Improving the Last Stages of Life

ISSUES BACKGROUNDERS

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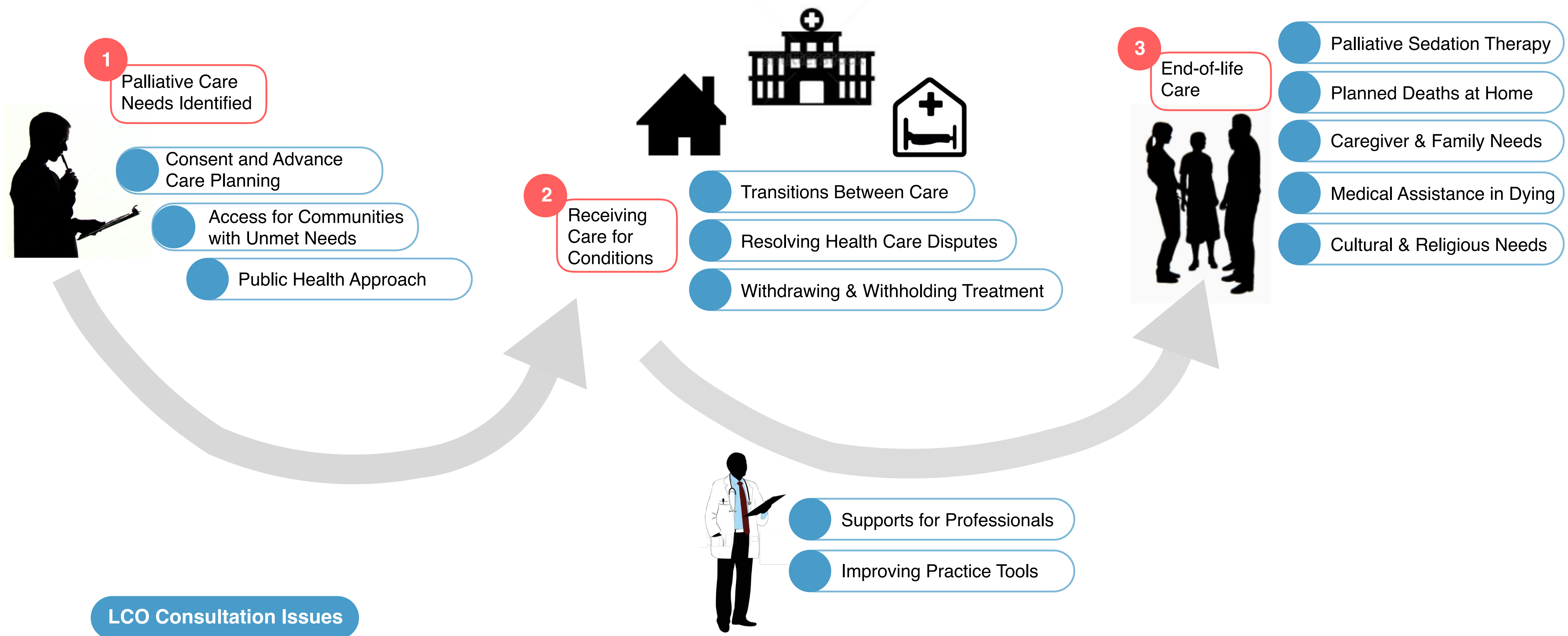
Improving the Last Stages of Life
Map to Consultation Issues



1 Palliative Care Needs Identified

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LCO Consultation Issues

Each issue on this map is explored in our Issue Backgrounders, online: www.lco-cdo.org/laststages

Improving the Last Stages of Life: Issues Backgrounders

LAW COMMISSION OF ONTARIO
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IMPROVING THE LAST STAGES OF LIFE

ISSUE BACKGROUNDER #1 – CONSENT AND ADVANCE CARE PLANNING

What is the Last Stages of Life Project?

The **Law Commission of Ontario** (LCO) is Ontario's leading law reform agency. The goal of our **Improving the Last Stages of Life** project is to identify and recommend law reforms in the "last stages of life." This is a broad and inclusive term that allows us to look at rights and legal issues in end-of-life planning, palliative care, medical assistance in dying, and other issues. An important aspect of this is **Consent and Advance Care Planning (ACP)**, the subject of this backgrounder. This backgrounder is one of a **series of consultation documents** the LCO has developed for this project.

This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

Why is Consent and Advance Care Planning Important in the Last Stages of Life?

Persons in the last stages of life may not have the ability (capacity) to direct (consent) to their health care at all times. ACP can play an important role in these circumstances.

ACP is a process that involves a person identifying and choosing a **substitute decision maker(s)** (SDM), and sharing the wishes, values and beliefs that an SDM must interpret when making decisions on the person's behalf. The LCO has adopted the definition of advance care planning used by the Hospice Palliative Care Ontario Health Care Consent Advance Care Planning Community of Practice (April 2016). Importantly, consent and ACP relies on legislation specific to Ontario. Approaches in other jurisdictions or provinces may be different.

Research and experience has proven that advance care planning conversations improve patient and family satisfaction with end-of-life care. These processes aim to ensure alignment between a person's values and treatment; lessen family distress; decrease hospitalizations and admissions to critical care; and decrease unwanted investigations, interventions and treatments, among other benefits.

If no SDM has been identified and chosen in advance, legislation sets out a hierarchy of people who can act as SDMs. In descending order of rank, the list names: guardians of the person; an attorney named in a power of attorney for personal care; representatives appointed by the Consent and Capacity Board (CCB); a spouse or partner; a child or parent; a sibling; and finally, "any other relative." Together, the *Health Care Consent Act, 1996* and *Substitute Decisions Act, 1992* govern informed consent, advance care planning and substitute decision-making in Ontario.

How does Advance Care Planning work with health care consent?

