of the health care system.

The 1970s and 1980s were “foundational years” for the palliative care movement in Ontario.<sup>174</sup> Ontario's first community-based hospice opened in 1979, an institute for research and education was founded in 1983 and, by the late 1980s, there were two provincial hospice palliative care organizations (which eventually merged into Hospice Palliative Care Ontario).<sup>175</sup> Important centres of excellence emerged in and around that time, such as the Temmy Latner Centre for Palliative Care, as did notable programs providing home-based palliative care.<sup>176</sup>

Whereas during its early years of development palliative care was aimed at persons with terminal illness, especially cancer, it gradually became more inclusive of different conditions along the life-course.<sup>177</sup> Throughout this early period, however, palliative care services reflected the demands of local challenges – they were largely confined to isolated programs established by community advocates in the locations where they worked.

Federal and provincial government involvement in palliative care grew from the 1990s on.<sup>178</sup> Ontario's commitment of funding in 1992 for community palliative care was a milestone for the movement, even if it was “not closely coordinated or distributed across the province”.<sup>179</sup> Furthermore, the federal Senate brought palliative care to the national stage in the 1990s, when it began a series of report on the subject.<sup>180</sup>

In 2005, Ontario launched a three-year End-of-Life Care Strategy, which aimed to shift end-of-life care from acute settings to the home and to enhance the coordination of service delivery.<sup>181</sup> Important components of the strategy were its funding for community providers and the establishment of palliative care “networks” embedded within some of Ontario's LHINs.<sup>182</sup> Not all LHINs have established networks and they do not all operate with the same degree of representation and participation. The networks that are functional bring together individuals and organizations interested in palliative care in order to promote integrated care, and they are linked at the provincial level.<sup>183</sup>

An evaluative review of the *End-of-Life Care Strategy* found that it had some positive impacts, but also challenges. For instance, more patients had been served and the strategy may have resulted in broader identification criteria; however, “individual patients did not use more home care or less acute care services after the implementation”.<sup>184</sup> And beyond the creation of the networked-approach to management at the LHIN level, the strategy did not establish an overarching regulatory framework for palliative care.<sup>185</sup>

## ii. Agreement on a *Declaration of Partnership*

In 2011, acknowledging that there was still “a tremendous gap” in services, the MOHLTC, LHINs and Quality Hospice Palliative Care Coalition of Ontario (QHPCCO) agreed on a vision document “to provide equitable access to safe, comprehensive and high quality palliative care and support for individuals and their families across the province”.<sup>185</sup>

The document, *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment Action* (Declaration of Partnership) accomplishes a number of tasks, including elaborating a coherent definition of palliative care, agreeing on core values and assumptions, and formulating a model for service delivery.

The *Declaration of Partnership* asserts that palliative care may enhance other types of restorative and rehabilitative care, is most effectively delivered in teams and should be integrated at multiple scales within Ontario’s regulatory framework – at the clinical, organizational and over-all system levels.

Important to the LCO’s project, it also recognizes an inclusive approach to identifying persons who could benefit from palliative care. According to the *Declaration of Partnership*, palliative care is “appropriate for any individual and/or family living with, or at risk of developing a life-threatening illness, at any time they are prepared to accept this type of care and support”.<sup>186</sup>

It links chronic disease management with palliative care, so that coordinated planning occurs throughout the chronic disease and aging process. Moreover, its model for service delivery requires that “[i]n each setting where individuals die, there is a clearly defined care program that is founded on the palliative care philosophy and approach”.<sup>187</sup>

In short, the *Declaration of Partnership* is the most comprehensive, ambitious vision for palliative care in Ontario to date.

A steering committee was formed in 2012 to implement the *Declaration of Partnership*.<sup>188</sup> The committee was comprised of representatives from government, LHINS, CCACs, Cancer Care Ontario, professional associations, hospitals, community organizations and others.<sup>189</sup> It held a series of meetings and delegated work items to be undertaken by a Clinical Council and Working Groups, some which produced expert reports.<sup>190</sup>

Despite these initial steps, however, in December 2014 the Auditor General of Ontario released the results of an investigation into the state of palliative care, which found that “three years after its creation, significant work still needs to be done to meet most of the commitments made in the Declaration of Partnership”.<sup>191</sup>

The Auditor General observed that services in Ontario evolved in a “patchwork fashion” according to the sites in which advocates were located and that, “although efforts have been made to create an integrated, co-ordinated system... no such system yet exists”.<sup>192</sup> Notably, she found that Ontario lacks standard eligibility criteria for services, a common process to identify patients, equitable access to palliative care across the regions and public education.

Among other recommendations, the Auditor General of Ontario proposed the design of a government-approved policy framework:

The Declaration of Partnership should be linked to a policy framework for approval by the government. This framework could outline the necessary direction and funding to support the implementation of the commitments.<sup>193</sup>

### **iii. Proposal for a provincial strategy and the Ontario Palliative Care Network**

In November 2014, while the Auditor General's report was being prepared, the Minister of Health and Long-Term Care mandated his Parliamentary Assistant, John Fraser, to lead the development of a strategy on palliative care. In addition, Fraser was mandated to oversee the expansion of residential hospices to almost double the number of beds in the province.<sup>194</sup> Fraser held 16 roundtables with dozens of individuals, organizations and hospices over the course of several months.<sup>195</sup> The results of his consultations were then reported in the *Palliative and End-of-Life Care Provincial Roundtable Report* (Fraser Report).<sup>196</sup>

*The Fraser Report* was released in March 2016 along with an announcement that the government invested increased funding through the Provincial Budget to strengthen community-based hospice and palliative care.<sup>197</sup>

*The Fraser Report* confirms much of what had been recorded previously in the *Declaration of Partnership* and Auditor General report on the state of palliative care in Ontario. It also makes new findings of interest to the LCO's project that we rely on in this discussion paper. Of particular interest to our project are the following findings:

- Families and caregivers find the health care system difficult to navigate.
- Diverse communities face unique barriers accessing palliative care, such as rural and northern communities, Francophone persons, cultural groups and Indigenous peoples.
- Long-term care homes should be a part of the continuum of palliative care.<sup>198</sup>
- Caregiver supports should be improved.
- Public education and awareness should be enhanced.



The LCO's project examines these issues as part of the remaining chapters of this report.

In conjunction with the Fraser Report's release, the government also announced the inauguration of a provincial-level "network" that brings together various partners to drive implementation of consistent quality hospice palliative care across the province, called the Ontario Palliative Care Network.<sup>199</sup>



## Ontario Palliative Care Network

The OPCN is an organized partnership of community stakeholders, health service providers and health system planners, accountable for the development of a coordinated, standardized approach to the delivery of hospice palliative care in Ontario. The OPCN's mandate is to

- act as a principal advisor to government on hospice palliative care in Ontario
- be accountable for quality improvement initiatives, data and performance measurement and system level coordination
- support regional implementation.

The OPCN governance structure is multifaceted. It includes an Executive Oversight with representation from the LHINs, Quality Hospice Palliative Care Coalition of Ontario, Cancer Care Ontario and HQO. There are several Advisory Councils that focus on clinical improvements, data and information, implementation and community partnerships (with representation from diverse providers, care settings, geographies and patient groups). There is also a Secretariat with staff to support the OPCN operational and tactical activities and, generally, execute the OPCN mandate.

As part of the OPCN structure, Regional Palliative Care Networks are being created for each of Ontario's 14 regions. For each region, the LHIN CEO and regional cancer program VP will jointly oversee the networks to ensure that planning and implementation is aligned with the OPCN's provincial standards.

The OPCN builds on existing institutional arrangements in Ontario. Therefore, providers will continue to deliver palliative care through the LHINs, MOHLTC and CCO. However, they will do so in conformity with the new provincial standards.

**FIGURE 3: Timeline of Recent Palliative Care Initiatives in Ontario**

2005	Ontario initiates <i>End-of-Life Strategy</i> (ending in 2008)
2011	MOHLTC, LHINs and QHPCCO release <i>Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action</i>
2014	Auditor General of Ontario releases a review of palliative care calling for improvements, including a government-approved policy framework
2014	Minister of Health and Long-Term Care mandates MPP, John Fraser, to support the development of a strategy on palliative care and oversee the expansion of residential hospices
2016	MOHLTC announces measures to improve palliative care, including <ul style="list-style-type: none"><li>• establishment of the Ontario Palliative Care Network</li><li>• proposal of \$75 million investment over three years</li><li>• release of <i>Palliative and End-of-Life Care Provincial Roundtable Report</i> (Fraser Report)</li></ul>

#### iv. Ongoing non-governmental initiatives

Another way in which the government has recently committed to improve palliative care is through partnering with HPCO to provide training to hospice volunteers.<sup>200</sup> Beyond this initiative and others that the government supports, community organizations, regulatory colleges and professional associations have maintained their record of leadership in this area, and they develop independent programs and resources.

For example, the Registered Nurses' Association of Ontario and CPSO have drafted policies and practice guidelines for providers.<sup>201</sup> The Ontario Medical Association (OMA) has been leading an end-of-life strategy and has published guiding documents.<sup>202</sup> HPCO offers a great variety of training and educational opportunities on all aspects of palliative care and it has initiated a community of practice on health care consent and advance care planning.<sup>203</sup>

Given the importance of non-governmental initiatives in this area, we have listed associated publications alongside key government documents in Figure 4, below.

**FIGURE 4: Essential Palliative Care Documents for Ontario**

*A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* (CHPCA, 2013)

*Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (MOHLTC, LHINs and QHPCCO, 2011)

*Palliative and End-of-Life Care Provincial Roundtable Report* (MOHLTC, 2016)

*End-of-Life Care During the Last Days and Hours* (RNAO Clinical Guideline, 2011)

*Planning for and Providing Quality End-of-Life Care* (CPSO Policy, 2015)

*End of Life Strategy Framework* (OMA, 2014)

*Health Care Consent Advance Care Planning Community of Practice Glossary* (HPCO, 2016)

*Patients First: Action Plan for Health Care* (MOHLTC, 2015)

### 3. Emerging directions: the public health approach to palliative care

#### i. Introduction

The public health approach to palliative care is a theoretical model that complements the main tenets of palliative care. It aims to have palliative care treated as a matter of broad public interest.

During the LCOs consultations we were urged to consider reviewing the public health approach as the next step in an evolving philosophy of palliative care. However, in our review process, it

became apparent that the approach itself is still developing and, therefore, difficult to study. Indeed, scholars acknowledge the “breadth”, “ambiguity” and “lack of clarity” in this emerging area<sup>204</sup> – there are limits to the available information among proponents, researchers and also for the LCO.

In this section, we nonetheless seek to draw out some of its major features from the existing literature. We pose questions that we believe require further clarity throughout and, particularly, in the concluding part. Notably, we ask what the public health approach might look like on the ground as a matter of law reform.

## **ii. Overview of the public health approach**

Not unlike palliative care, generally, the public health approach is premised on the “recognition of the limitations of traditional models of health care delivery”.<sup>205</sup> Some of the principles shared between palliative care strategies and this approach include person- and family-centred care, involvement of non-specialists (such as primary care providers, social workers and PSWs), and equitable access for the entire population.<sup>206</sup>

However, the public health approach has a distinctive focus on social aspects of care: it seeks to integrate palliative care into everyday living through raising public awareness, supporting healthy attitudes about death and dying, and fostering community engagement.<sup>207</sup> It critiques palliative care focused on “inpatient, outpatient, day care and home care services and not community development”.<sup>208</sup>

The public health approach overlaps with initiatives that go by the terms, “compassionate communities”, “compassionate cities”, and “health promoting palliative care”.<sup>209</sup> These initiatives have progressed over several decades in parallel with the palliative care movement and they have been integrated into government strategies in various jurisdictions.<sup>210</sup>

The major focus of these initiatives that can be discerned from the literature (and that do not overlap with recent palliative care models), include

- community capacity-building and engagement
- public awareness and education about death and dying.

We discuss these two major features of the public health approach below.

## **iii. Community capacity-building and engagement**

As discussed previously in this paper, advancements in palliative care first arose at the community level with the development of hospices and other centres of excellence. The public health approach to palliative care seeks to build on this history of past successes at the local level and to foster more community engagement with government support.

The rationale for community engagement is based on a number of principles. First, given the social-orientation of this approach, it views the responsibility to care for persons who are dying and their supporters not only as a responsibility for government, but also for surrounding community, including neighbours, workplaces, schools, local businesses and others.<sup>211</sup>

It is important to remark that the concept of community responsibility should not be mistaken for offloading responsibility onto communities in order to decrease government input and achieve certain outcomes. Rather, community engagement from the public health perspective can be understood “as an *empowerment* model” that strengthens community capacity to develop responses to caring for their own members.<sup>212</sup>

Prof. Allan Kellehear, the founder of health promoting palliative care, explains that some of the problems persons living with life-limiting illness encounter include social isolation, family breakdown, premature job loss and financial strain.<sup>213</sup> Many of these problems, he says, “are not easily addressed by health services”.<sup>214</sup> Moreover, he claims that palliative care services have struggled to provide bereavement support to family and friends.<sup>215</sup>

Whereas families have long shared responsibility with the health care system to provide for persons in the last stages of life, advocates of the public health approach claim that community members also have a role to play in addressing such challenges. In Kellehear’s words, “Health is everyone’s responsibility”.<sup>216</sup>

According Kellehear and other advocates, the public health approach means enabling communities to provide the social aspects of palliative care (e.g., food, transportation, company) that supplement clinical interventions provided through the health care system. Community engagement they claim,

allows for the provision of a continuous background level of support that is developed pertinent to specific needs within the community, upon which discrete episodes of professional intervention can occur.<sup>217</sup>

### **Examples of Community Capacity-Building and Engagement**

There are many examples of community capacity-building and engagement for palliative care in Ontario and abroad. In Ontario, local initiatives that emerged organically alongside the palliative care movement have begun to expand and self-identify with “compassionate communities” through initiatives, such as Pallium Canada’s national and the HPCO’s provincial compassionate communities community of practice.<sup>218</sup>

The Windsor-Essex project is an initiative that gives a good example. Among other components, it involves mobilizing youth, faith, cultural, senior and informal social networks to generate volunteer opportunities; introduces a phone service for advice in distressing situations; and includes the formation of care networks for people in the last year of life with dementia or who need personal support with daily living activities. The Windsor-Essex project involves partnering with government agencies and departments at the federal, provincial, LHIN, county and municipal scales.<sup>219</sup> *(continued on next page)*

Compassionate communities have also received considerable attention and support in other common law jurisdictions, including England, Australia and Scotland. In Australia, for instance, a national palliative care association published a guide for local health care service providers to foster community development and education.<sup>220</sup> A number of local initiatives have also been funded through the federal Department of Health and Ageing “Caring Communities” program.<sup>221</sup>

A “Compassionate Cities Charter” is being used by local governments to assist them formulate and achieve related goals.<sup>222</sup> The charter signals a government’s commitment to ensure that institutions within their jurisdiction support wellbeing in the context of death and dying, including schools, workplaces, faith communities, correctional facilities and shelters.<sup>223</sup> In Ontario, the Windsor-Essex project has created its own charter and statement of values.<sup>224</sup>

A notable claim of the focus on community engagement is that it is particularly supportive of marginalized and disadvantaged groups.<sup>225</sup> For instance, the public health approach has been tendered as a framework for “age-friendly communities” that promote participation and autonomy for older persons nearing end-of-life.<sup>226</sup> Community-mobilization has also been used to empower First Nations health care providers to create culturally appropriate locally designed and controlled palliative care programs in four diverse First Nations communities in Ontario.<sup>227</sup>

Given the public health approach’s focus on community capacity-building and engagement, the LCO would like to know more about how legal frameworks might empower community members to become involved in palliative care in a manner that is voluntary and not motivated by resource concerns.

#### **iv. Public awareness and education**

Public awareness and education is another core feature of the public health approach to palliative care.

In Ontario, public awareness of palliative care is limited.<sup>228</sup> However, a lack of knowledge or misperceptions can inhibit access to services and supports. The Auditor General’s report recognized this connection between education, awareness and access to care. It explains,

To help patients who could benefit from palliative care, more people need to learn what palliative care entails, what services exist in the community, and how to access these services. Otherwise, there is a risk that patients will suffer unnecessarily by not receiving timely palliative care....<sup>229</sup>

Participants in the Fraser Report consultations also spoke about the public’s misperceptions about palliative care, which they view as a final option when “nothing else is working”.<sup>230</sup> The report explains: “Too many people think that palliative care just helps people die comfortably, instead of helping them to live longer and better”.<sup>231</sup>

The public health approach recognizes the need for better understandings of palliative care, but it also focuses more specifically on the need for transformational change in the public's perceptions of death, dying, loss and bereavement.

A core objective of the approach is to promote healthy, life-affirming attitudes about dying and grieving as normal human experiences.<sup>232</sup> Thus, it seeks to combat “death-denying” practices that, potentially, lead to “many people and their loved-ones being unwilling or unable to openly discuss their preferences and priorities for care and death, views on organ donation, prepare a will or plan a funeral”.<sup>233</sup>

During the LCO's consultations, we heard from numerous stakeholders who held views akin to this perspective. For example, we heard that more needs to be done to secure the dignity of patients and their supporters by helping them understand the repercussions of their situation and the available options. This could better enable them to be actively engaged as participants in their own life course. We also heard that key messages from the public health perspective for Ontario would be a shift in thinking about death, dying, loss and bereavement.<sup>234</sup>

Community engagement is one of multiple channels through which the public health approach aims to enhance awareness.<sup>235</sup> Other channels might include combatting negative attitudes from an early age in school curriculums;<sup>236</sup> sensitizing non-specialized health care providers to identify those who might benefit from palliative care (such as family doctors and primary care nurse practitioners); and encouraging open conversations with individuals, families and providers about health care consent and advance care planning.<sup>237</sup>

## **v. Incorporating the public health approach into legal frameworks**

Earlier in this chapter, we summarized Ontario's regulatory framework for health care planning and delivery. The question for the LCO's project here is how the public health approach to palliative care would feature in this regulatory framework, if it were determined to be beneficial for Ontarians. This central question raises several lines of inquiry.

For instance, it is unclear to the LCO whether proponents of this approach seek to *replace* palliative care models with something wholly different or to *complement* dominant models with improved government support for community engagement and public education. In either case, we would like to know more about what these proposals would require in practice in terms of laws, policies, funding and service delivery.

Presently the MOHLTC and LHINs have ongoing initiatives both on community engagement and public education. For instance, local palliative care initiatives may already be aligned with the compassionate communities model, such as residential hospices and community support services (e.g., visiting hospice volunteers, day programs, and pain and symptom management education). These initiatives can be viewed as a marriage of bottom-up organizing by community members and top-down support from the government.

Furthermore, the Fraser Report highlights stakeholder submissions on the desire for innovative community-based models, and enhanced public awareness and education.<sup>238</sup> And the Erie



St. Clair LHIN has explicitly recognized the public health approach as well as community capacity-building and public awareness in its regional palliative care strategic plan.<sup>239</sup>

Taking into account these existing initiatives, we ask whether increased government support for such efforts would fulfil aspirations for the public health approach.

The LCO is also aware that advocates in this area are seeking to link palliative care directly to public health systems.<sup>240</sup>

In England and Scotland, partnerships between palliative care and the public health system have been called for in government policies on palliative care.<sup>241</sup> Additionally, in Scotland, the national Public Health Network has issued a report with recommendations for the public health system to develop the roles of public health specialists in the context of palliative care.<sup>242</sup>

At this moment in the project, the LCO has been unable to determine how successful these efforts are on the ground. Furthermore, we wonder how applicable these comparisons might be in the context of Ontario's unique public health system.

Previously in this paper we stated that the MOHLTC plays a role in funding and overseeing public health in Ontario. According to the MOHLTC, "The primary focus of public health is the health and well-being of the whole population through the promotion and protection of health and the prevention of illness".<sup>243</sup> Public health programs and services seek to address determinants of health – such as income, social support networks, education, working conditions and personal coping skills – and to reduce health inequities.<sup>244</sup>

A fundamental concern of the public health system is health promotion and chronic disease prevention through public awareness and capacity-building for municipalities, schools, workplaces and other community partners<sup>245</sup> – all of which might provide relevant experience for similar initiatives addressing palliative care.

However, a substantial part of public health work in Ontario is concerned with issues that are quite distant from palliative care principles and practices, such as emergency preparedness, environmental safety standards and infectious disease prevention and control.<sup>246</sup>

Moreover, public health institutions are quite separate from the overall health care system. Under the *Health Protection and Promotion Act*, programs and services are managed by 36 local boards of health and delivered by public health units with specially qualified staff. Also, municipalities are significant partners in funding and administering the public health system.<sup>247</sup>

Given the unique design of Ontario's public health system and its mandate, further information is needed to understand what advocates propose. The LCO would like to know more about what proponents believe involving Ontario's public health system in the planning and delivery of palliative care would achieve and require.

#### **4. *Issues for the LCO's project***

The above discussion makes it clear that Ontario's regulatory framework for palliative care is in a state of change. Reliable sources report that Ontario's system for palliative care suffers from a lack of coordination and difficulties serving certain populations – all of which have led to inequities in accessing care. The MOHLTC is moving forward to address these challenges with new investments and the establishment of a provincial network to coordinate and improve palliative care across the province, the OPCN.

As mentioned previously, the LCO's project avoids reviewing issues that fall within the MOHLTC and the OPCN's priorities. The most notable issue areas that we do not address as a result of their mandates are

- institutional coordination
- education and training for health care providers
- the overall enhancement of Ontario's palliative care services and supports.

The LCO's project does, however, address issues in Ontario's developing regulatory framework that supplement the MOHLTC and the OPCN's efforts.

Accordingly, among other issues, the LCO's project seeks to address the concerns of communities with unmet needs to ensure equitable access to care regardless of characteristics such as their age, sexual orientation and identity, abilities, and place of residence (chapter 5). We review benefits for caregivers and other family and friends (chapter 5.D.1). And we also review navigational supports that could assist individuals as they transition through the system from one care setting to another (chapter 7).

In addition, in this chapter, we presented various options for the integration of public health approaches into Ontario's legal frameworks. A question relating to this issue is posed at the end of this chapter at section 1, "Questions for Discussion".

### **D. Health Care Decision-Making**

#### **1. *Informed consent and advance care planning***

Whether a choice needs to be made to provide treatment for palliative or other forms of care, laws that regulate decision-making are an essential part of care during the last stages of life.

Ontario's statutory framework for informed consent and advance care planning took shape following a monumental reform effort spanning the late 1980s and early 1990s.<sup>248</sup> The regime that resulted is extensive, intricate and nuanced. It reflects principles of dignity and integrity, and it balances other principles that may conflict when making important choices about health care matters, such as autonomy and safety from harm.

At the core of Ontario's regime are two statutes:

- *The Substitute Decisions Act, 1992*, which addresses decisions related to property management and personal care, and identifies the appointment processes and the duties of guardians and those acting under powers of attorney (POA).
- *The Health Care Consent Act, 1996*, which addresses consent to treatment, admission to long-term care homes and personal assistance services for residents of long-term care homes.

The LCO's project on *Legal Capacity, Decision-Making and Guardianship* comprehensively reviews the SDA and HCCA. In contrast, this project addresses narrow issues that frequently arise for health care decision-making nearing the end of life. To address these narrow issues, it is necessary to first set out key features of Ontario's framework, which we briefly summarize here: capacity and informed consent, substitute decision-making, advance care planning and plans of treatment.

## **i. Capacity and informed consent**

Capacity and informed consent are fundamental to Ontario's legal framework for health care decision-making. Persons who are capable have the right to make decisions for themselves and are held to be responsible for those decisions. On the other hand, those who have been determined to lack capacity in an area of decision-making or for a particular decision may lose the right to make corresponding decisions: others will be responsible for making decisions on their behalf and can be held accountable for how the decisions are made.<sup>249</sup>

Health care providers are required by law to **obtain informed consent from a capable individual or a substitute decision-maker** prior to administering treatment, except in emergencies.<sup>250</sup> This means that health care providers are not permitted to make treatment decisions on a patient's behalf, unless an emergency situation requires it.

The HCCA defines treatment generally as "anything that is done for a therapeutic, preventative, palliative, diagnostic, cosmetic or other health-related purpose" with some exceptions set out in the legislation.<sup>251</sup> It also includes a course or plan of treatment.

Because determinations of capacity affect our autonomy interests, the HCCA codifies a clear presumption that we are all capable of making treatment decisions for ourselves.<sup>252</sup> This presumption of capacity is reinforced by the entitlement that health care providers and others have to rely on the presumption of capacity, unless they have reasonable grounds to believe that a person is incapable.<sup>253</sup>

If a health care provider must assess a patient's capacity, there is a statutory test to be followed. This test is commonly referred to as the "understand and appreciate" test. It requires that a person have the ability to understand information relevant to making a decision, and the ability to appreciate the reasonably foreseeable consequences of making a decision (or of not making a decision).<sup>254</sup>

The focus of Ontario's capacity test is on the functional requirements of a particular decision and not on a particular diagnosis, the outcome of the patient's decisions, or an abstract judgement of abilities.<sup>255</sup> Moreover, a patient may be capable with respect some decisions but not others, and his capacity may fluctuate over time.<sup>256</sup> For example, someone who is in the last days of her life, may experience the periodic loss of consciousness as a result of her condition or medications. She may be capable of making decisions about her treatment at certain times but not at others.

For a capable person to consent to health care treatment, his consent must relate to a specific treatment, be informed and voluntary, and must not be obtained through misrepresentation or fraud. Under the HCCA, "informed consent" requires that information is provided on the nature, expected benefits, material risks and material side effects of the treatment as well as on alternative courses of action and the likely consequences of not having the treatment. Informed consent also requires that the person receives responses to his or her requests for additional information about those matters.<sup>257</sup>

If a patient has been determined to lack capacity and a decision must be made, an SDM will be authorized to do so in her place.

## **ii. Substitute decision-making**

"Substitute decision-maker" is a generic term that refers to a person who is authorized to make decisions on someone else's behalf. In this context, an SDM is a person who is authorized to give or refuse consent to treatment on behalf of another person who has been found to lack the capacity to do so.

Due to the time-sensitive nature of decision-making related to health care, the HCCA sets up a simple system for determining the identity of an SDM where one is required. The statute lists persons who may act as SDMs in descending order of preference, as follows:

1. The person's guardian of the person, if the decision required falls within the guardian's scope of authority
2. The person's attorney for personal care, if the decision required falls within the attorney's scope of authority
3. A representative appointed by the Consent and Capacity Board, if the decision falls within the representative's scope of authority
4. The person's spouse or partner
5. A child or parent of the person, or a children's aid society or other person who is lawfully entitled to give or refuse consent in the place of a parent
6. A parent of the person who has only rights of access
7. A sibling of the person
8. Any other relative of the person (including those related by blood, marriage or adoption).<sup>258</sup>

There are a number of terms used in the list above that require an explanation, such as “guardian of the person” and “attorney for personal care”. Guardians of the person may be appointed following an application to the Superior Court of Justice. The procedures for such an application are stipulated in the SDA.<sup>259</sup> An attorney is a person named in a power of attorney, which is a legal document that an individual can use to authorize another person to make decisions on her behalf in accordance with the SDA.<sup>260</sup> The word “attorney” in this context should not be confused with a “lawyer”.

Regardless of whether an SDM is authorized to make a decision under this hierarchical list as a guardian, spouse or other type of individual, she must meet certain requirements. For instance, an SDM must be capable with respect to the decision to be made, available and willing to assume the responsibility.<sup>261</sup> If no person identified through the hierarchical list meets all of the HCCA requirements, the Public Guardian and Trustee must make the decision.<sup>262</sup>

Once an SDM is authorized to make a treatment decision, he must follow steps that are required under the HCCA to arrive at the decision. First, he must respect the prior capable wishes of the individual, if those wishes are applicable to the circumstances and are possible.<sup>263</sup> If the patient expressed no prior applicable wishes while capable, then the SDM must make a decision in the patient’s best interests, taking into consideration the following:

- The values and beliefs a person held when capable
- Other wishes expressed while incapable
- Whether treatment is likely to:
  - *improve the person’s condition or well-being*
  - *prevent the condition or well-being from deteriorating*
  - *reduce the extent or rate of deterioration*
- Whether the person’s condition or well-being is likely to improve, remain the same or deteriorate without the treatment
- Whether the benefit of the treatment outweighs the risks of harm
- Whether less restrictive or less intrusive treatment would be as beneficial as the proposed treatment.<sup>264</sup>

SDMs are entitled to receive all of the information a patient would receive in order to give or refuse informed consent through the above process.<sup>265</sup> Furthermore, prior to administering treatment, health care providers are required to ensure that SDMs give or refuse consent in accordance with the HCCA, including through this decision-making process.<sup>266</sup>

Considering the range of wishes, values and beliefs that an individual may hold, and the various conditions that a person may experience, SDMs may give or refuse consent to treatments that produce very different outcomes that may be appropriate in a given case, including administering, withholding or withdrawing life-supports.

### iii. Advance care planning

Advance care planning is a process that involves a patient identifying a future SDM for himself, and/or a patient sharing wishes, values and beliefs that an SDM must interpret when making decisions on his behalf.

The LCO has adapted the definition of advance care planning used by the HPCO Health Care Consent Advance Care Planning Community of Practice as follows:

#### Advance Care Planning (ACP)

*The Substitute Decisions Act, 1992* and *Health Care Consent Act, 1996* govern ACP in Ontario. ACP is a process that involves the **mentally capable patient**:

1. **IDENTIFYING** his/her future SDM, by either
  - a. Confirming his/her satisfaction with their default/automatic substitute decision-maker in the SDM hierarchy list in the HCCA (presented above)
  - OR
  - b. Choosing someone else to act as SDM by preparing a power of attorney for personal care (the formal written document, discussed above).
2. **SHARING HIS/HER WISHES, VALUES AND BELIEFS** through conversations with the SDM and others that clarify her/her wishes, values and beliefs, and more generally how he/she would like to be cared for in the event of incapacity to give or refuse consent (e.g., What is quality of life to the patient? What is important to the patient with respect to his or her health?)

ACP does not constitute consent to treatment. Except in emergencies, health care providers must always obtain consent from an individual or SDMs prior to administering treatment, even if the individual has engaged in ACP. Obtaining consent is a continuous process that must precede every treatment. When substitute consent is required, known wishes, values and beliefs serve to guide the SDMs' decision-making process. Because a person's wishes, values and beliefs may change over time, later wishes expressed while mentally capable prevail over earlier wishes.

ACP can be initiated and reviewed at any time, not just at end-of-life.<sup>267</sup>

Readers may be familiar with terms, such as advance directive, living will or advance care plan. These terms are not legally defined in Ontario law.<sup>268</sup> Although they are used commonly, they are borrowed from decision-making regimes in jurisdictions outside Ontario, including Canadian provinces and foreign jurisdictions.<sup>269</sup>

In those jurisdictions, these terms may refer to documents that can be used to instruct a health care provider to administer treatments directly when a patient becomes incapable, without first obtaining consent from an SDM. Ontario law, however, requires that health care providers always obtain consent – even where a patient has engaged in advance care planning or has documented wishes.<sup>270</sup>

The LCO's project on capacity and decision-making reviewed the HCCA's existing requirements for consent to treatment and found that

The HCCA strikes a careful balance on these issues.... This emphasis on the role of the SDM in conveying and interpreting the prior capable wishes and in providing consent as particular issues arise differs in important ways from the status in other jurisdictions where "advance directives" may bindingly speak directly to the treating health practitioner.<sup>271</sup>

In that project, the LCO did not recommend amending Ontario's laws on the process for obtaining consent and advance care planning. Furthermore, the LCO agrees with the HPCO community of practice's statement that using terminology, such as advance directive, "may cause confusion and misrepresentation of [health care consent] or ACP. It is suggested that these terms should not be used when referring to advance care planning to avoid confusion".<sup>272</sup> (Additional considerations related to advance care planning are discussed in section 6.B).

#### **iv. Plans of treatment**

Under the HCCA, the definition of "treatment" includes a plan of treatment. A plan of treatment is defined as a plan that is developed by one or more health care practitioners to deal with health problems that are present or likely in the future given the person's current health condition.<sup>273</sup> Plans of treatment provide for the administration of various treatments or courses of treatment, including the withdrawal and withholding of treatment, in light of the person's current health condition.<sup>274</sup>

As treatment decisions, plans of treatment require informed consent. Therefore, as with all consent to treatment, patients must be able to access the information necessary to make a decision within the context of their existing condition. Plans of treatment reflect the fact that "the HCCA limits consent to treatment to time-limited and contextualized decisions, grounded in the patient's current health condition".<sup>275</sup>

Plans of treatment should not be confused with advance care planning. Because plans of treatment require informed consent, both patients and SDMs can consent to a plan of treatment, whereas only a patient himself can engage in advance care planning.<sup>276</sup> (Withdrawal and withholding of treatment are discussed in greater detail in section 6.C.3).

## **2. Issues for the LCO's project**

In comprehensively reviewing the SDA and HCCA, the LCO's project on *Legal Capacity, Decision-Making and Guardianship* addresses significant questions in this area, which we may apply in the project, but do not reconsider. Some of the recommendations in that project include the following, among others:



- Creation of official *Guidelines* for capacity assessments under the HCCA
- Strengthening the role in this area of professional educational institutions and of the health regulatory colleges in providing training and education, as part of their quality assurances initiatives
- Amending the HCCA to allow individuals to exclude a particular individual or individuals from appointment under the hierarchy set out in that statute
- Creation of a central clearinghouse for information for SDMs and persons directly affected by the law
- Strengthening the provision of information under the HCCA to patients and SDMs.<sup>277</sup>

There are two major issues that stakeholders brought to our attention for this new project. The first issue concerns whether a “package” of informational supports and practice tools can be designed to promote decision-making about common end-of-life treatments that is meaningful and consistent with the law (see chapter 6.D). We briefly introduced this topic earlier in the discussion paper at section 2.B.

The other issue concerns who has legal authority to decide whether a person is offered or receives life-saving or life-sustaining treatment. There are ongoing debates about whether SDMs or health care providers ought to decide these matters for an incapable person when, in the health care provider’s opinion, life-supports would be of little or no “beneficial” value. These debates raise very sensitive issues about quality of life, rights to autonomy in decision-making and the security of patients who cannot make end-of-life choices for themselves. The LCO examines them in chapter 6.B.



The LCO commissioned two expert research papers on these subjects for this project and one for the capacity and decision-making project. Their findings were incorporated into ch. VI of this discussion paper. They can also be found online here: <http://www.lco-cdo.org/en/last-stages-of-life>.

## E. Medical Assistance in Dying

### 1. *State of the law on medical assistance in dying*

In the Supreme Court’s 2015 decision in *Carter*, the Court found that criminal sanctions against physician assisted dying under the *Criminal Code* violate the *Charter* in certain circumstances. The Court found that physician assisted dying is available to competent adults who consent to the termination of life and who have a grievous and irremediable medical condition that causes enduring, intolerable suffering to the individual.<sup>278</sup>

The Court suspended its declaration of invalidity of the *Criminal Code* provisions for 12 months.<sup>279</sup> Following a change in government at the federal level, the new Liberal government was granted a request to extend the suspension of the Supreme Court’s declaration of invalidity, which expired on June 6, 2016.<sup>280</sup>

## **i. Federal developments**

Prior to the Supreme Court's decision coming into effect, the federal government introduced a Bill in Parliament to regulate "medical assistance in dying".<sup>281</sup> The term "medical assistance in dying" (MAID) is now preferred in Canada's policy landscape because it recognizes that, in practice, this service is being delivered in teams of health care providers, not only by physicians.

The federal Bill, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, became law in late June 2016. Therefore, there was a period of adjustment and limited availability of physician assistance in dying before the federal legislation was passed. We discuss the implications of this period of adjustment after setting out the new legislative scheme, below.

Under the *Criminal Code*, medical assistance in dying can be delivered in two ways:

1. A physician or nurse practitioner can administer a substance that causes death to a person at that person's request.
2. A person can self-administer the substance obtained with a physician or nurse practitioner's prescription.

The *Criminal Code* exempts individuals involved in the process from criminal liability, including the physician, nurse practitioner and anyone who does anything to aide them.<sup>282</sup> It exempts anyone who aids the patient to self-administer at the patient's request.<sup>283</sup> Furthermore, it protects pharmacists who dispense associated medications with a valid prescription.<sup>284</sup>

The *Criminal Code* also now explicitly sets out eligibility criteria, procedural requirements and safeguards against abuse. Persons who are eligible for medical assistance in dying must be entitled to Canadian health insurance, be at least 18 years old, make a voluntary request, give informed consent and have a grievous and irremediable medical condition. A "grievous and irremediable medical condition" is further defined to limit eligibility to persons who are dying – which is to say that their natural death is "reasonably foreseeable". This criteria excludes individuals who may suffer as a result of physical or mental conditions, but who are not dying. The *Criminal Code* describes grievous and irremediable harm as follows:

### **Grievous and irremediable harm medical condition**

A person has a grievous and irremediable medical condition only if they meet all of the following criteria:

- (a) They have a serious and incurable illness, disease or disability;
- (b) They are in an advanced state of irreversible decline in capability;
- (c) That illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider to be acceptable; and
- (d) Their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

The other eligibility criteria mentioned above (i.e., informed consent and age) mean that children under 18 cannot receive medical assistance in dying, nor can persons who do not have legal capacity for health care decision-making. There is no provision for substitute decision-making for medical assistance in dying. A further requirement for consent immediately before receiving the service also restricts individuals from making a request in advance through an advance care planning document that would become effective if the person became incapable in future.<sup>285</sup>

In light of these particular considerations, the federal government is following through on commitments made on behalf of the Ministers of Justice and Health to initiate the independent review of issues relating to requests by mature minors..., to advance requests and to requests where mental illness is the sole underlying medical condition.<sup>286</sup> The government announced on December 13, 2016 that they have engaged the Council of Canadian Academies (CCA) to conduct independent reviews related to these specific types of requests for medical assistance in dying. As part of the review process, the CCA will consider evidence from national and international experts, other levels of government, health care providers, and stakeholders impacted by the issues under review. The studies will be completed within two years and will be made available to Parliamentarians and the public by December 2018.<sup>287</sup>

As for procedural issues and safeguards, the *Criminal Code* now contains several interrelated provisions. Among other requirements patients must

- be informed of alternative means to relieve their suffering, including palliative care, before giving consent
- make the request in writing before two independent witnesses
- obtain the opinion of two independent physicians or nurse practitioners that they satisfy all required criteria
- wait 10 days before receiving medical assistance in dying (unless their death or loss of capacity is imminent)
- be given another opportunity to withdraw immediately before receiving the service and, at that time, express consent again.<sup>288</sup>

Finally, the Minister of Health will make regulations respecting the collection of information relating to medical assistance in dying requests for the purposes of monitoring the practice.<sup>289</sup> After five years, the Act will be reviewed by a Parliamentary committee that is also mandated to report on the state of palliative care in Canada.<sup>290</sup>

## **ii. Ontario developments**

The federal government's action on medical assistance in dying is a skeletal framework that serves to create a "carve-out" or exemption to the *Criminal Code* – it does not speak clearly to the pathway that individuals and providers follow when it comes to accessing provincial health care services on the ground. Therefore, the provinces have supplemented the federal legislation with measures to enable medical assistance in dying as a publicly funded service.

In Ontario, MAG and the MOHLTC have worked together to clarify that patients should consult directly with their health care providers about medical assistance in dying and, in turn, health care providers should consult their regulatory colleges about any rules, guidelines or practices.<sup>291</sup> Each of the health regulatory colleges most affected (physician, nurses and pharmacists) has disseminated related policies to guide their members.<sup>292</sup> The MOHLTC is also making various informational services and template forms available for ease of access.<sup>293</sup> Other groups are also helping develop materials. For instance, the Joint Centre for Bioethics at the University of Toronto created a MAID Policy Template. The Template assists Ontario health institutions as an aid to local planning and seeks to operationalize the ethical principles of accountability, collaboration, dignity, equity, respect, transparency, fidelity and compassion.<sup>294</sup>

On the question of conscientious objections, the College of Physicians and Surgeons has affirmed that physicians must not abandon patients who have requested medical assistance in dying: an effective referral must be made in a timely manner. Similarly, the College of Nurses of Ontario has stated that nurses who conscientiously object must transfer the care of a client who has made a request for medical assistance in dying to another nurse or health care provider who will address the client's needs. MOHLTC has established a telephone Clinician Referral Service to support physicians and nurses who conscientiously object to fulfil this obligation.<sup>295</sup> The MOHLTC also recently committed to establishing a "care coordination service" to assist patients and caregivers in accessing additional information and services for MAID and other end-of-life options, with further information to follow in early 2017.<sup>296</sup> As for institutions, the MOHLTC has asked that objecting institutions make their policy known to members of the public. But, at the time of writing, the ministry was still investigating how conscientious objections might work in long-term care homes, which are required by law to provide end of life care.

In addition to these non-legislative measures, on May 10, 2017, the government of Ontario passed Bill 84, the *Medical Assistance in Dying Statute Law Amendment Act, 2016*.<sup>297</sup> Bill 84 aligns with the federal MAID legislation (Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)), to address areas relevant to MAID that fall under provincial jurisdiction.

- the *Coroners Act* and the *Vital Statistics Act*, mandating that the physician or nurse practitioner who provided the medical assistance in dying shall give notice of the death to a coroner, and clarifying that the Coroner does not need to sign the medical certificate of death for MAID deaths unless the Coroner investigates the death
- the *Excellent Care for All Act*, clarifying that MAID may not be used as a reason to deny a payout on insurance or other benefits, and providing immunity from proceedings for damages to physicians, nurse practitioners, and any other persons assisting them in the lawful performance of MAID
- the *Freedom of Information and Protection of Privacy Act* and the *Municipal Freedom of Information and Protection of Privacy Act*, to protect the identities of clinicians and institutions that provide MAID from being disclosed pursuant to an FOI request
- the *Workplace Safety and Insurance Act*, ensuring that a claim made under the WSIA where the worker received MAID would be determined based on the illness or disease for which the worker was determined to be eligible to receive MAID and not another cause of death.

How the LCO's consultation process will address Ontario's rapidly evolving legal regulatory scheme for MAID is outlined in sub-section 3, "Issues for the LCO's Project," below.

## **2. Areas of continued debate**

The LCO is aware that there are several points of contention on the state of the law that continue to be debated. The most visible areas of debate include the following:

- Whether advance requests will be permitted.
- Whether persons with medical conditions will be eligible if their death is not reasonably foreseeable (e.g., persons with disability and mental illness who are not dying).
- What the referral process should be for conscientiously objecting individual and institutional providers.
- Whether enhanced safeguards will be put in place to protect persons who may be incapable, suffer from suicide ideation or otherwise vulnerable to the undue influence of others.

There are several sources of information that put these points of contention into context.

First, following the *Carter* decision, but prior to federal legislation, a number of expert reports were commissioned and delivered at the federal and provincial levels over the course of 2015 and 2016.<sup>298</sup> These reports made various – sometimes congruent, sometimes conflicting – findings on regulating medical assistance in dying. Specific topics addressed in these reports include advance requests, conscientious objection and eligibility criteria. Debates surrounding conscientious objection have also been taken up in the expert academic literature. Legal professionals are actively considering the constitutional ramifications of balancing freedom of religion and conscience with patients' equitable access to care.<sup>299</sup>

Another source for these continued debates is Parliament itself. During Parliament's consideration of Bill C-14, the Senate made or suggested amendments to the Bill that would permit broader eligibility criteria for medical assistance in dying as well as advance requests. Legislative debates among parliamentarians were highly divisive and publicized in the media.<sup>300</sup>

Additionally, there is also a small body of case law that provides information on these issues. During an interim period before federal legislation was passed, persons were permitted to apply to a superior court to exercise their constitutional rights to medical assistance in dying.<sup>301</sup> This court process was used in at least seven cases in Ontario and the results are not entirely consistent with legal frameworks that have emerged since. For instance, based on the *Carter* decision, the Ontario Superior Court of Justice found that persons need not have a terminal or life-threatening illness.<sup>302</sup>

Last, the LCO is aware there has been considerable advocacy within the disability community to alter standards for consent through the implementation of "vulnerability assessments" along the course of the service pathway. Notably, the Canadian Association of Community Living (CACL)

published a report claiming that certain groups are vulnerable to making requests that are not “well-reasoned” due to risk factors, such as stigma, inducement and coercion, social isolation, chronic mental illness and suicidal ideation.<sup>303</sup> A notable concern of advocates, such as CACL, is that a spectrum of alternative supports be improved to mitigate the desire for medical assistance in dying – from palliative care to mental health supports and secure housing.

At the core of most areas of debate, listed above, are fundamental tensions, namely between rights to equality in access for all persons who are suffering intolerably, on the one hand, and a concern for safeguarding persons who may be vulnerable to involuntary requests, on the other. The concern for safeguards extends not only to people who are capable and vulnerable due to their social circumstances, but also to those who become incapable having bound themselves in the past through an advance request. While some argue that advance requests should be available in the event of capacity, others believe that individuals cannot predict future wishes accurately enough to bind themselves to a fatal decision.

The LCO is aware that there are several ongoing or intended *Charter* challenges to the new legislation as well as to regulatory college guidelines on the referral process for objecting clinicians.

### **3. *Issues for the LCO’s project***

In chapter 1 of this discussion paper, we explained that the LCO has sought to avoid duplication with ongoing government efforts in this project in the area of medical assistance in dying (see ch. 1.C, “The project scope incorporates ongoing developments”).

The actions taken, initiatives proposed, and measures introduced by the federal and provincial governments in December 2016, as outlined above, indicate the kind and scope of issues which will be subject to government regulation, the legislative process, and continued government leadership in 2017 and likely even into 2018. This greatly clarifies which issues the LCO should address in this project as complimentary to or beyond the scope of these government initiatives. Outside this scope of proposed legislation, the LCO has heard about several additional issues related to MAID. These include questions related to:

- transitions between care settings to receive MAID
- conscientious objection to the provision of MAID services in long-term care
- appeals of capacity determinations for persons requesting MAID, and
- policies and practices that could be put in place to preempt or resolve disputes arising from the above.



## F. Resolving Health Care Disputes

Death, dying and bereavement are highly emotional and important experiences for everyone involved – patients, family, friends and health care providers, alike. It is not surprising then that disputes arise in these circumstances and, when they do, that disputes can have serious repercussions on everyone’s well-being.

There are several avenues of recourse to resolve conflicts in Ontario. In this section, we briefly summarize administrative law procedures that have been put in place to deal with disputes in a streamlined fashion in the health care system.

As explained below, the LCO’s project considers whether additional policies and practices could be introduced to either preempt or resolve disputes prior to engaging these existing processes.

