



LAW COMMISSION  
OF ONTARIO



# LAST STAGES OF LIFE EXECUTIVE SUMMARY

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 is the Executive Summary to LCO's *Last Stages of Life: Final Report*. The Final Report summarizes our 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.

LCO's Final Report is available in accessible formats on the LCO's [Last Stages of Life website](http://www.lco-cdo.org).

# LAST STAGES OF LIFE PROJECT

## EXECUTIVE SUMMARY

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

This is the Executive Summary to the Law Commission of Ontario's (LCO) *Last Stages of Life: Final Report*.

The report considers how Ontario's legal and policy frameworks shape the rights, choices, and quality of life for persons who are dying and those who support them. The "last stages of life" is an adopted term that gives the project scope to look at legal issues arising in relation to palliative care, end-of-life care, and medical assistance in dying in Ontario.

Canadian and Ontarian approaches to these matters have changed profoundly in the last five years. The LCO's Final Report is a blueprint to ensure the law keeps pace with these changes and continues to meet the needs of all those impacted.

The report makes 56 law and policy reform recommendations across five major areas.

These recommendations, if implemented, would:

- activate the earlier involvement of people in discussing and planning for their last stages

of life, including through a standard definition of "palliative care;" a public health palliative care promotion mandate; and formal supports to encourage greater engagement in advance care planning and goals of care discussions (Recommendations 1-16);

- better support the professionals and paraprofessionals who provide care in the last stages of life through expanded workplace wellness supports (Recommendations 17-22);
- update and expand workplace wellness and leave provisions so families, friends and community members have flexible supports responsive to the unpredictable trajectory of care needs over time (Recommendations 23-30);
- increase access to equitable care for vulnerable communities with unmet needs, including prisoners, isolated individuals, children, and persons contemplating medical assistance in dying (Recommendations 31-49); and
- help resolve disputes by making rights-based information and mediation available earlier and expedite formal legal proceedings concerning the last stages of life (Recommendations 50-56).

The LCO's extensive province-wide consultations confirm these recommendations as timely, thoughtful, and very much needed. Our work reflects the lived experience of the 850 Ontarians we heard from across the 74 consultation sessions we convened; the nearly 600 pages comments submitted by the public; the seven expert reports we commissioned; and from the oversight provided by an external expert Advisory Group.

The LCO's *Last Stages of Life: Final Report* is the first of two LCO reports in this area.

The second, *Last Stages of Life for First Nation, Métis and Inuit Peoples: Preliminary Recommendations for Law Reform*, summarizes the LCO's dedicated engagement with Inuit, Métis, and First Nation communities in Ontario on "last stages of life" issues. This report will be released later this year.

A list of all 56 LCO Recommendations is available at the end of this document.

The LCO's full report is available on the [Last Stages of Life project website](#). This report includes the full text, more information about our research and consultations, a list of project contributors, and other information.

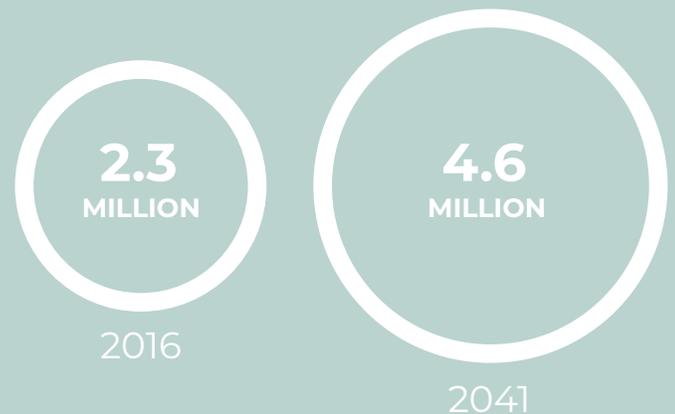
## DEFINITIONS



### 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>1</sup>

# LAST STAGES OF LIFE PROJECT

## CONTEXT

The timeliness of the LCO’s recommendations arises from the need for Ontario law to reflect a changing province. In the last 20 years, care in the last stages of life has gained prominence as a distinct pursuit within 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 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.<sup>2</sup>

