

# Medical Assistance in Dying: A Paediatric Perspective

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## Abstract

The Supreme Court decision in *Carter v. Canada* (2015) has led to changes to the Canadian *Criminal Code*, such that physician-assisted death is now a legal option for consenting adult patients who have a ‘grievous and irremediable medical condition’ that causes ‘enduring’ and ‘intolerable’ suffering. In June 2016, Bill C-14 was enacted, allowing medical assistance in dying (MAID) for an eligible adult whose death is ‘reasonably foreseeable’. An independent report on the status of ‘mature minors’ (who are currently excluded under federal legislation), with focus on their potential eligibility for MAID, was required by the 2016 Act and is expected to be presented to Parliament by December 2018. Ensuring that newborns, children and youth receive the highest possible standard of care as they are dying is a privilege and a responsibility for physicians and allied professionals. Bringing a thoughtful, respectful and personal approach to every end-of-life situation is an essential and evolving duty of care, and the process should meet each patient’s (and family’s) unique social, cultural and spiritual needs. This statement describes the current Canadian legal and medical context of MAID and articulates a paediatric perspective that has emerged from—and been informed by—the broad, structured consultation process unfolding in Canada and elsewhere. Although ‘mature minors’ are the only youth currently mandated for further legislative consideration in Canada, the need to examine requests for and attitudes around MAID for minors of all ages remains compelling for two main reasons:

- Canadian health care professionals are increasingly being approached by the parents of ‘never-competent’ infants and children, including those too young to make a reasoned decision, and by youth themselves, to discuss MAID-related issues. Results from a Canadian Paediatric Surveillance Program (CPSP) survey, discussed below, indicate that parents raise such questions with paediatricians more often than do minors.
- The discussion of MAID policy in Canada has been framed as much by the issue and context of suffering as by considerations of autonomy. While current legislation clearly prohibits MAID for incapable persons at the request of any other person, it is possible that parents may request MAID on behalf of their dying child.

**Keywords:** *Euthanasia; MAID; Mature minors; Medical assistance in dying*

# DEFINITIONS

Now that ‘physician-assisted death’ has been expanded in Canada to include participation by nurse practitioners, the term **Medical Assistance in Dying (MAID)** is used. MAID can take two forms:

- **Euthanasia:** At the patient’s voluntary request, a practitioner administers medication that causes the patient’s death.
- **Practitioner-assisted suicide (PAS):** At the patient’s voluntary request, a practitioner prescribes or provides medication that a patient can self-administer to cause their own death.

For the purposes of this statement, specific references to *Carter v. Canada* may also include the language used in that particular case (e.g., physician-assisted death or dying).

**A mature minor** is the category of minor identified by the government for further independent review under the Federal Act of June 2016, which amended the Canadian *Criminal Code* [1] to comply with *Carter v. Canada* [2].

**The mature minor doctrine** recognizes that a patient’s comprehension of the nature and consequences of a treatment has determinants beyond age, and that children’s wishes should be granted degrees of deference that reflect their evolving maturity. The doctrine provides an opportunity for physicians to determine a child’s capacity for consent, using similar considerations as for an adult [3]. The mature minor doctrine is acknowledged under common law but is not recognized as such in the province of Quebec, which operates under the *Civil Code of Quebec*. Minors aged 14 years or older may independently consent to some forms of medical care or treatment in Quebec. Parental (or substitute decision-maker) notification is required if the child is in hospital or another health care setting for more than 12 hours. A parent’s (or substitute decision-maker’s) consent may also be required if the proposed treatment is either not required by the state of the child’s health or if it entails a serious risk to health and could cause serious and permanent effects [4].

**Substantive criteria** are terms of eligibility that ‘qualify’ a person as a candidate to receive MAID [5]. Under the Federal Act, these include:

- Being 18 years of age and capable of making health decisions;
- Having a grievous and irremediable medical condition (more specifically, having a serious and incurable illness, disease or disability; being in an advanced state of irreversible decline in capability; experiencing enduring, intolerable physical or psychological suffering; with natural death being reasonably foreseeable);
- Making a voluntary request for MAID; and
- Being capable of giving informed consent (*after* having been informed of means available to relieve suffering, including palliative care).

**Procedural due care criteria** refer to the safeguards in place to ensure that the substantive criteria outlined above are, in fact, satisfied [5]. Under the Federal Act, before providing MAID, the practitioner must:

- Hold the opinion that a person meets all substantive criteria;
- Ensure that a request for MAID is made in writing and that the document is witnessed, signed and dated *after* a person has been diagnosed with and informed by a practitioner as having a grievous and irremediable medical condition;
- Ensure the person knows that a request for MAID can be withdrawn at any point;
- Ensure that a second independent practitioner confirms in writing that all substantive criteria have been met;
- Ensure a waiting period of at least 10 clear days between the date of a signed request and the date on which MAID is to be provided. A shorter waiting period is possible when both the practitioner and the independent practitioner share the opinion that the person’s death or loss of capacity to provide informed consent is imminent;
- Offer the person the opportunity to withdraw their request and elicit their express consent to proceed immediately before MAID is provided.