### 1. *Disputes regarding decision-making*

The Consent and Capacity Board was established as an independent, expert administrative tribunal with jurisdiction over issues raised by the HCCA (along with issues under statutes, such as the SDA and MHA).<sup>304</sup> The CCB may hear applications relevant to this project that seek to,

- review a health care provider’s finding that a patient is incapable of making treatment decisions<sup>305</sup>
- appoint a decision-making representative to make decisions about health care treatment<sup>306</sup>
- obtain permission for an SDM to depart from the prior capable wishes of a person who lacks capacity<sup>307</sup>
- determine whether an SDM is acting in compliance with the requirements of the HCCA as to how decisions must be made<sup>308</sup>
- receive directions to clarify the HCCA’s application with respect to a decision.<sup>309</sup>

In practice, the majority of applications that the CCB addresses are challenges to capacity determinations with respect to treatment under the HCCA, and to findings that an individual should be admitted or remain at a psychiatric facility on an involuntary basis under the MHA.<sup>310</sup> Nonetheless, reported CCB decisions demonstrate that it does also hear applications concerning treatment decisions at the end-of-life.

A study of CCB decisions concerning the determination of a patient’s best interests in end-of-life situations identified a number of prominent themes.<sup>311</sup> In such cases, health care providers typically suggested that life-sustaining treatments be withdrawn, while the patient’s SDM disagreed.<sup>312</sup> Among other findings, the study emphasized, “SDMs frequently relied on their own values and religious beliefs in their interpretations of best interest, and that [providers] focused primarily on clinical condition of the patient”.<sup>313</sup>



For the LCO, findings about the substance of CCB decisions offer a reliable way to understand the types of disputes taking place in Ontario, and we refer to them throughout the discussion paper.

Different individuals can initiate the CCB review process depending on the type of application. For instance, a health care provider can apply to determine whether an SDM has complied with the rules for decision-making under the HCCA, if he believes the SDM has not.<sup>314</sup> Health care providers and SDMs can also apply to the CCB for directions about an incapable person's treatment decisions.<sup>315</sup>

The CCB has broad remedial powers, based on the application at hand, which may include affirming an SDM's decision, appointing a representative to make a treatment decision under the HCCA or substituting a different decision about an incapable person's treatment.<sup>316</sup> In the area of end-of-life treatment decisions, the CCB has made a variety of findings on what decisions would be in a patient's best interests, taking into account the HCCA's requirements for decision-making on an incapable person's behalf and the facts of the case.<sup>317</sup> (Further discussion of decision making over life-sustaining practices is found in section 6.C).

The CCB prioritizes expeditious resolutions: hearings must commence within seven days of an application and decisions must be rendered within one day of the conclusion of the hearing.<sup>318</sup> Decisions of the CCB may be appealed to the Superior Court of Justice.<sup>319</sup>

## ***2. Disputes regarding the quality of services and supports***

Disputes about the quality of care provided in the last stages of life routinely arise in two main circumstances. First, patients or their supporters may allege that they received substandard services in terms of quality (i.e., improper treatments, lack of communication). Second, individuals applying for government-funded services that are administered at home or in the community through the CCACs may appeal a refusal to provide them with the level or type of services they requested.

Until recently, two administrative tribunals were the avenues of recourse in these situations, the Health Professions Appeal and Review Board and the Health Services Appeal and Review Board. However, the Ontario government has also established a Patient Ombudsman who is intended to "help meet the needs of patients who have not had their concerns resolved through existing complaint mechanisms".<sup>320</sup> We discuss these in turn below.

### **i. Regulatory college complaints and the Health Boards**

Under the *Regulated Health Professions Act, 1991*, regulatory colleges are required to maintain complaints procedures for members of the public who allege they received substandard care.<sup>321</sup> For instance, the College of Nurses of Ontario explains that its complaints procedure is designed to address concerns including the failure to provide adequate care, inadequate documentation and unsafe medication administration.<sup>322</sup>

Complaints to the regulated colleges are reviewed by specialized committees and may involve a combination of alternative dispute resolution, investigations and hearings.<sup>323</sup> These processes may result in a variety of remedies if the complainant is successful, such as a caution, discipline or an order to undertake actions.

If the complainant or health care provider wishes to dispute the resolution of a complaint, they can apply to HPARB. HPARB has a mandate to review health college committee decisions on a number of grounds. It also has powers to confirm the decision, refer the matter back, make recommendations, or require the committee to do things within its jurisdiction, such as requiring the health care provider to take remedial action.<sup>324</sup> Decisions of HPARB may be appealed to the Superior Court of Justice.<sup>325</sup>

HSARB plays a similar role as an administrative tribunal; however, its mandate involves reviewing determinations made by agencies acting under 12 different statutes (that do not include the regulated health colleges).<sup>326</sup> In terms of matters relevant to this project, HSARB reviews decisions of approved agencies under the *Home Care and Community Services Act, 1994* regarding eligibility for and the amount of community services (such as the CCACs). It also adjudicates appeals of OHIP decisions respecting eligibility for coverage and payment for services under the *Health Insurance Act*.<sup>327</sup> HSARB's authority depends on the legislation under which it is operating.

Both HPARB and HSARB are regulated under the *Ministry of Health and Long-Term Care Appeal and Review Boards Act, 1998*, and respective Rules of Practice and Practice Directions.<sup>328</sup>

As with the Consent and Capacity Board, the health boards provide insights into the types of disputes arising in the last stages of life. HPARB, in particular, has heard a significant number of cases relating to palliative and end-of-life care.<sup>329</sup> Complaints in those cases relate to delays in providing palliative care, failures to consult family members about transferring a patient to palliative care, and failures to communicate the risks of harm associated with treatments.<sup>330</sup>

One of the areas of high dispute also occurs when health providers allegedly issue “Do-Not-Resuscitate” (DNR) orders without obtaining informed consent from a patient or SDM.<sup>331</sup> Considering that this issue could be dealt with as a matter of capacity and decision-making law, there appears to be some overlap in the cases that individuals bring to the CCB and the health boards (by way of the regulatory college complaints procedures).

Compared to the CCB time frames, proceedings at the health boards can be somewhat longer. HSARB must hold a hearing respecting home and community services within 30 days after the appeals process begins and must make a decision within three days of the hearing.<sup>332</sup> More generally, the health boards resolve over 80 per cent of cases in less than one year.<sup>333</sup> In the LCO's capacity and decision-making project, we did hear from stakeholders, however, that complaints procedures within the regulatory colleges can be time consuming, and those procedures must conclude prior HPARB's review.<sup>334</sup>

In either case – the CCB or the health boards – the LCO has also been told that appeals to the Superior Court of Justice can be costly, difficult to understand and last for extended periods. Therefore, the time between bringing and finally resolving a dispute can be unpredictable.

## ii. Patient Ombudsman

The Patient Ombudsman is a recent addition to Ontario's health care system and there is little information currently available to understand its role and effectiveness. The Patient Ombudsman was formally established through a 2014 Bill amending the Excellent Care for All Act, 2010.<sup>335</sup> The position was filled and publicly announced in December 2015.<sup>336</sup>

At a general level, the provincial government's action plan for the health system, *Patients First: Action Plan for Health Care*, explains that the Patient Ombudsman will "help people who have an unresolved complaint about their care at a hospital, long-term care home or Community Care Access Centre".<sup>337</sup> Under the Act, a "patient" is defined to include patients of hospitals, residents of long-term care homes and clients of the CCACs as well as the substitute decision-makers for any of those individuals if they are incapable with respect to treatment or another matter.<sup>338</sup>

The Patient Ombudsman's powers and responsibilities include,

- responding to complaints from patients and caregivers about the patient's health care experience at a health sector organization, which includes hospitals, long-term care homes or CCACs
- investigating a health sector organization in response to the complaint or on her own initiative
- making recommendations to a health sector organization that is the subject of an investigation
- making reports to the MOHLTC on her activities and annual recommendations, and providing reports to LHINs as appropriate.<sup>339</sup>

The Act explains that, following a complaint, the Patient Ombudsman will work with the complainant, the health care organization and, potentially, the relevant LHIN to facilitate a resolution. After attempting to facilitate a resolution, the Patient Ombudsman can also conduct an investigation of the complaint, which could result in recommendations to the health care organization.<sup>340</sup>

However, the Patient Ombudsman might not respond to all complaints. Should she determine that the complaint relates to a matter falling within the jurisdiction of another body, she can refer the complaint to that other body.<sup>341</sup> The Government of Ontario's public announcement of the first Patient Ombudsman also characterizes her role as responding to "unresolved" complaints.<sup>342</sup> As a result, it is not clear at this time what formal and informal avenues of recourse patients and caregivers will be required to access before engaging the Patient Ombudsman, including the CCB, regulatory colleges and health boards.

### 3. Issues for the LCO's project

More than any concerns about existing avenues of recourse, during the LCO's consultations we heard when it comes to disputes in the last stage of life, there is a need for alternative dispute resolution (ADR) mechanisms that can be accessed prior to initiating administrative procedures.

Expediency and usability are critical assets for dispute resolution processes in this area of the law, especially when end-of-life decisions and services are at stake.

Stakeholders told us that the majority of disputes are actually resolved in a person's care setting through good communication practices between health care providers, patients and SDMs. Health facilities, such as hospitals, may also have internal policies and procedures to resolve escalations in conflict that bring in third parties, including ethicists, chaplains and legal counsel. These procedures can offer a low-cost and non-adversarial means of resolving issues.

However, the LCO is aware that there are various critiques of these existing processes, and we were asked to investigate other possibilities for ADR to standardize, simplify and increase access to conflict management (see chapter 7.B).

It is possible that the Patient Ombudsman might provide a means to fill the gap between informal complaints to health care facilities and administrative procedures. The LCO will keep updated on progress respecting the Patient Ombudsman's mandate and implementation, and address related issues in this project.

We also note here that, aside from our review of ADR, this discussion paper does also review topics that could *minimize* disagreements by getting to their source, such as clarifying the law surrounding the withdrawal and withholding of treatment (see chapter 6.B), and accommodations and supports for faith and cultural communities (see chapter 6.G).



Please also note that the LCO's capacity and decision-making project made recommendations concerning the CCB and the increased use of mediation, and we will rely on our work in that project here.

## G. Specific Laws Affecting Care in the Last Stages of Life

The LCO's project examines specific laws, policies and programs in Ontario that intersect with but are separate from the regulatory framework for the health care system. Although we address these in detail in the following chapters, a few examples are provided here.

An example of a law affecting care in the last stages of life that the project examines is the *Employment Standards Act, 2000*. Previously, we mentioned that caregivers are eligible for services and supports in the health care system through the CCACs and community support services, such as respite care and counselling, if they are available. In addition, the *Employment Standards Act, 2000* permits caregivers and other family members to take protected leave from work for stipulated periods of times.<sup>343</sup> Under these provisions, individuals are entitled to

take time to care for others without losing their employment. The LCO's project considers whether the Act's entitlements, coupled with other benefits, are sufficient to give caregivers and family members the supports they need (chapter 5.D.1).

Health care providers are also protected from work-related concerns under the *Occupational Health and Safety Act*.<sup>344</sup> Presently, these protections are fairly limited to particular types of hazards in the workplace, such as unsafe physical environments and harassment.<sup>345</sup> However, providing for the mental health of workers is a developing area.<sup>346</sup> Protections from the mental health effects of high-risk jobs are actively being considered by the Ontario government.<sup>348</sup> The LCO's project considers whether health care providers who work regularly with patients and their supporters could benefit from a similar expansion of occupational health and safety legislation to address the emotional repercussions of their work situation (chapter 6.F).

A final example of a distinctive law that the LCO reviews is the *Vital Statistics Act*.<sup>348</sup> There are many determinants that affect a person's place of death. One potential contributor of a legal nature is the efficacy of procedures to certify that a person has died of expected causes in the home. Funeral services routinely require receipt of a medical certificate of death before they will agree to transport the body of a person who has died away from the home. However, there are frequent administrative complications and delays that arise in this process that may cause suffering for grieving families. As a result, the LCO was informed that the Vital Statistics Act, which regulates associated issues, could need to be refined (chapter 6.E).



Ontario has proposed amendments to six existing statutes in order to provide clarity specifically in relation to MAID, including the Vital Statistics Act. See the discussion above at section 4.E.1.

Lastly, it is also worth recalling that this paper considers laws that cut across sectors, such as the *Charter*, *Human Rights Code* and *Regulated Health Professions Act, 1991* (which we introduced in chapter 3, above).

## H. List of Statutes the LCO's Project Considers

The remaining chapters of the discussion paper analyze issues to be addressed in the project. For a comprehensive list of these issues, we invite you to refer to the Table of Contents.

Below, you will find a list of statutes that we review to a greater or lesser extent, depending on the issues being addressed:

1. *Accessibility for Ontarians with Disabilities Act*
2. *Canadian Charter of Rights and Freedoms*
3. *Cancer Act*
4. *Constitution Act, 1867*

5. *Constitution Act, 1982*
6. *Coroners Act*
7. *Employment Standards Act, 2000*
8. *Excellent Care for All Act, 2010*
9. *Home Care and Community Services Act, 1994*
10. *Health Care Consent Act, 1996*
11. *Human Rights Code*
12. *Law Society Act*
13. *Local Health System Integration Act, 2006*
14. *Long-Term Care Homes Act, 2007*
15. *Occupational Health and Safety Act*
16. *Regulated Health Professions Act, 1991*
17. *Retirement Homes Act, 2010*
18. *Substitute Decisions Act, 1992*
19. *Vital Statistics Act*

## **I. Questions for Discussion**

**4. Legislation governing health care, housing, employment, professions, and other areas intersects with the last stages of life – what gaps exist that would benefit from greater certainty or clarity?**

**5. Should a public health approach to palliative care be integrated into Ontario's regulatory framework, and how would it look on the ground?**

**6. The LCO has identified several areas where medical assistance in dying could be clarified, including transitions in care, conscientious objection, and appeals of capacity determinations. Are there other additional issues to consider?**

## 5. ACCESS TO JUSTICE FOR COMMUNITIES WITH UNMET NEEDS

### A. Introduction

Ontario is committed to equality in access to quality care in the last stages of life, regardless of factors such as age, sexual orientation and identity, socioeconomic status, culture, ethnicity and place of residence.

The type of care required to address the needs of any one individual or group differs. Nevertheless, laws, policies and programs should be sufficiently flexible to address diverse experiences in a manner that is consistent with rights and principles established under the Constitution and Human Rights Code, among other legal frameworks.

This chapter reviews the experiences of communities that face particular barriers accessing care in the last stages of life. It begins with an overview of the issue and a reminder about relevant legal frameworks (see also chapter 3.C). Then, it provides select examples of communities with unmet needs in Ontario.

### B. Difficulties Achieving Equality in Access to Care in Ontario

Recent government reviews of palliative care confirm that Ontarians suffer marked disparities in accessing quality care in the last stages of life. For instance, the *Declaration of Partnership* (Ontario's vision for palliative care), the Auditor General report on palliative care, and the Fraser Report identify inequalities based on a variety of factors.

The Auditor General's report highlights that, in many ways, Ontario's difficulties achieving equality arise from the lack of a systemic approach to identifying persons who might be eligible for palliative care and the unequal distribution of services across regional LHINs. By way of example, the Auditor General found, "Because eligibility for and supply of palliative care services varies, patients who qualify for services in one area of the province may not have access to similar services in another area".<sup>349</sup>

The LCO is aware that the OPCN will be addressing systemic barriers relating to Ontario's decentralized institutional framework and the standardization of eligibility criteria, which may go a long way in bridging disparities in access. Furthermore, as recommended by the Auditor General, the Ontario government is developing a province-wide strategy.<sup>350</sup>

However, a range of other complex factors contributes to inequality in access. These factors overlap with issues surrounding basic eligibility and coordination, but they reflect **the diversity in experiences that must also be accounted for within any standardized approach.**

There is a dynamic relationship – sometimes tension – between standardized approaches and ensuring a level of customization that meets the unique needs of individuals, families and communities. For example, palliative care recognizes a set of core principles for treatment and accompaniments as well as the necessity of person- and family-centred approaches in each



specific case (see section 4.C.1). Consistent with “personalization” in palliative care, the LCO also believes that care in the last stages of life must respond to Ontario’s diverse *communities*.<sup>351</sup>

The Fraser Report raises awareness about the place of diversity in achieving equality in access. It relates information that stakeholders told the government and which mirrors what the LCO learned in our own consultations. According to Fraser,

If we were to take only one idea away from our province-wide consultations about palliative care, it would be that not all Ontarians have the same access. The barriers are many and diverse. They range from system fragmentation to geography to challenges providing culturally sensitive care.<sup>352</sup>

Fraser describes various communities affected by disparities in access, and he conveys a message that the LCO also heard repeatedly: Ontario should seek to respond to diverse communities with unmet needs. In his words,

Participants told us, time and again, about the importance of ensuring that all patients have access to culturally appropriate and safe palliative and end-of-life care, including those from urban, rural and remote communities, and including various cultural faith and linguistic groups, vulnerable populations (e.g., people who are homeless, have mental health or addiction issues), people with disabilities and Indigenous communities.

We also heard that the approach to palliative care should be tailored to each unique community.<sup>353</sup>

Not unlike the Fraser Report and Auditor General’s report, the *Declaration of Partnership* acknowledges there are groups that are underrepresented or marginalized in the current system. Furthermore, in that document, partners including the Government of Ontario, LHINs and community organizations, positively committed to “[p]rovide more equitable access across all population groups”.<sup>354</sup>

These and other documents attest to Ontario’s recognition of and commitment to achieving equality in palliative care, and the LCO believes that any future strategy should further such existing commitments. Additionally, from the LCO’s perspective, equality should go beyond access to palliative care to include medical assistance in dying (as defined by law) and, also, certain social and legal benefits that could achieve just outcomes for the many communities affected by death and dying. For instance, ensuring caregivers receive support when providing informal services to persons who are dying would fit within our broad understanding of equality for persons affected by this area of the law and, generally, our definition of access to justice.

The following table lists communities that have been identified as having unmet needs in documents including the Fraser Report, *Declaration of Partnership* and Auditor General’s report. It should be apparent from this table that, collectively, **these communities represent a significant proportion of Ontarians.**

To illustrate the need for customized care, we give examples of difficulties that at least some communities encounter later in the chapter.

FIGURE 5: Ontario’s Communities with Unmet Needs	
<ul style="list-style-type: none"><li>Caregivers, and other family and friends</li></ul>	<ul style="list-style-type: none"><li>First Nations, Inuit and Métis peoples</li></ul>
<ul style="list-style-type: none"><li>Older adults with serious frailties</li></ul>	<ul style="list-style-type: none"><li>Faith and culturally diverse communities</li></ul>
<ul style="list-style-type: none"><li>Persons living in long-term care</li></ul>	<ul style="list-style-type: none"><li>Newcomers to Canada</li></ul>
<ul style="list-style-type: none"><li>Persons living in retirement homes</li></ul>	<ul style="list-style-type: none"><li>Persons living in correctional facilities</li></ul>
<ul style="list-style-type: none"><li>Francophone persons</li></ul>	<ul style="list-style-type: none"><li>Persons living with HIV/AIDS</li></ul>
<ul style="list-style-type: none"><li>Person for whom English is not a principal language</li></ul>	<ul style="list-style-type: none"><li>Persons with mental health issues and addiction</li></ul>
<ul style="list-style-type: none"><li>Persons experiencing homelessness</li></ul>	<ul style="list-style-type: none"><li>Persons living in rural and remote areas</li></ul>
<ul style="list-style-type: none"><li>Persons with disabilities</li></ul>	<ul style="list-style-type: none"><li>LGBTQ persons</li></ul>
<ul style="list-style-type: none"><li>Children and infants</li></ul>	<ul style="list-style-type: none"><li>Persons with low income</li></ul>

To illustrate the need for customized care, we give examples of difficulties that at least some communities encounter later in the chapter.

C. Legal Frameworks Relevant to Communities with Unmet Needs

Chapter 3 of this discussion paper reviewed foundational laws applicable to care in the last stages of life, including the Constitution, *Canada Health Act*, *Excellent Care for All Act*, and *Human Rights Code*. Each of these laws speaks to issues of equality in access to care in the last stages of life for persons who are dying and their supporters.

We previously explored equality rights under s.15 of the *Charter*, which requires that public funded services be provided without discrimination based on grounds including age, sexual orientation, ethnic origin, religion or disability. Section 15 of the *Charter* may require that governments take steps to accommodate individuals and groups that suffer discrimination up to the point of undue hardship. However, claims to services that are not already within the basket of publicly funded health care may not necessarily be successful, since medicare coverage under the *Canada Health Act* and OHIP is intended to be a partial plan.

### A Note on “Equality” and “Equity”

In the legal field, we use the term “equality” to describe rights to services without discrimination.

This term recognizes that discrimination may be intentional or an *effect of global measures*. Therefore, equality does not always mean the “same” services for everyone, because standardized services may effectively discriminate against those who have unique needs.

Equality recognizes that positive steps to address discrimination may be required to achieve dignity and participation for all.

The concept of “equity” in the health care sector is aligned with the LCO’s understanding of “equality”.<sup>355</sup>

As mentioned previously in chapter 3, the *Ontario Human Rights Code* provides similar equality protections to s.15 of the *Charter*, but while the *Charter* applies to government, the Code also applies to the private sector, and it covers health services and facilities.

Policies and other guidance documents drafted at the Ontario Human Rights Commission (OHRC) elucidate how equality should be interpreted under the Code. The OHRC has disseminated policies on grounds that may be relevant to how care ought to be provided to Ontario’s diverse communities in the last stages of life. Their policies address

- creed and religious observances,
- gender identity and expression,
- sexual orientation,
- mental health disabilities and addiction,
- language,
- racism and racial discrimination,
- age (for older adults), and
- disability.<sup>356</sup>

Some OHRC guidance documents refer directly to accommodations in the health care sector. For example, in the OHRC policy on creed, the Code is interpreted as requiring “inclusive design”, which “means being aware of differences that characterize people from Code protected groups when making design choices to avoid creating barriers”.<sup>357</sup> In that policy, the OHRC provides the example of creating a “multi-faith prayer/reflection room for persons of diverse faiths to observe their creed beliefs and practices” in a health facility.<sup>358</sup>

Thus, the duty to accommodate as a matter of equality relates not only to the removal of overtly discriminatory barriers, such as obstructive infrastructure for persons with physical disabilities. Rather, it is intended to promote the full participation, dignity and citizenship of all Ontarians, and to foster their diversity. The OHRC explains,

The goal of accommodation is to help everyone have equal opportunities, access and benefits... The duty to accommodate stems, in part, from a recognition that the “normal ways of doing things” in organizations and society are often not “neutral” but rather may inadvertently disadvantage, privilege or better meet the needs of some groups relative to others. Instead of giving special privileges or advantages, accommodations help to “level the playing field” by ensuring that all Ontarians are equally included and accommodated.

“The Ontario *Human Rights Code* is meant to foster a society which will allow diversity to flourish...”<sup>359</sup>

Accommodations under the *Charter* and *Code* do, nevertheless, have their limitations. We mentioned the limitation on claims that allege new programs should be funded to improve the condition of specific groups that go beyond discrimination within the medicare basket of services. Another limitation is the requirement that individuals or groups belong to recognized “grounds” for equality. These grounds are listed in the *Charter* and *Code*, and analogous grounds may be recognized by courts.<sup>360</sup> We listed examples above (e.g., race, disability, age).

To the extent that some of Ontario’s communities with unmet needs in the last stages of life may hold rights associated with these grounds, the *Charter* and *Code* could provide a persuasive rationale for improving access to quality care. The LCO’s role as a law reform agency does not involve assessing the relative merits of any particular community’s equality claims. Nonetheless, we do often recommend systemic changes to existing law and policy frameworks that we believe could potentially advance equality.

For those communities that do not hold rights under a recognized ground or who might not be eligible for services because they exceed the law’s definition of non-discrimination, there are other rights and principles that may be instructive. These rights and principles sometimes overlap with a flexible understanding of equality, and they form part of the LCO’s definition of access to justice.

By way of example, s.7 of the *Charter* protects individuals from criminal sanction against medical practices that deprive them of rights to life, liberty and security of the person. Section 7 cases have expressly supported rights for persons with terminal illness and chronic disease. These include rights to make decisions about medications that alleviate the effects of illness and rights to security from interference with one’s physical and psychological integrity.<sup>361</sup> In *Carter*, the Supreme Court affirmed that concerns about autonomy and quality of life can be treated as liberty and security rights.<sup>362</sup>

In sum, legal rights and principles that are relevant to communities with unmet needs in the context of death and dying include the following:

- The right to equality (*Charter*, s. 15)
- The right to life, liberty and security of the person (*Charter*, s. 7)
- The right to freedom of conscience and religion ( *Charter*, s.2)
- Indigenous and treaty rights (*Constitution Act*, 1982, s.35)
- Universality in the terms and conditions to access insured health services under provincial plans (*Canada Health Act*, ss.7(a), 10)<sup>363</sup>
- Accessibility of insured health services that is reasonable, free of financial or other barriers, and free of discrimination (*Canada Health Act*, ss.7(e), 12)<sup>364</sup>
- High quality health care that is accessible, appropriate, effective, efficient, equitable, integrated, patient centred, population health focused, and safe (*Excellent Care for All Act*, 2010, Preamble).

Similar to our approach to equality rights, the LCO's project does not evaluate claims to services based on the above rights and principles. However, we do believe Ontarians should have equitable access to care, and that it might be inconsistent with existing rights and principles if only some communities have access to crucial public services nearing the end of life. Therefore, along with the LCO's own *Framework Principles* (see chapter 1.B), established rights and principles inform our approach to law reform, and we take them into account in this project.

In next section, we mention rights and principles when they relate to our examples of communities facing challenges with this area of the law. For the most part, however, we simply describe the experiences that stakeholders told us about, recognizing that certain communities might benefit from tailored laws, policies or programs.

## D. Examples of Communities with Unmet Needs

It should be clear from our review so far that Ontario is home to many distinctive communities that might benefit from a tailored approach to care. The reasons are complex, involving our Constitutional history, demographic trends, persisting discrimination and interrelated factors. At a high level, we consider the following factors as contributing to the importance of addressing particular needs in a nuanced, responsive manner:

- Dying, death and bereavement affect everyone
- Ontario is a province with a rich tradition of diversity
- Faith, cultural and other values, beliefs and practices have a strong bearing on how we define quality care
- Communities interact differently with the health care system, and sometimes their needs are underrepresented in standardized approaches.

Given the extensive variation in affected individuals and communities, we can provide only a few examples of communities with unmet needs.

Some were chosen as examples due to deficits in research and awareness. For example, we are mindful of the OPCN's plans to improve palliative care across Ontario's geographic regions, and we have not presented them here. We have also funded external papers on LGBTQ persons, and older adults with serious frailties and their caregivers. These are found on our website at [www.lco-cdo.org](http://www.lco-cdo.org). Furthermore, we address faith and cultural issues in a separate chapter because they permeate the experiences of nearly all communities (ch. VI.G).

For a list of these and other communities identified as having unmet needs in Ontario, please see the table on page 73. We also invite you to tell us about any other communities that the LCO should be considering during our consultations for the project.

Finally, the LCO acknowledges that **the discussions below provide only partial information** on the challenges that communities face. This chapter is by no means exhaustive; it is intended to provide helpful illustrations that we can build upon as the project proceeds.

## **1. Caregivers, and other family and friends**

During the LCO's background consultations, we heard that caregivers who support persons nearing the end-of-life, and other family and friends, desire improved services during the course of illness and after a person has died.

### **i. Caregiver supports**

Caregivers play an indispensable role in Ontario's health care system. They provide wide ranging assistance across care settings and substantially supplement publicly funded services.<sup>365</sup> Studies show many caregivers perceive their role in a positive light, as a reciprocal process that benefits them and the persons they support.<sup>366</sup> However, there is also reliable evidence demonstrating that negative health, social and financial repercussions of caregiving are common.<sup>367</sup>

The Change Foundation's 2016 report, *A Profile of Family Caregivers in Ontario* documents the many impacts of caregiving. For instance, it shows that juggling caregiving and work can have a destabilizing effect on employment.<sup>368</sup> Many caregivers report feelings of worry, anxiety, fatigue, depression, loneliness and being overwhelmed.<sup>369</sup> Almost 1 in 10 caregivers also report financial hardship resulting from their responsibilities including borrowing money, using savings and selling their assets.<sup>370</sup>

Presently, caregivers living in Ontario may possibly be eligible for four forms of support:

1. Protected leave from work in designated circumstances
2. Financial support from federal Employment Insurance (EI)
3. Respite care delivered through the provincial health system
4. Income tax credits.

*The Employment Standards Act, 2000* protects employees from losing their job when they take leaves of absence to care for family members, persons “like a family member” or in emergencies.<sup>371</sup> The provisions governing leave are quite complex because there are several types and each may depend on factors, including relationship, prognosis and length of employment.

Leave is also limited by a maximum number of weeks within a period of time. For example, under one type of leave called “Family Medical Leave”, employees are entitled to take up to eight weeks to care for an individual who has a significant risk of death within a period of 26 weeks. If the person does not pass away within that 26 week period, employees are entitled to another leave of up to 8 weeks, but only in a *subsequent* 26 week period.<sup>372</sup>

A consequence of existing requirements is that caregivers may exhaust their entitlements or may not be able to take leave without interruptions. Interruptions can be especially pronounced where the underlying condition causes ups and downs over a lengthy period of time. Continuity in leave for the actual time it takes to care for persons who are ill can therefore be difficult.<sup>373</sup> Furthermore, while Ontario’s protections were recently expanded,<sup>374</sup> they do not match protections for federally regulated employees. Under the *Canada Labour Code*, a type of protection similar to Family Medical Leave entitles employees to an additional 20 weeks.<sup>375</sup>

For employees who are able to take leave, the *Employment Standards Act, 2000* does not guarantee pay. Ontarians may be eligible for federal EI benefits, including the “Compassionate Care Benefit”.<sup>376</sup> Since EI is aligned with federal leave entitlements, these benefits may be available for 26 weeks.<sup>377</sup> That said, the LCO has heard that because they are linked to job-status, caregivers may not be eligible if, for instance, they have not accumulated sufficient work hours, are self-employed or are precarious employed. Furthermore, benefits are only available to caregivers of persons with a significant risk of death or critically ill children – they neglect to include other chronic conditions.<sup>378</sup>

Short-term respite provided through the health system and income tax credits are other sources of caregiver support.<sup>379</sup> On the whole, however, stakeholders told the LCO that existing caregiver benefits in Ontario are inadequate. The Fraser Report documents similar sentiments with respect to current levels of home care (which could offset the need for caregiving), respite services and financial compensation.<sup>380</sup>

The LCO is aware that community organizations in Ontario are advocating for a caregiver allowance, separate from employment regimes.<sup>381</sup> In Canada, Nova Scotia provides such a benefit in the amount of \$400 per month.<sup>382</sup> The UK and Australia also provide a spectrum of financial allowances for caregivers as well as statutory protections for “flexible” working arrangements.

In addition, the UK and Australia have legislation that specifically defines “carer”, and centralized gateways for informational supports (i.e., online portals and call-centres).<sup>384</sup> One of the challenges for caregivers identified in the LCO’s consultations is Ontario’s lack of such formal recognition of caregivers as a unique beneficiary group, which could improve the coordination of dedicated services and supports.



## **ii. Grief and bereavement services**

Aside from direct supports for caregiving activities, persons who are caregivers, and other family and friends, have expressed the need for improved grief and bereavement services.

The *Declaration of Partnership* accepts that grief and bereavement care are a core part of the vision for palliative care in Ontario. Access to grief and bereavement supports are listed among the document's priorities for action and it calls upon the LHINs and regional palliative care networks to ensure that appropriate support is available before and after a person dies.<sup>385</sup>

Generally speaking, in Ontario counselling and psychological care are not covered by public health insurance, unless they are provided by psychiatrists (because they are medical doctors) or offered through government-funded hospitals, clinics and programs.<sup>386</sup> There are many passionate and committed organizations that coordinate volunteering programs to help family and friends work through their experiences, and these often receive some public funding.<sup>387</sup>

However, stakeholders informed the LCO that communities require better capacity to provide the supports they strive to offer. As it is now, services are fragmented and psychological support has not been adequately integrated into palliative care. We were informed that, as a result, Ontario effectively has a "two-tiered" system for therapy, divided between those who can pay for private services and those who cannot.

We also heard the ESA provides insufficient leave to face the challenges arising after a person dies, such as arranging a funeral and managing grief. For instance, under Family Medical Leave, employees cannot remain on leave after the last day of the week in which the person dies.<sup>388</sup>

The Fraser Report strengthens many of the LCO's own findings. While he highlights innovative programs in the province, Fraser also remarks,

According to participants, families would benefit from stronger supports for anticipatory grief, loss and bereavement, including information, ongoing support groups and counselling services at all stages of care.<sup>389</sup>

## **2. Persons living in long-term care homes**

Challenges in the delivery and receiving of palliative care in long-term care homes was a pervasive theme repeated by numerous concerned individuals throughout the LCO's consultations.

Long-term care homes are internationally recognized as an important setting for palliative care.<sup>390</sup> While the vast majority of residents are older persons, they are also home to persons with disabilities and persons with serious health conditions that require constant access to care. As the Ontario Long Term Care Association explains,

Nearly all (97.4%) of people in long-term care have two or more chronic conditions that have seriously compromised their health. More than six in 10 (62%) have Alzheimer's disease or another dementia that has progressed to the point where they can no longer live at home or in a retirement home. Most residents are seniors, with more than half over the age of 85.<sup>391</sup>

Long-stay residents will almost always spend their final days there, and about one third of residents die each year.<sup>392</sup>

It is a fundamental principle of Ontario's long-term care system that these are homes. The *Long-term Care Homes Act, 2007* (LTCHA) emphasizes that these settings must be operated in a way that respects the dignity, security, safety and comfort of their residents, and must meet not only their physical, but also their psychological, social, spiritual and cultural needs.<sup>393</sup> Ontario's statutory framework includes a number of provisions aimed at providing holistic supports and services to persons at this stage of life:

- For each resident, there must be a written plan of care, based on an assessment of the resident and her or his needs and preferences, and addressing all aspects including medical, nursing, personal support, social, restorative, religious and spiritual care;<sup>394</sup>
- Every long-term care home must have a program addressing religious and spiritual practices;<sup>395</sup>
- Homes must apply interdisciplinary approaches.<sup>396</sup>

As mentioned before, the *Long-Term Care Homes Act, 2007* requires licensees to train all staff who provide direct care to residents on palliative care.<sup>397</sup> Licensees also have a statutory duty under the Regulations to "ensure that every resident receives end-of-life care when required in a manner that meets their needs".<sup>398</sup>

Nevertheless, several stakeholders have indicated that persons residing in long-term care could benefit from an approach to care that more fully draws on and includes palliative care models.

The literature and our background consultations show that consistent, quality palliative care is not available in many long-term care homes.<sup>399</sup> We heard that, despite improvements, residents' pain and symptoms are often left untreated,<sup>400</sup> transfers to hospital at the end-of-life are still too frequent, and death and dying are "hidden" rather than discussed as a normal stage in life.<sup>401</sup> These concerns point to regulatory and implementation barriers in the province that, it appears, research and policy are only beginning to address.

For example, one concern raised during our consultations relates to the identification criteria for palliative care. Stakeholders informed the LCO that there is a conceptual and practical divide between care for elderly persons who are "aging into death" with serious frailties, including comorbidity and dementia, and care for those who have been diagnosed with terminal or other life-limiting illnesses. Although there are prognostic tools available to assess frailty for clinical purposes, frailty has yet to be fully incorporated into eligibility for palliative care.<sup>402</sup>

Other concerns relate to the lack of precision in regulatory requirements for palliative care and implementation issues. Long-term care homes are required to ensure that legislated staffing and care standards are met, and to create written staffing plan that provides for a staffing mix that is consistent with residents' assessed care and safety needs.<sup>403</sup> However, research indicates that most homes in Ontario do not have formal palliative care strategies or programs, and staff does not receive adequate education (especially personal support workers (PSWs) who provide most front-line care).<sup>404</sup> Instead, the focus of care is on daily maintenance.<sup>405</sup> The LCO was informed that existing staffing levels, and performance and reporting requirements also do not account for residents' needs nearing the end-of-life.<sup>406</sup>

The LCO heard that, above all, such challenges result from the need for a "culture shift". This shift would move the health care system as a whole to greater recognition of the value and importance of the long-term care system. It would also re-orient the long-term care sector itself around the recognition that residents are increasingly older, frail and vulnerable persons with very complex medical needs, who could benefit from both higher levels and different forms of care, including palliative care.

These and other difficulties addressing the needs of long-term care home residents at the end of life can be summarized as follows:

- Imprecise guidance on how regulatory requirements for palliative care should be implemented in long-term care homes' policies, procedures and accountability.
- Lack of recognition of seriously frail individuals, including the elderly, within identification criteria for the palliative approach to care.
- As in the broader health system, attitudinal barriers to acknowledging the prevalence of death and dying.
- Insufficient staff levels and appropriate education to support care at the end of life.
- Lack of integration across long term care and health sectors.
- The need for an overall "cultural shift" based on the actual demographics of long-term care home residents.

### **3. *Persons living in retirement homes***

Retirement homes are a privately funded care setting; however, residents have varying means and are not necessarily affluent. At the same time, demand for retirement homes is increasing in part because of the lack of available space in Ontario's long-term care sector, and due to increasingly stringent admission criteria.<sup>407</sup> Yet retirement homes are not subject to the same level of scrutiny as long-term care homes and their residents do include vulnerable persons. As the Advocacy Centre for the Elderly (ACE) explains,

Residents of retirement homes are a potentially vulnerable group as they are often dependent on the institution that provides their care and shelter, in addition to the fact that they are 'out of sight' and sheltered from public scrutiny.<sup>408</sup>

The LCO has heard distressing accounts of the lack of higher level care and, specifically, palliative care in this setting. Under the *Retirement Homes Act, 2010* (RHA), retirement homes need only make two care services available to residents, directly or indirectly.<sup>409</sup> Care services are defined under the Act to encompass a wide range of services from assistance with dressing to the provision of meals.<sup>410</sup> Therefore, unlike long-term care homes, retirement facilities can but are not required to provide palliative and end-of-life care.

Aside from any limitations on facilities themselves providing care, the LCO received further feedback from stakeholders that there are significant barriers to receiving *external services* in retirement homes. For instance, we heard that service providers arranged through the CCACs and palliative care providers have been refused access to residents' apartments. Retirement homes are also known to have evicted residents when they needed palliative care. This situation has arisen while residents are living in their units and also upon their admission to hospital following a health event. Retirement homes have prohibited residents from returning home when they are discharged from hospital.<sup>411</sup>

The RHA established the Retirement Homes Regulatory Authority, which oversees standards, licensing, inspections, investigations and enforcement. Beyond this targeted legislation, retirement homes are also governed under the *Residential Tenancies Act, 2006* (RTA) because they are private tenancies. Together, this statutory regime creates rights of occupancy that are not always evident in residents' lived experience.

Both statutes explicitly entitle residents to apply for and receive external care services of their choosing in their homes. For example, the RHA reads as follows:

**External care providers**

- (1) a licensee of a retirement home shall not prevent a resident of the home from applying for care services from an external provider of the resident's choosing
- (2) a licensee of a retirement home shall not interfere with the provision of care services to a resident of the home by an external care provider.<sup>412</sup>

The Bill of Rights under the same Act and the RTA contain similarly clear guarantees.<sup>413</sup>

However, retirement homes are permitted to apply to the Landlord and Tenant Board to evict tenants requiring "a level of care that the landlord is not able to provide".<sup>414</sup> It should be noted that it is the Landlord and Tenant Board who is mandated to make the determination of whether an eviction order is appropriate; it is not at the landlord's discretion.

Moreover, the Landlord and Tenant Board may only issue an eviction order where it is satisfied that two criteria have been met:

1. Care services provided by the retirement home along with *external services* provided in the home (such as publicly funded home and community care) must be insufficient to meet the resident's needs
2. Appropriate alternative accommodations must be available.<sup>415</sup>

Residents may thus have avenues of recourse open to them, including making an application to the Landlord and Tenant Board if they are being unlawfully evicted as well as submitting a complaint to the Retirement Homes Regulatory Authority.<sup>416</sup>

But, in practice, retirement homes do evict residents or pressure them to leave without applying to the Landlord and Tenant Board.<sup>417</sup> We mentioned above that they have also prohibited residents from accessing external services to which they are entitled (in general and prior to any eviction order).

There are several resources available for residents and others seeking public legal education and advice, such as the Advocacy Centre for the Elderly and Community Legal Education Ontario (CLEO). Nonetheless, the LCO would like to know more about how compliance under the RHA and RTA could be improved, residents' rights better enforced and whether any legislative reform would be beneficial.

#### **4. First Nations, Inuit and Métis peoples**

Health care for Indigenous peoples in Canada is in dire need of reform. Indigenous peoples are affected by shorter life expectancy, higher rates of chronic conditions and distressing health crises.<sup>418</sup> Yet, they lack access to culturally appropriate, self-determined and safe services.<sup>419</sup>

The Truth and Reconciliation Commission's (TRC) *Calls to Action* lists a number of areas for collaboration between Indigenous, federal, provincial and territorial governments to improve health care in these circumstances. It calls upon them to

....acknowledge that Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.<sup>420</sup>

Over the past year, both the federal and provincial governments have pledged to invest new funding into health for Indigenous communities.<sup>421</sup> Ontario launched the First Nations Health Action Plan to ensure "access to more culturally appropriate care and improved outcomes".<sup>422</sup>

The action plan focuses on a number of critical priorities, including primary care, public health and health promotion, senior's care, and life promotion and crisis support.<sup>423</sup> Initiatives that receive increased funding in these areas could, possibly, devote some funds to palliative care.<sup>424</sup> However, the action plan does not explicitly mention palliative care. The government has promised to implement and review the action plan in partnership with Indigenous partners.<sup>425</sup>

There are extensive barriers to quality care nearing the end of life for First Nations, Inuit and Métis persons in Ontario that must be overcome. In Ontario, Indigenous peoples receive a mix of services delivered through complex arrangements involving federal and provincial funding and services, and First Nations governments. The palliative care that any one individual receives is highly dependent on factors such as status under the *Indian Act*, place of residence within or outside a First Nations jurisdiction, and the geographical location and resources of distinctive First Nation communities.

Given the Ontario government's commitments to palliative care and, also, Indigenous health, the LCO believes it is an opportune time to improve palliative care in a way that addresses disadvantages for Indigenous communities, including inequalities among those communities. To that end, below we describe existing challenges that should be considered.

Needless to say, the LCO cannot speak for Indigenous peoples. In the confines of this discussion paper, we can only describe a handful of barriers that have been already been reported.

These are examples of challenges that we would like to learn more about:

1. **Divisions between federal and provincial governments create a “gap” in health care:** The federal government regulates and funds health care for First Nations peoples living on reserve.<sup>426</sup> At the same time, Ontario must deliver insured services to everyone residing in the province.<sup>427</sup> Ambiguities arising from this division of power have given rise to “gaps” in care for persons living on reserve.<sup>428</sup> Recently, the Canadian Human Rights Tribunal recognized a robust interpretation of “Jordan’s Principle”, which requires the first agency that is contacted to pay for services for children living on-reserve and to determine jurisdictional issues later.<sup>429</sup> Nevertheless, jurisdictional conflicts affect the availability of palliative care, as special type of service, which we review below.
2. **Palliative care is inadequate for Indigenous peoples in Ontario:** Federal funding on reserve covers “essential health services”, which include home and community care but not dedicated long-term or palliative care.<sup>430</sup> Individuals living on reserve are eligible for provincial home and community care services as well.<sup>431</sup> However, provincially funded services on reserve vary and are often not available, especially in remote communities.<sup>432</sup> Indigenous peoples located or living off-reserve can generally access the same services as others in the province.<sup>433</sup> In these circumstances there may be cultural, language and other social barriers to access (see below). Moreover, if individuals have to leave their homes on-reserve to receive care for the last stages of life, it can have detrimental effects for them, their family and community.<sup>434</sup> The MOHLTC does fund Aboriginal Health Access Centres (AHAC), which provide some palliative care on and off-reserve.<sup>435</sup> But overall, Indigenous peoples’ access to palliative care is wanting.<sup>436</sup>
3. **There are inequalities among persons living on and off-reserve, and across First Nations communities:** Inequalities in services between persons living on and off-reserve can be gleaned from the two challenges presented above.<sup>437</sup> These distinctions also affect First Nations, Métis and Inuit individuals differently, since only First Nations receive federally funded services on reserve in Ontario. Although a recent Supreme Court case affirms that the federal government holds obligations toward Métis and Inuit peoples under the *Indian Act* and fiduciary duties, these obligations do not extend to the provision of health care.<sup>438</sup> Additionally, the LCO has heard there are great differences in the demographics, resources and capacities of various First Nations communities across Ontario, depending on complicated factors (e.g., proximity to urban areas).<sup>439</sup>



4. **Self-determination is an important part of health care:** Health care is planned and delivered in partnership with Indigenous governments and agencies. Each reserve has a different arrangement for health care administration. For example, some communities deliver health care through funding agreements between the federal government and Band Council, while others do so in partnership with regional Treaty organizations (e.g., Nishnawbe Aski Nation) or First Nations Health Authorities.<sup>440</sup> The provincial AHACs are community-led and they seek to promote self-determination: 60% of their professionals are Indigenous individuals and they also employ traditional healers (for a total of 360 employees in 10 centres).<sup>441</sup> Even so, the LCO heard that tensions arise in existing governance arrangements, and there is a desire for enhanced self-determination in Indigenous health care.
5. **Cultural appropriateness is related to “safety” in health care:** Cultural appropriateness is a goal for all care nearing the end-of-life. Cultural awareness and the ability to provide competent care for Indigenous peoples is sometimes referred to as “cultural safety”.<sup>442</sup> Framing this issue as a matter of safety captures the relationship between mainstream services and Indigenous experiences of colonization, discrimination and oppression, which have continuing, traumatic repercussions on multiple generations.<sup>443</sup> There are certainly efforts in Ontario to build cultural safety into care nearing the end-of-life.<sup>444</sup> However, there is no standardized guidance on cultural safety, and Indigenous beliefs, practices and languages have not been well integrated or reinforced.<sup>445</sup> For the LCO, claims to culturally appropriate health care as a Treaty right and, also, legal disputes about rights to traditional healing under the Constitution shed light on the urgency of articulating the scope of cultural safety.<sup>446</sup> We examine cultural issues, including Indigenous cultural issues, comprehensively in chapter 6 of this paper.

As mentioned above, the TRC’s *Calls to Action* makes recommendations to improve Indigenous health care. Recommendations include recognizing Indigenous healing practices, increasing the number of Indigenous professionals working in health care, and providing compulsory education on Indigenous history, rights, Treaties and practices, among others.<sup>447</sup>

During our consultations, the LCO learned there are many promising palliative care initiatives and pilots in Ontario that affirm Indigenous community mobilization and empowerment, such as the *Improving the End-of-Life Care in First Nations Communities* project conducted with four First Nations communities.<sup>448</sup>

In addition to Indigenous persons’ lived experiences, would like to know more about how these community-based programs and sources, such as the TRC report, might feed into ongoing work.



