

## LAST STAGES OF LIFE

### ISSUE BACKGROUNDER #11 – CAREGIVER AND FAMILY NEEDS

#### 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 **caregiver and family needs**, 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.*

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

Caregivers play an 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 Backgrounder](#).

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

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

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