## BACKGROUND

Debate around physician-assisted death in Canada came to the forefront of public policy in 2015, with the *Carter v. Canada* case [2] and Quebec's *Act respecting end-of-life care* (or Bill 52, hereafter referred to as the Quebec Act). The latter was enacted and came into effect in Quebec in December 2015, even though Canada's *Criminal Code* was not yet amended to comply with the ruling in *Carter v. Canada* [6]. See the Parliamentary report on the Federal Act for a full chronology and review of events [7]. Under the Quebec Act, euthanasia (or 'medical aid in dying') is a potential option for a capable, consenting patient 'of full age' who makes a 'free and informed' request and is suffering from 'serious and incurable' illness. Similar to the federal legislation, which allows access to assistance only for individuals 'at least 18 years of age' who are in an 'advanced state of irreversible decline in capability' and requires that death be 'reasonably foreseeable' [1], Quebec's legislation restricts MAID to patients of full age in an 'advanced state of irreversible decline in capability' and at 'end of life'. The Supreme Court did not expressly limit physician-assisted death to life-threatening or terminal physical illness in *Carter v. Canada*, which implies that a broader group of persons might eventually be eligible for medically-assisted death (e.g., those with a significant disability or intractable mental illness) [8].

## MAID AND PAEDIATRICS IN OTHER JURISDICTIONS

At present, The Netherlands and Belgium are the only two jurisdictions where legislation extends the practice of MAID to infants and/or children. In 1997, The Netherlands government ministry of security and justice convened a multidisciplinary commission to evaluate reporting on the frequency and reasons for 'deliberately ending the life of a newborn' (DELN) [9]. In 2005, the Dutch Paediatric Society (NVK) published the Groningen Protocol, a decisional process leading to DELN with parental consent [10]. This process is specific to infants who are judged by neonatologists to be experiencing 'hopeless and unbearable suffering'. Infants defined as suffering include those who:

- Are deemed to have no chance of survival (i.e., they will die soon after birth, despite optimal care);
- Have minimal chance of surviving beyond the intensive treatment period, with a poor prognosis and poor quality of life; or
- May not be dependent on intensive treatment, but whose prognosis is 'hopeless', along with a very poor anticipated quality of life.

It is beyond the scope of this statement to describe the Groningen Protocol in detail, but the process has been controversial [11][12].

With respect to minors other than newborns, a Dutch law of 2002 [13] allowed physicians to provide MAID to minors 16 to 18 years of age. Eligible minors must have a reasonable understanding of their interests and their parents or guardians must have been 'involved in the decision-making process', although they do not necessarily have to agree with their child's decision for MAID to be permitted. Minors 12 to 16 years of age may also receive MAID upon request, provided they are 'deemed to have a reasonable understanding' of their interests and their parent(s) or guardian(s) agree with the child's request. Surveys have shown that most Dutch paediatricians believe that physician-assisted dying can be an acceptable option for children younger than 12 years of age, although the practice is prohibited [14].

A 2002 Belgian law [15] allowed MAID for adults and 'emancipated minors' who were conscious and competent when making their requests [16]. In practice to date, an emancipated minor is at least 16 years old and a judge's involvement and determination is required [17]. A 2014 amendment extended permissibility for euthanasia—with the agreement from a legal guardian—to nonemancipated children without age restriction [18]. However, the child must possess 'capacity for discernment' as evaluated by a child psychiatrist or a psychologist, which will likely operate to exclude the youngest patients. Before euthanasia can be legal, the child's illness must be incurable and terminal, and the physical pain untreatable [19].

Other jurisdictions that allow MAID for adults, including Luxembourg and Columbia, prohibit this option for all minors,

including mature minors. Switzerland and all American states that allow PAS similarly restrict this option to adults.

## POTENTIAL ELIGIBILITY ISSUES FOR MATURE MINORS IN CANADA

A panel of provincial/territorial experts on MAID, tasked with exploring options for a legislative response to the *Carter* decision, released its final report on November 30, 2015. Recommendation 17 stated that access to PAS should not be ‘impeded by the imposition of arbitrary age limits’ and that relevant changes to the *Criminal Code* should be based on ‘competence rather than age’ [20]. This wording raised the issue of access to MAID for youth who met ‘mature minor’ doctrine requirements.

