## Law Commission of Ontario Last Stages of Life Public Survey

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## Section 1 - Intro

***Thank you very much for taking the time to share your views.***

This survey is being conducted by the Law Commission of Ontario (LCO) as part of the Improving the Last Stages of Life Project. The LCO is an independent organization that studies laws and makes recommendations to the government about how to make laws fairer, easier to use, and more effective.

***What is the “improving the last stages of life” project?***

We are studying the laws that apply in the “last stages of life”, which includes palliative care and end-of-life care. We are also considering how medical assistance in dying is being implemented in Ontario. Our goal is to make recommendations to government. We want to hear from you about your experiences, and the ways the law can be improved.

***What is the purpose of this survey?***

This survey makes our public consultations accessible to more Ontarians. We will use your answers to help us understand how the law is working. This feedback helps us make recommendations for change in our final report to government.

***Who sees the survey results?***

We will not use your answers for any other purpose outside these consultations. No one except the people at the LCO will be allowed to see the answers to your questions. We will never give out your name or personal information. If we write about your experiences in our reports, we will do it in a way that others cannot identify you.

***What issues does this survey cover?***

The LCO is looking for your views on 6 important issues in the last stages of life:

* Health care consent in the last stages of life
* Advance care planning and goals of care discussions
* Care transitions and planned deaths at home
* Withdrawing and withholding treatment
* Caregiver and family needs
* Medical assistance in dying

You can answer all these questions but you may skip sections that don’t apply to you. This survey will take about 10-20 minutes depending on which sections you choose to answer and how detailed your additional comments are.

***What if I need more information?***

This survey provides a short introduction to the issues. Our website has expanded information about each section of the survey, and links to additional resources. Please see <http://www.lco-cdo.org/laststages>.

***Thank you!***

We appreciate your time. Once you complete the final section of the survey, you may choose to receive more information and participate in future consultations.

If you need any assistance completing this survey, contact the LCO:

Law Commission of Ontario

2032 Ignat Kaneff Building, Osgoode Hall Law School, York University
4700 Keele Street
Toronto, ON M3J 1P3
Fax: (416) 650-8418
E-mail: LawCommission@lco-cdo.org

Local : (416) 650-8406
Toll-free : 1 (866) 950-8406
TTY : (416) 650-8082

## Section 2 – Preliminary Questions

***Let’s get started***

We have a few questions about you before moving on to questions about the last stages of life.

***What is your age range?***

Under 18
18-35
36-54
55-64
65-74
75-84
85+

***In which province or territory do you live? (Note that this survey relates to laws in Ontario, which are different from other provinces and countries)***

Ontario
Alberta
British Columbia
Manitoba
New Brunswick
Newfoundland and Labrador
Northwest Territories
Nova Scotia
Nunavut
Prince Edward Island
Quebec
Saskatchewan
Yukon
Outside of Canada

***Which of the following best describes you?***

Male
Female
Other, please specify (but not necessary) **[TEXT BOX]**
Prefer not to answer

***Do you identify as… (check all that apply)***

… a person with a disability?
… an Indigenous person (First Nations, Inuit or Métis)?
… a member of a visible ethno-cultural group?
… Other, please specify **[BOX]**
None of the above
Prefer not to answer

***Which of the following best describes your interest in last stages of life issues? (Choose all that apply)***

* I am a member of the general public
* I am receiving palliative care or end-of-life care
* I am a family member, close friend, or substitute decision maker for someone who has received palliative care or end-of-life care in the last few years
* I work in health care
* I am an academic, government employee, policy analyst, or other professional with knowledge of or experience in last stages of life issues
* I am a grief counsellor or faith leader / chaplain

**We want to know if this survey has been helpful to you. In your view, how important is law reform to improving the “last stages of life”? (We will ask this question again at the end of the survey).**

1 (not) 2 3 4 5 (very)
I don’t know

## Section 3 – Health Care Consent

The Law Commission of Ontario (LCO) released a report in 2017 looking at capacity, guardianship and substitute decision making in a general context. In this project, we’re asking specific questions about health care consent in the last stages of life.

It is firmly established that the decision-making process requires health practitioners to obtain informed consent before providing treatment. In Ontario, this is a requirement of the *Health Care Consent Act* (HCCA), which provides that consent be obtained from capable patients and otherwise, from their substitute decision-makers (SDMs).

