

Special Joint Committee on Physician-Assisted Dying 40 Elgin Street Chambers Building **The Senate of Canada** Ottawa ON K1A 0A4

Attention: Joint Clerks of the Committee

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## Re: Physician- Assisted Death and Children's Rights

The Canadian Coalition for the Rights of Children is a national coalition of child rights organizations and individuals dedicated to promoting, and educating the public about, the United Nations Convention on the Rights of the Child throughout Canada. Our work includes the development of educational tools about the Convention, symposia on how best to implement the Convention in Canada and monitoring how well Canada is doing to respect child rights in law, policy and action. In your deliberations in respect of your mandate to formulate recommendations on the framework of a federal response on physician-assisted dying that respects the Constitution, the Charter of Rights and Freedoms, and the priorities of Canadians, our Coalition urges you to consider the impact of your recommendations on children through the perspective of the rights of children and Canada's international obligations under the *Convention*. The following is a brief summary of the issues that we believe reflects that perspective.

*UN Convention of the Rights of the Child* - Article 12:

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being give due weight in accordance with the age and maturity of the child.

In an ideal world no child would ever suffer from a terminal disease. They would not endure intractable pain, nor face the indignity of losing control over one's own body and mind; nor would their parents have to watch their child suffer, knowing death was inevitable.

Despite advances in health care, in particular palliative care and pain management, there are cases where suffering cannot be alleviated. Further, physical suffering alone is not the sole motive of those who seek an end to life. Loss of dignity and autonomy as one's body succumbs to disease and injury, are most often stated as reasons alongside intractable pain, to control how and when the end comes. Losing control over bodily functions, the inability to communicate, and having to rely on family members and others for the most basic tasks of existing, all contribute to the underlying desire for physician-assisted death.

In 2015 the Supreme Court of Canada held that a law which prohibits a person from pursuing physician-assisted death "interferes with their ability to make decisions concerning their bodily integrity and medical care and thus trenches on liberty. And, by leaving people .... to endure intolerable suffering, it impinges on their security of the person." <sup>1</sup>

As the Government of Canada responds to the Supreme Court of Canada's decision in *Carter v. Canada* with new legislation, the question remains: Will the new law respect the rights of competent children and youth; or will the law deny them equal access to make decisions concerning their bodily integrity, such that they alone will be left to "endure intolerable suffering" when death is a certitude, without the right to seek physician-assisted dying? Such a decision would not only be cruel and unfair, but also in violation of Article 12 of the *UN Convention on the Rights of the Child*<sup>2</sup>, as well as inconsistent with Canadian common law and the majority of provincial laws, which grant the right to make one's own medical decisions based on capacity, not an arbitrary age maker.

In A.C. v. Manitoba (Director of Child and Family Services), a majority of the Supreme Court held that "The more a court is satisfied that a child is capable of making a mature, independent decision on his or her own behalf, the greater the weight that will be given to his or her views...." "If, after a careful and sophisticated analysis of the young person's ability to exercise

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<sup>&</sup>lt;sup>1</sup> Carter v. Canada (Attorney General), 2015 SCC 5, at para. 66.

<sup>&</sup>lt;sup>2</sup> ...which requires that age alone not be considered a determinates but also the maturity of the child, recognizing evolving capacities and the differences in ages upon which children develop capacities for decision-making.

mature, independent judgment, the court is persuaded that the necessary level of maturity exists, it seems to me necessarily to follow that the adolescent's views ought to be respected." <sup>3</sup>

Thus Canadian children and youth based on their capacity, not age, can request the removal of life-sustaining medical equipment such as ventilators, refuse artificial nutrition and hydration, and refuse life -saving treatments such as dialysis or chemotherapy even though that treatment may prolong their life. It is incoherent and unethical to acknowledge the right of capable children and youth to consent to end medical treatment which might result in their own death; but not extend to them the same right as adults, to assistance in ending their suffering from a "grievous and irredeemable dying".

To deny the rights based on age alone is an unacceptable denial of equality according to the majority of Toronto high school students who attended a workshop on physician assisted-death in 2015.<sup>4</sup> When asked to fill in a questionnaire on whether physician-assisted death should be available to competent adults only, or adults as well as youth, of those who supported the concept of physician-assisted death, 77.7% believed that it should be available to capable youth.

Furthermore, what about the right of children without capacity to hasten an end to intolerable suffering? In a study among parents whose children died of cancer 19% considered requesting a hastened death. One father of a five-year-old boy who died of cancer requested of his physician that if the child's soft-tissue tumor ever threatened to choke his son to a "horrible, horrible" death, "Can we just get it over with quickly?" With laws that did not support such a request, not only did the father endure the loss of his child, but was denied the solace of knowing there was a possible exit if the suffering became intolerable<sup>5</sup>. Canadian law as well as *the UN Convention on the Rights of the Child*, Article 3, requires that all decisions made for children must be in their best interests. Can one reasonably argue that it will never be in the best interest of a young child not to have the benefit of physician assistance to end prolonged suffering when the medical condition is terminal?

As in all discussions concerning physician assisted death, there are legitimate concerns about protecting the vulnerable, those who do not have capacity, and those who do not have the ability to express their wishes. The concerns about vulnerable populations is not age dependent, nor should concerns about adequate safeguards (as the Supreme Court has noted) justify denying the

<sup>&</sup>lt;sup>3</sup> A.C. v. Manitoba (Director of Child and Family Services), 2009 SCC 30, [2009] 2 S.C.R. 181, para. 87.

<sup>&</sup>lt;sup>4</sup> Fundamental Freedoms Conference; hosted by C C L A; workshop by Lee Ann Chapman PBO at SickKids.

<sup>&</sup>lt;sup>5</sup> Archives of Paediactric & Adolescent Medicine Journal 2010 Mar; 164(3):231-7. doi: 10.1001/archpediatrics.2009.295. **Considerations about hastening death among parents of children who die of cancer.**Dussel V, Joffe S, Hilden JM, Watterson-Schaeffer J, Weeks JC, Wolfe J.

most basic rights to the citizens of a country, the right of bodily integrity and security of the person as it applies to ending an unwanted life, dominated by intolerable and hopeless suffering. It is important that the Supreme Court's ruling that the suffering must be "grievous and irremediable" is respected and that all avenues of pain alleviation are offered, and that only those in a hopeless medical situation are offered assistance in dying as a relief from suffering. However, that desired relief should not be denied on the basis of age alone.

While the state has a legitimate interest in protecting those who are vulnerable, choosing an arbitrary age upon which to grant the right to assistance in ending the intolerable suffering of a prolonged dying, would not likely stand up to scrutiny under the *Charter* or the *UN Convention* on the Rights of the Child.

Submitted on behalf of the Coalition by Cheryl Milne, Chair and President LeeAnn Chapman, Vice-President