



LAW COMMISSION  
OF ONTARIO



# LAST STAGES OF LIFE **FINAL REPORT**

2021

Law Reform Recommendations  
for Palliative Care, End-of-Life Care,  
and Medical Assistance in Dying

# ABOUT THE LAW COMMISSION OF ONTARIO

The Law Commission of Ontario (LCO) is Ontario's leading law reform agency. The LCO provides independent, balanced, and authoritative advice on complex and important legal policy issues. Through this work, the LCO promotes access to justice, evidence-based law reform and public debate. The LCO evaluates laws impartially, transparently and broadly. The

LCO's methodology is informed by legal analysis; multi-disciplinary research; contemporary social, demographic and economic conditions; and the impact of technology. Every project of the LCO is deeply committed to broad consultations, public engagement, and public education.

The LCO is located at Osgoode Hall Law School, York University, Toronto. In 2018 the LCO celebrated 10 Years of Independence, Engagement, and Impact. More information about the LCO is available at [www.lco-cdo.org](http://www.lco-cdo.org).

## THANK YOU!

Our funders make independent law reform possible. This report benefitted from the support of the following organizations.



## FURTHER INFORMATION

This Final Report summarizes the LCO's findings and recommendations based on extensive consultations and research. Supplementary to this report are LCO's Research Annexes. These include detailed information on our consultation events; a collection of expert commissioned papers; legal research memos; analysis of recent legislation, cases and policy developments; and the archive of consultation materials including our 230-page Discussion Paper. Public material is available on the LCO's website. We invite inquiries related to the other material.

This report is available in accessible formats on the LCO's [Last Stages of Life website](#).

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# MESSAGE FROM THE CHAIR

Everything has changed. And so should Ontario's laws that shape experiences with palliative care, end-of-life care, and medical assistance in dying. This Final Report is the blueprint.

Canadian and Ontarian approaches to the “**last stages of life**” – comprising **palliative care, end-of-life care, and medical assistance in dying** – have changed profoundly in the last five years. What was once taboo is now openly discussed as a public health imperative. What only existed as an *ad hoc* patchwork of services is today regarded as a distinct branch of the health care system. And what was once too polarizing and impolite for public discussion has been transformed by ambitious provincial and federal strategies, and funding commitments.

And yet, after all this, everything has changed again. The COVID-19 pandemic has infected 564,331 Ontarians, and 9,498 have died.<sup>1</sup> Some 3,807 of these deaths occurred in long-term care.<sup>2</sup> Families have been turned away from the dying, health care staff are beyond exhaustion, and communities have endured isolation. Vaccines in Canada are widely available. But vaccines alone will not cure the serious shortcomings in Ontario's systems for providing care in the last stages of life, as laid bare and amplified by the COVID-19 pandemic.

The Law Commission of Ontario (LCO) believes our ***Last Stages of Life: Final Report*** is the blueprint to address these needs. We offer 56 law and policy reform recommendations across five major areas. These would activate the earlier involvement of people in discussing and planning for their last stages of life; better support the professionals and paraprofessionals who provide care and advice in the last stages of life; support the families, friends and community

members who act as caregivers; increase access to equitable care for vulnerable communities of unmet needs; and help resolve disputes by making rights-based information and services more effective and faster.

Our province-wide consultations confirm these recommendations as timely, thoughtful, and very much needed. Our work reflects the expertise and experience of the 850 Ontarians we heard from; the 74 consultation sessions we convened; and the nearly 600 pages comments submitted by the public. This report should be read alongside our complimentary report, [\*Last Stages of Life for First Nation, Métis and Inuit Peoples: Preliminary Recommendations for Law Reform\*](#).

The LCO's contributions to these discussions is unique. We are a neutral, non-partisan, non-governmental law reform agency. We take the time to research and consult independently, exhaustively, and through evidence-based insights. Our track record in this regard is strong. Our recent reports examine the impact of [AI on the justice system](#); fostered the first major update to Ontario's [class actions law](#) in 25 years; improved access to justice for those [resolving small estates](#); and are a leading voice in the Canadian discussion on modernizing [defamation law](#) in the age of the internet.

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**Raj Anand**

**CHAIR, BOARD OF GOVERNORS**



# LAST STAGES OF LIFE PROJECT

## OVERVIEW

Ontario's population is living longer, managing more chronic conditions, and are engaged as caregivers like never before. The law must reflect this reality.

The LCO's Last Stages of Life Project reviews the ways in which Ontario's legal and policy framework shapes the rights, choices, and quality of life for persons who are dying and those who support them. Our research and public consultations confirm that what we have termed **"the last stages of life"** – those hours, days, weeks, months and even years comprised of **palliative care, end-of-life care, or accessing medical assistance in dying** – is a distinct approach in health care, marked by different legal needs. The LCO makes 56 recommendations for law and policy reform to foster a coherent legal continuity between medical care, dying as a personal and community process, and the event of death. We believe these reforms, if enacted, will better reflect the lived reality and needs of everyone who has experienced, is experiencing, and ultimately will experience the last stages of life.

The timeliness of these recommendations arises from the need for our law to reflect a changing province. In the last 20 years, care in the last stages of life has gained prominence as a distinct stream of the broader health care system. Ontario is not alone among Canadian and international

jurisdictions in grappling with the increasing demand and unique legal issues arising with care in the last stages of life. The last five years have witnessed a flurry of commitments: national and provincial strategies, revised policy frameworks, new funding announcements, new goals, and transformative decisions of the Supreme Court of Canada.

The pace of these developments match dramatic demographic shifts defining a new normal across Canada. The population is aging, living longer, and requiring more chronic care.<sup>3</sup> Familial caregivers are raising children while increasingly caring for frail parents. Families are also more likely to live further apart and lack leave time or benefits, due to the growth of precarious work and self-employment. Simultaneously, nearly 30% of Canadians live alone – the highest proportion in history.<sup>4</sup>

These demographic shifts bring additional challenges. More medical support is provided at home, but it often downloads daily care and administrative burdens onto caregivers. Hospice care has expanded significantly, with ongoing commitments to add hundreds of more hospice beds over the coming years.<sup>5</sup> More health care professionals are working with patients who are in their last stages of life, creating new professional stresses, contributing to workplace injury and team burnout. And greater recognition of the diversity in cultural, spiritual, and Indigenous beliefs are changing expectations of "a good

death,” and how health and community care systems will better support it.<sup>6</sup>

At the same time, there is evidence that Ontarians are reembracing death as a natural and social phenomenon, not only a medical one. For instance, there is an emerging preference among Ontarians to die at home.<sup>7</sup> Further, a large majority of hospitalized elderly Canadians report wishes for comfort measures nearing the end of life, rather than life-prolonging interventions.<sup>8</sup>

Our report confirms that the law has not kept pace with these changes. Many will experience this “law lag” as a series of gaps or silences that provide them with no aid; which fail to support proactive planning and pre-empt disputes; which create frustrating barriers between unaligned services; and which subject them to outdated policies, inconsistent criteria, and unjust outcomes.

This project seeks to address the experiences of everyone involved in the dying process, including individuals, caregivers, health care institutions, health care professionals, government, other professionals and paraprofessionals (including lawyers and personal support workers), and community organizations. Our goal is to identify and recommend law reforms that are concrete and responsive.

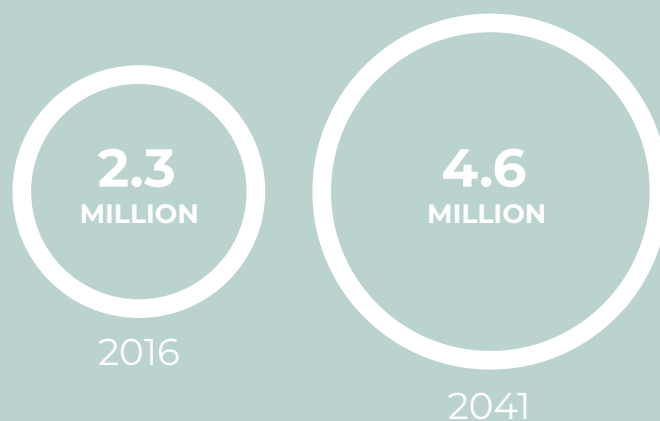
## DEFINITIONS



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

In this project the LCO adopted a unique definition of the “last stages of life.” We selected this term to distinguish the experience of persons who are dying as distinct from established models of care that may be beneficial during the dying process. The “last stages of life” is therefore intentionally broad and inclusive of palliative care, end-of-life care, and medical assistance in dying. We accordingly use the term “individuals in their last stages of life” where it applies broadly. Where applicable, we distinguish between “palliative care”, “end-of-life care” and “medical assistance in dying” (MAID) separately.

## ANTICIPATING TRENDS...



The population of seniors (65+) in Ontario is projected to almost double by 2041, and the population share will grow from 16.4% to 25%<sup>9</sup>

# LAST STAGES OF LIFE PROJECT

## OVERVIEW OF FINDINGS

### **Activating Involvement**

Ontarians are eager to be more actively involved in “living their rights” and engaging in discussions about palliative care. At the same time, the LCO heard a great deal of frustration. Members of the public, health care practitioners, and lawyers were uncertain about applicable laws and rights; how laws and legal rights should be interpreted and applied; who best to talk to about these issues; and how forward-looking medical considerations intersect with practical legal instruments. Given these challenges, the LCO has identified three promising avenues for change: strengthening engagement in person-centred conversations about advance care planning (ACP) and goals of care (GOC) throughout a person’s illness and last stages of life; adopting a public health approach to the last stages of life; and establishing a more consistent and holistic definition for palliative and end-of-life care aligned across important health and other support services.

### **Better Supports for Professionals**

More health care professionals are working with patients in their last stages of life, creating new stresses and contributing to workplace injury and team burnout. National and provincial medical associations have been ringing alarm bells for years about the personal toll exacted on health care practitioners. The COVID pandemic has only expanded the number of practitioners exposed to frequent death, making the experience unique to palliative care providers more widely evident. Legal clarity can help protect them. The LCO makes several recommendations that would: define a distinct class of coverage for workplace safety and occupational health supports to health care practitioners dedicating the majority of their practice to care in the last stages of life, or in critical incident health care services; expand the definition of “mental illness” eligible for coverage; and improve ease of access, and as-needed intermittent access, to mental health treatment, supports, and respite and recovery time.

### **Better Supports for Caregivers**

It is estimated that there are more than 3.3 million caregivers across the province — defined as people who provide support to loved ones without pay for many reasons, including frailty, palliative care, long-term illness, physical or mental disability or age-related conditions. It can be a demanding task: caregivers provide personal care, physical support, basic medical procedures, schedule appointments, translate information, and manage financial and legal responsibilities. Two-thirds admit they had no choice but to assume the work of caregiving and many face impacts on their employment. To better support caregivers, the LCO makes a series of recommendations that would: make workplace leave supports for family caregivers more flexible, extend to children, and provide additional coverage for respite care and those in the high-needs home care category; relieve administrative burdens; and encourage the development of supports to a class of contractually, self-employed, or precariously employed caregivers.





## **Supports for Communities with Unmet Needs**

The needs of specific groups are unique and deep. In the last stages of life they must be accommodated by design, protected from discrimination, and assured equal access to care. The LCO makes recommendations that would improve the last stages of life for groups including incarcerated individuals; persons experiencing care in transition and the home; children receiving palliative care; equity seeking groups and isolated individuals including Ontarians living with HIV, homeless and under-housed persons, and immigrant and refugee communities; and those who face challenges and barriers to equitably accessing MAID.

## **Resolving Disputes**

Death, dying, and bereavement are highly emotional and important experiences for everyone involved. Conflicts in the last stages of life may revolve around health care decision-making, a preference for treatment, or concerns about the quality of care being provided. The LCO makes several recommendations to reduce and better resolve conflicts in the last stages of life, including: introduction of a systemic, on-demand rights information and informal mediation services in conflicts among patients, substitute decision makers, health care providers, and health care facilities concerning patients in their last stages of life; expanding the mandate and jurisdiction of the Consent and Capacity Board to meet the needs associated with an aging population and increasing frequency of legal conflicts in the last stages of life; expedited timelines for disputes involving the last stages of life, including before the Superior Court of Justice; and better ensuring the Public Guardian and Trustee is equipped to support an increasing number of clients in the last stages of life.

“DYING IS NOT AN END.  
DYING IS A PROCESS OF LIVING.”

– CONSULTATION PARTICIPANT

# LAST STAGES OF LIFE PROJECT

## OVERVIEW

### What is the scope of this project?

LCO law reform projects share a principle in common with contemporary aspirations for the palliative care system: we aim to promote changes predicated in the concrete experiences, meaningful choices, and rights available to those who use the system. Accordingly, this project follows the pathway taken by individuals in their last stages of life, and those who care for them. This pathway develops in three broad stages, comprising 13 areas. The first stage begins with diagnosis. Issues identified at this stage include discussions about advance care planning, the potential for public health approaches, and equitable access to care for those with unmet needs and inequitable access to care. The second stage is when one is actively receiving care. In this stage legal issues are concerned with resolving disputes, transitions between care settings, and improved supports for health practitioners. The final stage looks at end-of-life supports and legal rules for planned deaths at home, the needs of caregivers and family, and the implementation of MAID supports and services in Ontario.

The project evolved alongside several federal and provincial initiatives related to the “last stages of life.” The LCO avoided duplicating these initiatives while addressing unexamined legal issues. Federal initiatives include *An Act Providing for the Development of a Framework on Palliative Care in Canada*; publication of the subsequent *Framework Report* in 2018; and several amendments to MAID legislation.

Provincial initiatives include reorganizing the

statutory role of LHINs around new “Ontario Health Teams;” implementing changes within the Coroner’s Office to better support MAID and expected deaths at home; and enacting Bill 3, the *Compassionate Care Act, 2020*. The Ontario Palliative Care Network (OPCN) also published the 2019 *Palliative Care Health Services Delivery Framework* (OPCN Framework). The OPCN Framework describes a model of care to improve palliative care in the community and includes recommendations intended to guide the organization and delivery of palliative care.<sup>10</sup> The LCO also relied on our earlier reports regarding capacity and decision-making, and older adults.<sup>11</sup>

### Provincial laws that intersect with the Last Stages of Life.

Legislation and policies affecting the last stages of life in Ontario includes:

- *Health Care Consent Act* (HCCA)
- *Substitute Decisions Act* (SDA)
- *Health Protection and Promotion Act* (HPPA)
- *Long-term Care Homes Act* (LTCHA)
- *Ontario Human Rights Code* (HRCCode)
- *Accessibility for Ontarians with Disabilities Act*
- *Compassionate Care Act, 2020* (CCA)
- *Regulated Health Professions Act* (RHPA)
- *Employment Standard Act* (ESA)
- *Occupational Health and Safety Act* (OHSA)
- *Coroner’s Act* (CA)
- *Patients First Act* (PFA)
- *Professional, institutional, and regulatory standards of health colleges.*

IDENTIFYING NEEDS		<ul style="list-style-type: none"> <li>● PUBLIC HEALTH APPROACH</li> <li>● ADVANCE CARE PLANNING</li> <li>● ACCESS FOR COMMUNITIES WITH UNMET NEEDS</li> </ul>
RECEIVING CARE		<ul style="list-style-type: none"> <li>● TRANSITIONS IN CARE</li> <li>● RESOLVING HEALTH CARE DISPUTES</li> <li>● WITHHOLDING &amp; WITHDRAWING TREATMENT</li> <li>● SUPPORTS FOR PROFESSIONALS</li> <li>● IMPROVING PRACTICE TOOLS</li> </ul>
END-OF-LIFE SUPPORTS		<ul style="list-style-type: none"> <li>● CAREGIVER AND FAMILY SUPPORTS</li> <li>● PLANNED DEATHS AT HOME</li> <li>● MEDICAL ASSISTANCE IN DYING IN ONTARIO</li> <li>● PALLIATIVE SEDATION THERAPY</li> <li>● FAITH, SPIRITUAL &amp; CULTURAL NEEDS</li> </ul>

## What falls outside the scope of the project?

The LCO received advice on several areas where law reform would be duplicative, outside our mandate or premature. For greater clarity, the following are areas outside the scope of this project:

- ➔ Matters of clinical medical practice and education falling outside our mandate as a law reform agency;
- ➔ Ongoing federal and provincial work on MAID, including amendments aligning Ontario legislation with federal law;
- ➔ Recent government authorization for alternative therapy pilot projects, such as those involving psychedelics;
- ➔ Ongoing and evolving litigation over the medical and legal “definition of death;” and
- ➔ Provincial policy choices relating to facilities that choose to opt-out of MAID.

# LAST STAGES OF LIFE PROJECT

## OVERVIEW

### Engaging with First Nations, Métis, and Inuit communities

In October 2020, people in Quebec and across Canada first came to know the traumatic and extremely upsetting events culminating in the death of Joyce Echaquan in a Joliette, Quebec hospital. As reported by international media, the death of the mother of seven, a member of the Atikamekw Nation in southwestern Quebec, “sparked outrage across Canada after a summer in which protests brought systemic racism against the country’s Indigenous people to center stage.”<sup>12</sup> Prime Minister Justin Trudeau was one of many politicians to speak about Echaquan’s death, calling it the “worst form of racism.”<sup>13</sup>

Beginning in 2018, LCO commenced a distinct engagement process with First Nations, Métis, and Inuit communities in Ontario out of the acknowledgement that health care for Indigenous peoples in Canada is in dire need of law reform. Indigenous peoples have shorter life expectancy, higher rates of chronic conditions, an aging population, and distressing health crises.<sup>14</sup> The home and community care needs of Elders and chronically ill community members have significantly increased in the last 10 years.<sup>15</sup> Several Indigenous communities have declared health emergencies.<sup>16</sup> And in the last stages of life, when many Indigenous people prefer to receive care at home and in familiar community settings, most currently die away from those communities in distant hospitals and long-term care homes.<sup>17</sup>

The LCO undertook these engagements with guidance from an Indigenous Engagement Advisory Group. The findings will be published alongside this final report as [\*The Last Stages of Life for First Nation, Métis and Inuit Peoples: Preliminary Recommendations for Law Reform\*](#).<sup>18</sup>

The LCO heard how Ontario’s health care law – and the halo of other legislation that intersects and supports it – largely reflects a colonial history and colonial values which, through the power of law, diminish, alienate, or wholly silence Indigenous culture, practices and laws that may play a role at the end of life.

Our aim is to share what we heard in conversation with Indigenous communities about the specific ways in which colonial law plays a significant role in maintaining an entrenched set of relationships, disadvantages, and barriers to quality and self-determined care for Indigenous persons in Ontario. The LCO views the need to name and explore these concerns not only as questions of law reform, but as the detailed work necessary to begin providing a meaningful account of health law in response to the Truth and Reconciliation Commission of Canada’s *Calls to Action*.<sup>19</sup>

Image:

“The Four Hills” (2021) by Don McIntyre  
[www.copperwolfconsulting.com](http://www.copperwolfconsulting.com)



**THE LAST STAGES OF LIFE FOR  
FIRST NATION, MÉTIS AND  
INUIT PEOPLES:**  
PRELIMINARY RECOMMENDATIONS  
FOR LAW REFORM



**LCO**  
**CDO**

# PROJECT MILESTONES

## ○ Roundtable on Legal Ethics in the Last Stages of Life

The LCO hosted over 30 participants in a Roundtable on Legal Ethics in the Last Stages of Life. The event identified outstanding legal questions from leading health and legal practitioners. These questions helped inform our public consultations. The event was held on the same day Parliament granted royal assent to Bill C-14, legalizing medical assistance in dying.

2016

## ○ Concept and Scope of the Last Stages of Life Project

The LCO began exploring the issues through preliminary consultations with some 70 groups and individuals. This confirmed the public importance and timeliness of the proposed project. An external Advisory Group was struck and the project scope approved by LCO's Board of Governors.

## ○ Discussion Paper Launches Public Consultations

LCO's public consultations took place between May 2017 to September 2018. A detailed exploration of 13 categories of legal issues was provided in an Executive Summary and full [Discussion Paper](#). The issues were more accessibly summarized in a visual Issues Map, short 3-page Issue Backgrounders on each discussion issue, and via a tablet and phone-based digital online public survey.

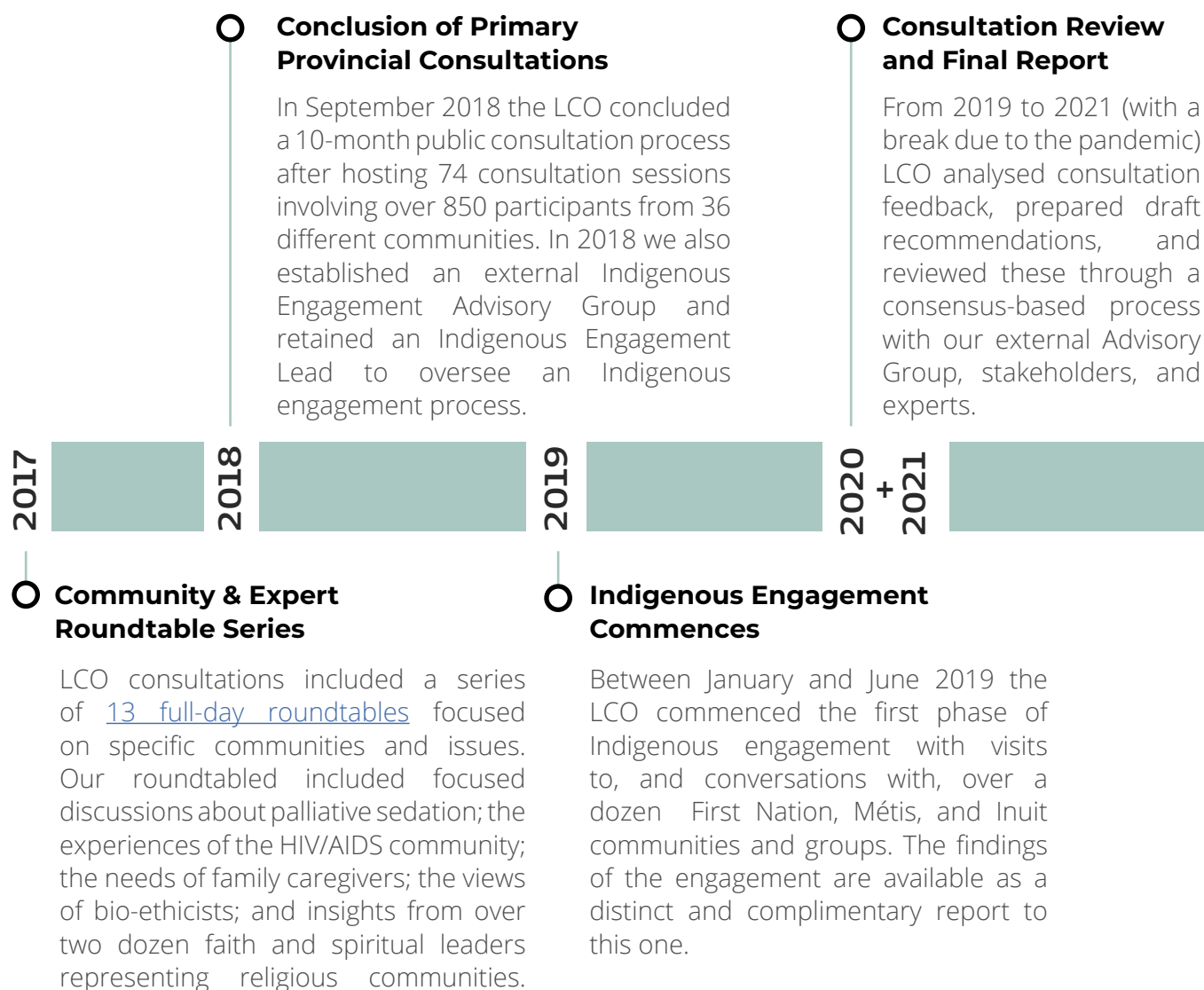
2017

## ○ LCO Publishes Seven Expert Reports

Between August 2016 and April 2017, the LCO released [seven research papers](#) commissioned from external subject matter experts from Ontario and across Canada. Each paper considers a specific aspect of the last stages of life. The papers are publicly available on the LCO's website.



LCO projects rely on rigorous, evidenced-based research; engagement and partnerships with leading institutions and subject matter experts; and broad community consultations that reflect Ontario's diversity.



# OUR CONSULTATIONS ACROSS ONTARIO

## OUR RESPONSIBILITY

Public consultations are the heart of every LCO law reform project. We take the time needed, and do the homework necessary, to meaningfully engage with the representative diversity of Ontarians impacted by the law in question. Among LCO projects, however, the Last Stages of Life was notably unique. As one participant put it to us: “Dying is a process of living.” It is a journey that is both intensely personal and inescapably universal. Every person in Ontario – no matter what their stage of life – has a stake in the dying experience. Life is also complicated. The process of dying involves much more than health care law. It impacts the worklife of family and friends; it impacts the workplace wellness and disability needs of professionals and para-professionals; it invokes substitute decision makers who may be lifelong friends or a unknown public guardian; and it now includes the right to pursue medical assistance in dying. Our consultations had to be simultaneously ambitious and nuanced, rigorous and accessible, forthright and sensitive.

