



# Improving the Last Stages of Life

Preliminary Feedback from Law Reform Consultations  
in Ontario

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ICEL2 Conference Halifax  
September 2017



## LCO's Improving Last Stages of Life Project

- ❖ The Law Commission of Ontario (LCO) commenced public consultations in June 2017 to consider law reform issues in Ontario's palliative, end-of-life, and medical assistance in dying systems
- ❖ To date, LCO has conducted 20+ live consultation sessions with 280+ participants
- ❖ This presentation outlines some popular themes and law reform opportunities identified by consultees
- ❖ **These themes are a partial selection** of feedback
- ❖ **These themes are preliminary**. They do not reflect any analysis or endorsement by the LCO as actual or potential law reform recommendations. LCO will issue a formal consultation report sometime in 2018 and request further feedback at that time



# The Law Commission of Ontario

- ❖ The Law Commission of Ontario (LCO) is Ontario's leading independent law reform agency. The LCO is neutral, non-partisan, and independent of government. LCO is supported by Ontario's law schools, the Law Foundation of Ontario, and the Ministry of the Attorney General
- ❖ Law reform initiatives may come from many sources: the public, government, academics, regulators, institutions, industry groups, etc.
- ❖ LCO is mandated to improve the effectiveness, relevance, and accessibility of the law
- ❖ LCO conducts research, undertakes public consultations, and publishes law reform reports
- ❖ LCO's recommendations are received by the Minister of the Attorney General



LAW COMMISSION OF ONTARIO  
COMMISSION DU DROIT DE L'ONTARIO

# Current Projects @ LCO




**Legal Capacity, Decision-making and Guardianship** >

The LCO released its Final Report on Legal Capacity, Decision-making and Guardianship on March 8, 2017.



**Class Actions** >

Ontario's Class Proceedings Act came into force in 1993, with three goals: to improve access to justice, to enable more efficient and effective judicial management of complex cases of mass injury, and to coerce behavioral modification through public accountability.



**Defamation Law in the Internet Age** >

Defamation law is a branch of tort law that attempts to protect a claimant's reputation from harm caused by false statements.



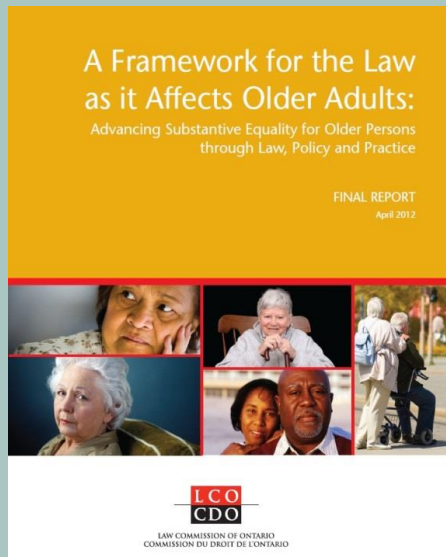
**Improving the Last Stages of Life** >

On September 18, 2014, the Law Commission of Ontario's (LCO) Board of Governors approved a project to consider improving the last stages of people's lives as they approach death.

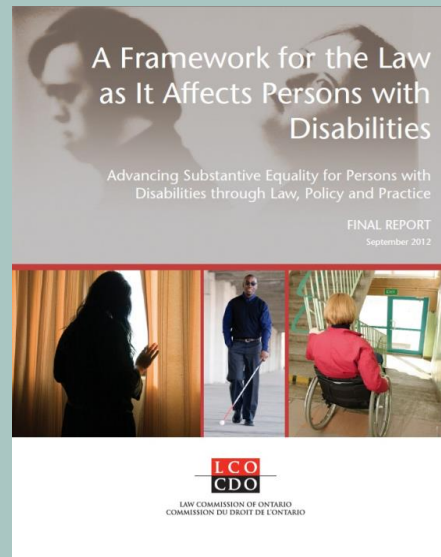


# Improving Last Stages of Life Project

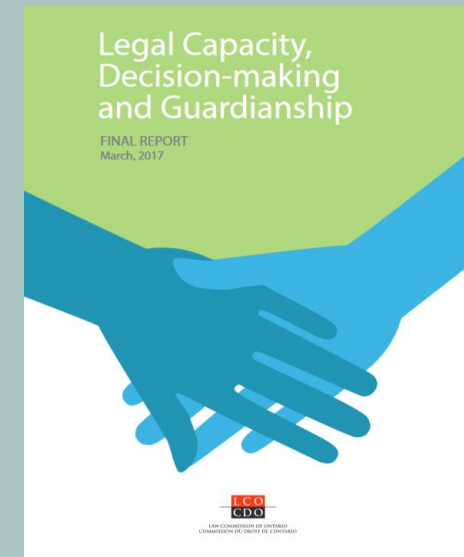
- ❖ LCO began research on the Improving the Last Stages of Life Project (LSL) in 2015
- ❖ The LSL builds on findings and recommendations made in several of LCO's earlier and most recent reports, including:



