

CANADIAN PAEDIATRIC SOCIETY'S SUBMISSION TO THE SPECIAL JOINT COMMITTEE ON PHYSICIAN-ASSISTED DYING

Dr. Dawn Davies MD FRCP(C) MA (Health Care Ethics and Law)
Dr. Mary Shariff LLB LLM PhD

DEFINITIONS

CPS: Canadian Paediatric Society

Physician assisted death can take two forms:

Euthanasia: the situation where a physician administers medication that intentionally brings about the patient's death, at the voluntary request of the patient.

Physician Assisted Suicide: the situation where a physician provides medication that intentionally brings about the patient's death, at the voluntary request of the patient.

Minor: Person who has not reached age of majority.

Mature Minor Doctrine recognizes that patients' comprehension of the nature and consequences of a treatment has determinants beyond age. That is a child's wishes should be granted degrees of deference reflective of his or her evolving maturity. This provides opportunity for physicians to make a determination of a child's capacity to consent similar to that of an adult.¹

Substantive Due Care Criteria: The substantive criteria that "qualify" a patient as a candidate to receive Physician Assisted Death² (for example: adult; conscious and competent when making request; voluntary request; medical condition; enduring suffering; intolerable suffering and so forth)³

The Supreme Court in *Carter v. Canada* identified the substantive due care criteria (conditions that "qualify" the patient as a candidate) as follows:⁴

- a competent adult person;
- who clearly consents to the termination of life; and
- has a grievous and irremediable medical condition (including an illness, disease or disability);
- that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.

¹http://www.royalcollege.ca/portal/page/portal/rc/common/documents/bioethics/section1/case_1_5_2_e.html Accessed November 15, 2015. *AC v Manitoba (Director of Child and Family Services)*, 2009 SCC 30, [2009] 2 SCR 181. Most jurisdictions require more significant parental and other (possibly judicial) oversight, the younger the child, and the greater the medical risk involved in making the medical decision.

² Barney Sneiderman, "Euthanasia Safeguards: Legal and Socio-Political" in Sneiderman and Kaufert (eds) *Euthanasia in the Netherlands: A Model for Canada?* (Legal Research Institute, 1994) 100 (Sneiderman)

³ See for example, *The Belgian Act on Euthanasia of May 28, 2002*, Section 3§1.

⁴ *Carter v. Canada (Attorney General)*, 2015 SCC 5, [2015] 1 S.C.R. 331 at para 127.

Procedural Due Care Criteria: Mechanisms or safeguards designed to ensure that the substantive criteria are in fact satisfied⁵ (for example: physician to advise patient about health condition and life expectancy, discuss request including therapeutic and palliative courses of action and consequences, have several conversations with patient to ensure durability and voluntariness of request; consultation and examination by second physician; and so forth).⁶

PHYSICIAN ASSISTED DEATH AS PERTAINS TO CHILDREN, ADOLESCENTS, AND PEDIATRIC PRACTICE

A. ELIGIBILITY CRITERIA / “SUBSTANTIVE DUE CARE CRITERIA”

The report from the expert panel convened on behalf of the Provinces and Territories was released November 30 2015. Recommendation 17 pertains to pediatrics when it states that eligibility for Physician Assisted Death should not be “impeded by an arbitrary age”, and that changes to the Criminal Code in this respect should be based on “competence and not age.”⁷

1. The CPS believes that while the issues of suffering and autonomy play out in children as well as adults, it is not arbitrary to restrict any first iteration of Canadian Physician Assisted Death legislation to “adult” patients (18 years).

Restricting access to Physician Assisted Death to “adult” patients is not arbitrary as this is one of the substantive due care criteria (or qualifying conditions) identified by the Supreme Court of Canada in *Carter v. Canada*.⁸

Furthermore, as acknowledged by the Supreme Court it was the finding of the trial judge 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).⁹ [emphasis added]

Accordingly, the question of whether access to Physician Assisted Death should be extended beyond adults to included children and adolescents is an ethical question which has yet to be contemplated and considered by Canadian society. The fact that “competency” can be assessed in children and adolescents in a variety of medical

⁵ Sneiderman note 2.

⁶ See for example, *The Belgian Act on Euthanasia of May 28, 2002*, Section 3§2.

⁷ Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying Final Report, November 30 2015, Recommendation 17, page 7.

⁸ *Carter v. Canada* (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331.

⁹ *Carter v. Canada* (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331 at para 24.

decision-making scenarios does not resolve the ethical question of “who” with respect to access to Physician Assisted Death, nor does it identify whether there is an unmet need.

If Canada is to consider extending Physician Assisted Death to children and adolescents, such consideration should include determining the priorities of Canadians, whether strong consensus exists, guided by reliable data and obtained through consultation, especially consultation with patients, families, child and adolescent specialists.