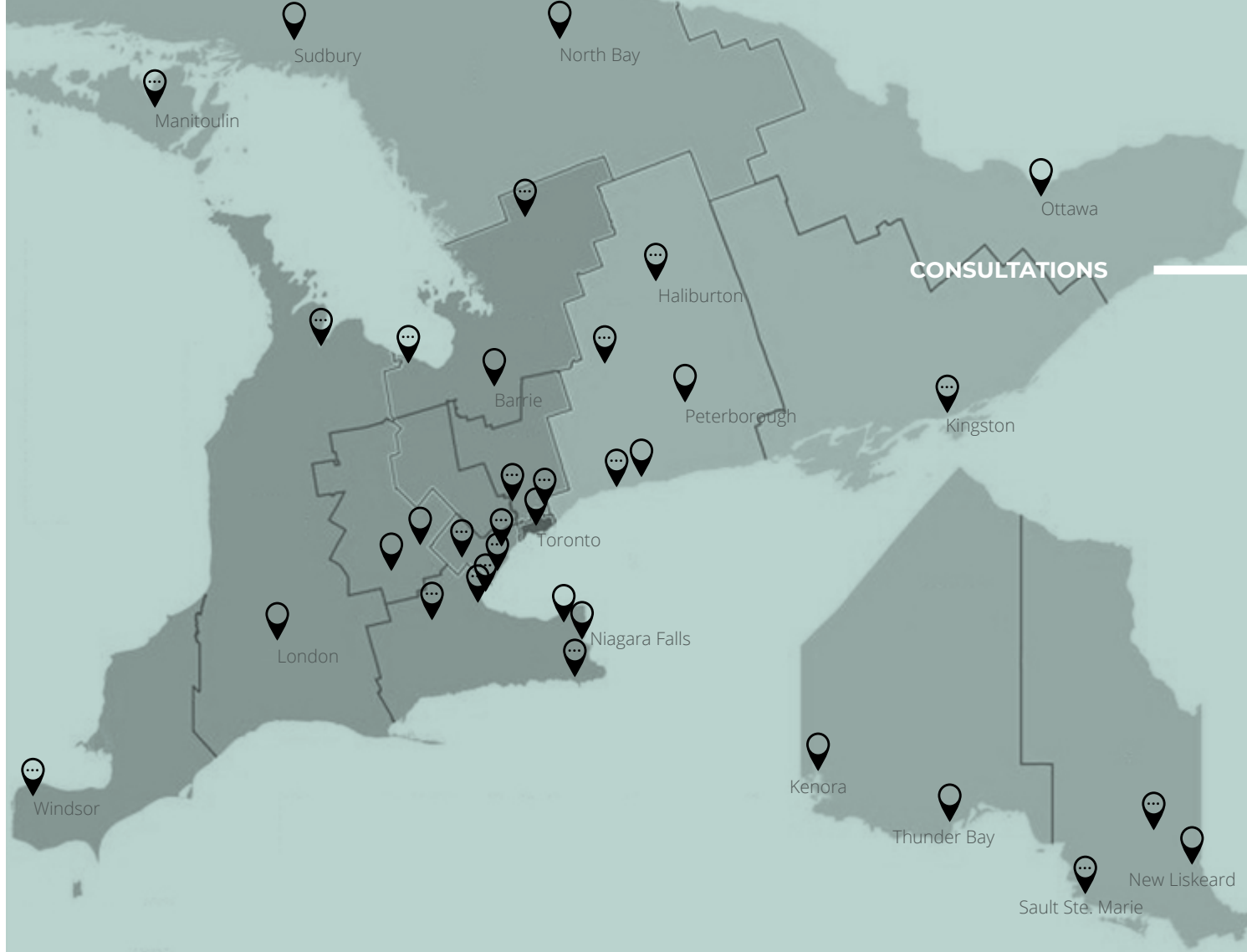
## OUR APPROACH

Our approach is to directly engage the public and discuss the issues they are facing. We then trace these experiences back to their origin in the law (or absence of laws). This generates discussion about options, alternatives, and potential recommendations. We then test our recommendations through continued discussion and consultations with the public and

experts. Our approach acknowledges that every community has a unique perspective to share, particularly those who are vulnerable, with unmet needs and inequitable access to care. We actively sought to hear from communities including different faith and spiritual communities; persons living in correctional facilities; persons experiencing homelessness and who are under-housed; those with chronic illnesses including Alzheimer’s, cancers, and cardio-obstructive pulmonary disease; LGBTQ persons; persons with disabilities; persons with mental health issues and addiction; persons living with HIV/AIDS and those in rural and remote areas.

## OUR METHOD

Consultations were facilitated by our 250-page [Discussion Paper](#) and [seven commissioned expert research papers](#). Engagements included 1-on-1 interviews, focus groups, open public meetings, and even “grand rounds” with dozens of healthcare professionals at major hospitals. We spoke with professional associations, academics, advocates, and leading institutions, both in-person and online. An online survey reached hundreds more and generated hundreds of pages of comments. Some of our largest events were the most dynamic. Some of our smallest events, the most profound. The LCO is deeply grateful for the time generously given by all participants.



## OUR CONSULTATIONS

### IN-PERSON EVENTS

Toronto  
Ottawa  
Peterborough  
Guelph  
Kitchener / Waterloo  
St. Catherines  
London

Niagara Falls  
Sudbury  
North Bay  
Thunder Bay  
Kenora  
New Liskeard  
Oshawa

### ONLINE PARTICIPANTS

Hamilton  
Windsor  
Mississauga  
Markham  
Vaughan  
Oakville  
Burlington  
Etobicoke  
Kingston  
Concord  
Haliburton  
Fort Erie

Barrie  
Brantford  
Whitby  
Milton  
Kawartha Lakes  
Sault Ste. Marie  
Huntsville  
Manitoulin  
Collingwood  
Owen Sound  
Kirkland Lake

# OUR CONSULTATIONS HIGHLIGHTS

The LCO's broad scope of issues, mixed consultation methodology, and open invitation events engaged an unprecedented number and diversity of Ontarians.

The LCO sought to engage the full range of perspectives on palliative care, end-of-life care and MAID issues. This meant we talked to caregivers and family members of patients; community members who surround and support them; faith and spiritual leaders; nurses, doctors and personal support workers; social workers; community care coordinators; patient navigators; bio-ethicists; health departments; advocates and vulnerable communities; large regional and small rural hospitals; hospices; community health centres; academics in law and health care; practicing lawyers; policy leads; communities of practice; and representatives from government Ministries, agencies, and the then Local Health Integration Networks (LHINs) and Community Care Access Centres (CCACs). A full account of LCO's consultations is in Research Annex C & D.

There were many notable consultation events, including "grand rounds" consultations with dozens of physicians, nurses, and patient advocates at hospitals in Niagara and North Bay; partnering with the Ontario Palliative Care Network in a four-session consultation reviewing LCO's entire scope of issues; several sessions with families, supporters and advocates of those

with Alzheimer's; province-wide participation from dozens of member institutions of the Ontario Hospital Association Rural and Remote Leadership Council; Hospice Palliative Care Ontario; AdvantAge Ontario long-term care home operators; spending a day with patients and staff at Haley House, who provide housing and care to incarcerated individuals on compassionate release; meeting with Toronto's PEACH Program, who provide care to underhoused persons; leads at the Ontario Ministry of Health, Office of the Public Guardian and Trustee, Ontario Patient Ombud, and Coroner of Ontario; two extended sessions with the entire palliative care team at Humber River Hospital; and several sessions with members of the Registered Nurses Association of Ontario from across Ontario.



**IN-PERSON  
DISCUSSIONS**



**ONLINE  
SURVEY**



**WRITTEN  
SUBMISSIONS**

## LCO's online survey

220

**COMPLETED  
SURVEYS**

580

**PAGES OF  
COMMENTS**

5280

**QUESTIONS  
ANSWERED**



LCO CONSULTATION  
SESSIONS CONVENED

74

INTERVIEWS, FOCUS  
GROUPS & OPEN EVENTS



## CONSULTATIONS

LCO COMMISSIONED

7

REPORTS FROM SUBJECT  
MATTER EXPERTS



LIVE EVENTS  
HEARD FROM

859

ACTIVELY ENGAGED  
PARTICIPANTS



LIVE EVENTS  
GENERATED

425

PAGES OF DISCUSSION  
FEEDBACK AND NOTES



IN-PERSON, ONLINE  
OR IN WRITING

36

DIFFERENT CITIES AND  
TOWNS PARTICIPATED



LCO ORGANIZED AND  
HOSTED

13

SPECIAL ROUNDTABLES  
WITH EXPERTS &  
COMMUNITIES OF NEED



- **49%**  
Health Care Worker
- **33%**  
Friend or Family Caregiver
- **18%**  
Interested Community Member

### SURVEY TOPIC RESPONSE RATE

Advance Care Planning	89%
MAID	87%
Withholding Treatment	81%
Caregiver Needs	79%
Health Care Consent	79%
Transitions in Care	77%

# OUR CONSULTATIONS

## KEY THEMES

Shared experiences point to root causes and a pathway to meaningful law reform.

LCO's participatory public consultations provided an incredible wealth of detail. But the sessions also tended to surface several broad and recurring themes. What emerged were commonly shared observations and insights about legal issues considered out-of-step with aspirations for improving the system. Opinions would differ on solutions, but most participants generally experienced and identified the same set of underlying problems.

Many of these themes were echoed in LCO's exhaustive program of legal and public policy research. We compiled and reviewed over four dozen reports, reviews, strategies, workbooks, action plans, resolutions, conference proceedings, and other such documents. We also kept up to date on major legislative and policy changes. A selection of leading documents are included in LCO's public consultation materials. See the Research Annex at the end of this report for more information.

These reports affirmed many of the central themes identified during this project. Consistent with our approach to avoid reproducing work done by others, the LCO adopts several findings and recommendations from these reports to inform our own recommendations. Most notably among these are the following:

➔ **The Ontario Palliative Care Network *Palliative Care Health Services Delivery Framework* (2019, OPCN Framework) and *Tools to Support Earlier Identification for Palliative Care* (2019).** These reports describe a model of care to improve adult palliative care in the community and better support their caregivers. While not a policy framework, several OPCN recommendations intended to guide the organization and delivery of palliative care are consistent with the LCO's findings, including: the need for earlier identification across different care settings using preferred identification tools; identifying a designated care coordinator to act as the central point of contact and advocate for patients and caregivers; and legislative re-alignment of staffing and service levels to adequately support patients receiving palliative and end-of-life care.<sup>20</sup>

➔ **The *Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System* (2019).** This Inquiry made several recommendations for improving the long-term care sector, including comprehensive ongoing training relating to the prevention of resident abuse and neglect and staff reporting obligations; an obligation on facilities to cover staff training costs and backfill positions; reduced reliance on casual and agency staffing models; and mandated expansion of funding parameters to meet the array of staff needed to provide quality care.<sup>21</sup>



### ➔ **The COVID-19 pandemic and other Recent Developments (2020-Present).**

The strain introduced by COVID-19, particularly in long-term care, triggered shifts in government policy on several major issues raised in LCO consultations including: professionalization and regulatory practice standards for personal support workers;<sup>22</sup> improved staffing levels and stable employment;<sup>23</sup> legal clarity around familial access to patients, particularly in long-term care and hospitals;<sup>24</sup> and improved care in congregate settings.<sup>25</sup> The provincial legislature also passed Bill 3, the *Compassionate Care Act, 2020*. Among other things, the Act mandates development of a framework by the end of 2021 “to ensure that every Ontarian has access to quality palliative care.”<sup>26</sup>

### Four key themes in LCO consultations

There were four central and recurring themes in our consultations.

### ➔ **Theme 1: The law is focused on health care as recovery. More needs to be said about dying as a process of living.**

Many suggested that palliative care presents a unique challenge to health care law. Palliative care isn’t a discrete treatment. It isn’t a transactional step in the return to recovery or wellness. It is not a temporary condition. It is, rather, a winding path, comprised of good days and bad, within the long-term trajectory of a progressive, life-limiting illness. We heard that health law and other laws do a poor job of accounting for dying as a process of living. Many suggested that “palliative care” should be a distinctive lens on

health care and law that looks beyond short-term, transactional interactions, and accounts for the variable conditions and flexibility needed to accommodate patients – and families – over time. The goal of palliative care is “cares not cures.” The LCO agrees and believes that this lens should inform legal reforms. Notably, the LCO’s views are consistent with recommendations from Canada’s Senate that call for a paradigm shift in favor of an understanding of palliative care that is far broader than the traditional association with cancers and short-term prognosis.<sup>27</sup>

### ➔ **Theme 2: Caregivers need more help amid shifting demographics and changing workplaces.**

Friends and family members play an increasingly active role in supporting individuals in their last stages of life. Estimates are that some 35,000 persons a year in Ontario acted as end-of-life caregivers in a private home or long-term care facility.<sup>28</sup> Almost all (99%) palliative home care clients had family or friends helping to care for them, making it possible for them to stay at home. Unfortunately, approximately 1 in 3 caregivers report serious distress.<sup>29</sup> The LCO frequently heard stories about the law worsening this. For instance, employment supports often focus on short-term leave and require notice periods that aren’t flexible enough for the variability of palliative care.

# OUR CONSULTATIONS

## KEY THEMES

➔ **Theme 3: Not enough people are planning for the last stages of life.** Many organizations are trying to de-stigmatize discussions about the last stages of life and encourage more end-of-life planning. Planning has been shown to improve patient outcomes; 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. Yet fewer than 1 in 5 Canadians have engaged in advance care planning.<sup>30</sup> This, we heard, will only change with more formal supports to help people "live their rights," a term often invoked by health care advocates to emphasize how rights must be proactively empowered so they aren't passively overlooked.

➔ **Theme 4: The needs of specific groups are unique, deep, and must be accommodated by design.** Specific communities with unmet needs are facing profound discrimination and barriers to equitably accessing palliative care, end-of-life care, and MAID. The LCO heard from many of these groups including incarcerated populations; homeless and underhoused; HIV+ community; cultural, faith and spiritual groups; persons with disabilities and mental health issues; those who are socially isolated and alone; and others. Each of these communities have specific and unique needs that can and must be accommodated by design.

### LCO PARTNERED TO CO-HOST SPECIAL ROUNDTABLE CONSULTATION EVENTS

LCO is very thankful for the assistance of many organizations who helped convene specialized consultation roundtables to focus on specific communities and needs. Roundtable consultation events included:

- Legal Ethics and Practice Roundtable at the Law Society of Ontario
- Ryerson University Diversity Institute Multi-Faith Roundtable
- Hospice Waterloo Advance Care Planning Steering Committee
- Joint Centre for Bioethics, University of Toronto
- Ontario Bar Association Trusts and Estates Section
- North Bay Regional Hospital
- St. Catharines Families of Patients Receiving Palliative Care
- Palliative Sedation Experts Roundtable
- HIV/AIDS Community Roundtable with HALCO and Casey House
- Mental Health Legal Committee
- Law & Mental Disorder Association

**"LIVING WELL  
MEANS LIVING  
YOUR RIGHTS. THAT  
SHOULDN'T END  
WHEN PALLIATIVE  
CARE BEGINS."**

– CONSULTATION PARTICIPANT



## CONSULTATIONS

# ACTIVATING INVOLVEMENT

Greater public awareness and earlier planning improves health outcomes and reduces conflict. But people need help to live their rights while at their most vulnerable.

Over the last 20 years, and in the last five years particularly, discussions about death and dying in Canadian society have dramatically changed. In less than a generation, discussions that were once “taboo” or discussed in guarded tones are now often free and open. The LCO’s consultations confirm this shift: of all the topics in this project, concern for more and earlier discussions about “a good death” were the most common. Nearly two-thirds of all consultations, and the greatest number of survey respondents, shared participant’s views and experiences with early end-of-life planning and the need for more public information and engagement.

Ontarians are eager to be more actively involved in “living their rights” and shaping their future. At the same time, the LCO heard a great deal of frustration. Members of the public, health care practitioners, and lawyers were uncertain about applicable laws and rights; how laws and legal rights should be interpreted and applied; who best to talk to about these issues; and how forward-looking medical considerations intersect with practical legal instruments. Given these challenges, the LCO has identified three promising avenues for change: strengthening engagement in person-centred conversations

about advance care planning (ACP) and goals of care (GOC) throughout a person’s illness and last stages of life; adopting a public health approach to the last stages of life; and establishing a more consistent and holistic definition for palliative and end-of-life care aligned across important health and other support services.

ACP can be a tremendously helpful component of palliative and end-of-life care. At present, however, ACP is often either not discussed or misunderstood when it is. This is unfortunate. ACP addresses many of the most important concerns of an individual in the last stage of their life. What does “a good death” look like to me? What are my wishes, values, and beliefs, and how might these help me think about future health care decisions like emergency CPR, different medical interventions, or withholding or withdrawal of treatment? Who do I trust to make decisions for me when I am incapable of doing so? How will my wishes, values, and beliefs be interpreted? How best can I communicate this to others, when I don’t necessarily know what I might be facing?

In Ontario, these issues are addressed, in part, in the *Health Care Consent Act* (HCCA), including the criteria required for a substitute decision-maker

**“WHILE 8-IN-10 CANADIANS THINK IT IS IMPORTANT TO DO ADVANCE CARE PLANNING, FEWER THAN 1-IN-5 HAVE AN ADVANCE CARE PLAN.”<sup>36</sup>**

(SDM) to make “best interests” medical decisions on behalf of an incapable person by relying on their last known wishes, values, and beliefs.<sup>31</sup>

It has been shown that addressing these concerns early and comprehensively is effective. Research and experience prove that ACP conversations improve patient and family satisfaction with end-of-life care.<sup>32</sup> ACP can better 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.<sup>33</sup> Yet for all this promise, ACP is drastically underutilized: eight-in-ten Canadians have given end-of-life care some thought, but fewer than one-in-five have an advance care plan.<sup>34</sup>

In addition to ACP, many LCO consultations discussed a public health approach to the last stages of life. Shifting social attitudes are fostering a greater interest in having a fuller understanding of care in the last stages of life, personal options, and issues to plan for in advance. Many public education initiatives exist to meet this need.<sup>35</sup> As yet, however, there is no formal public health mandate in Ontario to promote a coherent, coordinated, and comprehensive program of public health education, support, or promotion about the last stages of life.

And finally, to better ensure that everyone can have access to quality care that is appropriate for their needs, the LCO heard that “palliative care” should be a distinct framework for law reform. A distinctive framework would focus attention on accessing “cares not cures,” organize eligibility

for supports, services and admission around a standard definition; and foster collaboration between professional care teams and familial caregivers alike.

### **THE RELATIONSHIP BETWEEN HEALTH CARE CONSENT, ADVANCE CARE PLANNING, AND GOALS OF CARE**

The LCO’s commissioned paper notes that “The connections between HCC, ACP and GOC are often missed.”<sup>37</sup> In this project the LCO adopts the Hospice Palliative Care Ontario description of these concepts:

“Advance care planning consists of a series of conversations that help prepare the person and their SDM for future healthcare decisions. They focus on a person’s values, wishes and what is important to them in the context of their health. If the person has an illness, they also involve learning about that illness and what to expect in the future.

ACP conversations are not advanced consent. What distinguishes ACP from “goals of care” (GOC) discussions is the context. While ACP conversations happen in advance of any decision, GOC discussion occur at the time a decision is made. The aim of a GOC conversation is to align treatment with the person’s goals. Prior ACP conversations better prepare the capable person or their SDM for GOC conversations and informed consent.”<sup>38</sup>



# ACTIVATING INVOLVEMENT

## Key themes in LCO consultations

➔ **Theme 1: ACP is widely misunderstood and underutilized in Ontario.** LCO's consultation report and this final report adopt the description of ACP and GOC promoted by Hospice Palliative Care Ontario.<sup>39</sup> In our consultations, the LCO heard from many who were unsure about the role of ACP in helping prepare the person and their SDM for future health care decisions. Many suggested this uncertainty makes it more difficult to normalize appropriate conversations about health care consent, ACP, and GOC in health care. Furthermore, the LCO was told that misinterpretation of the role of ACP can result in its misuse by SDMs, health care providers, or institutions as a replacement for informed consent. ACP does not obviate the health care provider's duty to always obtain consent from a capable patient or SDM, or in any way limit a patient's right to change their mind.

➔ **Theme 2: People need help understanding how their wishes, values & beliefs intersect with legal and medical considerations.** ACP can be difficult to implement in practice. The LCO frequently heard that discussions about "wishes, values, and beliefs" take place in a vacuum with limited to no knowledge of foreseeable medical interventions, and uncertainty about how certain values or beliefs may be interpreted by others or in specific medical situations. Many favored a defined role for professionals in facilitating these conversations.

➔ **Theme 3: ACP is inconsistently understood between health professionals and lawyers.** ACP currently engages two professional solitudes largely working independently of one another: health professionals and lawyers. Among health professionals, HCC, ACP and GOC are at the intersection of law, health care and ethics. But "there appears to be limited consideration for legal issues, and legal involvement is rare."<sup>40</sup> Meanwhile, lawyers rarely have substantive knowledge of the kinds of medical interventions individuals face in their last stages of life and are prone to guide clients with misleading terms like "no heroic measures" or "no invasive procedures." Many people told the LCO that lawyers and physicians should share a commonly coordinated and developed resource to align an understanding across the professions about the HCCA and conversations about ACP and GOC.

➔ **Theme 4: ACP is more effective when supported through faith, spiritual and cultural groups, and communities of shared experience.** ACP may involve discussions about "wishes, values and beliefs" but people often need help formulating their own personal views. We heard that faith, spiritual, religious, and cultural groups can provide considerable assistance in this regard. Such groups, for instance, can provide meaning to terms like "withdrawal of treatment" that may have specific cultural, religious, or spiritual meaning. Participation in these kinds of programs is also beneficial to the faith or cultural group. As one faith leader put it, "Medical technology is evolving much faster than our spiritual doctrine; we have to be part of the conversation."



### Recommendations to define palliative care consistently across services and sectors

#### 01 RECOMMENDATION

The LCO recommends that the Government of Ontario adopt a definition of palliative and end-of-life care to ensure consistent and aligned recognition across related health and other support services, and the laws that govern them

As noted in the LCO's consultation paper, palliative and end-of-life care in the last stages of life is distinct from the "recovery" orientation of most health care, which is generally understood as a linear journey from illness to wellness. Instead, palliative and end-of-life care comprises multifaceted philosophical, clinical, and community dimensions: "palliative care strives to help individuals, families and caregivers address physical, psychological, social, spiritual, and practical issues from the point of diagnosis of a life limiting illness, through the dying process, and into bereavement. It emphasizes quality of life; reinforces the person's autonomy and right to be actively involved in his or her own care; and strives to give individuals and families a greater sense of control. Palliative care includes helping to prepare for and manage choices; cope with loss and grief; treat active issues; prevent new issues from occurring; experience personal self-actualization... [and is] delivered in teams" that may include a diverse array of professionals, supporters, and community caregivers.<sup>41</sup>

Since at least 2011, provincial health policy has sought to reflect this sentiment. Provincial guidance documents such as the *Declaration of Partnership and Commitment to Action* demonstrate both the need to strive for this multifaceted vision of palliative care, and a shared desire to do so.<sup>42</sup> More recently in 2019, the OPCN model of care and service delivery framework cited palliative care as a "philosophy of care" and made recommendations to better identify patients who would benefit from palliative care as early as possible.<sup>43</sup>

But where policy has led, Ontario law has yet to follow. Ontario law does not reflect this conception of palliative care. In Ontario's *Health Care Consent Act*, "palliative care" is only narrowly construed as one among a list of interventions defined as "treatment." To be clear, it is important that "palliative care" is on this list: it gives greater certainty about the kind and scope of medical treatments requiring "informed consent," and has a role in some key legal issues in the last stages of life like withholding and withdrawing treatment, and who is defined as a "patient." A further and tangible example of this issue is the current definition of "palliative care" in the OHIP Schedule of Benefits, which restricts it to care in the last year of life.

Many LCO participants felt current legislation and regulation inhibits the inclusive, aspirational goals for palliative care. Current laws also frustrate attempts to provide a consistent, frictionless continuity of care in the last stages

of life across conflicting eligibility policies, OHIP billing codes, and health providers who are often siloed between acute, long-term, and home care jurisdictions. LCO's consultations, by contrast, indicate clear support to go beyond this narrow conception, and to instead adopt an interpretive framework that would give full life to the multifaceted understanding of palliative care reflected in the current policy consensus.

Accordingly, LCO recommendation 1 states that the Government of Ontario adopt a standard definition of palliative and end-of-life care to ensure consistent and aligned recognition across related health and other support services, and any laws that govern them. The LCO believes that this step is merited based on our analysis of the shortcomings of the law and the themes we heard in our consultations. A better definition of palliative care will promote the following goals:

**Promote earlier identification and access.**

Defining palliative care will diminish the stigma associated with palliative care and the common reticence to discuss it. A definition would promote earlier identification, ease access to assessments, promote greater use of ACP, and expedite access to a coordinated set of related care needs. In our view, a standard definition would also help address how “currently in Ontario, the identification of palliative care needs is often left to the end of life, leaving a significant proportion of Ontarians dying without receiving palliative care.”<sup>44</sup>

**Balance the law at the end of life.** Many faith and spiritual groups felt strongly that palliative care risks being minimized and under-utilized if it does not share a status comparable to that of MAID. Other groups expressed

similar sentiments, including some health care professionals, and persons with disabilities.

**Promote reliable transitions in care across health sectors and services.**

An large number and range of interconnected services and supports hinge on a diagnosis of “palliative,” yet the lack of a standard definition results in inconsistent eligibility within and across home care, acute care, and long-term care contexts. The lack of a standard definition also confounds attempts to codify related initiatives, such as caregiver employment leave or workplace wellness programs.

**Promote equitable access for vulnerable groups.**

Many vulnerable groups advised the LCO that Ontario lacks a consistent approach to confronting discrimination and inequitable access to palliative services. We frequently heard that a standard definition would promote equitable access for all.

**Facilitate interdisciplinary teams, continuity of care, and professional supports.**

The lack of a standard definition of palliative and end-of-life care inhibits the formation of interdisciplinary teams that cut across acute, home, and long-term care silos to ensure continuity of care and patient familiarity. This is compounded in OHIP billing codes and health provider “privileges” at various sites. A lack of a standard definition also makes it difficult to tailor workplace wellness, leave, and whole-team employment supports for those working primarily with patients at the end-of-life that are needed to avoid burnout.

**Greatly improve public health promotion and advance care planning.**

A provincial definition of palliative and end-of-life care would

greatly improve the ability of public health promotion entities to proactively educate their regions and communities about the range of rights and options.

Other provinces have legislated frameworks to achieve these goals and better support the distinctive characteristics, trajectory and dignity of palliative and end-of-life care in the health care system. In Quebec, for instance, *The Act Respecting End-of-Life Care* provides “a framework for palliative care in order to ensure that everyone can have access to quality care that is appropriate for their needs throughout the course of their illness.”<sup>45</sup>

The LCO does not take a specific position on how Ontario should define palliative care and end-of-life care. We note, for example, that the OPCN has done considerable work on the issue.<sup>46</sup> And further, that consultations commenced under Bill 3 consider how best to define palliative care.<sup>47</sup>

The LCO’s consultations heard consistent support for a standard definition of palliative and end-of-life care to promote the following objectives:

- **Holistic model of care:** a definition of “palliative care” could be similar to that in Quebec, which includes “the total and active care delivered by an interdisciplinary team to patients.”<sup>48</sup>
- **Equitable access to care:** a definition of palliative and end of life care makes it a clear choice available to everyone, regardless of their stage of care, living situation, background, or vulnerability.

**“WE NEED TO LOOK AT HOW THEY DEFINE PALLIATIVE . YOU GET ARBITRARY POLICIES, RULES AND LIMITATIONS ON ACCESS. HOSPITAL PATIENTS ARE SUDDENLY NO LONGER PALLIATIVE WHEN THE HOSPITAL WANTS TO TRANSFER THEM OUT.”**

– HEALTH LAW LAWYER



- **The importance of a rights-based approach:** a standard definition of palliative care would promote more effective legal rights, including the distinct role of advance care planning in Ontario, expedited dispute resolution, caregiver rights to employment leave, and the like.
- **Support for caregivers:** a standard definition of palliative and end-of-life care more easily aligns related legislation. For instance, Quebec adopted a definition of palliative care in employment law to “provide patients and their close relations the support they need.”<sup>49</sup>

# ACTIVATING INVOLVEMENT

Recommendations to promote  
advance care planning in Ontario

## 02 RECOMMENDATION

The LCO recommends that the College of Physicians and Surgeons of Ontario and the College of Nurses of Ontario clarify a duty in college standard of practice policies, guidance, and statements that health practitioners and care teams must become knowledgeable about the definitions and relationships between advance care planning, goals of care and informed consent, and must become skilled and engage in these person-centred conversations to address the person's values, wishes and goals.