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*.<sup>3</sup> 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>4</sup> The LCO also relied on our earlier reports regarding capacity and decision-making, and older adults.<sup>5</sup>

The pace of these developments tracks dramatic demographic shifts defining a new normal across Canada. The population is aging, living longer, and requiring more chronic care.<sup>6</sup> Familial caregivers are raising children while increasingly caring for frail parents. Families are also more likely to live further apart and facing job market changes favouring precarious work and self-employment without leave time or benefits. Nearly 30% of Canadians now live alone – the highest proportion in history.<sup>7</sup> And greater recognition of the diversity in cultural, spiritual, and Indigenous beliefs are changing expectations of what “a good death” is.<sup>8</sup>

Finally, there is also 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>9</sup> And a large majority of hospitalized elderly Canadians report wishes for comfort measures nearing the end of life, rather than life-prolonging interventions.<sup>10</sup>

# LAST STAGES OF LIFE PROJECT

## OVERVIEW

### What is the scope of this project?

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.

### 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.

### 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.*

# OUR CONSULTATIONS ACROSS ONTARIO

## 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:

- 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.

The next pages is a visual “snapshot” of the LCO’s extensive consultations. More information about this process is included in our full report at pages 12-20.

**CONSULTATIONS**



LCO CONSULTATION SESSIONS CONVENED

74

**INTERVIEWS, FOCUS GROUPS & OPEN EVENTS**



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.

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.<sup>11</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.<sup>12</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>13</sup> improved staffing levels and stable employment;<sup>14</sup> legal clarity around familial access to patients, particularly in long-term care and hospitals;<sup>15</sup> and improved care in congregate settings.<sup>16</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>17</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.**

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.

### ➔ **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>18</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>19</sup>

### ➔ **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>20</sup>

### ➔ **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.

# LAST STAGES OF LIFE PROJECT

## RECOMMENDATIONS

### Activating Involvement Recommendations 1 – 16

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 four promising avenues for change.

**Recommendation 1:** Establish a standard definition for palliative and end-of-life care aligned across important health and other support services and sectors.

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. The LCO heard how Ontario law does not reflect this holistic conception of palliative care and that challenges this creates. 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. Employment law was frequently cited as providing workplace leave provisions that do not reflect the reality of caring for a person receiving palliative care. In contrast to these example, LCO’s consultations indicate clear support to go beyond a narrow conception of palliative and end-of-life care, and to instead adopt a standard definition that would better align care and support across different services and sectors.

The LCO therefore 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 2 to 6:** Strengthen 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.

**“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>23</sup>**

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.

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.

At the same time, 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.

### **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>24</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>25</sup>

This can result 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 have few opportunities to discuss their unmet needs and preferences, and who are less likely to successfully access legal recourse mechanisms.

To address these concerns, the LCO makes a series of recommendations that would clarify a duty in the standard of practice for physicians and nurses 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.

Supporting recommendations would amend the Schedule of Benefits to incorporate a specific billing code for advance care planning and goals of care conversations; establish an inter-professional training program to align and build capacity among both health practitioners and lawyers to engage in effective and meaningful ACP; and that Ontario fund acknowledged leaders in advance care planning best practices and education to continue promoting and supporting best practices.

**Recommendations 7 to 9:** Improve government-endorsed information materials such as the Power of Attorney Kit, and develop a standard due diligence practice within the Office of the Public Guardian and Trustee Treatment Decisions Unit to better understand the wishes, values and beliefs of the patient.

The LCO recommends 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.

Accordingly, 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.

**Recommendations 10 to 16:** Adopt a public health palliative care approach to the last stages of life, and better support the Compassionate Communities and Compassionate Corporations movements.

## RECOMMENDATIONS

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>21</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.

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.

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
- 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.