2. The CPS strongly recommends that comprehensive consultation with: 1) parents of children who are severely disabled or have terminal illness; 2) bereaved parents whose children died after terminal illness or severe disability; 3) pediatric health care professionals, (at minimum representatives from pediatric medicine and nursing, respiratory therapy, pediatric psychology, and social work associations); 4) representatives of major religious associations prior to further the implementation of Physician Assisted Death legislation that would include children and adolescents.

The Belgian law on euthanasia for adults came into force 2002, and was extended to children in 2014, but has been widely criticized for lack of appropriate broad consultation prior to this extension to children.¹⁰ As far as we are aware, no paediatric data has been published regarding the inclusion of minors in Physician Assisted Death legislation.

Furthermore, in *Carter v Canada* the issue of Physician Assisted Death for minors was simply not before the Court. The courts’ evaluation of safeguard evidence and data was critical to the Court’s finding that the criminal code provisions prohibiting Physician Assisted Death were of no force or effect to the extent they would prohibit competent adults with particular medical conditions and suffering from accessing Physician Assisted Death. As put by the Supreme Court,

The scope of this declaration is intended to respond to the factual circumstances in this case. We make no pronouncement on other situations where physician-assisted dying may be sought.¹¹

3. As there is no Canadian pediatric data of which we are aware regarding either requests for Physician Assisted Death for children and adolescents, the opinions of Canadian pediatricians about Physician Assisted Death generally, or their willingness to participate in Physician Assisted Death specifically, CPS will undertake a one-time survey through the Canadian Pediatric Surveillance Study to gather this information.

4. The CPS believes it prudent to evaluate and learn from the experience of Physician Assisted Death restricted to “adult” patients (18 years) in the Physician Assisted Death legislation anticipated for June 2016.

¹⁰ Friedel M. (2014) “Does the Belgian law legalizing euthanasia for minors really address the needs of life-limited children?” *International Journal of Palliative Nursing* 20(6) 265-267.

¹¹ *Carter v. Canada* (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331 at para 127.

Further changes can be made to legislation in a staged fashion, based on these initial evaluations before the practice is extended to those less than 18 years, recognizing that legal challenges could arise in the interim.

Patients younger than 18 years would pose special concern if they were not dying, nor having protracted physical suffering, but were having significant psychological suffering. Examples of this would be teens catastrophically injured with sudden onset of severe disability, who may initially wish themselves dead, or adolescents with serious mental health problems. It is this group of young patients who need to be protected from a blanket legislation that would possibly allow for Physician Assisted Death, without prior opportunity to learn from adult patients, their families and caregivers. This could only be possible with essential outcomes research regarding Physician Assisted Death once it is legislated.

5. The CPS recommends that Parliament be exceptionally clear as to the substantive ethical and legal foundation for legalization should Parliament extend Physician Assisted Death access beyond “adult” patients to include children and/or adolescent patients.

Parents of never-competent children: We are aware that all regulating authorities for the medical profession, in addition to expert panels, have stated that proxy decision makers will not be able to request Physician Assisted Death on behalf of any other person.

Canadian pediatric physicians have received requests for Physician Assisted Death by parents on behalf of their never-competent younger children. In light of media coverage of the *Carter v. Canada* case, some parents have erroneously inferred that parents will have the right to request Physician Assisted Death on behalf of their child. Anecdotally, these statements have been made by parents of children with known terminal illness (cancer) or catastrophic neurologic injury as examples. Supporting evidence is an American study of 141 bereaved parents whose children died of cancer. These parents reportedly considered requesting hastened death of their child in 13% of cases, and openly discussed it in 9% of cases. Thirty-four percent of the same parents believe they would have wished for a hastened death if their child were in uncontrolled pain, which establishes that excellent palliative care must be a precursor to the discussion of Physician Assisted Death.¹² (See also, Recommendation 6.2. below)

We think it is likely that, given the human rights framework in which the *Carter v. Canada* decision seems to have been based, that parents of dying and/or severely disabled children may apply to the Courts seeking the right to end the life of their child. Decision-making for treatment of never-competent children is based on the “best interests standard”.¹³ It is possible that parents will challenge the Courts on the basis that

¹² Dussel V, Joffe S, Hilden JM, Watterson-Schaeffer J, Weeks JC, Wolfe J. Considerations about hastening death among parents of children who die of cancer. *Arch Pediatr Adolesc Med.* 2010;164(3):231-237.

¹³ Kopelman, L. M. (2007). The best interests standard for incompetent or incapacitated persons of all ages. *Journal of Law, Medicine & Ethics*, 35(1), 187-196.

continued life, as experienced by their dying or profoundly disabled child, is not in their child's best interests.