In Ontario, ACP refers to a specific set of processes and legal issues that can take place at any time, including during the last stages of life. It is therefore important to distinguish ACP from the following:

- **ACP does not constitute consent to treatment.** The law in Ontario states that, except in emergencies, health care providers must always obtain consent from an individual or an incapable individual's SDM, prior to administering treatment, even if the individual has engaged in ACP**.** The law further states that when substitute consent is required, the person's known wishes, values and beliefs must guide the SDMs' decision-making process. If these are unknown, the incapable individual's SDM must interpret the wishes, values and beliefs of the individual.
- **ACP is often confused or conflated with other concepts.** As stated earlier, informed consent and ACP are specific to Ontario's consent legislation. Nonetheless, concepts or approaches that may be used in other jurisdictions – such as "advance directives" or "living wills" – may wrongly be invoked. These are terms which are not legally defined in Ontario, and so can cause confusion. Similarly, terms like "goals of care" can assist both health care providers and decision-makers explore which treatments and care decisions are best aligned with these goals, but as person-focused precursors to informed consent and decision-making.
- **ACP is not the same as "do not resuscitate" or "no CPR" notes.** These kinds of treatment decisions require consent. ACP can be used to identify wishes, values and beliefs to guide SDMs in their decision making. DNR and CPR situations are discussed in greater detail in LCO's Discussion Paper (ch. 6.C) and Issue Backgrounder #4 "Withdrawing and Withholding Treatment."
- **ACP does not replace consent in medical assistance in dying.** The requirement for consent immediately before receiving MAID restricts individuals from making a MAID request in advance through an advance care planning document. This issue of "advance requests" is under review by the Council of Canadian Academies, at the direction of the Federal Government.

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around consent and ACP in greater depth. Specifically, see the discussion at chapter 4.D and 6.B. Please also see the findings and recommendations made in the LCO's recently completed Legal Capacity, Guardianship and Decision-Making Final Report (March 2017).

What kinds of questions is the LCO asking?

The LCO's recent and comprehensive project on Legal Capacity, Guardianship and Decision-Making considered many issues relevant to ACP. This project takes this analysis further, and considers the use of ACPs specifically within the context of the last stages of life. Issues that the LCO is considering include:

- **ACP and decisions about life-saving or life-sustaining treatment.** 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) when, in the health care provider’s opinion, life-supports would be of little or no “beneficial” value. Can ACP play a role in decreasing conflicts, including consideration of cultural values, misunderstandings about consent, and disagreements over life-saving treatments? Can specific approaches to ACP better assist SDMs in interpreting values, beliefs and wishes?

- **The development of better consent and ACP tools and information.** LCO has heard widespread concerns about misunderstandings of the law, and shortcomings in its implementation, in relation to the last stages of life. What are your experiences with public information and practice tools? Given the wide array of practice tools that have been created for various contexts, how can the provision of accurate, consistent and meaningful information about consent and advance care planning be ensured? Is it desirable or possible to create standardized practice tools across Ontario? Should there be a systemic approach that better supports the consistent use of legally compliant terminology, education and enforcement? Can existing efforts be scaled up? Can good communication and goals of care discussion be better integrated into preparing for decision-making? How can institutions, professionals and the public be better supported to obtain meaningful and legally compliant health care consent?
- **Can more be done to support patients?** The process of discussing ACP may include conversations about informed consent and rights that can be confusing. Is there a need for greater or systematized supports to provide information to patients? DO you feel there is an effective way to achieve this, such as a system of providing rights information, or delegating an institution with supporting a strategy for outreach and education? Would SDMs be better empowered if they were obligated to be informed of their roles and responsibilities?

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We’ve also summarized other issues in a Consultation Issues Map and additional Issue Backgrounders.

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
- Watch live and archived webcast consultation sessions
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- Propose an in-person focus group for your community
- Contacting Project Research Lawyer Ryan Fritsch through the contact information below

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #2 – ACCESS FOR COMMUNITIES WITH UNMET NEEDS

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

Why is it important to look at different communities in the last stages of life?

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. But different communities have different traditions, values and expectations to the last stages of life, and thus different needs in terms of access, accommodation, information and outreach. LCO's inclusive approach to defining care in the last stages of life means we must account for diversity in Ontario's communities and regulatory frameworks.

We hope to learn more about these traditions, values and expectations in our consultations.

The LCO also wants to know about the views, perspectives, and values of the people and institutions who govern and implement these laws as professionals, health care agencies or institutions, government and delegated agencies. Our project strives to understand the difficulties they encounter in providing services and supports to persons who are directly affected.

Which communities are affected and what are their needs?

Recent government reviews of palliative care confirm that Ontarians suffer marked disparities in accessing quality care in the last stages of life. Changing demographics and social determinants of health such as age, disability, LGBTQ identity, Indigenous identity, income level, place of residence, mental health and culture can also strongly affect the setting, type and quality of care that Ontarians receive.

These are just a few examples of how different communities may have different needs in relation to the last stages of life:

- **Different medical conditions.** Persons with cancer receive the most publicly funded services for palliative care in Ontario (about 30%). But at least the same proportion of Canadians die from other categories of illnesses, including circulatory and respiratory diseases (about 29%). Multiple sclerosis, amyotrophic lateral sclerosis (ALS), and kidney disease are further examples of progressive illnesses that may affect fewer people, but could develop slowly, and should have access to high quality, personalized care.

- **Ontarians living with HIV.** The onset on HIV-associated neurocognitive disorders (HAND) is younger than those with Alzheimer's disease. The disorder comes as a surprise for many and can trigger concerns for financial planning, the availability of HIV-designated services, and intersecting needs.
- **Persons living with dementia.** Among deaths due to chronic conditions in Canada, Alzheimer's underwent the largest growth from 2000 to 2009 (growing about 25%). About 90% of persons diagnosed with dementia transition from living in the community to long-term care before their death. The important process of health care consent and advance care planning has thus been identified in our project as an important area of the law for this community of Ontarians to better ensure values, beliefs and wishes are made aware.
- **Caregivers.** 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. 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)
- **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, or directly providing counsel, leading prayer, mediating disputes and performing rituals after death.
- **First Nations, Inuit and Metis Communities.** Indigenous peoples are affected by shorter life expectancy, higher rates of chronic conditions and distressing health crises. 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. There is greater need for health care providers to create culturally appropriate and locally designed and controlled palliative care programs.
- **Homeless persons.** 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. Equitable and early access to effective palliative care can be a significant challenge for homeless and vulnerably housed patients. 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.
- **Rural and remote communities.** Diverse communities face unique barriers accessing palliative care, such as rural and northern communities, francophone persons, cultural groups and Indigenous peoples. 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, and a lack of access to medical assistance in dying.

