



## **Written Submission to the Special Joint Committee on Medical Assistance in Dying**

**May 2022**

## About Us

Founded in 1922, the Canadian Paediatric Society (CPS) is a voluntary professional association that represents more than 3,600 paediatricians, paediatric subspecialists, paediatric residents, and others who work with and care for children and youth.

## MAID and Mature Minors

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.<sup>1</sup> The doctrine provides an opportunity for physicians to determine a child's capacity for consent, using similar considerations as for an adult. Although issues of suffering and autonomy apply to children and youth as well as adults, the first iterations of Canadian MAID legislation restricted access to adults over 18 years of age.

In 2015, a Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying recommended that, "physician-assisted dying should not be impeded by the imposition of arbitrary age limits. Provinces and territories should recommend that the federal government make it clear in its changes to the *Criminal Code* that eligibility for physician-assisted dying is to be based on competence rather than age".<sup>2</sup>

In 2016, the Special Joint Committee on Physician-Assisted Dying urged government 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.<sup>3</sup> It recommended that the Government commit to facilitating a study of the moral, medical and legal issues surround the concept of mature minors and appropriate competence standards through broad-based consultations with health specialists, provincial and territorial child and youth advocates, medical practitioners, academics, researchers, mature minors, families and ethicists.<sup>4</sup>

In 2018, the Expert Panel Working Group on MAID for Mature Minors released a comprehensive report on *The State of Knowledge on Medical Assistance in Dying for Mature Minors*.<sup>5</sup> Since that time, there has been little substantive developments on the issue of MAID for those under the age of 18. The work of this Special Joint Committee will hopefully help to give the issue of MAID for those under the age of 18 in Canada the appropriate legal, medical and ethical considerations it deserves. A safe and open dialogue that engages people from a range of backgrounds and diverse customs, beliefs and experiences is essential for an optimal policy response to this sensitive and complex issue.

## 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.<sup>6</sup> In 2005, the Dutch Paediatric Society published the Groningen Protocol, a decisional processing leading to deliberately ending the life of a newborn with parental consent.<sup>7</sup> This process is specific to infants who are judged by neonatologists to be experiencing 'hopeless and unbearable suffering'.

With respect to minors other than newborns, a 2002 Dutch law allowed physicians to provide MAID to minors 16-18 years of age.<sup>8</sup> 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 12-16 years of age may also receive MAID upon request, provided they are ‘deemed to have a reasonable understanding’ of their interests and their parent/guardian(s) agree with the child’s request.<sup>9</sup>

A 2002 Belgian law allowed MAID for adults and ‘emancipated minors’ who were conscious and competent when making their requests.<sup>10</sup> A 2014 amendment extended permissibility for MAID – with the agreement from a legal guardian – to nonemancipated children without age restriction.<sup>11</sup> However, the child must possess ‘capacity for discernment’ as evaluated by a child psychiatrist or a psychologist. Before MAID can be legal, the child’s illness must be incurable and terminal, and the physical pain untreatable.<sup>12</sup>

## Canadian Paediatric Surveillance Program

In 2016, the Canadian Paediatric Surveillance Program surveyed paediatricians to gather data on the frequency of requests for MAID for minors.

Out of 1,050 respondents, 35 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.<sup>13</sup> 118 participants reported having had exploratory discussions about MAID with parents, on behalf of 419 never-competent patients. 45 respondents reported receiving explicit requests for MAID by parents, on behalf of 91 children within the previous year. Over half of these requests pertained to neonates or infants under a year old.

Findings indicate that while such consultations may be rare, minors and parents of never-competent patients are contemplating MAID 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.

## Recommendations

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 severe disability or terminal illness; and health care professionals who care for children and youth who are severely disabled or terminally ill
- 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 in homes and communities

Should legislation eventually allow competent minors to access MAID legally, 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 right of physicians not to participate in MAID be respected, provided they consult and refer requesting patients or families appropriately

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<sup>1</sup> Dawn Davies, Canadian Paediatric Society Bioethics Committee. Medical Assistance in Dying: A Paediatric Perspective. *Paediatr Child Health* 2018;23(2):125-130.

<sup>2</sup> Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying. Final Report. November 2015: [https://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport\\_20151214\\_en.pdf](https://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf) (Accessed May 4, 2022).

<sup>3</sup> PDAM Committee Report. Medical Assistance in Dying: A Patient-Centred Approach, Report of the Special Joint Committee on Physician-Assisted Dying. (Parliament of Canada: 25 February 2016). [www.parl.gc.ca/Content/HOC/Committee/421/PDAM/Reports/RP8120006/421\\_PDAM\\_Rpt01\\_PDF/421\\_PDAM\\_Rpt01-e.pdf](http://www.parl.gc.ca/Content/HOC/Committee/421/PDAM/Reports/RP8120006/421_PDAM_Rpt01_PDF/421_PDAM_Rpt01-e.pdf) (Accessed May 4, 2022).

<sup>4</sup> Ibid.

<sup>5</sup> Council of Canadian Academies, Expert Panel Working Group on MAID for Mature Minors. The State of Knowledge on Medical Assistance in Dying for Mature Minors. 2018: <https://cca-reports.ca/wp-content/uploads/2018/12/The-State-of-Knowledge-on-Medical-Assistance-in-Dying-for-Mature-Minors.pdf> (Accessed May 4, 2022).

<sup>6</sup> Ibid.

<sup>7</sup> Verhagen E, Sauer PJ. The Groningen protocol: Euthanasia in severely ill newborns. *N Engl J Med* 2005;352(10):959–62.

<sup>8</sup> Wet toetsinglevensbeëindiging op verzoekenhulpbijzelfdoding [Termination of Life on Request and Assisted Suicide (Review Procedures) Act. Bulletin of Acts and Decrees 2001, no. 194. English translation in Regional Euthanasia Review Committees, Annual Report 2015, 40–46. <https://english.euthanasiecommissie.nl/documents/publications/annual-reports/2002/annual-reports/annual-reports> (Accessed on May 5, 2022).

<sup>9</sup> Dawn Davies, Canadian Paediatric Society Bioethics Committee.

<sup>10</sup> Federal Government of Belgium. Loi relative à l'euthanasie (The Belgian Act on Euthanasia as of 28 May 2002 Unofficial Translation) *Ethical Perspectives* 2002;9(2-3):182-188.

<sup>11</sup> Loi modifiant la loi du 28 mai 2002 relative à l’euthanasie, en vue d’étendre l’euthanasie aux mineurs (Law of 28 May 2002 on Euthanasia, amended by the Law of 13 February 2014). [www.ejustice.just.fgov.be/cgi\\_loi/change\\_lg.pl?language=fr&la=F&table\\_name=loi&cn=2014022803](http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=fr&la=F&table_name=loi&cn=2014022803) (Accessed May 5, 2022).

<sup>12</sup> Friedel M. Does the Belgian law legalising euthanasia for minors really address the needs of life-limited children? *Int J Palliat Nurs* 2014;20(6):265–7.

<sup>13</sup> Canadian Paediatric Surveillance Program. 2016 Results: <https://cpsp.cps.ca/uploads/publications/CPSP-2016-Results.pdf> (Accessed May 5, 2022).