## 03 RECOMMENDATION

The LCO recommends that the Ministry of Health undertake a systemic review to ensure that health care professionals have specifically designated time and compensation to engage patients and substitute decision-makers in advance care planning and goals of care conversations. This could include, for example, amending the Schedule of Benefits to incorporate a specific billing code for advance care planning and goals of care conversations.

## 04 RECOMMENDATION

The LCO recommends that legal and health care professional regulators work with acknowledged ACP leaders (such as Hospice Palliative Care Ontario and others) to collaborate and jointly develop an inter-professional training program on health care consent and capacity, advance care planning, and goals of care.

## 05 RECOMMENDATION

The LCO recommends that the inter-professional training program be supported system wide through various initiatives that may include, for example, incorporation as standard of practice in hospital and long-term care policies. It could also be provided through industry associations and groups like the Canadian Medical Association, Ontario Bar Association, LawPro and Canadian Medical Protective Association.

## 06 RECOMMENDATION

The LCO recommends that the Ministry of Health fund acknowledged leaders in advance care planning best practices and education (such as Hospice Palliative Care Ontario and others) to continue promoting and supporting best practices.

The LCO heard consistent concerns that the function and role of “advance care planning” in the last stages of life is poorly understood and generally underutilized.

Many of those we spoke with suggested this is a significant contributor to much ambiguity, confusion, misuse, and underutilization of ACP despite acknowledged and ongoing efforts at education provincially and federally. As one hospital physician put it: “ACP is always a topic in our education sessions, but I can’t even give a definition for it.”

The working definition of ACP (promoted through entirely laudable provincial programs like Speak Up) confirm it as conversations that help prepare the person and their SDM for future healthcare decisions. ACP focuses on a person’s values, wishes and what is important to them in the context of their health. In the last stages of life context, ACP would also involve learning about the person’s illness and what to expect as end-of-life approaches. In contrast, GOC conversation occur in the context of an acute health event and involve aligning healthcare treatments and plans with the persons values and goals.

Uncertainty can arise when locating similar terms in the HCCA. For example, the term “wishes” is used in 23 different sections of the HCCA, including as grounds for procedural protections and access to justice mechanisms, such as review before the Consent and Capacity Board. In contrast, the term “values and beliefs” is rather more circumscribed

and exist only in relation to SDM decision-making on behalf of an incapable person where wishes applicable to the circumstance are unknown. In such circumstances, the SDM is acting in “best interests” as defined in three sections related to treatment consent, facility admission, and personal assistance services. The LCO has previously noted the absence of adequate access to justice and procedural protections in relation to best interest decision-making.<sup>50</sup> A review of various ACP tools would indicate that many of these issues and legal mechanisms are not given much consideration, if any.

The silence in Ontario’s law invites unwanted outcomes, like the importation of legal concepts from other jurisdictions that simply have no specific legal meaning here, including: “no heroic measures”, “comfort care only,” “advance directives,” and others. People misunderstand such terms as final and legally binding on health care decisions when they are not. Institutions exacerbate these problems. The LCO heard about facilities requiring written “advance

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FOR IT.”**

– EMERGENCY DEPARTMENT PHYSICIAN

# ACTIVATING INVOLVEMENT

directives” as a condition of admission, or who add such annotations in a patient’s chart that are later invoked as prior consent to withdraw or withhold emergency and other treatments.

Perhaps most significantly, the confusion about the proper definition and parameters of ACP in Ontario also means that ACP may be misused as a proxy for global consent to a wide array of procedures. Strikingly, the LCO even heard that ACP may be used as a standing “do not resuscitate (DNR) order.” One senior physician told the LCO frankly that: “ACP gets translated into DNR in practice.” This runs contrary to the HCCA and can impact all patients, particularly the most vulnerable. The LCO heard many examples of the misuse of ACP by SDMs, health care providers, and institutions as a replacement for informed consent. This is fundamentally wrong. ACP can never obviate the health care provider’s duty to always obtain consent from a capable patient or SDM. This is a crucial area for legal and policy reform.

Failure to engage in ACP was generally acknowledged as a missed opportunity to anticipate and avoid conflicts at several intersections between patients, treatment teams, SDMs, extended family members, and others, resulting in mediation, litigation, delayed treatment, prolonged admission to hospital, and the potential for coercion (from both the treatment team and families). Notably, this has a disproportionate impact on vulnerable Ontarians and communities of experience, who otherwise

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DIFFERENTLY  
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– PALLIATIVE CARE PHYSICIAN

have few opportunities to discuss their unmet needs and preferences, and who are less likely to successfully access legal recourse mechanisms. It is important to get this right. The importance of ACP is only going to grow. Each year more than 284,000 Canadians die, of which some 109,000 are in Ontario. By 2025, that number will increase to over 330,000 annually.<sup>51</sup> In Ontario, demographic projections find that the number of seniors aged 65 and over is projected to almost double from 16.4% of the population today (2.4 million people) to 25% of the population in 2041 (4.6 million people).<sup>52</sup>

Several health care providers told the LCO that a further significant legal problem in palliative care “are substitute decision-makers not knowing what to do, and the failure to broadly engage patients in meaningful ACP is related to that.”

To address these concerns, the LCO makes a series of recommendations that would establish



and support a professional regulatory standard for ACP among health practitioners working with patients receiving care in their last stages of life; ensure adequate resourcing so health care practitioners can satisfy this standard; and make available interdisciplinary training developed by acknowledged leaders in the field.

LCO recommendation 2 states that the College of Physicians and Surgeons of Ontario and the College of Nurses of Ontario clarify a duty in college standard of practice policies, guidance, and statements that health practitioners and care teams must become knowledgeable about the definitions and relationships between advance care planning, goals of care and informed consent, and must become skilled and engage in these person-centred conversations to address the person's values, wishes and goals.

Similarly, LCO recommendation 3 states that the Ministry of Health undertake a systemic review to ensure that health care professionals have specifically designated time and compensation to engage patients and substitute decision-makers in advance care planning and goals of care conversations. This could include, for example, amending the Schedule of Benefits to incorporate a specific billing code for advance care planning and goals of care conversations.

Recommendations 2 and 3 establish a professional standard to engage every patient in advance care planning and goals of care conversations prior to obtaining consent.

Embedding this in college standard of practice policies, guidance, and statements would make this standard measureable and enforceable under the *Regulated Health Professions Act*, and subject to oversight through existing college complaints and discipline mechanisms as well as the Health Professions Appeal and Review Board. Crucially, these recommendations would also ensure that resourcing is provided to health professionals to take the time and fairly bill OHIP for these conversations. This could include, for example, amending the Schedule of Benefits to incorporate a specific billing code for advance care planning. The value in fostering easier enforcement through measurable and reportable quality service targets and system-level improvements is self evident. As one physician noted emphatically, mere “education is the least effective form of quality improvement.”

Together, these recommendations operate as an important access to justice initiative. The

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– PALLIATIVE CARE PHYSICIAN

obligation to offer every patient a discussion about ACP and GOC upon a diagnosis of a progressive, life-limiting illness means those patients are activated and empowered in their care. This has a system-wide impact: as one palliative care physician told us, “You operate differently knowing that people know their rights.”

To ensure compliance with these rights and the law, LCO recommendations 4 and 5 work in tandem to support health care practitioners in becoming knowledgeable and skilled to engage in HCC, ACP and GOC conversations. These recommendations would see health care professional regulators work with acknowledged ACP leaders (such as Hospice Palliative Care Ontario and others) to collaborate and jointly develop an inter-professional training program. Recommendation 5 further states that any such interprofessional training program be adopted system-wide as a standard of practice by industry associations such as the Canadian Medical Association, Ontario Bar Association, and professional insurers including LawPro, and the Canadian Medical Protective Association.

Training is crucial. LCO consultations demonstrated that ACP conversations often take place in a vacuum without meaningful or effective information. Patients and their substitute decision-makers – whether their families, friends, or other caregivers – typically receive limited or no information about the foreseeable and practical legal and medical situations that arise during a palliative course of treatment. Professionals may amplify the problem by repeating colloquial terms (“no heroic measures,” “next of kin”) that have no legal basis in Ontario. These misunderstandings promote uncertainty and disputes.

Not surprisingly the LCO heard frequent and consistent enthusiasm for inter-professional ACP

materials and conversations. These materials would help legal and medical practitioners better understand their respective contexts. Clarifying the purpose and limits of ACP would also benefit patients and their families, thus reducing the medical communities misuse of ACP as a form of “advance directive” or DNR order. Similarly, professional development and related materials would help lawyers avoid empty or misleading terms that provide little or no practical guidance to SDMs or the medical practitioners in interpreting the wishes, values and beliefs of their clients, or their best interests. A particular role for faith and spiritual leaders was also suggested. Many of the two-dozen leaders participating in the LCO’s Multi-Faith Roundtable on the Last Stages of Life were frank that medical technology is greatly outpacing theological doctrine. The involvement of spiritual and faith leaders can help patients and families, along with health and legal practitioners, be at ease in their interpretation of difficult choices.

The benefits of such inter-disciplinary partnerships have been successfully demonstrated in pilot projects like the Wellington-Waterloo ACP Project, whose clients and members spoke highly of the approach, its efficacy in prompting meaningful ACP conversations, and the satisfaction professionals felt in providing better informed and more holistic information while receiving substantive knowledge translation across disciplines.

Interdisciplinary partnerships will also promote the recommendations in the LCO’s commissioned paper on ACP, namely, to ensure that “all stakeholders (including health practitioners, health care organization leadership responsible for professional practice, policy-makers, as well as patients, SDMs and the general public) must receive education on health care consent, goals of care, and advance care planning (as described in

Ontario law) and the interrelationships between these three concepts.”<sup>53</sup>

LCO recommendations 2, 3, 4 and 5 would also support that paper’s recommendations to improve the recognition and uptake of HCCA language and eliminate language from other jurisdictions; and to set a standard of legal accuracy to which funding and regulatory oversight requirements could be grounded and reinforced system-wide.<sup>54</sup>

Various other papers and tools also promote the kinds of information this training should include. For our part, we heard about the importance of including best practice guidelines, document templates, and decision-making trees. The content of these tools should also describe both the medical and legal aspects of issues including: “do not resuscitate” orders; common emergency treatment and resuscitation scenarios in the palliative context; advance care planning; the distinctiveness of various kinds of capacity assessment for property, personal care, and other scenarios; realistic scenarios for plans of care in the last stages of life; palliative sedation;

## ACTIVATING INVOLVEMENT

### WHO DID THE LCO CONSULT ABOUT ADVANCE CARE PLANNING?

While ACP was the most discussed topic across LCO’s consultations, several engagements merit highlighting:

- Hospice Palliative Care Ontario
- National Speak Up ACP Program
- Ontario Palliative Care Network
- Humber River Hospital Palliative Care Team
- Mental Health Legal Committee
- Law & Mental Disorder Association
- SickKids Pediatric Palliative Care Team
- Ryerson U. Diversity Institute Multi-Faith Roundtable
- Public Guardian and Trustee
- Ontario Bar Association, Trusts & Estates Section
- Hospice Waterloo ACP Steering Committee
- Ontario Hospital Association
- Alzheimer’s Society of Toronto and Ontario
- St. Catharines Families of Patients

### THE LCO’S LEGAL CAPACITY, DECISION-MAKING AND GUARDIANSHIP REPORT

In 2017 the LCO reviewed a range of related issues in our **Legal Capacity, Decision-Making and Guardianship Final Report**.<sup>55</sup> The report included recommendations promoting procedural rights and accommodation in capacity assessments; mandating rights information in standard forms; expanding independent right advice; expanding the responsibilities of long-term care homes in promoting consent and capacity rights and compliance; licensing system for professionalized substitute decision-makers; and a more sustainable mandate for the Office of the Public Guardian and Trustee (PGT) in relation to those without an SDM.

## 07 RECOMMENDATION

The LCO recommends that the Ministry of the Attorney General update the Public Guardian and Trustee Power of Attorney Kit (2012). This update would include clarifying the distinction between advance care planning, goals of care, and health care consent.

## 08 RECOMMENDATION

The LCO recommends that the Office of the Public Guardian and Trustee's Treatment Decisions Unit work with health care practitioners empowered to discuss advance care planning and consent with their patients, to develop a standard due diligence practice to better understand the wishes, values and beliefs of the patient and thereby more fully satisfy the PGT's responsibility as substitute decision maker of last resort under the *Health Care Consent Act*.

## 09 RECOMMENDATION

The LCO recommends that the Ministry of Health ensure that procurement and operational specifications and requirements for digital health records systems comport with Ontario health care and consent laws, including under the Health Care Consent Act, Substitute Decisions Act, the common law on consent, and best practices related to advance care planning and goals of care conversations.

and the conflict resolution process for substitute decision makers, powers of attorney, and the like.

And finally, LCO recommendation 6 states that the Ministry of Health fund acknowledged leaders in advance care planning best practices and education (such as Hospice Palliative Care Ontario and others) to continue promoting and supporting best practices.

LCO Recommendations 7, 8 and 9 are designed to entrench best practices.

Recommendation 7 states that information about HCC, ACP, and GOC be adopted into government-endorsed information materials such as the Ministry of the Attorney General and Office of the Public Guardian and Trustee (PGT) Power of Attorney Kit. Many of the people we consulted perceived how an "official government stamp" on a kit improves public confidence, promotes use of the materials, and helps others (such as health care providers and institutions) to recognize and act upon a Power of Attorney and the information they contain.

The LCO also heard concerns about persons who may not have an SDM or person to ensure their wishes, values and beliefs are respected. Under the HCCA, the PGT acts as the substitute decision-maker "of last resort." Practically speaking, this means the PGT steps in to assist medically incapable individuals who are often isolated, vulnerable, or who are far from home or community. We frequently heard concerns that the call to the PGT comes too late – that they only get involved when a patient is critically ill or incapable. The result may be decisions made on behalf of the patient that do not reflect their

wishes, values, and beliefs, which can include cultural, faith, spiritual, and Indigenous practices.

The fact that the PGT's mandate only comes into effect when the patient is incapable of making a decision makes it more difficult, despite the PGT's best efforts, to learn about any prior capable wishes, values or beliefs the patient may have expressed.

Recommendation 8 is meant to address this gap. It states that the Office of the Public Guardian and Trustee's Treatment Decisions Unit work with health care practitioners empowered to discuss advance care planning and consent with their patients, to develop a standard due diligence practice to better understand the wishes, values and beliefs of the patient and thereby more fully satisfy the PGT's responsibility as substitute decision maker of last resort under the *Health Care Consent Act*.

The LCO has concluded that a due diligence requirement would ensure that the PGT TDU will proactively liaise with the health professionals discussing advance care planning, goals of care, and health care consent with their patients, as discussed in recommendations 2 and 3.

In this way, the PGT TDU may better understand the patient they are acting for, what their wishes, values, and beliefs are in relation to health care, and thus better afford them their rights and dignity in their last stages of life.

## ACTIVATING INVOLVEMENT





# ACTIVATING INVOLVEMENT

Recommendations to establish  
a public health palliative care  
mandate in Ontario

## 10 RECOMMENDATION

The LCO recommends that the Minister of Health amend the Health Protection and Promotion Act to adopt a “public health palliative care” (PHPC) as an area for the provision of mandatory public health programs and services.

## 11 RECOMMENDATION

The LCO recommends that the Minister of Health amend the preamble to the Health Protection and Promotion Act to include the internationally recognized definition of “public health palliative care” as reflecting the five tenants of the World Health Organization’s Ottawa Charter for Health Promotion, namely: building public policies that support dying, death, loss and grief; creating supportive environments (in particular social supports); strengthening community action; developing personal skills in these areas; and re-orientating the health system.

## 12 RECOMMENDATION

The LCO recommends that the ongoing partnership between Public Health Ontario and the Ministry of Health fulfill the mandate to develop and promote a public health palliative care approach with necessary resources and supports to sustain a multi-year initiative and support for locally tailored programs.

## 13 RECOMMENDATION

The LCO recommends that the Minister of Health amend the Health Protection and Promotion Act to strengthen the relationship between Public Health Ontario and local and regional community groups with distinct public health palliative care needs – including faith and spiritual, cultural, linguistic, economic, indigenous, persons with disabilities, and other equity-seeking communities, along with compassionate communities and compassionate corporations – by mandating their engagement in development and deployment of annual public health palliative care initiatives.

## 14 RECOMMENDATION

The LCO recommends that the Minister of Health amend the Health Protection and Promotion Act to require an ongoing partnership between Public Health Ontario and the MOH, defined through annual work plans with measurable outcomes, to better align public health palliative care and the provision of health care.

Canada made an early and substantial contribution to the development of international health guidance on palliative care with the historic signing of the *Ottawa Charter for Health Promotion* (World Health Organization, 1986). The Ottawa Charter enshrines three core principles: advocacy (to ensure wishes of the dying person are met); enabling (to ensure the dying person and their family remain involved in decision making); and mediacy (to ensure caregivers facilitate the most appropriate place of dying). Collectively, these principles underpin a “public health palliative care” (PHPC) approach to support the last stages of life respectful of rights and dignity. Today, this approach is widely recognized and adopted in policies of the UK, European, and Australian governments.<sup>56</sup>

The public health approach has expanded in scope over the subsequent decades. It now builds on an increasing awareness of the need to look “at aspects of health beyond those within the mandate of health care services and just the health professionals involved in palliative care and end-of-life care.”<sup>57</sup> Contemporary PHPC approaches look at a wider array of intersecting social determinants of health equity – race and ethnic background, employment, income, education, immigration status, gender, linguistic background, and access to justice – which are now understood as at once “the most underdeveloped angle at this stage... and that has the most potential to enhance the quality of life and sense of wellbeing to the widest number of people... in all aspects of caring for one another” in the last stages of life.<sup>58</sup>

LCO consultation participants frequently spoke in favor of a public health promotion approach as a natural way to support and extend the formalization of advance care planning in Ontario. The LCO also heard about the need to support holistic public awareness campaigns that include practical and concrete discussions about the options and rights that meaningfully impact decisions and choices in the last stages of life. Fortunately, support for this approach is growing. The LCO learned about many independent efforts to raise public awareness of and engagement with advance care planning, and as well in the approach of Compassionate Care Communities movement. The LCO believes Ontario should formalize the PHPC approach in a dedicated public health promotion mandate.

In Ontario, the *Health Promotion and Protection Act* (HPPA) that governs the “organization and delivery of public health programs and services, the prevention of the spread of disease and the promotion and protection of the health of the people of Ontario.”<sup>59</sup> The HPPA establishes 34 public health units in Ontario which administer health promotion and disease prevention programs including immunization, food premises inspection, healthy growth and development including parenting education, health education for all age groups and selected screening services. Section 7 of the HPPA gives the Ministry of Health the authority to regulate the provision of mandatory health programs and services in the province, which it does through the Ontario Public Health Standards.<sup>60</sup> These standards in turn have contributed to public

health programs with “a stronger focus on the social determinants of health.”<sup>61</sup> Costs for these programs are shared between the province and municipalities.

LCO recommendations 10, 11 and 12 recommend a PHPC approach in Ontario.

Recommendation 10 states that the Minister of Health amend the *Health Protection and Promotion Act* to adopt “public health palliative care” as a formal part of the province-wide mandate. The information made available should be provided at the earliest opportunity. Many we spoke with recommended palliative and end-of-life education begin in high school, for instance. This information should also be holistic. As widely endorsed by those we consulted with, public health information should aim to tailor education and information to the specific needs and interests of local communities.

LCO recommendation 13 states that the Minister of Health amend the Health Protection and Promotion Act to strengthen the relationship between Public Health Ontario and local and regional community groups with distinct public

health palliative care needs – including faith and spiritual, cultural, linguistic, economic, Indigenous, persons with disabilities, and other equity-seeking communities, along with compassionate communities and compassionate corporations – by mandating their engagement in development and deployment of annual public health palliative care initiatives. Equity seeking groups include those we discuss later in this report, including homeless and precariously housed, inmates in provincial detention centres, immigration and refugee communities, linguistic and cultural communities, persons with disabilities, and persons with mental illness (see recommendations 31-49 below).

Engaging these communities of lived experience and the wider community in defining the public health information that is most important to them would ensure that information is locally tailored, locally relevant, and locally actionable.

The kinds of issues that local tailoring of public health programming could address was both diverse and frequently brought to the attention of the LCO. Many of these concerns are explored elsewhere in this report. For instance, local groups we spoke with suggested that local tailored public health promotion information could include information about:

- compassionate communities and compassionate corporations movement
- expected death in the home protocols in liaising with the coroner and funerary services
- expected out-of-pocket costs for home care that many are otherwise surprised by and fail to plan for

**“IT WAS CLEAR VERY EARLY ON THAT PEOPLE DIDN’T UNDERSTAND THE LAW AND MADE ASSUMPTIONS. WE SPENT TWO YEARS JUST ON THAT BECAUSE THE HEALTH CARE SYSTEM AND PUBLIC DIDN’T KNOW THE BASICS.”**

– PUBLIC HEALTH RIGHTS EDUCATOR

## ACTIVATING INVOLVEMENT

- the availability of medical assistance in dying services
- advance care planning and do not attempt resuscitation orders
- palliative sedation, and particularly challenging issues like withholding nutrition and hydration
- available supports for caregivers, such as family caregiver leave entitlements and EI special benefits for self-employed people.

Those we spoke with talked enthusiastically about the value in a PHPC approach. As one consultation group put it:

“The general public is hungry for this knowledge. We go to where people live, work, and pray, where they already are instead of asking them to go to a separate event or presentation. We go to workplace wellness initiatives, lunch and learns, we have an interfaith committee to encourage faith leaders to engage their communities in these difficult conversations. We’ve heard from faith leaders what their community thinks about this, and the leaders plant the seed to open the conversation. We go to where people live, retirement homes, LTC, seniors dining programs and they love the information we are able to share. The public wants this information, and it should be available everywhere.”

Despite this enthusiasm, attempts at working within existing structures, without a formal mandate or resourcing, have proven challenging: “We’ve approached public health a few times about partnering on our programs of ACP and

compassionate care communities, but it’s a consistent “that’s not our thing” from public health. They tend to deal with issues at the beginning of the life cycle and they support wellness. They’re good at staying very true to their mandate, which is supporting wellness for children and families and in our region. But there hasn’t been an ability to see outside that. What they don’t yet embrace is that wellness in dying is good public health too.”

Ensuring that these programs provide relevant and current information is key. LCO recommendation 14 states that the Minister of Health amend the *Health Protection and Promotion Act* to require an ongoing partnership between Public Health Ontario and the MOH, defined through annual work plans with measurable outcomes, to better align public health palliative care and the provision of health care.

**“HEALTH AND WELLNESS WORKSHOPS AT COMMUNITY CENTRES AND PUBLIC HEALTH EDUCATION VENUES HELP REMOVE THE CULTURAL FEARS AND AVOIDANCE AROUND END-OF-LIFE AND ACP.”**

– COMMUNITY NURSE

Other jurisdictions are already acting to change the status quo. Similar and contemporary efforts to those proposed here are emerging elsewhere. In January 2020, for instance, the state of New Jersey enacted Bill S-3118, legally mandating the state's Commissioner of Health to establish a public awareness campaign to foster community-wide discussions and to promote early conversations about ACP and patient preferences to improve decision-making at the end-of-life. This includes:

- information on the importance of having advance care planning in place
- how to effectively conduct advance care planning conversations with family members, friends, caregivers, healthcare providers, and other individuals involved in a patient's care
- how community leaders and members can appropriately, and in an ethnically, culturally, and linguistically sensitive way, facilitate community-wide discussions regarding advance care planning and end-of-life care
- standardized and approved definitions of palliative care, hospice care, comfort care, and other end-of-life-care terms, and
- partnerships with community-based initiatives and training programs that educate the general public.<sup>62</sup>

Adopting the LCO's PHPC recommendations would also respond to several other issues identified in this report, including the need to address the issues and conditions promoting conflict and disputes in the last stages of life, and affording good planning and dignity for those at that stage.

## 15 RECOMMENDATION

The LCO recommends that the Ministry of Health or Public Health Ontario expand support and grow province-wide Compassionate Communities strategies, such as those developed by Hospice Palliative Care Ontario.

## 16 RECOMMENDATION

The LCO recommends that the Ministry of Health, Public Health Ontario, or other Ministry support the development of a Compassionate Company designation and standard. The standard would recognize, guide, and encourage employers to adopt formal human resource policies that anticipate and support employees who need leave from work to care for a palliative loved one.

LCO recommendations 15 and 16 will further assist in public education and particularly work to support caregivers who are typically volunteer family members, friends, or members of the community offering care, comfort and support. These recommendations build on the substantial and promising work being done in the "compassionate communities" and "compassionate workplace" movements. An unquestioned leader in this has been Hospice Palliative Care Ontario (HPCO). The HPCO defines "compassionate communities" as "a community of people who feel empowered to engage with and increase their understanding about the experiences of those living with a serious illness, caregiving, dying and grieving and those who are isolated, marginalized or vulnerable. Community members will take an active role in caring for people, assist people to live comfortably in their homes, connect people to supports, raise



awareness about health, well-being and end of life issues, and develop the capacity of others by building supportive networks in the community.”<sup>63</sup>

The HPCO model aims to de-professionalize and de-medicalize care in the last stages of life by returning it to the community, and building-up social capital that can be mobilized when citizens come to the end of their life. Notably, “each community adopts its own approach to building more compassion in response to its needs.” Enthusiasm for this approach is growing. A recent 2020 snapshot indicates that there are currently around 25 compassionate communities around Ontario, each running a variety of programs.<sup>64</sup>

Similarly, compassionate workplace campaigns aim to foster more supportive environments for the increasing number of employees who are caregiving, grieving or dealing with a serious illness.<sup>65</sup> Approaches include promotion of a compassionate care benefit, and workplace policies that allow for support and flexibility, and which promote advance care planning.<sup>66</sup> Accordingly, recommendation 15 states that the Ministry of Health or Public Health Ontario expand support and grow province-wide Compassionate Communities strategies, such as those developed by Hospice and Palliative Care Ontario. Recommendation 16 further states that the Ministry of Health, Public Health Ontario, or other Ministry support the development of a Compassionate Company designation and standard. The standard would recognize, guide, and encourage employers to adopt formal human resource policies that anticipate and support employees who need leave from work to care for a palliative loved one. We see these as consistent with our earlier recommendations on expanding a public health palliative care approach.

## ACTIVATING INVOLVEMENT



### REINVIGOURATING THE PUBLIC HEALTH PARTNERSHIP WITH FAITH & SPIRITUAL COMMUNITIES

Faith, cultural and other values, beliefs and practices have a strong bearing on how we define quality care and interpret morally complex medical interventions. Our extraordinary Multi-Faith Roundtable event convened nearly two-dozen faith and spiritual groups in Ontario in this rich discussion. They spoke strongly in favor of a reinvigorated partnership between public health and the **Canadian Multi-Faith Federation** to create provincial and locally tailored programs for outreach and education to faith and spiritual groups. The Roundtable confirmed their assistance in clarifying doctrinal interpretation of medical interventions; helping to resolve interpretive disputes before they happen; ameliorating sources of stress and uncertainty among families and health care providers alike; and able to assist health and long-term care facilities to better accommodate under Ontario’s Human Rights Code.

