Brief on suggested amendments to Bill C-14 to the Standing Committee on Justice and Human Rights

Let me remind you that those requesting medical aid in dying (MAID) are competent adults not wards of the state. We expect that our autonomy, responsibility and authority for our end of life choices is preserved and protected. If we choose MAID we are asking for aid in dying. Anticipating intolerable suffering, we are trying to retain and exercise a small modicum of control over the timing and circumstances of our death.

Justice Minister Jody Wilson Raybould now acknowledges that Bill C-14 will face legitimate challenges before the Supreme Court of Canada (SCC). As drafted, Bill C-14 is badly flawed. To fix it, I suggest five amendments.

First, Bill C-14 restricts eligibility for MAID only to those who have "incurable" conditions. This restriction discriminates against all those suffering Canadians who don't want to undergo treatments unacceptable to them. The *Carter* decision qualified "irremediable" as "not acceptable to the individual".

Accordingly, in section `241.2 (2) (a), "incurable" should be replaced with "They have a serious illness, disease or disability that is irremediable or for which there is no treatment that is acceptable to the person."

Second, Bill C-14 restricts eligibility for MAID to those who are suffering in an "advanced state of irreversible decline in capability." This restriction discriminates against Canadians suffering from certain types of chronic, degenerative illnesses from rightfully accessing MAID.

People like me, who live with grievous and irremediable medical conditions like Freidriech's Ataxia, Multiple Sclerosis or ALS are condemned to endure years of severe, unwanted suffering because they haven't reached the final stage of their disease. This violates our Charter rights.

Worse, if advance requests for MAID, are prohibited, this criterion also excludes and discriminates against Canadians with dementia or other degenerative diseases like Huntington's because those people will lose competence once they reach an "advanced state".

Section 241.2 (2) (b) should remove "advanced state of irreversible decline in capability" entirely from the definition of "grievous and irremediable".

Third, *Carter* didn't require that the illness, disability or disease be "imminent". Hence, there is no warrant for adding the criterion "natural death has become reasonably foreseeable" as a condition of eligibility.

Ominously, this unnecessary restriction is vague. It enables eligibility to be interpreted as limiting MAID only to those people with a terminal illness or whose death is imminent. Again, this condemns Canadians to years of unwanted suffering.

K. Carter herself, suffered intolerably from a grievous and irremediable condition that wasn't immanent. Under Bill C-14, she wouldn't satisfy this criterion. This irony is both wicked and perverse, ignoring as it does the SCC's judgement in *Carter*.

To avoid this absurd result, "natural death has become reasonably foreseeable" in section 241.2 (2) d) should be excised completely from the definition of "grievous and irremediable".

Fourth, Bill C-14 doesn't include advance consent for MAID. Prohibiting advance consent discriminates against Canadians diagnosed with dementia or other degenerative conditions that rob people of competency who would otherwise be eligible for MAID. It should also be extended to include those who have family histories of any of these conditions. Doing so enables them to plan effectively for their preferred end of life care.

It also discriminates against those competent adults who consider themselves vulnerable and seek the protection of an advanced refusal of MAID under any circumstances. Bill C-14 provides no means for vulnerable competent adults to decide in advance and for themselves for or against MAID. Instead, their dignity as autonomous persons is ignored.

Section 241.2 must include advanced consent for MAID. It should embrace those who have a diagnosis of degenerative conditions including dementia but who are not yet suffering intolerably and those with family histories of such conditions. It should enable vulnerable competent adults to refuse MAID.

Fifth, requiring people accessing MAID to give "express consent to receive MAID" immediately before assisted death occurs discriminates against those who have lost competency but continue to suffer intolerably. This restriction violates the rights of competent adults who have already clearly expressed their request for MAID, so as not to prolong their suffering, but have since lost competency. This is the cruel circumstance the SCC sought to avoid in *Carter*.

Section 241.2 (3) (h) should include at the start, "If the person is still capable, then….". If they are no longer capable, MAID must proceed consistent with their prior request as spelled out in 241.2 (1) (d).

Thank you for your patience and consideration.

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