## **5. *Persons experiencing homelessness***

Homelessness affects diverse individuals who are living in extremely vulnerable circumstances – from persons affected by family violence staying in shelters and immigrants in temporary accommodations to “unsheltered” persons living on the streets. Although definitions of homelessness do vary in scope, the Canadian Observatory on Homelessness defines the term inclusively to describe

individuals or family without stable, permanent, appropriate housing, or the immediate prospect, means and ability of acquiring it.<sup>449</sup>

There is a true continuum of situations covered by this term since “homelessness does not discriminate on the basis of age, gender, sexuality or race”.<sup>450</sup> There are, however, groups that disproportionately experience homelessness, including some of persons we mentioned above:

- Persons seeking protection from abuse
- New immigrants
- Persons with mental health issues and cognitive disabilities
- Persons with addiction
- Individuals relocating from institutional care (e.g., group homes, child protection, mental health facilities, correctional facilities).

Persons living with a low income have less access to health services and worse health outcomes, and these consequences are particularly evident among homeless persons.<sup>451</sup> Homeless persons may have overlapping conditions and, frequently, struggle with mental health issues. Yet there are fewer resources available to address their intersecting physical, psychological and social conditions, and the community has a higher morbidity rate than the general population.<sup>452</sup> It is estimated that “[a]t the age of 25, men living in shelters, rooming houses and hotels are expected to live, on average, until 42.3 years”.<sup>453</sup>

When it comes to palliative care, however, stakeholders told the LCO that standard services are not conducive to reaching Ontarians experiencing homelessness and providing them with quality care.

There are certainly barriers unique to different individuals and groups within this community; however, there are also shared challenges. For example, most persons experiencing homelessness do not have a health card.<sup>454</sup> The lack of fixed address makes standard documents a challenge and, in turn, impedes the ability to access the health system as a whole.<sup>455</sup> There are also hospices that refuse to care for individuals without a permanent address or primary care provider – two things that homeless individuals might not have.<sup>456</sup> Even basic emergency services and hospital care may be beyond reach.<sup>457</sup>

Persons experiencing homelessness also tend to have priorities that compete with their health needs. Immediate necessities of life, such as food and shelter, often take precedence over health care, which can lead to delays in seeking help or a lack of continuity in care.<sup>458</sup> Individ-

uals may, for instance, be unable to make or keep appointments due to the transient nature of living arrangements.<sup>459</sup> Some individuals may also have difficulty obtaining prescription medications and adhering to medical advice.<sup>460</sup>

Moreover, the LCO heard that homeless persons suffer considerable prejudice, which affects not only the quality of care they receive, but also has a chilling effect on their willingness to seek out help.<sup>461</sup> We were told that health care providers often have trouble understanding or do not support the lifestyle choices of some persons, which exacerbates the lack of contact with the health system.

Other specific difficulties arising in this area include restrictive policies around drug use in care settings for persons with addiction and, also, reliance on housing staff or social workers due to isolation from family and friends.<sup>462</sup> But these are just a few of the impediments for this particular community.

The *Declaration of Partnership* recognizes that homeless persons are marginalized and require a better government response.<sup>463</sup> The Fraser Report also mentions homelessness and it cautions health care providers to “be flexible when delivering care to: patients who are homeless who may lack proper identification, health card or places for providers to visit...”.<sup>464</sup> However, in Ontario, there has been little effort made to bridge the gaps that affect this particular community. Initiatives to address their needs tend to be discrete and independent projects.<sup>465</sup>

These initiatives include “street nurses” as well as two projects that have garnered remarkably positive attention and merit at least a brief mention: the Palliative Education and Care for the Homeless (PEACH) program in Toronto, and the Mission Hospice Program in Ottawa.<sup>466</sup>

PEACH is a community outreach program that brings palliative care to persons in various situations of homelessness through a mobile-shelter approach.<sup>467</sup> It consists of 60 physicians as well as nurses who travel to shelters and drop-in sites to provide capacity building support to staff and direct care. The program helps persons who may have had little to no regular contact with doctors for years. It delivers early palliative care to persons no matter their stage of illness.<sup>468</sup>

The Mission Hospice Program provides shelter-based palliative care to residents of the Ottawa Mission.<sup>469</sup> The program uses a harm reduction approach for managing the particular needs of residents with addiction who are receiving palliative care. It seeks to reduce drug-related harm without requiring that persons with addiction stop their drug use. However, the program also has strict rules in place regarding injections at the shelter, and ensuring that medications are kept safe and administered solely by program staff.<sup>470</sup>

In our upcoming consultations, the LCO would like to learn more about the possibilities for leveraging initiatives, such as PEACH and the Mission Hospice Program, as well as for systemic change.

## 6. Persons with disabilities

The community of persons with disabilities has a strong tradition of advocacy for rights to full citizenship and participation in society. The community has successfully gained recognition of various accommodations and has eliminated certain inequalities arising from societal discrimination under the *Charter*, *Code*, *AODA* and *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*.<sup>471</sup> Yet persons with disabilities continue to advocate for the eradication of inequalities that persist in multiple areas, including care in the last stages of life.

All individuals who are nearing the end of life are in a position of vulnerability. But this vulnerability is heightened for persons with disabilities. Some elderly persons may develop physical and cognitive disability later in life and for those who experience disability prior to the onset of older age, their functional health could further decline in their later years.<sup>472</sup>

The heightened vulnerability of persons with disability who are nearing death is attributable to social factors including prejudice, marginalization, social isolation and substantial experiences of abuse and neglect.<sup>473</sup> Vulnerabilities are especially felt by persons with diminished cognitive capacity, who may not know their options, or face challenges communicating their needs and concerns.<sup>474</sup> Unfortunately, discrimination and vulnerability serve as a barrier to quality care because they limit the ability to gain services and, sometimes, to self-advocate.<sup>475</sup>

Lack of accessibility is another major barrier for persons with disabilities that affects admissions to palliative care.<sup>476</sup> For instance, health providers may have difficulties identifying when persons with disabilities are nearing the end of life.<sup>477</sup> Because persons with disabilities may have understudied or unpredictable illness trajectories, it can be hard to determine when a person might transition to different types of care or settings.<sup>478</sup>

There are also known obstacles to the quality of care provided to persons with disabilities who actually receive services. Persons with disabilities can have complex care needs which limit the breadth of options available to them.<sup>479</sup> An individual who uses a wheelchair, for example, may be restricted to facilities equipped with ramps or sufficiently wide hallways to accommodate this assistive device.<sup>480</sup> Persons with disabilities that affect hearing, speech, reading, writing or comprehension may also require supports for to overcome communication barriers.

Additionally, members of this community often have pre-existing relationships with the health system that are characterized by distrust.<sup>481</sup> There is a long history of paternalism toward persons with disabilities, including widespread institutionalization of those with diverse physical, cognitive and communicative abilities in Ontario and elsewhere.<sup>482</sup> As a result, institutionalization is viewed as the “worst case scenario” by many who would prefer to live at home with support or in supportive housing with the addition of palliative care services.<sup>483</sup>

The LCO has heard that transitions to long-term care for Ontarians with disabilities is a particularly sensitive area that merits attention. Stakeholders expressed concerns about the perception that long-term care is a form of “re-institutionalization,” that long-term care homes are often not equipped to deliver personalized care for those with complex needs, and that existing care services could be better enabled to adapt to the changing needs of persons with

disabilities as they age. Some individuals are particularly underrepresented in terms of supports for independent living, such as young persons with disabilities who may not fit into a system geared toward older adults. Clearly, addressing these concerns require innovative partnerships across Ontario's health and social care sectors.

These and other difficulties addressing the needs of persons with disabilities who are nearing the end of life can be summarized as follows:

- Lack of attention to the complex needs of persons with disabilities in the last stages of life, including accommodations in facilities and access to palliative care
- Attitudinal barriers about persons' abilities, including their capacity for treatment decision-making
- Lack of supports for communication barriers
- Difficult relationships with the health care system arising from social discrimination, including institutionalization
- Insufficient integration across health and social sectors.

There are select initiatives in Ontario that adopt a collaborative approach to address the concerns of persons with developmental disabilities nearing the end of life. For example, the Ontario Partnership on Aging and Developmental Disabilities (OPADD) is a network of partners including the MOHLTC, Ministry of Community and Social Services (MCSS) and medical facilities. OPADD has a Transition Taskforce that works on achieving a continuum of care.<sup>484</sup>

The MOHLTC and MCSS also developed a joint protocol for persons with developmental disabilities transitioning to long-term care, called the Long-Term Care Homes Access Protocol for Adults with Developmental Disability.<sup>485</sup> The protocol is currently being revised; however, to our knowledge it does not specifically address issues nearing the end of life, including palliative care.

As with the other communities explored in this project, we hope to learn more about further steps that might improve the dignity, participation and equality of persons with disabilities nearing the end of life.

## **E. Access to Justice as a Matter for Law Reform**

Insofar as fostering equality and access to justice nearing the end of life is a priority for the LCO's project, we must turn our minds to how this might be achieved, specifically, *as a matter of law reform*.

In this chapter, we reviewed connections between legal rights and principles, and access to services and supports. We showed that equality rights as well as other rights and principles provide a rationale for responding to Ontario's diverse communities in a manner that respects their dignity, participation, equality and safety. (Previously in chapter 3.C, we also gave an overview of foundational laws in this area.)

Furthermore, we summarized some of the government's prior commitments to equitable palliative care, and feedback the Province has received from stakeholders requesting that a "tailored" approach be used.

Taking into account all of these considerations, the LCO would like to know what Ontarians believe our role is in making recommendations regarding communities with unmet needs.

For instance, the LCO's project could recommend that the Ontario government's palliative care strategy, which is currently being formulated, adopt measures to ensure customized approaches to care for specific communities with unmet needs. This might include that any ongoing initiatives to standardize principles and eligibility criteria also account for persons who are often not identified for palliative care, such as older adults with serious frailties and persons with disabilities. We might include suggestions relating to the formal recognition of caregivers within the palliative care strategy. Among other matters, we might also propose that measures be adopted to ensure services are extended to care settings that currently struggle to provide residents with equitable care, such as group homes, shelters and long term care homes.

Another point of entry into law reform could consist of our assessing legal frameworks that affect diverse communities for their inclusion of relevant provisions concerning the last stages of life. For example, the LCO could analyze laws and policies within the provincial human rights system to determine whether they provide adequate protections for communities that are underrepresented in the health care system.

Finally, the LCO could intentionally focus on different communities to make targeted recommendations about their unique circumstances, such as caregivers, persons experiencing homelessness, First Nations, Inuit and Métis peoples or others.

Our goal in suggesting these options is to add value to reports that have already been released in this area – to take the next step in making **recommendations that are responsive, concrete, precise and implementable.**

At this stage of the project, we simply ask that members of the public comment on these options from a law reform perspective, so that we can refine our analysis in our consultations and, eventually, our later reports.

## F. Questions for Discussion

*7. What are your experiences as a member or supporter of a community of need going through the last stages of life?*

*8. What law reforms do you believe are needed for communities with unmet needs, and how would such reforms be most effectively implemented in law?*

*9. Are there any communities with unmet needs who are not identified in this paper that the LCO should consider?*

## 6. SPECIFIC CHALLENGES TO ACCESSING CARE IN THE LAST STAGES OF LIFE

### A. Introduction

This chapter addresses specific areas of the law that could improve access to care in the last stages of life through legal clarification, simplification or improved implementation. The chapter raises many novel issues that Ontarians told the LCO are in pressing need of reform.

While debates about medical assistance in dying are highly publicized, the issues addressed in this chapter raise equal concerns about autonomy, self-determination, beneficence and safeguards against abuse. The Supreme Court remarked in *Carter* that there is no reason to think persons receiving some of the end-of-life practices addressed here “are less vulnerable or less susceptible to biased decision-making than those who might seek more active assistance in dying”.<sup>486</sup> In fact, the practices reviewed in this chapter are more routine and widespread.

Decisions about whether to receive CPR, withdraw life support, or continue eating and drinking; the availability of supports to ensure culturally safe care; and the legal options for planning ahead – these are all issues that impact a great number of Ontarians.

In this chapter we examine them and others in the following sections:

- A. Practice Tools for Consent and Advance Care Planning
- B. Decision-Making Authority over Life-Sustaining Practices
- C. Certifying Expected Deaths at Home
- D. Regulating Palliative Sedation Therapy
- E. Work Conditions of Supporting Professionals
- F. Accommodations and Supports for Faith and Cultural Communities.

Summary information about these issues has been presented throughout the discussion paper so far, particularly in chapter 2.B, “Recent Debates about Rights Nearing the End of Life”. Underlying legal frameworks relevant to these issues are also explained in previous chapters, such as chapter 3, “The Law and Care in the Last Stages of Life”, and chapter 4, “Ontario’s Laws, Policies and Programs”. Therefore, readers are advised to consult those chapters prior to considering the specific challenges presented here.

For ease of reference, we pose questions for consultation at the end of each section.



## **B. Advance Care Planning: Developing Strategies and Tools for Effective Implementation**

### **1. *The central importance of health care consent and advance care planning***

Person-centred decision-making is an essential process for ensuring quality care aligned with a person's preferences and values.

As the demand for care in the last stages of life increases, so too does the demand for ways to plan for the future, and future decision-making. In Ontario, individuals can engage in a process known as advance care planning. This can include the identification of who they want to make decisions for them when they cannot, and can share wishes, values and beliefs to help their substitute decision-maker with this role, a process known as advance care planning. Advance care planning conversations, and the subsequent consent process, have been demonstrated to improve patient and family satisfaction with end-of-life care.<sup>487</sup> Advance care planning is situated along a continuum with goals of care discussions and health care consent comprising the person-centred health care decision-making process. In combination, these processes ensure alignment between a patient's values and treatment, lessen family distress, decrease hospitalizations and admissions to critical care, and decrease unwanted investigations, interventions and treatments, among other benefits.<sup>488</sup> Moreover, advance care planning "Respects an incapable patient's right to self-determination in critical illness and end-of-life".<sup>489</sup>

Both in this project and in our project on Legal Capacity, Decision-making and Guardianship, the LCO has heard widespread concerns about misunderstandings of the law, and shortcomings in its implementation. In response to implementation challenges, many practice tools have been created to help individuals, SDMs and health care providers implement the existing law consistently and accurately. The LCO's project seeks to clarify grey areas of the law that are unsettled or contested, such as these. In addition, our project looks at the challenges of effectively implementing the current legislative framework.

### **2. *Increasing demand for practice tools to plan for care nearing the end of life***

Conversations about consent and advance care planning have become a cornerstone of palliative care among community advocates and within care settings. Initiatives across many jurisdictions, including Ontario, have been created to promote pre-planning, and health care facilities have developed policies, practices and related forms to encourage (or require) patients to articulate preferences for future health care.<sup>490</sup>

#### **What We Mean by "Practice Tools"**

In this project, we refer to the various policies, toolkits and forms for consent and advance care planning that are being used in Ontario care settings as "practice tools" because they are used to put the law of consent and advance care planning into practice.

Although practice tools are about implementing the law, our use of this term does not imply that existing practice tools accurately reflect Ontario's legal framework. The LCO has heard that there are pervasive challenges with practice tools, which result in confusion among health care providers, the infringement of rights to consent and difficulties carrying out individual preferences about important life decisions.<sup>491</sup>

The purpose of this section is to discuss challenges with existing practice tools for advance care planning, goals of care and health care consent in Ontario, and to consider the possibilities for supporting meaningful decision-making, and effectively implementing the law.

Until now, there was a lack of evidence on practice tools in Ontario. Therefore, the LCO commissioned an expert research paper on this topic entitled, *Health Care Consent, Advance Care Planning and Goals of Care Practice Tools: The Challenge to Get it Right*.<sup>492</sup>

The authors of that report, Judith Wahl, Mary Jane Dykeman and Tara Walton conducted an extensive review and assessment of practice tools in Ontario, and gathered new qualitative information through interviews and focus groups. Their paper represents the most authoritative resource on this subject in our jurisdiction, and we rely on it considerably in this section.



To read the full research paper commissioned by the LCO on decision-making practice tools, please visit our website at [www.lco-cdo.org](http://www.lco-cdo.org).

### **3. Legal framework for consent and advance care planning**

Chapter 4 of this discussion paper sets out the basic elements of Ontario's legal framework for consent, advance care planning and substitute decision-making under the *Health Care Consent Act, 1996* and the *Substitute Decisions Act, 1992*. This framework represents a careful balance between needs for efficient decision-making for persons who lack legal capacity, the preservation of patient autonomy, and the ability to respond to changing circumstances.

The LCO is aware that misunderstandings about Ontario's decision-making laws are common and we recommend that readers consult those parts of the paper before reading this section. That said, here we do provide a brief summary of key aspects of the law and common misconceptions that are essential to our review of practice tools.

#### **i. Processes for obtaining consent and the role of advance care planning**

This summary is organized to show how the process of decision-making must take place under the law. The laws that underpin consent and advance care planning emphasize that decisions must always be specific to an individual's present condition and circumstances. Furthermore, framing decision-making as a *process* highlights the step-by-step approach that health care providers and decision-makers are required to follow to arrive at a valid decision.

The process for obtaining consent from a patient (or SDM, if the patient is incapable), is paramount – it enables health care providers to deliver quality care, protects them from liability, ensures that decisions are informed, and gives effect to the patient’s rights and preferences.

It is important to note that advance care planning is distinct from and instrumental to the process of obtaining consent. It allows a person to either confirm the default SDM identified in the HCCA or designate an SDM of his or her choosing, and to guide the SDM in making decisions that align with the person’s wishes, values and beliefs. The SDM must exercise his or her judgment in applying those wishes, values and beliefs to the context of a specific decision. There may, for example, be circumstances where an expressed wish is simply impossible to fulfill.

Advance care planning does not obviate the health care provider’s duty to always obtain consent from a capable patient or SDM. In Ontario, health care providers must obtain informed consent from a patient or SDM, before providing treatment, except in very limited cases of emergency.<sup>493</sup>

Health care providers must engage with patients to explain their health condition, discuss their goals and consider the options for treatment. Informed consent from the capable patient is required by law and is the first priority in the decision-making process. If health care providers have reason to believe a patient is incapable, they must assess the person to determine incapacity before turning to an SDM to make decisions on his or her behalf.<sup>494</sup>

When an SDM is authorized to make decisions on an incapable person’s behalf, he or she must follow the procedure for decision-making set out in the HCCA. This begins with following the person’s wishes expressed while capable, if they apply to the circumstances and are possible.<sup>495</sup> A person’s wishes may be expressed orally or in written form, such as a Power of Attorney for Personal Care (POAPC). Later wishes, if expressed while capable, prevail over earlier wishes.<sup>496</sup> This underscores the importance of advance care planning as a means to guide SDMs in making decisions on behalf of incapable patients.

If the person has no known prior expressed wishes that meet these criteria, then the SDM must make decisions in the person’s best interests, taking into account a variety of factors, including the person’s well-being, values and beliefs.<sup>497</sup>

Health care providers have a responsibility to give the patient and SDM all of the information necessary for consent to be informed. The HCCA stipulates what types of information this includes.<sup>498</sup> Consent that is not informed does not constitute legal consent under the HCCA.

Finally, consent to treatment decisions can be obtained immediately before the treatment is administered or through a plan of treatment. A plan of treatment is a plan that is developed by one or more health care providers to deal with health problems that are present or likely in the future given the person’s current health condition.<sup>499</sup> Plans of treatment provide for the administration of various treatments or courses of treatment, in light of the person’s current health condition.<sup>500</sup>

Plans of treatment should not be confused with advance care planning. Because plans of treatment require informed consent, both patients and SDMs can consent to a plan of treatment, whereas only a patient can engage in advance care planning.<sup>501</sup>

## ii. Relationship of “goals of care” to the legal framework

Another central concept to the health care decision-making process is that of “goals of care”. Health care providers may use the term “goals of care” to represent a framework that is relevant to decision-making for the contexts of serious or critical illness. The language of goals of care is not found in the HCCA or SDA, and there is variation among clinicians in understandings of the overall purpose, expected outcomes and approach to goals of care discussions.<sup>502</sup> The LCO has been told that conflation of goals of care discussions with decision-making processes under the law is resulting in confusion.

Dr. Jeff Myers, Dr. Leah Steinberg and Dr. Nadia Incardona explain that there are two main “conceptual orientations” for “goals of care” discussions: treatment focused and person-focussed. **Treatment-focused approaches** understand the purpose of “goals of care” discussions as eliciting treatment decisions, such as a transfer to palliative care or recording a wish not to receive CPR in a plan of treatment.<sup>503</sup> **Person-focused approaches** consider goals of care discussions as having a conversation about a patient’s personal life preferences and goals for their care in preparing for subsequent legal decision-making.<sup>504</sup>

In the first interpretation, goals of care discussions may be conflated with legal decision-making under the HCCA and SDA because they are focused on reaching a specific treatment decision. This confusion is understandable because other jurisdictions use the term expressly to denote legal decision-making.<sup>505</sup> However, the LCO has heard that this definition could increase misunderstandings about Ontario’s unique legal framework and thereby systemically undermine informed consent.

In the second interpretation, goals of care discussions are not aimed at reaching a specific treatment decision.<sup>506</sup> Instead, the focus is on identifying what is important to the patients, how they understand their condition, and creating a deeper understanding between health care providers, patients and SDMs about the relationship between care and achieving the patient’s goals in alignment with their personal values. In this interpretation, goals of care discussions aim to bring to bear a person-focussed approach to formulate meaningful preferences. These preferences are the foundation for later discussions, which address specific decisions (and require informed consent). In this sense, goals of care discussions can potentially improve informed and person-centered decision-making. Myers et al. explain,

The purpose [of goals of care discussions] would be to prepare for decision-making by gaining an appreciation of who the person is, how their values are reflected in the goals he or she has for their care and how these align with both the clinical picture and treatment approaches being considered. Elements of the discussion may include an exploration of the person’s past experiences, hopes, values, priorities, perception of quality of life and what he or she considers important. The clinician clarifies what the person understands about the meaning of the current condition, how the person would define and describe the goals he or she has for their care (i.e. being able to do or experience something) as well as the meaning and role for these goals.

Approached in this way, the [goals of care] discussion enables a clinician to elicit how the patient views his or her own clinical picture. It may illuminate misinformation and misunderstandings as well as any [goals of care] that are incongruent or even incompatible with the clinical picture as it is understood by the clinician.<sup>507</sup>

The authors of the LCO commissioned paper on practice tools for decision-making, Wahl et. al., favour the second interpretation of goals of care “as the best ‘fit’ for the Ontario legal framework for health decision-making”.<sup>508</sup> And the LCO agrees. Goals of care discussions can assist both health care providers and decision-makers grasp what types of care should be considered and proposed before seeking informed consent, in light of what is important to patients and is possible to reach their goals:

Once information needs have been met and using a person-focused approach the clinician understands the patient’s [goals of care], a decision-making discussion can then ensue. This involves exploring which treatments and care decisions are best aligned with these goals. Thus, person-focused [goals of care] discussions are precursors and fundamental to decision-making discussions.<sup>509</sup>

While goals of care discussions have the potential to improve the quality of care nearing the end of life, they are not *legal* decision-making. Therefore, we suggest they should be seen as a foundation for high-quality, informed consent under the HCCA and SDA.

### iii. Implications of Ontario’s decision-making process for practice tools

The legal process for obtaining informed consent and engaging in advance care planning conversations has several nuanced implications. Understanding these implications is necessary to reviewing existing practice tools and considering whether these or new practice tools can reflect the law.

As we explain later in this section, there are many practice tools that do not accurately reflect the law due to misconceptions about the parameters of consent and advance care planning as well as goals of care. The following five key implications of Ontario’s process for decision-making should, therefore, be borne in mind as we move forward in the project:

1. Advance care planning conversations, goals of care discussions, and informed consent are **distinct processes that form a continuum**
2. **Advance care planning** allows individuals to plan ahead for possible legal incapacity to consent to treatment
  - Through advance care planning, individuals can confirm or identify their SDM for treatment decisions
  - Advance care planning enables individuals to articulate their values, wishes and beliefs with respect to treatment

3. Conversations about goals of care create a space to share information about a person's condition and to articulate person-centered life goals
  - Discussing goals of care creates a foundation for later decision-making through Ontario's legal framework for informed consent
4. Within legal decision-making, **consent is distinct from advance care planning**
  - Receiving consent from a legally capable person is the first priority for health care providers proposing treatment
  - Capable individuals must give or refuse consent themselves; decisional authority cannot be delegated to an SDM or provider for a capable person
  - Health care providers must presume a person is capable of making decisions and determine that a person is incapable before turning to an SDM
5. Health care providers may obtain consent from the capable patient or their SDM (if incapable) for a course of treatment by proposing **a plan of treatment that is tied to the person's current health condition**
6. Conversations with health care providers about **information necessary to make a decision are an integral part of the consent process**
7. The **decision-making process is dynamic and ongoing** – consent is specific to a particular decision and must be updated when new information becomes available. An individual can change or withdraw their consent at any time.

A further implication of the process for legal decision-making is that individuals cannot bind themselves to future treatments by drafting a “directive” to health care providers. The purpose of advance care planning in Ontario is for the capable patient to delegate an SDM who would give or refuse consent on their behalf that would be informed, contextual and aligned with their preferences, should they become incapable.

In the LCO's project on *Legal Capacity, Decision-Making and Guardianship* we reviewed proposals to reform Ontario's laws to permit directives for future care that are available in other jurisdictions. However, the interim report suggests that Ontario's legal framework strikes an appropriate balance that emphasizes the role of the SDM in interpreting and conveying prior capable wishes and in providing informed consent as particular issues arise.<sup>510</sup>

Consequently, any practice tools that could be used in Ontario should avoid relying on tools in other jurisdictions that permit directives that purport to speak directly to health care providers. Instead, the LCO believes any possible practice tools must align with the language of the HCCA and SDA, and should promote consent and advance care planning as a nuanced, dynamic and ongoing process.

#### 4. Challenges with existing practice tools for decision-making

##### i. Practice tools being used in Ontario care settings

There are myriad practice tools that health organizations, ethicists and providers have created or adapted from online and other sources that are being used across care settings. During the LCO's background consultations, stakeholders described practice tools as belonging to several groups, including the following:

###### Types of "Practice Tools"

**Levels of care forms:** tick-box forms regularly used on admission to long-term care homes to record preferences for interventions nearing the end of life based on standardized categories.

**DNR Confirmation Form:** official form created by the MOHLTC to instruct emergency responders not to resuscitate a person residing in the community or long-term care, when they are called into the situation. The DNR Confirmation Form has a narrow scope and has no legal force in other situations.<sup>511</sup>

**DNR and No-CPR orders:** recorded in a patient's chart in hospital to document that CPR is not indicated or that consent has been given to withhold CPR (see section C, below, for disputes about legal authority to make these orders).

**Advance care planning policies, guides, forms and kits:** highly variable documents that may be available online and used across all care settings.

**Goals of care forms:** forms relating to documenting goals of care that are often used in the palliative care setting.

**Packaged tools:** usually containing information and forms on overlapping areas, such as advance care planning, goals of care, and consent.

As the above list suggests, there is no single practice tool being used for consent and/or advance care planning in Ontario. Rather, there are numerous tools that have been generated through discrete initiatives. The LCO commissioned paper on this topic by Wahl et. al. reviewed and assessed over 100 such practice tools.<sup>512</sup> The practice tools they reviewed had different focuses (e.g., consent, advance care planning, goals of care) with only 18 tools overlapping on two or more areas.<sup>513</sup>

There is "no one voice of 'authority and no one 'regulatory body'" that coordinates resources for health organizations and providers.<sup>514</sup> Because the health care system is fragmented across sectors, providers may receive inconsistent direction about how to prioritize and integrate consent and advance care planning into their practice. As a result, "health care practitioners and others on



the frontline occasionally receive mixed messages about what is a good practice in respect to [health care consent, advance care planning and goals of care]”.<sup>515</sup> That is, the proliferation of practice tools, as well as the inconsistencies among and frequent inaccuracies in these tools, have the same roots: Ontario’s decentralized approach to this area, which leaves institutions and professions searching for clarity and guidance.

We address specific problems with existing practice tools that flow from these concerns below.

## **ii. Problems with existing practice tools**

The LCO received comments from health care providers, ethicists, lawyers and community organizations about pervasive problems with existing practice tools in Ontario. We heard that practice tools are being characterized as mandatory forms in many care settings, especially long-term care homes, even though advance care planning is a voluntary process. The sheer number of and inconsistencies in practice tools is cause for confusion and, generally, reduces their credibility when shared across different care settings (for instance, when a “levels of care” form is taken to hospital).

Additionally, we were told time and again that many practice tools do not accurately convey the law of informed consent and advance care planning in the province – they are being proposed as consent “directives” (which have no legal basis in Ontario), may ask SDMs to express wishes on a person’s behalf, and list the wrong hierarchy of SDMs under the HCCA, among other concerns.

The LCO commissioned research by Wahl et al., confirms there are many problems with practice tools through their empirical assessment of a large sample of documents and consultations. We recommend that readers refer to their paper directly on our website for detailed information, but highlight at least some of the challenges they observed below:

- 1. Lack of accuracy with respect to all elements of the law, especially informed consent:** Many practice tools contain legal errors about Ontario’s legal framework.<sup>516</sup> In particular, they do not emphasize the priority of obtaining consent as a dynamic and ongoing process that begins with engaging the patient. Most practice tools do not explain the respective rights and responsibilities of health care providers, patients and SDMs.<sup>517</sup> Some list the SDM as the “next of kin”, rather than follow the list of mandatory SDMs under the HCCA. Moreover, practice tools may seek to have an SDM express wishes on the patient’s behalf, which is not permitted by law.<sup>518</sup>
- 2. Incorrect use of tools to obtain consent or to limit treatment options:** Practice tools are frequently used to obtain consent to treatment, including the withdrawal and withholding of treatment, in a manner that resembles a “directive” to health care providers.<sup>519</sup> Practice tools are often used to solicit a specific outcome or treatment decision (e.g., consent to no-CPR), rather than focusing on the decision making process. However, unless the document is a valid plan of treatment (see definition above), individuals cannot consent to future treatments; they can only express wishes to be interpreted by an SDM should they become incapable.

3. **Missing connections between advance care planning, goals of care and informed consent:** There are crucial misunderstandings reflected in practice tools about the intersection of advance care planning, goals of care discussions and informed consent.<sup>520</sup> Currently, goals of care may be treated as consent or advance care planning, when each should be considered separately, as part of a continuum.<sup>521</sup> Consent and advance care planning may also be conflated.<sup>522</sup> This hampers the appropriate use of practice tools and further compounds inaccuracies about the respective roles of health care providers, patients and SDMs.
4. **Reliance on documents obtained elsewhere:** A treating health care provider is responsible for ensuring that informed consent has been obtained. This includes the responsibility to confirm consent that was previously expressed to another care provider before being transferred elsewhere.<sup>523</sup> Practice tools are particularly problematic where they are used to indicate a person has consented to withholding life-sustaining measures because the quality of information provided to the patient cannot be ascertained and the circumstances may have changed.<sup>524</sup> An example is the misuse of DNR Confirmation Forms which are only intended for emergency responders.<sup>525</sup> These forms are a narrow solution to a practical problem (to fill a gap in emergency responders' scope of practice); yet they are being used in hospitals as confirmation of DNR status on admission, which may not reflect the person's changed health condition and is simply not legally authorized.<sup>526</sup>
5. **Limited legal review:** The involvement of legal professionals in reviewing practice tools appears to be rare.<sup>527</sup> Ethicist and health care providers may be asked to review documents or are retained to manage projects to develop tools, but lawyers are not regularly retained or included as part of the teams.<sup>528</sup> Also, although long-term care homes are required to have documents containing consent and advance care planning matters certified by a lawyer to ensure compliance with the law, this does not appear to consistently happen in practice.<sup>529</sup> The MOHLTC inspection protocols for long-term care homes also do not appear to require specific review of this requirement, although inspectors do look at regulated documents when a complaint comes in or a concern is identified during a Resident Quality Inspection related to resident charges or other concerns where a regulated document is used.<sup>530</sup>

While there are other challenges associated with practice tools, the role of education about the law is a final challenge that we draw attention to at this moment, reserving more discussion of these issues to our conversations with members of the public in our dedicated consultation phase.

We encourage you to contact us about your experiences with additional challenges with practice tools that would add to our review.

### iii. The role of education about the law

During background consultations to this project, as well as more extensively during the LCO's multi-year project on *Legal Capacity, Decision-Making and Guardianship*, there was a widespread perception among stakeholders that misunderstanding of this area of the law is endemic at all levels, and that this is causing significant and serious misapplications of the law.

Education is one response to this widespread misunderstanding, and many stakeholders have emphasized the importance of more effective and extensive education in this area.

However, it is important to keep in mind that education, on its own, is not a panacea to resolving the issue if the forms and tools that professionals are using are incorrect, if standard processes do not include appropriate mechanisms for consent, or if there are systemic disincentives or barriers to proper implementation of the law. That is, education is just one component of any broader initiative to ensure effective implementation of Ontario's laws for advance care planning and consent.

That said, a prominent theme in the LCO's background consultations and external research is the lack of education among health care providers and members of the public on advance care planning, goals of care, and consent. Health care providers have been described as "having basic knowledge" of these processes, "but not always recognizing the distinction between these concepts".<sup>531</sup> Knowledge translation from concept to practice has been found to face difficulties.<sup>532</sup> Incorrect or deficient practice tools can also drive inappropriate habits.

The LCO's project on *Legal Capacity, Decision-Making and Guardianship* includes an examination of education about the law, which we rely on in this project. Our interim report in that project made thoroughly researched findings about gaps in education following multiple years of consultations across the province. It also makes recommendations on solutions to remedy this problem.

For ease of reference, below we provide you with an overview of key findings and draft recommendations in that project, which are also relevant here.



To read more about the LCO's project scope, please see ch. 1.C, "The project scope incorporates ongoing developments," and ch. 1.D.2, "Project development, research and consultations."

#### LCO's proposals affecting education about the law

The LCO's *Legal Capacity, Decision-making and Guardianship Interim Report* found there is insufficient education and guidance for providers who assess capacity for treatment decisions.<sup>534</sup> A lack of clear standards under the HCCA, together with shortfalls in education within some professions, has led to confusion and anxiety around assessments.<sup>535</sup> Furthermore, there is limited awareness among many providers about their obligations to assess capacity and provide rights information to patients whom they determine to be incapable.<sup>536</sup>

Taking into account these and other factors, the LCO proposed that official guidelines be developed for assessments under the HCCA. We suggested a number of basic principles and procedural rights to be included in these guidelines.<sup>537</sup> We made recommendations on how the provision of rights information to patients could be reformed through requirements for minimum standards under the HCCA.<sup>538</sup> Also, we suggested that the HCCA be amended to include a clear and explicit duty on health care providers to inform SDMs of their roles and responsibilities, stating that the creation of a standard form may support them in this regard.<sup>539</sup>

Other pertinent recommendations relate to outreach, education, information, quality assurance and the allocation of regulatory authority over these matters. Within the constraints of this discussion paper, we cannot describe all of the LCO's proposals. We invite readers to access our reports for more details, but highlight that our recommendations address the roles of the following institutions in strengthening these areas based on their mandates:

- Professional educational institutions
- Health regulatory colleges
- Health Quality Ontario
- Local Health Integration Networks
- Ministry of Health and Long-Term Care.<sup>540</sup>

For instance, the report suggests that professional educational institutions re-examine their curriculum and consider strengthening coverage of issues related to capacity, decision-making and consent.<sup>341</sup> Additionally, we proposed that health regulatory colleges include issues concerning these areas of the law as a priority in their quality assurance programs, including for the identification and assessment of core competencies.<sup>542</sup>

Our recommendations in the capacity and decision-making project also propose the Government of Ontario to lead the development of an overarching strategy for outreach, education and information to be delegated to an appropriate institution.<sup>543</sup>

This last recommendation was intended to benefit professionals who advise on and apply the law as well as users who are directly affected by capacity and decision-making. Thus, any future institution would facilitate public education and professional education for health care providers and others relating to capacity and decision-making.



The LCO's final report on capacity and decision-making was released in March 2017. It can be accessed on our website at [www.lco-cdo.org](http://www.lco-cdo.org).

## **5. Opportunities to improve understanding of the law of consent and advance care planning**

The LCO was asked to consider strategies to overcome the problems arising from multiple, inconsistent and inaccurate practice tools being used for decision-making nearing the end of life. This project does not reconsider the decision-making process for informed consent and advance care planning in Ontario.

We believe the HCCA strikes the right balance in putting consent front and center by first requiring informed consent from a capable person. Should the person become incapable, having an SDM interpret and convey prior wishes, values and beliefs in the circumstances at hand promotes the patient's autonomy and self-determination. It also reduces the risks inherent in binding instructions for future care that cannot be properly understood outside a person's current health condition.

Therefore, our task concerns the translation of Ontario's laws for consent and advance care planning into practice for health care providers, patients and SDMs. This task raises a number of questions that we would like to investigate through further consultations.

The first question relates to whether creating standardized practice tools would be desirable or, even, possible to implement Ontario.

There are several jurisdictions in Canada and the US that have created standardized practice tools, such as the Alberta Health "Green Sleeve" package, which contains a "Personal Directive" (to designate an SDM) and "Goals of Care Designation" (which is recorded as a medical order).<sup>544</sup> However, these jurisdictions, including Alberta, have different laws than Ontario and they would not meet our standards for informed consent.<sup>545</sup>

Another example are the British Columbia Fraser Health Authority materials, which again do not reflect Ontario law because of differences in legal distinctions between consent and advance care planning, and Ontario's emphasis on consent as an ongoing process.<sup>546</sup>

Given that Ontario's laws require a continuous decision-making process that is always context specific and changeable, the LCO wonders whether standardized documents could uphold the law.

Following their expert review of Ontario's legal framework, existing practice tools and stakeholder experiences, Wahl et al. conclude that "a set of standardized practice tools would not be possible".<sup>547</sup> To begin, they explain that the business of practice tools is too widespread and entrenched that it would be impossible to stop. Second, they find that "there is no one set of 'perfect' practice tools" that would meet all needs for different types of health care services.<sup>548</sup>

Depending on what we hear during our consultations in this project, the LCO's second question asks what alternatives to the design of standardized tools could be pursued. Wahl et. al. propose the implementation of a systemic approach that seeks to shift behavior within the health care system, including health care organizations and providers, and members of the public. They focus on four key elements:

- Using HCCA terminology in all existing practice tools
- Educating all stakeholders
- Ensuring legal accuracy of all practice tools
- Promoting compliance with the law through enforcement methods.

The authors recommend a multipronged strategy to creatively integrate these aspects of systemic change that engages all levels of governance, including the MOHLTC, LHINs, HQO, health regulatory colleges, long-term care home operators, the Patient Ombudsman, accreditation bodies and others.

It merits noting briefly here that there are significant efforts underway within community organizations in Ontario to gather and assess existing practice tools against the legal framework, and to coordinate knowledge sharing about best practices.

For example, the ACE and the HPCO Health Care Consent and Advance Care Planning Community of Practice are two centres of excellence for integrating Ontario's laws into practice into practice tools. In addition to a centralized leadership advisory team, which includes an ACE representative, the HPCO initiative includes regional leaders, representing each of the province's regional LHINs.<sup>549</sup> Both ACE and the HPCO community of practice review practice tools, disseminate public legal education and host workshops for service providers.<sup>550</sup> Therefore, strong efforts for creating systemic change are apparent in the province, though perhaps not to a degree that would be required to generate a full culture shift.

The LCO would be interested to learn about whether ongoing efforts could be scaled-up to be embedded within other community or regulatory systems. In particular, we would like to know whether our recommendations in the *Legal Capacity, Decision-Making and Guardianship* project on strengthening information and education could be further detailed in this project to include a dimension relating to quality assurance for practice tools.

A final question that LCO would like to hear more about is the content of any potential practice tools or other approaches to education and implementation. The content of such tools could potentially differ across care settings, while still highlighting a core set of fundamental rights and principles under the HCCA and SDA to be integrated across the board.

Specific objectives for content development might look at how the nature of legal decision-making as a process can be emphasized. Or, whether good communication and goals of care discussions could be better integrated into preparing for decision-making. They might also address ways to incorporate the primacy of informed consent (including plans of treatment) into initiatives focused on advance care planning.

For further examples we direct you to the funded research paper appendix which makes recommendations for content areas by target audience (e.g., health care provider, patients, SDMs, health care organizations).

## **6. Questions for discussion**

**10. *How can institutions, professionals and the public be better supported to obtain meaningful and legally compliant health care consent?***

**11. *How can practice tools achieve the goal of providing accurate, consistent and meaningful information about consent and advance care planning?***

### **C. Decision-Making Authority over Life-Sustaining Practices**

#### **1. Introduction**

Many Ontarians have personal experience making decisions about life-sustaining practices from our own health conditions or those of our family and friends. Some of these questions are about whether to receive lifesaving treatment (i.e., CPR) or life-sustaining treatment (i.e., life support). Aside from medical treatment, assistance with the necessities of eating and drinking also becomes increasingly vital nearing the end of life.

Decision-making in these situations is extremely difficult; it relies on confronting and defining our defining values and emotions. It also raises ethical concerns for health care providers who view their role as only providing what they see as clinically beneficial treatment. Sometimes patient and SDM values conflict with those of health care providers when it comes to deciding whether life-sustaining measures should be provided to a person who is nearing the end of life. These situations can be confusing and stressful, especially when the law about who has decision-making authority is unclear.

Adding to the challenge is the difficulty that many of us have in communicating and making decisions effectively in stressful and emotional situations. Patients and families may not be well-prepared for conversations about the end of life. A number of stakeholders have suggested that popular culture encourages unrealistic expectations of modern medicine. In a paper prepared for the LCO, Cartagena et. al. noted that for some patients even speaking about suffering at the end of life was difficult or impossible: it requires individuals to face what is coming, and so requires great courage.<sup>551</sup>

As well, families may be understandably reluctant to discuss with each other the possibility of death. As a result, some families and patients may not be ready to accept the realities of their situation, and continue to hope for “a miracle”. Family members may not be prepared for the emotional and ethical burdens of end-of-life decisions: they may find themselves reluctant to shoulder the responsibility for decisions that result in death, even if they believe that such decisions may be for the best or indeed reflect the wishes and values of their loved one.



For their part, some health care practitioners may also find these conversations difficult. Cartagena et. al. identify time, training and resources as constraints on the ability of providers to address the needs of patients and families at the end-of-life.<sup>552</sup>

The LCO accepts the need to balance the interests of patients, SDMs and health care providers in decision-making, as a general matter, but there are important questions about who has legal authority to make decisions in particular circumstances nearing the end-of-life that need clarity.

Here we review the state of the law on this subject and ethical debates surrounding it. Specifically, we review who has authority to decide whether a person is offered or receives life-sustaining measures in the two areas mentioned above:

- health care treatment
- the necessities of life (i.e., food and water).

In some respects, the law is clear on these issues, but to a large extent the law is unsettled. The ultimate purpose of this section is, therefore, to ask what the law ought to be.



For ease of reference, we use the term “life-sustaining practices” to refer to the various types of practices considered in this chapter.

## **2. Identifying values and concepts influencing decisions**

Decisions about the withdrawal and withholding of life-sustaining practices may be influenced by a number of values and concepts, which are briefly outlined below. These values may underpin law, ethical frameworks, or professional obligations. They may also influence the approaches or decisions of patients, families or health providers. These values may have their sources in ethical or legal frameworks, or more broadly in religious or spiritual values.

This discussion is not meant to provide a comprehensive list of relevant values or concepts, or to thoroughly explore any of them. Rather, it is intended to provide some basic starting points for consideration.

**Autonomy and self-determination:** Autonomy and self-determination are generally acknowledged as central principles in the provision of any treatment, recognizing the fundamental importance of bodily integrity.

The principle of autonomy has been particularly recognized in the context of treatment decisions. In *Fleming v Reid*, the Ontario Court of Appeal emphasized that “The common law right to bodily integrity and personal autonomy is so entrenched in the traditions of our law as to be ranked as fundamental and deserving of the highest order of protection. ... [T]he common law right to determine what shall be done with one’s own body and the constitutional right to security of the person, both of which are founded on the belief in the dignity and autonomy of each individual, can be treated as co-extensive”.<sup>553</sup> The HCCA specifically identifies the enhancement of autonomy among its purposes.<sup>554</sup>

These core principles of autonomy and independence are both reflected in two recent LCO project, the *Framework for the Law as It Affects Persons with Disabilities* and the *Framework for the Law as It Affects Older Adults* (the “Frameworks”).<sup>555</sup> The definitions in both *Frameworks* emphasize that the achievement of autonomy or independence may require the provision of supports, and that autonomy should be understood in the context of the individual’s relationships. This is particularly relevant in the end of life context, as individuals become more frail and family relationships tend to become more important.

Perspectives that favour principles of autonomy and self-determination reveal serious concerns about taking away the “voice” of the very persons whom treatment is intended to benefit.<sup>556</sup> The dying experience is incredibly personal. It engages our innermost sense of identity as individuals, family members and community participants. There are significant apprehensions among some that giving health care providers authority to make decisions about life-sustaining treatment might not adequately capture the importance of non-medical, personal values in the dying process.

In the view of some, as a culture, we may over-burden autonomy, both culturally and legally, particularly at the end of life, when the very nature of the process is one of becoming less autonomous, less in control and less aware. Cartagena et. al. quote one provider as follows:

And when we are in our threat system, we are not utilizing our frontal cortex. Our thinking is very limited and it’s all about ‘How do I make myself safe?’ So if someone is in their threat system, and worried about dying a horrible death, it might make sense in that to say, of course, ‘Hastening my life is going to make sense. That’s going to, it’s going to get it all over with.’ ... So in terms of capacity, I think if somebody is in their threat system, they might make a decision that is different than they would if they were actually in the wise part of the brain, not feeling isolated and alone, feeling connected to other people and connected to their own strength.<sup>557</sup>

Providers also pointed out that many other cultures do not place such a heavy emphasis on autonomy, and that it may be a disservice to the end of life experience of some individuals to automatically assume that autonomy should override other values.<sup>558</sup>

**Beneficence:** The principle of beneficence refers to the ethical and professional obligations of a health care provider to alleviate suffering and provide treatment that benefits the patient. Similarly, the principle of non-maleficence requires health care providers to refrain from providing treatment that would harm the patient.<sup>559</sup>

The Manitoba Law Reform Commission highlights that the primary goal of medical treatment is to restore or maintain patient health as much as possible, maximizing benefit and minimizing harm.<sup>560</sup>

In a paper commissioned by the LCO on suffering and capacity at the end of life, the authors emphasized that providers may experience moral distress from the provision of non-beneficial treatment that causes suffering.<sup>561</sup>

**Utility:** Concepts of utility are often referenced in discussions of beneficence, and the two are sometimes confused or conflated.

Where a proposed treatment is useless or ineffective, it may be inappropriate to offer or continue it. The Manitoba Law Reform Commission helpfully distinguishes two aspects of “futility”:

Physiological futility describes a treatment that will not work or one which cannot achieve its desired goal. It is largely a matter of clinical medical judgment. Qualitative futility introduces the highly controversial concept of treatment which is not worth doing or one that will not produce a desirable outcome. The word futile tends to emphasize the qualitative connotation of the word and suggests that a predominantly value laden judgment is being made. This has led to the term falling into disrepute. In particular, it generates discomfort in vulnerable groups such as persons with disabilities and the elderly.<sup>562</sup>

The Manitoba Law Reform Commission suggested that a more helpful approach is to focus on “medical inappropriateness”, as emphasizing the clinical aspects of decision-making.