# SUPPORTING PROFESSIONALS

More health care professionals are working with patients in their last stages of life, creating new stresses and contributing to workplace injury and team burnout. Legal clarity can help protect them.

National and provincial medical associations have been ringing alarm bells for years about the personal toll exacted on health care practitioners in the last stages of life.<sup>67</sup> The COVID pandemic has only expanded the number of practitioners exposed to frequent death, making the experience unique to palliative care providers more widely evident. Indeed, a recent national survey indicates the burnout rate of doctors practicing emergency medicine is 86%.<sup>68</sup> And “burnout” is not just a colloquialism for overwork: it is a measurable psychological condition that leads directly to lower quality care, increased medical errors and lower patient satisfaction.<sup>69</sup> Palliative care providers have a very high burnout rate, particularly among nurses, social workers and chaplains.<sup>70</sup> Palliative care staff are also “at risk of poor psychological outcomes as a result of insufficient ability to cope with these demands.”<sup>71</sup> One seasoned palliative practitioner notes amid the COVID pandemic: “our grief circles have doubled in number, we’re having more than ever before because more people are sick and more people are dying than ever before... that mental anguish, it has doubled, it has tripled, it is exponentially grown.”<sup>72</sup> These trends are poised to continue after COVID: the proportion of older

adults is set to expand by almost 50% by 2040, and the number of those managing progressive, life-limiting illnesses continues to rise.

Other factors should also be mentioned. The main source of stress cited by MAID providers was not the provisions themselves, but administrative and institutional obstacles to providing MAID. Practitioners became stressed when faced with relays that put the patient at risk of no longer remaining eligible. This was often triggered by “difficulty finding second assessors and backup providers, institutional blocks like a long-term care home not having a policy in place, or colleagues dragging their heels.”<sup>73</sup>

The LCO heard a clear and unambiguous consensus that the time for law reform has come. Discussions on the role of wellness and supports for palliative health care practitioners arose in nearly a third of LCO’s 74 consultations, indicating a high level of concern. Notably, many of these were among the larger consultation events held with 10, 20 or 30+ participants, often comprising entire palliative teams and hospital departments. The LCO heard about workplace-related experiences like compassion fatigue; trauma and post-traumatic stress disorder (PTSD); workplace wellness and self-care programs; employee assistance programs (EAPs); and supports defined in legislation under the Occupational Health and Safety Act (OHSA), the Workplace Safety and Insurance Act (WSIA), and in related policies and programs.

The LCO also heard that wellness and support needs vary between the professions and specific roles they may occupy. Nevertheless, those working closely and predominantly with patients in their last stages of life shared similar experiences and expressed similar needs and suggestions. These groups include physicians and nurses based in hospitals; those in mobile and community-based roles in long-term care, hospices, and home care settings (often as contracted staff); as providers of medical assistance in dying; and personal support workers (PSWs) working in all those same environments.

To their credit, governments at the federal and provincial levels have begun to act. At the same time, many people characterize these efforts as symbolic recognition of the problem, and only a tentative first step.

Finally, the LCO heard that health practitioners need the support of decision-makers outside the clinical setting so that resources can be devoted to addressing the underlying problems and maintaining a viable working environment for practitioners of palliative care, end-of-life care, and medical assistance in dying.<sup>74</sup>

## Key themes in LCO consultations

➔ **Theme 1: Workplace stress, trauma, and compassion fatigue must be recognized as pervasive among palliative professionals.** Health care practitioners candidly and bravely described how workplace stress, trauma and compassion fatigue are not outlier events but systemically experienced by nearly all palliative care practitioners. It is wrong to think that these impacts are only felt occasionally, or by a few. Instead, these kinds of injuries need to be recognized as systemic workplace injuries that will, if left unsupported, deplete entire health care teams with burnout. As one practitioner put it: “after several years, every single member of the team had to take a year off and lost wages, some went bankrupt. And all because of unsupported workplace burnout.”

➔ **Theme 2: It’s not just long hours: factors unique to palliative care contribute to workplace stress and trauma.** Many of those we spoke with described the unique context of working in palliative care: frequent moral distress over patient choices contrary to the practitioner’s duty of safety; juggling systemic pressures while being respectful of patient independence and autonomy; compassion fatigue that makes it harder to communicate and accommodate patients; family tensions manifesting as proxy fights over health care; high-conflict (and violent) patients and families

# SUPPORTING PROFESSIONALS

with little options for on-site de-escalation or rapid legal resolution. The LCO also heard about the unique comradery of team members, the need for whole-of-team wellness supports and practices, and how many home care, long-term care, hospice, and hospital practitioners are contract staff without access to many (or any) wellness supports.

➔ **Theme 3: Existing supports are weak and reactive, rather than proactive, accessible, and ongoing.** The LCO heard that the formal array of employment related supports – including those provided through EAPs and legislated through the OHSA and WSIA – are simply inadequate to the task. EAP program providers are rarely equipped to support moral distress or compassion fatigue and are often provided ad hoc at the discretion of (and cost to) the employer. These and legislated supports are almost all reactive, rather than proactive, allowing injury to fester and build. Eligibility thresholds can be unclear, too onerous, too restrictive, and are only triggered too late. Moreover, support programs are generally individuated rather than helping the whole team, contributing to underreporting and underutilization to avoid the sense of letting colleagues down

Recommendations to better support health care providers of patients in the last stages of life.

## 17 RECOMMENDATION

The LCO recommends that the Minister of Labour explore options within the *Workplace Safety Insurance Act* to identify health care practitioners dedicating the majority of their practice to care in the last stages of life, or in critical incident health care services, as a distinct class for coverage. This should improve ease of access, and as-needed intermittent access, to mental health treatment, supports, and respite and recovery time.

## 18 RECOMMENDATION

The LCO recommends that the Minister of Labour explore options within the *Occupational Health and Safety Act* to identify health care practitioners dedicating the majority of their practice care in the last stages of life, or to critical incident health care services, as a distinct class for coverage. Provisions should consider workplace approaches known to improve practitioner wellness including practitioner respite time, critical incident debrief time, and sufficient staffing levels to anticipate redundancy needs.

## 19 RECOMMENDATION

The LCO recommends that the Ministry of Labour explore available options to expand the definition of “mental illness” eligible for coverage to the proposed worker class defined under the WSIA as dedicating the majority of their practice to care in the last stages of life, or critical incident health care services. This definition and process should be tailored to the needs of this class of workers, including an option for more rapid access to coverage, and to more intermittent and shorter-term leave. As part of this, the Ministry should review the efficacy of policies providing access to chronic mental stress (CMS) and traumatic mental stress (TMS) under existing WISB standards and procedures.

## 20 RECOMMENDATION

The LCO recommends that regulatory colleges widely adopt Health and Well-Being Standards — similar to those introduced for paramedics in April 2018 — to cover other health care practitioners providing care in the last stages of life or critical incident health care.

## 21 RECOMMENDATION

The LCO recommends that government should explore policy options that would prioritize assistance for individuals working with patients receiving care in the last stages of life who are contractually employed, self-employed, precariously employed, or otherwise ineligible for employee assistance programs have access to mental health supports.

## 22 RECOMMENDATION

The LCO recommends that health care professional regulators develop clear, definitive, quick reference tools for practitioners working with patients in the last stages of life. These tools would provide guidance on professional roles in relation to issues like CPR, withholding treatment, or conscientious objection so the practitioner is better able to communicate clearly to families, other staff, and management. These tools should address issues that may involve moral distress, such as MAID, palliative sedation, and conscientious objection.

**“WE KNOW WITHOUT A DOUBT THE EMOTIONAL CONSEQUENCES OF DOING A GOOD JOB, PROVIDING CARE, AND EXTENDING OUR COMPASSIONATE HEARTS OUT THERE EVEN WITH MANY BEDSIDE DEATHS A DAY... BUT THERE NEEDS TO BE OFFICIAL ACKNOWLEDGEMENT OF THIS STRAIN AS PART OF OUR WORK.”**

– HOSPITAL PALLIATIVE PROVIDER



Providing for the mental health of workers is a developing area in the law. Federal and provincial governments have demonstrated concern for these issues but have made only modest – and sometimes contradictory – moves to support them. In general, these efforts indicate a willingness to acknowledge the unique needs and vulnerabilities of specific workers or of specific illnesses, such as first responders, and post-traumatic stress disorder (PTSD). But there is little evidence these approaches match the needs and address the systemic nature of practitioners experiencing the constant life-and-death stresses directly related to working with individuals in their last stages of life.

At the federal level, national consultations were commenced in 2018 on the specific needs of first responders exposed to significant trauma. Overall, these consultations echoed concerns we heard more broadly over “insufficient access to affordable, timely, and effective treatment options.” Parliament made several recommendations in favor of a clear and inclusive definition of “Operational Stress Injuries” that accounts for PTSD and secondary mental health problems, such as depression or substance use. Additionally, the federal government was directed to “consider” encouraging all provinces and territories to develop presumptions in favor of recognizing Operational Stress Injury with a minimum of eligibility hurdles. Notably, some provinces already have taken this step, though access to care and coverage varies across provincial and territorial boundaries.<sup>75</sup>

Subsequently, in 2018, Parliament enacted the Federal Framework on Post-Traumatic Stress Disorder Act, culminating in the 2019 release of a federal policy framework to better support PTSD

through national data tracking and awareness raising education materials.<sup>76</sup> The Mental Health Commission of Canada has also drawn attention to workplace wellness issues in reports and conferences as recently as 2017. These included directions that disability support policies should recognize that those with mental health issues “often have intermittent work capacity” and should therefore have access to flexible supports; enable rapid re-entry onto disability support to former recipients unable to maintain stable employment; limit onerous application processes and documentation requirements; and ensure that disability support programs are flexible to the extent that they accommodate the “cyclical nature of many mental health issues.”<sup>77</sup>

The legislative road in Ontario has been rather more twisting. Work by the Ministry of Labor to study work-related traumatic stress culminated in 2016 with amendments to the Workplace Safety and Insurance Act (WSIA) to better account for the prevalence of PTSD in first responders, including paramedics and emergency medical attendants. Under this legislation the Workplace Safety and Insurance Board (WSIB) must presume that PTSD is work-related, unless the contrary is proven, to lighten the employee’s burden in claiming benefits.<sup>78</sup> These were obviously welcome and laudable accomplishments.

Since 2016, there have been no fewer than five competing pieces of legislation modifying aspects of the coverage in fits and starts.<sup>79</sup> These reforms expanded coverage for eligible groups to work-related chronic mental stress (CMS) and traumatic mental stress (TMS), and included eligibility for employment with such high routine stress that usually involves “responsibility over matters involving life and death, or routine work in

extremely dangerous circumstances.” Additional coverage was later introduced to extend presumptive PTSD coverage to front-line nurses. But WSIB interpretation and implementation policies have been harshly criticized for creating an onerous and high threshold for eligibility. These are viewed as introducing unconscionable delay that hinders immediate support for mental stress injuries; imposing requirements for an expert DSM mental disorder diagnosis confirming the illness (which can take months to arrange); imposing requirements for mental illness well above and beyond those of physical injury; excluding claims from workers who developed mental stress gradually over time due to general workplace conditions; and creating a burden of proof to show “excessive in intensity and/or duration” of stress compared to others doing the same job. Appeals from any of these determinations can take several years.

Needless to say, many workers seeking support for mental illness are in a poor state to advocate for themselves and engage in an onerous application process. Fewer still will have adequate time, finances, or emotional stability to follow through with lengthy litigation following from an adverse decision.

The LCO has concluded that this system is incoherent and does not provide effective coverage that any palliative care professional would find accessible, adequately supportive, and responsive to their particular professional vulnerabilities. Indeed, an internal WSIB audit confirmed that the provincial workers’ compensation board has denied 94% of chronic

mental stress cases since new legislation extended benefits coverage to employees experiencing long-term trauma or harassment on the job. Between January and May of 2018, just 10 of 159 claims for work-related chronic mental stress were approved by the WSIB.<sup>80</sup> Overall, the LCO believes the inconsistent mix of high eligibility requirements with procedural complexity leaves palliative care practitioners with few workable options for workplace injury supports.

To respond to the obvious and increasing distress of practitioners of palliative care, end-of-life care, and MAID, LCO recommendation 17 states that the Minister of Labour explore options within the Workplace Safety Insurance Act to identify health care practitioners dedicating the majority of their practice to care in the last stages of life, or in critical incident health care services, as a distinct class for coverage. This should improve ease of access, and as-needed intermittent access, to mental health treatment, supports, and respite and recovery time.

**“OUR ORGANIZATION  
IS VERY MUCH ON THE  
LOOKOUT FOR PHYSICAL  
RISKS AND TAKING STEPS  
TO PREVENT THEM.  
BUT MENTAL DISTRESS  
DOESN’T EVER MAKE THE  
LIST.”**

– HOSPITAL BIOETHICIST

This approach is consistent with our overall commitment to clarify and standardize “palliative care law” as a set of legally distinct and emergent practices. As we defined earlier in this paper, palliative care practices diverge from the general health care narrative of “recovery” and merit a stand-alone definition as a “progressive, life-limiting illness.” This, in turn, makes it easier to align legislation to system goals that foster access to palliative care for vulnerable groups, formalize ACP services and advice, standardize the use of forms, improve compliance, and globally define service eligibility and priority policies.

Similarly, to better clarify and standardize access to a range of workplace supports for practitioners working with patients in their last stages of life, recommendation 17 proposes a definition of workplace that would recognize “health care practitioners dedicating the majority of their practice to care in the last stages of life, and to those working in critical incident health care services” as a distinct class for coverage. This definition would cut through the incrementally expanded coverage for narrowly and incompletely defined groups of practitioners introduced since 2016 and better achieve the original intent of supporting those all those in positions of “such high routine stress that usually involves responsibility over matters involving life and death.” In practice, the proposed LCO definition would likely include physicians, nurses, PSWs and front-line emergency responders with a majority of their practice involving palliative care, end-of-life care, and medical assistance in dying. The definition would prioritize practitioners who are most frequently exposed to death related stresses, simplify eligibility, and create the foundation on which to provide a responsive, flexible, intermittent or short-term approach

that would be more responsive to those working with patients in their last stages of life. This would additionally align with recommendations for workplace wellness from the Mental Health Commission of Canada.

Our consultations also indicated clear and urgent agreement on the need for law reform recommendations promoting a proactive approach to workplace standards that better support palliative practitioners.

LCO recommendation 18 states that the Minister of Labour explore options within the OHSA to identify health care practitioners dedicating the majority of their practice to care in the last stages of life, and to those working in critical incident health care services, as a distinct class for coverage. Provisions should consider workplace approaches known to improve HCP wellness including practitioner respite time, critical incident debrief time, and sufficient staffing levels to anticipate redundancy needs. Recommendation 18 would set standard workplace conditions to better protect these workers by responding to concerns for adequate respite staffing, taking a “whole team” approach, and ensuring critical incident debrief time. Without proposing specific amendments, this recommendation is designed to invite the Ministry to explore the creation of a separate category of workplaces where provisions could be tailored to those specific issues. This approach reflects federal standards on psychological health and safety in the workplace.

Recommendations 17 and 18 are supported by recommendation 19: to expand the definition of “mental illness” eligible for coverage to those health care practitioners dedicating the majority

of their practice to care in the last stages of life, or critical incident health care services under the WSIA. The rationale for this recommendation stems from the unfortunate reality that legislation, definitions and policies have changed significantly over the years, resulting in coverage often limited to specific recognized classes of work (first responders, for example). Meanwhile, others workers facing similar conditions and issues must meet onerous eligibility criteria with a high and demanding burden of diagnostic proof. Recommendation 19 addresses these inconsistencies by inviting the government to tailor solutions to the urgent and growing needs of all palliative, end-of-life and MAID practitioners. We suggest that this is best achieved through either a stand-alone definition and/or by reviewing the eligibility criteria for chronic mental stress and traumatic mental stress in general. Comparison can also be made to Manitoba's presumptive and universal PTSD coverage for all workers, as well to the federal government recommendation that provinces adopt a clearer, more inclusive, and presumptive definition of "Operational Stress Injuries."

Another important contributor to health care provider wellness is the adoption of new professional practice standards. Recommendation 20 states that health regulatory colleges should widely adopt health and well-being standards akin to those introduced for paramedics in 2018, and as announced by Ontario's Minister of Labour. These standards — the Psychological Health and Safety in the Paramedic Service Organization — were commissioned by the Paramedic Association of Canada and developed by the Canadian

**"WHEN WE'VE HAD A VERY TRAUMATIC ISSUE IN THE ICU, MANAGEMENT MAY SOMETIMES BRING EAP IN. BUT ONLY A FEW TIMES, AND ONLY AT THEIR DISCRETION."**

— PALLIATIVE CARE NURSE

Standards Association, with funding through the province's Occupational Health, Safety and Prevention Innovation Program. This Standard offers sector-specific guidance for developing and maintaining a psychologically healthy and safe workplace. The Standard also encourages paramedic service organizations "to identify potential areas and activities that give rise to occupational stressors and implement measures before harm can occur."<sup>81</sup> This approach has broad national support and is based on the CSA's 2013 National Standard on Psychological Health and Safety in the Workplace. In LCO's consultations, we heard how the adoption of similar standards to support physicians, nurses, PSWs could transform the workplace. As one physician put it: "first responders have something in place, but what they fail to forget is we're second responders and we're ongoing responders. It's a day on thing, it's daily and weekly or monthly, cumulatively. You finish with one person and move on to the next, and it affects providing efficient care and links to burnout."

Employment related mental health supports are an important legislative backstop to support both short- and long-term mental wellness of health care professionals. The LCO heard how a more sustainable and resilient workplace is built around peer support and cohesive, stable teams. Indeed, most practitioners spoke ardently about how essential teams are to workplace wellness. Practitioners greatly favored team-based supports like critical incident team debriefing but decried the lack of support or planning to make it a core workplace feature rather than something “optional.” As a result, the onus is often placed on the health care practitioner to seek mental health supports on their own. Other practitioners suggested that hospitals and LTCHs should have mandated organizational practices built-in, like shifting schedules to accommodate short leaves, de-stress time, and time to accommodate routine team debriefs. Practitioners also highlighted how “some other disciplines can leave for a few hours and regain their composure, but we’re just supposed to carry on.” Teams can help facilitate such opportunities “to step back” and let another team member take the lead. Reasonable staffing levels should take such team-based activities and mutual support into account. The value in supporting a team model for care providers in the last stages of life has been validated in leading Ontario studies. These have found how care workers share “a common emphasis on team building, which was foundational to their ability to provide quality care[...] avoid burnout and compassion fatigue, as well as enable the team to sustain and grow their model.”<sup>82</sup> The 2019 OPCN Delivery Framework similarly sets out a vision for palliative care teams that seeks to build on existing team models as interdisciplinary, collaborative and at the heart of palliative care delivery across the province.<sup>83</sup>

Recommendation 21 addresses how the team model often relies on contract staff. As essential members of a team providing care in the last stages of life, the LCO recommends that the Ministry of Labour should explore policy options that would prioritize assistance for those health

**“FOR ALL THE TALK ABOUT IMPROVING PEOPLE’S HEALTH AND HEALTH CARE, WE SPEND VERY LITTLE TIME SUPPORTING OUR OWN MENTAL HEALTH, RESILIENCE, AND WELL-BEING.”**

– PALLIATIVE CARE PHYSICIAN

care providers who are contractually employed, self-employed, precariously employed, or otherwise ineligible for employee assistance programs have access to mental health supports. The LCO heard considerable concern for the fate of a significant proportion of HCPs employed at arms-length from a facility and who are thus ineligible for employment support coverage either in legislation or through employee assistance plans. Many provincial studies have been done on contract, precarious, and self-employed labour and how they need greater access to such services and benefits.<sup>84</sup> The LCO notes that this was of particular concern to PSWs.

Finally, recommendation 22 addresses the need for improved reference tools. The LCO heard that moral distress contributes to occupational stress in part because practitioners are uncertain about the expectations of their professional role. As one hospital bioethicist put it: “our organization is very much on the lookout for preventable risks, but they’re usually physical. Moral distress doesn’t make it to the list.” It was suggested that regulatory colleges develop a set



of standard “quick reference” tools specifically for palliative HCPs would be of benefit to new and long-practicing practitioners alike, and that these tools should be inter-professionally developed and consistent with LCO’s recommendations 4 and 5.

“It’s a whole thing to even get assistance from an EAP; it’s limited to 3 sessions and it sometimes doesn’t even target the trauma. And it’s self-referral. When you’re traumatized you just try to keep going, so to opt in to self-declare that you need help is hard. And finding a doctor to prove you have trauma. But even before that, you have to prove it to your manager that you need the day off. How do you do that. There are many steps before and it makes you not bother trying. And then you have chronic trauma.”

– PALLIATIVE CARE PHYSICIAN

**“WE’RE SEEING MORE AND MORE STRESS ON STAFF’S MINDS. WE’RE TRYING TO WORK ON THE HEALTH AND SAFETY AROUND THEM FEELING THAT WAY... BUT ACCESS TO COUNSELLING ISN’T COVERED, IS VERY COSTLY AND WE HAVE TO PROVIDE IT. THIS HAS TO CHANGE.”**

– LONG-TERM CARE HOME OPERATOR

## SUPPORTING PROFESSIONALS

### WHO DID THE LCO CONSULT ABOUT PRACTITIONERS’ SUPPORTS?

Our consultations on workplace wellness greatly benefitted from the time generously given by several professional groups and operators, including:

- Joint Centre for Bioethics, U. of Toronto
- Palliative Sedation Experts Roundtable
- Palliative Care Coalition Nurses
- Registered Nurses’ Association of Ontario
- Regional Pediatric Palliative Care Leads
- Ontario Personal Support Worker Assoc Executive
- AdvantAge Long-term Care Home Operators
- Dying with Dignity Clinicians Advisory
- Humber River Hospital Palliative Care Team
- Sick Kids Hospital Palliative Care Team



# SUPPORTING CAREGIVERS

Patients and the system increasingly aspire to more care at home. But caregivers need more help to make this goal a sustainable reality.

It is estimated that there are more than 3.3 million caregivers across the province — defined as people who provide support to loved ones without pay for many reasons, including frailty, palliative care, long-term illness, physical or mental disability or age-related conditions.<sup>85</sup> Nearly half of caregivers were born outside of Canada, and over half report significant emotional stress in caring for loved ones. It can be a demanding task: caregivers provide personal care, physical support, basic medical procedures, schedule appointments, translate information, and manage financial and legal responsibilities. Two-thirds admit they had no choice but to assume the work of caregiving. And COVID has expanded the proportion of Ontarians experiencing these demands and increased the demand for a better system of supports. Headlines report that many are under “massive stress” with the “lonely task” looking after ailing loved ones amid the pandemic lockdown and withdrawn care services.<sup>86</sup>

Caregivers are eligible for a range of services and supports in the health care system through community support services, such as respite care and counselling, if they are available. Caregivers and other family members may also be eligible for protected leave from work for stipulated periods of times. Under these provisions, individuals are entitled to take time to care for others without losing their employment.

## OUR SURVEY FINDINGS

CAREGIVER NEEDS  
HAD A

**79%**

RESPONSE  
RATE

WE ASKED PRACTITIONERS  
ABOUT CAREGIVER NEEDS:

**43%**

REPORTED  
LEAVE BENEFITS  
AS THE #1  
CAREGIVER  
ISSUE

**29%**

CITED  
UNEXPECTED  
OUT-OF-  
POCKET  
COSTS

**17%**

CITED DAILY  
BURDEN OF  
MEDICAL &  
PHYSICAL  
CARE

LCO consultations considered whether these legislated entitlements, coupled with other benefits, are sufficient to give caregivers and family members the supports they need and with the flexibility unique to caring for palliative loved ones. The LCO also heard how compassionate care communities and corporations supports caregivers of individuals in their last stages of life. (See recommendations 13, 15 and 16 for further discussion).

### Key themes in LCO consultations

➔ **Theme 1: Employment supports do not reflect the variability of progressive, life-limiting illness.** Ontario offers a variety of employment and bereavement leave supports. But we heard strongly how these provisions legislate assumptions about health care as a trajectory of short-term illness, followed by either recovery or bereavement. These provisions do not reflect the needs of caregivers of individuals in their last stages of life. A palliative course of treatment may be neither acute nor predictable. Conditions may onset and abate suddenly, or last for an indeterminate amount of time. They may persist for years. They involve chronic care that must account for caregiver respite and the considerable burden of attending to physical needs and administrative overhead. In short, current employment supports and protections simply do not reflect the day-to-day variability of caring for palliative loved ones.

➔ **Theme 2: Employment supports fail those who are self- and precariously employed.** The need to update employment standards legislation to better protect

precarious workers was addressed in an earlier LCO report. That report, *Vulnerable Workers and Precarious Work: Final Report* (2012), confirmed that “Precarious work has an impact on areas of vulnerable workers’ lives other than employment itself. This work leads to a greater risk of injury and illness, stress and challenges to accessing entitlements to health care.”<sup>87</sup> Similar findings were made in the Changing Workplaces Review (2017), which recommended that government prioritize finding mechanisms to make basic insured benefits available not only to part-time, contract, and temporary workers, but to the self-employed and small employers as well.<sup>88</sup>

➔ **Theme 3: Out-of-pocket expenses greatly add to caregiver strain.** The LCO heard of the crushing financial and emotional toll unexpected costs can have on a caregiver: respite care, counselling, medications and medical supplies, medical transfers, and supplemental home workers (to name but a few). A recent report highlights that 42% of caregivers are using their savings to help pay for expenses related to caregiving.<sup>89</sup> Several ameliorative approaches are being explored, including flexible “health spending account” programs available both through employers and in changes proposed to Ontario’s social assistance programs.<sup>90</sup> These programs could provide flexible funding available for general costs. Income security groups caution that such programs should be funded to take different levels of need into account, and that funding should not be on a reimbursement basis.<sup>91</sup>

# SUPPORTING CAREGIVERS

Recommendations to better support caregivers of individuals in their last stages of life in Ontario

## 23 RECOMMENDATION

The LCO recommends that the Ministry of Labour, Training and Skills Development explore options to amend provisions in the *Employment Standards Act* related to “family caregiver leave” to provide that the leave taken by the caregiver of an individual in their last stages of life is available in daily rather than weekly increments.

## 24 RECOMMENDATION

The LCO recommends that the Ministry of Labour, Training and Skills Development explore options to amend provisions in the *Employment Standards Act* to create a category of “family caregiver leave for minor children” that would make the existing 37 weeks leave entitlement for critical illness leave (and the entitlement to additional leaves) available to caregivers of minor children receiving care in their last stages of life.

## 25 RECOMMENDATION

The LCO recommends that the Ministry of Labour, Training and Skills Development explore options to amend provisions in the *Employment Standards Act* to clarify that entitled leave periods include periods where respite care is provided for the insured.