Experience has shown, however, that not all patients or substitute decision makers feel satisfied. Some of the concerns include not having enough information to make informed decisions, not having information in a timely way, feeling pressured to make health care decisions, and care not reflecting what has been communicated. This can be of particular concern in the last stages of life if spiritual, faith, and cultural values are not recognized, or may conflict with medical options being offered.

The LCO wants to ask about health care consent in context of the last stages of life and how it could be improved.

1. As a patient, do you agree that you have a good understanding of providing informed consent for treatment?
	* Strongly agree
	* Agree
	* Neither agree nor disagree
	* Disagree
	* Strongly disagree
2. As a health practitioner, has anyone ever asked you if you understand the process of obtaining health care consent in context of discussing or planning for the last stages of life?
	* Yes
	* No
	* (I am not a health practitioner)
3. Think back to a recent health care decision you’ve made for yourself, or as a substitute for others. Do you agree that you had the information you needed to provide consent and that your decisions were followed?
* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree
1. Have you ever been in a conflict about health care decisions in the last stages of life? What were the circumstances? What would have helped resolve the issue? **[TEXT BOX]**
2. What approaches to health care consent might better support faith, spiritual, cultural or other wishes, values and beliefs in the last stages of life? **[TEXT BOX]**
3. How can institutions, professionals, and the public be better supported to obtain meaningful and legally compliant health care consent? **[TEXT BOX]**
4. Please provide any other feedback you may have related to health care consent. **[TEXT BOX]**

## Section 4 - Advance Care Planning and Goals of Care Discussions

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

“Advance care planning” is a process of reflection and communication. It is a time for you to reflect on your values and wishes, and to let people know what kind of health and personal care you would want in the future if you were unable to speak for yourself. Advance care planning is about having conversations with family and friends, especially your substitute decision maker (SDM) – the person who will speak for you if you cannot speak for yourself. It may also include writing down your wishes, and talking with healthcare providers and financial or legal professionals. More information can be found at [Speak-Up Ontario](http://www.speakupontario.ca/): <http://www.speakupontario.ca/>

The potential benefits of advance care planning include early identification of substitute decision makers, and the ability to clarify wishes, values, and beliefs in relation to care at the end of life, that help to prepare the substitute decision maker to make future health care decisions.

Goals of care discussions are different from advance care planning. While advance care planning focuses on the future and preparing your SDM, goals of care discussions are based on the current context and are discussions with your health care provider(s). Goals of care discussions focus on making sure you understand the nature of your illness, and help healthcare providers (e.g., nurse, doctor, or social worker) understand the goals you have for your current care. They help prepare you and your healthcare providers to make health care decisions.

Health consent, advance care planning, and goals of care are shown in this graphic **[click to see consent graphic].**

Despite the importance of advance care planning and goals of care discussions, experience shows that very few people engage in these processes. About 103,000 Ontarians die each year, but only about 10% died suddenly. Many people who have not yet talked about advance care planning may benefit from doing so.

The LCO wants to ask about your advance care planning and goals of care experience in the last stages of life and how could they be improved.

1. Were you aware of advance care planning before taking this survey?
* Yes **[go to 1.A below]**
* No **[jump to (B)]**

1.A) You answered yes. Where did you hear about advance care planning? **[text box]**

1.B) Do you know who your substitute decision maker would be, if you were not able (capable) to make a decision for yourself?

* Yes
* No

1.C) Have you had conversations with your friends, family and/or substitute decision maker about your wishes, values and beliefs as it relates to future health care?

* Yes **[jump to A]**
* No **[jump to B]**

**Branching Subsection A**

1. You answered yes to the last question.
2. What prompted you or helped you to engage in advance care planning? **[TEXT BOX]**
3. Do you feel that your substitute decision maker or health care provider are aware of your wishes, values and beliefs, and are clear about the decisions you would want to make?
* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree
1. Do you feel that the advance care planning process helped you express your wishes, values and beliefs in relation to end-of-life care, to prepare your SDM to make health decisions for you? (For example: location of care, emergency resuscitation, or withdrawing life support)?
* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree
1. Did you record or share your wishes, values and beliefs, and confirm your substitute decision maker? If yes, how so and with whom? **[TEXT BOX]**
2. How could the process of advance care planning be improved for you, or for others? **[TEXT BOX]**

**Branching Subsection B**

1. You answered no to the last question.
2. What do you think would help you to engage in advance care planning? What are the barriers? **[TEXT BOX]**
3. How would you like to get more information about advance care planning? **[TEXT BOX]**

**Final Subsection (all participants)**

1. What kinds of supports, programs or systems do you think would help improve advance care planning for you or others? **[TEXT BOX]**
2. Have you ever had a discussion with your health care provider about your goals of care?
* Yes **[jump to 4]**
* No **[end of section]**
1. Do you feel that your health care provider has included these goals as part of the treatment plan that they have created for you?
* Yes
* No

## Section 5 - Withdrawing and Withholding Treatment

Many Ontarians have personal experience making decisions about life-sustaining practices. This may be 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.