LCO recommendations 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. The LCO also recommends more formal government support to build on the substantial and promising work being done in the “compassionate communities” and “compassionate workplace” movements.

Our full report discusses the “compassionate communities” movement in more detail, including an important initiative developed by Hospice Palliative Care Ontario.”<sup>22</sup>

## Supporting Professionals Recommendations 17 – 22

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 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.

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.

Given these challenges the LCO has identified several areas for change.

**Recommendations 17 and 18:** Define a distinct class of coverage under the WSIA and OHSA that identifies 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.

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).

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. These were obviously welcome and laudable accomplishments.

## RECOMMENDATIONS

Since 2016, there have been no fewer than five competing pieces of legislation modifying aspects of the coverage in fits and starts.<sup>26</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. Appeals from any of these determinations can take several years.

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.

**Recommendations 19:** 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 WSIB standards and procedures.

**Recommendation 20:** 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 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. This approach has broad national support and is based on the CSA’s 2013 National Standard on Psychological Health and Safety in the Workplace.

**Recommendations 21:** 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.

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 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>27</sup> The LCO notes that this was of particular concern to PSWs.

**Recommendation 22:** Address 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, and how to communicate this to others. It was suggested that regulatory colleges develop a set of standard “quick reference” tools specifically for palliative health care providers. These tools would provide guidance on professional roles in relation to issues like CPR, withholding treatment, and should address issues that may involve moral distress, such as MAID, palliative sedation, and conscientious objection.



## Supporting Caregivers Recommendations 23 – 30

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>28</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>29</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 time. Under these provisions, individuals are entitled to take time to care for others without losing their employment.

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).

To better support caregivers, the LCO makes the following recommendations:

**Recommendations 23 to 26:** Amend the *Employment Standards Act* (ESA) leave provisions to better support family caregivers.

The LCO makes a series of recommendations to amend the ESA leave provisions related to “family caregiver leave” to improve supports, including that:

- the leave taken by the caregiver of an individual in their last stages of life is available in more flexible increments;
- that it includes respite care for the caregiver;
- that it is available to caregivers of minor children receiving care in their last stages of life; and
- expanding 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.

**Recommendation 27:** Ensure that 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.

The LCO heard how 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.

**Recommendations 28 and 29:** Amend the ESA to better support contractually, self-employed, or precariously employed caregivers supporting an individual in the last stages of life.

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>30</sup> That report defined precarious workers as "contract, part-time, self-employment or temporary work."<sup>31</sup> The LCO's analysis was confirmed by later studies, including the 2017 Changing Workplaces Review.<sup>32</sup>

The LCO heard that existing programs are 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.

The LCO makes a series of recommendations to explore options or consider amending the ESA to better support contractually, self-employed, or precariously employed caregivers supporting

an individual in the last stages of life, including:

- expanding eligibility criteria for self-employed people under the ESA to EI special benefits programs;
- exploring opportunities at the provincial level to create new incentives and enhance enrollment in this program; and
- extending 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.

**Recommendation 30:** Use the Bill 3 mandate to review municipal and provincial policies, programs and laws that impact individuals in last stages of life, caregivers and health care professionals.

Bill 3, the *Compassionate Care Act*, gives the Ministry of Health a mandate 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.

## Supporting Communities with Unmet Needs

### Recommendations 31 – 49

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.

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:

- 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.

To better support these communities the LCO makes several recommendations.

**Recommendations 31 to 35:** Improve access to palliative care and end-of-life care for 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. Moreover, 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.

As well, 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.

The LCO recommends addressing these needs by:

- establishing a compassionate release provision and clarifying that incarcerated individuals in their last stage of life are eligible for temporary absences and compassionate release;
- developing a “transitions in care” strategy to address discrimination in eligibility to facilities including long-term care, hospices, and housing;
- creating a flexible communication and visitation policy that accommodates the timely involvement of substitute decision-makers to incarcerated persons in their last stages of life;

## RECOMMENDATIONS

- developing a strategy to address the primary health care needs specifically of incarcerated persons in their last stages of life; and
- developing a provincial corrections policy that responds to the unique circumstances and concerns related to MAID requests from incarcerated individuals

**Recommendations 36 to 39:** Improve care in transition and in 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. 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.

