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End of Life Planning Canada
Brief on Recommended Changes to Bill C-14
Submitted to the Standing Committee on Justice and Human Rights
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1. End of Life Planning Canada, a registered charity, helps Canadians to navigate the end-of-life experience with confidence and dignity. We provide information, education and support to assist individuals and their families to plan for a gentle dignified death, and to navigate the health care system with confidence that their rights will be respected to the very end. We publish Advance Care Planning kits specific to each province. Our staff psychotherapist helps people to think about and prepare for an approaching death.
2. The Supreme Court in the Carter decision showed wisdom and compassion, setting out criteria for access to assistance to die that respect the autonomy of each Canadian to determine if and when their own life has become intolerable because of a grievous and irremediable illness or medical condition. In crafting their decision, the justices seemed to ‘walk in the shoes’ of desperately ill Canadians. Our representatives in Ottawa must craft legislation based on these same values of wisdom and compassion.
3. We have two major concerns with Bill C-14:

Remove the Reasonably Foreseeable Natural Death criterion

4. Some Canadians suffering terribly from debilitating conditions are not facing a reasonably foreseeable death. Under the current wording, their pain is not considered on an equal basis to that of someone suffering equivalent pain but also having a terminal condition (such as cancer). This kind of inequity cannot be what the drafters of Bill C-14 intended in selecting the term ‘reasonably foreseeable natural death’, which is drawn from no known precedent.
5. ‘Reasonably foreseeable natural death’ is a criterion untenable in practice. The margins of ‘reasonably foreseeable’ will of necessity have to be defined by the courts because third parties opposed to assistance to die will claim that a natural death was not ‘reasonably foreseeable’ in particular cases. This will cause front line chill and result in medical or nursing practitioners shying away from helping patients who would otherwise meet all Supreme Court criteria for assistance in dying. It is a bad idea for estimates of remaining time to be anywhere in legislation.
6. Bill C-14 should make patients, in consultation with medical or nursing practitioners, the sole decision-makers having autonomy to determine that assistance to die is a legal option in their particular circumstances. The standard must apply to each specific patient, without the need to petition a court or other adjudicator for an advance determination.



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Advance Directives Should Survive the Loss of Capacity to Consent

7. The number of persons suffering from dementing diseases such as Alzheimer's is rising at an alarming rate. We justly fear these diseases that kill vital brain cells and rob us of our mind, our judgement, our memories, and our ability to communicate, dress, feed and toilet ourselves. The end stages of dementing diseases reduce some to a vegetative state that can last for years before death occurs naturally. Families are helpless before the cruel dementing diseases that steal their loved ones away, slowly and inexorably.
8. How can Bill C-14 address the tragedy that is the rising tide of dementia? It can return to the values of wisdom and compassion that informed the Supreme Court in the Carter case: giving to the individual the autonomy to decide in advance when they have reached such an advanced state of debilitation that their life, looking ahead, would be intolerable to them.
9. A valid advance directive can clearly describe a state of debilitation so severe that it would cause intolerable suffering to its author. If the legally-appointed substitute decision maker, in consultation with medical or nursing practitioners, is able to confirm that the described state of debilitation has been reached, then this advance directive should survive its author's loss of capacity, and serve as that person's competent request and consent to receive assistance to die.
10. Such an advance directive would comfort individuals as they descend into the fog of dementia. It would also comfort their family knowing that the author's wishes clearly expressed in the advance directive would be respected at the very end.
11. Just as Bill C-14 has put into place steps to ensure that Canadians will not be abandoned by the health care system should they request assistance to die, so Bill C-14 should put into place criteria to ensure that we not abandon to a pitiable fate an entire generation of Canadians who because of dementia will lose the capacity to provide contemporaneous consent for assistance in dying.

Respectfully submitted,

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Chair

End of Life Planning Canada