April 2012



Sept 2012



March 2017

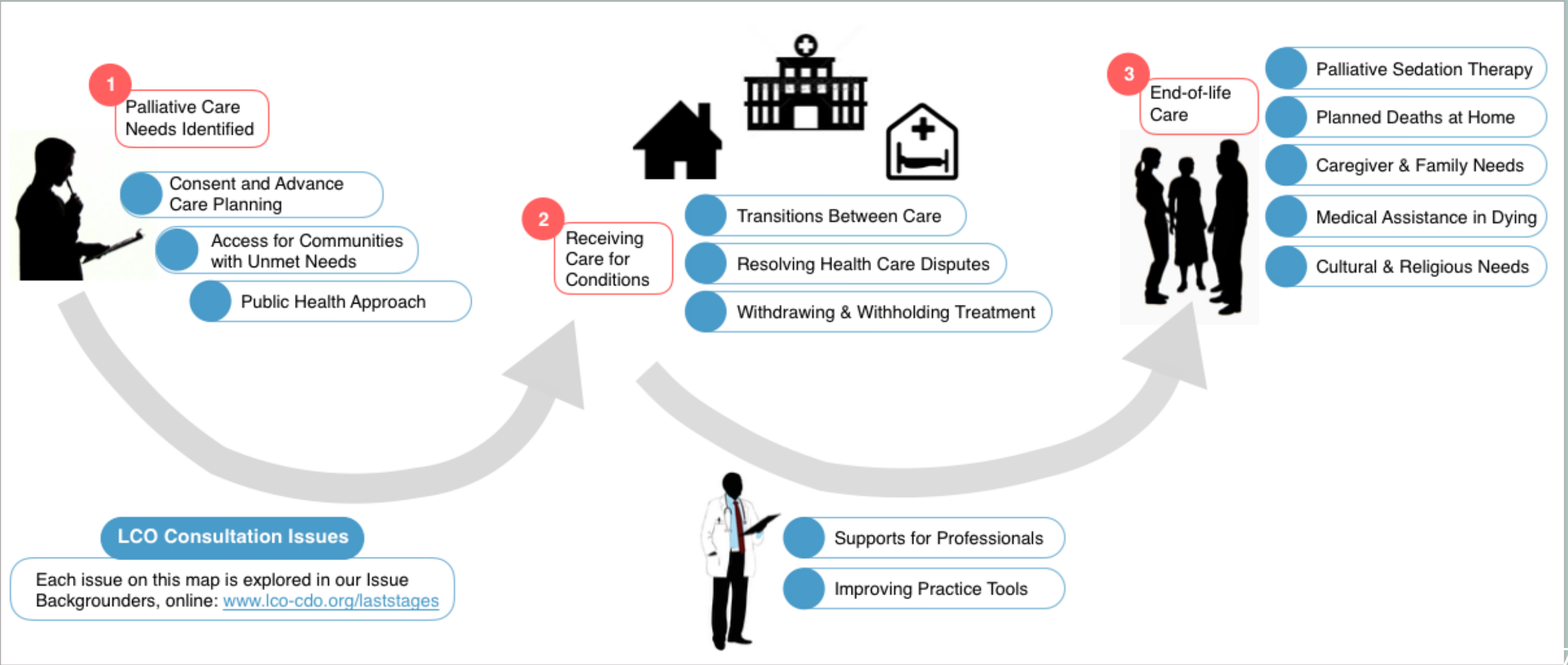
- ❖ The LSL project does not duplicate recent and ongoing government work, including the Canadian Council of Academies assessment further to Bill C-14, or Ontario's Bill 84.