The LCO recommends addressing these needs by:

- improving access to more robust hospice care and services to support care in the home;
- ensuring that long-term care homes are resourced to provide quality end of life care for all residents;
- expanding 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; and

- reviewing compensation models for health care workers serving patients in their last stages of life in home and community settings that act as barriers to coordination and continuity of care.

**Recommendation 40:** Amend the *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.

To ensure Ontario adopts measures to ensure tailored approaches to care for these and other specific communities with unmet needs, this recommendation would 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 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.

**Recommendations 41 and 42:** Improve access to care in the last stages of life for transient populations.

This would include:

- ensuring access to palliative care services for individuals with unclear status as non-resident or non-registered resident, refugee, or immigration status; and
- 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.

**Recommendations 43 to 45:** Ensure better access to care in the last stages of life for vulnerable communities.

To achieve this, the LCO makes a series of recommendation that would:

- update the language of the Patient Bill of Rights #19 to include LGBTQ2+, BIPOC, and other equity-seeking groups;
- improve existing anti-oppression and anti-discrimination training by involving acknowledged experts on LGBTQ and HIV+ discrimination in health care; and
- create and implement a palliative pediatric hospice strategy to ensure access to end-of-life care for terminally ill children across Ontario.

These recommendations address systemic barriers to equitably accessing care. We particularly heard about discrimination in long-

term care against LGBTQ and HIV+ communities, both of whom could be better protected under the Patient Bill of Rights. The LCO also heard about the unique differences between children and adults who are receiving care in the last stages of life. The LCO therefore goes beyond earlier recommendations aimed at supporting care givers, and additionally identifies the need for 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 46 to 49:** Improve access to Medical Assistance in Dying (MAID) in Ontario.

The LCO heard how interest in MAID has grown considerably since MAID was legalized in 2016. Yearly MAID deaths in Ontario grew from 839 in 2017 to 2,378 in 2020.<sup>33</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>34</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.

The LCO addresses these barriers with a series of recommendations that:

- improve access to MAID in Ontario by expanding the MAID Care Co-ordination Service telephone line to assist with the administration, coordination, and oversight of an application and any requested services;

- tailor OHIP allowances for travel and administrative requirements to align with the practical requirements of providing medical assistance in dying on a mobile basis;
- review protocols governing the availability of required drugs in rural and remote areas so as to avoid delays and increase access; and
- require that 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 50 – 56

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.

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.

**Recommendations 50 to 56:** Reduce and better resolve conflicts in the last stages of life.

Given the multiple challenges to resolving disputes, nearly all LCO participants endorsed the need for more robust and responsive dispute resolution options.

## RECOMMENDATIONS

To meet these needs, the LCO proposes a series of recommendations, including:

- development 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;
- expansion of the CCB's mandate and jurisdiction to meet the needs associated with an aging population and increasing frequency of legal conflicts in the last stages of life;
- expediting timelines for disputes involving the last stages of life, including before the Superior Court of Justice; and
- updating guidelines on continuous palliative sedation as would incorporate social, medical, legal, equitable, and ethical issues unique to palliative sedation therapy in Ontario.

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 can better fulfill its statutory mandate when making treatment decisions for persons receiving care in their last stages of life. The LCO frequently heard these concerns ascribed to the limited resources and staff capacity of the PGT to take the time necessary in complex cases involving the last stages of life.