**“I NEVER HAD A WEEKEND TO RECHARGE, NEVER A WEEKEND OFF. THAT WAS WHEN I PROVIDED THE CARE, FOR TWO YEARS. IT WAS EXHAUSTING.”**

– FAMILY CARE GIVER

## 26 RECOMMENDATION

The LCO recommends that the Ministry of Labour, Training and Skills Development explore options to amend the *Employment Standards Act* as would act to expand the job-protected and insured family medical leave provisions to better support caregivers of an individual in their last stages of life in the high-needs homecare category (defined as receiving 14+ hours of care a week).

## 27 RECOMMENDATION

The LCO recommends that the Ministry of Health explore the development of a mandate that all individuals in their last stages of life in the high-needs homecare category (defined as receiving 14+ hours of care a week) be assigned a health care practitioner that is responsible for the administration, coordination, and oversight of home care services.

Among the wide range of issues discussed in our caregiver consultations, the overwhelming concern was for the impact on their employment. More than two thirds of caregivers are employed, but as characterized in one recent report, “it can be like juggling two full-time jobs at once.” About 45% of caregivers find balancing caregiving with work stressful, while 35% are worried about losing their job.<sup>93</sup> Most caregivers report dedicating around 10 hours a week or fewer. Importantly, other situations may be different. For instance, “intense caregivers,” such as those caring for children with chronic care needs, report higher overall stress with the management of caregiving, with the difficulty of juggling work and caregiving, and about finances.<sup>94</sup> It is also estimated that some 35,000 persons a year acted as end-of-life caregivers in a private home or long-term care facility in Ontario. The number who support long-term individuals in their last stages of life is thought to be much higher given the extended and uncertain trajectory of chronic illness.<sup>95</sup>

Existing legislation provides for a variety of income support and right of return programs related to medical, critical incident, bereavement, and other conditions of leave. These provisions are summarized in Chapters 2 and 5 of the LCO’s ***Last Stages of Life Discussion Paper***. Presently, caregivers living in Ontario are potentially eligible for four forms of support:

- protected leave from work in designated circumstances
- financial support from federal Employment Insurance (EI)
- respite care delivered through the provincial health system
- income tax credits.

## SUPPORTING CAREGIVERS

AMONG WORKING  
CAREGIVERS

1 in 5

HAVE REDUCED OR ALTERED  
THEIR WORKING HOURS TO  
MANAGE CAREGIVING

EVERY YEAR CANADA  
LOSES ABOUT

560,000

FULL-TIME EMPLOYEES  
DUE TO THE DEMANDS OF  
CAREGIVING

AMONG WORKING  
CAREGIVERS

48%

WISH THEIR EMPLOYER  
GAVE THEM MORE  
SUPPORT

COSTS TO WORKPLACE  
PRODUCTIVITY ARE

\$1.3B

ON TOP OF THE IMPACTS OF  
STRESS ON THE EMPLOYEE<sup>92</sup>

### The complex demands on caregivers, in their own words.

“I was not prepared for the mental health impact of depression, stress and physical fatigue. Then there is the cost of lost wages – in my case equivalent of lost four months wages during the year. Medical professionals expect the caregiver to make all these decisions, but they don’t really give me much information on the impact of those decisions or alternate options. The LHINs expect a caregiver to provide clinical support similar to that of an RN/RPN. There is little to no respite for the caregiver. While the act of caregiving is gratifying, if it’s an extended period of time, more than 1 year, it’s emotionally, financially and physically draining on the caregiver. Yes, there are caregiver resources to learn more about taking care of yourself but the question is always this: when would that be possible?”

– CAREGIVER OF A FAMILY MEMBER

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 ESA provisions governing leave are quite complex because there are several types and each may depend on factors, including relationship, prognosis, and length of employment. Leave is also limited by a maximum number of weeks within a period of time. A consequence of existing requirements is that caregivers may exhaust their entitlements or may not be able to take leave without interruptions. For employees who can take leave, the ESA does not guarantee pay. Ontarians may be eligible for federal EI benefits, including the “compassionate care benefit.” But these are linked to job status, accumulated work hours, and are limited to caregivers of persons with a significant risk of death or critically ill children. Nor do these provisions account for other chronic conditions. For example, the LCO heard that the ESA does not provide sufficient leave to face the challenges arising after a person dies, such as arranging a funeral and managing grief. For instance, under the family medical leave provisions, employees cannot remain on leave after the last day of the week in which the person dies. Additionally, LCO consultation participants have noted how “Ontario has the weakest bereavement leave policy in Canada” with the ESA requiring only a minimum of two unpaid days of job-protected leave to employees who experience the death of a prescribed family member.<sup>96</sup>

Ontario has declared its intention to support more health and palliative care in the home. The LCO heard of many situations where the present ESA provisions are an impediment to this goal. Caregiver and family needs arose at nearly every

consultation we convened, whether expressed by caregivers and family member or through the vicarious experiences of health care practitioners, lawyers, or other professionals. Gaps between the law and the goals of homecare included:

- a lack of alignment between assistance programs and the unpredictable, long-term, and/or intermittent trajectory of palliative and end-of-life care
- poor or no harmonization between provincial legislation and employee assistance plans
- how contractual, precarious, and self-employed workers may have difficulty accessing coverage or have none at all
- difficulty navigating, applying for, and planning home care due to unclear definitions under the ESA, overlapping types of leave, and poor eligibility criteria
- limited or no government coordination or support for initiatives like compassionate care communities and corporations, and
- limited or no formal linkage between entitlements and respite models and services

LCO recommendations 23, 24, 25, 26 and 27 address these issues. Recommendation 23 states that Ontario should review the ESA provisions related to “family caregiver leave” to provide that the leave taken by the caregiver is available in daily rather than weekly increments. Many people told the LCO that leave provisions are not “finely grained” enough to meet the up-and-down and intermittent needs of individuals in their last stages of life. At present the legislation sets weekly increments running from Sunday to Saturday. If a caregiver needs to begin the benefit on a Tuesday, it counts as entire week. If the caregiver only needs one day, it will count as an entire week. This is very problematic given that the entitlement is capped at a total of eight weeks.



The current ESA rules exacerbate the stress already placed on caregivers. Caregivers often must choose between caring for their loved ones, depleting limited entitlements, and risking their already-precarious employment. In these circumstances, it is not surprising that care for a palliative loved one may suffer.

Recommendation 24 states that Ontario should explore opportunities in the ESA to create a category of “family caregiver leave for minor children” that would make the existing 37 weeks of critical illness leave apply to longer-term care of children in their last stages of life. At present, eligibility for palliative leave for parents tending to a child who is receiving palliative care is limited and fails to distinguish between the qualitative difference between an adult death and the death of a child. Parents spoke eloquently about the need to spend as much time as possible with children in their last stages of life, and expressed significant anguish over the limited leave current legislated provisions provide. As a result, the LCO proposes that “critical care” leave provisions extend to a “last stages of life” leave criteria as well.

Recommendation 25 states that Ontario should review the ESA to clarify that entitled leave periods include periods where respite care is provided for the insured. We heard of situations where “respite care” was classified as regular leave time and would interrupt the leave period, resulting in ineligibility and bureaucratic mazes.

Recommendation 26 states that the Ministry of Labour explore expanded job-protected and insured family medical leave provisions to

better support caregivers of individuals in their last stages of life in the high-needs homecare category (defined as receiving 14+ hours of care a week). Under current criteria, receipt of high-needs home care can invalidate eligibility for employment protections otherwise available to caregivers. In this manner, the current criteria mistakenly assume that the availability of in-home “high-needs care” meets the needs of the caregiver’s responsibilities. In reality, persons receiving high-needs care typically require significant coordination between services that may be provided by frequently rotating contract

**“I WAS A CAREGIVER FOR MY MOM FROM WHEN I WAS 17 TO 26. THE SYSTEM WAS REALLY DIFFICULT TO NAVIGATE, AND THAT WAS REALLY FRUSTRATING BECAUSE THERE WERE POTENTIALLY SUPPORTS AVAILABLE THAT WE REALLY NEEDED AND COULD HAVE RECEIVED, BUT DIDN’T.”**

– FAMILY CARE GIVER

### WHO DID WE CONSULT WITH ABOUT SUPPORTS FOR CAREGIVERS?

Our consultations greatly benefitted from the time generously given by several groups, including:

- Dying with Dignity Local Chapters
- St. Catharines Families
- Hospice Waterloo-Wellington ACP Committee
- Alzheimer Society of Toronto Clients and Families
- Several parents and family members of patients receiving palliative care
- SickKids Hospital Pediatric Palliative Care Team

staff. This effectively turns the caregiver into an administrator, with a constant burden to ensure critical care is adequately covered. This burden is in addition to the care required when in-home services are off shift. Accordingly, the LCO proposes this provision cease discriminating against high-needs caregivers in these circumstances.

Recommendation 27 states that the Ministry of Health explore development of a mandate that all individuals in their last stages of life in the high-needs homecare category (defined as receiving 14+ hours of care a week) be assigned a health care practitioner that is responsible for the administration, coordination, and oversight of home care services. As discussed above, high-needs patients often require a very high level of care coordination between multiple contracting agencies and regularly rotating staff. This administrative burden can be overwhelming when organizing, for instance, round-the-clock care. Accordingly, the LCO recommends that Ontario explore a case manager / navigator / administrator to take on this function, particularly considering the demise of the community care access centres. This recommendation is consistent with recommendations from the Ontario Palliative Care Network about the role and functions a “system navigator” can perform in supporting caregivers.

**“THE LOST TIME AT WORK CAN NEVER BEEN REGAINED. THE CAREGIVER IS GIVING SO MUCH OF THEIR TIME AND THAT IS SAVING THE GOVERNMENT A LOT OF MONEY.”**

– FAMILY CAREGIVER

## **28** RECOMMENDATION

The LCO recommends that the Ministry of Labour, Training and Skills Development review eligibility criteria for self-employed people under the *Employment Standards Act* to El special benefits programs and explore opportunities at the provincial level to create new incentives and enhance enrollment in this program.

## **29** RECOMMENDATION

The LCO recommends the Ministry of Labour, Training and Skills Development Review explore opportunities under the *Employment Standards Act* to extend supports to a class of contractually, self-employed, or precariously employed caregivers who are supporting an individual in their last stages of life and who are otherwise ineligible for any entitlements or benefits in these circumstances.

## **30** RECOMMENDATION

The LCO recommends that the Minister of Health use the mandate under Bill 3, *Compassionate Care Act*, to develop “a framework to ensure that every Ontarian has access to quality palliative care” that would call on municipal governments and provincial Ministries to review policies, programs, laws, and regulations for their impact on individuals in their last stages of life, their caregivers, and health care providers.

Recommendation 28 states that Ontario review the ESA eligibility criteria for employment insurance special benefits for self-employed people and explore opportunities at the provincial level to create new incentives and enhance enrollment in this program. The LCO heard that this program was widely under-utilized and often of little practical assistance. For example, the LCO learned that it is often very difficult to apply for this benefit, and that benefits can be unpredictable.

Recommendation 29 states that Ontario review opportunities to extend ESA coverage, or coverage through some other means, to a class of contractually, self-employed, or precarious employed “caregiver of an individual in their last stages of life” who currently have no such entitlements or benefits in these circumstances. As noted above, the LCO’s ***Vulnerable Workers and Precarious Work: Final Report*** report confirmed that “Precarious work has an impact on areas of vulnerable workers’ lives other than employment itself. This work leads to a greater risk of injury and illness, stress and challenges to accessing entitlements to health care.”<sup>97</sup> That report defined precarious workers as “contract, part-time, self-employment or temporary work.”<sup>98</sup> The LCO’s analysis was confirmed by later studies, including the 2017 Changing Workplaces Review.<sup>99</sup>

Finally, recommendation 30 recommends that the Minister of Health use the mandate under Bill 3, ***Compassionate Care Act***, to develop “a framework to ensure that every Ontarian has access to quality palliative

care” that would call on municipal governments and provincial Ministries to review policies, programs, laws, and regulations for their impact on individuals in their last stages of life, their caregivers, and health care providers.

The review contemplated by this recommendation might identify municipal bylaws or provincial regulations that discriminate against, or place an undue burden upon, caregivers and patients in the last stages of life.

The LCO learned of many such bylaws or regulations, including:

- “no overnight parking” on streets while caring for a person in the last stages of life
- the loss of a transit subsidy because of cohabitating with a loved one needing care
- public housing regulations that may make tenants ineligible for benefits and subsidies if cohabitating with a caregiver for longer than 30 days.

The LCO heard of many other such examples.

The impact of these rules on persons receiving care in the last stages of life, and on their caregivers, cannot be underestimated. Such disincentives run counter to stated goals of expanding care at home. As a result, provincial government should proactively review laws, by laws and regulations through the lens of those receiving care in the last stages of life, and thereby better foster systemic supports.

# SUPPORTING COMMUNITIES WITH UNMET NEEDS

The needs of specific groups are unique and deep. In the last stages of life they must be accommodated by design, protected from discrimination, and assured equal access to care.

## **Incarcerated Individuals**

The incarcerated population is aging, experiences premature onset of chronic health conditions and comorbidities, and a higher prevalence of infectious diseases. Although provincial jurisdiction over incarcerated individuals is limited to sentences of “two years less a day,” carceral institutions create significant challenges for those managing chronic conditions including access to health care in a facility; barriers to receiving medications; and frequently missed medical appointments due to lockdowns, short-staffing or long waiting lists. The compassionate release process is onerous and protracted. And substitute decision makers may be considered “visitors” who have to book weeks in advance or travel a great distance to the facility — only to be turned away due to unforeseen circumstances.

## **Care in Transition and the Home**

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, and in residential hospices. Participants in LCO’s consultations 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. But people felt largely unsupported or inadequately supported in their effort to care for a loved one at home and manage transfers within and between care settings, and for out of pocket expenses.

## **Equity Seeking Groups & Isolated Individuals**

Recent government reviews 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, Indigenous identity, income level, place of residence, mental health and culture can strongly affect the setting, type and quality of care that Ontarians receive. In LCO’s consultations, we heard about marked disparities in equitable access to palliative and end of life care for several groups. This includes Ontarians living with HIV; persons living with dementia; homeless and under-housed persons; persons with disabilities; immigrant and refugee communities; and incarcerated individuals. More and more Canadians are also living alone, meaning their engagement in advance care planning and substitute decision making is all the more vital.



### **Children Receiving Palliative Care**

“Intense caregivers,” such as those caring for children with chronic care needs, report higher overall stress with the management of caregiving, juggling work and caregiving, and about finances. As one health practitioner characterized it: “Equity is the biggest issue. Children have no benefits, no RRSPs to cash-in, no home to sell, no long-term care facilities. There is nothing for them, not even hospices. It all falls on the family.” Earlier in this report the LCO made recommendations to improve supports available to caregivers of children receiving palliative care (see recommendations 23-25). Here we make additional recommendations to better ensure equitable access to palliative care and development of a pediatric hospice strategy for Ontario.

### **Medical Assistance in Dying**

Medical Assistance in Dying (MAID) was legalized in 2016. Interest in MAID has grown considerably since then. Yearly MAID deaths in Ontario grew from 839 in 2017 to 2,378 in 2020.<sup>100</sup> Importantly, palliative care is reported as a significant component of care at the end of life for MAID recipients: nationally, some 83% of MAID recipients reported receiving palliative care.<sup>101</sup> However, the LCO heard from many in Ontario who continue to face challenges and barriers to equitably accessing MAID, and doing so while often in a vulnerable state. This was particularly on behalf of services delivered on a mobile basis, and in more rural and remote areas of the province.

### **First Nations, Métis, & Inuit communities**

Beginning in 2018, LCO commenced a distinct engagement process with First Nations, Métis, and Inuit communities in Ontario out of the acknowledgement that health care for Indigenous peoples in Canada is in dire need of law reform. Indigenous peoples are affected by shorter life expectancy, higher rates of chronic conditions, an aging population, and distressing health crises.

The LCO undertook these engagements with guidance from an Indigenous Engagement Advisory Group. The findings are published alongside this final report as ***The Last Stages of Life for First Nation, Métis and Inuit Peoples: Preliminary Recommendations for Law Reform.***

# SUPPORTING COMMUNITIES WITH UNMET NEEDS

Recommendations to  
better support incarcerated  
individuals in Ontario

## 31 RECOMMENDATION

The LCO recommends that the Ministry of the Solicitor General amend the *Correctional Services and Reintegration Act, 2018* to establish a compassionate release provision and clarify that incarcerated individuals in their last stage of life are eligible for temporary absences and compassionate release. This mechanism should operate expeditiously given the urgent care needs.

## 32 RECOMMENDATION

The LCO recommends that the Ministry of the Solicitor General create a “transitions in care” strategy to facilitate compassionate release of individuals in their last stages of life. This strategy should anticipate and address discrimination in eligibility to facilities including long-term care, hospices, and housing, and ensure oversight review of transitioned individuals as “deaths in custody.”

## 33 RECOMMENDATION

The LCO recommends that the Ministry of the Solicitor General implement a flexible communication and visitation policy that accommodates the timely involvement of substitute decision-makers to incarcerated persons in their last stages of life, as is required to facilitate conversations about advance care planning and goals of care, and to facilitate compliance with the *Health Care Consent Act*.

## 34 RECOMMENDATION

The LCO recommends that the Ministry of the Solicitor General study and report on a strategy to address the primary health care needs specifically of incarcerated persons in their last stages of life. This would include access to a palliative team including specialists, liaison relationships to local hospitals, and pain and medication management.

## 35 RECOMMENDATION

The LCO recommends that the Ministry of the Solicitor General engage advocates and stakeholders in the study of a provincial corrections policy that responds to the unique circumstances and concerns related to MAID requests from incarcerated individuals.



Incarcerated individuals in Ontario provincial and Canadian federal correctional institutions are known to face significant barriers to health equity and access.<sup>102</sup> They have higher rates of mental health and addictions,<sup>103</sup> age faster than the general population, have a higher prevalence of infectious diseases, and experience the premature onset of chronic health conditions and comorbidities typically associated with advanced age. The median age of first-time incarcerated persons is also rising in Ontario, and many institutions now provide primary care to a growing number of medically vulnerable older prisoners.<sup>104</sup> As Canada's Federal Correctional Investigator recently pointed out: "Prisons and jails were never intended to be nursing homes, hospices, or long-term care facilities... yet in Canada they are being required to fulfill those functions."<sup>105</sup>

These trends raise increasing concern that provincially incarcerated persons nearing or in their last stages of life may not be receiving the equivalent care they should, and as mandated under the *Canada Health Act* and the "Mandela Rules" for the treatment of prisoners.<sup>106</sup> It also raises concerns over a lack of clarity, consistency and accessibility of procedures facilitating release for prisoners nearing or in their last stages of life.

At present in Ontario, there is no strategy responding specifically to palliative and end-of-life care for prisoners. While elements of the recent *Independent Review of Ontario Corrections* (2017) touch on issues relevant to palliative care -- such as calling for a strategy to manage medications -- the Report does not take a holistic or comprehensive look specifically at palliative or end-of-life care, nor the potential

**"FINDING ANY NEXT OF KIN IS OFTEN DIFFICULT ENOUGH NEVER MIND A SUBSTITUTE DECISION MAKER. FACILITIES MAY NOT BOTHER CALLING THE SDM TO COMPLY WITH SUBSTITUTE CONSENT LAWS."**

– EXPERT ON INCARCERAL POLICY

**"IF AN INMATE IS SICK, GETTING EVERYTHING IN PLACE TO GET A VISIT CAN BE VERY DIFFICULT. INMATES SOMETIMES DIE BEFORE PAPERWORK IS ARRANGED."**

– EXPERT ON INCARCERAL POLICY

#### **WHO DID THE LCO CONSULT ABOUT INCARCERATED INDIVIDUALS?**

Our work reviewing the rights and access of incarcerated individuals to palliative care, end-of-life care, and MAID would not have been possible without the input of:

- Haley House staff and residents (Peterborough)
- Dalhousie Roundtable on Prison Health Law
- Howard Sapers and Andrea Monteiro, Independent Review of Ontario Corrections
- Dr. Adelina Iftene, Schulich School of Law at Dalhousie University
- John Howard Society of Ontario
- Physician providing Correctional Health Care
- Prisoners' Legal Services, British Columbia

for MAID requests. This is despite noting how other jurisdictions, such as the UK, include some consideration of palliative care and alternatives to incarceration for those receiving it.<sup>107</sup>

The applicability of these recommendations will become increasingly evident in the coming years. Ontario incarcerates around 50,000 individuals each year in 25 correctional facilities across the province. On any given day there are about 7,500 incarcerated adults in Ontario.<sup>108</sup> The population is quite transient: 91% of sentenced individuals served less than six months on a provincial sentence, and 57% served sentences of less than one month. The average length of detention for the remand population is around 43 days. But deaths still take place in custody. Ontario reported 25 incarcerated deaths in 2019, 26 in 2018, and 26 in 2017.<sup>109</sup> Prisoners face additional health risks following release, including reduced life expectancies compared to the general population. Efforts should be made to reduce the gap in mortality between people who experience incarceration and those who do not. Time in custody could serve as an opportunity to intervene to decrease risk, and link persons with appropriate services on release.<sup>110</sup>

**“I’VE NEVER HEARD OF ANYONE GETTING COMPASSIONATE CARE RELEASE OR ANYONE APPLYING FOR IT WHERE I’VE WORKED FOR 10 YEARS. IF IT EXISTS, THE FACT THAT A DOCTOR DOESN’T KNOW ABOUT IT SHOULD BE TROUBLING.”**

– PHYSICIAN PROVIDING  
CORRECTIONAL HEALTH CARE

Given these needs, recommendations 31, 32, 33, 34 and 35 propose a series of forward-looking recommendations that will better ensure alignment between health law rights and protections and equity in care for incarcerated individuals. These recommendations aim to establish:

- a timely, expeditious and reliable mechanism to facilitate compassionate release for palliative and end-of-life patients, such that the priority and process favors care outside the correctional facility
- equitable, discrimination-free access and reliable transfers into long-term care, hospice care, or half-way housing, along with extended systemic oversight review as “deaths in custody”
- policy and procedures in correctional facilities that ensure equitable health law rights for inmates by way of supporting advance care planning and the role of substitute decision making
- creation of policies that address the multidisciplinary primary health care needs of palliative incarcerated persons, and
- recommending further study as will support creation of a provincial corrections policy that responds to unique concerns including MAID requests

First, recommendation 31 states that Ontario amend the *Correctional Services and Reintegration Act, 2018* to establish a compassionate release provision and clarify that palliative and end-of-life care are bona fide reasons for temporary absences and compassionate release. Neither of the existing release mechanisms — an application to the Ontario Parole Board for parole, or a superintendent’s opinion that a temporary absence may be

granted where “necessary or desirable” for a prisoner on medical or humanitarian reasons” — satisfy the proactive and urgent care needs of persons with a progressive, life-limiting illness. Both mechanisms have been criticized by the Auditor General as having low participation rates.<sup>111</sup> Those the LCO spoke with noted several recurring concerns that the referral and review process is long and complicated, and individuals may die before paperwork is complete; that there is excessive rigidity with respect to the consideration of health-related criteria in regular parole hearings; and inadequate training of parole board members in relation to health issues. By way of follow-up, the 2016 Ontario Auditor General Report further emphasized that inmates did not have sufficient support when applying for parole or temporary absence, and [the then] Ministry of Community Safety and Correctional Services was not addressing the delays in completing the parole and temporary absence program applications or the reasons for the high denial rates.<sup>112</sup>

Current practices contradict the assumption of most LCO commentators that palliative care, end-of-life care, or MAID should be provided outside of a correctional facility. The LCO agrees that the principle of health care equivalency for incarcerated persons must be respected, and that providing palliative services inside a jail is challenging. Accordingly, in crafting a compassionate release mechanism, consideration should be given to ensure sufficient support at each correctional institution to assist inmates who want to apply for compassionate release. One option would be to create a model of care adopting a “designated care coordinator” role similar in concept to that recommended in the OPCN Delivery Framework. This role aims

### THE SHIFTING RESPONSIBILITY FOR HEALTH CARE SERVICES IN ONTARIO CORRECTIONS

The Independent Review of Ontario Corrections recommended the transformation of health care in Ontario provincial corrections in 2017, including transferring health service responsibilities to the Ministry of Health. The *Correctional Services and Reintegration Act, 2018*, would affirm the provincial government’s obligation to provide patient-centred, equitable health care services for individuals in custody. Notably, the act specifies that pregnant inmates shall be given the opportunity to give birth outside of the correctional institution (s. 58(2)). This would appear to reflect a dignity-based principle that could also recognize and apply to the provision of palliative care. Also unknown is how long-term care needs are now envisioned as part of this transformation. To date, the Act remains unproclaimed.

**“INMATES MAY BE DENIED ACCESS TO THEIR PRESCRIBED MEDICATIONS WHILE WAITING FOR A PHYSICIAN ASSESSMENT OR DUE TO LACK OF INVENTORY, WHICH MAY ALLOW THEIR HEALTH CONDITIONS TO WORSEN OR DESTABILIZE.”**

– PHYSICIAN PROVIDING  
CORRECTIONAL HEALTH CARE

to ensure that one person coordinate all care care, serve as the central point of contact for services and resources, and act as the patient and caregivers' advocate.

Recommendation 32 states that the Solicitor General create a "transitions in care" strategy to facilitate compassionate release. This strategy should address discrimination in eligibility to facilities including long-term care, hospices, half-way housing, and housing in general, and ensure oversight review as "deaths in custody." The LCO frequently heard that transfer and discharge planning is limited: "Jails may coordinate care with a designated hospital and usually have a backup. But there won't be any formal arrangements with any other health care providers. It's always case by case and that causes a lot of delay, problems, and a lack of awareness and expertise in-house with treatment and corrections staff." The LCO also heard that in transitions to "long-term care discrimination is a huge problem; they don't want the inmates and will find any excuse to invoke the safety of other residents despite the fact that the parolee was using a walker and was low risk."

Significantly, there are developments in this area in the federal corrections sector. Haley House is a 10-bed halfway house that assists older and ailing federal inmates by providing hospice care in a safe and secure environment.<sup>113</sup> Their program directly supports nearly a dozen inmates and supports all their medical and social support needs. A similar program for Ontario corrections would align with recommendations by the Auditor General noting the potential cost-effectiveness of reintroducing half-way housing for parolees to act as a bridge between the institution and the community through gradual, supervised release.<sup>114</sup> Related amendments to

the *Coroners Act* would broaden the definition of "death in custody" to include deaths involving the transfer of incarcerated individuals to a hospital, long-term care, hospice, halfway house, or on compassionate leave who might not be in the actual custody of a person employed at the correctional institution. Broadening the definition of "death in custody" to include individuals noted above would help identify prisoners as a distinct health care area and population, and better address palliative, end of life, and MAID needs in these populations.