## What do we mean by the “last stages of life”?

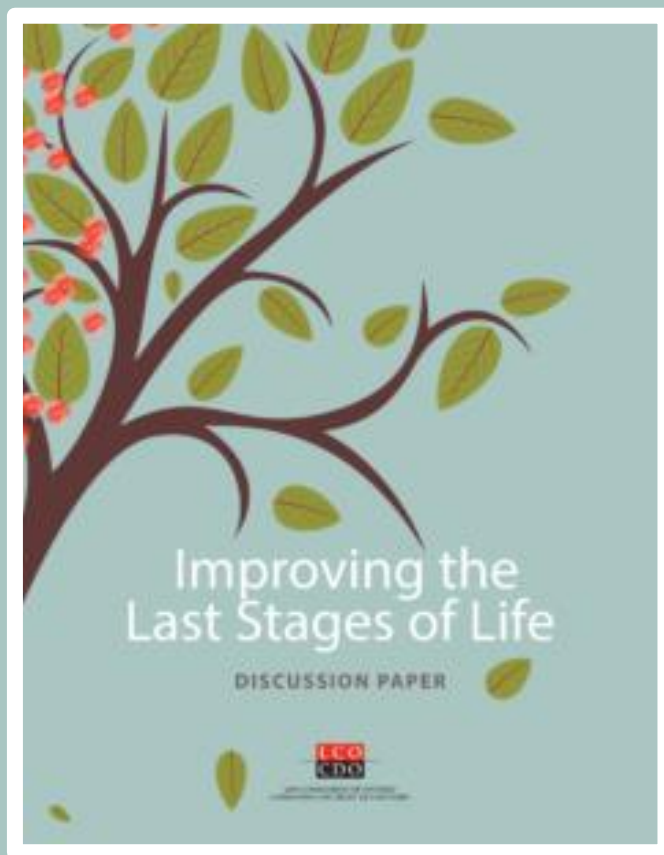
- ❖ LCO adopted “last stages of life” as a broad, inclusive term
- ❖ The project considers legal issues, rights, and experiences in end-of-life care, palliative care, dying at home, and other issues – while recognizing that these are all distinct
- ❖ “Last stages of life” distinguishes the *experience* of persons who are dying – as a particular stage in life – from *established* models of care
- ❖ The project will recommend law reforms, if appropriate



# LCO has identified 13 specific consultation issues



# Improving Last Stages of Life Project



All consultation materials are online  
<http://www.lco-cdo.org/laststages>

- ❖ Public consultations launched in June 2017 and continue through November 2017
- ❖ Public consultations are driven by live in-person sessions, but also include webinars, focus groups, individual interviews, written submissions, and a forthcoming public survey
- ❖ To date: 20+ consultation sessions with 280+ participants
- ❖ Some highlight events include:
  - ❖ A full-day roundtable with 22 faith and spiritual leaders, co-hosted with Ryerson U's Diversity Institute
  - ❖ A focus group with 20 practicing bio-ethicists from Toronto region facilities, co-hosted with UToronto's Joint Centre for Bioethics
  - ❖ A focus group with two dozen members of the Wellington-Waterloo Advance Care Planning Project
  - ❖ A full-day roundtable with two dozen lawyers to discuss legal practices resulting from Bill C-14 (in July 2016)



# Consulting on the 13 Issues

## Groups Impacted

- ❖ Patients
- ❖ Caregivers
- ❖ Health care providers
- ❖ Lawyers
- ❖ Facilities
- ❖ Ethicists
- ❖ Government
- ❖ Administrative Tribunals
- ❖ Academics
- ❖ Advocacy organizations
- ❖ Regulatory colleges

## Our Research to Date

- ❖ Preliminary consultations with over 70 individuals and groups
- ❖ External Project Advisory Group
- ❖ Publication of 7 commissioned research papers
- ❖ 250 page Discussion Paper
- ❖ 13 Issue Backgrounders
- ❖ Consultation Issues Map
- ❖ Webinars
- ❖ Survey App for mobiles, tablets, web

## Laws Impacted

- ❖ Health Care Consent Act
- ❖ Substitute Decisions Act
- ❖ Coroner’s Act
- ❖ Employment Standards Act
- ❖ Occupational Health and Safety Act
- ❖ Public Hospitals Act
- ❖ Long-term Care Homes Act
- ❖ Etc!