# 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.

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## 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

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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

- 1 Ontario Ministry of Health and Long-term Care, *Aging with Confidence: Ontario's Action Plan for Seniors* (November 2017), 9, online: <https://www.ontario.ca/page/aging-confidence-ontario-action-plan-seniors>.
- 2 See the *Framework on Palliative Care in Canada Act* (S.C. 2017, c. 28), online: <https://laws-lois.justice.gc.ca/eng/acts/F-31.5/page-1.html>. The legislation resulted in publication of *Health Canada, Framework on Palliative Care in Canada* (2018), online: <https://publications.gc.ca/site/eng/9.865130/publication.html>.
- 3 Legislature of Ontario, *Bill 3: Compassionate Care Act, 2020* (S.O. 2020, c. 30) (assented to December 2, 2020), online: <https://www.ontario.ca/laws/statute/s20030>.
- 4 Ontario Palliative Care Network, *Palliative Care Health Services Delivery Framework* (April 2019), online: <https://www.ontariopalliativecarenetwork.ca/resources/health-services-delivery-framework>.
- 5 Law Commission of Ontario, *Legal Capacity, Decision-Making and Guardianship* (March 2017), online: <http://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/final-report/>; Law Commission of Ontario, *Framework for the Law as it Affects Older Adults* (July 2012), online: <https://www.lco-cdo.org/en/our-current-projects/a-framework-for-the-law-as-it-affects-older-adults/>.
- 6 See for example: "Palliative Care" in Auditor General of Ontario, *Annual Report 2014* (Toronto: Queen's Printer for Ontario, 2014), 260, which reports that: "People aged 85 and over constituted the fastest-growing segment of Ontario's population between 2006 and 2011, with their number increasing by 29% over that period. The number of people aged 65 and over is expected to more than double from 2 million in 2012, when baby boomers began to turn 65, to over 4 million by 2036, when seniors will constitute 24% of Ontario's population." See also Allison Williams, Mary Lou Kelley, Sarah Dykeman & Lily DeMiglio, "A Timeline of Hospice Palliative Care Policy and Practice in Ontario, Canada" (Canadian Institute of Health Research, February 2010), 3; François-Pierre Gauvin & John N. Lavis, "Improving End-of-Life Communication, Decision-Making and Care in Ontario: Evidence Brief" (Prepared for the McMaster Health Forum, September 11, 2013).
- 7 Statistics Canada, *Living Alone in Canada* (March 6, 2019), online: <https://www150.statcan.gc.ca/n1/pub/75-006-x/2019001/article/00003-eng.htm>  
See for instance, Ontario Ministry of Health, "Ontario Improving Access to Care by Building More Hospice Beds in Durham" (February 6, 2020), online: <https://news.ontario.ca/en/release/55679/ontario-improving-access-to-care-by-building-more-hospice-beds-in-durham>
- 8 A "good death" has been found broadly to encompass three domains: adequate alleviation of unpleasant symptoms, optimization of psychosocial and spiritual issues, and maintaining patient-centred decision-making (see Siuebe J Swart, Agnes Van Der Heide, Lia Van Zuylen, et al., "Continuous Palliative Sedation: Not Only a Response to Physical Suffering" (17:1 *Journal of Palliative Medicine* 27 (2014), 27). A "dignified death" most people quite understandably expect pain and other symptoms to be adequately relieved. "Preparing for death" could mean saying goodbye to loved ones, gaining a sense of completion, or addressing psychosocial, existential, or religious issues. See: "Healthy dying: time for health promotion to get serious" (*John Catford Health Promotion International* 33:2 (April 2018), 183-186
- 9 Canadian Hospice Palliative Care Association, *What Canadians Say: The Way Forward Survey Report* (December 2013), 22, online: <http://www.hpcintegration.ca/resources/what-canadians-say.aspx>.
- 10 Health Quality Ontario, "Health Care for People Approaching the End of Life: An Evidentiary Framework" (14:14 *Ontario Health Technology Assessment Series* 1, 9, citing Deborah Cook & Graeme Rocker "End of Life Care in Canada: A Report from the Canadian Academy of Health Sciences Forum" 36:3 *Clin Invest Med.* (2013) E112-E113.
- 11 See: Ontario Palliative Care Network, *Palliative Care Health Services Delivery Framework* (April 2019), online: <https://www.ontariopalliativecarenetwork.ca/resources/health-services-delivery-framework> (OPCN Framework). See also: Ontario Palliative Care Network, *Tools to Support Earlier Identification for Palliative Care* (April 2019), online: <https://www.ontariopalliativecarenetwork.ca/resources/tools-support-earlier-identification>. As explained within the document, it "complements the OPCN Framework... [which] included the element of "Identification and Assessment" as key component of the service delivery model... [and] can be used to promote the scale and spread of earlier palliative care, encouraging broader use of these tools across care settings." (at 3, 12).
- 12 Ontario, *Long-Term Care Homes Public Inquiry, Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System – Final Report* (July 2019), online: <https://longtermcareinquiry.ca/en/final-report/>. See recommendations 3, 5, 11-13, 19, 21, 85.
- 13 In April 2021 Ontario introduced *Bill 283, Advancing Oversight and Planning in Ontario's Health System Act, 2021* (assented to June 3, 2021), online: <https://www.ola.org/en/legislative-business/bills/parliament-42/session-1/bill-283>. Among other things, the Act proposes to