Recommendation 33 states that the Solicitor General create a flexible communication and visitation policy that accommodates the timely involvement of substitute decision-makers of incarcerated persons. The LCO heard how "facilities and their procedures are simply not designed to contemplate the SDM decision-making process, much less basic privacy for having a confidential conversation." It takes between 24 hours to several days to arrange family visit, and if people show-up on an as-needed basis they are often told to leave. Scheduled visits are also often cancelled due to operational concerns, such as lockdowns. This can be very difficult for families, especially if they've travelled long distances and cannot simply come back the next day. We also heard that the role of substitute decision-makers is often ignored for incarcerated persons. This was attributed to restrictive and onerous visitor access procedures and timelines that simply don't meet the unpredictability of progressive, life-limiting illness and periods of incapacity. The minimization of the SDMs role as decision-maker encourages a culture in which rights may be overlooked. As one policy expert pointed out: "Despite 50,000 people passing through provincial corrections each year, it

is rare that attention is ever paid to consent and capacity laws unless the patient/prison themselves are not following recommended treatment. Patient inmates feel coercion if what they want might require more resources, or be seen as demanding, or annoying their superior.” Recommendation 33 would also improve the use of advance care planning, which is essential to understanding the specific wishes, values and beliefs of the prisoner as would better facilitate the earlier arranging of medical services to meet these needs.

Recommendation 34 states that the Solicitor General study and report on a strategy to address the primary health care needs of palliative incarcerated persons. This review should consider how to improve access to a palliative team including specialists, liaison relationships to local hospitals, and pain and medication management. Palliative care typically requires a collaborative, multidisciplinary team approach with close and constant monitoring and frequent sharing of health information between team members. Patient care frequently involves appointments to get specific assessments, consults with specialists, regular monitoring to changes in medication, the facilitation of pain management, and ongoing availability of prescriptions and medical equipment. The Ontario Ombudsman reports on several specific incidents in which incarcerated individuals have been denied access to prescribed medications for weeks while waiting to be assessed by a physician. Individuals also report not having access to pharmaceuticals for a range of conditions, including cancer and post-operative pain management.<sup>115</sup> These

challenges are compounded by a lack of digital health monitoring and records keeping, resulting in an episodic or reactive model of delivering care<sup>116</sup> and scattered, hand-written notes about prisoner health care.<sup>117</sup>

Some of these issues have been addressed at the federal level where palliative care, end-of-life care, and MAID policies have been introduced. For instance, where release to the community is not granted for incarcerated persons, Correctional Service of Canada (CSC) has palliative care guidelines which provide that a multidisciplinary team must be in place for each palliative inmate, along with a care plan and effective pain management. Notably, all these types of guidelines remain at the discretion of the facility and will only be accommodated “where possible.”<sup>118</sup>

Recommendation 35 states that the Ontario Solicitor General engage advocates and stakeholders in the study of a provincial corrections policy that responds to the unique circumstances and concerns related to MAID requests from prisoners. There is a very strong view among prison reform advocates that compassionate care should be provided outside of the facility. The complexities of MAID requests from prisoners raises significant questions about duress and coercion. It also invariably gives rise to questions about the mental health of the prisoner. Challenges in providing for the mental health of prisoners are very well known. The Solicitor General (and preceding Ministries) have seen multiple reports and reviews on the need for an overhaul.<sup>119</sup>

# SUPPORTING COMMUNITIES WITH UNMET NEEDS

## Recommendations to improve Care in Transition and in the Home

### 36 RECOMMENDATION

The LCO recommends that the Government of Ontario ensure smoother transitions in care for patients in their last stages of life by improving access to more robust hospice care and services to support care in the home.

### 37 RECOMMENDATION

The LCO recommends that the Ministry of Long-term Care ensure that LTC homes are resourced to provide quality end of life care for all residents.

### 38 RECOMMENDATION

The LCO recommends that the Ministry of Health expand the range of what patient transfers are defined as “medically necessary” specifically in relation to patients in their last stages of life to avoid downloading costs of travel onto patients. This should particularly address those defined as “high needs home care” patients.

### 39 RECOMMENDATION

The LCO recommends that the Ministry of Health undertake a systemic, comprehensive review of compensation models for health care workers serving patients in their last stages of life in home and community settings. This should review jurisdictional divisions (particularly between geographic “catchment areas” as well as between institutional and home care settings) that act as barriers to coordination and continuity of care and should review compensation that matches the needs of mobile providers.

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 within and between care settings increase distress for those who are already in an emotionally charged and difficult situation. Participants in LCO consultations identified numerous examples of inappropriate transitions for palliative and end-of-life patients, including:

- people are often transferred from one place to another when they require a higher level of care, rather than having services come to them
- people are pressured to discharge from hospital to their home without care in place, often related to the unavailability of space in long-term care or alternate level of care
- transitions between care settings can be lengthy, administratively confusing, stressful, and unexpectedly expensive, particularly for routine care and in rural and remote areas
- family members often request transfers to palliative care but are denied the opportunity to do so expediently
- transitions to long-term care for Ontarians with disabilities are perceived as a form of “re-institutionalization,” and 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 relate mainly to health care challenges and resource constraints. LCO commissioned



research found that most persons who die in hospital after a transfer from a private home had not been receiving home care services in the first instance. 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.<sup>120</sup>

The LCO is aware of forward-looking proposals to improve models of care for home care services. For example, the OPCN Delivery Framework recommends a designated care coordinator role. That role would follow patients in their last stages of life from the time they are diagnosed with a progressive, life-limiting illness, across transitions in care, and through the entire course of their treatment. Their role would be to ensure that individuals and their caregivers have a designated care provider to coordinate their care, who will be the central point of contact for services and resources and act as the patient and caregivers' advocate. They could better ensure patients and caregivers "experience seamless transitions in care that are coordinated effectively among settings and health care providers." This aspires to "regularly assess the patient and their family/caregivers' transportation needs to ensure that their access to care is not impeded."<sup>121</sup>

In a positive step, Ontario is seeking to introduce "a bundled care approach" in which services will follow individual patients, and "self-directed care" to enable patients and caregivers to receive an allowance for purchasing services from providers of their own choosing. Ontario is also giving greater priority to more "alternate level of care" beds to provide for higher needs patients neither suited to home or hospital care. And



ACROSS ONTARIO  
THERE ARE SOME

5000

**ALTERNATE LEVEL OF CARE  
PATIENTS IN HOSPITAL  
AWAITING TRANSFER TO  
HOME OR LONG-TERM CARE**

OTTAWA AREA  
HOSPITALS REPORT

1 in 5

**BEDS ARE OCCUPIED  
BY ALTERNATE LEVEL  
OF CARE PATIENTS<sup>122</sup>**

**"THERE IS AN INHUMANE PROCESS THAT REQUIRES PATIENTS TO WAIT MONTHS OR EVEN YEARS FOR A LTCH PLACE ONLY TO BE GIVEN 24-48 HOURS TO MOVE OUT OF THEIR HOME. INFO ABOUT WHETHER ONE CAN REFUSE A PLACEMENT IS OFTEN UNCLEAR OR DECEITFUL. THIS IS FINANCE DRIVEN RATHER THAN PATIENT NEED DRIVEN AND NEEDS TO CHANGE."**

– FAMILY CAREGIVER

**"LONG-TERM CARE IS REALLY LONGER TERM PALLIATIVE CARE. WHAT HAS NOT KEPT UP IS THE STAFFING AND SERVICE PROVISION. THESE REGULATIONS FOR LONG-TERM CARE ARE SERIOUSLY IN NEED OF REVISION."**

– NURSE WORKING IN LONG-TERM CARE

most recently, Ontario announced pilot projects that would give alternate level of care hospital patients direct priority access to a long-term care bed, with the Minister of Long-term Care noting that “One of the challenges facing our health care system is the length of time hospital patients wait to be discharged to long-term care homes.”<sup>123</sup>

Notwithstanding these developments, the LCO remains concerned that:

- individuals in their last stages of life may not have mandated, priority access to services at the time they are most needed
- medical transportation services do not reflect patient needs and result in unexpected costs that are at odds with systemic goals to provide more care at home and in place
- billing and jurisdictional silos in health care frustrate attempts to provide holistic, interdisciplinary and continuity of care across care settings, and
- expected deaths in the home can result in anguish where post-mortem services are not immediately available.

Recommendations 36, 37, 38 and 39 propose a series of actions to improve care in transition and in the home.

Recommendation 36 states that the Government of Ontario ensure smoother transitions in care for patients in their last stages of life by improving access to more robust hospice care and services to support care in the home. LCO consultations confirmed that there are many individuals in their last stages of life who are unable to transition from hospital or home to long-term care predictably, and on a priority basis when needed. Transitions in care is a major issue in

Ontario. There are over 600 long-term care facilities in Ontario with nearly 79,000 residents, and an admission wait list of 35,000 people.<sup>124</sup>

The LCO also heard from many how long-term care may not be the appropriate care setting for many in the last stages of life. For instance, more than half of long-term care residents are over age 85 and some 64% have dementia.<sup>125</sup> Comparatively, individuals in the last stages of life comprise a diverse range of ages and stages in life. While their care needs may be complex, chronic, and requiring 24/7 care, long-term care may not be the most appropriate care setting. LCO consultations confirmed that many would prefer care at home or in hospice. Hospice care has expanded significantly, with ongoing commitments to add hundreds of more hospice beds over the coming years.<sup>126</sup> Groups like the OPCN have also made a considerable number of recommendations to improve upon the model of care for home services and delivery. Greater support for hospice and home care is needed.

Recommendation 37 states that the Ministry of Long-term Care ensure that LTC homes are resourced to provide quality end of life care for all residents. When someone is admitted to long-term care, the LCO heard many concerns expressed that that necessary medical staff, equipment, medication, and expertise in

**“PSWS DO THE MAJORITY OF END OF LIFE CARE BUT THEY’RE NOT TRAINED TO DO IT. MEANWHILE REGISTERED STAFF MIGHT BE ONE PERSON OVERSEEING ABOUT 30-100 LTCH RESIDENTS.”**

– NURSE WORKING IN LONG-TERM CARE

supporting conditions at the end-of-life may not be readily available. In some cases, this can result in frequent transitions into hospital care; in other cases, it means service through itinerant services which may not incorporate an interdisciplinary team-based approach. Noting variations between facilities in “access to specialist providers, psychosocial support, medications and equipment,” the OPCN Delivery Framework finds that to better ensure “Residents in long-term care homes should have the same access to palliative care services as those in other community settings” there may be a need for “changes to existing legislation and/or regulations that govern long-term care homes.”<sup>127</sup>

Concerns with adequate staffing levels, a team-based model, training, and expertise were emphasized in the *Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System* (July 2019).<sup>128</sup> Recommendations there echo those proposed by the LCO, including the mandated expansion of funding parameters to meet the array of staff needed to provide quality care; adequate staff training, and team backfill capacity; the minimization of casual and agency staff; a funding for a broader array of interdisciplinary staff; and an emphasis on adequate staffing to meet resident safety needs.<sup>129</sup>

Recommendation 38 states that the Ministry of Health promote clarity in what patient transfers are “medically necessary” specifically in relation to palliative care in order to expand coverage for such care and avoid downloading costs of travel onto patients. The LCO heard that non-emergency medical transportation costs can be very high and are often borne by the home caregiver or family. These costs often do not

reflect the reality of getting frail patients to regular appointments, particularly in rural and remote communities. The LCO heard a telling example of an 87-year-old woman who made five trips to hospital in eight days, with two hours of travel each way. The LCO also heard many examples of end-of-life patient transfers being given low priority, resulting extraordinary delays in transfers from home to hospital or hospice. Some cited delays as long as 13 hours from the time of call. Palliative care nurses and hospice workers report that such patients arrive at the hospice in very bad shape and frequently near death. This is obviously very serious for the patient and family in addition to being very difficult for hospice workers.

**“DEFINITELY AMBULANCE TRANSFER COSTS. WHEN PATIENTS ARE TRANSFERRING FROM HOME TO HOSPICE THE FAMILIES MAKE THESE ARRANGEMENTS AND COVER THE COSTS. THIS IS A HUGE BARRIER FOR MOST AT END OF LIFE.”**  
— PALLIATIVE CARE PHYSICIAN

At present, only “medically necessary” ambulance transport is covered under the Health Insurance Act as an insured service. This can be subject to a \$45 co-payment fee, but the fee does not apply for inter-facility transport by ambulance (such as between hospitals, or from hospital to a long-term care home or to a home where the patient is receiving home care services). An emerging practice is for hospitals to use non-emergency, unregulated medical transport services for transports not deemed as “medically necessary.” In these circumstances, there are no restrictions on charges between care settings. The cost of these services in

most circumstances is billed to the patient and can range between \$300-500 for each transfer. These fees introduce inconsistency and inequity between communities where transport is provided by ambulance services and communities that rely on private transport. In the home care context, patients typically have no financial assistance in transfers to hospice. These are long-standing issues, having been reviewed by the Ombudsman of Ontario in 2011 and subject to renewed concern of the Patient Ombudsman as recently as 2019.<sup>130</sup> These fees are surprising to most caregivers, and are a disincentive to participate in provincial strategies favoring care at home. A review of “medically necessary” transportation might provide some consistency or lead to further modernization of patient transit services to align with provincial health care priorities.

Finally, recommendation 39 states that the Ministry of Health undertake a systemic, comprehensive review of compensation models for health care workers serving patients in their last stages of life in home and community settings. This should review jurisdictional divisions (particularly between geographic “catchment areas” and between institutional and home care settings) that act as barriers to coordination and continuity of care and should review compensation that matches the needs of mobile providers. This review should also consider necessary supplements to account for travel by mobile palliative home care providers in rural and remote areas. This is a key issue in developing community-based, mobile, and outreach teams that can follow the patient and provide continuity of service across different home and facility care settings. The LCO also heard about legal and regulatory barriers to billing; confusion about

integrating team members from hospital or community care sectors; “turf wars” between competing teams; reimbursement for travel costs and times; restrictions on how family health teams are formed that make it harder to establish a shared on-call system; family health team members being compensated at different rates under billing codes; and a reticence to consult on a team basis or with secondary level specialized assessments.

#### **CASE STUDY IN PALLIATIVE PATIENT TRANSFERS: THE PROVINCIAL PARAMEDIC PILOT PROJECT**

Sudbury and Peterborough are among 33 municipalities included in a new paramedic pilot program for Ontario that aims to demonstrate how greater flexibility better serves palliative home care patients. The provincial government announced a new 9-1-1 model of care in which eligible palliative patients can receive appropriate care directly by paramedic in their home or community facility as appropriate. This alleviates the need for physician or nurse visits; trips to the emergency department; and gives caregivers greater peace of mind that support is just a phone call away. The patient remains in control of the care they receive and can at any time request to be taken to the emergency department. If they agree, patients will be referred for follow-up care with their primary palliative care team or local hospice, and allows paramedics to be a part of a Community Palliative Care model within the municipality.<sup>131</sup>

### RECENT IMPROVEMENTS TO BETTER SUPPORT EXPECTED DEATHS IN THE HOME

A recurring issue in LCO consultations concerned the need to review the Coroner's Act and Vital Statistics Act to better facilitate a process for pronouncing expected deaths in the home and the expedited attendance of funeral service providers. Many caregivers experienced this as a significant barrier to supporting patients in the last stages of life to receive care at home. The Coroners Act requires the coroner or police to be notified where there is reason to believe that the death was suspicious or requires investigation. The LCO heard that funeral services routinely ask family members to obtain a death certificate before they will transport the deceased. Death certificates can only be issued by one of three professionals: a physician, nurse practitioner or the coroner. Delays in obtaining such certificates can cause suffering for grieving families and create a barrier to planned deaths at home. The Vital Statistics Act also creates some restrictions on how the deceased can be treated, requiring documentation before burial, cremation, funeral services, and transportation outside a municipality can occur.

To address these issues, some communities implemented local programs, often referred to as "expected death in the home protocols" (EDITH protocols). But while highly regarded, these protocols created a patchwork of jurisdictional arrangements and inconsistency across the province. Subsequent to our consultations, the government of Ontario took steps beginning in 2020 to create an electronic process in which primary care physicians and nurse practitioners are able to send a medical certificate of death from their desktop to the funeral home via a private portal and secret passcode. The form allows the funeral home to access the body and death certificate and thus expedite attendance. This service is slowly rolling out across Ontario and expanding in long-term care homes.<sup>132</sup>





# SUPPORTING COMMUNITIES WITH UNMET NEEDS

Recommendations to support  
equity-seeking groups and  
isolated individuals

## 40 RECOMMENDATION

The LCO recommends that the Ministry of Health amend The People's Health Care Act, 2019 and the Connecting Care Act (enacted as Schedule 1 to Bill 74) to require any Ontario Health Team which provides palliative and end-of-life care to develop equity, access, and engagement plans for vulnerable groups in the service area. This should consider the needs of homeless and precariously housed, inmates in provincial detention centres, immigration and refugee communities, linguistic and cultural communities, disability communities, and persons with mental illness.

## 41 RECOMMENDATION

The LCO recommends that the Ministry of Health review access to palliative care services for individuals with unclear status as non-resident or non-registered resident, refugee, or immigration status, particularly in relation to eligibility for personal support worker services; waiting periods for OHIP coverage; eligibility and funding for home and community care; funding for such patients in hospices; and funding for access to necessary medications, equipment, etc.

## 42 RECOMMENDATION

The LCO recommends that the Ministry of Health amend the *Health Insurance Act* and the *Home Care and Community Services Act, 1994* so that a person who moves to Ontario from another province or territory and who had public health insurance in the province or territory will not be subject to any waiting period for funded palliative care services under the Act that may otherwise be applicable to new Ontario residents.

## 43 RECOMMENDATION

The LCO recommends that the Ministry of Long-term Care update the language of the Patient Bill of Rights #19 to include LGBTQ2+, BIPOC, and other equity-seeking groups to strengthen the commitment to diversity, equity, and inclusion in long-term care facilities.

## 44 RECOMMENDATION

The LCO recommends that to improve existing anti-oppression and anti-discrimination training undertaken by, for example, AdvantAge Ontario, the Ontario Long-Term Care Association, the College of Physicians and Surgeons, the College of Nurses, and the Ontario Personal Support Worker Association, such training is to involve acknowledged experts on LGBTQ and HIV+ discrimination in health care, such as the HIV & AIDS Legal Clinic of Ontario, and other groups.

## 45 RECOMMENDATION

The LCO recommends that the Ministry of Health facilitate the creation and implementation of a palliative pediatric hospice strategy to ensure access to end-of-life care for terminally ill children across Ontario.



Ontario is committed to equality in access to quality care in the last stages of life, regardless of factors such as age, sexual orientation and identity, socioeconomic status, culture, ethnicity and place of residence. Accordingly, laws, policies and programs must be sufficiently flexible to address diverse experiences in a manner that is consistent with rights and principles established under the Canadian *Constitution* and *Ontario Human Rights Code*, among other legal frameworks. Broadly speaking, these frameworks include:

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

Unfortunately, the generality of these provisions, and their lack of specificity about palliative and

end-of-life care, create a persistent gap in efforts to ameliorate equity in access. Recent government reviews of palliative care confirm that Ontarians suffer marked disparities in accessing quality care in the last stages of life. For instance, the Declaration of Partnership (Ontario's vision for palliative care), the Auditor General report on palliative care, and the Fraser Report identify inequalities based on a variety of factors.<sup>133</sup> The OPCN Delivery Framework makes recommendations proposing an ideal model of community service and delivery to "improve equitable access for patients and caregivers and ensure that they are able to receive the holistic, proactive, timely and continuous care and support they need through the entire spectrum of care" with a close look at the unmet needs particularly of homeless, francophone and Indigenous communities.

These and other documents attest to Ontario's commitment to achieving equality in palliative care. The LCO believes that any future strategy should further existing commitments. Importantly, any such strategy must place at its heart the dynamic relationship – sometimes tension – between standardized approaches and ensuring tailored approaches which meet the unique needs of individuals, families, and communities. In this manner, palliative care should recognize a set of core principles for treatment and accompaniments as well as the necessity of person- and family-centred approaches in each specific case. Consistent with "personalization" in palliative care, the LCO also believes that care in the last stages of life must respond to Ontario's diverse communities. Each community must be recognized at the

local level and engaged in defining the services and programs that meet their needs, including:

- First Nations, Inuit and Métis
- Newcomers to Canada
- Incarcerated persons
- Persons with HIV
- Persons with mental health
- Persons with low income
- Children and infants
- Under-housed persons

To ensure Ontario adopts measures to ensure tailored approaches to care for these and other specific communities with unmet needs, recommendation 40 states that the Ministry of Health amend legislation guiding the health system transformation to require Ontario Health Teams incorporating palliative and end-of-life care services to conduct an equity and access assessment of vulnerable populations in the service area and account for persons who are often not identified for palliative care. This assessment should include consideration of the homeless and precariously housed, inmates in provincial detention centres, immigration and refugee communities, linguistic and cultural communities, disability communities, and other equity-seeking groups. Consistent with LCO's earlier recommendations regarding public health palliative care, this review should engage local equity seeking groups in defining accessible services that meet unmet needs.

The LCO intentionally focused on specific communities to make targeted recommendations about their unique circumstances. The next two recommendations address the needs of mobile populations. First, recommendation 41 states that the Ministry of Health review

access to palliative care services for individuals with unclear status as non-resident or non-registered resident, refugee, or immigration status. Ostensibly some services are in place for persons without an OHIP number, but the gaps are multiple. For instance: home care for people living in precarious rooming or illegal housing; eligibility for personal support worker services; waiting periods of six months for OHIP coverage; a lack of hospice funding resulting in refusal of service and hospital admission; and a lack of funding for access to necessary medications or equipment. The LCO heard these are frequent problems that repeatedly arise.

Recommendation 42 states that the Ministry of Health amend the Health Insurance Act and the Home Care and Community Services Act, 1994 so that a person who moves to Ontario from another province or territory and who had public health insurance in the province or territory will not be subject to any waiting period for funded palliative care services. Many palliative people return home to Ontario to spend their last days in the comfort of friends, family, and familiar places. But OHIP eligibility creates a 90-day barrier to eligibility for coverage. A private member's bill was introduced to address this, but "Dan's Law" only exists in regulation and can be varied or amended. Subsequently, and due to the COVID-19 pandemic, Ontario suspended the 90-day interprovincial wait time for OHIP eligibility. For greater certainty, recommendation 42 would see this exception codified in legislation, and aligned with recommendation 1 to establish a standard definition of "palliative care" that applies across government.

Among those who find themselves isolated are some members of Ontario's HIV-positive and LGBTQ communities. Over 68,000 individuals are currently living with HIV in Canada, 14% of whom are unaware of their HIV status.<sup>134</sup> Around 30,000 live in Ontario and there are around 1,000 new diagnoses each year.<sup>135</sup> Some of these individuals "struggle with low incomes, unemployment, depression, substance use, cognitive impairments, and stigma."<sup>136</sup> Further, the onset on HIV-associated neurocognitive disorders (HAND) is younger than those with Alzheimer's disease and prevalence is high: 50-60% for milder forms and 2-3% for more severe forms.<sup>137</sup> Accordingly the LCO heard concerns for equitable care in long-term care. Participants highlighted the need to address vulnerabilities arising from intersecting stigma related to dementia, HIV diagnosis, and LGBTQ status in long-term care facilities. These can result in discriminatory eligibility and significant discrimination in care. The greatest and most consistent concern we heard was for treatment in long-term care. Existing expectations and protections under the Human Rights Code were said to be too weak to change a culture of fear and discrimination among LTCH operators and staff. Moreover, the burden of addressing the discrimination often fell to the patient themselves. Given their health condition, this puts patients in the impossible position of having to assert their legal rights and commence a human rights complaint process. Patients spoke of the fear in being seen by their caregivers and treatment team as a non-compliant troublemaker. Patients also often fear reprisals that diminish the level and quality of care received.

To address this systemic challenge, improve staff and operator knowledge about HIV/AIDS, and change the culture in long-term care, the LCO makes two recommendations. Recommendation 43 states that the Ministry of Long-term Care update the language of the Patient Bill of Rights #19 to include LGBTQ2+, BIPOC, and other equity-seeking groups to strengthen the commitment to diversity, equity, and inclusion in long-term care facilities. The language of this provision is discriminatory and does not assist in setting a standard for training, care, or compliance and enforcement compatible with Ontario human rights frameworks. The LCO further makes recommendation 44 in order to improve existing anti-oppression and anti-discrimination training undertaken by, for example, AdvantAge Ontario, the Ontario Long-Term Care Association, the College of Physicians and Surgeons, the College of Nurses, and the Ontario Personal Support Worker Association, such training is to involve acknowledged experts on LGBTQ and HIV+ discrimination in health care, such as the HIV & AIDS Legal Clinic of Ontario, and other groups.

**"I HAVE A MEETING WITH THE ENTIRE PSW CONTINGENT AT A HOME CARE ORGANIZATION TO EDUCATE THEM ABOUT HIV AND HEP-C. THIS NEEDS TO BE ONE OF THE MANDATORY TRAINING COMPONENTS. WE'VE DONE 40 SESSIONS THIS YEAR BUT AND IT'S ALWAYS NEW STAFF. TURNOVER IS HUGE."**

— PALLIATIVE FACILITY OPERATOR

The LCO also believes it is important to better support children and infants who are receiving care in their last stages of life. It goes without saying that parents, family, caregivers, and health professionals working with children in their last stages of life are extraordinary. They should be first and foremost in the mind of anyone reviewing LCO's earlier recommendations related to caregiver and health professional needs, especially more flexible employment supports and leave, the availability of respite care, a team-based model of continuous care, and easier access to mental health and grief supports. As a result, the LCO reiterates our finding that much more needs to be done to support the resourcing, care planning, and care team management on behalf of parents of children in their last stages of life. Recommendation 45 goes further, and restates the broad consensus that the Ministry of Health should facilitate the creation and implementation of a palliative pediatric hospice strategy to ensure access to end-of-life care for terminally ill children across Ontario. As one pediatric palliative physician noted: "There are "dead zones" where the hospital team cannot find community based pediatric palliative care, and many hospices will not take patients under age 18 or only serve their area." Services offered through existing hospices should be expanded to ensure equal access for children in their last stages of life everywhere in Ontario. This strategy should acknowledge the choices families often make in these circumstances. For many the death of a child is unnatural, and unlike adults, the preference is to die outside the home in hospital or hospice.

**"OUR CLIENTS CAN'T GET INTO LONG-TERM CARE. ONCE YOU'RE HOMELESS IT'S BASICALLY AN EXCLUSION CRITERIA: BEHAVIOURAL, ADDICTIONS, POT, MENTAL HEALTH, SMOKING... THE PATIENTS WITH DWINDLING DISEASES WON'T GET INTO LONG-TERM CARE."**

– COMMUNITY HEALTH CARE WORKER

#### **THE SIGNIFICANT DISTINCTIONS BETWEEN PEDIATRIC AND ADULT PALLIATIVE CARE**

The LCO heard about the many and significant distinctions between pediatric and adult palliative care. For instance, discussions about death and dying must be approached much more cautiously. Many children are incapable of having such conversations, while others can do so with special supports. Decision-making and conflicts are also managed differently. One physician told the LCO that "the pediatric context is unique because parents are always around. So the decision makers are always present and issues of capacity and consent do not typically arise." A final example is the preference in where to die. Whereas a majority of adult palliative patients prefer not to die in hospital, the LCO learned that preferences in the pediatric context are about equally divided between home, hospital or hospice.