In Canada, it is legal for capable persons or their substitute decision makers to refuse life-sustaining and lifesaving treatment. The law is also clear that consent must be obtained from persons (or their substitute decision maker) to withdraw treatment from a person who is already being treated. However, the law is less clear – or at least unsettled – as to whether a doctor can withhold treatment in the first place by simply not proposing it, if they believe it would not benefit the person. Nor is the law clear if and when patients/persons (or SDMs) can insist on treatment when health care providers do not agree.

This can have practical consequences. For example, it is unclear whether a doctor has authority to not offer CPR in the first place, or if they need consent to withhold providing CPR. It is also unclear if a substitute decision maker can insist that CPR be provided when it has not been proposed.

Decision-making in these circumstances can also raise complex issues of medical ethics and legal 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 they should have the right to request treatments above and beyond those that are clinically beneficial.

1. Have you ever thought about making a decision about withdrawing or withholding life sustaining measures?
* Yes
* No
1. Have you ever made a decision about withdrawing or withholding life sustaining measures in your role as:
* A patient receiving care or services in the last stages of life
* A substitute decision maker for an incapable person, such as a family member or power of attorney?
* A health care professional, such as a doctor or nurse
* Other (please tell us who)
* No **[jump to 8]**
1. If you wish, please provide some context in which the decision was made: **[TEXT BOX]**
2. Who provided you with information to help you make a decision about your rights? (check all that apply):
* A lawyer
* A community agency
* A health care professional, such as a doctor or nurse
* Someone else at a health facility, such as a social worker or patient navigator
* A counsellor, faith leader or chaplain
* A family member or friend
* A government official
* Written materials or the internet
* Other (please tell us who): **[TEXT BOX]**
1. Did you feel you have a good understanding of your rights under the law?
* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree
1. Do you feel that you had the information you needed to provide consent?
* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree
1. Do you feel that your decisions were followed?
* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree
1. What was the most helpful thing that assisted you in making this decision? **[TEXT BOX]**
2. What do you need to better support your rights, or to help you better understand your rights? How might the law better support faith, spiritual, and cultural views on withholding or withdrawing treatment? **[TEXT BOX]**

## Section 6 - Care Transitions and Planned Deaths at Home

Care in the last stages of life may be provided in a variety of locations. This can include private homes (with or without community based services); long-term care and retirement homes; hospital departments; or residential hospices. (In the questions that follow we will refer to these together as “care locations”).

“Transitions in care” refers to movement between care locations, and also within them. For instance, a patient in hospital may be transferred from intensive care to complex continuing care (for a longer stay) or to a dedicated palliative care unit. Experience shows that a key aspect of quality health care is the smooth and appropriate transitions for persons who are ill, frail and vulnerable as well as for those who support them in navigating the system.

Transitions in care may be unwelcome for other reasons. Studies have found that most people identify “home” as their desired place to die. “Home” may include a private home, residential hospice, retirement home or long-term care home. Despite this, Statistics Canada reports that most people died in hospital (66%), some in the community (24% in the home, hospice, or retirement home), and fewer in long-term care (12%).

The LCO wants to ask about transitions in care and planned deaths at home, and how these experiences could be improved.