- create a new regulatory body for personal support workers known as the Health and Supportive Care Providers Oversight Authority. This regulatory framework would include establishing consistency in education, training, and standards of practice.
- 14 Ontario, Ministry of Long-Term Care, Long-term Care Staffing Study (July 30, 2020), online: <https://www.ontario.ca/page/long-term-care-staffing-study>.
  - 15 See for instance CityNews, "Not just a visitor: Campaign wants more access to care homes, hospitals for family caregivers" (October 9, 2020), online: <https://edmonton.citynews.ca/2020/10/09/visitors-care-homes-hospitals-family-caregivers-covid/>.
  - 16 Ontario Ministry of Health, "COVID-19 Guidance: Congregate Living for Vulnerable Populations" (May 28, 2020) online: [http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/2019\\_congregate\\_living\\_guidance.pdf](http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/2019_congregate_living_guidance.pdf).
  - 17 Legislature of Ontario, Bill 3: Compassionate Care Act, 2020 (S.O. 2020, c. 30) (assented to December 2, 2020), online: <https://www.ontario.ca/laws/statute/s20030>.
  - 18 S. Baidoobonso, "Effect of Supportive Interventions on Informal Caregivers of People at the End of Life: A Rapid Review" (Toronto: Health Quality Ontario, 2014), 7.
  - 19 Canadian Institute for Health Information, "Access to Palliative Care in Canada" (September 2018), 7, online: <https://www.cihi.ca/en/access-data-and-reports/access-to-palliative-care-in-canada>.
  - 20 Advance Care Planning Canada, "Advance Care Planning in Canada Released A New National Poll 2019" (July 2019), online: <https://www.advancecareplanning.ca/news/advance-care-planning-canada-releases-new-national-poll-2019/>.
  - 21 The operationalising of public health palliative care as an extension of the Ottawa Charter was first explicitly done in Allan Kellehar's 1999 book *Health Promoting Palliative Care* (Oxford University Press, 1999) who's connection to the Ottawa charter has been cited by several international governments as the basis for their policy positions, as well as to the WHO World Health Assembly 96.18 resolution, which remains a key directive for palliative care as an essential component of health care. See for instance: World Health Organization, *Planning and Implementing Palliative Care Services: A Guide for Programme Managers* (WHO, 2016); Council of Europe (Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care, Adopted by the Committee of Ministers on 12 November 2003 at the 860th meeting of the Ministers' Deputies, affirmed in Council of Europe Parliamentary Assembly Draft Resolution (adopted unanimously by the committee on 17 September 2018); WHO Collaboration Centre for Public Health Palliative Care Resolution 1649 "Palliative care: a model for innovative health and social policies" (2009). This has also resulted in the establishment of <https://www.phpci.info/>.
  - 22 See for example: Hospice Palliative Care Ontario, "Compassionate Communities," online: <https://www.hpcoc.ca/compassionate-communities/>; Pallium Canada, "Compassionate Workplace Campaign," online: <https://www.pallium.ca/cwc/>; and Canadian Hospice Palliative Care Association, "Canadian Compassionate Corporations," online: <https://www.chpca.ca/campaigns/ccp/#companies>.
  - 23 Advance Care Planning Canada, "Advance Care Planning in Canada Released A New National Poll 2019" (July 2019), online: <https://www.advancecareplanning.ca/news/advance-care-planning-canada-releases-new-national-poll-2019/>.