Both the concepts of beneficence and utility are grounded in the health care provider’s expert clinical judgment and standards of practice.

Understanding the potential application of these principles requires basic knowledge about potential physiological and social consequences of life-sustaining treatment as well as commonly held beliefs within the health profession. In Ontario, there is no *legal* definition of what constitutes utility, medical appropriateness, beneficence and malfeasance in this context.

**Distributive Justice:** In a recent paper, Downie, Wilmott and White identified distributive justice as a relevant consideration in withdrawal and withholding of potentially life-sustaining treatment. No health system has unlimited resources, and resources such as intensive care beds are expensive and in limited supply. The authors emphasize that “It is not immoral to ration resources. It happens frequently and is necessary: no country can afford to provide all that is medically possible to everyone .... If just policies are in place, then it can be ethically defensible to deny treatment to some individuals.”<sup>563</sup>

In considering the concept of distributive justice, it is important to acknowledge the concerns of, for example, older persons and persons with disabilities. Negative and stereotypical assumptions about the quality or value of the lives of particular groups could inappropriately influence decisions about the provision of life-sustaining treatment. The *Framework for the Law as It Affects Older Adults*, for example, highlights attitudes that see older persons as having nothing further to contribute and as simply waiting for death.<sup>564</sup>

**Value of life:** The value of life is a fundamental starting point in any discussion of the withholding and withdrawal of life-sustaining treatments. In some cases, this value draws on religious understandings of the sacredness of life, but it also has roots in broader ethical and legal frameworks that see life as having intrinsic value. In *Rodriguez v. British Columbia (Attorney General)*, the Supreme Court emphasized that the sanctity of life must be considered, along with liberty and security of the person, in weighing issues related to the end of life.<sup>565</sup>

In some decisions, these values will be harmonious. In others, there will be tensions between them. Downie, Wilmott and White have suggested that a clear statutory framework that is addressed through legitimate and accessible processes can go some way to effectively addressing the values that should underlie these difficult decisions.<sup>566</sup>

### **3. Decisions about the withdrawal and withholding of life-sustaining treatment**

#### **i. Defining withdrawal and withholding of life-sustaining treatment**

The *withholding* of lifesaving treatment refers to allowing death to occur naturally in the face of a life-threatening event, such as a heart attack. Typically, the term is used in circumscribed situations where CPR might be offered. CPR may be given or withheld wherever a person may be located, including a private home, long-term care home or in hospital.

In contrast, the *withdrawal* of life-sustaining treatment means ceasing life supports that are already being provided, such as artificial ventilation and nutrition in hospital. The result of withdrawing life-sustaining treatment is similar to withholding treatment in the sense that death may naturally ensue.

The withdrawal and withholding of life-sustaining treatment are not synonymous with palliative care. However, they may precede and are intertwined with the receipt of palliative care, including pain and symptom management, and accompaniments.<sup>567</sup>

#### **ii. Areas of legal decision-making authority**

In Canada, it is legal for capable persons to refuse life-sustaining treatment and for SDMs to do so on behalf of another person who is incapable.<sup>568</sup>

In the case of *Malette v. Shulman*, the Ontario Court of Appeal found the common law entitles capable persons to refuse lifesaving treatment, consistent with rights to autonomy and self-determination.<sup>569</sup> The Supreme Court has also recognized the legality of consenting to these end-of-life practices in several cases.<sup>570</sup> Most recently, the Supreme Court affirmed in *Carter* that although death may result from a person's decision, this does not vitiate the right to self-determination.<sup>571</sup> The HCCA also codifies the right to refuse treatment.<sup>572</sup>

The law is clear that individuals (or SDMs) have the right to *refuse* life-sustaining treatment. However, the law is less clear – or at least contentious – as to whether health care providers are required to *propose* treatment that they believe would not benefit the patient in the first place, and whether patients (or SDMs) can insist on treatment when health care providers do not agree.

For instance, can health care providers choose not to offer CPR if they believe it would not benefit the patient? Can SDMs demand that all treatments be provided to do everything possible to prolong a patient's life?

In these situations, “The problem is that of conflicts between patients’ (or families’) interest in determining their medical treatment and physicians’ interest in not being required to practice medicine contrary to their professional ethics”.<sup>573</sup>

### **iii. Competing perspectives on legal decision-making authority**

There are two main competing perspectives on who should have decision-making authority over the withdrawal and withholding of life-sustaining treatments.

Some claim that health care providers should have authority to choose what treatments are offered, based on their clinical judgment about what would be beneficial to the patient. Others claim that health care providers must offer life-sustaining treatment, so that patients or SDMs can themselves decide.

These approaches are not always at odds: in a given case, they may be aligned where patients or SDMs agree with health care provider views about what beneficial treatment would entail.

Nonetheless, conflicts do occur between health care providers, patients and SDMs about whether life-sustaining treatment should be provided. The LCO has observed that conflicts are especially common where the most vulnerable person in the dispute – the patient – is unconscious or otherwise incapable and a decision must be made on his or her behalf.

A person who is seriously frail might recover from a health event with CPR, but remain in the ICU until death. Someone on life support might not regain consciousness and decline indefinitely, developing complications along the way. Others might not be able to live as independently as before receiving treatment. Still others might fully recover their physical and psychological abilities. These are examples of situations that health care providers, patients and SDMs might judge differently in terms of quality of life, and the benefits or harm of treatment.

In the clinical environment, health care providers may have their own definitions of beneficence and malfeasance. According to an expert study commissioned by the LCO, “Canadian clinicians generally share similar definitions of ‘non-beneficial treatment’”.<sup>574</sup> Citing prior qualitative research the authors, Downar et al., explain

...ICU-based physicians, nurses and respiratory therapists generally defined non-beneficial treatment to be “the use of considerable resources without a reasonable hope that the patient would recover to a state of relative independence or be interactive with his or her environment”. A subsequent survey found that the most commonly accepted definitions of non-beneficial treatment were: “advanced curative/life-prolonging treatments that would almost certainly result in quality of life that the patient has previously stated that he/she would not want” and “advanced curative/life-prolonging treatments that are not consistent with the goals of care (as indicated by the patient)”.<sup>575</sup>

Thus, Downar et. al. explain that health care providers often take patient values into account when determining beneficial treatment. Those authors acknowledge that, where patient values are unknown or where health care providers perceive known values to be unrealistic or incorrectly conveyed, patient values cannot always be easily incorporated into the health care provider's assessment.<sup>576</sup>

In general, health care providers need not offer treatment that is not clinically indicated: "Physicians ought not to prescribe antibiotics for viral illnesses [or] perform therapeutic surgery without clinical indicators of illness or injury".<sup>577</sup> Moreover, as we've explained previously, there is no positive right to health care in Canada.

However, as the Manitoba Law Reform Commission (MLRC) describes in its 2003 report, *Withholding or Withdrawing Life Sustaining Medical Treatment*, the health care provider's power to choose what treatment to offer is undeniably different in end-of-life care:

The sanctity and value of all human life, the profound and irreversible consequences... the personalized circumstances of the patient's family, spiritual and cultural life and the patient's fear of losing personal control at the most vulnerable of times explain the emotional and intuitive attraction to the notion of personal autonomy and support for a patient's right not only to refuse life sustaining treatment but also to demand life sustaining measures.<sup>578</sup>

The LCO also heard that concerns exist about the lack of consistent, transparent standards to assess beneficial treatment.<sup>579</sup> Legal professionals, in particular, have expressed fears about the potential for bias against certain groups who may be frail or vulnerable – such as the elderly and persons with disabilities – when qualitative judgments about quality of life are involved.<sup>580</sup> We heard concerns that in some cases financial resources may be prioritized over the lives of these groups who may be viewed (inappropriately) as less worthy of care. We were also told about possible disregard for faith and cultural beliefs, which health care providers may not always share.<sup>581</sup>

For example, CCB decisions attest to disagreements among health care providers and SDMs due to differing views on the balance between faith and cultural beliefs, quality of life, and perceptions of medical benefit.<sup>582</sup> Moreover, several HPARB decisions evidence allegations made by SDMs that lifesaving treatment was not proposed for their family members due to stigma about older age.<sup>583</sup>

The LCO heard from more than one individual about instances where health care providers placed a "Do-Not-Resuscitate" order in their family member's medical records in hospital before they were consulted (which would prevent CPR from being delivered in the event of cardiac arrest). Shock and anger were expressed and feelings of unfairness. HPARB decisions also evidence disputes concerning the authority of health care providers to make DNR orders and the role of consent, communication and documentation.<sup>584</sup>

Even advocates who suggest greater authority be awarded to health care providers, speak about the overall benefits of sensitive and open communication with patients and SDMs, better education about the risks of life-sustaining treatments and improved collaborative decision-making methods.



#### iv. Ontario's existing legal framework

As alluded to above, decision-making authority over life-sustaining treatment is clear in some areas, but not others.

Specifically, while consent must be obtained to *withdraw* treatment from a person who is already being treated, the law is unsettled as to whether providers can legally *withhold* treatment by simply not offering it to the patient or SDM from the outset (or by refusing to provide it on request). That said, some continue to advocate for legal reform in the areas that are already settled.

##### **Areas of Debate over Decision-Making Authority**

There are multiple areas of ongoing debate about who should have decision-making authority over life-sustaining treatment.

The primary medical treatment that is subject to debate is CPR – does withholding (not offering) CPR require consent from a patient or SDM under the law? Or, can CPR be withheld based on the health care provider's judgment?

Nevertheless, some advocates also propose that Ontario's existing laws that require consent from a patient or SDM to withdraw life support should be re-evaluated.

The most reliable source for Ontario's legal framework is the Supreme Court case, *Cuthbertson v. Rasouli*.<sup>585</sup> Otherwise, the jurisprudence is conflicting.<sup>586</sup> Below, we summarize *Rasouli* and other key sources of law that feature at the center of public debate.

##### Withdrawal of life-sustaining treatment under *Rasouli*

In *Rasouli*, the Supreme Court confirmed that the HCCA requires providers to obtain consent from a patient or SDM before life support can be withdrawn.<sup>587</sup>

Mr. Rasouli developed an infection causing brain damage after undergoing surgery for a benign tumor. He was first diagnosed as being in a persistent vegetative state, but was later diagnosed as being “minimally conscious”. Mr. Rasouli's cognitive functioning was severely compromised and he was being kept alive on life support (Mr. Rasouli remains in this condition today).<sup>588</sup> The health care providers treating Mr. Rasouli found that continuing treatment would not benefit him and proposed palliative care to his wife, who refused consent as his SDM. The providers responded that they did not require her consent, claiming that withdrawing life support is not treatment under the HCCA. His SDM then applied to the courts to prohibit the withdrawal of life support.<sup>589</sup>



The Supreme Court interpreted the HCCA's language to establish that withdrawal of treatment constitutes treatment and, therefore, requires consent. As Handelman and Gordon explain,

based on the HCCA's definition of treatment, withdrawal of life support is a treatment. It is done for a therapeutic, palliative, or other health-related purpose. And, except in emergency situations, initiating a treatment requires consent – even when the treatment to be initiated is the withdrawal of treatment.<sup>590</sup>

The Supreme Court in *Rasouli* also confirmed the process to be followed in providing substitute consent under the HCCA, and the avenues of recourse open to SDMs and health care providers when disputes occur. Important aspects of this HCCA process can be summarized as follows:

- SDMs must adhere to the decision-making process stipulated by the HCCA, which begins with realizing the patient's prior capable wishes, if they apply to the circumstances. If the patient's wishes are unknown, not applicable or impossible to carry out, the SDM must make decisions in the patient's best interests.
- The best interests test requires a range of factors to be considered, including the patient's values and beliefs along with the risks and benefits of treatment.
- Health care providers have an obligation to obtain informed consent from an SDM who complies with the principles for decision-making under the HCCA.
- If health care providers do not believe the SDM is complying with the HCCA, and are unable to resolve the issue, they can apply to the CCB for a determination of the patient's wishes or best interests, as the case may be.

For the purposes of the LCO's project, several elements of this process must be highlighted.

First, Ontario law already seeks to balance the principles of autonomy, self-determination and security with principles of beneficence and non-maleficence. Beyond considering the patient's values and beliefs, SDMs must also consider other factors, including whether treatment is likely to improve the person's condition or well-being and prevent deterioration, and whether the benefits outweigh the risk of harm.<sup>591</sup>

The HCCA does not, however, provide guidance on how these diverse factors should be balanced. Therefore, applying the best interests test under the HCCA (or the patient's wishes for that matter) can result in very different outcomes, depending on the patient's wishes, values and beliefs, and medical condition.<sup>592</sup> In fact, unlike *Rasouli*, in the majority of cases where the CCB was consulted on end-of-life disputes, the CCB adopted the health care providers' submissions that treatment *would not* be in the patient's best interests.<sup>593</sup>

Still, health care providers told the LCO that the best interests test does not sufficiently address the principles of beneficence and non-maleficence, and that they should have greater authority to make unilateral decisions about life-sustaining treatment. Part of their concern relates to efficiencies in the CCB process, which we discuss in chapter 7 on alternate dispute resolution (ADR). Yet health care providers also object to the prospect that they may be required by law to provide treatment they believe contradicts their professional and ethical responsibilities.

*Rasouli* is a statutory interpretation case. Therefore, the Supreme Court made no pronouncement on who ought to have decision-making authority based on questions of “philosophical” and ethical legitimacy.<sup>594</sup> Instead, the Court read the HCCA on its face to determine what Ontario statutory law mandates at present.

The Supreme Court did acknowledge the health care providers’ concerns about ethical responsibilities. But, in the end, it found that health care providers cannot be faulted for following the law, and that creative solutions might be necessary where there are unresolvable conflicts between the law and a provider’s ethics:

...a physician may feel that his legal obligation not to withdraw life support is in tension with his professional or personal ethics. Such tensions are inherent to medical practice...

Wherever one tries to draw the line, it is inevitable that physicians will face ethical conflicts regarding the withdrawal of life support. No legal principle can avoid every ethical dilemma. What may be needed is a practical solution that enables physicians to comply with the law and to satisfy their professional and personal ethics.<sup>595</sup>

#### Ongoing debates about withholding CPR

The Supreme Court limited its determination in *Rasouli* to the narrow set of facts in that case.<sup>596</sup> It did not explicitly find that not offering treatment, such as CPR, requires consent under the HCCA.<sup>597</sup> As a result, debates on whether health care providers have decision-making authority *to not offer CPR* are highly controversial in Ontario. The LCO’s project is designed, in part, to address some of these controversies and to make thoughtful recommendations.

In its 2016 policy on *Planning for and Providing Quality End-of-Life Care*, the CPSO recognizes, “The law is currently unclear regarding the consent requirements for a no-CPR order”.<sup>598</sup> There are a considerable number of cases, administrative tribunal decisions and professional guidance documents that have come to contradictory conclusions on this issue.<sup>599</sup> A recent HPARB decision interpreted *Rasouli* to mean that consent is required before providers place a DNR order in a patient’s chart while in hospital.<sup>600</sup> This case has, in turn, incited critique and activism within the health community.

One of the expert papers commissioned by the LCO for this project canvasses various stakeholder positions on this topic. The authors claim that, in practice, providing CPR has become a “default” treatment for a few reasons. Providing CPR does not require the patient or SDM’s consent, as it is considered an emergency treatment under the HCCA.<sup>601</sup> But the law surrounding not offering CPR is fraught with ambiguity. Thus, although it is inappropriate to offer non-beneficial treatments as a default in many other contexts, the authors assert there is a “double standard” when it comes to CPR.<sup>602</sup> On the other hand, many health care providers, they say, “wish to avoid CPR in patients nearing the end of life, reasoning that it can cause suffering for no apparent medical benefit”.<sup>603</sup>

At this juncture, it is important to recall that legal authority to decide whether life-sustaining treatment is provided is not equivalent to an outcome, as was the point made in *Rasouli* over withdrawing life support. The HCCA and *Rasouli* require consent to withdraw life support because doing so is equivalent to an outcome (likely, death). But not offering CPR in narrow circumstances may fall within the provider's discretion (i.e., where CPR would not achieve its physiological purpose). If patients and SDMs have legal authority to decide, they may very well choose a natural death and palliative care, especially as social acceptance of these practices grows.

The LCO is aware that providers, patients, SDMs and lawyers have a range of views on life-sustaining treatment generally as well as on who should ultimately have authority to decide whether it is offered.

CPSO's policy on end-of-life care proposes a compromise of sorts. Acknowledging the law is unclear, it gives *process-oriented guidance* to physicians. The policy advises as follows:

- Where physicians wish to place a DNR order in a patient's chart, they cannot do so unilaterally. Instead, they must discuss this with the patient or SDM and explain why CPR is not being proposed.
- If the patient or SDM disagrees and insists that CPR be provided, physicians must engage in a conflict resolution process (which the LCO addresses in chapter 7).
- While conflict resolution is underway, **physicians cannot write a DNR order.**
- If an event requiring CPR actually occurs, physicians **must provide CPR unless the patient's condition will prevent the intended physiological goals of CPR from being achieved** (i.e., providing oxygenated blood flow to the heart and brain).
- Aside from informal conflict resolution (such as an ethics consult), if a conflict arises from an SDM's interpretation of a wish or because the physician believes the SDM is not complying with the HCCA, he or she may apply to the CCB.<sup>604</sup>

The CPSO policy is current as of May 2016 and, therefore, takes into consideration *Rasouli*, the HPARB decision and stakeholder submissions on the policy. As can be seen from the above, it prohibits health care providers from issuing DNR orders without consent; however, it allows them not to offer CPR if an actual event occurs and CPR will not be physiologically effective. This recognizes the relative time considerations in both cases (there may be time to discuss DNR orders in hospital), and health care provider discretion in narrow circumstances, where a qualitative assessment about quality of life would be less likely.

The CPSO policy has received little comment to date, albeit some have argued that it still does not give health care providers sufficient clarity or flexibility.<sup>605</sup>

## **v. Achieving legal clarity and consistency**

It should be apparent from the CPSO policy and the differences in opinion between withdrawal of life support and not offering CPR that a variety of possibilities exist for law reform. The principles of beneficence, non-maleficence, autonomy, self-determination and security may yield nuanced solutions to these different types of practices.

The LCO believes the law should be clear and consistent for all stakeholders when it comes to decisions about life-sustaining treatment.<sup>606</sup> Consistency does not necessarily require that each medical practice be regulated in the same way. In some jurisdictions, including Ontario, separate end-of-life treatments are managed differently. But these differences must not be arbitrary; they must reflect a justifiable balance of principles.

Ontario's existing legal framework includes the HCCA, the Supreme Court's decision in *Rasouli*, conflicting case law and various policies. The CPSO's policy distinguishes between consent requirements for different types of end-of-life treatment. It says that the HCCA and *Rasouli* require consent to withdraw life support and that DNR orders also require consent, but that not offering CPR in narrow circumstances fall within the provider's discretion (i.e., where CPR would not achieve its physiological purpose).

Other jurisdictions have confronted the same issues as we do in this project and have come up with a variety of responses.

For example, the Australian state of Queensland has a fairly similar framework to the CPSO policy.<sup>607</sup> Consent is required to place a DNR order in a patient's medical chart, since there may be time for consultation and discussion. However, health care providers are permitted to withhold CPR without obtaining consent from an SDM in "acute emergencies", if the patient is incapable, the provider unaware of wishes to the contrary, and the provider reasonably believes that CPR would not be good medical practice.<sup>608</sup> Queensland law sets out further nuanced rules in other circumstances, including the withdrawal of life support with consent.<sup>609</sup>

In the United Kingdom, physicians are generally entitled to determine the appropriateness of life-sustaining treatment.<sup>610</sup> However, physicians must seek judicial direction from the Court of Protection about both the withdrawal and withholding of life-sustaining treatment for patients in a permanent vegetative or minimally conscious state.<sup>611</sup>

There are also many jurisdictions that simply prioritize the health care provider's discretion.<sup>612</sup> After reviewing a considerable range of reform options, the MLRC recommended this approach, which is now regulated through the College of Physicians and Surgeons of Manitoba.<sup>613</sup> The MLRC's report was issued prior to the *Rasouli* case, and it is not certain if this approach would withstand a challenge given the Supreme Court's decision.<sup>614</sup>

Taking into account experiences in other jurisdictions and Ontario's particular context, the LCO would like to know whether our current mix of approaches achieves the best possible balance for Ontarians.

In concluding this section, we would like to acknowledge the difficulties addressing this area of the law apart from concerns about education and communication, tools for consent and advance care planning, and dispute resolution. The literature demonstrates a dire lack of education and communication among health care providers, patients and SDMs, alike, as well as the inadequacy of existing strategies to resolve conflicts.

Various proposals emphasize the benefits of these other practices in achieving amicable resolutions among the affected parties:

in most cases, when physicians, patients and SDMs discuss whether or not to provide life-sustaining treatment, all stakeholders are able to reach agreement. Clinicians, patients and SDMs alike show a strong preference for consensus approaches to decision-making rather than unilateral decisions. Disagreements and intractable disputes are relatively rare.<sup>615</sup>

As these issues cut across many other concerns, the LCO has chosen to address them later in the discussion paper (see section D, below, and chapter 7).



For more information on Ontarians' views about decision-making authority over life-sustaining treatment, we invite you to access the report commissioned by the LCO, Downar et. al., "Balancing the interests of patients, substitute decision-makers, family and health care providers in decision-making over the withdrawal and withholding of treatment", online: <http://www.lco-cdo.org>.

#### **4. *Decisions about offering the necessities of life in daily living assistance***

##### **i. *Defining the necessities of life in daily living assistance***

There are life-sustaining practices aside from what might be considered "treatment" that are common nearing the end of life. In this section we review laws that regulate decisions about offering the necessities of life in daily living assistance, namely food and water.

Support with eating and drink is different from treatments including artificial nutrition and hydration that may be part of life support although, evidently, they are just as necessary to maintain life. Food and water may be offered to persons receiving care in a private home, long-term care home, retirement home, hospice or even in hospital. During the LCO's preliminary consultations, stakeholders primarily referred to residents in long-term care, who depend heavily on others for daily living activities.

The issues in this section of this paper arise primarily in the context of persons who have an SDM making decisions about activities of daily living. Where individuals are capable, they may voluntarily stop eating and drinking (VSED). Some capable patients may voluntarily stop eating and drinking as a means of hastening death.<sup>616</sup>

Anecdotal evidence suggests that SDMs have at times instructed nurses and PSWs not to offer an individual food and water in order to comply with prior expressed wishes or their interpretation of the HCCA's best interests test. A recent British Columbia case, *Bentley v. Maplewood*, has also brought this issue to public attention (further discussed below).<sup>617</sup>

Therefore, the LCO was asked to examine whether SDMs have the right to refuse consent to the provision of food and water. We were also asked to determine if there is a conflicting legal duty in these situations that require services providers, such as PSWs and nurses, to offer food and water to residents in their care.

It is important in this context to distinguish between *offering* food and water, and *forcing* food or water on an individual. The discussion in this section focusses on whether providers have a duty to *offer* food and water.

Again, the law is unsettled in this area – in this case due to overlapping laws that potentially conflict. We address their interaction by seeking to answer the two questions posed above.

## **ii. Can SDMs refuse consent to food and water?**

It is normal for persons nearing the end-of-life to lose their appetite or to face difficulties eating and swallowing.<sup>618</sup> They may stop eating and drinking if they choose to do so as a matter of self-determination and physical integrity. Our inquiry about consent to food and water is less about individuals refusing food themselves, than the possibilities for SDMs to refuse consent to food and water on another's behalf.

The *Bentley* case, mentioned above, illustrates how this inquiry affects people in reality. In *Bentley*, family members requested that a care facility cease spoon feeding Mrs. Bentley, an elderly woman in the advanced stage of Alzheimer's. Mrs. Bentley had previously recorded wishes that if she came to have no reasonable expectation of recovery from extreme physical or mental disability, she wished to be allowed to die, including through "no nourishment or liquids".<sup>619</sup> She also asked that she be "euthanized" in the event she was unable to recognize members of her family.<sup>620</sup> Against the family's request, the care facility continued to spoon feed Mrs. Bentley, claiming they were required to provide the "necessaries of life" under provincial legislation and the *Criminal Code*.

The *Bentley* case is complex to review for this project because decision-making laws in British Columbia are not the same as in Ontario. In Ontario, a similar case might well have a different outcome. It is also important to remember that the court found that Mrs. Bentley was capable of making her own decisions. Nonetheless, the court made a few findings that could be relevant here.

The court found that nourishment in a care facility constitutes *personal care*, rather than *treatment*. It also held that withdrawing food and water from an incapable person is not permitted by law under provincial care legislation because it would amount to neglect. It did not address issues surrounding the *Criminal Code*.<sup>621</sup>



Below, we address whether an SDM is prohibited by law to consent to the withdrawal of food and water. Here, we first consider whether an SDM could, possibly, refuse consent to nutrition under relevant sources of provincial law.

### *Health Care Consent Act, 1996*

The HCCA addresses various considerations relating to daily living assistance, called “personal assistance services”.<sup>622</sup> This applies only to services provided in long-term care homes. The statute defines personal assistance services to include assistance with eating and drinking. It does, however, exclude personal assistance services from the definition of treatment.<sup>623</sup> As a result, the positive requirement to obtain consent to treatment in the HCCA does not apply to providing food and water. The HCCA also does not contain an explicit provision requiring that a provider obtain consent before giving daily living assistance, which contrasts with the requirement to obtain consent to treatment.<sup>624</sup>

Arguably, the requirement for consent is nonetheless implied in the HCCA. For instance, the HCCA sets out who can provide substitute consent for personal assistance services. The HCCA also permits individuals to express prior wishes about personal assistance services, and requires SDMs to follow a similar process for substitute decision-making as they would for treatment.<sup>625</sup>

### *Long-Term Care Homes Act, 2007*

The *Long-Term Care Homes Act, 2007* requires long-term care homes to obtain consent to assess residents in determining their “plan of care”, and states, “Nothing in this Act authorizes a licensee...to provide care or services to a resident without the resident’s consent”.<sup>626</sup> The “Residents’ Bill of Rights” also affirms the right of residents of long-term care homes to participate fully in the development, implementation and revision of their plans of care, and in any decision regarding any aspect of his or her care, as well as to give or refuse consent to any treatment, care or services for which consent is required under the law.<sup>627</sup> Therefore, a resident’s consent is required to provide care, and an SDM can provide substitute consent for an incapable person in a long-term care home. It is also helpful to place these provisions in the broader context of the duty of the licensee not only to protect residents from abuse but to ensure that they are not neglected by the licensee or by staff.<sup>628</sup>

### *Substitute Decisions Act, 1992*

Daily living assistance under the SDA is called “personal care”.<sup>629</sup> The SDA sets out appointment processes for a guardian or attorney for personal care. Personal care under the SDA is not specific to the long-term care setting, it applies to home and community care as well, and it expressly includes “nutrition”.<sup>630</sup> The SDA also states that if a person grants a POA for personal care, the POA “may contain instructions with respect to the decisions the attorney is authorized to make”.<sup>631</sup>



### Home Care and Community Services Act, 1994

The *Home Care and Community Services Act, 1994* makes a statement about consent that resembles that for long-term care, which is to say that providers cannot “provide a community service to a person, without the person’s consent”.<sup>632</sup> The CCAC Client Services Policy Manual affirms that an SDM may provide consent where a community service involves nutrition.<sup>633</sup>

### Health College and Association Policies

Most Ontario regulatory college and provider association policies do not specifically address this issue. Although consent is often highlighted as an important and mandatory aspect of care, in general, practice guidelines on care nearing the end-of-life also emphasize providing adequate food and water.<sup>634</sup> One policy advises providers to develop a care plan for “nutritional/hydration approaches” and to “offer fluids and diet as tolerated and as desired by the resident”.<sup>635</sup> The LCO has also heard that facilities adopt conflicting informal policies on whether to continue to offer food and water nearing the end-of-life.

To summarize this section, Ontario’s legal framework implies that an SDM’s consent is required to withhold food and water to a person who is incapable.

In practice, however, the LCO is aware that the relationship between providers and SDMs is much more fluid and consent is not provided on a regular basis for long-term, and home and community care. This could contribute to varied expectations among providers and SDMs about their respective decision-making authority.

### **iii. Are health care providers required by law to provide food and water?**

Any possible requirements to obtain consent before providing food and water, discussed above, would appear to conflict with other provisions in the *Long-Term Care Homes Act, 2007* and the *Criminal Code*. These statutes seek to ensure that persons who are in a relationship of dependence with care providers are regularly provided with food and water by law.

The *Criminal Code* imposes legal duties on individuals in stipulated circumstances to provide the “necessaries of life”, unless they have a “lawful excuse”.<sup>636</sup> Food and water fall within the definition of necessaries of life.<sup>637</sup> The relevant *Criminal Code* provision reads as follows:

#### **Duty of persons to provide necessaries**

Every one is under a legal duty:

- (c) to provide the necessaries of life to a person under his charge if that person
  - (i) is unable, by reason of detention, age, illness, mental disorder or other cause, to withdraw himself from that charge, and
  - (ii) is unable to provide himself with necessaries of life.<sup>638</sup>

The application of this provision to the circumstances at hand is not clear.<sup>639</sup> Professor Jocelyn Downie has argued that the “[a]bsence of consent or, even more pointedly, the explicit refusal of the necessities of life through a clear and explicit instruction... is arguably a lawful excuse” for not providing food and water.<sup>640</sup> Insofar as a “lawful excuse” would mean a criminal offence does not arise, under this interpretation, an SDM could refuse consent to food and water on another’s behalf.

Another source of law which could potentially require providers to offer food and water for some individuals is the *Long-Term Care Homes Act, 2007*. The Act states that licensees “shall ensure that residents are provided with food and fluids...”, and the regulations stipulate facilities must offer each resident three meals daily, beverages at regular intervals and a snack in the afternoon and evening.<sup>641</sup> The Act also has detailed provisions to prevent and address neglect that could, conceivably, prohibit the withdrawal of food and water.<sup>642</sup>

Again, one might argue that refusing consent would eliminate concerns about neglect. At the same time, however, it could be difficult to argue that long-term care homes should not continue to simply *offer* food and water (without force) as required by legislation.<sup>643</sup>

#### **iv. Achieving legal clarity and consistency**

As with our analysis of withholding and withdrawal of treatment, the LCO is concerned that there be clarity and consistency under the law to ensure equal access to care for Ontarians. Currently, there appear to be conflicting laws in Ontario respecting whether SDMs can refuse consent to the provision of food and water. This could, in turn, affect whether individuals can realize their own prior expressed wishes to die in this manner, similar to Mrs. Bentley.

If SDMs cannot refuse consent to the provision of food and water, there could be potential inconsistencies with laws that do permit them to refuse consent to treatment, such as life support. Whether these inconsistencies are principled, not arbitrary, is something to consider for this project.

Not unlike current approaches to regulating different types of life-sustaining treatment differently, providing the necessities of life at home and in the community could, ostensibly, be regulated separately under the law. Our project asks whether refusing consent to food and water is substantively different from refusing consent to treatment, although the ultimate outcome might be similar.

The LCO would like to hear about how decision-making about the necessities of life should be regulated from a law reform perspective. For instance, could providing food and water be defined as “treatment” under the HCCA to clarify that consent from a person (or SDM) is required in these situations? Or, could the *Long-Term Care Homes Act, 2007* and *Home Care and Community Services Act, 1994* be amended to clearly and expressly exclude SDMs from refusing to consent to the provision of food and water?

## **5. Questions for discussion**

**12. *There are connecting laws, principles and policies regarding decision making for life-sustaining practices such as CPR, DN, and nutrition. What are the strengths, weaknesses and gaps in Ontario's current legal framework for decision-making authority over life-sustaining practices?***

**13. *Who should have authority to determine whether life-sustaining and life-saving treatment (e.g., CPR, DNR) is offered to, or withdrawn from, a patient – the patient (or SDM) or a health care provider? Under what circumstances?***

**13. *Should Ontario regulate the offering of food and water to persons nearing the end of life, including the authority of SDMs to consent to withholding necessities of life?***

## **D. Palliative Sedation Therapy**

### **1. *Understanding palliative sedation therapy***

Palliative sedation therapy is an end-of-life treatment that is clinically and legally accepted in Canada. Palliative sedation therapy is intended to address the needs of patients who experience intolerable suffering from refractory symptoms by administering medications that have the effect of reducing consciousness.<sup>644</sup>

The object of this therapy is not sedation itself, but symptom relief.<sup>645</sup> Refractory symptoms are present if all other possible treatments have failed or, in the patient's circumstances, there are no available or acceptable means to alleviate symptoms.<sup>646</sup> Palliative sedation therapy may, nonetheless, be combined with other palliative care treatments and accompaniments, such as pain management.<sup>647</sup>

Palliative sedation therapy is intended to be a proportional response to symptoms, meaning that the level of sedation and duration vary.<sup>648</sup> There are two main forms of palliative sedation:

1. **Continuous palliative sedation**, which involves providing therapy until a person dies as a result of the natural course of illness. Continuous palliative sedation may be clinically indicated in the last days or hours of life. Continuous palliative sedation is not usually recommended for patients who are more than two weeks away from death.<sup>649</sup>
2. **Respite sedation**, which is provided temporarily, as needed, and monitored. Respite sedation involves an agreement with the patient about a timeframe for sedation (e.g., 24 to 48 hours), after which the patient is awakened to determine if he or she would benefit from further therapy or if the rest and stress reduction improved the ability to tolerate symptoms.<sup>650</sup>

Palliative sedation therapy raises significant ethical concerns, especially when it is provided continuously. Generally speaking, this treatment engages similar principles to those arising in the context of other end-of-life practices, including beneficence, non-maleficence, autonomy, self-determination and security (see our discussion of these principles in section 6.C.2).

In addition, as mentioned above, proportionality is a core principle for palliative sedation therapy.<sup>651</sup> Proportionality comes into play when assessing whether palliative sedation should be used from the outset, since it is not clinically indicated when there are less-invasive interventions that could be effective.<sup>652</sup> Proportionality also means that when palliative sedation is used, “the dose of sedatives administered to the patient should not be higher than that needed to alleviate the patient’s suffering”.<sup>653</sup>

The definition of symptoms gives rise to ethical concerns as well. In particular, the presence of psychological (sometimes called “existential”) suffering is a very controversial grounds for palliative sedation therapy.<sup>654</sup> Most guidelines and policies do not recommend that psychological symptoms be considered sufficient for intervention, except in rare cases, and then only in consultation with a palliative care team that can provide advice on alternative options.<sup>655</sup> Nonetheless, psychological suffering is recognized as a contributor to the inability to tolerate physical refractory symptoms.<sup>656</sup> And some argue that short life-expectancy and patient preferences could justify the expansion of therapy to psychological suffering.<sup>657</sup>

Another ethical concern that engages all of the principles listed above is that palliative sedation not be used to hasten death. Although palliative sedation may be provided until the point of death and may sometimes involve the withdrawal of life supports, from an ethical standpoint, it is not *intended* to hasten death.<sup>658</sup> Sometimes this is referred to in terms of the doctrine of “double effect”: since the intent of the provider administering the sedatives is to control the suffering at the end of life, and not to shorten life, the practice is ethically distinct from the practice of intentional killing.<sup>659</sup>

The principle of proportionality is essential to concerns about hastening death because continuous palliative sedation without life-support could conceivably affect life-expectancy when it is provided to a person whose death is not imminent.

There is a complex relationship between palliative sedation and medical assistance in dying. The LCO has heard that some patients, family and friends do seek to use palliative sedation as a form of medical assistance in dying.<sup>660</sup> The LCO heard there is a risk that palliative sedation could be used for patients who are not eligible for medical assistance in dying, such as those whose death is not reasonably foreseeable or who rely on an SDM to consent to treatment due to incapacity. (On the eligibility criteria for medical assistance in dying, see chapter 4.E.) Some patients may forego palliative sedation now that MAID is available. As MAID is integrated into the legal, policy and practice landscape, approaches to palliative sedation may see some adjustments.

For persons who are nearing death, there is no evidence that nutrition or hydration is physiologically relevant to hastening the death of a sedated person.<sup>661</sup>

Although palliative sedation therapy is clinically and legally accepted, it is not yet regulated under statute or in standardized policies that apply across the province of Ontario. Given that the practice raises concerns about abuse or misuse, capacity and informed consent, and equality in access, the LCO's project considers whether it ought to be addressed, and if so, how.

## **2. Legal framework for palliative sedation therapy**

Palliative sedation is not currently the subject of a specific or separate regulatory regime in Ontario. And unlike the withdrawal and withholding of treatment and medical assistance in dying, palliative sedation has not been subject to a constitutional or other legal challenge. Therefore, there is no case law to guide the practice in terms of eligibility criteria, procedural requirements and safeguards against abuse. Moreover, in Ontario there is no statute that purposefully addresses palliative sedation therapy.<sup>662</sup>

The Supreme Court referred to palliative sedation therapy in *Carter* as a matter of dignity and autonomy in the face of a grievous and irremediable medical condition.<sup>663</sup> In comparing palliative sedation and other end-of-life practices to medical assistance in dying, the Supreme Court did note that palliative sedation raises equal concerns about capacity and decision-making, vulnerability and the possibilities of bias and misuse, remarking "Concerns about decisional capacity and vulnerability arise in all end-of-life medical decision-making".<sup>664</sup>

There are no special procedural or other requirements for palliative sedation therapy in Ontario.<sup>665</sup> In terms of consent and decision-making, the *Health Care Consent Act, 1996* applies to palliative sedation just as it does to other treatment decisions nearing the end of life. Thus, health care providers must obtain consent to provide therapy from a patient or SDM in the patient is incapable. The person (or SDM) must have the ability to understand the information that is relevant to making the specific decision at hand, and to appreciate the reasonably foreseeable consequences the decision.<sup>666</sup>

Applying the same legal framework to palliative sedation as to other treatments is akin to the regulation of withdrawal and withholding of treatment in Ontario, but it differs from medical assistance in dying. In the latter case, there are heightened safeguards against abuse, including the requirements for a second opinion, documented request, signatory witnesses and the

presence of mental capacity up until the person receives treatment.<sup>667</sup> In all end-of-life decision-making, capacity is decision-specific.

While there are no statutory or case law requirements for palliative sedation therapy in Ontario, various regions and organizations have adopted policies and guidelines to regulate the practice.

For instance, in 2012 a number of clinicians with the Canadian Society of Palliative Care Physicians developed the *Framework for Continuous Palliative Sedation Therapy in Canada*. The framework addresses a wide-range of issues including definitions, aims, ethical considerations, decision-making and policy strategies. The framework suggests that palliative care institutions and programs should adopt policies, possibly, in consultation with regulatory and legal authorities.<sup>668</sup> Among other recommendations, the framework proposes enhanced conversations about and documentation of informed consent for palliative sedation therapy.<sup>669</sup>

Further organizational guidance has been provided by CPSO and the RNAO Palliative Care Nurses Interest Group.<sup>670</sup> The LCO located separate guidelines published by three regions in Ontario.<sup>671</sup> We are also aware that some clinicians in Ontario favour standards developed in other jurisdiction, such as the British Columbia, Fraser Health, Refractory Symptoms and Palliative Sedation Therapy Guideline.<sup>672</sup>

Studies have demonstrated that a large majority of Canadian physicians agree on core issues relating to clinical aspects of palliative sedation therapy, such as the kinds of symptoms it is indicated to treat, the exercise of caution around psychological suffering, and the use of certain medications.<sup>673</sup> Nevertheless, the available sources in Ontario and Canada do vary in their level of detail and recommendations.

For example, the Fraser Health guidelines apply to adults age 19 and over, while other documents do not specify age limits, and the LCO is aware that children do receive palliative sedation in practice.

A recent study of an Ontario hospital also revealed a lack of consistency in operational definitions and documentation.<sup>674</sup> The authors found that patient records had no documentation of palliative sedation in 65% of cases, no identification of symptoms in 46% of cases and no records on informed consent in 41% of cases. In cases where consent was documented, “the consent provider was often unclear” and “[t]here were no documented discussions about artificial nutrition and hydration before [palliative sedation] initiation”.<sup>675</sup>

To be sure, the lack of documentation in this one study does not indicate that discussions about palliative sedation had not, in fact, taken place.<sup>676</sup> Nor does it speak to practices in other care settings. Nonetheless, our overall discussion above shows that there are concerns about the existing regulatory framework for palliative sedation in Ontario relating to consent, vulnerability, inconsistent terminology, lack of documentation and fragmentation in standards.

### **3. Possible avenues to address challenges with palliative sedation therapy**

There are multiple avenues to improve clarity, consistency, safety and other challenges with palliative sedation therapy. Options for reform might include the following:

- creating a legislative framework
- elaborating clinical guidelines through a taskforce or network approach (e.g., with OPCN or MOHLTC involvement)
- requesting that regulatory colleges adopt thorough clinical guidelines.

In considering approaches to clarifying the issues surrounding palliative sedation, it is important to think carefully about both the benefits and the downsides of legislative and non-legislative approaches.

Approaches in other jurisdictions may provide insights into how these options might work. For example, Quebec's *An Act Respecting End-of-Life Care* establishes a statutory framework for requesting and documenting palliative sedation therapy. Quebec's legislation only applies to continuous palliative sedation therapy. It stipulates what must be provided for consent to be "informed", and requires a request from a patient or SDM to be documented in a prescribed form and filed in the patient's record.<sup>677</sup>

Alberta has taken a different approach. Alberta Health Services has recommended that a provincial palliative sedation clinical guideline be developed by an expert panel in conjunction with the government and a provincial steering committee that is working on broader palliative care advancements. Alberta's recommendations are situated within its overall provincial strategy, the *Palliative and End-of-Life Care Provincial Framework*.

As Ontario moves toward developing our own provincial strategy on palliative care, we may also be able to build on lessons learned from organizational and regional guidelines that are already being used in this province.

### **4. Questions for discussion**

- 15. Should Ontario regulate the clarity, consistency and safety of palliative sedation therapy considering the ethical challenges, medical assistance in dying, and the need for safeguards like informed consent?**



## **E. Managing Planned Deaths at Home**

### **1. *Dying in the comfort of home***

A majority of Canadians would prefer to die at home.<sup>679</sup> “Home” in this context denotes a range of settings, including but not limited to a private home, residential hospices, retirement home and long term care homes. “Home” is distinguishable from hospital settings for acute care, such as the ICU.

Despite this preference, several studies demonstrate that hospitals are a common place of death in Canada. In a report commissioned by the LCO, Wilson and Birch found that 41.2% of Ontario residents who died in 2014-2015, died in hospital.<sup>680</sup> Various social determinants have an impact on place of death, and reports by Health Quality Ontario, among others, provide some information on what these may be.<sup>681</sup>

LCO’s background consultation identified two potential contributors to a good home death of a *legal* nature. These are: the sufficiency of decision-making tools to support consent and advance care planning (which we review in section D, above); and the accessibility of processes to certify that a person has died in the home.

This chapter addresses legal barriers to planning for and managing deaths that are expected to occur in the comfort of one’s own home.

### **2. *Difficulties family and friends encounter when a person dies at home***

When a person dies at home, surrounding family and friends are not always well-informed about what to do to. In Ontario, there are processes that exist to facilitate the direct transfer of the deceased from home by funeral services, namely, the “expected death in the home” (EDITH) protocols and guidelines of the Coroner. However, people may not have planned ahead or know what these processes involve and, understandably, people often call 911 for help.<sup>682</sup>

Once 911 is called, emergency responders become involved – such as the police, ambulance and firefighters – as well as the Coroner’s office.<sup>683</sup> This can lead to distressing and confusing administrative complications that disrupt the natural bereavement process that many family and friends experience immediately after someone’s death.

If family or friends do not call 911 and, instead, contact a funeral home directly, the LCO has heard that funeral services routinely ask family members to obtain a death certificate before they will transport the deceased. However, there are frequent delays in obtaining death certificates that many stakeholders informed the LCO cause suffering for grieving families.

Addressing improved planning and management of deaths that are expected to occur in the home was one of the foremost challenges that stakeholders cited during the LCO’s preliminary consultations. Moreover, while the CPSO was updating its policy on end-of-life, it released a brief paper documenting this as an area as one in need of change.<sup>684</sup>

### **3. Legal framework for transferring the deceased to a funeral home**

There are two *ad hoc* tools that have been created in Ontario to aid expected deaths at home: Expected Death in the Home (EDITH) Protocols and Office of the Chief Coroner for Ontario guidelines. This section considers gaps in the legislative framework that have given rise to these stop-gap approaches. We consider EDITH Protocols and Office of the Chief Coroner guidelines in the next section on strategies for reform.

When individuals are at the end of their lives and are able to die naturally at home, rather than in hospital, their family and friends are not required to initiate a police or coroner's investigation when death occurs. In normal circumstances, a funeral service can transport the deceased away from the home to prepare for burial, cremation or other services. In the less usual circumstances, the coroner or police must be notified under the *Coroners Act* where there is reason to believe that the death was suspicious or requires investigation (e.g., violence, negligence, suddenly and unexpectedly).<sup>685</sup> Otherwise, a funeral service can transport the deceased away from the home to prepare for burial, cremation or other services.

The *Vital Statistics Act (VSA)* creates some restrictions on how the deceased can be treated. For instance, burial, cremation, funeral services and transportation outside a municipality cannot take place until required documentation has been obtained.<sup>686</sup> Documentation under the VSA includes various documents that the funeral director plays a role in coordinating; however, they also include a "Medical Certificate of Death", which funeral services rely on others to prepare.<sup>687</sup> In Ontario, death certificates can only be issued by one of three professionals: a physician, nurse practitioner or the coroner.<sup>688</sup> Legislation was also recently introduced that, if passed, will clarify the operation of the VSA in circumstances involving MAID-related deaths (see section 4.E).

To be clear, the VSA does not require funeral services to obtain a death certificate before transporting the deceased away from the home as long as they remain in the municipality. Therefore, there is no prohibition against quickly alleviating family and friends of the organizational tasks involved in obtaining a death certificate. Nonetheless, on the ground, funeral services commonly refuse to follow a request to do so. The LCO was informed that funeral services fear the potential liability that could be attached to transporting a deceased where the death actually was suspicious and they prefer the reassurance of a death certificate in advance. In addition, we were told that if funeral services take charge of the deceased, it can be challenging for them to assume the burden of arranging the death certificate.

At the same time, we were told that it can be incredibly difficult for family and friends to arrange for a physician or nurse practitioner to visit their home to issue a death certificate, as many professionals are not habituated to making home visits after hours or on weekends. In context of a MAID death, a physician may be present or not as people have the right to self-administer. Consequently, family and friends may end up contacting the police or coroner's office in the event of either a natural or MAID death to reduce any delay associated with the burdensome process or arranging the attendance of a physician or nurse practitioner.