## LCO Consultation Process

- ❖ LCO are consulting on these issues across Ontario, now through Fall 2017
- ❖ LCO wants to identify communities of interest, experience, and practice across Ontario who are interested in these issues
- ❖ Please let your colleagues know about our work and invite them to contact us for a consultation

We want to hear from you  
[lawcommission@lco-cdo.org](mailto:lawcommission@lco-cdo.org)

Our consultation website  
[www.lco-cdo.org/laststages](http://www.lco-cdo.org/laststages)

## Theme 1 – Public Health Approach

- ❖ Considerations
  - ❖ The public health approach to palliative care aims to have palliative care treated and promoted as a matter of broad public interest
  - ❖ 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”

### More information



The [Last Stages of Life Discussion Paper](#), ch 4.C.

See also Issue  
Backgrounder 3.

## Theme 1 – Public Health Approach

- ❖ What people are saying
  - ❖ There is a lack of awareness of the palliative care and end-of-life care systems
  - ❖ There is a stigma about talking about and planning for death, which limits the efficacy of legislation and the role of tools like Advance Care Planning
  - ❖ People are often first exposed to these issues amidst a health care crisis with inadequate preparation or forethought
  - ❖ This leads to conflict with family members, treatment teams, and unrealistic demands on health care system

## Theme 1 – Public Health Approach

- ❖ Key Perceived Benefits / Impacts
  - ❖ View that public health approach would reduce conflicts and confusion in care
  - ❖ Change the perception that palliative care is only about last stages of life
  - ❖ Earlier, more proactive, and widespread Advance Care Planning. Pre-empt family conflicts by identifying preferred SDMs; clarifying wishes, values and beliefs; early consulting on religious and spiritual views for greater clarity
  - ❖ People can die at any time! So should have plans in place
  - ❖ Greater understanding about the role of SDMs (and consequences of not having one); educating SDMs on role, obligations and situations that may arise so they are better “ready, willing and able” to act (reducing conflicts / litigation)
  - ❖ Help people understand practical situations, like outcomes of “all heroic measures”, or identifying care options that may remove perceived barriers



## Theme 1 – Public Health Approach

- ❖ Key Perceived Benefits / Impacts
  - ❖ Better inter-professional understanding, for example, lawyers having greater awareness of how to incorporate Advance Care Planning into conversations about Powers of Attorney for Personal Care
  - ❖ increase public understanding of available caregiver tax credits/benefits when caring for sick relatives
  - ❖ Clarifying public awareness of distinction between health care consent, advance care planning, and confusion around “advance directives”

## Theme 1 – Public Health Approach

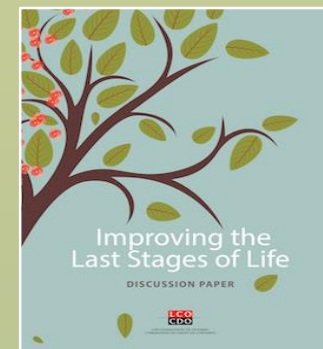
- ❖ Law Reform Opportunities Suggested by Consultees
  - ❖ Adopt palliative and end-of-life care as part of the public health promotion mandate
  - ❖ Consider the model of Ontario's Trillium Gift of Life organ donation campaign and the success it has had by providing people with advisers and opportunities for conversation
  - ❖ Consider model of "compassionate care community charters"
  - ❖ Consider model of "Canadian Compassionate Company" designation. Specifies supports and protections for employees who need flexibility to care for a loved one suffering from a life-limiting illness or at end-of-life
  - ❖ Include as part of the high school curriculum to remove stigma around talking about last stages of life

## Theme 2 – Resolving Disputes

### ❖ Considerations

- ❖ 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.
- ❖ Ontario offers many reactive dispute resolution mechanisms, but there is the sense that more could be done to pre-empt conflicts, and to proactively address frequent sources of conflict

### More information



The [Last Stages of Life Discussion Paper](#), ch 4.F and 7.C. See also Issue Backgrounder 5, and LCOs [Capacity & Guardianship Final Report](#) at ch 7, “Rights Enforcement and Dispute Resolution.”

## Theme 2 – Resolving Disputes

- ❖ What people are saying
  - ❖ Faith and spiritual beliefs are often a source of conflict, but also of confusion, as there may be varying interpretations within a belief system, particularly as medical technology continues to advance
  - ❖ Ontario’s hierarchy of SDMs may not align with cultural views, leading to conflict within families and with care providers
  - ❖ There is confusion about “advance directives”, consent and advance care planning, leading to uncertainty around the use and limitations on mechanisms like “do not resuscitate orders”
  - ❖ Patients and family members are often frustrated by barriers to quickly accessing palliative or end-of-life care; assessments and transitions in care are sources of delay and anxiety; the “medical model” is interventionist (risk)
  - ❖ Lawyers treat Powers of Attorney for Personal Care like wills that don’t anticipate likely scenarios