  - 24 Judith Wahl, Mary Jane Dykeman, and Tara Walton, "Health Care Consent, Advance Care Planning, and Goals of Care Practice Tools: The Challenge to Get it Right" (Law Commission of Ontario, December 2016), at iii, online: <https://www.lco-cdo.org/wp-content/uploads/2010/10/ACE%20DDO%20Walton%20Formatted%20Dec%202016%20LCO.pdf>.
  - 25 Description provided to the LCO in correspondence from the HPCO (Sept 21, 2021), on file with the Commission. HPCO maintains a wealth of information for clinicians and the public alike. A very clear summary of the relationship between advance care planning, goals of care, and consent is available through the HPCO's website *Person Centred Decision-Making Toolkit*: <https://www.speakupontario.ca/person-centred-decision-making/>. See also Nadia Incardona and Jeff Myers, "Advance Care Planning Conversation Guide: Clinician Primer" (2016), online: <https://www.speakupontario.ca/wp-content/uploads/2020/04/ACP-Conversation-Guide-Clinician-Primer.pdf>.
  - 26 A full account of this legislative history is too long to describe here. Please see LCO Research Annex E and F for more information.
  - 27 See for example: Ontario, Ministry of Labour, *The Changing Workplaces Review* (May 2017), online: <https://www.ontario.ca/document/changing-workplaces-review-final-report>; Law Commission of Ontario, *Vulnerable Workers and Precarious Work: Final Report* (April 2013), online: <https://www.lco-cdo.org/en/our-current-projects/vulnerable-workers-and-precarious-work/>.
  - 28 See the Ontario Caregiver Organization, "3rd Annual Spotlight on Ontario's Caregivers: COVID Edition" (December 2020), online: <https://ontariocaregiver.ca/spotlight-report/>. See also Ontario Caregiver Organization, "Profile of Ontario Caregivers", online: <https://ontariocaregiver.ca/publications/profiles/>.
  - 29 See the Ontario Caregiver Organization, "3rd Annual Spotlight on Ontario's Caregivers: COVID Edition" (December 2020), online: <https://ontariocaregiver.ca/spotlight-report/>. See also Ontario Caregiver Organization, "Profile of Ontario Caregivers", online: <https://ontariocaregiver.ca/publications/profiles/>; and the Toronto Star, "Who's caring for the caregivers? Many under massive stress looking after ailing loved ones during the pandemic" (December 9, 2020), online: <https://www.thestar.com/news/gta/2020/12/09/by-april-i-was-completely-lost-caregivers-under-massive-strain-looking-after-ailing-loved-ones-during-pandemic.html>.
  - 30 Law Commission of Ontario, *Vulnerable Workers and Precarious Work: Final Report* (December 2012), 1, online: <https://www.lco-cdo.org/en/vulnerable-workers-final-report>.
  - 31 Law Commission of Ontario, *Vulnerable Workers and Precarious Work: Final Report* (December 2012), 1, online: <https://www.lco-cdo.org/en/vulnerable-workers-final-report>.
  - 32 Ontario, Ministry of Labour, *The Changing Workplaces Review* (May 2017), online: <https://www.ontario.ca/document/changing-workplaces-review-final-report>.

workplaces-review-final-report.

33 Government of Canada, Second Annual Report on Medical Assistance in Dying in Canada 2020 (June 2021), online: <https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2020.html>.

34 Government of Canada, Second Annual Report on Medical Assistance in Dying in Canada 2020 (June 2021), online: <https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2020.html>.