The legislative framework is, however, clear that a physician who has been attending to a person in the dying process or is aware of the illness must issue a death certificate. The relevant provision of the VSA regulations reads

[A physician] who has been in attendance during the last illness of a deceased person or who has sufficient knowledge of the last illness shall immediately after the death complete and sign a medical certification of death...and shall deliver the medical certificate of death to the funeral director.<sup>689</sup>

The CPSO policy on *Planning for and Providing Quality End-of-Life Care* emphasizes the obligatory nature of this role and advises physicians,

When a decision is made for a patient stay at home as long as possible or to die at home, it is recommended that the physicians plan in advance by designating the physician(s) or nurse practitioner(s) who will be available to attend to the deceased in order to complete and sign the medical certificate of death. It is also recommended that physicians inform caregivers of this plan.<sup>690</sup>

The VSA regulations contain similar provisions regarding nurse practitioners with primary responsibility for the person's care. Nurses are also mandated to issue a death certificate and deliver it to the funeral director immediately, but in more limited circumstances.<sup>691</sup> As nurse practitioners will often be the provider with whom the person has more frequent contact, there are several educational tools designed for them from the RNAO, CNO and Government of Ontario.<sup>692</sup>

Despite the straightforward legal responsibilities in this area there remains a lack of education for individuals, families and friends (and therefore a lack of planning) as well as a lack of responsiveness from health care providers in visiting the deceased's home to issue a death certificate in a timely manner.

#### **4. Strategies to better plan for and manage home deaths**

We mentioned above that there are two stop-gap strategies currently being used in Ontario to enable a timely transfer of the deceased to a funeral home without having to engage the coroner's mandate. The first avoids emergency services and the coroner's office altogether: EDITH Protocols.

EDITH Protocols evolved as a grassroots response to a perceived gap. These are community-based tools, developed on the basis of shared principles and common needs, but regionalized in response to local needs and differing somewhat in their specific contents. EDITH Protocols are overwhelmingly favoured in the palliative care community across Ontario as the community-based tool to facilitate at home deaths. Moreover, the CPSO end-of-life policy refers to EDITH Protocols when advising physicians to take into account community strategies.<sup>693</sup>

It is important to understand that there is not a single EDITH Protocol. Cancer Care Ontario along with several CCACs, and LHINs disseminate an EDITH Protocol with instructions.<sup>694</sup> The specific contents of EDITH protocols vary.

EDITH Protocols provide funeral homes with the reassurance that they may transport the deceased after death upon a so-called “pronouncement” of death, before a death certificate is provided. They enable nurses, beyond nurse practitioners, to make a pronouncement and states that a physician will provide the funeral home with a death certificate within 24 hours. It thus gives funeral homes the security they seek and permits physicians added time to issue the death certificate. EDITH Protocols also contains information to confirm that CPR is not included in the treatment plan, identifies the primary health care provider and an alternate with their after-hours contact information, and contains information on alternative courses of action should problems arise.<sup>695</sup>

While the LCO has heard criticism of the specific content of particular EDITH protocols, the LCO has heard that EDITH protocols generally viewed as effective and easy to use. The major concern is inconsistent adoption across the province as an optional tool that some may not be aware of.

Ontario’s second stop-gap tool was created by the Office of the Chief Coroner as guidelines to simplify the process of obtaining a death certificate in cases where they have already been called in.<sup>696</sup> The guidelines specify a process for Office of the Chief Coroner employees to manage the situation in a timely manner and to avoid investigatory proceedings. The LCO was informed that the coroner’s guidelines have been updated over time and are operating very well in practice.

To the extent that the coroner’s mandate is to investigate unexpected and suspicious deaths, their involvement in facilitating home deaths is being provided out of the Chief Coroner’s generous vision of good public service. However, the coroner should not be required to be called-in to facilitate the transfer of a deceased to a funeral home during a very private and sensitive time.<sup>697</sup> The LCO heard that family and friends prefer the familiarity of physicians or nurses with whom they’ve been in contact rather than new and unfamiliar faces immediately after a loved one has died.

Because EDITH Protocols are working well, a significant number of stakeholders suggested the LCO recommend law reform measures to standardize this approach. Ensuring that health care providers broach conversations about planning for at home deaths would be an important part of this strategy.

The LCO also found that British Columbia has taken a novel approach to instituting a province-wide protocol, called the *Joint Protocol for Expected/Planned Home Deaths in British Columbia*.<sup>698</sup> The protocol allows family and friends to dispense with both a pronouncement of death and death certificate prior to funeral services transporting the deceased.

The British Columbia protocol may be used when the patient’s physician completes the form, sends it to the funeral home *before* the death, and agrees to fill out the death certificate within 48 hours after the death. In these situations, family and friends can themselves contact the funeral home directly to arrange for transportation without the involvement of a health care provider at all. Due to the advance documentation and information sharing, the funeral home should be prepared when the time comes.

Participants in the protocol include the provincial government, Office of the Chief Coroner, health regulatory colleges and the Funeral Services Association of British Columbia, among others.<sup>699</sup> It is also buttressed by specific provisions in provincial legislation, listing who has a right to contact funeral services after the death.<sup>700</sup> The legislation contains a hierarchical list of delegates beginning with the personal representative named in the deceased's will, then the spouse and onto others from there.<sup>701</sup>

With this range of possible options available, the LCO would like to hear more during our consultations about what types of reform would be more appropriate for Ontario. EDITH Protocols are already being widely used across the province and have proven to be effective. On the other hand, the British Columbia model would limit the formal requirements to arrange for funeral services to transport the deceased without delay. In particular, the LCO would like to hear about the potential benefits and drawbacks of a legislative or regulatory response, as opposed to, for example, policies or standardized protocols.

## **5. Questions for discussion**

**16. Which options are preferred to better plan for and manage expected deaths at home? Would it be beneficial to have a province-wide strategy or formal regulation?**

## **F. Understanding the Experiences of Supporting Professionals**

### **1. Addressing the concerns of health and legal professionals**

Improving the last stages of life will depend in large part on understanding and addressing the experiences of professionals who support persons who are dying and their family and friends. Professionals themselves require practical, ethical and moral supports to effectively provide for others. They are also individuals in their own right who are deserving of dignity and equality under the law.

The LCO's project examines how work-related challenges can be minimized for two types of professionals that play an essential role in this domain: health care providers and legal professionals. The health care providers we address mainly offer services to patients, SDMs, family and friends, while legal professionals advise these persons as well as health care providers, facilities, government and organizations such as regulatory colleges.

In the following section, we review employment protections for health care providers who suffer mental and moral distress as a result of continuously supporting persons through death and dying. Then, we consider legal professionals' challenges receiving guidance on practice and ethics in this growing legal field.

## **2. Health care provider mental and moral distress**

### **i. Explaining the scope of the LCO's review on health care provider interests**

The LCO received many comments from members of the public about several challenges that health care providers face in providing palliative care. The foremost challenges that were identified were the lack of moral supports for psychological distress, lack of clinical education (especially for primary care providers), and the desirability of expanding aspects of registered nurses' scope of practice to increase accessibly to a range of services (e.g., medications, death certifications, treatments).

Of these issues, the LCO's project will only address health care providers' employment-related psychological supports for a number of reasons. First, when we asked stakeholders about limitations on the LCO's project, we were advised not to address matters of clinical practice, and we agree. The LCO views the analysis of health care providers' scope of practice as falling outside our mandate as a law reform agency. Second, the LCO is concerned that making recommendations about strengthening education for health care providers relating to palliative care would duplicate the ongoing efforts of the OPCN and MOHLTC.

Moreover, any review of education for health care providers relating to capacity, consent and advance care planning would overlap with the LCO's own project on *Legal Capacity, Decision-Making and Guardianship*. A final report with detailed recommendations was released in early 2017, and is available on the LCO's website.

We also provided you with an overview of key findings and recommendations relating to education, information and quality assurance in the capacity and decision-making project in section D.3 of this chapter.



To read more about the LCO's project scope, please see ch. 1.C, "The project scope incorporates ongoing developments," and ch. 1.D.2, "Project development, research and consultations."

### **ii. Work-related mental and moral distress**

The serious mental and moral stress that health care providers experience when working continuously with persons nearing death was a recurring theme during the LCO's consultations. Stakeholders requested that the LCO consider opportunities under the law to support health care providers across all care settings with psychological wellness.

The existing literature confirms that persons working as health care providers experience a higher incidence of stress and "burnout" than employees in other sectors.<sup>702</sup> Burnout is a



“persistent, negative work-related state of mind” characterized by feelings of exhaustion and distress, and the “development of dysfunctional attitudes and behaviours”.<sup>703</sup> Aside from stress and burnout, the LCO heard that health care providers can develop mental health issues relating to trauma and depression if they do not receive adequate care.

Health care providers naturally have psychological responses to their professional environments, which include emotional responses to contact with patients who are suffering and dying.<sup>704</sup> Palliative care providers, in particular, have a very high burnout rate that is especially high among nurses, social workers and chaplains.<sup>705</sup> Specific stressors for palliative care providers include

...absorption of negative emotional responses, breaking bad news, challenges to personal beliefs, coping with inability to cure, immersion in emotional clashes, poorly defined roles, recurrent exposure to death, working in an area of uncertainty, patient suffering, and secondary trauma.<sup>706</sup>

Palliative care staff has been found to be “at risk of poor psychological outcomes as a result of insufficient ability to cope with these demands”.<sup>707</sup>

Nurses and PSWs in long-term care homes also face stressors connected to caring for persons with declining health and dementia, and to their regular exposure to death.<sup>708</sup> One study in Ontario by the Quality Palliative Care in Long-Term Care Alliance found that staff often goes through a process of grief and bereavement after a resident passes away. About 80 to 90% of services in long-term care are provided by PSWs who offer very personal forms of assistance, such as bathing, feeding, dressing and caring for residents’ psychosocial needs.<sup>709</sup> Residents and staff may develop close bonds through intimate contact, and staff may experience intense grief upon a resident’s death.<sup>710</sup>

However, this same study found there is a lack of systemic education and supports for providers’ mental wellness:

The LTC setting provides little formal support for staff in managing their grief and loss when a resident dies... staff does not systematically receive training on grief and bereavement, despite the regular occurrence of death. As more residents live and die in LTC homes, it is important for staff to have access to support that enhances their ability to continue providing compassionate and quality care.<sup>711</sup>

These findings on long-term care homes mirror what the LCO heard about the inadequacy of wellness supports for health care providers in other care settings as well.

Unfortunately, supports for providers to alleviate stressors and address grief and bereavement are not well researched or understood.<sup>712</sup> Therefore, implicit in our discussion about legal frameworks for employment protections is a recognition that more reliable information is necessary to understand what successful interventions might look like.



### iii. Legal framework for employment health and safety protections

Some providers will fall within the ambit of Ontario's *Occupational Health and Safety Act*. The *Occupational Health and Safety Act* protects employees from health and safety “hazards” in the workplace that could potentially result in harm.<sup>713</sup> The Act requires employers to internalize workplace responsibilities by imposing various legal duties to minimize hazards and respond to harms. In most situations, employers shoulder the greatest burden to protect the health and safety of their employees.<sup>714</sup>

Workplace protections are fairly limited to particular types of hazards in the workplace, such as unsafe physical environments and harassment.<sup>715</sup> However, in addition to specific protections, the *Occupational Health and Safety Act* establishes a general duty to take precautionary measures and provide resources to protect workers:

#### Duties of employers

s.25(2) ...an employer shall,

(a) provide information, instruction and supervision to a worker to protect the health or safety of the worker

...

(h) take every precaution reasonable in the circumstances for the protection of a worker.<sup>716</sup>

There are no provisions in the Act that expressly deal with the mental health of workers. Moreover, the LCO received information indicating that workplace environments that may negatively impact employees' mental health are not considered to be “hazards” that could give rise to any legal duties under the statute.

In 2013, the Standards Council of Canada, a federal Crown corporation, published voluntary standards on protecting employees in the workplace from mental health issues, called *Psychological Health and Safety in the Workplace*.<sup>717</sup> However, the Occupational Health and Safety Branch of the Ministry of Labour (MOL) has prepared guidance for inspectors stating that this standard should not be considered a reasonable precaution, which employers are required to implement in order to comply with the general duty to protect workers.

Providing for the mental health of workers is, nevertheless, a developing area. In 2014, the MOL was mandated to support mental health in the workplace by engaging with companies that have introduced strong mental health programs and working with employers to expand on employer-provided services.<sup>718</sup> The following year, MOL hosted a summit on work-related traumatic stress.<sup>719</sup> These initiatives culminated in new legislation in 2016, which amended the *Workplace Safety and Insurance Act, 1997* to better account for the prevalence of post-traumatic stress disorder (PTSD) in first responders, including paramedics and emergency medical attendants.<sup>720</sup>

Under the new legislation, the Workplace Safety and Insurance Board (WSIB) must presume that PTSD is work-related, unless the contrary is proven, which lightens the employee's burden in

claiming benefits.<sup>721</sup> The Ministry of Labour is now also authorized to direct employers to report on their plans to prevent employment-related PTSD.<sup>722</sup>

Needless to say, these gains are extraordinarily positive. Still, amendments to the *Workplace Safety and Insurance Act, 1997* are limited in terms of the types of providers who might be touched by stressors considered in this project. Many health care providers are not covered who might experience workplace distress, such as nurses, social workers and PSWs.<sup>723</sup> The legislation is also aimed at employees whose injury rises to the level of a diagnosed psychiatric disorder (i.e., PTSD).<sup>724</sup>

Therefore, beyond these recent gains, the LCO's project considers whether health care providers who habitually support patients who are dying could benefit from a similar expansion of occupational health and safety legislation to address the emotional repercussions of their work situation, or if there are other legislative or policy reforms which would be effective and appropriate.

#### **iv. Competing rights and the health care context**

LCO's background consultations heard from health professionals who identified ways in which the challenges of providing care during the last stages of life may be compounded by competing rights or duties. The challenges associated with these competing rights are particularly complex because of the range of settings in which end of life care takes place, including patient's homes.

Given the incredible diversity of Ontario society, it is not surprising that situations arise where there are conflicts between the rights of individuals, and it is likely that the incidence of these types of conflicts will only increase.

These may be conflicts between competing human rights. The right to be free from discrimination on the basis of gender or sexual orientation may come into conflict with rights related to creed, for example where a patient makes a request based on his or her creed, for care to be provided by a professional of a particular sex or sexual orientation.

There may be conflicts between different types of rights and responsibilities. For example, a patient may, for reasons related to creed or culture, request that a service provider remove footwear in the home or certain areas of the home, but this may conflict with health and safety requirements related to foot protection.

There may be circumstances where a patient unintentionally engages in offensive behaviours that violate the rights of health care providers – for example, because of dementia.

Health care professionals provided us with many examples of these types of conflicts.

These challenges are not unique to the health care setting, and within the health care setting, are not particular to end of life care. However, the gravity and emotional weight of end of life care may bring an increased pressure and difficulty to managing and resolving these conflicts at the end of life.

In an effort to assist Ontarians with addressing these challenges, the Ontario Human Rights Commission released a *Policy on Competing Rights* in 2012. The *Policy* is intended as a tool for individuals and organizations, and sets out a process for analyzing and reconciling competing rights.<sup>725</sup>

The OHRC's *Policy* points out that no rights are absolute, and no right is more important than any other right. All rights must be given consideration. Rights have limits in circumstances where they substantially interfere with the rights of others.<sup>726</sup>

The *Policy* suggests processes for resolving competing rights claims that involve human rights issues, including informal dispute resolution processes and more formal ADR approaches. In some cases, disputes may find their way to the Human Rights Tribunal of Ontario.

Competing rights raise issues far beyond the scope of this project, and it is not the intent of the LCO to broadly address these challenges. However, these challenges are an important consideration in understanding the needs for supports among those working to provide care at the end of life. Strategies for improving supports should take these challenges into account.

## **v. Opportunities to improve mental health supports in the workplace**

We mentioned above that there is inadequate information on successful interventions to prevent and respond to mental distress for health care providers providing services to persons in the last stages of life. Yet some suggestions in the literature include strategies to

- integrate education and awareness about mental health into the workplace, including strategies to manage grief and loss
- clearly delegate responsibility to plan and implement mental health protection measures within the organization
- educate employees in leadership roles to promote and address the psychological health of employees (e.g., supervisors, managers, unions)
- reduce financial barriers to care through health care benefit coverage
- encourage peer support and conversations about their experiences.<sup>727</sup>

The LCO would like to know whether such strategies could be incorporated into employment health and safety legislation (i.e., *Occupational Health and Safety Act*), into sectoral frameworks, such as the *Long-Term Care Homes Act, 2007*, or through the LHIN's mandate under the *Local Health System Integration Act, 2006*. Improved supports for palliative care providers could also possibly be included in Ontario's developing provincial palliative care strategy.

The LCO believes that further investigation of opportunities to improve psychological services for health care providers could build on advancements for first responders at risk of PTSD as well as systemic programs that counter harms which are not always physical, but have gained acceptance over time, such as workplace harassment.<sup>728</sup>

### **3. Ethical and practice difficulties for legal professionals**

#### **1. The role of legal professionals nearing the end of life**

When individuals become ill or transition into their older years, they often go to lawyers to assist with drafting a will or POA, or to seek out advice about their rights. Legal professionals are usually advocates: they represent clients in disputes and offer supports to help them navigate through the complexity of Ontario's health, social and legal systems. In addition to individuals, their clients may be counsel for government, regulatory colleges, health care providers and facilities. Legal professionals may also be educators and adjudicators in administrative tribunals or the courts.

Legal professionals may face a variety of challenges when it comes to advising clients who are dying and those around them. Similar to our approach to health care providers, this project does not consider challenges with education for legal professionals on decision-making issues due to our work on that subject in the *Legal Capacity, Decision-Making and Guardianship* project (see section 3.D of this chapter). However, legal professionals who work with those who are dying have particular experiences that should be acknowledged.

In order to gain an appreciation of their interests, the LCO held an event to gather evidence from legal professionals with expertise in this practice area, called the "Roundtable on Legal Ethics and Practice for the Last Stages of Life". The roundtable is introduced briefly in section 1.D.2 of this discussion paper and more thoroughly in Appendix E. We primarily rely on information received at the roundtable in this section.

#### **2. Understanding the experiences of legal professionals working with end of life issues**

In their practice of law, legal professionals may face challenges or require support in understanding their responsibilities concerning the practice of law (e.g., advising clients, resolving disputes) as well as ethical duties that arise from practice. The Law Society of Upper Canada (LSUC) governs Ontario's lawyers and paralegals in accordance with the *Law Society Act*.<sup>729</sup>

Legal professionals must conduct themselves in a manner that is consistent with the LSUC's *Rules of Professional Conduct* and By-Laws (Rules).<sup>730</sup> Like health care providers, other sources of guidance for legal professionals might include rules established under the common law or knowledge gained from professional development opportunities and community networks.

Since legal professionals deal with the law, by definition, ambiguities in Ontario's legal system pose significant problems for them. Without clarity in law, it can be stressful to advise clients with confidence and certainty about their options. Lawyers may also inadvertently perpetuate misinformation in the community as a result. As one lawyer told us, "lawyers don't know what they don't know".<sup>731</sup> During the Roundtable, some lawyers expressed their view that greater clarity would be beneficial with respect to the withdrawal and withholding of life-sustaining practices, and use of DNR orders (see section B, above).

Apart from complications with the law, legal professionals at the Roundtable reported a number of practice and ethical challenges. Examples of core issues they struggle with involve the following:

1. **Duties towards persons who may be indirectly affected by immediate clients:** Nearing the end of life, planning and decision-making can involve patients, family members, SDMs, health care providers and facility operators. When a lawyer represents anyone of these individuals there could be ramifications for the other parties. Lawyers owe a duty of loyalty to their clients and the *Rules of Professional Conduct* require them to advocate for the client, but they do not speak to broader obligations to others (except when a child's health, welfare or security is affected). Some lawyers questioned whether, for example, a lawyer representing a health care provider treating a patient should have obligations toward the patient, given that the client itself (the health care provider) owes duties to the patient? What might this look like if a lawyer is representing an SDM, who is not acting in the patient's best interests? The LCO heard from attendees at the roundtable that the reach of a lawyer's responsibilities might be revised to include other vulnerable persons when essential health care issues are at stake.
2. **Determining the lawyer's role in assessing capacity:** In this discussion paper, we have concentrated on capacity to grant a POA for personal care and to make treatment decisions, but there are other domains of decisional capacity as well. Capacity is decision-specific. For example, lawyers may need to determine whether a client has capacity instruct counsel. Legal professionals at the Roundtable expressed a need for greater practical guidance on the standard for capacity to instruct counsel and how to conduct such an assessment. Greater guidance was also desired on the practical and ethical issues associated with representing clients who may be legally incapable with respect to treatment. The Rules require lawyers to "as far as reasonably possible, maintain a normal lawyer and client relationship" when a client has diminished capacity.<sup>733</sup> However, the LSUC's commentary on the Rule is general and does not discuss the interaction of different capacity issues. Related issues were raised in the LCO's project on *Legal Capacity, Decision-making and Guardianship*, and were the subject of proposals for reform in recommendations 33 and 34.
3. **Knowing how to manage dynamic family relationships:** Lawyers are regularly approached to represent a patient by a family together or, even, separately by a spouse, parent, sibling or child. Family relationships nearing the end of life can be marked by disputes and heightened emotion and they may give rise to possible conflicts of interest for lawyers who become involved in family dynamics. Family members may contact lawyers seeking private health or legal information. Furthermore, capable patients may defer to their family members to make treatment decisions for them. The *Rules of Professional Conduct* advise lawyers on managing conflicts of interest and confidentiality.<sup>734</sup> However, legal professionals expressed a desire for more practical and specific guidance on these issues.
4. **Representing children who are nearing the end of life:** Representing children can be a challenge because of family and health care team dynamics. For example, the LCO was told that children's voices are not always heard within the context of prevailing models for decision-making that are used when children are ill. Health care providers often adopt a team approach involving the providers, parents and child together in decision-making; however, the LCO heard that children's voices

can sometimes be subsumed or influenced by that of their parents in the process. Health care providers may not assess a child's capacity for decision-making and children may not be informed about their rights – adults speak about them, rather than to them. Participants in the roundtable mentioned that children have two options for legal representation: advocates (when the lawyer represents the child) and child protection. Questions about whether to represent a child or involve child protection or other independent counsel are ones that lawyers find hard to answer. Although the *Rules of Professional Conduct* require lawyers to advise clients to take the child's best interests into account in adversarial proceedings, they do not address how lawyers proceed when they are representing children.<sup>735</sup>

5. **Disclosing information regarding medical assistance in dying:** Overall, legal professionals did not see many practice and ethical dilemmas for lawyers resulting from the availability of medical assistance in dying since it will be delivered by health care providers. However, they did observe two topics for review: the creation of rules on lawyers' conscientious objections and referrals, and the revision of existing Rules on disclosure of confidential information. The *Rules of Professional Conduct* currently permit lawyers to disclose information if the lawyer believes there is an imminent risk of the client's death.<sup>736</sup> Legal professionals expressed concern that this Rule could lead to the disclosure of sensitive information about medical assistance in dying to family and friends, who the client would rather not have know.
6. **Recognizing where the lawyer's competence ends and facilitating referrals:** Legal professionals may have limited expertise when it comes to clinical practices, religious beliefs, alternative courses of action or other knowledge and skills that feature in health care matters. Under the *Rules of Professional Conduct*, when lawyers lack competence they should decline to act, obtain the client's consent to consult or collaborate with a lawyer who is competent, or seek out advice from experts in non legal fields.<sup>737</sup> Yet the LCO was informed that legal professionals may not be compensated for assuming such a "liaison" role or for making referrals to non-legal experts, such as religious leaders or social workers. Participants were hesitant to say that lawyers ought to take on this responsibility, rather some suggested that strengthened independent advocacy, for instance through an end of life care coordinator, would be preferable.

#### **4. Questions for discussion**

**17. How can strategies for addressing the needs of health care providers assist with mental and moral stress? How can health care practitioners be better prepared to manage disputes?**

*(continued)*



**18. Do legal professionals require specific education and guidance on matters relating to the last stages of life, and what form might this best take?**

## **G. Accommodations and Supports for Faith and Cultural Communities**

### **1. Introduction**

Palliative care's holistic philosophy was originally conceived by Cicely Saunders, a deeply religious person who sought to integrate pain management with community environments and spiritual engagement.<sup>738</sup> As a result, "Religion has had a profound role in shaping the development of the international hospice movement", as has respect for community membership.<sup>739</sup>

Saunders' use of the term "spiritual" was connected to her own religious traditions.<sup>740</sup> It preceded contemporary usage of the same term to mean a value system apart from, or at least not necessarily, connected to religion.<sup>741</sup> In this section, we explore the relationship between concepts including "religion", "faith", "spirituality", and "culture" to understand how they overlap and differ before beginning our review.

Following our discussion of terminology, we consider the significance of faith and culture to quality care in the last stages of life. We then review Ontario's existing legal frameworks for faith and cultural rights. Finally, we analyze challenges and opportunities for reform.

Much of this section relies on a report the LCO commissioned from external experts. The paper, *Integrating Religious and Cultural Supports into Quality Care in the Last Stages of Life in Ontario*, presents new qualitative information that the authors gathered in consultation with health care providers, faith leaders and representatives of cultural communities in Ontario.<sup>742</sup>



To read the full research paper commissioned by the LCO on faith and cultural issues, please visit our website at [www.lco-cdo.org](http://www.lco-cdo.org).

### **2. Significance of faith and culture nearing the end of life**

#### **i. Defining faith and culture**

The LCO has chosen to use the terms "faith" and "culture" in our report for their broad scope and regular usage among stakeholders whom we consulted. We intended these terms to be inclusive of other words relevant to the issues the project reviews such as "religion", "ethnicity", "ancestry" and "language". We also acknowledge they might overlap with additional social concepts such as "race".



The Ontario Human Rights Commission (OHRC) recognizes that individuals see themselves and others as a “unique combination of identities”.<sup>743</sup> Within the human rights system, there are distinctive attributes associated with each ground for equality (e.g., sex, age, race), but people also have intersecting identities that may not be captured by one ground. If individuals face discrimination, ideas about identity – such as faith and culture – are not easily separable.

In considering issues related to faith, it is useful to reference the OHRC’s definition of “creed”, which includes religious traditions and other “belief systems that, like religion, substantively influence a person’s identity, worldview and way of life”.<sup>744</sup> The OHRC explains that a creed

- is sincerely, freely and deeply held
- is integrally linked to a person’s identity, self-definition and fulfilment
- is a particular and comprehensive, overarching system of belief that governs one’s conduct and practices
- addresses ultimate questions of human existence, including ideas about life, purpose, death, and the existence or non-existence of a Creator and/or a higher or different order of existence
- has some “nexus” or connection to an organization or community that professes a shared system of belief.<sup>745</sup>

Approaches to the concept of “creed” remain controversial. The LCO is sensitive to apprehensions about the OHRC’s definition of “creed” as being overly broad because its capacious scope includes social movements that are not at all akin to religion (for instance, worshipping extra-terrestrials).<sup>746</sup> From a practical perspective, an overly broad definition could confuse or dilute attempts to delineate religious accommodations. During the LCO’s preliminary consultations, we heard considerable confusion about how to appropriately apply this definition in this context.

At the same time, however, the LCO values the OHRC’s definition for its potential to encompass variations within traditions and between individual and group beliefs. The OHRC’s definition also validates beliefs and practices that are intimately tied to history, tradition, ethnicity and culture, such as Indigenous spirituality.

“Cultural competence” is an established term in the health care context. Culture is not an enumerated ground under the *Human Rights Code* or the *Charter*. However, there are linkages to grounds enumerated under the Code such as ancestry, place of origin, ethnic origin, race and creed. The possible overlap between these concepts is evident in the following definition of culture:

A way of life common to a group of people, including a collection of beliefs and attitudes, shared understandings, and patterns of behavior that allow those people to live together in relative harmony, but that set them apart from other peoples. These practices also produce behavior that falls within a range of variation the members consider proper and acceptable.<sup>747</sup>

In this discussion paper, we write about faith and culture together, and distinguish them where appropriate. For instance, a newcomer to Canada may belong to a cultural community but hold no faith beliefs. Later in this section, we explain that the *Charter* protects freedom of religion under a separate provision from equality.<sup>748</sup> Equality rights extend to religion, but they also protect individuals and groups that may not be religious (or may not have been discriminated against as a result of religion). The legal tests to assert a rights claim under these *Charter* provisions differs.

### A Note on “Spirituality”

Spirituality may refer to an individual’s religious experience. However, in contemporary usage, the word often does not refer to experiences with a single formal religious tradition. People who are atheist or agnostic may consider themselves spiritual as well.<sup>749</sup>

In present-day palliative care, psychosocial “spiritual” supports are not usually associated with religion. They may be provided by health care providers, chaplains and social workers who lead conversations on existential issues about meaning and loss.<sup>750</sup> Understood in this way, the application of legal frameworks to spiritual rights and accommodations is ambiguous.

## ii. How faith and cultural affect access to quality care

*Spiritual care and faith based care is somebody’s way of life. It is how they know themselves and how they known how to interact with others... In the medical world we say we are providing total care, you know, we are providing holistic care. It is not holistic, if spiritual and faith based care [are not there] and particularly... when you are not looking at the culture that... the client is telling us he is a part of or feels strongly [about].*<sup>751</sup>

— Registered nurse

Faith and culture are integral to attitudes about care nearing the end of life and perceptions of quality in health care services. While Ontario strives to improve equitable and high quality palliative care, it should consider strengthening services that reflect deeply held patient values and wishes for community engagement. As the Fraser Report explains, Ontarians have pronounced views “about the importance of ensuring that all patients have access to culturally appropriate and safe palliative and end-of-life care”.<sup>752</sup>

Perhaps it is because faith and culture have profound meaning at the end of life that disagreements – even misunderstandings – about suitable care may lead to conflict. Nearly each person whom the LCO has spoken to referenced faith and culture as factors leading to disputes between

patients, SDMs and health care providers. Much of the case law that affirms decision-making rights in this context also results from disputes between health care providers and faith adherents.<sup>753</sup> Thus, in addition to promoting experiences of good care, avoiding disputes is a material rationale for integrating faith and culture into the health system.

These disputes may arise in a wide variety of ways. Faith may shape a decision to request or reject a particular treatment contrary to the recommendation of the health provider. In cases where the patient has become legally incapable, disputes have arisen as to how the patient's faith should affect the interpretation of their advance care planning documents. These disputes may be particularly challenging where individual beliefs do not cleanly conform with institutional orthodoxy. In some situations, a patient's faith may lead to a request to have services provided by an individual of a particular gender or sexual orientation. Or, health providers may have conscientious objections to providing a requested treatment.

Some of these disputes raise concerns about competing rights. For example, a patient's faith-based request to receive treatment or services only from professionals of a particular gender, or not to receive services from persons who are LGBTQ, may have a discriminatory effect on the service provider. The Ontario Human Rights Commission has explored these issues in its *Policy on Competing Rights*.<sup>754</sup> These issues are discussed at more length in Chapter 6. F.

The LCO commissioned paper explains these two interrelated ways in which faith and culture affect access to quality care:

A recurring theme of our research [is] an acceptance and acknowledgement of the importance of faith and cultural beliefs as vital components in shaping how Ontarians choose and direct their care at the end of life. However, these beliefs also act as unexpected barriers to health care providers providing the best services for Ontarians as they approach death.<sup>755</sup>

Within the confines of this discussion paper, the LCO cannot describe examples of beliefs and practices among Ontario's diverse communities without being reductive. We recommend sources that readers can access for that information at the end of this part.

Below, we simply highlight general ways in which faith and culture influence care for the dying. Our purpose is to identify *moments* when heightened attention to faith and culture is due:

1. **Treatment decisions:** Patients and SDMs may take faith and cultural beliefs into account when making decisions about life-sustaining treatments. Some belief systems are uncomfortable with mainstream health services; others maintain that life support should be provided indefinitely until a person dies. Between the two, there is a spectrum of beliefs about withholding and withdrawing life support, medical assistance in dying and the receipt of non-traditional treatment.<sup>756</sup>
2. **Practices during illness:** Faith and cultural communities may exercise meaningful practices during illness, such as prayer and ceremonies. Practices are expressive and may require adaptive physical environments that can accommodate singing and music, smoke, prostration and visitations from community members that may

exceed standardized allowances.<sup>757</sup> Practices may occur at key junctures in the illness trajectory that could require adjustments to procedural routine.

3. **Significant community figures:** Community figures may embody a sense of history and collective experience. For instance, elderly persons who survived past atrocities emanating from hate and discrimination can hold special significance for community members.<sup>758</sup> Family and community members might expect these figures to receive particularly respectful treatment.
4. **Care for the deceased:** Caring for the deceased may involve a variety of practices, ranging from prayer to tending to the body and burial ceremonies. There may be a critical order for the succession of practices. Community members may also request to be involved in physical after-death care, and to exclude health care providers. Keeping the deceased's body "whole" is a central belief for many faiths and cultures, which organ donation or autopsies might offend.<sup>759</sup>

The above description of moments when faith and culture are engaged during the dying process is admittedly limited. Other recurring themes that the LCO heard about include food preferences, language needs and continued contact with faith and cultural peers, especially in long-term care homes.

For detailed examples of common beliefs and practices among Ontario's diverse communities, readers might consider the following sources:

#### Summaries of End of Life Beliefs and Practices

Ruby Latif, Omar Ha-Redeye & Kashif Pirzada, *Integrating Religious and Cultural Supports into Quality Care in the Last Stages of Life in Ontario* (2016)<sup>760</sup>

Harold Coward & Kelli Stajduhar, eds, *Religious Understandings of a Good Death in Hospice Palliative Care* (2012)<sup>761</sup>

Paul Bramadat, Harold Coward & Kelli Stajduhar, eds, *Spirituality in Hospice Palliative Care* (2013)<sup>762</sup>

Canadian Multifaith Federation, *Multifaith Information Manual* (2011)<sup>763</sup>

### iii. First Nations, Inuit and Métis cultural safety

Legal responsibility for health care in First Nations, Inuit and Métis communities in Ontario is complex because it is shared between Indigenous, federal and provincial governments. In chapter 5 of this discussion paper, we outlined key barriers to care for Indigenous peoples living in Ontario. In this section, we consider the necessity of integrating Indigenous beliefs and practices into care nearing the end of life as a matter of “cultural safety”.

The term cultural safety was coined in New Zealand with respect to Maori peoples’ health care. However, it has developed into a way of speaking about culturally appropriate health care for Indigenous peoples around the world, including in Canada.<sup>764</sup>

There is no single definition of cultural safety. Generally, it aims to convey the interconnectedness of Indigenous health with the continuing repercussions of colonization, cultural and social assimilation and persisting systemic discrimination, which have led to trauma within communities and a loss of culture.<sup>765</sup> Health care that does not respond to these factors has been considered to generate “risks” to security.<sup>766</sup>

Cultural safety is sometimes placed on a continuum alongside the term “cultural competence”; however, some proponents consider it to be a “paradigm shift” – a more dramatic change in approach.<sup>767</sup> Whereas cultural competence may be characterized as health care provider education about and sensitivity to various cultures (and, therefore, a service provision model), cultural safety is envisioned as an *outcome* from the patient’s viewpoint. Thus, cultural safety involves awareness about power imbalances between health care providers and Indigenous patients, and a fundamental power shift toward the patient’s experience of quality care.<sup>768</sup>

The Assembly of First Nations describes the shift in location of power and control that cultural safety entails as follows:

The person who receives the services defines whether it was culturally safe. This shifts the power from the provider to the person in need of the service. This is an intentional method to also understand the power imbalance that is inherent in health service delivery.<sup>769</sup>

The National Collaborating Centre for Aboriginal Health has accumulated definitions of cultural safety from organizations that endorse this language, including the National Aboriginal Health Organization, Indigenous Physicians Association of Canada and Canadian Indigenous Nurses Association of Canada. Key aspects of their and other descriptions of cultural safety include

- Analyzing colonial relationships, discrimination and power imbalances
- Having service providers reflect on their own culture and its impacts on their providing care
- Understanding the pervasiveness of health problems within Indigenous communities
- Respecting the patient’s definition of what “safe” service means.<sup>770</sup>

In practice, cultural safety calls upon policymakers, service providers and communities to reformulate approaches to health care. It requires the incorporation of Indigenous understandings of death and dying, healing practices, traditional foods, spirituality, and language and cultural translation, and true engagement with community members in service planning and delivery.

Specific barriers to these goals that the LCO has heard about include the lack of long-term and palliative care on reserves and in rural and remote communities; the insufficiency of paid translators; and the need for spaces that accommodate ceremonies and large groups of people, including immediate family, elders and extended community members. Although not all First Nations, Inuit and Métis individuals will want to access traditional healing, integrating traditional medicine into palliative care approaches has also been said to be important for many diverse groups.<sup>771</sup>

In a paper describing the development of an innovative community-based palliative care program in Six Nations of the Grand River Territory, the authors identified several policy challenges for First Nations communities seeking to develop palliative care, including accessing human resources and equipment, jurisdictional issues as barriers to funding, the need for education and training to develop qualified First Nations healthcare professionals from the community, and the lack of dedicated funding allotted for end of life care in First Nation communities.<sup>772</sup>

As a first step, in terms of the LCO's project, we could consider making recommendations that build on the many best practices that community members brought to our attention. In addition to the program at Six Nations of the Grand River Territory referenced above, examples of best practices in Ontario include the Sioux Lookout Meno Ya Win Health Centre, which primarily serves Anishinabe communities in Northern Ontario, and the Lakehead University *Improving End-of-Life Care in First Nations Communities* project, which is a "bottom-up" model for First Nations capacity-building at the local level.<sup>773</sup> Each of these initiatives is based on principles of community mobilization, self-determination and cultural safety.

### **3. Legal framework for faith and cultural rights**

#### **i. Freedom of religion, provincial human rights and Indigenous rights**

Previous chapters in this paper summarize equality rights under s.15 of the *Charter* and the *Human Rights Code* as well as other rights and principles relevant to ensuring equality and substantive justice in health care services. In particular, chapter 5 addressed legal frameworks germane to communities with unmet needs. Faith and cultural communities are among those with unmet needs and the legal frameworks presented earlier in this paper apply to them. (See also, chapter 3.C, "Legal Rights and Principles Affecting Health Care".)

Here, we supplement prior chapters with a brief account of further rights and principles that could apply to faith and cultural communities: freedom of religion under s.2(a) of the *Charter*, the OHRC policy on creed, and Indigenous rights.

On the whole, these laws do not paint a cogent picture of what rights faith and cultural communities are entitled to on the ground when it comes to requesting positive, culturally competent and safe health care services nearing the end of life. This is due, in part, to tensions between laws. Faith and cultural rights are complicated by their connection with capacity and decision-making, and child protection laws. In some respects, these other laws may already incorporate faith and cultural considerations, albeit as factors to be balanced against other rights and principles (especially, security and wellbeing).

The OHRC policy on creed provides the most pragmatic lessons for the LCO's project due to its focus on positive accommodations across both government and private sectors. The OHRC policy and other sources of rights and principles are summarized below:

1. **Freedom of religion (*Charter*, s.2(a)):** Freedom of religion is protected as a fundamental right under the Constitution.<sup>774</sup> It guarantees individuals and groups freedom from government activity that interferes with their sincerely held religious beliefs and related practices.<sup>775</sup> The relationship between freedom of religion and health care services has not been clearly delineated. The Supreme Court has heard just a few claims where the *Charter* was invoked directly or indirectly to assert a patient or SDM's right to refuse consent to treatment on religious grounds. These cases concern both the right to refuse the provision and withdrawal of treatment.<sup>776</sup> Most recently, religious beliefs have been generally characterized as implicit in "best interests" tests that factor in values and beliefs.<sup>777</sup> Where matters of child protection are involved, the Court has repeatedly split on whether prohibiting a parent to refuse lifesaving treatment on a child's behalf violates s.2(a) of the *Charter*.<sup>778</sup> However, even Justices who found there to be a rights violation have concluded it was justifiable as a reasonable limit.<sup>779</sup>
2. **OHRC policy on creed:** The OHRC describes the Code protections for creed as going beyond freedom of religion under the *Charter*, which it says "is primarily concerned with preserving individual *liberty*".<sup>780</sup> The Code promotes equality and non-discrimination in requiring that individuals and groups "may *equally* access, benefit from, and are equally treated".<sup>781</sup> Under the Code, health care providers and facilities have a duty to accommodate sincerely held beliefs and practices to the point of undue hardship.<sup>782</sup>

Accommodations may require "inclusive design" to remove barriers to full access and participation that flow from standardized policies. They must also be individualized. While persons seeking accommodations must help to secure them, the provider is responsible for putting solutions in place with the person's cooperation.<sup>783</sup>

Based on the OHRC policy, health facilities and providers should assess whether staff have necessary cultural competency. The policy states that cultural competency is "key to recognizing and meeting human rights-related needs of different groups and communities" and gives the example of a hospital that could meet its duties by training staff and maintaining a "roster of counsellors and chaplains on hand to support end-of-life care".<sup>784</sup>



3. **Indigenous rights:** Existing aboriginal and treaty rights are recognized and affirmed under s.35 of the *Constitution Act, 1982*. The definition of “aboriginal peoples” under the Constitution includes First Nations, Inuit and Métis peoples. In chapter 5.D, we explained how First Nations, Inuit and Métis health care is regulated in Ontario. Whether culturally safe health care rises to the level of a constitutional right engages another line of inquiry. One Ontario case considered whether child protection laws violate Indigenous rights, when a parent refused consent to treatment on behalf of her daughter to pursue traditional medicine.<sup>785</sup> That case is controversial and the results, which were subsequently amended, do not provide clarity on the balance of rights in such cases.

Aside from s.35, First Nations assert that the government has a fiduciary duty to provide quality health services to Indigenous peoples.<sup>786</sup> A recent Supreme Court case affirmed that the Ontario government is subject to fiduciary duties in dealing with Indigenous interests in some circumstances; although, it does not speak to fiduciary duties to provide culturally safe health care.<sup>787</sup> It also should be recalled that a new landscape of partnership is forming between Indigenous, federal and provincial governments. The federal and provincial governments have made new funding commitments to Indigenous health to be managed in partnership with Indigenous governments.<sup>788</sup>

The OHRC policy on creed devotes a full chapter to Indigenous spirituality. The policy recognizes a flexible and robust definition of Indigenous spirituality and requires accommodation for Indigenous peoples’ beliefs and practices, including ceremonies and customs. It specifically addresses the need to accommodate smudging in hospitals, for health care providers to develop cultural competency skills, and for extended time for bereavement leave. It also recommends service providers create a complete strategy to prevent and address issues affecting Indigenous spirituality.<sup>789</sup>

Finally, the LCO supports non-binding sources of law, such as the TRC’s *Calls to Action*, which establish compelling objectives for culturally safe health care. In 2016, Canada also ratified the *United Nations Declaration on the Rights of Indigenous Peoples* – an international treaty with standards for the attainment of health, involvement in determining health programs, right to traditional medicines and health practices, and the protection of culture.<sup>790</sup>

Again, it is possible that legal frameworks do not provide the practical guidance required to integrate positive, faith and cultural supports into health care services in the last stages of life. The OHRC policy on creed has the most robust formulation of what equality means in these situations, and it recommends that employers, facilities and health care providers implement concrete strategies to prevent and address diverse faith-related needs.

One question for the LCO’s project is whether the OHRC policy goes far enough in relying on “accommodations” to guarantee supports for what could simply be good, quality care. In this

project, the LCO uses the terminology of “accommodations and supports” to acknowledge that although some services may not be protected rights, they may be part of a person, family and community centered approach to quality care that can be integrated into sectoral laws, discussed below.

## **ii. Sectoral laws: hospital, long-term, home and community care**

Because Ontario’s health care system is fragmented across sectors, separate laws may contain various provisions relating to faith and cultural preferences.

For instance, the *Long-Term Care Homes Act, 2007* and *Home Care and Community Services Act, 1994* establish rights to receive services that respond to preferences based on ethnic, spiritual, religious, linguistic, familial and cultural factors.<sup>791</sup> In developing a plan of care or services, providers must ensure that these factors are incorporated or considered.<sup>792</sup> Moreover, in assisting a resident with placement in a long-term care home, coordinators must consider faith and cultural preferences.<sup>793</sup>

There are long-term care homes in Ontario for First Nations peoples on reserve and for cultural and linguistic communities across the province. Such institutions are protected by provisions of the *Human Rights Code* for special interest institutions.<sup>794</sup> However, the LCO has been told there are too few. A 2016 study found that persons who apply for culturally specific long-term care homes wait longer than other applicants. It explains, “those from linguistic and ethnic minority communities may have to wait for years to enter their preferred homes that serve traditional cuisines and activities and provide care and nursing services by staff who speaks their mother tongues”.<sup>795</sup> The LCO also spoke to service providers who told us that coordinating appropriate faith and cultural supports remains a challenge in home and community care. This can be especially difficult in regions that serve high populations of newcomers to Canada.

With regards to retirement homes, the *Retirement Homes Act, 2010* states that residents have the right to have their “lifestyle and choices respected and to freely pursue [their] social, cultural, religious, spiritual and other interests”.<sup>796</sup> However, as retirement homes are residential tenancies, these rights are limited; they must not substantially interfere with the reasonable enjoyment of the home for the licensee and other residents.<sup>797</sup>

The LCO commissioned research study offers insights into the adequacy of faith and cultural accommodations and supports in hospitals. The authors surveyed 19 leading Ontario hospitals through website searches and the distribution of questionnaires (three hospitals answered the questionnaires). Interviews with health care providers, and faith and community leaders also complemented the research.

Their findings demonstrate that there appears to be no uniform approach across the province to achieving faith and culturally sensitive care. Regulatory colleges and professional associations advise their members to provide services that respond to the faith and cultural needs of their patients, such as the RNAO guidelines on cultural competence and the CPSO policies on end of life and human rights.<sup>798</sup> Nevertheless, education for health care providers is variable.

Health care providers indicate they do not feel comfortable providing culturally competent and safe care because they receive little formal education to serve patients in this respect. Aside from the lack of education, they spoke about difficulties with requiring health care providers to take on added areas of competence, which could increase their workload - some said there should be a dedicated person with the expertise to address faith and cultural preferences in facilities.<sup>799</sup>

Currently in hospitals, there are few formal policies on faith and cultural issues.<sup>800</sup> Traditionally, chaplains have played a significant role in care settings as experts in faith counselling. Chaplains may belong to one faith or be able to support patients in multiple faiths and spirituality.<sup>801</sup> Many facilities do not, however, have full-time chaplains and most are Christian, creating inequalities across religious traditions.<sup>802</sup> Additionally, there is a common perception in Ontario that chaplaincy programs are not essential services, and they are the first to be cut when resources are low or system restructuring takes place. Often, patients and families are not asked about their preferences at the bedside and are left to coordinate their own faith and cultural supports.<sup>803</sup>

There are certainly centres of excellence in the province; however, as Latif et al. report, “Where excellent programs exist, they seem to be driven by individual communities and motivated professionals”.<sup>804</sup> The piecemeal approach to integrating cultural competence into care settings has led to inconsistencies in services and, overall, inequalities in access.<sup>805</sup>

The authors of the LCO commissioned paper summarize these and other barriers to integrating faith and cultural preferences as follows:

- Lack of cultural competence in health care
- Inconsistent policies supporting culturally sensitive and faith-based care for all denominations
- Insufficient resources provided to faith-based and cultural supports
- Inadequate consultation with faith and cultural groups in health policy development.<sup>806</sup>

#### ***4. Strategies to improve culturally competent and safe care in Ontario***

There are a number of practical challenges in strengthening accommodations and supports for members of faith and cultural communities during the last stages of life.