## Theme 2 – Resolving Disputes

- ❖ Law Reform Opportunities Suggested by Consultees
  - ❖ Access to early alternative dispute resolution (ADR) mechanisms on-site, in-person or via phone. Most disputes are already resolved less formally, but concerns with internal resolution policies, processes, and neutrality
  - ❖ ADR mechanisms could serve multiple related purposes: public health education, rights information, assistance with advance care planning, system navigation and transitions planning, staff education, and facility policy development
  - ❖ ADR mechanisms would reduce knowledge and time burden on treatment team
  - ❖ Facilities could designate services independent of the treatment team, by using bio-ethicists, chaplains, social workers, a roster of local lawyers, etc.



## Theme 2 – Resolving Disputes

- ❖ Law Reform Opportunities Suggested by Consultees
  - ❖ Greater role for or more ready access to spiritual and faith advisers to help resolve disputes, for example, by formalizing a role for the Ontario Multi-Faith Federation
  - ❖ Clarify law withholding of treatment, “best interests”, and conditions under which CPR is performed (or not)

## Theme 3 – Caregiver and Family Needs

### ❖ Considerations

- ❖ LCO's commissioned study estimates 35,000 persons/yr act as end-of-life caregivers in a private home or long-term care facility
- ❖ Studies show caregivers perceive their role in a positive light, but there is reliable evidence demonstrating negative health, social and financial repercussions
- ❖ Many caregivers report feelings of worry, anxiety, fatigue, depression, loneliness and being overwhelmed
- ❖ Almost 1 in 10 caregivers also report financial hardship
- ❖ LCO's preliminary consultations heard that caregivers desire improved services during the course of illness and after a person has died

### More information



The [Last Stages of Life Discussion Paper](#), ch 2.C & 5.D, and Issue Backgrounder 12. See also LCO's commissioned study on the [experience of caregivers](#)

## Theme 3 – Caregiver and Family Needs

- ❖ What people are saying
  - ❖ Provisions under the Employment Standards Act protecting leave of absences or in emergencies are fragmented and unclear, and don't necessarily align with episodic care needs or long-term and continuing care needs
  - ❖ There are several types of leave dependent on relationship, prognosis, length of employment, etc., making eligibility uncertain
  - ❖ There is no guarantee of pay, continuity of leave, not necessarily eligible for EI or compassionate care benefit, and insufficient bereavement leave
  - ❖ Other supports exist but are also fragmented, like income tax credits, and respite provided through the provincial health system
  - ❖ Grief and bereavement care are among the priorities for Ontario's vision of palliative care. But counselling and psychological care are not generally covered by public health insurance, and existing programs are fragmented

## Theme 3 – Caregiver and Family Needs

- ❖ Law Reform Opportunities Suggested by Consultees
  - ❖ Consider a legislated definition of “carer” in employment and compassionate leave legislation to clarify this role and better build programs and services around it
  - ❖ Compassionate leave should be amended to account for the ill individual’s circumstances; should be more flexible and not a fixed number of weeks a year can use
  - ❖ community organizations in Ontario are advocating for a caregiver allowance, separate from employment regimes
  - ❖ Consider formalizing model of “Canadian Compassionate Company” designation
  - ❖ Recognize that grief, bereavement and respite needs are central and ongoing features of caring for sick persons, not supplemental or subsequent to doing so

## Theme 3 – Caregiver and Family Needs

- ❖ Law Reform Opportunities Suggested by Consultees
  - ❖ Personal expenses promote hospitalization. Greater assistance in managing expenses, such as affording medications, capping non-emergency medical transportation costs, and even hospital parking passes would help
  - ❖ Use public health approach or alternate dispute resolution providers to better involve caregivers and families in care planning and educating them on situations that may arise, limits of “do not resuscitate orders” and so forth
  - ❖ Implement formalized, province-wide EDITH protocols with coroner to make planned deaths at home easier to manage
  - ❖ Consider clarifying mandatory disclosure of deaths in the home when re-selling property to remove stigma and negative potential financial impacts of choosing a death at home



## Questions & Discussion

- ❖ What is your own experience with any of these issues, and where do you see opportunities for law reform?
- ❖ How is your province addressing these issues?
- ❖ Has your province implemented measures like these? What is the experience with these kinds of measures?
- ❖ What initiatives are underway that provide a good model?



# Connect with the LCO



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