- **Persons with disabilities.** 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. Vulnerabilities are especially felt by persons with diminished cognitive capacity, who may not know their options, or face challenges communicating their needs and concerns. Even where services are accessed, persons with disabilities can have complex care needs which limit the breadth of options available to them.

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) offers a detailed discussion of the law and practices around providing access for communities with unmet needs. Specifically, see the discussion at chapter 2.C and chapter 5.

What kinds of questions is the LCO asking?

The LCO has made efforts to explore how diversity influences the issues under consideration in the project. We hope to learn more about these traditions, values and expectations in our consultations:

- Within the scope of LCO's project, are there any additional affected individuals, communities, and institutions that should be taken into account?
- What has your experience been with the last stages of life as a member or ally of a community of need?
- What law reforms do you believe are needed for communities with unmet needs, and how would such reforms be most effectively implemented in law?

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders.

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #3 – PUBLIC HEALTH APPROACH

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

What is a public health approach to palliative care?

The public health approach to palliative care aims to have palliative care treated and promoted as a matter of broad public interest.

There are many overlapping interests and values between the public health approach and palliative care. Both recognize the limitations of traditional models of health care delivery. 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.

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. The public health approach overlaps with initiatives that go by the terms, "compassionate communities", "compassionate cities", and "health promoting palliative care."

The public health approach 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. This does not mean "offloading" or "downloading" responsibility onto others. Rather, it is understood as an empowerment model that strengthens community capacity for care around these issues.

What are some examples of the public health approach in practice?

Various "compassionate communities" projects have been initiated in Ontario. Pallium Canada and the Hospice and Palliative Care Ontario have established provincial programs and community of practice. A project in Windsor-Essex 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. In other areas, a "Compassionate Cities Charter" is being used by local governments to assist them formulate and achieve related goals.

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. 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.

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. A lack of knowledge or misperceptions can inhibit access to services and supports, and foster misperceptions that view palliative care as a "final option when nothing else is working." 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.

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) discusses the public health approach to palliative care in greater detail. Specifically, see the discussion at chapter 4.C.

What kinds of questions is the LCO asking?

Ontario's various laws that apply to palliative care are in a state of change. A key question for the LCO's project is how the public health approach to palliative care would feature in a regulatory framework for health care planning and delivery, if it were determined to be beneficial for Ontarians.

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.

In this light, the LCO is interested in hearing your thoughts:

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

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders.

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #4 – TRANSITIONS BETWEEN CARE

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

What are the transitions in care 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. But the illness trajectory for each person is unique. People 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.

Why are transitions in care an important issue to consider?

Timely, well-coordinated and appropriate transitions are a crucial part of quality care for persons in the last stages of life. During the LCO's preliminary 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. However, inappropriate or poorly timed transitions increase distress for those who are already in an emotionally charged and difficult situation.

What are some of the issues that arise with transitions in care?

Stakeholders identified numerous examples of inappropriate transitions, including:

- 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

- discharge from hospital to inappropriate settings, such as hotels or shelters
- patients who exceed the hospital limit for palliative care, and may be admitted or transferred back to emergency room services or into a long-term care home
- hospital patients who wish to receive medical assistance in dying (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.
- transitioning between care settings that can be lengthy, confusing and stressful
- family members requesting transfers to palliative care, but being denied the opportunity to do so expediently
- transitions to long-term care for Ontarians with disabilities raises concerns with the perception that long-term care is a form of "re-institutionalization," and that long-term care homes are often not equipped to deliver personalized care for those with complex needs.

Explanations for these issues may not lie in the legal framework. The LCO heard that causes often relate mainly to health care challenges and resource constraints. For example, LCO commissioned research 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. And 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.

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, and the availability of a provincial information and coordination telephone service – 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.

Because palliative care is not planned, managed, delivered or evaluated as a core healthcare program, communication and service coordination barriers between care settings can be another major problem.

What steps are being taken?

The Government of Ontario is currently taking steps to improve the coordination of health care across sectors to ensure that patients experience seamless services. For example, Ontario is seeking to introduce "a bundled care approach" in which 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. The establishment of the Ontario Palliative Care Network and of a provincial palliative care strategy also creates possibilities to strengthen palliative care across all care settings, which might also minimize unnecessary transitions.

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around transitions between care in greater depth. Specifically, see the discussion at chapter 7.B and 6.E. An experts report has also been commissioned by the Law Commission for this project that looks at "Improved care setting transitions in the last year of life".

What kinds of questions is the LCO asking?

The LCO is interested in hearing feedback on steps being taken to address these kinds of issues:

- what are your experiences as a patient or caregiver transitioning between care settings in the last stages of life? How has a transition impacted or accommodated your particular needs?
- are law reform measures needed to improve access, navigational supports and the coordination of care within the health care system?
- what effective strategies, policies or supports for collaboration might look like? are there further measures that would complement announced government efforts?

How can I share my views on this issue?

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ISSUE BACKGROUNDER #5 – RESOLVING HEALTH CARE DISPUTES

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

What kinds of legal disputes arise in the last stages of life, and how are they addressed?

Death, dying and bereavement are highly emotional and important experiences for everyone involved – patients, family, friends and health care providers, alike.

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. Disagreements can take place in multiple care settings about many different matters. Disputes may involve patients, SDMs, family members, health care facility and providers. Some of the most common disputes within the context of the LSL include:

Disputes regarding Consent and Decision Making

Experience has demonstrated that there are many disputes regarding the provision of health care consent during the last stages of life. For example, health care providers and SDMs may disagree about whether life-sustaining procedures should be withheld or withdrawn.

Disputes of this kind can adjudicated by the Consent and Capacity Board (CCB). The CCB is an independent tribunal with jurisdiction over issues raised under Ontario's *Health Care Consent Act* (HCCA). Different individuals can initiate the CCB review process depending on the type of application. For instance, a health care provider can apply to determine if a substitute decision maker (SDM) has complied with the rules for decision-making. Health care providers and SDMs can also apply to the CCB for directions about an incapable person's treatment decisions. Many disputes may also resolve informally among those involved, without resort to the CCB, or where a facility offers their own dispute resolution mechanisms.