The complex web of laws and policies surrounding accommodations for faith and cultural communities makes it difficult for those working in this environment to identify responsibilities and good practices. Persons of good will may be genuinely confused or ill-informed on these issues. The challenge is heightened where legal obligations are inconsistent, such as where the duty to accommodate a faith related need is in contradiction to a health and safety requirement.

As well, this is a setting where resources are scarce and pressures are significant, a reality that must be taken into account in crafting strategies towards holistic approaches to care.

Individuals in the last stages of life and their families may not be aware of the available supports, or be in a position to advocate for them. If accommodations or supports are denied, pathways to enforcement are unclear.

There are multiple strategies that could be used to improve culturally competent and safe care in Ontario. The LCO proposes that these strategies should be framed as accommodations and broader supports that may be part of a person-, family- and community-centred approach to quality care.

Possible solutions that service providers and community members spoke to LCO about include creating educational tools for cultural competence and safety. There are several existing manuals that summarize the traditional beliefs and practices of diverse communities respecting health care, such as the Canadian Multifaith Federal information manual, mentioned above. However, it is unclear how widely these resources are disseminated and how well they are working on the ground. The LCO would like to know more about the usefulness of these tools and whether they might be improved to ensure they are not overly general. We would particularly like to know whether such tools would be helpful in the end of life context.

The LCO could also review the possibilities for requiring Ontario's regulatory institutions and care settings to create and implement formal policies on faith and cultural integration. We heard that the LHINs, CCACs, long-term care homes and hospitals do not currently serve diverse populations appropriately in terms of language needs, education about eligibility for health care, providing faith and cultural supports onsite and facilitating contact with leaders in the community. Consequently, we wonder if a more coherent approach to systemic change could be realized through a mandatory policy approach.

Although the LCO's understanding of faith and cultural competence and safety goes beyond accommodations, we would also like to know if more detailed guidance from the OHRC is warranted. The OHRC has a mandate to address systemic discrimination in both government and private sectors, and has recently published its policy on creed. While that policy does give instruction on the overall framework for human rights accommodations, the OHRC could go further in consulting with health care institutions and care settings to establish protocols that prevent and respond to core barriers in this context.

Finally, the LCO recognizes that cultural competence within a multicultural society is not necessarily the same as cultural safety for First Nations, Inuit and Métis peoples. Certain individuals suggested that cultural safety can be used as a lens for all faiths and cultures, yet others said it is most applicable to the contemporary experiences of Indigenous peoples.

As with the LCO's review of palliative care in Indigenous communities more generally, we recognize that our project can only address cultural safety if there is a desire for us to do so within Ontario's Indigenous communities. Therefore, we will begin exploring what the LCO's role concerning cultural safety might possibly be through additional community engagement in early 2017.

## **5. Questions for discussion**

- 19. *What approaches are best suited to address barriers, accommodations and supports to better integrate faith, cultural and spiritual practices into care nearing the end of life?***

## 7. ASSISTANCE WITH THE LAW: NAVIGATION, DISPUTE RESOLUTION AND PUBLIC LEGAL EDUCATION

### A. Introduction

This final chapter of the discussion paper considers assistance with the law, including supports to understand what options and services people may be eligible for, and to navigate the health care system and rights in health care. It draws on the lived experience of individuals who use the law, focusing on challenges that become apparent when the law “on the books” is implemented or when conflicts occur.

We begin by examining strategies to address the lack of coordination between care settings that persons typically transition through as they near the end of life (for instance, from home to hospital, hospital to long-term care home, or retirement home to residential hospice). Then, we consider ways to prevent and resolve disputes without having to pursue a formal complaint through existing administrative law processes. Finally, we conclude the discussion paper with a review of the need for greater public education on relevant laws, policies and programs.

At this time, we also remind readers that a comprehensive list of questions the LCO has posed in this discussion paper is listed in Appendix G, “Questions for Discussion”.

### B. Navigating Transitions between Care Settings

#### ***1. Moving from place to place in the last stages of life***

Nearly all persons who are dying will transition between care settings at some point in the course of their illness. Because the illness trajectory for each person is unique – it may be long or brief, relatively stable or fluctuating – a common feature of the dying process is moving from place to place, from one care setting to another in response to changing circumstances.

As we have mentioned previously in this paper, people in Ontario may receive care in a variety of locations, including their own homes through community-based services, long-term care and retirement homes, hospital departments and in residential hospices. When we use the term “transitions” in this paper, we refer to movement between these locations and also within them. For instance, a person in hospital may be transferred from the ICU to complex continuing care (for a longer stay) or to a dedicated palliative care unit.

Timely, well-coordinated and appropriate transitions are a crucial part of quality care for persons in the last stages of life.<sup>807</sup> During the LCO’s consultations, stakeholders spoke about the value of smooth and appropriate transitions for persons who are ill, frail and vulnerable as well as for those who support them in navigating the system.

A key component of end-of-life care involves eliminating emotional, social and physical distress for individuals and their supporters.<sup>808</sup> However, inappropriate or poorly timed transitions increase distress for those who are already in an emotionally charged and difficult situation.<sup>809</sup> An expert research paper that the LCO commissioned for this project confirms the importance of seamless transitions to the quality of care. Their report fills a gap in available information on Ontarians' experiences with transitions by reviewing the literature and new evidence from statistical analysis and interviews. The authors, Donna Wilson and Steven Birch, explain the importance of transitions in the last stages of life as follows:

The ultimate aim of all [end-of-life] care efforts is a “good” death through a good dying process. Good deaths and good dying processes are extremely important to the dying person, their loved ones, their family and other caregivers, and society as a whole....

Of prime importance to a good death and a good dying process is appropriate and high quality care setting transitions. Mishap-free and mistake free care setting transitions are essential when moving from one care setting to another. Rapidly accomplished moves are also important when moving is required.... Every move has considerable personal, family, healthcare team, healthcare system, economic, and other costs.<sup>810</sup>

However, many Ontarians do experience problematic transitions. The LCO was told that people are often transferred from one place to another when they require a higher level of care, rather than having services come to them. Stakeholders identified numerous examples of inappropriate transitions, including, among others:

- discharge from hospital to inappropriate settings such as hotels or shelters
- readmission of persons from palliative care to emergency room services, because the patient has exceeded the hospital limit for palliative care
- hospital patients who wish to receive MAID at home may face challenges where the hospital physician or nurse practitioner is not permitted to perform this service outside of the hospital setting.

We heard that the process of transitioning between care settings can be lengthy, confusing and stressful. Within care settings, the situation can be much the same, as when a person waits in hospital for a palliative care bed or receives care from a new service provider who lacks necessary information, requiring patients to talk about their condition repeatedly.<sup>811</sup>

Transitions can also be a source of conflict among those involved in making decisions about changes in care. For example, the LCO has heard several accounts of family members requesting transfers to palliative care, but being denied the opportunity to do so expediently by health care providers. (For more information on dispute resolution, see section C, below.)

Uneasy transitions are clearly a source of frustration for everyone involved. Service providers told the LCO that they would like constructive solutions that improve the “hand off” of their patients moving to another setting. Delays in processing transitions can leave residential hos-



pice beds underutilized, increase hospital stays, and reduce the possibility that patient wishes regarding their preferred place of care are respected.<sup>812</sup>

The lack of coordination among care providers was reported as a recurring theme in consultations for the Fraser Report as well. The Fraser Report found “The system struggles to ensure continuity of care, particularly when patients move from one care setting to another”.<sup>813</sup>

## **2. *Explaining problematic transitions between care settings***

There are a number of explanations for why unnecessary, delayed or complicated transitions take place.

For the most part, these explanations do not lie in the legal framework. As has been noted elsewhere in this paper, there is no generalized right to health or palliative care. There are specific rights in law, although, as with laws related to the last stages of life as a whole, these are fragmentary, and tend to provide rights of refusal rather than rights of access. For example, while there is no right not to be discharged, to remain in a hospital bed or to receive palliative care, consent (by the individual or the substitute decision-maker) is required for admission to a long-term care home, so that an individual can not be discharged from hospital to long-term care without consent.<sup>814</sup>

Rather, the causes relate mainly to health care challenges and resource constraints.

The inability to receive a level of care necessary to die in place was one of the primary reasons for transitions identified in the LCO commissioned report.<sup>815</sup> Through an analysis of hospital admission data, Wilson and Birch found that the vast majority of persons who die in hospital after a transfer from a private home had not been receiving home care services.<sup>816</sup> Notably, most of the persons who died in hospital upon a return admission in the last year of life had previously been discharged to home with no home care services.<sup>817</sup> In addition, the LCO was informed that long-term care home residents may be transferred to hospital when they experience adverse health events nearing the end of life, because long-term care homes may not be equipped to provide end-of-life care as required by statute.<sup>818</sup>

If individuals who are in the last stages of life can receive the care they need in their preferred care setting, transfers to other locations (in particular, hospitals) could potentially be avoided.<sup>819</sup> However, there will still be clear instances where a change of care setting is unavoidable. For instance, a person’s condition may deteriorate to the point where they would benefit from the constant, intensive care that a residential hospice can offer. When transfers are necessary, they should be well-understood, fast and smooth. Yet Ontario’s system suffers from a lack of planning, coordination and supports for transfers.<sup>820</sup>

Another practical concern arises where a patient seeks MAID at a facility that doesn’t offer it. While certain protections are proposed – such as the requirement to facilitate a referral – the patient may struggle to reconcile their values and wishes with their vulnerable state, and the desire to avoid moving facilities or potentially causing conflict.

Palliative care is provided as a service within existing regulated sectors, which are fragmented and have limited capacity to offer care that follows the individual throughout the system.<sup>821</sup> Because care settings are regulated under separate statutes, funding structures and accountability mechanisms, the LCO heard there is often no legally mandated focal point to provide support with information about eligibility for external services and next steps. No one organization across the system is legally responsible for coordinating palliative care for individuals and families.<sup>822</sup> Most moves are not planned, but reactive to acute symptoms or new care needs.<sup>823</sup> As a result, individuals and families may be left to educate themselves about where to go for services.<sup>824</sup>

Communication barriers between care settings are another major problem. Communication barriers include delays in forwarding medical records to new providers and a general lack of information sharing.<sup>825</sup> The Fraser Report explains that poor communication results in confusion and stress for patients and caregivers. According to Fraser,

When a patient has to move between settings, communication is key. Everyone in his or her circle of care needs to know what is going on.... While the need for two-way sharing on information and coordination of care may seem obvious, it doesn't happen often enough. As a result, patients and families – who are already under stress – may have to endure unnecessary duplication of tests and assessments, and longer wait times.<sup>826</sup>

Wilson and Birch emphasize that because end of life care is not planned, managed, delivered or evaluated as a core healthcare program but is instead included in care delivered under other healthcare programs, there is a limited capacity to assess, plan and evaluate these services. These limitations in coordination and communication are a major cause of inappropriate care setting transitions, low quality care setting transitions, and the delay of necessary transitions.<sup>827</sup>

Taken together, explanations for inappropriate, untimely or poorly coordinated transfers can thus be summarized as arising from these and other factors:

- difficulties receiving an adequate level of care in one's preferred place of residence
- insufficient coordination and communication across care settings, which are regulated separately
- lack of supports for patients and their supporters navigating Ontario's system.

### **3. Creating navigational supports for transitions**

The care needs of persons in the last stages of life will naturally change over time. Depending on the circumstances, transitions from one care setting to another may be avoidable or they may be necessary. Quality care in the dying process demands that these moves be minimized, as much as possible, and that they occur seamlessly when they are necessary through careful planning, communication and timely transfers.

The Government of Ontario is currently taking steps to improve the coordination of health care across sectors to ensure that patients experience seamless services as part of its initiative, *Patients First: A Roadmap to Strengthen Home and Community Care*.<sup>828</sup>

For example, Ontario is seeking to introduce “a bundled care approach, in which a group of providers will be given a single payment to cover all the care needs of an individual patient”.<sup>829</sup> Under this model, services will follow individual patients, rather than patients having to find and coordinate multiple providers themselves. Ontario is also introducing “self-directed care” to enable patients and caregivers to receive an allowance for purchasing services from providers of their own choosing.<sup>830</sup> Additionally, the Province has committed to implementing a “comprehensive program to improve access to and equity in palliative and end-of-life care at home and in the community”,<sup>831</sup> which could potentially decrease avoidable transitions.

Aside from the government’s initiatives in home and community care, it recently initiated the restructuring of the health care system under Bill 41 the *Patients First Act, 2016* which received royal assent December 8, 2016. The Act partly aims to ground “health services in patient needs, with better transitions between different types of care”.<sup>832</sup> Among other measures, the Act promotes easier transitions between acute, primary, home and community, and long-term care; to improve communication with patients and families; and to improve communication among providers through reporting and information sharing.<sup>833</sup>

The establishment of the OPCN and development of a provincial palliative care strategy also creates possibilities to strengthen palliative care across all care settings, which might also minimize unnecessary transitions.

With respect to MAID, Ontario has made several announcements to enhance access to and navigation of services.

While the government is continuing to look at ways to integrate palliative care across the various health care sectors to provide patients with a more seamless experience, there still may be opportunities for the LCO’s project to consider ways to help ease transitions.

The new Patient Ombudsman may have a role to play in addressing problematic transitions. As was described at more length in Chapter 4.F, the Patient Ombudsman has a mandate to help people who have an unresolved complaint about their care at a hospital, long-term care home or Community Care Access Centre. The Ombudsman can respond to complaints from patients and caregivers, but can also investigate on her own initiative. Investigations may result in recommendations to the health care organization in question.<sup>834</sup>

The LCO's project could investigate further measures to complement the government's efforts. For instance, we could review the possibilities for the establishment of a focal point, specifically designated to support persons who are dying and caregivers. Such a focal point could act as a care coordinator, providing basic education on eligibility for services, facilitating communication with health care providers, and generally assisting with navigating the health care system.

Given the complexity of this area, it may be challenging to establish a single focal point that can truly coordinate across all the interacting sectors. Another approach may be to identify strategies, policies or supports that can encourage collaboration within each sector. The LCO would be interested in hearing the benefits and disadvantages of such an approach, and what effective strategies, policies or supports for collaboration might look like.

During our consultations, the LCO would like to know more about the nature of transitions that Ontarians experience and what they believe are the options for reform.

## **C. Early Access to Dispute Avoidance and Resolution**

### ***1. Importance of addressing disputes nearing the end of life***

Death and the dying process are emotionally charged experiences for everyone involved – individuals, family, friends and health care providers, alike. Expectations and decisions in this context are bound up in perceptions of what health care can achieve, ethical views, deeply rooted beliefs, and legal rights and duties.<sup>835</sup>

It is not surprising that disputes arise in these circumstances and that, when they do, they can have serious repercussions on everyone's well-being. As a result, effective mechanisms to avoid and resolve disputes in the last stages of life are an essential component of quality of care.

Conflicts in the last stages of life may revolve around health care decision-making, eligibility for services or concerns about the quality of care being provided. As such, depending on the case, disagreements can take place in multiple care settings about many different matters. Disputes may occur among the various individuals involved in decision-making, including patients, SDMs, family members, health care facility and providers.<sup>836</sup>

For this project, stakeholders spoke to the LCO most often about conflicts taking place in hospital, especially in the ICU, where urgent choices must be made about a fairly narrow range issues. They said areas of heightened dispute in this setting include

- decisions over whether life-sustaining treatment is provided or withdrawn, including differing views on cultural values, clinical benefits and the patient's best interests<sup>837</sup>
- the availability of and timeliness of transfers to palliative care
- discharges from hospital into the community.

For example, the family of a patient who has very little time left may face resistance from hospital staff when they request a transfer from the ICU to a palliative care unit. A health facility might propose to discharge a patient from complex continuing care back home into the community over the family's objections. Substitute decision-makers might also decide to keep someone on life support indefinitely against health care provider recommendations.

To an extent, ongoing developments in Ontario to strengthen palliative care may help to diffuse certain sources of conflict – as may any reforms resulting from the LCO's own projects. In this discussion paper, specifically, we address challenges relating to the following issues, which could go a long way in decreasing conflicts about end-of-life care:

- Equitable access to care for all Ontarians
- Decision-making authority over life-sustaining treatment
- Practice tools for consent and advance care planning
- Palliative sedation therapy
- Coordinating transitions between care settings
- Accommodations and support for faith and cultural communities.

Ideally, clear legal frameworks on these issues could tackle the root causes of disputes, including cultural differences, misunderstandings about consent and advance care planning, bad transitions and disagreements over life-sustaining treatments.<sup>838</sup> Nevertheless, there will inevitably be situations where the parties cannot resolve their differences through legal clarity. Therefore, the LCO's project considers what practices can be used to both minimize and resolve disputes.

Specifically, we consider mechanisms to decrease conflicts at an early stage *before* pursuing a formal avenue of recourse through the courts, regulatory colleges or administrative tribunals. As we explain below, we were told that such formal avenues of recourse may work well in some cases, but may not be suited to cases that require expeditious and sensitive strategies to diffuse conflicts in the setting where individuals are located, such as the ICU.

## **2. Existing avenues of recourse**

There are several formal avenues of recourse to resolve conflicts in the last stages of life in Ontario. In chapter 4 of the discussion paper, we summarized these processes, which include the following:

- Complaints to regulatory health colleges, such as the CPSO and College of Nurses of Ontario
- Applications to the Consent and Capacity Board (on decision-making issues)
- Applications to the health boards (to review regulatory college decisions as well as OHIP, and home and community care eligibility decisions)
- Complaints to the Patient Ombudsman.

In that previous chapter, we outlined many of benefits and limitations of these formal dispute resolution processes. In particular, we explained that the CCB can hear applications that are stipulated in the *Health Care Consent Act, 1996*, but these only concern a slim set of decision-making matters, not issues about the quality of care.<sup>839</sup> Although the CCB process can be fairly fast, appeals to the courts can also last a significantly long time.<sup>840</sup> Furthermore, while HPARB can review decisions of regulatory colleges about whether health care providers have met their practice standards (and therefore about the quality of care), the initial complaints process that passes through the regulatory colleges can be quite lengthy.<sup>841</sup>

More generally, patients and their families usually have only limited understanding of the available dispute resolution processes, and so may not access them or may not use them effectively. During the LCO's project on Legal Capacity, Decision-making and Guardianship, many health care providers expressed reluctance to CCB processes. These professionals viewed the process as inappropriately adversarial, time-consuming, and in some cases, as not aligned with their values and their understanding of their roles. While the CCB was intended as a faster, simpler, less adversarial and more expert forum for these issues than the courts can provide, it is clear that there are inherent tensions in its mandate and that it faces many practical challenges.

During the LCO's consultations for this project, we heard considerable interest in alternative dispute resolution methods that can be accessed *prior* to initiating administrative procedures. Expediency and usability are critical assets for dispute resolution processes in this area of the law, especially when end-of-life decisions and services are at stake.

As a practical matter, most dispute resolution in this context is taking place through internal or informal processes.

Stakeholders told us that the majority of disputes are actually resolved in a person's care setting through good communication between health care providers, patients and SDMs.<sup>842</sup> Health facilities, such as hospitals, may have internal policies and procedures to promote good communication and to resolve escalations in conflict within their facilities. These practices can offer a low-cost and non-adversarial means of resolving issues.

Examples of existing practices for informal dispute resolution within health care facilities include:

1. **Patient relations processes:** Under the *Excellent Care for All Act, 2010*, hospitals are required to have a "patient relations process" to review complaints from patients and caregivers.<sup>843</sup> The MOHLTC has prepared a guidance document on how to design these processes. Among other suggestions, the MOHLTC's guidance recommends the establishment of an impartial, confidential and easily accessible process for patients and family to raise concerns about their experiences. It also suggests that a dedicated patient relations role should include "facilitation, mediation and conflict resolution of patient and family concerns" as well as "coaching staff and physicians on communication styles and stakeholder perspectives, mediation, and conflict resolution."<sup>844</sup> Despite the MOHLTC's guidance, the *Excellent Care for All Act, 2010* does not expressly set out what the patient relations process should comprise and, in practice, it varies from hospital to hospital. An LCO survey of Ontario hospital



websites illustrates that that interpretation of the patient relations process differs substantially, ranging from a feedback mechanism to a more robust tool for conflict resolution.<sup>845</sup>

2. **Patient advocates:** Hospitals may employ “patient advocates”, who are dedicated staff that hear patient and family concerns. In some hospitals, patient advocates are part of the patient relations office while, in others, they are specialized personnel. The role of patient advocates has been characterized as a means to fix the breakdown in relationship between the health team, and the patient and family.<sup>846</sup> Patient advocates may also “take on some of the attributes of an ombudsman” because they are independent of the team arranging the person’s care.<sup>847</sup> However, the LCO was informed that patient advocates are, or maybe be seen, to be partial to the facility’s interests, given their employment relationship with the hospital.
3. **Ethicists:** Ethicists (working in ethics offices or on committees) may be called upon to intervene in difficult conflicts.<sup>848</sup> They may mediate between the parties or provide advice to health care providers and facilities based on a matrix of ethical, legal and medical considerations. The LCO learned that ethicists may become involved in disputes about matters, including life-sustaining treatment, capacity and consent, and when discharges may or may not be appropriate. Yet similar concerns exist to those respecting patient advocates – ethicists are or may be perceived to be representing the health care providers or facility, rather than the patients or family members needing supporting.

There are a number of other dispute resolution practices that stakeholders spoke to the LCO about, such as the involvement of legal counsel on behalf of the health team, the use of private lawyers and legal aid clinics to represent patients and family members (either external to the facility or as satellite clinics onsite),<sup>849</sup> and medico-legal partnerships involving law student volunteers or others who give advice about the law onsite.<sup>850</sup>

The available practices discussed above are also consistent with the CPSO’s guidance on managing conflicts in its policy on end of life care. The CPSO’s policy requires physicians to take specific steps in order to minimize and resolve disputes, which could involve an ethics consultation, seeking legal advice and applying to the CCB, as appropriate. It also prioritizes good communication by requiring physicians to,

- Communicate clearly, patiently, and in a timely manner information regarding:
  - *The patient’s diagnosis and/or prognosis*
  - *Treatment options and assessments of those options*
  - *Availability of supportive services (e.g., social work, spiritual care, etc.) and*
  - *Availability of palliative care resources.*
- Identify misinformation and/or misunderstandings that might be causing the conflict and take reasonable steps to ensure that these are corrected and that questions are answered.<sup>851</sup>



Some of the shortcomings of informal practices in health care facilities have already been noted above. For example, the implementation of statutory requirements for a patient relations process may differ in each facility. When the LCO asked participants in our preliminary interviews what policies and programs are used most commonly to resolve disputes nearing the end of life, most participants were at a loss to describe a clear pathway within health care facilities.

Concerns have also been expressed as to whether internal processes are adequately informed by and ensure compliance with the law.

In addition, informal processes are generally administered by a party with an interest in the dispute – the hospital.<sup>852</sup> This potentially compromises the process or creates a perception of bias that may make patients and caregivers uncomfortable.<sup>853</sup> Informal processes must also be able to address power imbalances between the health team and members of the public. Professionals tend to have better knowledge and expertise in highly technical medical environments, which may be unfamiliar to the public.<sup>854</sup> This power imbalance is further exacerbated by feelings of anxiety, fear and denial that make it difficult for patients, family and friends to absorb information.<sup>855</sup> There may be insufficient focus in these processes on ensuring that families understand their roles and responsibilities as substitute decision-makers. The LCO has heard that families may feel that these processes are being used to pressure them into agreement with the viewpoint of the health institution.

There are undoubtedly certain benefits to having a person, such as a patient's advocate or ethicist, work onsite at a care facility. They are familiar with the facility's policies and practices, have experience with medical issues, and may be able to respond quickly as needed.<sup>856</sup>

Still, for the LCO, alternative dispute processes must be – and be seen to be – fair, impartial and consistent with the law. The challenge is to find the balance between a person who is neutral but also knowledgeable about medical matters, the requirements of the law and the nature of the institution.

### **3. *Early and effective dispute resolution mechanisms***

There may be a range of strategies to improve ADR in the end-of-life context. The LCO has heard that although various avenues of recourse are available in Ontario through complaints processes to health colleges and applications to the CCB, there is a need for new solutions when urgent decisions are being made about death and dying, especially in the hospital context.

In the LCO's report on *Legal Capacity, Decision-Making and Guardianship*, we proposed recommendations that could change the landscape of options for dispute resolution where decision-making issues are engaged. We suggested, for example, the expansion of the CCB's jurisdiction to hear certain applications.<sup>857</sup> We also proposed that "greater room should be made within Ontario's legal capacity, decision-making and guardianship system for mediation and other forms of alternative dispute resolution".<sup>858</sup>

Furthermore, as we noted earlier in this paper, the Patient Ombudsman is a recent addition to Ontario's health care system that could change the options for dispute resolution. Following

a complaint from a patient or caregiver, the Patient Ombudsman is mandated to work with the complainant, the health care organization and the relevant LHIN, as appropriate, to facilitate a resolution. The Patient Ombudsman can also conduct an investigation of the complaint, which could result in recommendations to the health care organization, or conduct investigations on her own initiative.<sup>859</sup>

Because the Patient Ombudsman's office is relatively new, there is little information available to understand its role and effectiveness. Additionally, it is not clear at this time what formal and informal avenues of recourse patients and caregivers will be required to access before engaging the Patient Ombudsman, including the patient relations process, patients advocates, ethics consults, legal advice or accessing the CCB, regulatory colleges and health boards.<sup>860</sup>

The LCO's project faces challenges considering recommendations in the area of ADR because it is in a state of development. In general, it will be important to set clear benchmarks for effective and appropriate alternative dispute resolution in this area, and to build in strategies for monitoring and regularly evaluating the use of alternative dispute resolution in this area.

As a matter of law reform, we might consider whether the Patient Ombudsman could be charged with investigating informal dispute resolution in health care facilities, identifying problems and making recommendations for improvement, specifically in the end-of-life context.

Our project might also consider whether the *Excellent Care for All Act, 2010* provisions on patient relations processes should be more detailed or revised to achieve consistency across care settings, address power imbalances between health teams and members of the public, and ensure impartiality through the independence of patient representation.

The LCO also wonders if strategies being considered under other issues in our project could minimize and facilitate dispute resolution. For instance, in our section on transitions between care settings, we suggested that the LCO could review the creation of a legally mandated focal point (such as care coordinator or system navigator) for persons in the last stages of life (see section 7.B, above). We would like to hear more from you about the advantages and drawbacks of establishing such a position, and whether it could involve better conflict resolution supports.

## **D. The Provision of Public Legal Education**

Ontario's legal framework for care in the last stages of life is rapidly evolving through a number of initiatives within government, community programs and the LCO's own project. These are immensely positive developments in an area that is in serious need of reform as Ontario's community ages, becomes more diverse and adopts new values about death and dying. However, these reforms cannot be successful without awareness about the laws that underpin services and supports.

In this discussion paper, we have written about education throughout in different contexts. For instance, we examined education about death and dying as a special focus of the public health approach to palliative care (chapter 4.C.3). We discussed the lack of education for health care

providers on palliative and end-of-life care in long-term care homes and other settings (chapter 5.D). Furthermore, we summarized the LCO's recommendations in our project on *Legal Capacity, Decision-Making and Guardianship* relating to strengthening education for health care providers, legal professionals, SDMs, patients, family members and others on the law of capacity and decision-making (chapter 6.D.3).

Without repeating those previous sections, we would like to briefly emphasize the necessity for education specifically about Ontario's laws or "public legal education".

From the LCO's consultations to date, we received the strong message that laws affecting care in the last stages of life are generally not well-understood, even by legal professionals. Capacity and decision-making laws are incredibly complex and require enhanced education, as we have addressed in our project on that subject. Yet there are other laws related to care nearing the end of life that are equally confusing that this new project reviews, such as the *Human Rights Code*; *Long-Term Care Homes Act, 2007*; *Home Care and Community Services Act, 1994*; *Vital Statistics Act*; *Occupational Health and Safety Act*; laws related to medical assistance in dying; and the *Canadian Charter of Rights and Freedoms*.

One of Ontario's overarching visions for the health care system is the integration of services across sectors and a seamless experience for patients and families.<sup>861</sup> However, integration and seamlessness are challenging to realize when regulation of the system fragmented. In total, the LCO's project reviews 19 pieces of legislation and many more policies, guidelines and other legal tools. (A full list of statutes that the LCO's project reviews is found in this paper at section 4.H).

Aside from enhancing coordination of health care services through other means, such as legislative reform, what this indicates is that coherent, user-friendly education about what the law provides is indispensable to comprehensive care.

Legal eligibility criteria for home care, procedures to apply for caregiver leave, requests for faith and cultural accommodations and how to file a complaint with the Patient Ombudsman – these are examples of rights that are created under separate laws, but that affect persons who are dying and their supporters at the "center" of care. Consequently, in this project, we ask whether public legal education about laws affecting the dying process could be more responsive to the lived experience of individuals.

Moving forward in the project, we would like to learn more about how public legal education could be reinforced. For instance, there are established initiatives for education about the law within the legal community. What role might these initiatives play?

Community Legal Education Ontario (CLEO) is an example of an established public legal education program.<sup>862</sup> CLEO is a legal aid clinic that works in partnership with other legal aid clinics to provide legal education and information that helps people understand and exercise their rights. It also hosts a website, called "Your Legal Rights" that has basic legal information on various topics, answers to common questions and links to resources produced by external organizations.<sup>863</sup> CLEO has a focus on access to justice in areas including health and disability, social assistance, employment and work, and the justice system, which potentially overlap with laws affecting the last stages of life.<sup>864</sup>

Another strategy might be to consider whether the proposals we received on creating a legal focal point or care coordinator for issues concerning transitions between care settings and ADR could also be a source of public legal education.

Although the above options might be most relevant to patients, caregivers, SDMs, and other family and friends, the LCO recognizes that public legal education would also benefit professionals who support these individuals, regulatory colleges, advocacy organizations and health facilities.

Providing education in accessible formats and languages, and user-friendly dissemination strategies are also elements of possible future recommendations about public legal education on which the LCO would like to receive your feedback.

## **E. Questions for Discussion**

***20. What are your experiences as a patient or caregiver transitioning between care settings in the last stages of life?***

***21. Are law reform measures needed to improve access, navigational supports, and the coordination of care within the health care system?***

***22. What strategies, processes, or institutions are best suited to resolving disputes in the last stages of life?***

***23. How can legal information or education about the law be made more relevant, timely, and effective in the last stages of life?***

# APPENDICES

## APPENDIX A: GLOSSARY OF TERMS

### Accompaniment

The term “accompaniment” is derived from the French “accompagnement”, which is commonly used in France and Quebec alongside the word “treatment” (fr. “soins”) to describe two interconnected elements of palliative care. Accompaniment complements medical treatment and involves a range of services and supports for persons transitioning through the dying process such as being present; listening; and providing cultural, spiritual, psychological and social counselling. Various individuals provide accompaniment, including health care providers, caregivers, family, friends, community members and volunteers.<sup>865</sup>

### Advance care planning

The LCO has adapted the definition of advance care planning used by the Hospice Palliative Care Ontario “Health Care Consent Advance Care Planning Community of Practice” as follows:

The *Substitute Decisions Act, 1992* and *Health Care Consent Act, 1996* govern ACP in Ontario. ACP is a process that involves the mentally capable patient:

1. **IDENTIFYING** his/her future SDM, by either  
**Confirming** his/her satisfaction with their default/automatic substitute decision-maker in the SDM hierarchy list in the HCCA (presented above)

OR

**Choosing** someone else to act as SDM by preparing a power of attorney for personal care (the formal written document, discussed above).

2. **SHARING HIS/HER WISHES, VALUES AND BELIEFS** through conversations with the SDM and others that clarify her/her wishes, values and beliefs, and more generally how he/she would like to be cared for in the event of incapacity to give or refuse consent (e.g., What is quality of life to the patient? What is important to the patient with respect to his or her health?)

ACP does not constitute consent to treatment. Except in emergencies, health care providers must always obtain consent from an individual or SDMs prior to administering treatment, even if the individual has engaged in ACP. Obtaining consent is a continuous process that must precede every treatment. When substitute consent is required, known wishes, values and beliefs serve to guide the SDMs’ decision-making process. Because a person’s wishes, values and beliefs may change over time, later wishes expressed while mentally capable prevail over earlier wishes.

ACP can be initiated and reviewed at any time, not just at end-of-life.<sup>866</sup>

### Advance care plan, living will, advance directive

These terms are not legally defined in Ontario law.<sup>867</sup> Although they are used commonly, they are borrowed from decision-making regimes in jurisdictions outside Ontario, including Canadian provinces and foreign jurisdictions.<sup>868</sup>

In those jurisdictions, these terms may refer to documents that can be used to instruct a health care provider to administer treatments directly when a patient

becomes incapable, without first obtaining consent from an SDM. Ontario law, however, requires that health care providers always obtain consent – even where a patient has engaged in advance care planning or has documented wishes.<sup>869</sup>

## **Capacity**

Under the HCCA, a person is capable with respect to a health care decision if he or she is able to understand information that is relevant to making a decision and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.<sup>870</sup> In Ontario, where an individual lacks capacity and a decision must be made, a substitute decision-maker will be authorized to do so in his or her place.

## **Care**

We use the term “care” broadly to include all forms of treatment, accompaniment and assistance with daily living that individuals may receive as they approach death. The definition of care used in this document also recognizes service and supports for caregivers, family and friends, such as respite and bereavement counselling.

## **Caregiver**

Caregivers are individuals who provide care to family, friends, neighbours and community members with health conditions, disabilities or aging needs. For the purposes of this project, the term “caregiver” includes those who provide care informally and on a voluntary basis and does not include professional providers.

## **Care setting**

Care settings are locations where care is provided to persons who are dying, including private homes, the community, group homes, shelters, long-term care homes, hospitals, residential hospices and retirement homes, among others.

## **Consent**

Under the HCCA, health care providers must obtain consent from a capable individual or an SDM prior to administering treatment, except in emergencies.<sup>871</sup> Consent must relate to a specific treatment, be informed and voluntary, and must not be obtained through misrepresentation or fraud. Informed consent requires that information is provided on the nature, expected benefits, material risks and material side effects of the treatment as well as on alternative courses of action and the likely consequences of not having the treatment. Informed consent also requires that the person receives responses to his or her requests for additional information about those matters.<sup>872</sup>

## **End-of-life care**

End-of-life care refers to care provided to persons whose death is likely imminent.<sup>873</sup> Persons at the end of life are typically in the advanced stages of a life-limiting condition, are in their last weeks or days of life and may require intensive services. The terms “end-of-life care” and “palliative care” are often used synonymously in the literature; however, they are distinguishable. End-of-life care is only one aspect of palliative care. As defined below, palliative care is a philosophy of care and it encompasses a broader range of treatments and accompaniments throughout the dying process.



**Frailty**

Frailty is a syndrome that some older adults experience when they are particularly vulnerable to adverse health outcomes. Frailty is associated with the presence of multiple physical or cognitive conditions that put older adults at risk when they face additional stressors. Even seemingly minor stressors can trigger major changes in frail persons' health and social functioning, potentially resulting in disability, death and hospitalization.<sup>874</sup>

**Goals of care**

Discussions about goals of care may take place between persons receiving care, SDMs, health care providers and family members and are intended to support goal-oriented decision-making.<sup>875</sup> Common goals of care include preferences to live longer, to maintain independence or to be comfortable at the end of life, among others.<sup>876</sup> In Ontario, goals of care are not defined under the HCCA and conversations about goals of care do not constitute consent to treatment. Instead, discussing goals of care is a precursor to informed and person-centred decision-making through legal frameworks for consent and plans of treatment under the HCCA.

**Guardian**

Guardians may be authorized to make decisions on behalf of another person with respect to property management or personal care. Guardians of the person may be appointed following an application to the Superior Court of Justice. Guardians of the person who have authority to give or refuse consent to treatment on an incapable person's behalf are the first individuals identified in the hierarchical list of automatic SDMs under the HCCA.<sup>877</sup>

**Last stages of life**

The "last stages of life" is a broad and inclusive umbrella term that we use in this project to capture the experience of all persons who are approaching the end of their life, whether as a result of terminal illness, chronic conditions or serious frailties that could progress until the end of life. During the last stages of life, individuals might benefit from different forms of care, including palliative and end-of-life care.

**Medical assistance in dying**

There are two forms of medical assistance in dying in Canada. Under the *Criminal Code*, medical assistance in dying means 1) the administering by a physician or nurse practitioner of a substance to a person, at their request, that causes their death; or 2) the prescribing or providing by a physician or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.

There are eligibility and procedural restrictions on medical assistance in dying, which are described in chapter 4.E of this discussion paper.

**Palliative care or hospice palliative care**

Palliative care has philosophical and clinical dimensions. As a philosophy of care, palliative care strives to help individuals, families and caregivers address physical, psychological, social, spiritual and practical issues from the point of diagnosis

throughout the dying process. Palliative care includes helping to prepare for and manage choices, cope with loss and grief, treat active issues, prevent new issues from occurring, and experience personal self-actualization. Palliative care represents a shift in focus along a continuum of care, when the goals of care move away from curative treatment toward the relief of suffering, improved quality of life and comfort measures; however, it does not exclude life-prolonging treatments.<sup>878</sup> Patients may be eligible to receive specific treatments and accompaniments that are available in the health care system and reflect the philosophy of palliative care. Palliative care, hospice care and hospice palliative care are often used interchangeably, and they are not defined in health legislation.

We discuss nuanced understandings of palliative care in chapter 4.C.

#### **Palliative sedation therapy**

Palliative sedation therapy is intended to address the needs of patients who experience intolerable suffering from refractory symptoms by administering medications that have the effect of reducing consciousness. Refractory symptoms are present if all other possible treatments have failed or, in the patient's circumstances, there are no available means to alleviate symptoms that he or she finds acceptable.<sup>879</sup> Palliative sedation therapy may be combined with other palliative care treatments and accompaniments.

#### **Physician-assisted dying**

The Supreme Court of Canada has used the term “physician assisted dying” to describe a physician providing or administering medication that intentionally brings about a patient's death, at the patient's request.<sup>880</sup> More recently, the federal and provincial governments have adopted the term “medical assistance in dying” (see above) as a means to capture the involvement of other health care providers, such as nurses and pharmacists, in this type of treatment.

In this document, we use physician assisted dying only when referring to the Supreme Court's decision and its ramifications. Otherwise, we use medical assistance in dying.

#### **Plan of treatment**

Under the HCCA, a plan of treatment is defined as a plan that is developed by one or more health care practitioners to deal with health problems that a person has and may, in addition, deal with health problems that the person is likely to have in the future given the person's current health condition.<sup>881</sup>

Plans of treatment provide for the administration of various treatments or courses of treatment and may, in addition, provide for the withdrawal and withholding of treatment, in light of the person's current health condition.<sup>882</sup>

#### **Power of attorney**

A power of attorney is a legal document that an individual can use to authorize another person to make decisions on her or his behalf for property management or personal care. As one specific area of decision-making for personal care, a power of attorney may confer authority to give or refuse consent to treatment on the grantor's behalf, in the event he or she becomes incapable.<sup>883</sup>

## Hospice

Hospice care is used interchangeably with palliative care and hospice palliative care. However, the term “hospice” is also used to describe a variety of specific services and supports, and care settings. Residential hospices create a home-like environment for patients who are at the end of their lives and need constant, sometimes intensive, care.<sup>884</sup> In contrast, visiting hospices offer care through out-patient facilities or by travelling to a patient’s home. Finally, virtual hospices offer online resources to members of the public on palliative care, advance care planning and other issues relevant to the last stages of life.<sup>885</sup>

## Respite

Respite provides relief to caregivers who need a break from supporting a person with daily living activities. Examples of respite include having a personal support worker attend to the person’s needs during the day or supplying a space for caregivers to rest for a few hours or overnight. As in these examples, respite may take place in the home or involve travelling to another care setting. Respite may be regular and planned in advance or provided in unexpected moments of need.

## Substitute decision-maker

“Substitute decision-maker” is a generic term used to identify a person who is authorized to make decisions on someone else’s behalf. They include but are not limited to guardians, persons acting under a power of attorney and persons authorized to make decisions in accordance with the hierarchical list of automatic SDMs under the HCCA.

In this project, we primarily refer to SDMs who are authorized to give or refuse consent on a behalf of an incapable person with respect to health care treatment. These SDMs are identified in the hierarchical list of automatic SDMs under the HCCA. Health care providers proposing treatment must follow this list when a patient has been found to be incapable of making a treatment decision.



The full list of SDMs who can give or refuse consent to treatment under the Health Care Consent Act, 1996 is reproduced in Appendix F.

## Treatment

The HCCA defines treatment as “anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose” with some exceptions set out in the legislation.<sup>886</sup>

## APPENDIX B: INDIVIDUALS AND ORGANIZATIONS CONSULTED

This is a partial list based on our preliminary consultations. This list does not imply these individuals and organizations endorse the LCO's report, nor does it attribute any information in the report to them whatsoever.

Additional individuals and organizations we have consulted are listed in Appendix E, "Details on Roundtable on Legal Ethics and Practice". We have also respected the confidentiality of individuals and organizations that requested not to be listed.

- 
1. Alzheimer Society of Ontario
  2. ARCH Disability Law Centre
  3. Dr. Benjamin L. Berger, Associate Dean (Students) & Associate Professor, Osgoode Hall Law School
  4. Dr. Jeff Blackmer, Vice-President, Medical Professionalism, Canadian Medical Association
  5. Dr. Carrie Bourassa, Professor, Indigenous Health Studies, First Nations University
  6. Sandra Carpenter, Centre for Independent Living Toronto
  7. Dr. Paula Chidwick, Director Research & Corporate Ethics, William Osler Health System
  8. Consent and Capacity Board
  9. Nancy Cooper, Ontario Long Term Care Association
  10. Dr. Naheed Dosani, Project Lead & Palliative Care Physician, Palliative Education and Care for the Homeless (PEACH), Inner City Health Associates
  11. Dr. James Downar, Palliative Care and Critical Care, University Health Network and Sinai Health System
  12. Prof. Jocelyn Downie, Dalhousie University, Health Law Institute and Schulich School of Law, Faculties of Law and Medicine
  13. Mary Jane Dykeman, DDO Health Law
  14. Dr. Ian Ferguson, Regional Geriatric Program of Toronto
  15. Andréa Foti, College of Physicians and Surgeons of Ontario
  16. Prof. Michelle Giroux, University of Ottawa, Faculty of Law
  17. Dr. Russell Goldman, Director, Temmy Latner Centre for Palliative Care, Mount Sinai Hospital
  18. Mark Handelman, Whaley Estate Litigation
  19. Cathy Hecimovich, Central West Community Care Access Centre
  20. Dr. Daren Heyland, Professor of Medicine, Queen's University & Director, Canadian Researchers at the End of Life Network

21. Hospice Palliative Care Ontario
22. Hospice Palliative Care Provincial Steering Committee
23. Dr. André Hurtubise, Centre de santé communautaire du Témiskaming
24. Dirk Huyer, MD, Chief Coroner for Ontario
25. Prof. Joan Gilmour, Osgoode Hall Law School
26. Janet Kasperski, Ontario Psychological Association
27. Prof. Mary Lou Kelley, Lakehead University and Northern Ontario School of Medicine
28. Liz Laird, Palliative Pain and Symptom Management Consultation Program, Southwestern Ontario (Grey Bruce Counties)
29. Local Health Integration Network, Erie St. Clair
30. Dr. Denise Marshall, Division of Palliative Care, McMaster University
31. Dena Maule, Hospice Toronto
32. Kay McGarvey, RN, Saint Elizabeth Health Care
33. Dr. Jeff Myers, Sunnybrook Health Sciences Centre, Palliative Care Consult Team
34. Ministry of the Attorney General
35. Ministry of Community and Social Services
36. Ministry of Health and Long-Term Care
37. Patricia Mosnia, Regional Director of Pharmacy, William Osler Health System, Central West Community Care Access Centre & Headwaters Health Care Centre
38. Office of the Children's Lawyer
39. Ontario Association of Social Workers
40. Ontario Bar Association
41. Ontario Caregiver Coalition
42. Ontario College of Pharmacists
43. Ontario Hospital Association
44. Ontario Medical Association
45. Ontario Multifaith Federation
46. Ontario Personal Support Workers Association
47. Ontario Seniors Secretariat
48. Kathryn Pilkington, Ontario Association of Non-Profit Homes and Services for Seniors
49. Dipti Purbhoo, Senior Director, Client Services, Toronto Central Community Care Access Centre
50. Quality Hospice Palliative Care Coalition of Ontario
51. Registered Nurses' Association of Ontario

52. Prof. Hsien Seow, McMaster University, Department of Oncology
53. Robert Sibbald, London Health Sciences, Clinical and Corporate Ethics
54. Deborah Simon, Chief Executive Officer, Ontario Community Support Association
55. Six Nations Health Services
56. Dr. Ann Stewart, Casey House
57. Treatment Decisions Unit, Office of the Public Guardian and Trustee
58. Sara Urowitz, Cancer Care Ontario & Ontario Palliative Care Network Secretariat
59. Sara van der Vliet, Health Boards Secretariat
60. Frank Wagner, Joint Centre for Bioethics, University of Toronto
61. Judith Wahl, Advocacy Centre for the Elderly
62. Tara Walton, Ontario Palliative Care Network Secretariat
63. Eta Woldeab, Ontario Council of Agencies Serving Immigrants
64. Basil Ziv, Registrar & Bhupinder Sharma, Past President, College of Homeopaths of Ontario
65. Randi Zlotnik Shaul, JD, LLM, PhD, Department of Bioethics, The Hospital for Sick Children

## APPENDIX C: ADVISORY GROUP MEMBERS

1. **Sandra Carpenter**, Centre for Independent Living Toronto
2. **Nancy Cooper**, Ontario Long Term Care Association
3. **Julie Darnay**, Quality Hospice Palliative Care Coalition of Ontario & Hospice Palliative Care Ontario
4. **Martha Forestell**, Ontario Medical Association (until July 2016)
5. **Professor Joan Gilmour**, Osgoode Hall Law School
6. **Professor Michelle Giroux**, University of Ottawa, Faculty of Law
7. **Dr. Doris Grinspun and Tim Lenartowych**, Registered Nurses' Association of Ontario
8. **Mark Handelman**, Whaley Estate Litigation
9. **Cathy Hecimovich**, Central West Community Care Access Centre
10. **Pia Hundal**, Ontario Bar Association
11. **Pearl Ing**, Ministry of Health and Long-Term Care (until March 2016)
12. **Vena Persaud**, Ministry of Health and Long-Term Care (from April 2016)
13. **Janet Kasperski**, Ontario Psychological Association
14. **Dr. Denise Marshall**, Division of Palliative Care, McMaster University
15. **Dena Maule**, Ontario Caregiver Coalition
16. **Ada Maxwell-Alleyne**, Ontario Medical Association (from August 2016)
17. **Laura Metrick**, Ministry of the Attorney General (until August 2016)
18. **Dr. Jeff Myers**, Sunnybrook Health Sciences Centre, Palliative Care Consult Team
19. **Imam Abdul Hai Patel**, Ontario Multifaith Federation
20. **Kathleen Scott**, Ontario Personal Support Worker Association
21. **Sara Urowitz**, Ontario Palliative Care Network Secretariat (until April 2016)
22. **Tara Walton**, Ontario Palliative Care Network Secretariat (from May 2016)
23. **Sara van der Vliet**, Health Boards Secretariat
24. **Frank Wagner**, Joint Centre for Bioethics, University of Toronto
25. **Judith Wahl**, Advocacy Centre for the Elderly



## APPENDIX D: COMMISSIONED RESEARCH PAPERS

In December 2015, the LCO issued a Call for Research Papers related to its project on *Improving the Last Stage of Life*. The deadline to submit proposals in response to our Call for Research Papers closed on January 22, 2016.