During our many consultations, the LCO often heard about the needs of the socially isolated. Nearly 30% of Canadians now live alone – the highest proportion in history.<sup>138</sup> Many of these individuals are neither lonely nor socially isolated. But those who are face significant risks. Research has linked social isolation and loneliness to higher risks for a variety of chronic conditions: high blood pressure, heart disease, obesity, a weakened immune system, anxiety, depression, cognitive decline, Alzheimer’s disease, and even death.<sup>139</sup> When chronic conditions turn to palliative or end-of-life considerations, isolated individuals rely on the substitute decision-maker of last resort – the Public Guardian and Trustee (PGT). The LCO heard from many individuals and organizations that there are many ways in which the PGT could take proactive measures to better engage isolated individuals. A common sentiment among those the LCO consulted with was reflected in the comment of one palliative care physician: “The HCCA says the PGT is the default person. And it isn’t uncommon for someone to never have an SDM. But you can’t talk to PGT about ACP. PGT often only wants to deal with financial aspects, not health consent... and only during business hours.”

This perception is driven, in part, by misunderstandings about the PGT’s mandate. The earlier discussion about recommendation 8 notes how the PGT’s mandate often only comes into effect when a patient is incapable of making a decision. Additionally, the PGT has authority to deal with health care matters when the PGT is guardian of the person or when mandated under the HCCA. The PGT treatment decision consultants are available seven days a week. However, when the PGT’s authority is property

guardianship only, the PGT does not have authority to address health care matters and staff are only available during business hours.

Some of these concerns are discussed in an earlier report of the LCO. Our 2017 ***Final Report on Legal Capacity, Decision-Making and Guardianship*** includes recommendations related to substitute decision making and the role of the PGT.<sup>140</sup> These emphasize procedural rights and accommodation in capacity assessments; mandating rights information in standard forms; expanding independent rights advice; expanding the responsibilities of long-term care homes in promoting consent and capacity rights and compliance; licensing system for professionalized substitute decision-makers; and a more sustainable mandate for the PGT in relation to those without an SDM.

A key recommendation in that report was that the Government of Ontario conduct further research and consultations towards the goal of enabling community agencies — who often know the person best — to provide substitute decision-making for day-to-day decisions, such as basic budgeting, bill paying and accessing supports and services, through a program which includes:

- a process for identifying appropriately qualified community agencies
- clear standards for quality assurance, accountability, avoidance of conflicts of interest, and responding to abuse
- oversight mechanisms, including reporting and audit requirements, and
- dispute resolution mechanisms.

The LCO has concluded that enabling community agencies in this manner would greatly benefit socially isolated individuals receiving care in their last stages of life. Community agencies are ideally suited to liaise with the PGT to engage socially isolated individuals on issues including ACP, care and treatment preferences, goals of care, and generally improving ongoing communication between the care team and the PGT as SDM (having obtained the necessary consent to do so). It was also brought to the LCO's attention that children who are in their last stages of life and under the care of the Children's Aid Society may similarly benefit from this type of initiative. It was noted that staff often know best what the preferences, wishes, values and beliefs of the child may be, but they are precluded from voicing how they feel and what they think when it comes to end-of-life decisions.

**“OTHER PALLIATIVE CARE AGENCIES HAVE DECLARED AREAS OF THIS CITY A ‘NO GO ZONE.’ IF YOU OVERLAY SOCIO-ECONOMIC STATUS IT’S ALL THE POOR AREAS. WE’RE STRUCTURALLY CREATING BARRIERS TO PALLIATIVE CARE... DEATH IS VERY MUCH A SOCIAL JUSTICE ISSUE.”**

– COMMUNITY PALLIATIVE CARE PHYSICIAN

## **HOW WILL AN EQUITY AND ACCESS REVIEW HELP COMMUNITIES WITH UNMET NEEDS? THE PEACH EXAMPLE**

The *Declaration of Partnership* recognizes that homeless persons are marginalized and require a better government response to ensure equitable access to care in the last stages of life. The *Fraser Report* also mentions homelessness in cautioning the health care system to “be flexible when delivering care to: patients who are homeless who may lack proper identification, health card or places for providers to visit...” While Ontario has made some progress in attending to these issues and to bridge the gaps that affect this particular community, initiatives to address their needs tend to be discrete and independent projects rather than systemic initiatives.

Nonetheless, groups like PEACH show how such programs can transform lives. PEACH is a supportive palliative service fostered by Inner-City Health Associates (ICHA). PEACH operates as a “trailblazing” mobile unit, providing attentive care on the streets, in shelters, and with community-based service in collaboration with Toronto community health providers. PEACH understands how discharge from hospital to inappropriate settings, such as hotels or shelters, as well as the earlier onset on chronic conditions and age-related illnesses, demonstrate how care in the last stages of life is very much a social justice disorder.<sup>141</sup>



# SUPPORTING COMMUNITIES WITH UNMET NEEDS

## Recommendations to Improve Medical Assistance in Dying in Ontario

### 46 RECOMMENDATION

The LCO recommends that the Ministry of Health expand the MAID Care Co-ordination Service telephone line to assist with the administration, coordination, and oversight of an application and any requested services.

### 47 RECOMMENDATION

The LCO recommends that the Ministries of Health and Long-Term Care tailor OHIP allowances for travel and administrative requirements to align with the practical requirements of providing medical assistance in dying on a mobile basis.

### 48 RECOMMENDATION

The LCO recommends that the Ministry of Health ensure greater equity in access to medical assistance in dying by reviewing protocols governing the availability of required drugs in rural and remote areas.

### 49 RECOMMENDATION

The LCO recommends that the Ministry of Health, Ontario Health, and the Ontario Mental Health and Addictions Centre of Excellence require and support all public hospitals designated as Schedule 1 psychiatric facilities under the Mental Health Act to develop and implement protocols for assessing medical assistance in dying requests from patients.

The LCO's final recommendations in this section improve the provision of medical assistance in dying for Ontarians. Recommendation 46 states that the Ministry of Health explore options to turn the MAID Care Coordination Service into a full-featured case management system. This recommendation mirrors recommendation 27, described earlier. Provinces such as Alberta demonstrate the value of this role in reducing the administrative burden of initiating, assessing, coordinating and reporting on every request for MAID.

Mobile health providers are effectively burdened with coordinating the totality of care while operating out of the trunk of the car. In urban, suburban, and rural areas their travel time and expenses are not adequately compensated in current OHIP billing allowances. Moreover, many necessary drugs are inconsistently or not readily available in rural areas. These factors contribute to inequitable access: MAID may be more likely to be taken up in higher-income postal codes than others.<sup>142</sup>

Finally, the LCO is aware that psychiatric inpatients face challenging circumstances in making MAID requests. Their unique circumstances would benefit from consistent policy and access procedures on behalf of all "Schedule 1" psychiatric hospitals in Ontario. Anecdotally, however, only very few hospitals have made efforts to develop any such policy.

# RESOLVING DISPUTES

## Recommendations to reduce and better resolve conflicts in the last stages of life

Death, dying, and bereavement are highly emotional and important experiences for everyone involved – patients, family, friends and health care providers. Conflicts in the last stages of life may revolve around health care decision-making, a preference for treatment, 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.

Finding ways to better resolve disputes in the last stages of life was among the most frequently discussed topics in LCO's consultations and a concern shared equally by health care practitioners and the public. As one palliative care physician stated it plainly: "Resolving SDM disputes is the biggest problem with end-of-life care." But practitioners were frank that the ethical, medical, and legal issues arising in the last stages of life "are nuanced and are not straightforward to anyone." Even prior to the COVID pandemic, there was unanimity among those who spoke with the LCO that: "the frequency of these issues in these circumstances is increasing. People are more aware of their rights and question the wisdom of health care provider. Faith and cultural conflicts arise too, and sometimes within the families themselves as well as with care providers." The pandemic has obviously accelerated these issues.

The LCO considered many issues that give rise to disputes in the last stages of life. In our public engagement we asked about conflicts related to:

- withdrawing treatment, typically against SDM wishes or values
- withholding treatment where contraindicated, futile or against the standard of care, including CPR and issuing "Do Not Resuscitate orders" without consent
- palliative sedation, including voluntary stopping of eating and drinking
- determinations of "death" against values, culture, or faith
- the need for greater clarity around the meaning of "best interests" decision making specifically in the last stages of life, and in relation to concepts like beneficence and non-maleficence
- limitations or confusion about the role of the PGT in resolving conflicts between SDMs
- minimizing the causes of disputes and increasing awareness of resolution mechanisms
- increasing access to early dispute resolution mechanisms

These are challenging and long-standing issues that exist at the intersection of law, medicine, and deeply held personal and community convictions. The LCO acknowledges the complexity of these questions and the lack of agreement on many, perhaps most, of these issues. The discussion that follows identifies areas of consensus where we have found it. The discussion also highlights areas where further engagement by regulatory, governance and standards organizations is needed.

### Key themes in LCO consultations

➔ **Theme 1: Faster access to a “step up” in/formal mediated dispute resolution mechanism for issues arising at the end of life.** Many participants noted how some health care facilities benefit from having a “step up” dispute resolution and education process for SDMs. This typically involves a third party entering a conversation between SDM and treatment team that has become polarized. Facilities may provide this assistance through bioethicists, risk managers, social workers, or spiritual chaplains, who step-up to provide guidance to both SDMs and staff, and before resort to the CCB is made. There was a very broad consensus that a province-wide, on-demand rapid information service could greatly help transform disputes into a consensus-seeking.

➔ **Theme 2: A modernized dispute resolution mandate for the Consent and Capacity Board (CCB).** Many people believe the mandate of the CCB to address conflicts in the last stages of life is ambiguous. As a result, many patients, SDMs and practitioners admitted to “trying to shoe-horn CCB applications in hopes the Board sorts it out at hearing.” Common conflicts where people are unable to apply, or where the board may decline jurisdiction, include: conflicts between SDMs involving Powers of Attorney; when physicians seek to withdraw life support where “death” is contested; patient desire to trigger a “Form G” when wishes aren’t being followed by treatment team; and when Form C applications take so long that the person in question dies.

➔ **Theme 3: A made-in-Ontario guideline for palliative sedation.** Palliative sedation therapy is an end-of-life treatment that is clinically and legally accepted in Canada. It 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. This may involve continuous palliative sedation, which provides therapy until the person dies. Palliative sedation therapy raises significant ethical concerns but is not currently the subject of a specific or separate regulatory regime in Ontario or any recognized province-wide guideline.



# RESOLVING DISPUTES

## Understanding the legal sources of conflict in the last stages of life

Under the *Excellent Care for All Act, 2010*, Ontario 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, bioethicists, social workers, spiritual chaplains, or may involve legal counsel on behalf of the hospital or health team. We heard that privately retained lawyers or patient advocacy services are the exception: most families or SDMs act on their own. Some facilities also support medico-legal partnerships involving legal aid clinics or law student volunteers who attend at hospitals or other facilities to provide legal information and advice about a wide range of issues, though generally not in regard to patient advocacy within the health facility itself.

Dispute and investigatory mechanisms are also available in other contexts. For instance, complaints may be filed with the Director of a long-term care facility in relation to abuse, neglect or negligent care, or to a home and community care agency. The Patient Ombudsman additionally serves as an office of last resort. Complaints about care may also be made to regulatory health colleges and reviewed by the Health Professions Appeal and Review Board. However, the majority of LCO participants were less concerned with practice

standards than expeditiously resolving the conflict at hand. The LCO learned that a majority of these conflicts arose in relation to legal ambiguities around consent, substitute decision making, withholding treatment, and practices around palliative sedation.

The Consent and Capacity Board (CCB) adjudicates disputes about capacity and decision-making, including issues surrounding the suitability of a substitute decision-maker’s (SDM’s) provision of consent for end-of-life treatments. But not all issues arise in the same way or fall clearly within the jurisdiction of the Board. The array and complexity of these issues became readily apparent during the LCO’s engagement.

In Canada, it is legal for capable persons to refuse life-sustaining and lifesaving treatment and for SDMs to do so on behalf of a person who is incapable. Consent must also 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 treatment to the patient or SDM if the provider believes it would not benefit the patient. Nor is the law clear if and when patients or SDMs can insist on treatment when health care providers do not agree, often on the basis of futility or as against the standard of care.

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.

Health care providers object to the prospect that they may be required by law to provide treatment they believe contravenes their professional and ethical responsibilities. They pointed to the absurdity of “slow codes”: situations where practitioners know CPR is futile but go through the motions to satisfy the demands of the family or SDM. Practitioners told the LCO about many similar circumstances, such as administering pointless medications (despite escalating side effects or inefficacy); introducing life sustaining measures despite brain death or other major organ failure; and doing surgeries despite a prognosis of just a few days or weeks to live, or during brain death.

The law is clear that SDMs must consider the patient’s prior capable wishes, values, and beliefs, if known and applicable. If these are unknown, the SDM will 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. At present, Ontario’s HCCA does not provide guidance on how these diverse factors should be balanced, or if the issues are different at the end of life.

Concern was also raised with the legal ambiguities of palliative sedation. Palliative sedation therapy is an end-of-life treatment that is clinically and legally accepted in Canada. It 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. This may involve continuous palliative sedation, which provides therapy until the person dies because of the natural course of illness; or 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. Palliative sedation therapy raises significant ethical concerns, especially when it is provided continuously. Palliative sedation is therefore a distinct kind of medical care, but one which is not currently the subject of a specific or separate regulatory regime in Ontario. Among other provinces, Quebec is notable for having a legislative regulatory regime for palliative sedation.<sup>143</sup> The common law is also of little assistance. 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 Ontario, it is unclear whether SDMs can refuse consent to the provision of food and water and through means of artificial nutrition as part of palliative sedation. This uncertainty includes whether individuals can rely on their own prior expressed wishes to die in this manner. If

**“SDMS FEEL CONFLICTED  
BETWEEN PRIOR WISHES  
AND WHAT A DOCTOR IS  
SAYING IS FUTILE. YOU  
END UP WITH EMBEDDED  
MISUNDERSTANDINGS ABOUT  
CARE, TRANSITIONS, AND WHO  
MAKES THE DECISIONS.”**

– HEALTH LAW LAWYER

SDMs cannot refuse consent to the provision of food and water, there could be potential inconsistencies with laws that permit SDMs 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? There have been a few cases from across Canada on these issues, but the implications for Ontario may be limited.<sup>144</sup> Facts related to condition and care can be very specific, and differences in provincial consent and capacity law and other related laws may narrow the applicability of these findings.

There is another important ethical concern regarding palliative sedation: 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. Notwithstanding this, LCO has been told that that some patients, family, and friends request palliative sedation as a form of medical assistance in dying.

Finally, the introduction of MAID legislation has caused some to worry that elements of palliative sedation may now be considered criminal.<sup>145</sup> As a result the Canadian Society of Palliative Care Physicians recommends “that all physicians create or adopt a specific policy on CPST for their practice group or institution.”<sup>146</sup> Notwithstanding this recommendation, CSPCP guidelines on palliative sedation have not been significantly updated since 2012. There is thus considerable variation in policies and guidelines in use in

Ontario and across Canada.

Health care practitioners consistently advised the LCO that the legal framework and regulatory college policies governing withholding treatment and palliative sedation are ambiguous, and do not consider realistic circumstances that routinely arise. Further, where the practitioner’s view of the standard of care is contrary to patient or SDM demands, or is medically futile, decision making by the practitioner may be inconsistent and less than transparent. Finally, patients and SDMs may make demands that would place the practitioner in violation of medical ethics or the standard of care.

Not surprisingly, these situations create tension and conflict between patients, families, caregivers and health care practitioners. This tension was articulated by one palliative physician: “We want the end-of-life experience to be with the least amount of suffering as possible; we want this process to go well, and we generally find discussions are the best way to do it but some physicians believe discussions are a waste of time and a problem and that it should be a unilateral decision.” Other palliative physicians spoke of the need to develop a collaborative relationship with the patient and decision-makers: “The idea that the medical standard should trump families’ wishes and goals is wrong because the medical standard is always changing. If that was the case, we would never progress as a field [...] Our goal is not to get families to sign DNR papers; we care less about choices families make and more about establishing good relationships with families to make sure they’re thinking ahead of time of potential outcomes so that they come out of the process with the least amount of regret as possible.”



Some practitioners sought opportunities to draw clearer boundaries within existing legal frameworks, particularly around the role of SDMs in the palliative care context. For instance, some practitioners favored legislative amendments that would clarify conditions where their authority to withhold treatment is confirmed or presumed, and the onus to challenge the decision is placed on the patient or SDM.

Other practitioners sought a greater fiduciary duty on SDMs. Generally, under the HCCA, SDMs only need be “willing and available” to fulfill their role, and to make decisions consistent with the “best interests” of the patient. Across the province there is substantial variation in how these terms are interpreted. “Available” for some facilities means immediately, on-call, or in two days, or in reply to registered mail. Some suggested that the HCCA capacity test requiring an ability to appreciate the “reasonably foreseeable consequences of a decision or lack of decision” be explicitly part of an SDMs capacity to act.

The debates on these issues are complex, consequential and often polarized. The LCO is wary of legislation or policy changes in these areas in the absence of a clear public mandate and social licence to do so. The LCO believes these issues will remain unsettled and will often require focussed and specialized consultations. That said, the LCO believes it is possible to improve dispute resolution processes if and when these issues appear. Before doing so, however, it is necessary to take a closer look at the role of the Consent and Capacity Board.

**“WHEN FAMILIES ARE TOLD ‘NO, THIS IS A MEDICAL FUTILITY DECISION AND YOU DON’T HAVE A CHOICE’ THERE IS MIXED MESSAGING AND A LACK OF CONSISTENCY. THIS HEIGHTENS THE ADVERSARIAL NOTION. ONCE PEOPLE ARE TOLD THEY CAN’T HAVE SOMETHING IT’S MORE DIFFICULT TO REACH A RESOLUTION.”**

– PALLIATIVE CARE TEAM LEAD

### WHO DID WE CONSULT WITH ABOUT RESOLVING DISPUTES?

Resolving disputes was among the most frequently discussed topic in LCO’s consultations. Groups with whom it was a focus for sustained discussion include:

- Consent and Capacity Board
- Public Guardian and Trustee
- Joint Centre for Bioethics, University of Toronto
- Ontario Bar Association
- St. Catharines Families
- OPCN Network
- Palliative Sedation Experts Roundtable
- Mental Health Legal Committee
- Law & Mental Disorder Association
- SickKids Pediatric Palliative Care Team
- NiagaraHealth Group St. Catherine’s Hospital Grand Rounds
- Palliative Care Coalition Nurses
- Registered Nurses’ Association of Ontario

The CCB was established as an independent, expert administrative tribunal with jurisdiction over issues raised by the HCCA (along with issues under other statutes, including the SDA and MHA).

In context of last stages of life issues, the CCB may hear applications to:

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

A study of CCB decisions concerning the determination of a patient's best interests in end-of-life situations identifies several prominent themes.<sup>147</sup> In such cases, health care providers typically suggest that life-sustaining treatments be withdrawn, while SDM's typically disagreed. The study found that "SDMs frequently relied

on their own values and religious beliefs in their interpretations of best interest, and that [providers] focused primarily on clinical condition of the patient."<sup>148</sup>

The CCB has broad remedial powers, based on the application at hand, which may include affirming an SDM's decision, appointing a representative to make a treatment decision under the HCCA, or substituting a different decision about an incapable person's treatment. In the area of end-of-life treatment decisions, the CCB often makes decisions considering a patient's best interests in light of HCCA requirements and the facts of the case.

The CCB prioritizes expeditious resolutions: hearings must commence within seven days of an application and decisions must be rendered within one day of the conclusion of the hearing. Decisions of the CCB may be appealed to the Superior Court of Justice. Notwithstanding these objectives, the LCO heard many criticisms about the timeliness, availability, complexity, and adversarial nature of a CCB proceeding regarding the last stages of life.

During our consultations, the LCO heard considerable interest in alternative dispute resolution methods that can be accessed prior to initiating administrative procedures, such as an application to the CCB. These consultations confirmed how dispute resolution mechanisms must be expedient and procedurally simple when end-of-life decisions and services are at stake.

As a practical matter, most dispute resolution in this context already takes place through internal or informal processes. Stakeholders told us that

**"I WORK IN ICU. THE CCB PROCESS IS TIME CONSUMING. NOT FOR ME, BUT THE PHYSICIAN MUST TAKE A LONG TIME OUT OF THEIR PRACTICE. THERE HAS TO BE A FASTER AVENUE."**

– ICU NURSE

most disputes are resolved within a person's care setting, typically through good communication between health care providers, patients and SDMs. To support these efforts, health facilities, such as hospitals, may have internal policies and procedures to promote good communication and to resolve conflicts within their facilities. These practices can offer a low-cost and non-adversarial means of resolving issues. Notably, the practices discussed above are consistent with the CPSO's guidance on managing conflicts in its policy on end-of-life care. For example, the CPSO's policy requires physicians to take specific steps to minimize and resolve disputes.

However, more intractable, high-conflict cases do occur. As one practitioner said: "It's complicated. But ironically the vast majority of my cases go fine. Even when there's never been a discussion, people usually have common sense and realize what's happening and most people we don't have huge conflicts. It's the minority of cases that become nightmares."

High conflict cases highlight shortcomings of existing informal resolution process that might make any case more difficult, or the outcome less satisfying and transparent. For example, the implementation of statutory requirements for a patient relations process may be different in each facility. When the LCO asked participants what policies and programs are used most commonly to resolve disputes nearing the end of life, most participants could not identify the dedicated or specific policies/programs within their facilities.

Moreover, many participants were concerned that internal processes may not be legally compliant.

In practise, it appears many hospital bioethicists, social workers, and chaplains are trying to help people through the dispute without the benefit of legal information or institutional guidance. As a result, institutional policies and practices may not be fully compliant with the law.

Finally, informal processes are generally administered by a party with an interest in the dispute – the hospital. This potentially compromises the process or creates a perception of bias that may make patients and caregivers uncomfortable. It also reflects a reality frequently noted by nurses and physicians that they are often left without access to legal counsel of their own, and thus less certain in their position and that of the other parties. This creates additional barriers to narrowing problems and working towards solutions.



# RESOLVING DISPUTES

Recommendations to  
reduce and better resolve  
conflicts in the last stages

## 50 RECOMMENDATION

The LCO recommends that the Ministry of the Attorney General, Public Guardian and Trustee, Consent and Capacity Board, and Legal Aid Ontario explore options that would create systemic capacity to provide on-demand rights information and informal mediation services in conflicts among patients, substitute decision makers, health care providers, and health care facilities concerning patients in their last stages of life. This should include capacity to assist with powers of attorney, advance care planning, goals of care, and rights information where a MAID applicant has been found incapable of consenting.

## 51 RECOMMENDATION

The LCO recommends that persons in the Ontario Palliative Care Network's proposed designated care provider role be required to establish linkages and strong referral pathways with legal services developed further to Recommendation 50.

## 52 RECOMMENDATION

The LCO recommends that the Ministry of the Attorney General and the Consent and Capacity Board work with health care providers, health law practitioners, and patient advocates to review the mandate and jurisdiction of the Board to ensure the CCB meets the needs associated with an aging population and increasing frequency of legal conflicts in the last stages of life. This review should consider situations where parties are presently unable to apply to the Board, or where the Board may decline jurisdiction over any of the following:

1. The lack of CCB jurisdiction to determine the validity of a Power of Attorney for Personal Care (POAPC) when a dispute arises over who the SDM is, and without needing reference to the Superior Court of Justice
2. A right of patients or substitute decision makers to initiate a Form G application for directions when wishes aren't being followed by treatment team, for instance, in relation to withdrawing life support or withholding treatment (CPR, other late-stage interventions deemed to be falling short of standard of care)
3. In instances of withholding or withdrawing treatment when a physician declares a patient dead or brain dead and thus no longer a "patient" and so vacating the CCB from jurisdiction
4. That Form C applications are becoming more contested and taking so long that the person in question dies
5. Updated Board powers responsive to the contingencies of end-of-life cases, such as allowing emergency applications that cancel all prior findings without the need to refer to the Superior Court of Justice.

Given the multiple challenges to resolving disputes, nearly all LCO participants endorsed the need for more robust and responsive dispute resolution options. Accordingly, recommendation 50 states that the Ministry of the Attorney General, PGT, CCB, and Legal Aid Ontario explore options that would create systemic capacity to provide on-demand rights information and informal mediation services in conflicts among patients, substitute decision makers, health care providers, and health care facilities concerning patients in their last stages of life. This should include capacity to assist with powers of attorney, advance care planning, goals of care, and rights information where a MAID applicant has been found incapable of consenting.

As one palliative physician put it: “Having an on-call mediator would be helpful when there is intra-family or intra-team conflict; sometimes the bioethicist fills this role but that can put them in a compromising situation, and bioethicists rarely provide definitive answers to such problems... the demand for something like this would likely be about a handful year for the rarer cases.” This proposal is not without its own challenges: “bringing something like this into the culture of [our facility] would ruffle a few feathers because they focus on a family-centered approach.”

The LCO also heard that most high-conflict cases are related to a lack of clarity in planning tools, chiefly Powers of Attorney or in discussing ACP. Yet these tools are often integral to interpreting wishes and values in relation to withholding and withdrawing treatment. As one health practitioner put it: “When you have a POA or ACP, it’s so vague. You can say I don’t want anything,

or I want everything. And no one knows what everything means. It’s often an interpretation of the POA and the guilt of the SDM. It’s complex, it’s not simple and it depends on the relationship the patient has, and cultural considerations too.”

A review of this informal, systemic rights information and mediation function should be explored through further consultation. This review should include consideration of how to improve assistance in interpreting powers of attorney and advance care planning wishes and values.

Recommendation 51 states that to facilitate greater awareness and access to these justice services, the LCO makes the complimentary recommendation that persons in the Ontario Palliative Care Network’s proposed designated care provider role be required to establish linkages and strong referral pathways with legal services developed further to recommendation 50.

The LCO often heard about the need to ensure the mandate and jurisdiction of the CCB reflects contemporary issues and needs. COVID has

**“A MEDIATOR WOULD BE HELPFUL AS A STEP BEFORE REACHING THE CCB; AN IMPARTIAL PERSON TO COME IN AND SAY “THIS IS WHAT THE LAW SAYS”... MEANS IT’S NOT JUST DEPENDENT ON WHO’S WORKING THAT WEEK.”**

– PALLIATIVE CARE PHYSICIAN

further emphasized the need to modernize this process. For instance, in response to the increased number of end-of-life cases arising and the need to resolve cases quickly, Legal Aid Ontario very recently reinstituted legal aid certificate coverage for “Form G” hearings before the CCB. These hearings typically arise where a health provider believes an SDM is not fulfilling their role and should be replaced. The reintroduction of legal aid coverage speaks to pressures on the dispute resolution system that will grow alongside the inexorable trend of more end-of-life cases as Ontario’s population ages. It also speaks to the need for active legal support for SDMs to resolve issues fairly and expeditiously.