A study of CCB decisions concerning a patient's best interests in end-of-life situations identified several themes, including where health care providers suggest that life-sustaining treatments be withdrawn where the SDM disagrees; and where SDMs rely on their own values and religious beliefs in their interpretations of best interest of the patient.

Disputes regarding eligibility for, and quality of, services and supports

When a member of the public believes they received substandard care, or were found ineligible for services and supports, there are several dispute mechanisms in place.

Regulatory colleges like the College of Physicians and Surgeons of Ontario or the College of Nurses of Ontario are required to maintain complaints procedures for members of the public who allege they received substandard care. If the complainant or health care provider wishes to dispute the resolution of such a complaint they can apply to the Health Professions Appeal and Review Board (HPARB). HPARB 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.

Individuals applying for government-funded services that are administered at home or in the community may appeal a refusal to provide them with the level or type of services they requested to the Health Services Appeal and Review Board (HSARB).

Other existing dispute resolution mechanisms

In addition to these mechanisms, Ontario also has the following dispute resolution 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. Practices vary from hospital to hospital. These services may include access to patient advocates, medical ethicists, or involve legal counsel on behalf of the health team.
- Privately retained lawyers and other private patient advocacy services often represent patients and family members.
- Ontario has a number of medico-legal partnerships involving legal aid clinics or law student volunteers who attend at hospitals and other facilities to provide legal information and advice about a wide range of issues, though generally not in regards to patient advocacy within the health facility itself
- The Ontario government has established a Patient Ombudsman intended to "help meet the needs of patients who have not had their concerns resolved through existing complaint mechanisms" and covering public hospitals, long-term care homes and community care access corporations.

What are some issues with dispute resolution?

The LCO has heard a number of concerns regarding these processes. For example:

- **Do Not Resuscitate orders.** 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. As 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).

- **Cases relating to palliative and end-of-life care.** HPARB in particular has heard a significant number of complaints related to delays in providing palliative care, failures to consult family members about transferring a patient to palliative care, discharges from hospital into the community, and failures to communicate the risks of harm associated with treatments. (See also Issue Backgrounder #4, "Transitions Between Care").
- **Access to early alternative dispute resolution (ADR) mechanisms.** 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. However, the LCO is aware that there are various critiques of internal resolution policies and processes. In these circumstances, earlier and expeditious access to ADR may be beneficial.
- **Minimizing the causes of disputes.** The LCO also heard that disagreements could be minimized by getting to their source, such as clarifying the law surrounding the withdrawal and withholding of treatment (see Issue Backgrounder #6, "Withdrawing and Withholding Treatment") and providing accommodation and supports for faith and cultural communities (see Issue Backgrounder #13, "Faith and Cultural Needs").
- **Awareness of resolution mechanisms.** 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. On the other hand, many health care providers expressed reluctance to use 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.

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around dispute resolution in greater depth. Specifically, see the discussion at chapter 4.F and chapter 7.C. Please also see the findings and recommendations made in the LCO's recently completed Legal Capacity, Guardianship and Decision-Making Final Report (March 2017) at chapter 7, "Rights Enforcement and Dispute Resolution: Empowering Individuals."

What kinds of questions is the LCO asking?

The LCO's project is considering a number of related questions about how to improve dispute resolution processes in the last stages of life:

- What strategies, processes or institutions are best suited to quickly or even pre-emptively resolving disputes nearing the end of life?
- How can legal information or education about dispute resolution mechanisms and frameworks be made more relevant, timely and effective in the last stages of life?
- Are there issues that would benefit from greater legal clarity and preempt disputes?

- What kinds of dispute resolution mechanisms do you think are accessible and effective?

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders.

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LAW COMMISSION OF ONTARIO
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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #6 – WITHDRAWING AND WITHHOLDING TREATMENT

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

What is the role of withdrawing and withholding treatment in the last stages of life?

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 **withhold** lifesaving treatment (i.e., CPR) when the situation appears hopeless, or to **withdraw** life-sustaining treatment (i.e., life support) when there is little or no chance of recovery. Aside from medical treatment, assistance with **eating and drinking** also becomes increasingly vital nearing the end of life. These are important – but subtle – distinctions in medical care and practise. Each has different implications in law and policy about who has authority to make decisions, and when.

What kinds of principles, rights or values influence these situations?

Decision-making in these situations is extremely difficult; it relies on confronting and defining our values and emotions. Decision-making in these situations also raises complex issues about the relationship between medical and legal ethics, principles and rights. For example, health care providers may view their role as only providing what they see as clinically beneficial treatment. By way of contrast, patients or family members may believe that they should have the right to request treatments above and beyond those that are clinically beneficial. Patients, family and health care providers may also disagree about what constitutes a "benefit." As a result, decision-making regarding withdrawing or withholding treatments raise important medical and legal questions regarding:

- **autonomy and self-determination**
- **beneficience** (the ethical and professional obligations of a health care provider to alleviate suffering and provide treatment that benefits the patient)

- **non-maleficence** (to refrain from providing treatment that would harm the patient)
- **utility** (refraining from offering or continuing a treatment that is useless or ineffective)
- **distributive justice** (given that no health system has unlimited resources to provide all that is medically possible to everyone), and
- the **value of life** (its intrinsic value in religious, ethical and legal frameworks)

What questions arise in these situations?

In Canada, it is legal for capable persons to refuse life-sustaining and lifesaving treatment and for their substitute decision makers to do so on behalf of a person who is incapable.

The law is also clear that individuals (or SDMs) have the right to refuse life-sustaining treatment. And further, that consent must be obtained to withdraw treatment from a person who is already being treated.

However, the law is less clear – or at least unsettled – as to whether providers can legally *withhold* treatment by simply not proposing it to the patient or SDM from the outset if they believe it would not benefit the patient in the first place. Nor is the law clear if and when patients (or SDMs) can insist on treatment when health care providers do not agree.

The lack of clarity in the law has very important practical consequences. For example, there are many debates on whether health care providers have authority to not offer CPR, or if CPR can only be withheld on consent, or if CPR can be insisted upon by an SDM where it has not been proposed. Similarly, there appear to be outstanding questions regarding decision-making authority to place "do not resuscitate" orders on patient's charts.