On or before February 5, 2016, the LCO extended offers to fund seven successful multidisciplinary teams to undertake research on the topics indicated below. This research is being taken into account in the LCO's analysis and recommendations, along with other research, consultations and feedback on our other published documents. The views expressed in the research papers do not necessarily reflect the views of the LCO, nor does the LCO take responsibility for their content.

1. **Judith Wahl (Advocacy Centre for the Elderly), Mary Jane Dykeman (Dykeman Dewhirst O'Brien LLP) & Tara Walton:** Informed consent, advance care planning and substitute decision-making: using practice tools to ensure meaningful decision-making in the last stages of life
2. **Dr. Donna Wilson & Dr. Stephen Birch:** Improved care setting transitions in the last year of life
3. **Dr. Mary Chiu, Dr. Adrian Grek, Sonia Meera, LJ Nelles, Dr. Joel Sadavoy & Dr. Virginia Wesson:** Understanding the lived experience of individuals, caregivers and families touched by frailty, chronic illness and dementia in Ontario
4. **Omar Ha-Redeye, Ruby Latif & Dr. Kashif Pirzada:** Integrating religious and cultural supports into quality care in the last stages of life in Ontario
5. **Susan Brown, Dr. James Downar, Dr. Jennifer Gibson, Dr. Laura Hawryluck, Dr. Csilla Kaloscai, Dr. Joy Richards, Robert Sibbald & Alexi Wood:** Balancing the interests of patients, substitute decision-makers, family and health care providers in decision-making over the withdrawal and withholding of life-sustaining treatment
6. **Dr. Arne Stinchcombe, Dr. Katherine Kortes-Miller & Dr. Kimberley Wilson:** Perspectives on the final stage of life from LGBT elders living in Ontario
7. **Sandy Buchman, Rosario Cartagena, Rose Geist, Mark Handelman, Kaveh Katebian, Wendy Lawrence, Trudo Lemmens, Harvey Schipper, Gilbert Sharpe & Alison Thompson:** The impact of suffering on decision-making and methods of assessing capacity in the last stages of life

In addition to the research papers commissioned specifically for this project, the LCO benefited from the following research paper completed for in our project on *Legal Capacity, Decision-Making and Guardianship*.

1. **Judith Wahl (Advocacy Centre for the Elderly), Mary Jane Dykeman (Dykeman Dewhirst O'Brien LLP) & Brendan Gray:** Health care consent and advance care planning in Ontario.

## APPENDIX E: DETAILS ON ROUNDTABLE FOR THE LEGAL PROFESSION

### I. BACKGROUND

On June 24, 2016, the Law Commission of Ontario and partners hosted a unique opportunity for the legal profession. As part of the LCO's project, *Improving the Last Stages of Life*, we co-hosted the Roundtable on Legal Ethics and Practice for the Last Stages of Life. Our partners for the roundtable were three lawyers specialized in trusts and estates, and mental health law: D'Arcy Hiltz, Alexander Procope and Ryan Fritsch.

The purpose of the roundtable was to bring together practicing lawyers, academics, government counsel, policymakers and others from the legal community to share the professional and ethical practice challenges they face or foresee in this area of the law.

The roundtable was a workshop-style event involving intensive discussion in small groups. Activities throughout the day centered around the following themes:

#### Themes for The Roundtable Activities

1. *Advising clients on the last stages of life*
2. *Resolving common disputes nearing the end of life*
3. *Expectations for medical assistance in dying*

In each case, participants were asked to answer questions on their experiences with related practice issues and, later, to link their answers to concerns about *professional ethics*.

Results of the roundtable have been incorporated into the discussion paper for the Law Commission's project and will be taken into account when we consider possible recommendations for reform. They will also be summarized in a brief report that will publicly disseminated.

### II. LIST OF ROUNDTABLE ATTENDEES

1. **Julie Zamprogna Balles**, Legal Counsel, McKenzie, Lake, Lawyers LLP
2. **Mark Berlin**, Board of Governors, Law Commission of Ontario
3. **Shelley Birenbaum**, Legal Counsel, Shelley R. Birenbaum Professional Corporation
4. **Saara Chetner**, Legal Counsel, Office of the Public Guardian and Trustee
5. **Kerri L. Crawford**, Legal Counsel, Whaley Estate Litigation
6. **Julia Evans**, Legal Counsel, Ministry of the Attorney General
7. **Angela Fallow**, Legal Counsel, Cunningham, Swan, Carty Little & Bonham LLP
8. **Arthur Fish**, Partner, Borden Ladner Gervais LLP
9. **Colleen Flood**, Professor, Faculty of Law, University of Ottawa

10. **Andrea Foti**, Manager, Policy Department & Privacy Officer, College of Physicians and Surgeons of Ontario
11. **Ryan Fritsch**, Policy Counsel, Legal Aid Ontario
12. **Alana Georgas**, Counsel, Ministry of Health and Long-term Care
13. **Jan Goddard**, Partner, Goddard Gamage Stephens LLP
14. **The Honourable Stephen Goudge**, Board of Governors, Law Commission of Ontario
15. **Mark Handelman**, Legal Counsel, Whaley Estate Litigation
16. **D'Arcy J. Hiltz**, Barrister & Solicitor
17. **Pia Hundal**, Trusts and Estates Executive Committee, Ontario Bar Association
18. **Daphne Jarvis**, Partner, Borden Ladner Gervais LLP
19. **Trudo Lemmens**, Professor, Faculty of Law, University of Toronto
20. **Johanna Macdonald**, Staff Lawyer, ARCH Disability Law Centre
21. **Jane Martin**, Partner, Dickson Appell LLP
22. **Sarah Mason-Case**, Research Lawyer & Project Head, Law Commission of Ontario
23. **Laura Metrick**, Legal Counsel, Ministry of the Attorney General
24. **Diana Miles**, Executive Director, Law Society of Upper Canada
25. **Linda Omazic**, Legal Counsel, Property Rights, Office of the Children's Lawyer
26. **Ryan Peck**, Executive Director, HIV & AIDS Legal Clinic of Ontario
27. **Brendan Pooran**, Founder/Principal Lawyer, Pooran Law
28. **Alexander N. Procope**, Swadron Associates
29. **Lonny Rosen**, Partner, Rosen Sunshine LLP
30. **Marshall Swadron**, Swadron Associates
31. **Aneurin (Nye) Thomas**, Executive Director, Law Commission of Ontario
32. **Mary-Alice Thompson**, Partner, Cunningham, Swan, Carty, Little & Bonham LLP
33. **Amy Wah**, Staff Lawyer, HIV & AIDS Legal Clinic of Ontario
34. **Judith Wahl**, Executive Director, Advocacy Centre for the Elderly

## APPENDIX F: RELEVANT STATUTORY PROVISIONS

Health Care Consent Act, 1996, S.O. 1996, Ch. 2, Sch.A

### Interpretation

2. (1) In this Act,

“course of treatment” means a series or sequence of similar treatments administered to a person over a period of time for a particular health problem; (“série de traitements”)

“plan of treatment” means a plan that,

- (a) is developed by one or more health practitioners,
- (b) deals with one or more of the health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person’s current health condition, and
- (c) provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of treatment in light of the person’s current health condition; (“plan de traitement”)

“treatment” means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan, but does not include,

- (a) the assessment for the purpose of this Act of a person’s capacity with respect to a treatment, admission to a care facility or a personal assistance service, the assessment for the purpose of the *Substitute Decisions Act, 1992* of a person’s capacity to manage property or a person’s capacity for personal care, or the assessment of a person’s capacity for any other purpose,
- (b) the assessment or examination of a person to determine the general nature of the person’s condition,
- (c) the taking of a person’s health history,
- (d) the communication of an assessment or diagnosis,
- (e) the admission of a person to a hospital or other facility,
- (f) a personal assistance service,
- (g) a treatment that in the circumstances poses little or no risk of harm to the person,
- (h) anything prescribed by the regulations as not constituting treatment. (“traitement”)  
1996, c. 2, Sched. A, s. 2 (1); 2000, c. 9, s. 31; 2007, c. 8, s. 207 (1); 2009, c. 26, ss. 10 (1, 2); 2009, c. 33, Sched. 18, s. 10 (1).

## **Capacity**

4. (1) A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision. 1996, c. 2, Sched. A, s. 4 (1).

## **Presumption of capacity**

(2) A person is presumed to be capable with respect to treatment, admission to a care facility and personal assistance services. 1996, c. 2, Sched. A, s. 4 (2).

## **Exception**

(3) A person is entitled to rely on the presumption of capacity with respect to another person unless he or she has reasonable grounds to believe that the other person is incapable with respect to the treatment, the admission or the personal assistance service, as the case may be. 1996, c. 2, Sched. A, s. 4 (3).

## **Wishes**

5. (1) A person may, while capable, express wishes with respect to treatment, admission to a care facility or a personal assistance service. 1996, c. 2, Sched. A, s. 5 (1).

## **Manner of expression**

(2) Wishes may be expressed in a power of attorney, in a form prescribed by the regulations, in any other written form, orally or in any other manner. 1996, c. 2, Sched. A, s. 5 (2).

## **Later wishes prevail**

(3) Later wishes expressed while capable prevail over earlier wishes. 1996, c. 2, Sched. A, s. 5 (3).

## **List of persons who may give or refuse consent**

20. (1) If a person is incapable with respect to a treatment, consent may be given or refused on his or her behalf by a person described in one of the following paragraphs:

1. The incapable person's guardian of the person, if the guardian has authority to give or refuse consent to the treatment.
2. The incapable person's attorney for personal care, if the power of attorney confers authority to give or refuse consent to the treatment.

3. The incapable person's representative appointed by the Board under section 33, if the representative has authority to give or refuse consent to the treatment.
4. The incapable person's spouse or partner.
5. A child or parent of the incapable person, or a children's aid society or other person who is lawfully entitled to give or refuse consent to the treatment in the place of the parent. This paragraph does not include a parent who has only a right of access. If a children's aid society or other person is lawfully entitled to give or refuse consent to the treatment in the place of the parent, this paragraph does not include the parent.
6. A parent of the incapable person who has only a right of access.
7. A brother or sister of the incapable person.
8. Any other relative of the incapable person. 1996, c. 2, Sched. A, s. 20 (1).

### **Principles for giving or refusing consent**

21. (1) A person who gives or refuses consent to a treatment on an incapable person's behalf shall do so in accordance with the following principles:

1. If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or refuse consent in accordance with the wish.
2. If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person's best interests. 1996, c. 2, Sched. A, s. 21 (1).

### **Best interests**

(2) In deciding what the incapable person's best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

(a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;

(b) any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and

(c) the following factors:

1. Whether the treatment is likely to,
  - i. improve the incapable person's condition or well-being,
  - ii. prevent the incapable person's condition or well-being from deteriorating, or
  - iii. reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.

2. Whether the incapable person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment.

3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.

4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed. 1996, c. 2, Sched. A, s. 21 (2).

## Information

22. (1) Before giving or refusing consent to a treatment on an incapable person's behalf, a substitute decision-maker is entitled to receive all the information required for an informed consent as described in subsection 11 (2). 1996, c. 2, Sched. A, s. 22.

Criminal Code, R.S.C. 1985, c.C-46

## Medical Assistance in Dying

### Definitions

**241.1** The following definitions apply in this section and in sections 241.2 to 241.4.

*medical assistance in dying* means

(a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or

(b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death. (aide médicale à mourir)

*medical practitioner* means a person who is entitled to practise medicine under the laws of a province. (médecin)

*nurse practitioner* means a registered nurse who, under the laws of a province, is entitled to practise as a nurse practitioner — or under an equivalent designation — and to autonomously make diagnoses, order and interpret diagnostic tests, prescribe substances and treat patients. (infirmier praticien)

*pharmacist* means a person who is entitled to practise pharmacy under the laws of a province. (pharmacien)



## **Eligibility for medical assistance in dying**

**241.2** (1) A person may receive medical assistance in dying only if they meet all of the following criteria:

- (a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada;
- (b) they are at least 18 years of age and capable of making decisions with respect to their health;
- (c) they have a grievous and irremediable medical condition;
- (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and;
- (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

## **Grievous and irremediable medical condition**

(2) A person may receive medical assistance in dying only if they meet all of the following criteria:

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

## **Safeguards**

(3) Before a medical practitioner or nurse practitioner provides a person with medical assistance in dying, the medical practitioner or nurse practitioner must:

- (a) be of the opinion that the person meets all of the criteria set out in subsection (1);
- (b) ensure that the person's request for medical assistance in dying was
  - (i) made in writing and signed and dated by the person or by another person under subsection (4), and
  - (ii) signed and dated after the person was informed by a medical practitioner or nurse practitioner that the person has a grievous and irremediable medical condition;

- (c) be satisfied that the request was signed and dated by the person — or by another person under subsection (4) — before two independent witnesses who then also signed and dated the request;
- (d) ensure that the person has been informed that they may, at any time and in any manner, withdraw their request;
- (e) ensure that another medical practitioner or nurse practitioner has provided a written opinion confirming that the person meets all of the criteria set out in subsection (1);
- (f) be satisfied that they and the other medical practitioner or nurse practitioner referred to in paragraph (e) are independent;
- (g) ensure that there are at least 10 clear days between the day on which the request was signed by or on behalf of the person and the day on which the medical assistance in dying is provided or — if they and the other medical practitioner or nurse practitioner referred to in paragraph (e) are both of the opinion that the person's death, or the loss of their capacity to provide informed consent, is imminent — any shorter period that the first medical practitioner or nurse practitioner considers appropriate in the circumstances;
- (h) immediately before providing the medical assistance in dying, give the person an opportunity to withdraw their request and ensure that the person gives express consent to receive medical assistance in dying; and
- (i) if the person has difficulty communicating, take all necessary measures to provide a reliable means by which the person may understand the information that is provided to them and communicate their decision.

### **Unable to sign**

(4) If the person requesting medical assistance in dying is unable to sign and date the request, another person — who is at least 18 years of age, who understands the nature of the request for medical assistance in dying and who does not know or believe that they are a beneficiary under the will of the person making the request, or a recipient, in any other way, of a financial or other material benefit resulting from that person's death — may do so in the person's presence, on the person's behalf and under the person's express direction.

### **Independent witness**

(5) Any person who is at least 18 years of age and who understands the nature of the request for medical assistance in dying may act as an independent witness, except if they

- (a) know or believe that they are a beneficiary under the will of the person making the request, or a recipient, in any other way, of a financial or other material benefit resulting from that person's death;
- (b) are an owner or operator of any health care facility at which the person making the request is being treated or any facility in which that person resides;

- (c) are directly involved in providing health care services to the person making the request; or
- (d) directly provide personal care to the person making the request.

### **Exemption for medical assistance in dying**

**241** (2) No medical practitioner or nurse practitioner commits an offence under paragraph (1)(b) if they provide a person with medical assistance in dying in accordance with section 241.2.

### **Exemption for person aiding practitioner**

(3) No person is a party to an offence under paragraph (1)(b) if they do anything for the purpose of aiding a medical practitioner or nurse practitioner to provide a person with medical assistance in dying in accordance with section 241.2.

### **Exemption for pharmacist**

(4) No pharmacist who dispenses a substance to a person other than a medical practitioner or nurse practitioner commits an offence under paragraph (1)(b) if the pharmacist dispenses the substance further to a prescription that is written by such a practitioner in providing medical assistance in dying in accordance with section 241.2.

### **Exemption for person aiding patient**

(5) No person commits an offence under paragraph (1)(b) if they do anything, at another person's explicit request, for the purpose of aiding that other person to self-administer a substance that has been prescribed for that other person as part of the provision of medical assistance in dying in accordance with section 241.2.

## APPENDIX G: QUESTIONS FOR DISCUSSION

1. *Within the scope of LCO's project, are there any additional affected individuals, communities, and institutions that should be taken into account?*
2. *Are there any additional recent debates or legislative frameworks that LCO should be aware of?*
3. *What legal rights and principles are important for shaping care and establishing professional standards in the last stages of life?*
4. *Legislation governing health care, housing, employment, professions, and other areas intersects with the last stages of life – what gaps exist that would benefit from greater certainty or clarity?*
5. *Should a public health approach to palliative care be integrated into Ontario's regulatory framework, and how would it look on the ground?*
6. *The LCO has identified several areas where medical assistance in dying could be clarified, including transitions in care, conscientious objection, and appeals of capacity determinations. Are there other additional issues to consider?*
7. *What are your experiences as a member or supporter of a community of need going through the last stages of life?*
8. *What law reforms do you believe are needed for communities with unmet needs, and how would such reforms be most effectively implemented in law?*
9. *Are there any communities with unmet needs who are not identified in this paper that the LCO should consider?*
10. *How can institutions, professionals and the public be better supported to obtain meaningful and legally compliant health care consent?*
11. *How can practice tools achieve the goal of providing accurate, consistent and meaningful information about consent and advance care planning?*
12. *There are connecting laws, principles and policies regarding decision making for life-sustaining practices such as CPR, DN, and nutrition. What are the strengths, weaknesses and gaps in Ontario's current legal framework for decision making authority over life-sustaining practices?*

13. *Who should have authority to determine whether life-sustaining and lifesaving treatment (e.g., CPR, DNR) is offered to, or withdrawn from, a patient – the patient (or SDM) or a health care provider? Under what circumstances?*
14. *Should Ontario regulate the offering of food and water to persons nearing the end of life, including the authority of SDMs to consent to withholding necessities of life?*
15. *Should Ontario regulate the clarity, consistency and safety of palliative sedation therapy considering the ethical challenges, medical assistance in dying, and the need for safeguards like informed consent?*
16. *Which options are preferred to better plan for and manage expected deaths at home? Would it be beneficial to have a province-wide strategy or formal regulation?*
17. *How can strategies for addressing the needs of health care providers assist with mental and moral stress? How can health care practitioners be better prepared to manage disputes?*
18. *Do legal professionals require specific education and guidance on matters relating to the last stages of life, and what form might this best take?*
19. *What approaches are best suited to address barriers, accommodations and supports to better integrate faith, cultural and spiritual practices into care nearing the end of life?*
20. *What are your experiences as a patient or caregiver transitioning between care settings in the last stages of life?*
21. *Are law reform measures needed to improve access, navigational supports, and the coordination of care within the health care system?*
22. *What strategies, processes, or institutions are best suited to resolving disputes in the last stages of life?*
23. *How can legal information or education about the law be made more relevant, timely, and effective in the last stages of life?*

## ENDNOTES

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8. Law Commission of Ontario, “Improving the Last Stages of Life: Project Scope Statement”, online: <http://www.lco-cdo.org/en/last-stages-of-life-project-scope> (last accessed 25 July 2016).
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11. Parliament of Canada, Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, 1st Sess., 42nd Parliament, 2015-2016 (assented to June 16, 2016) [Bill C-14], online: <http://www.parl.gc.ca/LegisInfo/BillDetails.aspx?Language=E&Mode=1&billId=8177165> (last accessed 25 July 2016).
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63. Medical Advisory Secretariat, *Aging in the Community: Summary Evidence-Based Analysis* (2008) 8:1 Ontario Health Technology Assessment Series, 19.
64. Medical Advisory Secretariat, note 63, 19.
65. Martin Turcotte, *Family Caregiving: What Are the Consequences?* (Ottawa: Statistics Canada, 2013), 1; The Change Foundation, *Out of the Shadows and into the Circle: Partnering with Family Caregivers* (The Change Foundation: Toronto, 2015).
66. Health Quality Ontario, *Measuring Up: A Yearly Report on How Ontario’s Health System is Performing* (Toronto: Queen’s Printer for Ontario, 2015) [HQO 2015], 68; The Change Foundation, note 65, 7; Canadian Institute for Health Information, *Home Care Reporting System Quick Stats 2013-2014* [CIHI Quick Stats], online: [https://www.cihi.ca/sites/default/files/document/stats\\_hcrs\\_2013\\_14\\_en.xlsx](https://www.cihi.ca/sites/default/files/document/stats_hcrs_2013_14_en.xlsx) (last accessed March 21, 2017). See also: A. Paul Williams, Janet Lum, Frances Morton-Chang and others, “Integrating Long-Term Care into a Community-Based Continuum: Shifting from ‘Beds’ to ‘Places,’” IRPP Study No.59 (Montreal: Institute for Research on Public Policy, February 2016), 3.
67. The Change Foundation, note 65, 6.
68. The Change Foundation, note 65, 6. See also: HQO 2015, note 66; Maire Sinha, *Portrait of Caregivers, 2012* (Statistics Canada, 2013) [Sinha], 4.
69. Sinha, note 68, 4.
70. Baidoobonso, note 5, 7.
71. Baidoobonso, note 5, 6-7, citing Karl A. Lorenz, Joanne Lynn, Sally C. Morton and others, “Methodological Approaches for a Systematic Review of End-of-Life Care” (2005) 8:1 Journal of Palliative Medicine S-4.
72. HQO 2015, note 66, 68; Sinha, note 68, 3. Also see: Baidoobonso, note 5, 7, noting that caregivers provide support in long-term care homes; CIHI Quick Stats, note 66, demonstrating that a caregiver was present for 97.7% of home care clients while in hospital.
73. Law Commission of Ontario, *Legal Capacity, Decision-making and Guardianship: Discussion Paper* (Toronto: May 2014) [LCO Capacity Discussion Paper], 55, citing Linda Duxbury, Christopher Higgins & Bonnie Schroeder, *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada* (January 2009), 9 (based on a survey of family caregivers).

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75. The Change Foundation, note 65, 12.
76. Baidooobonso, note 5, 7.
77. O.Reg. 79/10, s.42, a regulation made under the *Long-Term Care Homes Act, 2007*, S.O. 2007, c. 8 [LTCHA].
78. Paul Barker, “Local Health Integration Networks: The Arrival of Regional Health Authorities In Ontario”(Paper prepared for presentation at the Annual Meeting of the Canadian Political Science Association, University of Saskatchewan, May 2007).
79. Ontario 2016, note 12.
80. *Patients First Act, 2016*, S.O. 2016, c 30, online: [http://www.ontla.on.ca/web/bills/bills\\_detail.do?locale=en&BillID=4215&isCurrent=false&detailPage=bills\\_detail\\_the\\_bill](http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&BillID=4215&isCurrent=false&detailPage=bills_detail_the_bill) (last accessed December 22, 2016).
81. See for instance: *Home Care and Community Services Act, 1994*, S.O. 1994, c 26, s. 1; Expert Group on Home and Community Care, *Bringing Care Home: Report of the Expert Group on Home and Community Care* (March 2015), 6.
82. Provincial End-of-Life Network, “Ontario Hospice Palliative Care Networks”, online: <http://www.hospicenorthwest.ca/wp-content/uploads/2015/10/ontario-hospice-palliative-care-networks.pdf> (last accessed 25 July 2016); Declaration of Partnership, note 38, 58; Erie St. Clair Hospice Palliative Care Network, “About Us”, online: [http://esceolcn.ca/apps/about\\_us\\_history.html](http://esceolcn.ca/apps/about_us_history.html) (last accessed 25 July 2016).
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86. College of Physicians and Surgeons of Ontario, “Planning for and Providing Quality End-of-Life Care” Policy No. 6-16 (updated 2016); Ontario Medical Association, “End of Life Care Strategy”, online: <http://www.cpso.on.ca/Policies-Publications/Policy/Planning-for-Providing-Quality-End-of-Life-Care> (last accessed 25 July 2016); Registered Nurses’ Association of Ontario, “RN Voice in National Discussion Regarding End-of-Life Care” RNAO Board of Directors Resolution and Backgrounder, online: [http://rnao.ca/sites/rnao-ca/files/1\\_End\\_of\\_Life\\_Care\\_Resolution.pdf](http://rnao.ca/sites/rnao-ca/files/1_End_of_Life_Care_Resolution.pdf) (last accessed 25 July 2016); Registered Nurses Association of Ontario, *End-of-Life Care During the Last Days and Hours* (RNAO Clinical Guideline, 2011), online: <http://rnao.ca/bpg/guidelines/endoflife-care-during-last-days-and-hours> (last accessed 25 July 2016).
87. Government of Ontario, “Ontario Selects Christine Elliot as First-Ever Patient Ombudsman” (December 10, 2015), online: <https://news.ontario.ca/mohltc/en/2015/12/ontario-selects-christine-elliott-as-first-ever-patient-ombudsman.html> (last accessed March 21, 2017). 88. *Excellent Care for All Act, 2010*, S.O. 2010, c. 14, ss.1, 13.1(2) [ECAA]. See also: Government of Ontario, note 87.
89. ECAA, note 88, s.13.1(2). See also: Government of Ontario, note 87.
90. *Regulated Health Professions Act, 1991*, S.O. 1991, c.18, Schedule 1 [RHPA].
91. *Human Rights Code*, R.S.O. 1990, c.H.19 [HRCode].
92. See for instance: Canadian Medical Protective Association, “Clinical Practice Guidelines: What Is Their Role in Legal Proceedings?” (CMPA, September 2011), online: <https://www.cmpa-acpm.ca/-/clinical-practice-guidelines-what-is-their-role-in-legal-proceedings-> (last accessed July 26, 2016).
93. Theories of “legal pluralism” highlight the coexistence of multiple formal and informal legal systems – Aboriginal legal traditions, religious laws and immigrants’ experiences, for example. See: Howard Kislowicz, “Sacred Laws in Earthly Courts: Legal Pluralism in Canadian Religious Freedom Litigation” (2013) 39:1 Queen’s Law Journal 175; Amar Bhatia, “We Are All Here to Stay? Indigeneity, Migration and ‘Decolonizing’ the Treaty Right to Be Here” (2013) 31 Windsor Year Book of Access to Justice 39.

94. *Constitution Act, 1982*, being Schedule B to the *Canada Act, 1982*, 1982 c.11 (UK), s.35 & Part I, *Canadian Charter of Rights and Freedoms* (“Charter”), s. 2(a). We refer to the *Constitution Act, 1867*, (UK), 30 & 31 Vict, c.3, reprinted in RSC 1985, App.II, No.5 and *Constitution Act, 1982* together as the Canadian “Constitution”; HRCODE, note 91, s.1.
95. *Charter*, note 94, ss. 7, 15, 16.
96. *Canada Health Act*, R.S.C. 1985, c. C-6 [CHA]; William Lahey, “Medicare and the Law: Contours of an Evolving Relationship” in Jocelyn Downie, Timothy Caulfield & Colleen Flood, eds., *Canadian Health Law and Policy* (3<sup>rd</sup> ed) (Markham, Ont.: LexisNexis Canada Inc., 2007), 25-26.
97. Lahey, note 96, 25.
98. *Auton (Guardian ad litem of) v. British Columbia (Attorney General)*, [2004] 3 SCR 657 [Auton], para. 43.
99. Lahey, note 96.
100. Nola Ries, “Charter Challenges” in Downie, note 96, 540. See also: Odette Madore, *The Canada Health Act: Overview and Options* (Ottawa: Parliamentary Information and Research Service of the Library of Parliament, 2005), 8; Commission on the Future of Health Care in Canada, *Medically Necessary: What is it and who decides? Issue/Survey Paper* (July 2002); J.C. Herbert Emery & Ronald Kneebone, “The Challenge of Defining Medicare Coverage in Canada” (2013) 6:32 SPP Research Papers, University of Calgary School of Public Policy; Colleen Flood, Mark Bernard Stabile & Carolyn Hughes Tuony, *Defining the Medicare “Basket”* (Ottawa: Canadian Health Services Research Foundation, 2008).
101. CHA, note 96, s.2; Madore, note 100; Flood, note 100.
102. Section 2 of the CHA, note 96, explicitly excludes nursing home intermediate care services, adult residential care services, home care services, and ambulatory health care services. For a discussion about amending the CHA to improve palliative care, see: External Panel on Options for a Legislative Response to *Carter v. Canada, Consultations on Physician-Assisted Dying: Summary of Results and Key Findings Final Report* (Government of Canada, 2015), 128-131.
103. Lahey, note 96, 25; *Auton*, note 98, paras. 33, 35.
104. Ontario Ministry of Health and Long-Term Care, “The Ontario Drug Benefit (ODB) Program”, online: <http://www.health.gov.on.ca/en/public/programs/drugs/programs/odb/odb.aspx> (last accessed July 26, 2016).
105. Flood, note 100.
106. *Chaoulli v. Quebec (Attorney General)*, (2005) 1 SCR 791, para. 104 [Chaoulli].
107. *Eldridge v. British Columbia (Attorney General)*, [1997] 3 SCR 624 [Eldridge].
108. *Eldridge*, note 107, paras. 79-80.
109. Ries, note 100, 553. Notably, in *Auton*, note 98, the Supreme Court dismissed a request that the government be required to fund a specific therapy for children with autism, stating “the legislative scheme...does not have as its purpose the meeting of all medical needs”. *Auton*, note 98, para. 43.
110. See for instance: *R. v. Parker*, 2000 CanLII 5762 (ONCA) [Parker]; *Carter*, note 10; *R. v. Morgentaler* [1998] 1 SCR 30.
111. *Carter*, note 10, para. 66.
112. *Carter*, note 10, para. 68.
113. *Parker*, note 110, para. 85; Ries, note 100, 543-548.
114. *Chaoulli*, note 106; Ries, note 100, 547.
115. Ries, note 100, 547; *Charter*, note 94.
116. Ries, note 100, 548.
117. *An Act Respecting End-of-Life Care*, note 33, s.4.
118. See for instance: BakerLaw, “The Right to Palliative Care in Canada: Think Paper”, online: <http://www.bakerlaw.ca/wp-content/uploads/The-Right-to-Palliative-Care-Think-Paper.pdf> (last accessed July 26, 2016).

119. See for instance: *Hamilton Health Sciences Corp. v. D.H.*, 2014 ONCJ 603; *Rasouli*, note 20; *A.C. v. Manitoba (Director of Child and Family Services)*, [2009] 2 SCR 181.
120. See for instance: Declaration of Partnership, note 38, 80, 84; Holly Prince, Dr. Mary Lou Kelley, Dr. Kevin Brazil and others, *Provision of Palliative and End-of-Life Care Services to Ontario First Nations Communities: An Environmental Scan of Ontario Health Care Provider Organizations* (April 2013), 19. Also note that the Supreme Court of Canada has declared Métis and non-status Indians to be “Indians” under s.91(24) of the *Constitution Act, 1867*. In so doing, the Supreme Court explained in *Daniels v. Canada (Indian Affairs and Northern Development)*, 2016 SCC 12, that federal and provincial governments had both denied having legislative authority over these Aboriginal communities, and that this new clarity “has the undeniably salutary benefit of ending a jurisdictional tug-of-war” (at para. 15). For the LCO’s project, questions remain as to what the impacts of this declaration could have on care in the last stages of life.
121. *Home Care and Community Services Act, 1994*, note 81, s.26; LTCHA, note 77.
122. *An Act Respecting End-of-Life Care*, note 33; Government of British Columbia, *The Provincial End-of-Life Care Action Plan for British Columbia* (Ministry of Health, 2013); Government of British Columbia, *A Provincial Framework for End-of-Life Care* (Ministry of Health, 2006); Albert Health Services, *Palliative and End of Life Care: Alberta Provincial Framework* (Albert Health Services, 2014); Ontario 2016, note 12.
123. ECAA, note 88, Preamble.
124. ECAA, note 88, Preamble.
125. ECAA, note 88, Preamble.
126. HRCode, note 91, ss.9, 47(1), 47(2).
127. HRCode, note 91, 47(2).
128. HRCode, note 91, s.1.
129. See for instance: Ontario Human Rights Commission, *Policy on Preventing Discrimination Based on Creed*, ch.9 “The Duty to Accommodate”, (Toronto: Ontario Human Rights Commission, 2015).
130. HRCode, note 91, Preamble.
131. Government of Ontario, Ontario Seniors’ Secretariat, *Independence, Activity and Good Health: Ontario’s Action Plan for Seniors* (Toronto: Queen’s Printer for Ontario, 2013); *Accessibility for Ontarians with Disabilities Act, 2005*, S.O. 2005, c.11; Government of Ontario, Ministry of Community and Social Services, *About the Accessibility for Ontarians with Disabilities Act, 2005 (AODA)* (Toronto: Queen’s Printer for Ontario, 2008).
132. Another crosscutting area of the law is privacy; however, we do not consider privacy law in the project because, although it is relevant, it was not identified as a major issue for the LCO’s project in our preliminary research and consultations.
133. The HCCA recognizes a presumption of capacity and requires health care providers who propose treatment to obtain consent before doing so. HCCA, note 16, ss.4(2), 10.
134. HCCA, note 16, ss.5, 21.
135. HCCA, note 16, ss. 10, 25.
136. *Fleming v. Reid*, [1991] 4 OR (3d) 74, para.29.
137. For an example of a standard of care in statute see: RHPA, note 90, s.30.
138. *Crits v. Sylvester*, [1956] OR 132 (CA), aff’d SCR 991; Canadian Medical Protective Association, note 92.
139. HCCA, note 16, s.10; Patricia Peppin, “Informed Consent” in Downie, note 96; Ellen Picard & Gerald Robertson, *Legal Liability of Doctors and Hospitals in Canada* (Toronto: Thomson Carswell, 2007).
140. See for instance: Canadian Medical Protective Association, note 92.
141. RHPA, note 90, Schedule 2 “Health Professions Procedural Code”; *Law Society Act*, R.S.O. 1990, c.L.8.
142. RHPA, note 90, Schedule 1 “Self-Governing Health Professions.”
143. College of Physicians and Surgeons of Ontario, “The Complaints Process”, online: <http://www.cpso.on.ca/policies-publications/make-a-complaint/the-complaints-process> (last accessed July 26, 2016); RHPA, note 90, s.10 & Schedule 2, ss.25-28; Law Society of Upper Canada, “The Complaints Process: How it Works,” online: <https://www.lsuc.on.ca/complaints/> (last accessed July 26, 2016).



144. RHPA, note 90, Schedule 2, ss. 29-35, 70; CPSO, note 143.
145. Ontario Ministry of Health and Long-Term Care, "Hospital Chronic Care Co-Payment/Questions and Answers" (July 2016), online: <http://www.health.gov.on.ca/en/public/publications/chronic/chronic.aspx#chroniccare> (last accessed July 26, 2016).
146. See: LTCHA, note 77, s.91; O.Reg. 79/10, note 77, ss. 247, 253.
147. *Retirement Homes Act, 2010*, S.O. 2010, c.11 [RHA]; *Residential Tenancies Act, 2006*, S.O. 2006, c.17 [RTA].
148. RHA, note 147, s.2; O. Reg. 166/11, s.2, a regulation made under the RHA.
149. For more detailed information on how residential hospices and services provided within their walls are funded, see: Residential Hospice Working Group of the Hospice Palliative Care Provincial Steering Committee, *Environmental Scan for Strengthening Residential Hospice Care in Ontario* (March 2015), 16 -18.
150. AG 2014, note 1, 259; *Health Insurance Act*, R.S.O. 1990, c.H.6, s.2, 11.2; R.R.O. 1990, Reg. 552, ss.7, 37.1; Ministry of Health and Long-Term Care, "Ontario Public Drug Programs", online: <http://www.health.gov.on.ca/en/public/programs/drugs/#> (last accessed July 26, 2016).
151. Government of Ontario, "Public Health in Ontario", online: <https://www.ontario.ca/page/public-health-ontario> (last accessed July 26, 2016).
152. Paul Barker, "Local Health Integration Networks: The Arrival of Regional Health Authorities in Ontario"(Paper prepared for presentation at the Annual Meeting of the Canadian Political Science Association, University of Saskatchewan, May 2007).
153. *Local Health System Integration Act, 2006*, S.O. 2006, c. 4, ss. 1, 4; Komal Bhasin & A Paul Williams, *Understanding the LHINs: A Review of the Health System Integration Act and the Integrated Health Services* (Canadian Research Network for Care in the Community & Ontario Community Support Association, 2007).
154. See for instance: Sunnybrook Health Sciences Centre, "Palliative Care Consult Team", online: <http://sunnybrook.ca/content/?page=palliative-care-consult-team> (last accessed July 26, 2016); Hamilton Health Sciences, "Palliative Care Consultation Teams", online: <http://www.hamiltonhealthsciences.ca/body.cfm?id=2269> (last accessed July 26, 2016).
155. See for instance: Sunnybrook Health Sciences Centre, note 154; Mount Sinai Hospital, "What is the Temmy Latner Centre?", online: <http://www.tlcpc.org/tlcpc/about-us> (last accessed July 26, 2016); William Osler Health System, "Supportive Palliative Care", online: <http://www.williamoslerhs.ca/health-care-professionals/programs-services/palliative-care> (last accessed July 26, 2016).
156. *Public Hospitals Act*, R.S.O. 1990, c.P.40.
157. HQO 2015, note 66, 86, reports that "today, residents of long-term care homes have much higher needs than ever before. The number of long-term care residents who are older than 75 years of age is growing rapidly. So too is the proportion of residents with chronic conditions...and approximately 70% of Ontarians in long-term care have some type of dementia." See also: Ontario Long-Term Care Home Association, *This is Long-Term Care 2015* (November 2015).
158. Daryl Bainbridge, Hsien Seow, Jonathan Sussman and others, "Factors Associated with Acute Care Use among Nursing Home Residents Dying of Cancer: A Population-based Study" (2015) 21:7 *International Journal of Palliative Nursing* 349, 349. The proportion of deaths each year has been estimated as high as 50%. See: Quality Palliative Care in Long Term Care Alliance, *Long-Term Care Homes: Hospices of the Future* (prepared as a submission to the Canadian Nursing Association Expert Commission), online: [www.palliativealliance.ca/assets/files/CNA-Final.pdf](http://www.palliativealliance.ca/assets/files/CNA-Final.pdf) (last accessed July 26, 2016).
159. LTCHA, note 77, s.76(7).
160. O.Reg. 79/10, note 77, s.42.
161. Expert Group on Home and Community Care, note 81, 6; *Home Care and Community Services Act, 1994*, note 81, s. 2(4).
162. See for instance: Hospice Toronto, "Services and Programs", online: <https://hospicetoronto.ca/services-programs/> (last accessed July 26, 2016).
163. *Home Care and Community Services Act, 1994*, note 81.

164. Ministry of Health and Long-Term Care, “Community Care Access Centres”, online: <http://www.health.gov.on.ca/en/public/contact/ccac/> (last accessed July 26, 2016).
165. O. Reg. 386/99, *Provision of Community Services*, a regulation made under the *Home Care and Community Services Act*, note 81, s.3(1).
166. This is done through the creation of a plan of service, which may not necessarily provide for maximum level of services. *Home Care and Community Services Act*, note 81, s.22.
167. Ministry of Health and Long-Term Care, *Community Care Access Centres: Client Services Policy Manual* (January 2007), 7.2.1; O. Reg 386/99, note 165, ss. 3(3), 4(1.1).
168. *Cancer Act*, R.S.O. 1990, c. C.1; Cancer Care Ontario, “Who We Are”, online: <https://www.cancercare.on.ca/about/who/> (last accessed July 26, 2016); AG 2014, note 1, 259.
169. CCO, note 168.
170. PFA note 80. See also: discussion at chapter 2.C.4; Government of Ontario, *Patients First: Reporting Back on the Proposal to Strengthen Patient-Centred Health Care in Ontario* (Government of Ontario, June 2016). The MOHLTC’s action plan responds to the findings of an expert report that it had previously commissioned to review the sector and make recommendations for reform. Expert Group on Home and Community Care, note 81.
171. WHO Global Atlas, note 38.
172. Declaration of Partnership, note 38, 58.
173. Lily DeMiglio, Sarah Dykeman, Allison Williams and others, “Evolution of Palliative Care in Ontario: The Impact of Geography, Funding and Advocacy” (2012) 7(4) *Journal of Rural and Community Development* 109, 112; AG 2014, note 1, 260.
174. DeMiglio, note 173.
175. DeMiglio, note 173, 113, 115; Emma Ferguson, “End of Life Care from 1970 to 2005: Development of Hospice Palliative Care Nursing” (2010) University of Ottawa, 8, online: [http://www.med.uottawa.ca/historyofmedicine/hetenyi/assets/documents/End\\_Life\\_Care.pdf](http://www.med.uottawa.ca/historyofmedicine/hetenyi/assets/documents/End_Life_Care.pdf) (last accessed July 26, 2016); Allison Williams, note 2, 4, 5.
176. Among others, Dr. Frank Ferris and Dr. Larry Librach were pioneers in programmatic and home-based palliative care services in Ontario. See: Temmy Latner Centre for Palliative Care, “History of the Temmy Latner Centre for Palliative Care”, online: <http://www.tlcpc.org/tlcpc/history-document> (last accessed July 26, 2016).
177. Furthermore, social advocates fostered targeted care for new patient groups, such as Ontarians with HIV/AIDS, who were not represented among many proposals for hospices in the 1980s and who endured considerable social stigma. Ferguson, note 175, 16, 17; Casey House, “25 Years of Giving Compassion a Home” (2013), online: <http://www.caseyhouse.com/about-casey-house/our-history/25-years/> (last accessed July 26, 2016). See also: Bruce House, “History”, online: <http://brucehouse.ca/history/> (last accessed July 26, 2016).
178. DeMiglio, note 173, 113-116; Williams, note 2, 5-6.
179. DeMiglio, note 173, 113; Williams, note 2, 5-6.
180. The Special Committee on Euthanasia and Assisted Suicide, *Of Life and Death* (June 1995); Subcommittee to update “Of Life and Death”, *Quality End-of-Life Care: The Right of Every Canadian* (June 2000); *Still Not There* (June 2005). See also: Senator Carstairs’s account of her involvement in studying palliative care on the Senate from 1995 to 2010 in The Senate of Canada, *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada* (June 2010), 5.
181. Government of Ontario, *2004 Ontario Budget: Budget Papers* (Queen’s Printer for Ontario, 2004), 17; Government of Ontario, *2005 Ontario Budget: Budget Papers* (Queen’s Printer for Ontario, 2005), 21, 61.
182. Hsien Seow, Lisa Barbera, Doris Howell and others, “Did Ontario’s End-of-Life Care Strategy Reduce Acute Care Service Use?” (2010) 13:1 *Healthcare Quarterly* 93 [Seow & Barbera]; Hsien Seow, Susan King & Vida Vaitonis, “The Impact of Ontario’s End-of-Life Care Strategy on End-of-Life Care in the Community” (2008) 11:1 *Healthcare Quarterly* 56; Ministry of Health and Long-Term Care, “McGuinty Government Improving End-Of-Life Care” (4 October 2005), online: <http://news.ontario.ca/archive/en/2005/10/04/McGuinty-Government-Improving-EndOfLife-Care.html> (last accessed 17 May 2016).



183. Provincial End-of-Life Network, note 82; Declaration of Partnership, note 38, 58.
184. Seow & Barbera, note 182, 99.
185. Declaration of Partnership, note 38, 6.
186. Declaration of Partnership, note 38, 3.
187. Declaration of Partnership, note 38, 12.
188. AG 2014, note 1, 280.
189. Hospice Palliative Care Provincial Steering Committee, “Advancing High Quality and High Value Palliative Care: Update 4” (February 2014); Denise Marshall, “Palliative Care in Ontario and the Declaration of Partnership and Commitment to Action” (Prepared for the Canadian Association of Health Services and Policy Research Conference, May 2014), online: <https://www.cahspr.ca/en/presentation/5384b53937dee8ac2fd50194> (last accessed July 26, 2016).
190. See for instance: Clinical Council of the Hospice Palliative Care Provincial Steering Committee, *Essential Minimum Clinical Standards for Hospice Palliative Care in Ontario* (January 2015); Residential Hospice Working Group, note 149; Residential Hospice Working Group of the Hospice Palliative Care Provincial Steering Committee, *Strengthening Ontario’s End-of-Life Continuum: Advice Regarding the Role of Residential Hospices- Final Report of the Residential Hospices Working Group* (March 2015).
191. AG 2014, note 1, 260.
192. AG 2014, note 1, 260.
193. AG 2014, note 1, 280.
194. Government of Ontario, “2014 Parliamentary Assistant Mandate Letter: Health and Long-Term Care (Health)”, online: <http://www.ontario.ca/page/2014-parliamentary-assistant-mandate-letter-health-and-long-term-care-health> (last accessed July 26, 2016).
195. Ontario 2016, note 12.
196. Fraser Report, note 46, 2; Ontario 2016, note 12.
197. Ontario 2016, note 12.
198. As mentioned above, the LTCHA already requires all facility licensees to train staff on palliative care and requires them to ensure that residents receive end-of-life care in a manner that meets their needs. However, the LCO has heard that residents still face significant barriers accessing palliative care in long-term care homes. LTCHA, note 77, s.76(7); O.Reg. 79/10, note 77, s.42.
199. Ontario 2016, note 12.
200. Ontario 2016, note 12.
201. RNAO, note 86; CPSO, note 86. See also: RNAO, “RN Voice in National Discussion Regarding End-of-Life Care” RNAO Board of Governors Resolution and Backgrounder, online: [http://rnao.ca/sites/rnao-ca/files/1\\_End\\_of\\_Life\\_Care\\_Resolution.pdf](http://rnao.ca/sites/rnao-ca/files/1_End_of_Life_Care_Resolution.pdf) (last accessed July 26, 2016).
202. For the strategy framework and other documents from the OMA on end-of-life care, see: <http://www.ontariosdoctors.com/end-of-life-planning-care/> (last accessed July 26, 2016).
203. Hospice Palliative Care Ontario (HPCO), *Health Care Consent Advance Care Planning Community of Practice Glossary* [HPCO 2016], online: <http://www.speakupontario.ca/wp-content/uploads/2016/04/HCC-ACP-Glossary-of-Terms-April-2016.pdf> (last accessed July 26, 2016).
204. Colleen Dempers & Merryn Gott, “Which Public Health Approach to Palliative Care?” (2016) *Progress in Palliative Care* 1, 2.
205. Libby Sallnow & Sally Paul, “Understanding Community Engagement in End-of-Life Care: Developing Conceptual Clarity” (2015) 25:2 *Critical Public Health* 231, 232.