Although issues of suffering and autonomy apply to children and youth as well as adults, the first iteration of Canadian MAID legislation restricted access to services to adults  $\geq 18$  years of age. This decision was not arbitrary. A leading criteria (or qualifying condition) in the Supreme Court ruling was that the person seeking physician-assisted death must be an adult. Furthermore, the Supreme Court acknowledged (in para. 24) the trial judge’s finding in *Carter v. Canada* that:

... while there is no clear societal consensus on physician-assisted dying, there is a strong consensus that it would only be ethical with respect to voluntary adults who are competent, informed, grievously and irremediably ill, and where the assistance is ‘clearly consistent with the patient’s wishes and best interests, and [provided] in order to relieve suffering’ (para. 358) [2].

Whether children and adolescents can have legal access to MAID is a complex question that has yet to be fully considered and adjudicated by Canadian society, in Parliament and through courts of law. Competency can be assessed in children and adolescents in a variety of medical decision-making scenarios but does not resolve the ethical question of who can or should be able to access MAID.

To help answer this fundamental question, an appointed Special Joint Committee on Physician-Assisted Dying advised the government, in a February 2016 report to Parliament (recommendation 6), to:

... implement a two-stage legislative process ... the first stage applying immediately to competent adult persons 18 years or older, ... followed by a second stage applying to competent mature minors ...; and That the Government ... commit to facilitating a study of the moral, medical and legal issues surrounding the concept of ‘mature minor’ and appropriate competence standards ... and that this study include broad-based consultations with health specialists, provincial and territorial child and youth advocates, medical practitioners, academics, researchers, mature minors, families and ethicists ... [21].

This comprehensive consultation process provides an opportunity to study, reflect on and deliberate MAID issues as they relate to the mature minor population. Key stakeholders with valuable perspectives to share include:

- The parents/guardians of children and youth who are severely disabled or have terminal illness;
- Youth who are severely disabled or have a terminal illness;
- Bereaved parents whose children died from a severe disability or terminal illness; and
- Health care professionals who care for such children and youth.

A safe and open national dialogue that engages people with a range of backgrounds and diverse customs, beliefs and experiences, is essential for an optimal policy response on this sensitive and complex issue.

# CANADIAN PAEDIATRICIANS AND MAID

Until recently, there were no Canada-specific data on the frequency of requests for MAID for minors. Nor were there data reflecting the opinions of Canadian paediatricians on MAID issues generally or their willingness to participate in MAID specifically. In response to this critical knowledge gap, the Canadian Paediatric Society (CPS) surveyed members and associates using two methods. The first study involved a one-time survey of the 2597 paediatricians who participate in the Canadian Paediatric Surveillance Program (CPSP-MAID). This tool was designed to document actual requests for MAID by and on behalf of minors (both mature minors and from the parents of infants or children who were considered 'never competent'). The second study was designed to survey the MAID-related attitudes and opinions of CPS members (CPS-Attitudes). Key findings are summarized below.

## Exploratory conversations and explicit requests from mature minors

CPSP-MAID had 1050 respondents, a response rate of 40%. Thirty-five respondents reported having had exploratory discussions with 60 minor patients in the preceding year and nine reported explicit requests for MAID from a total of 17 minor patients. Findings indicate that while such consultations may be rare, minors in Canada are contemplating MAID-related concepts and approaching health care providers with MAID-related questions. Given the evolving legislative landscape, it is reasonable to anticipate that such questions will increase in the near future.

The CPS-Attitudes survey received 574 responses out of a possible 1979 (a 29% response rate), with only 487 completing all the questions. Almost one-half (46%) of respondents were in favour of extending the MAID option to mature minors experiencing progressive or terminal illness or intractable pain. Fewer believed access should be extended to children or youth with an intolerable disability (29%) or with intolerable mental illness as the sole indication (8%). Thirty-three per cent of respondents said MAID should not be extended to the mature minor population under any circumstance. Regarding eligibility for MAID, 55% of respondents believed that an individual's capacity was most important, compared with 22% who favoured a minimum stated age.

## Questions and requests from parents of never-competent children or youth

As of September 2017, both the Federal Act and the Quebec Act clearly prohibit non-voluntary euthanasia for all patients. However, given the human rights framework advanced in *Carter v. Canada*, the parents of a dying and/or severely disabled child who is deemed to be suffering may, in the near future, be looking to the courts to support a right to end their child's life. Decision-making for treatment of never-competent children is based on the 'best interest standard': choosing among options that reasonable persons, acting in good faith on another's behalf, would consider acceptable in similar circumstances [22]. In the foreseeable future, parents may challenge health care decisions in court on the grounds that continued life, as experienced by their dying or profoundly disabled child, is not in that child's best interests.

According to the CPSP-MAID study, 118 (11.2%) of participants reported having had exploratory discussions about MAID with parents, on behalf of 419 never-competent patients. No regional variability was evident. Practice types for these respondents included general paediatrics (32%), neonatology (18%) and palliative care (11%). Other specialties were represented by fewer than 10% of respondents.