Further issues arise regarding the powers exercised by SDMs

Ontario law specifies that SDMs must consider the patient's prior capable wishes, values and beliefs, if known and applicable. If not, then to 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. Ontario's *Health Care Consent Act* does not, however, provide guidance on how these diverse factors should be balanced. The best interests test under the HCCA can result in different outcomes depending on the patient's wishes, values and beliefs, and medical condition.

Moreover, many health care providers told the LCO that the best interests test does not sufficiently address the principles of beneficence and non-malfeasance, and that they should have greater authority to make unilateral decisions about life-sustaining treatment. Health care providers also object to the prospect that they may be required by law to provide treatment they believe contravenes their professional and ethical responsibilities.

Other jurisdictions have taken various approaches. Australian legislation requires consent to place a DNR order, but also allow the withholding of CPR in "acute emergencies" under certain conditions. The UK legislates that physicians are generally entitled to determine the appropriateness of life-sustaining treatment, however, only a tribunal may permit both the withdrawal and withholding of life-sustaining treatment for patients in a permanent vegetative or minimally conscious state.

What about the necessities of eating and drinking?

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. 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 or withdraw consent to treatment, such as life support.

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 legislation governing long-term care and home care be amended to clearly and expressly exclude SDMs from refusing to consent to the provision of food and water?

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around withdrawing and withholding treatment and other life-sustaining practices. Specifically, see the discussion at chapter 6.C, "Decision-Making Authority over Life-Sustaining Practices."

What kinds of questions is the LCO asking?

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.

- 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?
- 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?
- 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?

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders.

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #7 – SUPPORTS FOR PROFESSIONALS

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

What kinds of supports do professionals need in caring for people in the last stages of life?

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.

What are the support needs of health care providers?

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 preliminary consultations.

The existing literature confirms that persons working as health care providers experience a higher incidence of stress and "burnout" than employees in other sectors. 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." 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. At the same time, there is a lack of systemic education and supports for providers' mental wellness.

What legislative workplace protections exist for health care providers?

Several pieces of legislation touch on these issues, but are often limited in some way. For example:

- the ***Occupational Health and Safety Act*** protects employees from health and safety "hazards" in the workplace that could potentially result in harm, but doesn't specifically include workplace environments that may negatively impact employees' mental health
- the ***Workplace Safety and Insurance Act*** was amended in 2016 to better account for the prevalence of post-traumatic stress disorder (PTSD) in first responders, including paramedics and emergency medical attendants. The Workplace Safety and Insurance Board (WSIB) must also now presume that PTSD is work-related, unless the contrary is proven. Still, many health care providers are not covered who might experience workplace distress, such as nurses, social workers and PSWs.
- there may also arise **competing rights** between health care providers and their patients. For instance, a patient of a particular creed may request that care be provided by professional of particular sex or sexual orientation (raising potential discrimination issues), or request that a service provider remove footwear in the home or certain areas of the home (conflicting with health and safety requirements).

What are the support needs of legal professionals?

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.

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.

Across these issues, lawyers have told the LCO they face several issues:

- **Duties to third parties.** The reach of a lawyer's responsibilities might be revised to include other vulnerable persons when essential health care issues are at stake. 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
- **The lawyer's role in assessing capacity.** Lawyers 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.
- **Managing family dynamics.** 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; however, legal professionals expressed a desire for more practical and specific guidance on these issues.

- **Representing children nearing the end-of-life.** The LCO heard that children's voices can sometimes be subsumed or influenced by that of their parents in the process, and health care providers may not assess a child's capacity for decision-making and children may not be informed about their rights. Questions about whether to represent a child or involve child protection or other independent counsel are ones that lawyers find hard to answer.
- **Disclosing information regarding medical assistance in dying**. Lawyers identified two potential gaps in confidentiality provisions: rules on lawyers' conscientious objections and the obligation to provide referrals; and rules that permit lawyers to disclose information if the lawyer believes there is an imminent risk of the client's death – which could lead to the disclosure of sensitive information to, for example, friends or family members.

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around supports for professionals in greater depth. Specifically, see the discussion at chapter 6.F, "Understanding the Experiences of Supporting Professionals."

What kinds of questions is the LCO asking?

The LCO's project is considering the following issues respecting supports for professionals:

- What strategies would be effective to improve health care worker protections, such as improvements incorporated into employment health and safety legislation, into sectoral frameworks such as long-term care homes legislation or the mandate of the local health integration networks, or in Ontario's developing provincial palliative care strategy?
- How can strategies for addressing the needs of health care providers assist with mental and moral stress?
- Do legal professionals require specific education and guidance on matters relating to the last stages of life, and what form might this best take?

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders.

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #8 – IMPROVING PRACTICE TOOLS

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

What is the role for practice tools in the last stages of life?

We refer to the various policies, toolkits and forms for informed health care 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.

Both in this project and LCO's project on Legal Capacity, Decision-making and Guardianship, the LCO has heard 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, and what measures could be taken to improve or standardize practice tools.

What kinds of practice tools are being used in Ontario care settings?

During the LCO's background consultations, stakeholders described practice tools as belonging to several groups, including the following:

- **Levels of care forms:** standardized tick-box style forms regularly used on admission to long-term care homes to record preferences for interventions nearing the end of life
- **DNR Confirmation Form:** official form created by the MOHLTC to instruct emergency responders not to resuscitate a person residing in the community, long-term care, or in other settings like retirement homes, when they are called into the situation. This form is limited to use in these specific situations.

- **DNR and No-CPR orders:** recorded in a patient's hospital chart to document that consent has been given to withhold resuscitation (see below for disputes about legal authority to make these orders).
- **Health care consent and advance care planning policies, guides, forms and kits:** documents that may be available online and used across all care settings, often having a great deal of variation in their format, approach, and legal interpretation
- **Goals of care forms:** forms relating to documenting goals of care that are often used in any form or care setting, including in relation to palliative care.
- **Packaged tools:** usually containing discussion guides, policies, system pathways, and forms on overlapping areas, such as consent and advance care planning, and goals of care.

There is no single practice tool being used for consent and/or advance care planning in Ontario. A study commissioned by the LCO found and reviewed some 100 different sets of forms and policies from different health facilities.

What kinds of issues arise in the use of practice tools?

The widespread use of practice tools demonstrates the intention or desire of health care professionals to improve care and planning, and to achieve patient-centred and legally compliant health care. These can be effective means to obtain and record patients' consent, and for discussing patients' wishes, values and beliefs regarding end-of-life care.