206. On linkages between palliative care and the public health approach, see: Sallnow & Paul, note 205, 232; John Rosenberg, “‘But we’re already doing it!’: Examining Conceptual Blurring between Health Promotion and Palliative Care” in Libby Sallnow, Suresh Kumar & Allan Kellehear, eds, *International Perspectives on Public Health and Palliative Care* (Abingdon, Oxon: Routledge, 2012).
207. See for instance: Michelle Gillies, *Palliative and End of Life Care in Scotland: The Rationale for a Public Health Approach* (Scottish Public Health Network, 2016).
208. Allan Kellehear, “Compassionate Communities: End-of-Life Care as Everyone’s Responsibility” (2013) 106 Q J Medicine 1071, 1071. See also: John P. Rosenberg, Jason Mills & Bruce Rumbold, “Putting the ‘Public’ into Public Health: Community Engagement in Palliative and End of Life Care” (2016) 24:1 Progress in Palliative Care 1.
209. Sallnow & Paul, note 205, 232; Gillies, note 207, 49.
210. For a history and overview of the public health approach to palliative care see: Sallnow, note 206. For more information on the public health approach, see the 2016 special issue on the subject in Progress in Palliative Care with contributions from Libby Sallnow, Joachim Cohen, Allan Kellehaer and others. Special Issue: Public Health (2016) 24:1 Progress in Palliative Care, online: <http://www.tandfonline.com/toc/yppc20/24/1> (last accessed 5 August 2016).
211. Kellehear, note 208.
212. Sallnow & Paul, note 205, 232.
213. Kellehear, note 208, 1072.
214. Kellehear, note 208, 1072.
215. Kellehear, note 208, 1072.
216. Kellehear, note 208, 1074.
217. Sallnow & Paul, note 205, 233.
218. Pallium Canada, “Pallium Canada’s Compassionate Communities Community of Practice”, online: <http://pallium.ca/compassionate-communities-2/> (last accessed July 26, 2016). The HPCO will be launching its Provincial Compassionate Communities Community of Practice and will work closely and in alignment with the national Pallium Canada initiative.
219. Pallium Canada, “Windsor-Essex Compassionate Community Initiative: Compassionate, Citizen-Driven Community Care”, online: <http://pallium.ca/compassionate-communities-2/canadian-compassionate-communities-projects/cc-windsor-essex/> (last accessed July 26, 2016).
220. Bruce Rumbold, “Public Health Approaches to Palliative Care in Australia” in Sallnow, note 205.
221. Rumbold, note 206.
222. Allan Kellehear, “The Compassionate City Charter” in Klaus Wegleitner, Katharina Heimerl & Allan Kellehear, eds, *Compassionate Communities: Case Studies from Britain and Europe* (London: Routledge, 2016).
223. Kellehear, note 222.
224. Windsor-Essex Compassionate Community Coalition, “Resources”, online: <http://compassionatecarecommunity.com/resources/> (last accessed July 26, 2016).
225. Sallnow & Paul, note 205, 231.
226. See for instance: “What Does a Public Health Perspective Bring to Understandings of Ageing and End of Life”, Chapters 7 to 11 in Meryn Gott & Christine Ingleton, eds, *Living with Ageing and Dying: Palliative and End of Life Care for Older People* (Oxford: Oxford University Press, 2011).
227. We discuss this model more in this discussion paper in chapter 6. See generally: “Improving End-of-Life Care in First Nations Communities”, online: <http://eolfn.lakeheadu.ca/> (last accessed July 26, 2016).
228. Fraser Report, note 46, 17.
229. AG 2014, note 1, 276.
230. Fraser Report, note 46, 17.
231. Fraser Report, note 46, 17.

232. See generally: Gillies, note 207.
233. Gillies, note 207, 43. See also: Allan Kellehear, *Health Promoting Palliative Care* (Melbourne: Oxford University Press, 1999).
234. See also: Fraser Report, note 46, 18.
235. See for instance: Kellehear, note 208.
236. Shyla Mills & Jason Mills, “Future Directions for Community Engagement as a Public Health Approach to Palliative Care in Australia” (2016) 24:1 *Progress in Palliative Care* 15. See also: Kellehear, note 208.
237. See for instance: K. McLoughlin, S. McGilloway, R. Lloyd, M. O’Connor, J. Rhatigan, M. Shanahan, M. Richardson & A. Keevey, “Walls, Wisdom, Worries, and Wishes: Engaging Communities in Discussion about Death, Dying, Loss, and Care Using Café Conversation” (2016) 24:1 *Progress in Palliative Care* 9; Eman Hassan, *The Public Health Approach to Palliative Care: Principles, Models and International Perspectives* (White Paper prepared for the British Columbia Centre for Palliative Care, August 2015).
238. Fraser Report, note 46, 14, 17-18.
239. Erie St. Clair Hospice Palliative Care Network & Local Health Integration Network, *Hospice Palliative Care in Erie St. Clair: Strategic Plan* (February 2015), iv, 9, 12, 57, 59.
240. See also: Dempers & Gott, note 204, 5.
241. Government of Scotland, *Strategic Framework for Action on Palliative and End of Life Care: 2016 to 2021* (December 2015), 7, 12; National Health System England, *NHS England’s Actions for End of Life Care: 2014 to 2016* (November 2014), 5, 20,
242. Gillies, note 207, 15.
243. Ontario Ministry of Health and Long-Term Care, *Ontario Public Health Standards 2008* (revised October 2015), 4 (Public Health Standards).
244. Public Health Standards, note 243, 4.
245. Public Health Standards, note 243, 27-31.
246. Public Health Standards, note 243, 43-72
247. Public Health Standards, note 243, 4-10. See also *Health Protection and Promotion Act*, R.S.O. 1990, c.H.7; Government of Ontario, note 151.
248. For a short history of these reform efforts, see: Law Commission of Ontario, note 73, Ch.3.B “A Little History: Advocacy, Law Reform and the Current Legislative Scheme”.
249. Law Commission of Ontario, note 73, 4; Law Commission of Ontario, note 73, 55.
250. HCCA, note 16, ss. 10, 25.
251. HCCA, note 16, s. 2.
252. HCCA, note 16,, s.4(2).
253. HCCA, note 16,, s.4(3).
254. HCCA, note 16,, s. 4(1).
255. Law Commission of Ontario, note 73, 14.
256. HCCA, note 16, s.15.
257. HCCA, note 16, ss. 11, 25.
258. HCCA, note 16, ss. 20(1).
259. SDA, note 16, s. 55.
260. SDA, note 16, s.46; HPCO, note 203, “Power of Attorney”, 6.
261. HCCA, note 16, s. 20(2).
262. HCCA, note 16, s. 20(5).

263. HCCA, note 16, s. 21(1).
264. HCCA, note 16, ss. 21(1), 21(2).
265. HCCA, note 16, ss.11(2), 22.
266. HCCA, note 16, s.10(1)(b).
267. HPCO, note 203, “Advance Care Planning”, 1.
268. HPCO, note 203, “Advance Care Plan, Living Will, Advance Directive”, 1.
269. HPCO, note 203, “Advance Care Plan, Living Will, Advance Directive”, 1.
270. HPCO, note 203, “Advance Care Plan, Living Will, Advance Directive”, 1.
271. Law Commission of Ontario, note 73, 19.
272. HPCO, note 203, “Advance Care Plan, Living Will, Advance Directive”, 1.
273. HCCA, note 16, s.2. See also: Wahl 2014, note 44, 20, 49-50.
274. HCCA, note 16, s.2.
275. Wahl 2014, note 44, 50.
276. Wahl 2014, note 44, 20.
277. A summary of the recommendations are available in the “Executive Summary” to the Law Commission of Ontario, *Final Report on Legal Capacity, Decision-making and Guardianship* (LCO, March 2017), online: <http://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/> (last accessed March 21, 2017).
278. *Carter*, note 10, para. 127.
279. *Carter*, note 10, para. 128.
280. *Carter v. Canada (Attorney General)* 2016 SCC 4.
281. Bill C-14, note 11.
282. *Criminal Code*, note 33, ss.241(2)-(3).
283. *Criminal Code*, note 33, s.241(5).
284. *Criminal Code*, note 33, s.241(4).
285. *Criminal Code*, note 33, s.241.2(3).
286. Bill C-14, note 11, s.9.1(1).
287. Government of Canada, “Government of Canada Initiates Studies Related to Medical Assistance in Dying” (December 13, 2016), online: <http://news.gc.ca/web/article-en.do?nid=1167919&tp=1> (last accessed December 22, 2016).
288. *Criminal Code*, note 33, ss.241.2(1)(e), 241.2(3).
289. *Criminal Code*, note 33, ss.241.31(3).
290. Bill C-14, note 11, s.10.
291. Government of Ontario, “Statement by Ontario’s Ministers of Health and Long-Term Care and Attorney General on Medical Assistance in Dying”, online: <https://news.ontario.ca/mohltc/en/2016/06/statement-by-ontarios-minister-of-health-and-long-term-care-and-attorney-general-on-medical-assistan.html> (last accessed July 26, 2016).
292. Government of Ontario, note 291; College of Nurses of Ontario, *Guidance on Nurses’ Roles in Medical Assistance in Dying* (June 23, 2016); College of Physicians and Surgeons of Ontario, *Medical Assistance in Dying* (Policy Statement #4-16, June 2016); Ontario College of Pharmacists, *Medical Assistance in Dying: Guidance to Pharmacists & Pharmacy Technicians* (June 27, 2016).
293. Government of Ontario, note 291.

294. University of Toronto, Joint Centre for Bioethics, *Medical Assistance in Dying Policy Template* (October 11, 2016), online: <http://www.jcb.utoronto.ca/news/maid-policy-template.shtml> (last accessed December 22, 2016).
295. CPSO, note 292, 5; CNO, note 292, 3; Government of Ontario, note 291.
296. Ministry of Health and Long-term Care, “Medical Assistance in Dying: Proposed Legislative Amendments (Bill 84), Stakeholder Presentation” (December 9, 2016) at slide 15.
297. Bill 84, note 14.
298. See for instance: Special Joint Committee on Physician-Assisted Dying, note 36; Provincial-Territorial Expert Advisory Group, note 36.
299. See for instance: Hilary Young, “Physician Conscientious Professional Discretion in Canada and the United Kingdom” (*forthcoming*, *McGill Journal of Law and Health*, 2017); Bruce Ryder, “Physicians’ Rights to Conscientious Objection” in Benjamin Berger & Richard Moon, eds, *Religion and the Exercise of Public Authority* (Oxford: Hart Publishing, 2016).
300. See for instance: Laura Stone & Sean Fine, *The Globe and Mail*, “Senate Backs Down, Passes Assisted-Dying Legislation” (June 17, 2016), online: <http://www.theglobeandmail.com/news/politics/senate-passes-assisted-dying-legislation/article30507549/>; Laura Stone, *The Globe and Mail*, “Senate Passes Amended Assisted-Dying Bill, Setting Stage for Showdown with House” (June 15, 2016), online: <http://www.theglobeandmail.com/news/politics/assisted-dying-bill/article30482321/>.
301. *Carter*, note 280, para. 7. Also, when the Supreme Court’s declaration came into effect on June 6, before the federal law was passed, MAG and the MOHLTC encouraged patients and providers to continue to access the court system to clarify how *Carter* might apply to their circumstances, although a court application was no longer required. This process was intended to fill a temporary gap in the absence of federal legislation. See Government of Ontario, note 291.
302. *I.J. v. Canada (Attorney General)*, 2016 ONSC 3380.
303. Canadian Association for Community Living, *Assessing Vulnerability in a System for Physician-Assisted Death in Canada* (April 2016), online: <http://www.cacl.ca/sites/default/files/uploads/CACL%20Vulnerability%20Assessment%20Apr%208%202016%20-%20Final.compressed.pdf> (last accessed July 26, 2016).
304. See generally: Law Commission of Ontario, note 73, 239-243.
305. HCCA, note 16, s. 32.
306. HCCA, note 16, ss. 33, 51, 66.
307. HCCA, note 16, ss. 35, 53, 68.
308. HCCA, note 16, ss. 37, 54, 69.
309. HCCA, note 16, ss. 35, 52, 67.
310. For the fiscal year 2011-2012, over 80 per cent of all applications fell into these categories: Consent and Capacity Board, *Annual Report 2011 – 2012*, 5, online: <http://www.ccboard.on.ca/scripts/english/governance/Annual-Reports.asp> (last accessed July 26, 2016).
311. Paula Chidwick, Robert Sibbald, Laura Hawryluck, “Best Interests at End of Life: An Updated Review of Decisions Made by the Consent and Capacity Board of Ontario” (2013) 28 *Journal of Critical Care* 22.
312. Chidwick, note 311, 23-24.
313. Chidwick, note 311, 24.
314. HCCA, note 16, s.37; Consent and Capacity Board, “Applying to Determine Whether or Not the Substitute Decision Maker Has Complied with the Rules for Substitute Decision-Making (Form G)”, online: <http://www.ccboard.on.ca/scripts/english/publications/infosheets.asp#sdm> (last accessed July 26, 2016).
315. HCCA, note 16, s.35; Consent and Capacity Board, “Applying to the Board for Directions (Form D)”, online: <http://www.ccboard.on.ca/scripts/english/publications/infosheets.asp#sdm> (last accessed July 26, 2016).
316. HCCA, note 16, ss.33(5), 33(7), 35(3), 37(3), 37(4).

317. See generally: Chidwick, note 311.
318. HCCA, note 16, s. 75.
319. HCCA, note 16, s. 80.
320. Government of Ontario, note 87.
321. RHPA, note 90, Schedule 2, *Health Professions Procedural Code*, s.25.
322. College of Nurses of Ontario, *Addressing Complaints at the College of Nurses of Ontario: Process Guide* (October, 2015), online: [http://www.cno.org/globalassets/docs/ih/42017\\_resolvingcomplaints.pdf](http://www.cno.org/globalassets/docs/ih/42017_resolvingcomplaints.pdf).
323. RHPA, note 90, Schedule 2 Health Professions Procedural Code, ss.25-56.
324. See for instance: Health Professions Appeal and Review Board, “Health Professions Appeal and Review Board Complaint Reviews”, online: <http://www.hparb.on.ca/scripts/english/default.asp> (last accessed July 26, 2016); Health Professions Appeal and Review Board, “About Us”, online: <http://www.hparb.on.ca/scripts/english/about.asp> (last accessed July 26, 2016). HPARB also adjudicates other matters relating to health professionals registration within the regulatory colleges. See generally: Health Professions Appeal and Review Board, “Frequently Asked Questions”, online: <http://www.hparb.on.ca/scripts/english/faq.asp> (last accessed July 26, 2016).
325. Health Professions and Health Services Appeal and Review Boards, *Consolidated Rules of Practice and Procedure* (effective May 1, 2013), Rule 17.
326. Of most relevance to this project, HSARB has a review and appeal mandate under the *Health Insurance Act*, note 150; *Home Care and Community Services Act, 1994*, note 81; *Long-Term Care Homes Act 2007*, note 77. See: Health Services Appeal and Review Board, “About Us”, online: <http://www.hsarb.on.ca/scripts/english/about.asp> (last accessed July 26, 2016).
327. Health Services Appeal and Review Board, “Welcome”, online: <http://www.hsarb.on.ca/scripts/english/default.asp> (last accessed July 26, 2016).
328. *Ministry of Health and Long-Term Care Appeal and Review Boards Act, 1998*, S.O. 1998, c.18, Sch. H. Other sources of authority can be accessed on their websites along with legal sources for the administrative bodies that HPARB and HSARB review. Health Services Appeal and Review Board, “Legal”, online: <http://www.hsarb.on.ca/scripts/english/legal.asp> (last accessed July 26, 2016); Health Professions Appeal and Review Board, “Legal”, online: <http://www.hparb.on.ca/scripts/english/legal.asp> (last accessed July 26, 2016).
329. The LCO has conducted case law research into the decisions of HPARB and HSARB. A search on CanLII using the terms “palliative”, “end of life”, “do not resuscitate” and “DNR” produced a total of 132 results for HPARB of which 57 were deemed to be relevant, while a similar search produced only 8 relevant cases for HSARB.
330. See for instance: *A.D. v. A.R.*, 2013 CanLII 19385; *J.D.S. v. E.G.D.*, 2013 CanLII 331; *J.M. v. J.K.*, 2012 CanLII 37860; *M.G. v. S.C.*, 2013 CanLII 97219; *H.L. v. G.M.*, 2013 CanLII 28828; *N.F. v. Y.B.*, 2014 CanLII 25304.
331. See for instance: *D.M. v. F.G.S.*, 2016 CanLII 8871; *R.S. v. S.K.*, 2015 CanLII 51943; *H.T. v. B.S.P.*, 2015 CanLII 21986; *E.G.J.W. v. M.G.C.*, 2014 CanLII 49888; *R.R. v. G.R.N.*, 2014 CanLII 29254; *J.T. v. D.L.*, 2013 CanLII 60999; *C.H. v. K.R.M.*, 2013 CanLII 56307; *C.A.H. v. M.S.*, 2012 CanLII 81785; *M.C. v. J.M.J.L.*, 2012 CanLII 24422; *E.P. v. L.M.H.*, 2012 CanLII 24450; *C.S. v. S.K.D.*, 2012 CanLII 8649; *J.R. v. D.B.*, 2012 CanLII 11358; *C.H. v. M.S.*, 2011 CanLII 34788; *T.F. v. T.J.B.*, 2010 CanLII 43571.
332. *Home Care and Community Services Act, 1994*, note 81, ss.41(2), 48(3).
333. Health Professions Appeal and Review Board, Health Services Appeal and Review Board & Ontario Hepatitis C Assistance Plan Review Committee, *2015 Annual Report* (June 2015), 7.
334. Law Commission of Ontario, note 73, 238.
335. Bill 8, *Public Sector and MPP Accountability and Transparency Act, 2014* (Royal Assent received 11 December 2014); *Excellent Care for All Act*, note 88, s.13.1.
336. Government of Ontario, note 87.



337. Government of Ontario, note 47 , 14.
338. *Excellent Care for All Act*, note 88, s.13.1(9).
339. *Excellent Care for All Act*, note 88, s.13.1(2). See also: Government of Ontario, note 87.
340. *Excellent Care for All Act*, note 88, s.13.1(2), 13.3.
341. *Excellent Care for All Act*, note 88, s.13.2(3).
342. Government of Ontario, note 87.
343. *Employment Standards Act* , 2000, S.O. 2000, c.41, ss. 49.1, 49.3, 49.4, 50.
344. *Occupational Health and Safety Act*, R.S.O. 1990, c. O.1
345. OHS Act, note 344, ss.25-26, Part III.0.1.
346. For example, the Standards Council of Canada has published a national standard psychological health and safety in the workplace. Standards Council of Canada, *Psychological Health and Safety in the Workplace: Prevention, Promotion, and Guidance to Staged Implementation*, National Standard of Canada Doc: CAN/CSA-Z1003-13/BNQ 9700-803/2013 (Ottawa: Standards Council of Canada, 2013).
347. Ontario Ministry of Labour, “Roundtable of Traumatic Mental Stress: Ideas Generated”, online: <http://www.labour.gov.on.ca/english/hs/pubs/tms/index.php> (last accessed July 26, 2016); Ontario Ministry of Labour, *Summit on Work-Related Traumatic Mental Stress: Summary Report* (March 2015).
348. *Vital Statistics Act*. R.S.O. 1990, c.V.4.
349. AG 2014, note 1, 261.
350. The Auditor General recommended that the MOHLTC link the *Declaration of Partnership* to a policy framework for approval by the government. AG 2014, note 1, 280. See also: Government of Ontario, note 194.
351. For a discussion of the need for customization of palliative care for communities, see: Mary Lou Kelley & Holly Prince, *A Framework to Guide Policy and Program Development for Palliative Care in First Nations Communities* (January 2015), online: <http://eolfn.lakeheadu.ca/project-results/reports> (last accessed July 26, 2016). On the personalization of care, generally, see: Registered Nurses’ Association of Ontario, *Person- and Family-Centred Care* (Clinical Best Practice Guideline, 2015), online: <http://rnao.ca/bpg/guidelines/person-and-family-centred-care> (last accessed July 26, 2016).
352. Fraser Report, note 46, 8.
353. Fraser Report, note 46, 10-11.
354. Declaration of Partnership, note 38, 19, 34.
355. The World Health Organization has acknowledged that the terms “inequality” and “inequity” are synonymous in this context. Margaret Whitehead & Göran Dahlgren, *Concepts and Principles for Tackling Social Inequities in Health: Levelling up Part 1*, (Copenhagen: World Health Organization Regional Office for Europe, 2006), 4. For discussions about health inequity, also see: World Health Organization, “Social Determinants of Health: Key Concepts”, online: [http://www.who.int/social\\_determinants/thecommission/finalreport/key\\_concepts/en/](http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/) (last accessed 26 July 2016); Paula Braveman, “What Are Health Disparities and Health Equity? We Need to Be Clear” (2014) 129:2 *Public Health Reports* 5; Mary Chiu, Adrian Grek, Sonia Meera and others, “Understanding the lived experience of individuals, caregivers and families touched by frailty, chronic illness and dementia in Ontario” (Commissioned by the Law Commission of Ontario, 2016).
356. To see a full list of the OHRC policies and guidelines and to access the same, see: Ontario Human Rights Commission, “Policies and Guidelines”, online: [http://www.ohrc.on.ca/en/our\\_work/policies\\_guidelines](http://www.ohrc.on.ca/en/our_work/policies_guidelines) (last accessed July 26, 2016).
357. Ontario Human Rights Commission, *Policy on Preventing Discrimination based on Creed* (Ontario Human Rights Commission, 2015), 55.
358. OHRC, note 357, 55.
359. OHRC, note 357, 54-55, also citing *Janssen v. Ontario Milk Marketing Board* (1990), 13 C.H.R.R. D/397 (Ont. Bd. Inq.) at para. 30.



360. See for instance: *Corbiere v. Canada (Minister of Indian and Northern Affairs)* [1999] 2 SCR 203, where the Supreme Court explored how new analogous grounds can be identified. In that case the Supreme Court found the following (at para. 13):

What then are the criteria by which we identify a ground of distinction as analogous? The obvious answer is that we look for grounds of distinction that are analogous or like the grounds enumerated in s. 15 — race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability. It seems to us that what these grounds have in common is the fact that they often serve as the basis for stereotypical decisions made not on the basis of merit but on the basis of a personal characteristic that is immutable or changeable only at unacceptable cost to personal identity. This suggests that the thrust of identification of analogous grounds at the second stage of the *Law* analysis is to reveal grounds based on characteristics that we cannot change or that the government has no legitimate interest in expecting us to change to receive equal treatment under the law. To put it another way, s. 15 targets the denial of equal treatment on grounds that are actually immutable, like race, or constructively immutable, like religion. Other factors identified in the cases as associated with the enumerated and analogous grounds, like the fact that the decision adversely impacts on a discrete and insular minority or a group that has been historically discriminated against, may be seen to flow from the central concept of immutable or constructively immutable personal characteristics, which too often have served as illegitimate and demeaning proxies for merit-based decision making.

361. See for instance: *Parker*, note 110; *Morgentaler*, note 110.

362. *Carter*, note 10, paras. 62, 64.

363. *Madore*, note 100, 7.

364. *Madore*, note 100, 7.

365. See for instance: The Change Foundation, note 65, 6; HQO 2014, note 27; Sinha, note 68.

366. The Change Foundation, note 65, 12; Law Commission of Ontario, note 73, 55; Carole A. Cohen, Angela Colantonio & Lee Vernich, “Positive Aspects of Caregiving: Rounding out the Caregiver Experience” (2002) 17:2 International Journal of Geriatric Psychiatry 184. See also: Sinha, note 68, 14, stating that 92% of caregivers felt that the experience of providing care was rewarding and that 70% expressed that their relationship with the care receiver had strengthened over the last 12 months.

367. See for instance: Baidooobonso, note 5, 7.

368. The Change Foundation, *A Profile of Family Caregivers in Ontario* (Toronto: The Change Foundation, 2016), 14.

369. The Change Foundation, note 368, 15.

370. The Change Foundation, note 368, 14.

371. There are several types of leave protection under the *Employment Standards Act* that caregivers could potentially take advantage of, including Family Medical Leave, Family Caregiver Leave, Critically Ill Child Care Leave and Personal Emergency Leave. For a summary of these categories, including what they require and provide, see: Ontario Ministry of Labour, “Leaves of Absence”, online: [https://www.labour.gov.on.ca/english/es/pubs/brochures/br\\_leaves.php](https://www.labour.gov.on.ca/english/es/pubs/brochures/br_leaves.php) (last accessed 28 July 2016). See also ESA, note 343, ss. 49.1, 49.3, 49.4, 50.

372. ESA, note 343, ss. 49.1.

373. See also: Fraser Report, note 46, 16-17.

374. *Employment Standards Amendment Act (Leaves to Help Families)*, 2014, S.O. 2014, c. 6; Government of Ontario, “Caregivers Leaves to Help Families Now in Effect”, online: <https://news.ontario.ca/mol/en/2014/10/caregiver-leaves-to-help-families-now-in-effect.html> (last accessed 28 July 2016).

375. There are, however, different heads for leave under the federal regime just as there are in Ontario. The federal leave protections for critically ill children provide for fewer weeks than in Ontario. See: *Canada Labour Code*, R.S.C 1985, c.L-2, ss. 206.3, 206.4; Employment and Social Development Canada, “Information on Labour Standards No. 5A – Compassionate Care Leave,” LT-172-10-14E; Employment and Social Development Canada, “Information on Labour Standards No. 5B – Leave Related to Critical Illness,” LT-263-10-14E.

376. *Employment Insurance Act*, 2010, S.C. 1996, c.23, ss.23.1 (2), 23.2 (1).

377. There is a 2 week waiting period to receive EI benefits, which accounts for the difference between 28 weeks of leave and 26 weeks of benefits. ESA, note 343, s. 13.

378. Samir Sinha, Bailey Griffin, Thom Ringer, and others, *An Evidence-Informed National Seniors Strategy for Canada* (January 2016), 121, 123. For information on challenges with federal caregiver benefits see the following (but note that these articles were published prior to recent changes in the duration of benefits from 6 to 26 weeks): British Columbia Law Institute & Canadian Centre for Elder Law, *Care/Work: Law Reform to Support Family Caregivers to Balance Paid Work and Unpaid Caregiving* (BCLI/CCEL Study Paper No. 4, February 2010); Jenny Flagler & Weizhen Dong, “The Uncompassionate Elements of the Compassionate Care Benefits Program: A Critical Analysis” (2010) 17:1 *Global Health Promotion* 50; Allison M. Williams, Jeanette Eby, Valorie Crooks and others, “Canada’s Compassionate Care Benefit: Is it an Adequate Public Health Response to Addressing the Issue of Caregiver Burden in End-of-Life Care?” (2011) 11:335 *BMC Public Health* 1; Melissa Giesbrecht et al., Valorie A Crooks, Allison Williams and others, “Critically examining diversity in end-of-life family caregiving: implications for equitable caregiver support and Canada’s Compassionate Care Benefit” (2012) 11 *International Journal for Equity in Health* 65; Valorie A Crooks, Allison Williams, Kelli I Stajduhar and others, “Family caregivers’ ideal expectations of Canada’s Compassionate Care Benefit” (2012) 20:2 *Health and Social Care in the Community* 172; Melissa Giesbrecht, Valorie A Crooks, Allison Williams, “Perspectives from the frontlines: palliative care providers’ expectations of Canada’s compassionate care benefits programme” (2010) 18:6 *Health and Social Care in the Community* 643.

379. Regarding respite care, Ontario offers two types of services. One type provides home-based services (for example, homemaking services) to the person under care, giving the caregiver temporary relief. The legislation generally establishes maximum hours in any given period for which homemaking and personal support services may be provided to a qualifying person under care. These services would be paid by the government if the person under care qualifies. As well, it is possible to request that the person under care who otherwise lives at home, stay in an institution temporarily as respite for the caregiver, if certain qualifications are met. The duration of each short-term residency may generally reach up to 60 days per visit to a maximum of 90 days per year. See also: Government of Ontario, “Temporary Respite Care for Caregivers”, online: <https://www.ontario.ca/page/temporary-respite-care-caregivers> (last accessed 28 July 2016); O. Reg. 386/99, note 165, ss. 2, 3. On tax credits, see: *Income Tax Act*, R.S.C 1985, c.1, ss. 118(1)(c.1), 118(1)(d); *Taxation Act*, 2007, S.O. 2007, c.11, Sch.A, ss.9(5). 9(6).

380. Fraser Report, note 46, 16-17.

381. Ontario Caregiver Coalition, “Where We Stand”, online:

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411. See for instance: Brantford Expositor, “Couple Evicted from Retirement Home,” (July 2012), online: <http://www.brantfordexpositor.ca/2012/07/17/couple-evicted-from-retirement-home> (last accessed 28 July 2016); ACE, *Retirement Homes*, note 407, 8.
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413. RHA, note 147, Residents’ Bill of Rights; RTA, note 147, s.147.
414. RTA, note 147, s.148(1).
415. RTA, note 147, section 148.
416. Retirement Homes Regulatory Authority, “Complaints”, online: <http://www.rhra.ca/en/complaints/>; RHA, note 147, ss.81-84; Social Justice Tribunals of Ontario, Landlord and Tenant Board, “Application and Hearing Process”, online: <http://www.sjto.gov.on.ca/lrb/application-and-hearing-process/#step2>; *Residential Tenancies Act, 2006*, note 147, ss.9, 29.
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419. National Aboriginal Health Organization, note 418, 1-7; Ontario First Nations Health Action Plan, note 418.
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435. Aboriginal Health Access Centres, note 433, 11.

436. National Aboriginal Health Organization, note 418, 1-7; Ontario First Nations Health Action Plan, note 418.

437. See also: Office of the Auditor General of Canada, “Access to Health for Remote First Nations Communities” (2015), 3, online: [http://www.oag-bvg.gc.ca/internet/English/parl\\_oag\\_201504\\_04\\_e\\_40350.html](http://www.oag-bvg.gc.ca/internet/English/parl_oag_201504_04_e_40350.html) (last accessed 3 August 2016); TRC, note 420, 18.

438. *Daniels v. Canada (Indian Affairs and Northern Development)*, 2016 SCC 12.

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444. For instance: Len Kelly and Alana Minty, “End of Life Issues of Aboriginal Patients” (2007) 53:9 Canadian Family Physician 1459; Len Kelly, Barb Linkewich, Natalie St Pierre-Hansen, and others, “Palliative Care of First Nations People” (2009) 55:4 Canadian Family Physician 394; Thunder Bay Regional Health Sciences Centre, “Aboriginal Patient Navigators Provide Support to Aboriginal Patients” (2016) online: <http://www.tbrhsc.net/aboriginal-health-at-tbrhsc/> (last accessed August 4, 2016); Joseph M. Kaufert, “Cultural Mediation in Cancer Diagnosis and End of Life Decision-Making: The Experience of Aboriginal Patients in Canada” (1999) 6:3 Anthropology & Medicine 405. See also: RNAO, “Embracing Cultural Diversity in Health Care: Developing Cultural Competence” (2007), online: <http://rnao.ca/bpg/guidelines/embracing-cultural-diversity-health-care-developing-cultural-competence> (last accessed August 4, 2016).

445. National Aboriginal Health Organization, note 418, 1-7.

446. Direct references to health services can be found in Treaties, such as in Treaty 6, which covers Central Alberta and Saskatchewan. Treaty 6 contains a ‘medicine chest provision’ and stipulates that medicines should be used “for the use and benefit of the Indians at the discretion of [the Indian agent]”. While no such explicit language is found in any of the numbered or historical Treaties in Ontario, the Nishnawbe Aski Nation (NAN) has taken the official position that there is a treaty right, or a fiduciary duty, on the part of the Crown to provide health services for Indigenous peoples. See: Nishnawbe Aski Nation, “Political Bilateral Framework on Healthcare” (Resolution 01152, March 2001), online:



[http://www.sfnha.com/files/6113/9999/3848/NAN\\_01-52\\_Political\\_Bilateral\\_Framework\\_on\\_Health\\_Care.pdf](http://www.sfnha.com/files/6113/9999/3848/NAN_01-52_Political_Bilateral_Framework_on_Health_Care.pdf) (last accessed March 21, 2017). Further, the current Regional Chief of NAN argues that the First Nation treaty partnership with Ontario is not upheld by the current regional health scheme of the LHINs. He stated: “LHINS reduce local control of health delivery by existing First Nation health authorities, making the system even more ‘centralized’ and culturally insensitive than it already is”. See: KNet Media, “NAN Defends Treaty Rights to Health Services in Rejection of Provincial LHINs” (March 1, 2006), online: <http://media.knet.ca/node/1881> (last accessed March 21, 2017). As for claims regarding Aboriginal rights to traditional healing, one Ontario case is illustrative. It reveals tensions at the interface of Aboriginal rights under the Constitution, decision-making laws under the HCCA and child protection laws. *Hamilton Health Sciences Corp v D.H.*, 2014 ONCJ 603 [*Hamilton Health Sciences Corp.*], concerned a dispute over whether child with cancer from Six Nations of the Grand River (J.J.) should be treated with chemotherapy. Her mother considered chemotherapy to fall outside the bounds of traditional medicine, and refused to consent to treatment on J.J.’s behalf. The treating physician and health facility disputed the mother’s authority to make this decision as a matter of child protection and the Brant Family and Children’s Service became involved. In the first instance, the court recognized a section 35 Aboriginal right in the area of traditional healing practices and allowed for J.J.’s mother to reject treatment. However, this judgement raised serious concerns about the balance between child protection and Aboriginal rights, and the Attorney General for Ontario became involved in a motion before the presiding judge. The judge subsequently amended his reasons at *Hamilton Health Sciences Corp. v. D.H.*, 2015 ONCJ 229, stating instead that “implicit in this decision is that recognition and implementation of the right to use traditional medicines must remain consistent with the principle that the best interests of the child remain paramount. The Aboriginal right to use traditional medicine must be respected, and must be considered, among other factors, in any analysis of the best interests of the child, and whether the child is in need of protection” (at para 83(a)).

447. TRC, note 420.

448. Centre for Education on Aging & Health, note 432; Northwest LHIN, note 439, 10; Northeast LHIN “Annual Report 2014/2015”, 25, online: <http://www.nelhin.on.ca/accountability/annualreports.aspx> (last accessed August 4, 2016).

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493. HCCA, note 16, ss.10, 25.
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495. HCCA, note 16, s.21.
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523. Wahl 2016, note 44, 60.
524. Wahl 2016, note 44, 60.
525. DNR Confirmation Forms were created as a practical solution to the limited scope of practice for emergency responders who must attempt resuscitation by law if a person has had a cardiac arrest. The DNR Confirmation Form, online:  
<http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/FormDetail?OpenForm&ENV=WWE&NO=014-4519-45>  
(last accessed August 18, 2016).
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552. Cartagena, note 551, 34-35.
553. *Fleming*, note 136.
554. HCCA, note 16, s. 1(c).
555. LCO, note 18.
556. Manitoba Law Reform Commission, note 43, 37.
557. Cartagena, note 551, 54.
558. Cartagena, note 551, 53.
559. See for instance: Molly L. Olsen, Keith M. Swetz & Paul S. Mueller, “Ethical Decision Making with End of Life Care: Palliative Sedation and Withholding or Withdrawing Life-Sustaining Treatments” (2010) 85:10 Mayo Clin Proc 949, 951.
560. Manitoba Law Reform Commission, note 43, 92.
561. Cartagena, note 551, 23-25.
562. Manitoba Law Reform Commission, note 43, 15.
563. Jocelyn Downie, Lindy Wilmott, Ben P White, “Next Up: A Proposal for Values-Based Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment” (2017) 54(3) *Alberta Law Review* (forthcoming).
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566. Downie, note 563.
567. *Rasouli*, note 20, paras. 64-68.
568. Joan Gilmour, “Death, Dying and Decision-Making about End of Life Care”, in Jocelyn Downie, Timothy Caulfield & Colleen Flood, eds, *Canadian Health Law and Policy* (4<sup>th</sup> ed) (Markham, Ont.: LexisNexis Canada Inc., 2011), 387-388.
569. *Malette v. Shulman*, (1990) 72 OR (2d) 417 (CA).
570. *Carter*, note 10, paras. 63, 67.
571. *Carter*, note 10, para. 67, citing *Fleming*, note 136. Also referring to: *Ciarlariello v. Schacter* [1993] 2 SCR 119; *Malette*, note 569; *Nancy B. v. Hotel-Dieu de Quebec* (1992) 86 DLR (4<sup>th</sup>) 385 (Que. Sup. Ct).

572. The HCCA defines treatment as “anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health related-purpose and includes a... plan of treatment”. It also explicitly states that a plan of treatment may “provide for the withholding or withdrawal of treatment in light of the person’s current health condition”. HCCA, note 16, s.2.

573. Young, note 299.

574. James Downar, Laura Hawryluck, Alexi Wood and others, *Balancing the Interests of Patients, Substitute Decision-Makers, Family and Health Care Providers in Decision-Making over the Withdrawal and Withholding of Life-Sustaining Treatment* (commissioned by the Law Commission of Ontario, March 2017), 41, online: <http://www.lco-cdo.org/laststages> (last accessed April 10, 2017).

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579. See also: Gilmour, note 568, 415; Jocelyn Downie & Karen McEwan, “The Manitoba College of Physicians and Surgeons Position Statement on Withholding and Withdrawal of Life-Sustaining Treatment (2008): Three Problems and a Solution” (2009) 17 Health Law Journal 115.

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581. See also: Manitoba Law Reform Commission, note 43, 70-72.

582. See for example: *E (Re)*, 2009 CanLii 28625 (CCB); *EJG (Re)*, 2007 CanLii 44704 (CCB); *MN (Re)*, 2012 CanLii 18287 (CCB); *CA (Re)*, 2013 CanLii 76685 (CCB); *SR (Re)*, 2011 CanLii 79858 (CCB); *P (Re)*, 2005 CanLii 56634 (CCB); *SS (Re)*, 2012 CanLii 85612 (CCB). See also: Chidwick, note 311.

583. See for example: *C.H. v. M.S.*, 2011 CanLii 34788; *C.A.H. v. M.S.*, 2012 CanLii 81785; *T.F. v. T.J.B.*, 2010 CanLii 43571; *T.F. v. R.G.M.*, 2010 CanLii 43570.

584. See for example: *M. v. F.G.S.*, 2016 CanLii 8871; *R.S. v. S.K.*, 2015 CanLii 51943; *H.T. v. B.S.P.*, 2015 CanLii 21986; *E.G.J.W. v. M.G.C.*, 2014 CanLii 49888; *R.R. v. G.R.N.*, 2014 CanLii 29254; *J.T. v. D.L.*, 2013 CanLii 60999; *C.H. v. K.R.M.*, 2013 CanLii 56307; *C.A.H. v. M.S.*, 2012 CanLii 81785; *M.C. v. J.M.J.L.*, 2012 CanLii 24422; *E.P. v. L.M.H.*, 2012 CanLii 24450; *C.S. v. S.K.D.*, 2012 CanLii 8649; *J.R. v. D.B.*, 2012 CanLii 11358; *C.H. v. M.S.*, 2011 CanLii 34788; *T.F. v. T.J.B.*, 2010 CanLii 43571.

585. *Rasouli*, note 20.

586. CPSO, note 86, 8.

587. *Rasouli*, note 20, para.116.

588. Following the outcome in the case, Mr. Rasouli is still on life support at an Ontario hospital.

589. Mark Handelman and Michael Gordon provide a good description of the *Rasouli* case in Mark Handelman & Michael Gordon, “Last Rights: *Cuthbertson v. Rasouli* What the Supreme Court Didn’t Say about End-of-Life Treatment Decisions” (2015) 35:2 Health Law in Canada 106.

590. Handelman & Gordon, note 589, 109.

591. HCCA, note 16, s.21.

592. Young, note 299.

593. See for instance: Chidwick, note 311, 22, 23.

594. *Rasouli*, note 20, para. 4.

595. *Rasouli*, note 20, paras. 73, 75.

596. Handelman & Gordon, note 589, 109.

597. Simon JW Oczkowski, Bram Rochweg & Corey Sawchuck, “Withdrawing Versus not Offering Cardiopulmonary Resuscitation: Is there a Difference?” (2015) 22:1 Can Respir J 20.

598. CPSO, note 86, 8.

599. See for instance the Canadian Medical Association's policy, *Statement on Life-Saving and -Sustaining Interventions* (December 2013), online: <https://www.cma.ca/Assets/assets-library/document/en/advocacy/PD14-04-e.pdf> (last accessed March 23, 2017) which states that CPR is not clinically indicated in all cases; where there will be no medical benefit to treatment, intervention is inappropriate and there is no obligation to provide non-beneficial treatment. The policy also recognizes, "As a general rule a person should be involved in determining medical futility in his or her case," and that in provinces with statutory mechanisms to resolve disagreements, "they must be adhered to." See also Downar, note 574.

600. *EGJW v MGC*, 2014 CanLII 49888 (ON HPARB).

601. Downar, note 574, 41-42.

602. Downar, note 574, 41-42.

603. Downar, note 574, 41-42.

604. CPSO, note 86, 7-8, 11.

605. Downar, note 574, 22.

606. Manitoba Law Reform Commission, note 43, 11.

607. Queensland Government, *End-of-Life Care: Decision-Making for Withholding and Withdrawing Life-Sustaining Measures from Adult Patients* (Queensland Health, Implementation Guidelines).

608. Queensland Government, note 607, Part 1, 14-16.

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610. Downar, note 574, 31-35; Young, note 299.

611. United Kingdom Court of Protection Practice Rules, "Practice Direction 9E – Applications Relating to Serious Medical Treatment" (July 2015), online: <https://www.judiciary.gov.uk/wp-content/uploads/2015/06/copd-pd-9e-serious-medical-treatment.pdf> (last accessed March 23, 2017). Downar, note 574, 31-35.

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615. Downar, note 574, 37.

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617. *Bentley v. Maplewood Seniors Care Society*, 2014 BCSC 165, aff'd 2015 BCCA 91 [*Bentley*].

618. National Initiative for the Care of the Elderly, "When someone close to you is dying – what you can expect and how you can help", 9, online: [http://www.nicenet.ca/files/When\\_Someone\\_Close\\_to\\_you\\_is\\_Dying\\_English\\_version.pdf](http://www.nicenet.ca/files/When_Someone_Close_to_you_is_Dying_English_version.pdf) (last accessed March 23, 2017).

619. *Bentley*, note 617, para.2.

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621. *Bentley*, note 617, para.7.

622. HCCA, note 16, s.2.

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624. HCCA, note 16, s.10.
625. HCCA, note 16, ss.58-59.
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629. SDA, note 16, s. 45. The LTCHA also refers to “personal care”.
630. SDA, note 16, s. 45.
631. SDA, note 16, 46(7).
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634. See for example: RAO *End-of-Life Care*, note 86, 33; College of Nurses of Ontario, “Practice Standard: Ethics” (updated June 2009), 6, 12, online: [https://www.cno.org/globalassets/docs/prac/41034\\_ethics.pdf](https://www.cno.org/globalassets/docs/prac/41034_ethics.pdf) (last accessed March 23, 2017); Ontario Personal Support Worker Association, “Standard of Practice: Feeding,” 1, online: [http://media.wix.com/ugd/207a84\\_Occ3c371aeb44836b3bfc937f18004ee.pdf](http://media.wix.com/ugd/207a84_Occ3c371aeb44836b3bfc937f18004ee.pdf) (last accessed March 23, 2017).
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757. See for example the wide array of beliefs examined in Latif, note 742.

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777. In *Rasouli* this was only indirectly addressed, as freedom of religion was not argued. See also the reasons for judgment of Abella J. (LeBel, Deschamps and Charron JJ. concurring) in *A.C.*, note 119, paras. 112-117.

778. *A.C.*, note 119; *B.R.*, note 753.

779. *A.C.*, note 119; *B.R.*, note 753.

780. OHRC, note 357, 24-25.

781. OHRC, note 357, 24-25.

782. Substantial costs and significant health and safety risks could indicate undue hardship. OHRC, note 357, 54, 69-72.

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829. Government of Ontario, note 47, 7.
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846. Paola Loriggio, "Q&A with a patient advocate" Toronto Star (November 20, 2012), online:  
[https://www.thestar.com/life/2012/11/20/qa\\_with\\_a\\_patient\\_advocate.html](https://www.thestar.com/life/2012/11/20/qa_with_a_patient_advocate.html) (last accessed March 23, 2017).
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849. For instance, the Health Justice Program is a partnership between St. Michael’s Hospital and legal clinics (ARCH Disability Law Centre, Aboriginal Legal Services Toronto, HIV & AIDS Legal Clinic of Ontario and Neighbourhood Legal Services). It is funded by Legal Aid Ontario and provides services that include legal information and advice, referrals to legal services, and advocacy. Health Justice Program at St. Michael’s, online: <http://www.stmichaelshospital.com/pdf/programs/family-practice/health-justice-initiative-presentation.pdf> (last accessed August 19, 2016).

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852. For example, Hamilton Health Services has the Office of Patient Experience, online: [http://www.hamiltonhealthsciences.ca/workfiles/CLINICAL\\_ETHICS/Patientexperience.pdf](http://www.hamiltonhealthsciences.ca/workfiles/CLINICAL_ETHICS/Patientexperience.pdf); University Health Network has Patient Relations – Office of the Ombudsman, online: <https://www.oha.com/CurrentIssues/keyinitia-tives/patientrelations/DepartmentalStructureandFunction/Documents/Examples%20of%20Policies,%20Flow%20Charts%20and%20Process%20Maps%20for%20Managing%20Feedback/Academic%20Hospitals/University%20Health%20Network.pdf> (last accessed August 19, 2016).

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857. LCO Interim Report, note 17, 219-220.

858. LCO Interim Report, note 17, 228.

859. ECAA, note 88, ss.13.1(2), 13.2, 13.3(1), 13.3(4), 13.4.

860. The Patient Ombudsman can decline to address a complaint “Where the complaint relates to a matter that is within the jurisdiction of another person or body.” ECAA, note 88, s. 13.2(3).

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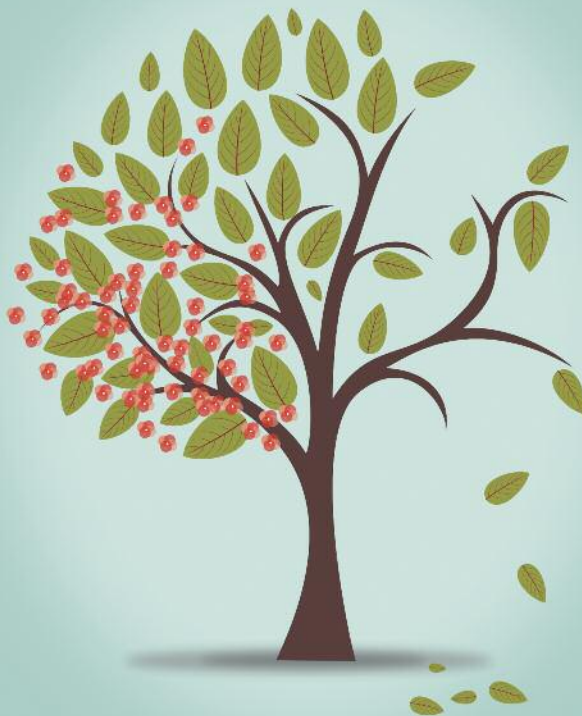
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