B. PROCESSES AND PROCEDURES / "PROCEDURAL DUE CARE CRITERIA"

6. Should Parliament decide to extend Physician Assisted Death access beyond adult patients to include children and/or adolescent patients:

6.1 The CPS recommends that the complex procedures for of assessing a minor's capacity, should be left to the minor's parents and immediate clinical team and parents with recourse to the courts.

As is specifically stated in the *Carter v. Canada* ruling, physicians are able to make assessments of individuals' vulnerability using procedures that they apply when assessing "informed consent" and "decisional capacity".¹⁴ However, as has always been the case with mature minors, the greater the risk of serious harm or death, the more vigilant health care providers must be in their assessment of a minor's capacity to make the decision, and to ensure that it is free from duress of parents or other authority figures. These assessments are not easy to make, and thus referral to the courts for life and death cases involving minor patients is not uncommon.¹⁵

Regulatory processes as outlined by numerous Provincial Colleges of Physicians and Surgeons may be a reasonable starting point for adults. How they should be altered for children, adolescents, mature minors or other pediatric situations that may arise is not currently known.

6.2 The CPS recommends enhanced pediatric-specific palliative care, funded and equipped to care for children and their families in the setting of their choosing, especially in their homes and home communities.

High quality palliative care must be accessible for children and youth. Extrapolating from research in British Columbia, it is estimated that 10 children of every 10,000 in the population 18 years and younger are in need of palliative care services.¹⁶ For 2002, a Canada-wide study estimated that only 5-12% of children who may have benefitted from specialized palliative care services actually received them.¹⁷ A follow-up study done 10 years later shows some improvement, with 18% of eligible children receiving these

¹⁴ "We accept the trial judge's conclusion that it is possible for physicians, with due care and attention to the seriousness of the decision involved, to adequately assess decisional capacity". *Carter v. Canada* (Attorney General), 2015 SCC 5, [2015] 1 S.C.R. 331 at 116, 115.

¹⁵ *B.H. (Next friend of) v. Alberta (Director of Child Welfare)* 2002 ABQB 371

¹⁶ Cavoshi N, Miller T, Siden H. "Mortality trends for pediatric life-threatening conditions." *American Journal of Hospice & Palliative Medicine* 32(4):464-469.

¹⁷ Widger K, Davies D, Drouin D, et al. (2007). Pediatric patients receiving palliative care in Canada: Results of a multicentre review. *Archives of Pediatrics & Adolescent Medicine*, 161, 597-602.

services, but still leaving enormous scope for improvement.¹⁸ In addition to small, specialized palliative care teams affiliated with most Canadian children’s hospitals, enhanced education and skill of community based physicians and Home Care Services will be required to meet this need.

6.3. The CPS maintains the position that palliative care and Physician Assisted Death are philosophically and clinically distinct and should organizationally remain as such.

C. ROLES AND REGULATION OF HEALTHCARE PRACTITIONERS

7. Given the rapid societal shift since the *Carter v Canada* decision, and short timeline to enacting legislation, **the CPS strongly enshrines the physician’s right to conscientiously object to being involved in Physician Assisted Death generally, but especially in the cases of children and adolescents.**

Apart from most citing a strong personal aversion to providing Physician Assisted Death, a frequently cited professional reason is that patients, parents and clinicians already fear the notion of “palliative care”, and education is often required to explain palliative care’s role in optimizing quality of life for as long as it lasts. If the same physicians were also to participate in Physician Assisted Death, it is anticipated that this fear and apprehension of palliative care might intensify.

While there may be pediatric or family physicians willing to provide Physician Assisted Death, we further believe they will be in the very small minority, so hinging access to Physician Assisted Death on a balance between the rights of patients and the rights of physicians (the apparent result from the *Carter v. Canada* decision)¹⁹ could be highly problematic, especially within the child’s own clinical care team. Pediatric care is very interdisciplinary in nature. Although Physician Assisted Death is the issue, legislation needs to be cognizant of the impact this will have on other health care professionals on the pediatric team (pharmacists, nurses, social workers, and many others).

Further the CPS re-iterates the position that compliance with *Carter v Canada* does not mandate physician participation in Physician Assisted Death. As per the Supreme Court, “In our view, nothing in the declaration of invalidity which we propose to issue would compel physicians to provide assistance in dying. The declaration simply renders the criminal prohibition invalid.”²⁰

¹⁸ Widger K, Davies D, Daoust L, et al. “How have we changed? Pediatric palliative care in Canada, 2002-2012”, in draft.

¹⁹ *Carter v. Canada (Attorney General)*, 2015 SCC 5, [2015] 1 S.C.R. 331 at para 132.

²⁰ *Carter v. Canada (Attorney General)*, 2015 SCC 5, [2015] 1 S.C.R. 331 at para 132.