1. Has your care, or the care of someone you are assisting, involved transfer(s) between or within different care locations as described above?
* Yes **[Go to 2]**
* No **[jump to 3]**
1. Did any issues or concerns arise as a result of the transfer in care location(s)? What could have made the transition(s) easier, or avoided it altogether? **[TEXT BOX]**
2. Have you thought about planning for a death at home, either for yourself or someone you know?
* Yes
* No
* Unsure what I want to do
1. Have you done any planning for a death at home?
* Yes **[jump to next sub-question]**
* No **[jump to 5]**

Did you encounter any barriers to planning for a death at home, such as legal, medical or administrative issues? **[TEXT BOX]**

1. Not all costs are covered when receiving care at home in the last stages of life, such as medications, non-emergency transfers to hospital, or extra care support.
2. Have you encountered other unexpected expenses like these when planning for or supporting someone to die at home? What were they? **[TEXT BOX]**
3. Do you agree that these kinds of costs could impact your choice to die at home?
* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree
1. Once someone dies at home, delays in obtaining a medical certificate of death may prolong the time before the body can be removed by a funeral services provider. Does the possibility of delays of this sort affect your choice to die at home?
* Strongly agree
* Agree
* Neither agree nor disagree
* Disagree
* Strongly disagree
1. Please provide any other feedback you may have related to care transitions and planned deaths at home. **[TEXT BOX]**

## Section 7 - Caregiver and Family Needs

A study commissioned by the LCO estimates that each year in Ontario, at least 35,000 friends or family members act as end-of-life caregivers in a private home or long-term care facility. Studies show many caregivers perceive their role positively, and as something that benefits them and the persons they support.

Evidence also shows that caregivers may also face negative impacts on their health, finances, jobs, and social relationships. Many caregivers report feelings of being overwhelmed. And almost 1 in 10 caregivers report financial hardship that can mean borrowing money, using up savings, or selling assets.

Caregivers might be eligible for four forms of support under Ontario law. This may include: protected leave from work in some circumstances; financial support through federal employment insurance, if eligible; respite care delivered through the provincial health system; and income tax credits. Ontario’s *Employment Standards Act* also 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, but it does not guarantee pay. 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.

The LCO wants to ask about your experiences as a patient, or as a family member or care giver of someone in the last stages of life, and how supports may be improved.

1. I am a person who (select all that apply):
	* is a friend, family member, or other supporter that has acted as a caregiver to a person in the last stages of life
	* has received support from a friend, family member, or other supporter acting as a caregiver in the last stages of life
	* has thought about what might be involved in supporting someone in the last stages of life, or in receiving support during the last stages of life
	* Other **[TEXT BOX]**
2. When thinking about your experience as a caregiver, or as someone with a caregiver, were there any challenges with employment, such as loss of income or loss of employment? **[TEXT BOX]**
3. When thinking about your experience as a caregiver, or as someone with a caregiver, tell us about other impacts you experienced. For example, unexpected costs, or health care you didn’t feel prepared to provide. Did these impact your ability to provide or receive support from a caregiver? **[TEXT BOX]**
4. When thinking about your experience as a caregiver, or as someone with a caregiver, did you rely on friends, neighbours or community members not funded by government or a charity? Who helped, and what did they help with? **[TEXT BOX]**
5. When thinking about your experience as a caregiver, or as someone with a caregiver, were there opportunities to give the caregiver a break, such as through overnight or daytime respite programs funded by government or a charity? **[TEXT BOX]**
6. When thinking about your experience, were you able to access support for the kinds of issues that come with illness, isolation, and loss? This could include: grief or bereavement counselling, faith and spiritual support, opportunities to socialize, supports for daily living, getting legal and financial affairs in order, or planning for a death at home? **[TEXT BOX]**
7. Are there any other issues you think need to be addressed as a caregiver, or as someone being helped by a caregiver? **[TEXT BOX]**

## Section 8 – Medical Assistance in Dying

In June 2016, the federal government implemented legislation to regulate “medical assistance in dying” (MAID). MAID is now permissible for 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. You can learn more about how Ontario is implementing MAID here: <https://www.ontario.ca/page/medical-assistance-dying-and-end-life-decisions>

The LCO has heard issues about how MAID is available in Ontario. Some of these are concerns about: accessing MAID and where to get information; options for patients at health care facilities that don’t offer MAID; the transfer of frail patients to different facilities that do offer MAID; different medical opinions about eligibility for MAID; the difficult paperwork, and the process of finding an available MAID provider; the administrative burden for MAID providers, including paperwork and travel time; the ready availability of medications throughout the province; better supporting MAID at home; and supporting faith, spiritual and cultural beliefs and practices in health care facilities.

The LCO is therefore interested in hearing your views. The following questions ask about the experiences and views of everyday Ontarians, patients, and caregivers. The final question is open-ended, and is available for feedback from health practitioners or other professionals.