Forty-five respondents reported receiving explicit requests for MAID by parents, on behalf of 91 children, within the previous year. Over one-half of these requests pertained to neonates or infants under a year old. The CPS-Attitudes survey showed less support for parents accessing MAID on behalf of their never-competent children. However, 32% of respondents felt access could be supported in rare situations involving terminal illness or intractable pain, provided that the process was accompanied by significant oversight. Narrative comments from over 100 respondents revealed collective unease or disagreement concerning nonvoluntary euthanasia by parents (i.e., initiated without patient consent). Many narratives

described a critical requirement for appropriate safeguards, such that MAID for never-competent children could only be considered by practitioners and parents as a last resort, and only provided that a formal process, with oversight by other external experts, was also in place.

## THE ROLE OF PALLIATIVE CARE

For all young patients facing life-limiting illness or an illness associated with prolonged suffering, having access to quality, evidence-based, compassionate paediatric palliative care is paramount. Health systems must provide and fund hospital, community and home-based palliative care services, and guarantee universal access to essential care. Current evidence suggests that many patients who could benefit from specialized paediatric palliative care do not receive it [23]–[26]. To meet this critical need, paediatric palliative care specialists need more support, and community-based physicians, nurses and home care providers need enhanced education and skills development.

Palliative care and MAID provide philosophically and clinically distinct—though interconnected—medical services. Some parents and clinicians fear palliative care as being focused on death rather than on life, and education around palliative care often involves explaining its essential role in optimizing quality of life for as long as possible. If palliative care physicians were also to engage in the MAID process, some practitioners believe that fear and apprehension might intensify [27]. At the same time, however, palliative care practitioners have acquired invaluable wisdom and experience caring for individuals and families living with advanced illness. Requests for MAID may still arise in the context of excellent palliative care, and the expertise and experience of palliative care specialists must remain available to families considering MAID. Furthermore, paediatric palliative care physicians may also wish to participate in MAID [28], if and when legislative changes extend MAID to some paediatric patients. Irrespective of personal beliefs, access to high quality palliative care must be seamless for those in need, whatever end-of-life options are being contemplated.

As Canadian legislation evolves, all requests for assisted death from or on behalf of children and youth must be treated with compassion and respect. Physicians should make sure to elicit and acknowledge the goals, fears, concerns and unmet needs of young patients receiving end-of-life care, and their families. Consultation with palliative care specialists is essential in situations where families are discussing MAID for a minor. Other interdisciplinary team members include spiritual care providers, nurses, psychologists, psychiatrists, social workers and child life specialists. Working together, a palliative care team can provide holistic and supportive counselling for end-of-life decisions. The CPS has a comprehensive statement on advance care planning [23].

## THE CLINICIAN'S DECISION TO PARTICIPATE IN MAID

Even if Canadian legislation were to evolve toward increasing access to MAID for paediatric patients, the CPS-Attitudes survey suggested that only 19% of responding clinicians would be willing to provide MAID to minors. MAID policy must strike a balance between the rights of patients to ask for medically hastened dying and the rights of physicians to conscientiously object to participating in MAID, especially given the additional considerations when minors are involved. Individual physicians are legally entitled to accept or refuse to participate in MAID. Obligations to inform or possibly refer a patient requesting MAID, however, arise through current professional codes and guidelines.

## RECOMMENDATIONS

An extensive and inclusive national discussion on MAID eligibility is currently underway in Canada. Access to high quality palliative care is an essential prerequisite for children or youth facing death, including those patients or parents who may be considering or exploring MAID.

The Canadian Paediatric Society recommends that clinicians advocate within health systems to:

- Design, fund and deliver child- and youth-focused palliative care, equipped to serve children and families in settings of their choosing, while improving access to palliative care services in homes and communities.

To better understand the risks and benefits of extending MAID to mature minors in the Canadian context, the CPS recommends that governments:

- Evaluate and learn from current MAID policies and experiences for adult patients, both in Canada and elsewhere.
- Undertake a comprehensive consultation involving: the parents/guardians of children and youth who are severely disabled or terminally ill; youth who are severely disabled or terminally ill; bereaved parents/guardians whose children died from a severe disability or terminal illness; and health care professionals who care for children and youth who are severely disabled or terminally ill.

Should legislation eventually permit competent minors to access MAID, the CPS recommends that:

- Governments at every level develop policies and procedures to safeguard young people from possible risks, harms or abuses of MAID, given their unique vulnerabilities.
- Procedures for assessing a minor's personal capacity to make health decisions rest with the patient's clinical team and parents, in consultation with other designated experts (e.g., bioethicists, psychologists, psychiatrists).

The physician's right not to participate in MAID must be respected, provided they consult and refer requesting patients or families appropriately.

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