At the same time, the LCO heard that, in Ontario, "Do-Not-Resuscitate", "levels of care," "goals of care" and other such forms are inconsistent across care settings, often misstate the law, use legal terms incorrectly, and are disregarded by some health care providers. This inconsistency can result in confusion among health care providers, drive inappropriate habits, infringe rights to consent, and create difficulties in carrying out the decisions of individuals.

The LCO also heard that many practice tools used in Ontario are adopted from other jurisdictions but have no basis on Ontario health care consent legislation. Such concepts as "advance directives" may not align or reflect Ontario's health care consent and decision-making legislation, and encourage a health care provider to overlook their duty to always obtain consent from a capable patient or SDM.

Finally, the LCO heard that while ethicists and health care providers may be asked to review documents or are retained to manage projects to develop tools, lawyers are not regularly retained or included as part of the teams.

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around professional practice tools in greater detail. Specifically, see the discussion at chapter 6.B. See also the expert paper commissioned by the Law Commission for this project, "Health Care Consent, Advance Care Planning, and Goals of Care Practice Tools: The Challenge to Get it Right." LCO's Issue Backgrounder #1, Consent and Advance Care Planning, also raises relevant questions.

What kinds of questions is the LCO asking?

The LCO was asked to consider strategies to address the kinds of concerns outlined above as they impact upon the last stages of life. We are therefore interesting in learning more about the following:

- How can practice tools achieve the goal of providing accurate, consistent and meaningful information about consent and advance care planning? Is it desirable or possible to create standardized practice tools across Ontario?
- How can legal information or education about the law be made more relevant, timely, and effective for professionals working in the last stages of life? Should there be a systemic approach that better supports the consistent use of legally compliant terminology, education and enforcement?
- How can practice tools do a better job of educating the public, and obtaining legally compliant consent to health care in the last stages of life?

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders.

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #9 – PALLIATIVE SEDATION THERAPY

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

What is 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" that cannot be controlled by any tolerable therapy other than medications that reduce consciousness. The object of this therapy is not sedation itself, but symptom relief.

Palliative sedation therapy is intended to be a proportional response to symptoms, meaning that the level of sedation and duration vary. There are two main forms of palliative sedation:

- **Continuous palliative sedation**, which involves providing therapy until a person dies as a result of the natural course of illness, usually in the last hours or days of life.
- **Respite sedation**, which 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.

What are some of the issues that arise with palliative sedation therapy?

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-malfeasance, autonomy, self-determination and security (for more on those matters see Issue Backgrounder #6, "Withdrawing and Withholding Treatment"). Ethical concerns also arise with palliative sedation therapy for certain symptoms, such as psychological suffering. Most guidelines and policies do not recommend that psychological symptoms be considered sufficient for intervention, except in rare cases.

Proportionality is also a core principle for palliative sedation therapy. Proportionality comes into play when assessing whether palliative sedation should be used from the outset when there are less-invasive interventions that could be effective, and that doses should not be higher than needed to relieve suffering.

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, is thus ethically distinct from the practice of intentional killing. Nonetheless, 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.

What is the 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. 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.

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, and thus requires informed consent from the patient or their substitute decision maker.

In Ontario, various regions and organizations have adopted policies and guidelines to regulate the practice, including the Canadian Society of Palliative Care Physicians, the College of Physicians and Surgeons of Ontario, and the Registered Nurses Association of Ontario. Other jurisdictions, like Quebec, have established a statutory framework for requesting and documenting palliative sedation therapy. This 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.

The LCO has heard that this lack of an overarching framework can lead to complications, like a lack of consistency in operational definitions, a lack of documentation and recording of consent in patient records, limited safeguards to address vulnerabilities, and inconsistent use of terminology.

Where can I get more detailed information on this topic?

The LCO’s Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around palliative sedation therapy in greater depth. Specifically, see the discussion at chapter 6.D. See also the related matters discussed in Issue Backgrounder #6, “Withdrawing and Withholding Treatment”

What kinds of questions is the LCO asking?

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 to formalize the provision of palliative sedation with procedural protections that could describe requesting and documenting palliative sedation therapy, stipulating what must be provided for consent to be "informed", and requiring documentation in a prescribed form. How would this consider existing laws around informed consent and medical assistance in dying?
- elaborating clinical guidelines through a taskforce or network approach (e.g., with the involvement of the Ontario Palliative Care Network or Ministry of Health and Long-term Care)
- requesting that regulatory colleges adopt thorough clinical guidelines.

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders.

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #10 – PLANNED DEATHS AT HOME

What is the Last Stages of Life Project?

The **Law Commission of Ontario** (LCO) is Ontario's leading law reform agency. The goal of our **Improving the Last Stages of Life** project is to identify and recommend law reforms in the "last stages of life." This is a broad and inclusive term that allows us to look at rights and legal issues in end-of-life planning, palliative care, medical assistance in dying, and other issues. An important aspect of this is **planned deaths at home**, the subject of this backgrounder. This backgrounder is one of a **series of consultation documents** the LCO has developed for this project.

This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

The last stages of life and planning for death at home

A majority of Canadians would prefer to die at home. "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. A report commissioned by the LCO found that 41.2% of Ontario residents who died in 2014-2015, died in hospital.

Wishes to die at home can also face practical challenges. It is not always possible for a substitute decision-maker or family member to honor such wishes.

In light of these matters, LCO's background consultation identified two approaches that might better facilitate planned deaths at home: the process of considering and planning for deaths at home, including obtaining informed consent and advanced care planning; and the accessibility of processes to certify that a person has died in the home.

What difficulties do 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. Some people may not know about options like the "Do-Not-Resuscitate Confirmation Form." This is a formal mechanism developed by the Ministry of Health and Long-term care which directs that a paramedic or firefighter will not initiate basic or advanced CPR and will provide necessary comfort measures.

Once 911 is called, emergency responders become involved – such as the police, ambulance and firefighters – as well as the Coroner's office. This can lead to distressing and confusing administrative complications that disrupt the natural bereavement process.

In the alternative, a funeral home may be contacted directly, rather than calling 911. The LCO has heard that funeral services routinely ask family members to obtain a death certificate before they will transport the deceased, but frequent delays in obtaining such certificates can cause suffering for grieving families.