1. Have you ever asked about or started a MAID process, either as a patient or as a caregiver for someone in the last stages of life?
* Yes **[go to A]**
* No **[got to 2]**
1. Who did you first talk to about starting a MAID process?
* Family physician
* Nurse
* Other health practitioner
* Friend or caregiver
* Faith, spiritual or cultural leader
* Called the Ontario Care Coordination Service for MAID
* Other: **[text box]**
1. Where did the person potentially eligible for MAID live at the time?
* Hospital
* Long-term care
* Retirement home
* Hospice
* Family home
* Other **[TEXT BOX]**
1. After asking about MAID for the first time, did you face any barriers to accessing the information you wanted?
* Yes **[Go to C.1]**
* No **[go to D]**

C.1) If you wish, tell us more about the barriers you faced in asking about MAID: **[text box]**

D) If you started the MAID process, tell us about any difficulties you encountered. This may be things like delays, finding an available MAID provider, concerns with paperwork, transfers between facilities, supports for faith, spiritual or cultural beliefs and practices, or other issue. **[TEXT BOX]**

1. When thinking about the last stages of life, many people are unsure about differences between palliative care, end-of-life care, and MAID. Do you feel that you have a good understanding of these differences?
* Yes
* No
* Not sure
1. Who are you most likely to first approach if you have questions about MAID?
* Family physician
* Nurse
* Other health practitioner
* Friend or caregiver
* Faith, spiritual or cultural leader
* Call the Ontario Care Coordination Service for MAID
* Other: **[text box]**
1. Prior to taking this survey, did you know that Ontario offers a 24 hour, telephone-based Care Coordination Service for MAID, available anywhere in the province?
* Yes
* No
1. Health care facilities in Ontario – including hospitals, long-term care, and hospices – may choose not to offer MAID services. In thinking about admitting yourself or someone you care for to a health facility, how likely are you to ask if the facility offers MAID or not?
* Very likely
* Somewhat likely
* Neither likely or unlikely
* Unlikely
* Very unlikely
* Not sure
1. Ontario’s Care Coordination Service for MAID is a 24 hour phone line that provides referrals to available MAID providers anywhere in the province. Following referral, there are many additional steps typically coordinated by the patient, caregiver, or health provider. This can include arranging medical assessments, completing documentation, obtaining medications, and preparing arrangements following death. How important is it to you that a comprehensive service is available to coordinate some, or all steps, triggered by a MAID request?
	* Very important
	* Somewhat important
	* Neither important or unimportant
	* Somewhat unimportant
	* Very unimportant
2. Please provide any other feedback or recommendations you have regarding MAID in Ontario. **[TEXT BOX]**

## Section 9 – Closing Questions

1. Let’s return to our earlier question. Now that you’ve completed this survey, how important do you think law reform is to improving the “last stages of life”?

1 (not) 2 3 4 5 (very) I don’t know

1. Is there anything else you would like to share with the Law Commission of Ontario as it continues to consult on the last stages of life project? This could include things you think are missing from the survey, suggestions to address the different issues raised in the survey, or anything else you feel is an important consideration.

**[LARGE TEXT BOX]**

## Section 10 – Wrap-up Questions

**Some background information about you**

These last few questions help us better understand your background. All responses remain confidential. We will not use your answers for any other purpose than this survey. No one except the people at the LCO will be allowed to see the answers to your questions.

**Which of the following best describes your household income for 2017?** That is, the total income of all persons in your household combined, before taxes?

Under $20,000
$20,000 to just under $40,000
$40,000 to just under $60,000
$60,000 to just under $80,000
$80,000 to just under $100,000
$100,000 to just under $150,000
$150,000 and above
I prefer not to answer

**Do you live in…**

… a remote or isolated community, with a population under 1,000?
… a small population centre, with a population of between 1,000 and 29,999?
… a medium population centre, with a population of between 30,000 and 99,999?
… a large urban population centre, consisting of a population of 100,000 or more

Please enter the first three characters of your postal code: **[BOX]**

**Please check all that apply:**

* I’m interested in receiving information about future consultations in my area
* I would like to receive more information about the Law Commission of Ontario’s Last Stages of Life Project
* I would like to receive more information about the LCO’s future projects

Please provide your email so that we may contact you regarding the above: **[EMAIL SUBMISSION BOX]**

**[BUTTON: COMPLETE THE SURVEY]**

Thank you. Your survey has been received.

**[Graphic for Section 4, page 8]**