Recommendation 52 proposes a comprehensive series of actions in which the Ministry of the Attorney General and the CCB work with palliative care providers, health law practitioners, and patient advocates to review the mandate and jurisdiction of the Board to ensure it meets the needs associated with the increasing frequency of legal conflicts as the population ages and receives palliative care. Among other issues, this review should consider situations where parties are presently unable to apply to the Board, or where the Board may decline jurisdiction in several different instances. For example, the LCO frequently heard that Powers of Attorney for Personal Care are often misunderstood, but that the CCB is limited its ability to investigate these issues directly. As a result, disputes often end up in the Superior Court of Justice, a process that is more complex, expensive and likely to cause further delays.

Recommendation 52 further proposes that CCB jurisdiction should be reviewed to receive “Form G” applications from patients or SDMs.

This would grant jurisdiction to the CCB to issue directions when wishes aren’t being followed by the treatment team, for instance, in relation to withdrawing life support or withholding treatment (such as CPR, other late-stage interventions deemed to be falling short of standard of care). This recommendation would also ensure the CCB has jurisdiction to review wishes where a patient has been declared dead. The “definition of death” in Ontario law is presently a clinical decision, but it has the practical legal consequence of vacating the CCB of jurisdiction as the person may no longer be a “patient.” SDMs thus resort to emergency injunctions before the Superior Court of Justice. This is a much more costly, delayed, and procedurally complex process than might alternatively be achieved through the CCB.

Recommendation 52 also includes recommendations to expedite end-of-life hearings. This was particularly suggested in relation to “Form C” hearings, which the LCO heard are becoming more complex and taking longer to resolve. The LCO also heard that the complexities and changing conditions inherent to end-of-life cases result in multiple and ongoing hearings in respect of the same patient. Changes in patient status and other contingencies can render certain proceedings or previous findings

**“THE CCB PROCESS CAN BE PARTICULARLY BRUTAL FOR EOL PATIENTS. IN ONE HEARING, A PATIENT LITERALLY WENT INTO CARDIAC ARREST TWICE IN THE HEARING AND WERE BOTH TIMES REVIVED.”**

– PALLIATIVE CARE PHYSICIAN



of the tribunal moot or out of date, but there may not be an ability to consolidate or cancel all prior findings without the need to refer to the Superior Court of Justice.

Recommendations 53 and 54 would further streamline dispute resolution concerning the last stages of life. Recommendation 53 states that disputes in the last stages of life be resolved on an expedited basis through priority status among responsible authorities. During COVID-19 pandemic, for instance, Legal Aid Ontario granted presumptive and priority eligibility to a legal aid certificate for cases involving the last stages of life. The LCO recommends that these not only be made permanent, but that similar opportunities be explored in cases involving the last stages of life.

Finally, recommendation 54 states that the Ministry of Health amend the *Health Care Consent Act* to clarify that appeals taken from decisions of the CCB in cases involving the last stages of life should have an expedited hearing before the Superior Court of Justice. At present, appeals from the CCB to the Superior Court of Justice are scheduled “at the earliest date compatible with a just disposition.”<sup>149</sup> The LCO recommends that legislation should be amended to specify defined, rapid timelines for cases involving the last stages of life.

### 53 RECOMMENDATION

The LCO recommends that the Ministry of the Attorney General, Public Guardian and Trustee, Consent and Capacity Board, and Legal Aid Ontario explore options to align policies and programs as would accelerate timelines for disputes involving the last stages of life.

### 54 RECOMMENDATION

The LCO recommends that the Ministry of Health amend the *Health Care Consent Act* to clarify that appeals taken from decisions of the CCB in cases involving the last stages of life should have an expedited hearing before the Superior Court of Justice.

**“SO I LIKE THE IDEA OF A TRIGGER... WHERE THE NEUTRAL PARTY COMES IN, DOES AN ASSESSMENT, AND GUIDES THE CONVERSATION.”**

– PALLIATIVE CARE PHYSICIAN

## 55 RECOMMENDATION

The LCO recommends that whereas existing Canadian guidelines on continuous palliative sedation therapy were last updated in 2012, that the Minister of Health work with OPCN, regulatory colleges, and with acknowledged subject matter experts (such as the Joint Centre for Bioethics (University of Toronto)) to develop a made-in-Ontario practice guideline. This would incorporate social, medical, legal, equitable, and ethical issues unique to palliative sedation therapy in Ontario.

## 56 RECOMMENDATION

The LCO recommends that the Ministry of the Attorney General provide adequate resources to ensure the Office of the Public Guardian and Trustee Treatment Decisions Unit can better fulfill its statutory mandate when making treatment decisions for persons receiving care in their last stages of life.

The LCO is also making two recommendations to better clarify the legal status and practices related to palliative sedation. The LCO does not believe Ontario needs a dedicated legislative framework to govern palliative sedation. That said, the LCO supports the development of an overarching practice guideline that would foster consistent practices across the province. The LCO has heard that the 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.

Accordingly, recommendation 55 states that recommends that the Minister of Health work with OPCN, regulatory colleges, the Joint Centre for Bioethics (University of Toronto) and others to develop a made-in-Ontario practice guideline for palliative sedation. This practice guideline should incorporate social, medical, legal, equitable, and ethical issues unique to palliative sedation therapy, and provide guidance in relation to MAID. The LCO further suggests that this review also consider the paediatric palliative context, particularly in relation to withholding artificial nutrition and hydration. As one pediatric palliative physician noted, “extreme cases where the decision has been made to withhold artificial nutrition for an infant are really tough for clinicians and families to watch their babies die in this way and there is nothing typically gained from that time spent together... [yet] MAID in these circumstances is not possible.”

The LCO’s final recommendation addresses the role of the PGT in end-of-life cases. Recommendation 56 states that the Ministry of the Attorney General provide adequate

resources to ensure the Office of the Public Guardian and Trustee Treatment Decisions Unit is able to better fulfill its statutory mandate when making treatment decisions for persons receiving care in their last stages of life. The LCO heard many concerns that involvement of the PGT in end-of-life cases was often perceived as perfunctory and that the PGT often deferred to the suggestions of a facility or health provider. Concerns were specifically raised that personal, cultural, and spiritual values related to palliative sedation and withholding nutrition and hydration may be summarily over-looked, or the nuances of these decisions poorly understood.

These concerns were often ascribed both to the limited mandate of the PGT to more proactively engage persons receiving care in their last stages of life (discussed earlier around recommendation 8) and to the limited capacity of the PGT to take the time necessary in complex cases involving the last stages of life. The PGT TDU have roughly the same number of staff as they did in 1995, yet see a significantly increased number of decisions involving palliative care and end-of-life care. These require greater efforts at due diligence, dispute resolution, and issues that may involve palliative sedation, withholding nutrition and hydration, spiritual and religious beliefs, and other complex and crucial considerations. Sufficient resources and staffing are required to ensure this mandate and related diligence requirements can be met.



# LCO RESEARCH ANNEXES

This Final Report summarizes our findings and recommendations based on extensive consultations and research. The following Research Annexes organize this background work and are available online, or by request.

## RESEARCH ANNEX A

**Collection of LCO Commissioned Expert Papers.** LCO commissioned seven research papers from leading subject-matter experts. Immediate access is available through [the project website](#). Paper topics include: perspectives of LGBT Community Elders; caregivers of those with frailty, chronic illness, and dementia; transitions in care settings; advance care planning and goals of care tools; suffering and capacity to consent at the end-of-life; withdrawal and withholding of life-sustaining treatment; and integrating religious and cultural supports in the last stages of life.

## RESEARCH ANNEX B

**Collection of LCO Published Primary Project Materials.** LCO's background research and preliminary consultations culminated in the release of a 232 page Discussion Paper, executive summary, 13 shorter Issue Backgrounders, and other such materials. LCO additionally relied on recommendations made in our *Legal Capacity, Decision-Making and Guardianship Final Report* (March 2017). Immediate access to all these materials is available through [the project website](#).

## RESEARCH ANNEX C

**Detailed Account of LCO Consultation Events.** This database records details from each of the 74 public consultation sessions convened as part of the Last Stages of Life Project. Notes and transcripts from these events comprise over 400 pages of material. This material additionally includes analysis aids such as summary memos and issue tracking from each of the sessions.

## RESEARCH ANNEX D

**Collection of Public Online Survey Materials and Feedback.** LCO drafted and released a public survey eliciting responses to, and open-form feedback on, six key topics in the project (see page 13). There were over two dozen questions. LCO also received 582 pages of additional comments from the public. Results and analysis of this feedback may be made available with conditions, by request.

## RESEARCH ANNEX E

**Summary of Major Legislation, Cases, Policies and Reports Released During the Course of LCO's Work.** This memo provides an overview of significant relevant developments in the palliative, end-of-life and MAID system during this project. This includes nearly a dozen pices of legislation, a handful of important court decisions, and several major policy frameworks, government programs and funding announcements.

## RESEARCH ANNEX F

**Collection of LCO Legal, Policy and Consultation Feedback Memos on each Subject Area in the Project.** This collection of memos summarize LCO's research, analysis and synthesis into draft law reform recommendations for each of the subject areas in the project.

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## Acknowledgements

Ryan Fritsch is experienced in teaching, litigating, and leading community and corporate social justice initiatives as a Toronto-based health law, human rights, and administrative law lawyer. He currently leads LCO projects on AI in the Criminal Justice system, and Consumer Rights in the Digital Marketplace.

Ryan previously served as policy counsel leading Legal Aid Ontario's province-wide Mental Health Strategy, and as legal counsel to Ontario's Psychiatric Patient Advocate Office.

Ryan also taught as a sessional lecturer at the University of Windsor Faculty of Law (2011-2019) and in the Osgoode Professional LLM in Health Law Program (2021).

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LCO law reform projects would not be possible without the invaluable contributions of expertise and time from our staff, Board, and Advisory Members

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- Michael Tamblyn

# LAST STAGES OF LIFE

## TABLE OF RECOMMENDATIONS

### ACTIVATING INVOLVEMENT

#### **Recommendations to define palliative care consistently across services and sectors**

1. The LCO recommends that the Government of Ontario adopt a definition of palliative and end-of-life care to ensure consistent and aligned recognition across related health and other support services, and the laws that govern them.

#### **Recommendations to promote advance care planning in Ontario**

2. The LCO recommends that the College of Physicians and Surgeons of Ontario and the College of Nurses of Ontario clarify a duty in college standard of practice policies, guidance, and statements that health practitioners and care teams must become knowledgeable about the definitions and relationships between advance care planning, goals of care and informed consent, and must become skilled and engage in these person-centred conversations to address the person's values, wishes and goals.

3. The LCO recommends that the Ministry of Health undertake a systemic review to ensure that health care professionals have specifically designated time and compensation to engage patients and substitute decision-makers in advance care planning and goals of care conversations. This could include, for example, amending the Schedule of Benefits to incorporate a specific billing code for advance care planning and goals of care conversations.

4. The LCO recommends that legal and health care professional regulators work with acknowledged ACP leaders (such as Hospice Palliative Care Ontario and others) to collaborate and jointly develop an inter-professional training program on health care consent and capacity, advance care planning, and goals of care.

5. The LCO recommends that the inter-professional training program be supported system wide through various initiatives that may include, for example, incorporation as standard of practice in hospital and long-term care policies. It could also be provided through industry associations and groups like the Canadian Medical Association, Ontario Bar Association, LawPro and Canadian Medical Protective Association.

6. The LCO recommends that the Ministry of Health fund acknowledged leaders in advance care planning best practices and education (such as Hospice Palliative Care Ontario and others) to continue promoting and supporting best practices.

7. The LCO recommends that the Ministry of the Attorney General update the Public Guardian and Trustee Power of Attorney Kit (2012). This update would include clarifying the distinction between advance care planning, goals of care, and health care consent.

8. The LCO recommends that the Office of the Public Guardian and Trustee's Treatment Decisions Unit work with health care practitioners empowered to discuss advance care planning and consent with their patients, to develop a standard due diligence practice to better understand the wishes, values and beliefs of the patient and thereby more fully satisfy the PGT's responsibility as substitute decision maker of last resort under the *Health Care Consent Act*.

9. The LCO recommends that the Ministry of Health ensure that procurement and operational specifications and requirements for digital health records systems comport with Ontario health care and consent laws, including under the Health Care Consent Act, Substitute Decisions Act, the common law on consent, and best practices related to advance care planning and goals of care conversations.

### **Recommendations to establish a public health palliative care mandate in Ontario**

10. The LCO recommends that the Minister of Health amend the Health Protection and Promotion Act to adopt a "public health palliative care" (PHPC) as an area for the provision of mandatory public health programs and services.

11. The LCO recommends that the Minister of Health amend the preamble to the Health Protection and Promotion Act to include the internationally recognized definition of "public health palliative care" as reflecting the five tenants of the World Health Organization's Ottawa Charter for Health Promotion, namely: building public policies that support dying, death, loss and grief; creating supportive environments (in particular social supports); strengthening community action; developing personal skills in these areas; and re-orientating the health system.

12. The LCO recommends that the ongoing partnership between Public Health Ontario and the Ministry of Health fulfill the mandate to develop and promote a public health palliative care approach with necessary resources and supports to sustain a multi-year initiative and support for locally tailored programs.

13. The LCO recommends that the Minister of Health amend the Health Protection and Promotion Act to strengthen the relationship between Public Health Ontario and local and regional community groups with distinct public health palliative care needs – including faith and spiritual, cultural, linguistic, economic, indigenous, persons with disabilities, and other equity-seeking communities, along with compassionate communities and compassionate corporations – by mandating their engagement in development and deployment of annual public health palliative care initiatives.

14. The LCO recommends that the Minister of Health amend the Health Protection and Promotion Act to require an ongoing partnership between Public Health Ontario and the MOH, defined through annual work plans with measurable outcomes, to better align public health palliative care and the provision of health care.

15. The LCO recommends that the Ministry of Health or Public Health Ontario expand support and grow province-wide Compassionate Communities strategies, such as those developed by Hospice Palliative Care Ontario.

## LAST STAGES OF LIFE

# TABLE OF RECOMMENDATIONS

16. The LCO recommends that the Ministry of Health, Public Health Ontario, or other Ministry support the development of a Compassionate Company designation and standard. The standard would recognize, guide, and encourage employers to adopt formal human resource policies that anticipate and support employees who need leave from work to care for a palliative loved one.

### SUPPORTS FOR PROFESSIONALS

#### **Recommendations to better support health care providers of patients in the last stages of life**

17. The LCO recommends that the Minister of Labour explore options within the Workplace Safety Insurance Act to identify health care practitioners dedicating the majority of their practice to care in the last stages of life, or in critical incident health care services, as a distinct class for coverage. This should improve ease of access, and as-needed intermittent access, to mental health treatment, supports, and respite and recovery time.

18. The LCO recommends that the Minister of Labour explore options within the Occupational Health and Safety Act to identify health care practitioners dedicating the majority of their practice care in the last stages of life, or to critical incident health care services, as a distinct class for coverage. Provisions should consider workplace approaches known to improve practitioner wellness including practitioner respite time, critical incident debrief time, and sufficient staffing levels to anticipate redundancy needs.

19. The LCO recommends that the Ministry of Labour explore available options to expand the definition of “mental illness” eligible for coverage to the proposed worker class defined under the WSIA as dedicating the majority of their practice to care in the last stages of life, or critical incident health care services. This definition and process should be tailored to the needs of this class of workers, including an option for more rapid access to coverage, and to more intermittent and shorter-term leave. As part of this, the Ministry should review the efficacy of policies providing access to chronic mental stress (CMS) and traumatic mental stress (TMS) under existing WISB standards and procedures.

20. The LCO recommends that regulatory colleges widely adopt Health and Well-Being Standards — similar to those introduced for paramedics in April 2018 — to cover other health care practitioners providing care in the last stages of life or critical incident health care.

21. The LCO recommends that government should explore policy options that would prioritize assistance for individuals working with patients receiving care in the last stages of life who are contractually employed,

self-employed, precariously employed, or otherwise ineligible for employee assistance programs have access to mental health supports.

22. The LCO recommends that health care professional regulators develop clear, definitive, quick reference tools for practitioners working with patients in the last stages of life. These tools would provide guidance on professional roles in relation to issues like CPR, withholding treatment, or conscientious objection so the practitioner is better able to communicate clearly to families, other staff, and management. These tools should address issues that may involve moral distress, such as MAID, palliative sedation, and conscientious objection.

## SUPPORTS FOR CAREGIVERS

### **Recommendations to better support caregivers of individuals in their last stages of life in Ontario**

23. The LCO recommends that the Ministry of Labour, Training and Skills Development explore options to amend provisions in the Employment Standards Act related to “family caregiver leave” to provide that the leave taken by the caregiver of an individual in their last stages of life is available in daily rather than weekly increments.

24. The LCO recommends that the Ministry of Labour, Training and Skills Development explore options to amend provisions in the Employment Standards Act to create a category of “family caregiver leave for minor children” that would make the existing 37 weeks leave entitlement for critical illness leave (and the entitlement to additional leaves) available to caregivers of minor children receiving care in their last stages of life.

25. The LCO recommends that the Ministry of Labour, Training and Skills Development explore options to amend provisions in the Employment Standards Act to clarify that entitled leave periods include periods where respite care is provided for the insured.

26. The LCO recommends that the Ministry of Labour, Training and Skills Development explore options to amend the Employment Standards Act as would act to expand the job-protected and insured family medical leave provisions to better support caregivers of an individual in their last stages of life in the high-needs homecare category (defined as receiving 14+ hours of care a week).

27. The LCO recommends that the Ministry of Health explore the development of a mandate that all individuals in their last stages of life in the high-needs homecare category (defined as receiving 14+ hours of care a week) be assigned a health care practitioner that is responsible for the administration, coordination, and oversight of home care services.

28. The LCO recommends that the Ministry of Labour, Training and Skills Development review eligibility criteria for self-employed people under the Employment Standards Act to EI special benefits programs and explore opportunities at the provincial level to create new incentives and enhance enrollment in this program.

29. The LCO recommends the Ministry of Labour, Training and Skills Development Review explore opportunities under the Employment Standards Act to extend supports to a class of contractually, self-employed, or precariously employed caregivers who are supporting an individual in their last stages of life and who are otherwise ineligible for any entitlements or benefits in these circumstances.

# LAST STAGES OF LIFE

## TABLE OF RECOMMENDATIONS

30. The LCO recommends that the Minister of Health use the mandate under Bill 3, Compassionate Care Act, to develop “a framework to ensure that every Ontarian has access to quality palliative care” that would call on municipal governments and provincial Ministries to review policies, programs, laws, and regulations for their impact on individuals in their last stages of life, their caregivers, and health care providers.

### COMMUNITIES WITH UNMET NEEDS

#### **Recommendations to better support incarcerated individuals in Ontario**

31. The LCO recommends that the Ministry of the Solicitor General amend the Correctional Services and Reintegration Act, 2018 to establish a compassionate release provision and clarify that incarcerated individuals in their last stage of life are eligible for temporary absences and compassionate release. This mechanism should operate expeditiously given the urgent care needs.

32. The LCO recommends that the Ministry of the Solicitor General create a “transitions in care” strategy to facilitate compassionate release of individuals in their last stages of life. This strategy should anticipate and address discrimination in eligibility to facilities including long-term care, hospices, and housing, and ensure oversight review of transitioned individuals as “deaths in custody.”

33. The LCO recommends that the Ministry of the Solicitor General implement a flexible communication and visitation policy that accommodates the timely involvement of substitute decision-makers to incarcerated persons in their last stages of life, as is required to facilitate conversations about advance care planning and goals of care, and to facilitate compliance with the Health Care Consent Act.

34. The LCO recommends that the Ministry of the Solicitor General study and report on a strategy to address the primary health care needs specifically of incarcerated persons in their last stages of life. This would include access to a palliative team including specialists, liaison relationships to local hospitals, and pain and medication management.

35. The LCO recommends that the Ministry of the Solicitor General engage advocates and stakeholders in the study of a provincial corrections policy that responds to the unique circumstances and concerns related to MAID requests from incarcerated individuals.



## **Recommendations to improve Care in Transition and in the Home**

36. The LCO recommends that the Government of Ontario ensure smoother transitions in care for patients in their last stages of life by improving access to more robust hospice care and services to support care in the home.

37. The LCO recommends that the Ministry of Long-term Care ensure that LTC homes are resourced to provide quality end of life care for all residents.

38. The LCO recommends that the Ministry of Health expand the range of what patient transfers are defined as “medically necessary” specifically in relation to patients in their last stages of life to avoid downloading costs of travel onto patients. This should particularly address those defined as “high needs home care” patients.

39. The LCO recommends that the Ministry of Health undertake a systemic, comprehensive review of compensation models for health care workers serving patients in their last stages of life in home and community settings. This should review jurisdictional divisions (particularly between geographic “catchment areas” as well as between institutional and home care settings) that act as barriers to coordination and continuity of care and should review compensation that matches the needs of mobile providers.

## **Recommendations to support equity-seeking groups and isolated individuals**

40. The LCO recommends that the Ministry of Health amend The People’s Health Care Act, 2019 and the Connecting Care Act (enacted as Schedule 1 to Bill 74) to require any Ontario Health Team which provides palliative and end-of-life care to develop equity, access, and engagement plans for vulnerable groups in the service area. This should consider the needs of homeless and precariously housed, inmates in provincial detention centres, immigration and refugee communities, linguistic and cultural communities, disability communities, and persons with mental illness.

41. The LCO recommends that the Ministry of Health review access to palliative care services for individuals with unclear status as non-resident or non-registered resident, refugee, or immigration status, particularly in relation to eligibility for personal support worker services; waiting periods for OHIP coverage; eligibility and funding for home and community care; funding for such patients in hospices; and funding for access to necessary medications, equipment, etc.

42. The LCO recommends that the Ministry of Health amend the Health Insurance Act and the Home Care and Community Services Act, 1994 so that a person who moves to Ontario from another province or territory and who had public health insurance in the province or territory will not be subject to any waiting period for funded palliative care services under the Act that may otherwise be applicable to new Ontario residents.

43. The LCO recommends that the Ministry of Long-term Care update the language of the Patient Bill of Rights #19 to include LGBTQ2+, BIPOC, and other equity-seeking groups to strengthen the commitment to diversity, equity, and inclusion in long-term care facilities.

## LAST STAGES OF LIFE

# TABLE OF RECOMMENDATIONS

44. The LCO recommends that to improve existing anti-oppression and anti-discrimination training undertaken by, for example, AdvantAge Ontario, the Ontario Long-Term Care Association, the College of Physicians and Surgeons, the College of Nurses, and the Ontario Personal Support Worker Association, such training is to involve acknowledged experts on LGBTQ and HIV+ discrimination in health care, such as the HIV & AIDS Legal Clinic of Ontario, and other groups.

45. The LCO recommends that the Ministry of Health facilitate the creation and implementation of a palliative pediatric hospice strategy to ensure access to end-of-life care for terminally ill children across Ontario.

### **Recommendations to Improve Medical Assistance in Dying in Ontario**

46. The LCO recommends that the Ministry of Health expand the MAID Care Co-ordination Service telephone line to assist with the administration, coordination, and oversight of an application and any requested services.

47. The LCO recommends that the Ministries of Health and Long-Term Care tailor OHIP allowances for travel and administrative requirements to align with the practical requirements of providing medical assistance in dying on a mobile basis.

48. The LCO recommends that the Ministry of Health ensure greater equity in access to medical assistance in dying by reviewing protocols governing the availability of required drugs in rural and remote areas.

49. The LCO recommends that the Ministry of Health, Ontario Health, and the Ontario Mental Health and Addictions Centre of Excellence require and support all public hospitals designated as Schedule 1 psychiatric facilities under the Mental Health Act to develop and implement protocols for assessing medical assistance in dying requests from patients.

## RESOLVING DISPUTES

### **Recommendations to reduce and better resolve conflicts in the last stages of life**

50. The LCO recommends that the Ministry of the Attorney General, Public Guardian and Trustee, Consent and Capacity Board, and Legal Aid Ontario explore options that would create systemic capacity to provide on-demand rights information and informal mediation services in conflicts among patients, substitute decision makers, health care providers, and health care facilities concerning patients in their last stages of life. This should include capacity to assist with powers of attorney, advance care planning, goals of care, and rights information where a MAID applicant has been found incapable of consenting.

51. The LCO recommends that persons in the Ontario Palliative Care Network's proposed designated care provider role be required to establish linkages and strong referral pathways with legal services developed further to Recommendation 50.

52. The LCO recommends that the Ministry of the Attorney general and the Consent and Capacity Board work with health care providers, health law practitioners, and patient advocates to review the mandate and jurisdiction of the Board to ensure the CCB meets the needs associated with an aging population and increasing frequency of legal conflicts in the last stages of life. This review should consider situations where parties are presently unable to apply to the Board, or where the Board may decline jurisdiction over any of the following:

- 1) The lack of CCB jurisdiction to determine the validity of a Power of Attorney for Personal Care (POAPC) when a dispute arises over who the SDM is, and without needing reference to the Superior Court of Justice
- 2) A right of patients or substitute decision makers to initiate a Form G application for directions when wishes aren't being followed by treatment team, for instance, in relation to withdrawing life support or withholding treatment (CPR, other late-stage interventions deemed to be falling short of standard of care)
- 3) In instances of withholding or withdrawing treatment when a physician declares a patient dead or brain dead and thus no longer a "patient" and so vacating the CCB from jurisdiction
- 4) That Form C applications are becoming more contested and taking so long that the person in question dies
- 5) Updated Board powers responsive to the contingencies of end-of-life cases, such as allowing emergency applications that cancel all prior findings without the need to refer to the Superior Court of Justice.

53. The LCO recommends that the Ministry of the Attorney General, Public Guardian and Trustee, Consent and Capacity Board, and Legal Aid Ontario explore options to align policies and programs as would accelerate timelines for disputes involving the last stages of life.

54. The LCO recommends that the Ministry of Health amend the Health Care Consent Act to clarify that appeals taken from decisions of the CCB in cases involving the last stages of life should have an expedited hearing before the Superior Court of Justice.

55. The LCO recommends that whereas existing Canadian guidelines on continuous palliative sedation therapy were last updated in 2012, that the Minister of Health work with OPCN, regulatory colleges, and with acknowledged subject matter experts (such as the Joint Centre for Bioethics (University of Toronto)) to develop a made-in-Ontario practice guideline. This would incorporate social, medical, legal, equitable, and ethical issues unique to palliative sedation therapy in Ontario.

56. The LCO recommends that the Ministry of the Attorney General provide adequate resources to ensure the Office of the Public Guardian and Trustee Treatment Decisions Unit can better fulfill its statutory mandate when making treatment decisions for persons receiving care in their last stages of life.

# LCO FINAL REPORT

## END NOTES

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