What legal frameworks deal with planned deaths at home?

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). As mentioned above, family and friends are otherwise not required to initiate a police or coroner's investigation when death occurs.

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. In Ontario, death certificates can only be issued by one of three professionals: a physician, nurse practitioner or the coroner. This can again introduce delay. If the deceased remains within the municipality the VSA does not require a death certificate before transporting the deceased. However, the LCO heard that funeral services commonly insist on first obtaining a death certificate, often out of fears for liability where the death was actually suspicious.

Ontario also recently introduced legislation that, if passed, will clarify the operation of the VSA in circumstances involving MAID-related deaths (more information on MAID is available in Issue Backgrounder #12, "Medical Assistance in Dying").

There are two improvised tools that have been created in Ontario to aid expected deaths at home: Expected Death in the Home (EDITH) Protocols and Guidelines from the Office of the Chief Coroner for Ontario.

EDITH protocols evolved as a grassroots response to a perceived gap and are overwhelmingly favored in the palliative care community across Ontario. The 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, thus reducing delay. There is not a single EDITH Protocol for Ontario, and several jurisdictions (including Toronto) do not use them. Several EDITH Protocols have been developed, and they share many common features:

- 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
- confirm that CPR is not included in the treatment plan, including use of the DNR Confirmation form
- identifies the primary health care provider and an alternate with their afterhours contact information, along with information on alternative courses of action should problems arise

The Guidelines of the Office of the Chief Coroner simplify the process of obtaining a death certificate in cases where they have already been called in, and help employees to manage the situation in a timely manner and to avoid investigatory proceedings.

What are the opportunities to improve planned deaths at home?

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. Other jurisdictions, like British Columbia, take a more proactive approach. A provincial protocol and companion legislation allows the patient's physician to complete a form and send it to the funeral home before the death, along with an agreement to complete the death certificate within 48 hours after the death (and thus goes further than Ontario's DNR Confirmation form). 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.

The LCO was also told that it can be 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 option 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.

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around planned deaths at home in greater depth. Specifically, see the discussion at chapter 6.E. For more information also see Issue Backgrounder #1, "Consent and Advance Care Planning".

What kinds of questions is the LCO asking?

The LCO is interested in hearing what you think:

- Would it be beneficial to have a government initiative or formal regulation standardize approaches across Ontario, such as any or all the various aspects of the EDITH protocols?
- Are more formal or proactive approaches, like those used in other jurisdictions, needed to help surrounding family and friends reduce any delay in arranging the attendance of a physician or nurse practitioner after death?
- If you have been involved in a planned death at home, what approaches would have made the process easier on you and your loved ones?

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders.

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #11 – CAREGIVER AND FAMILY NEEDS

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

How do caregivers and families support people in the last stages of life?

Caregivers play in indispensable role in Ontario's health care system. A study commissioned by the LCO estimated that 35,000 persons a year acted as end-of- life caregivers in a private home or long-term care facility. They provide wide ranging assistance across care settings and substantially supplement publicly funded services. Studies show many caregivers perceive their role in a positive light, as a reciprocal process that benefits them and the persons they support. However, there is also reliable evidence demonstrating that negative health, social and financial repercussions of caregiving are common.

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.

What challenges do caregivers and families face?

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. Many caregivers report feelings of worry, anxiety, fatigue, depression, loneliness and being overwhelmed. Almost 1 in 10 caregivers also report financial hardship resulting from their responsibilities including borrowing money, using savings and selling their assets.

How are caregivers and family members currently supported when assisting someone in the last stages of life?

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* (ESA) 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. 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. For employees who are able to take leave, the ESA does not guarantee pay. Ontarians may be eligible for federal EI benefits, including the "Compassionate Care Benefit." But the LCO also heard that 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.

Another challenge is that leave is also limited by a maximum number of weeks within a period of time. A consequence of existing requirements is that caregivers may exhaust their entitlements or may not be able to take leave without interruptions. Continuity in leave for the actual time it takes to care for persons who are ill can therefore be difficult. 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.

Short-term respite provided through the health system and income tax credits are other sources of caregiver support. On the whole, however, stakeholders told the LCO that existing caregiver benefits in Ontario are inadequate.

What about grief and bereavement services?

Grief and bereavement care are understood as 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.

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. The LCO heard that 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.

What else would help caregivers and families support someone in the last stages of life?

The LCO is aware that community organizations in Ontario are advocating for a caregiver allowance, separate from employment regimes. In Canada, Nova Scotia provides such a benefit in the amount of $400 per month. 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" so that employment laws can properly take this role into account.

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around caregiver and family needs in greater depth. Specifically, see the discussion at chapter 2.C and 5.D. An expert report was also commissioned by the Law Commission for this project, "Understanding the lived experience of individuals, caregivers and families touched by frailty, chronic illness and dementia in Ontario."

What kinds of questions is the LCO asking?

Ontario's Fraser Report in 2016 echoes many of the issues the LCO is raising, remarking that "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."

The LCO is therefore interested in hearing what you think:

- What strategies or law reform measures would effectively address the grief, bereavement, employment and support needs of caregivers and family members supporting someone in the last stages of dying?

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders.

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #12 – MEDICAL ASSISTANCE IN DYING

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

How did medical assistance in dying develop in Canada?

In 2015, the Supreme Court of Canada released its landmark decision in *Carter v. Canada*, overturning criminal sanctions against physician assisted dying. 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. In June 2016, the federal government implemented legislation to regulate "medical assistance in dying." "Medical assistance in dying" or "MAID" is now the preferred term in Canada because it recognizes that, in practice, this service is being delivered in teams of health care providers, not only by physicians.

MAID is now an accepted practice across Canada. As of December 2016, media outlets reported that some 744 medically assisted deaths occurred across Canada since legislation went into effect that year, of which 180 took place in Ontario.

How is medical assistance in dying delivered in Canada?

Medical assistance in dying can be delivered in two ways:

- A physician or nurse practitioner can administer a substance that causes death to a person at that person's request.
- 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, pharmacists, and anyone who does anything to aid them, including anyone who aids the patient to self-administer at the patient's request.

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.” These criteria exclude individuals who may suffer as a result of physical or mental conditions, but who are not dying.

MAID legislation also commits the federal government to study three special cases: issues relating to MAID requests by mature minors under 18 years of age; to advance requests or “advance directives” that would authorize MAID when the person became incapable; and to MAID requests where mental illness is the sole underlying medical condition. The government announced in December 2016 that the Council of Canadian Academies will conduct independent reviews related to these specific types of requests and deliver a final report to Parliament in December 2018.

How is medical assistance in dying defined in Ontario?

Because federal legislation serves to create exemption to the *Criminal Code*, it is up to the provinces to define how health care services will be defined on the ground.

In Ontario, the Ministers of the Attorney General and Health and Long-term Care 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.

Several of these professional colleges have now developed guidelines that speak to issues including MAID eligibility, capacity assessments, voluntariness and informed consent, and documentation and reporting requirements.

One particular issue concerns “conscientious objection.” The College of Physicians and Surgeons (CPSO) Policy on MAID, for instance, directs that “Where a physician declines to provide medical assistance in dying for reasons of conscience or religion, the physician must not abandon the patient. An effective referral must be provided.”

Ontario established a Clinician Referral Service to assist physicians in making an effective referral for consultation and assessment for possible medical assistance in dying cases. This includes a roster of physicians willing to provide MAID services.

Neither federal nor provincial legislation compels physicians to provide or assist in providing MAID, and the CPSO has clarified that it does not consider “providing the patient with an “effective referral” as “assisting” in providing MAID.” Nonetheless, some professionals see that as the case and are urging greater clarity on the issue.

Ontario also recently re-iterated its commitment to give patients direct access to a proposed care coordination service for MAID. The system is said to model that in Alberta, which has provincial care coordinators who respond to patient requests for MAID via phone or email. They help patients complete necessary paperwork, find doctors to perform the eligibility assessment, and help arrange the assisted death itself. Some Ontario hospitals have also created their own assisted-death co-ordination teams.

What other steps has Ontario taken to support medical assistance in dying?

Ontario introduced Bill 84, the *Medical Assistance in Dying Statute Law Amendment Act, 2016*, to clarify several issues that fall within provincial jurisdiction. This includes amendments to:

- 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 (see also our Issue Backgrounder #10, "Planned Deaths at Home")
- 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.

Where can I get more detailed information on this topic?

The LCO's Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around medical assistance in dying in greater depth. Specifically, see the discussion at chapter 3.C and 4.E.

What kinds of questions is the LCO asking?

Outside this scope of proposed legislation, the LCO has heard about several additional provincial-level issues related to MAID. These include questions related to:

- transitions between care settings to receive MAID (see our Issue Backgrounder #4, "Transitions Between Care"), and challenges in receiving MAID at home (see our Issue Backgrounder #10, "Planned Deaths at Home")
- 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 (see our Issue Backgrounder #5, "Resolving Health Care Disputes").

How can I share my views on this issue?

A fuller examination of these issues is available in our Executive Summary and Discussion Paper. We've also summarized other issues in a Consultation Issues Map and Issue Backgrounders.

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LAST STAGES OF LIFE

ISSUE BACKGROUNDER #13 – FAITH AND CULTURAL NEEDS

What is the Last Stages of Life Project?

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This document is a brief overview intended to raise issues and stimulate discussion for the purposes of LCO's consultations. This document should not be relied on as a source of law.

What is the role of faith and cultural needs in the last stages of life?

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."

The LCO has chosen to use the terms "faith" and "culture" 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." We further acknowledge that the LCO cannot describe examples of beliefs and practices among Ontario's diverse communities without being reductive.

How does faith and culture influence decisions in the last stages of life?

LCO's discussion paper examines a wide array of cultural and faith practices, and commissioned research adds to this discussion. 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:

- **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.

- **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, and impact on other patients too. Practices may occur at key junctures in the illness trajectory that could require adjustments to procedural routine.
- **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. Family and community members might expect these figures to receive particularly respectful treatment.
- **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.

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.

It is also important to recognize the distinct need for "cultural safety." This term aims to recognize 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. Thus, cultural safety involves awareness about power imbalances between health care providers and Indigenous patients, the incorporation of Indigenous understandings of death and dying, healing practices, traditional foods, spirituality, and language and cultural translation as integral to the provision of quality care.

What is the legal framework for faith and cultural rights in the last stages of life?

Our discussion paper goes examines Canadian and provincial law protecting faith and cultural rights. This can include the *Charter of Rights*, the *Human Rights Code*, as well as other rights and principles relevant to ensuring equality and substantive justice in health care services. Further rights and principles that could apply to faith and cultural communities stem from the Ontario Human Rights Commission 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. Faith and cultural rights are complicated by their connection with capacity and decision-making, and child protection laws.

Ontario's health care system is also fragmented across sectors, meaning separate laws may contain various provisions relating to faith and cultural preferences. For instance, legislation governing long-term care homes establish rights to be placed in facilities and to receive services that respond to preferences based on ethnic, spiritual, religious, linguistic, familial and cultural factors. These rights are balanced by the fact that long-term care is a group living environment, and residents frequently share rooms. Similarly, tenants in retirement homes also have a right to have their “lifestyle and choices respected and to freely pursue [their] social, cultural, religious, spiritual and other interests.” However, as retirement homes are residential tenancies, these rights may not substantially interfere with the reasonable enjoyment of the home for the licensee and other residents.

What are some issues in supporting faith and cultural needs in practice?

The LCO commissioned a research study that offers insights into the adequacy of faith and cultural accommodations and supports in hospitals. 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 association provide guidance, but 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. Currently in hospitals, there are few formal policies on faith and cultural issues. 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. They 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.

Where can I get more detailed information on this topic?

The LCO’s Improving the Last Stages of Life Discussion Paper (May 2017) discusses the law and practices around faith and cultural needs in greater depth. Specifically, see the discussion at chapter 3.C, chapter 5, and chapter 6.G. See also the expert paper commissioned by the Law Commission for this project, “Integrating religious and cultural supports into quality care in the last stages of life in Ontario.”

What kinds of questions is the LCO asking?

There are multiple strategies that could be used to improve culturally competent and safe care in Ontario. Possible solutions that service providers and community members spoke to LCO about include creating educational tools for cultural competence and safety. 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. 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.

- 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?

How can I share my views on this issue?

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