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Special Joint Committee on Physician Assisted Dying
Parliament of Canada
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Dear Sir/ Madame:

I would like to share some of my thoughts with you as you consider what legislative framework will be put forward to your parliamentary colleagues in preparation for the coming legalization of physician assisted dying in Canada.

I was extremely impressed by the recommendations of the Provincial and Territorial Expert Advisory Group, and hope the compassionate and carefully considered guidance provided by this expert panel may serve as a foundation for your own deliberations on the matter.

The most indispensable aspect of the Expert Advisory Group's recommendations was not only that they respected the SCC ruling, but that they completely avoided discrimination against any identifiable group within our society by focusing on an individual's competence to provide fully informed consent, thereby ensuring that each Canadian is treated fairly and equally.

The Advisory Group successfully resisted pressure from special interest groups to prevent access, or introduce extra barriers to this essential medical service, for already stigmatized populations within our society, such as the disabled or those with mental health issues.

Of course, unless a physically disabled person also suffers from mental challenges which leave them incapable of giving informed consent, it is completely offensive to suggest they not have the same right to decide about their own life and death as the rest of us.

Similarly, unless a mental health condition renders an individual incompetent there is absolutely no excuse for denying them access to end of life choice. Society would never seek to override the free choice of such a competent individual regarding any other health decision (including the provision/cessation of life sustaining care). Access to PAD is no different. *The patient is either competent to make decisions for themselves, or they are not.* Let us adhere to this objective and well established assessment modality, rather than pander to the prejudice which already effects this marginalized group of Canadians (i.e. the misinformed and derogatory notion that they don't have any idea what they want, or what is best for them, or that they are all incapable of reasoned rational thought).

The SCC carefully made no differentiation between mental and physical suffering, which they clearly could have chosen to do, had they believed it to be consistent with our constitution. It is not. Suffering from constant mental agony is just as horrific for many patients as suffering from physical pain. The ignorance that surrounds this issue is also based on the incorrect belief that mental illness is somehow easier to treat than physical illness.

If one looks at depression, for instance, while almost everyone with the condition is fully capable of informed consent, their mood disorder can usually not be treated successfully by medication. Less than one third of patients remit, and that remission is rarely enduring, despite suggestions to the contrary by pharmaceutical interests and the physicians who prescribe antidepressant drugs for a living (1, 2).

The long-term success rate for any type of 'talk therapy' is similarly dismal, but as the scientific method cannot be used to assess these treatments (as 'sham' therapy is rightly considered unethical) the placebo effect cannot be ruled out as the cause of any reported improvement.

Unfortunately, depression is often a persistent and recurrent illness which causes untold suffering for those afflicted.

As suffering is a very subjective experience, and we can never accurately assess others' pain, *only the person in question can possibly decide when they have had enough*, and that is equally true with regards to mental or physical suffering. A significant proportion of those with mental illness face a life of chronic unbearable mental pain, treatments lacking in efficacy, or the drugs causing side-effects which are almost as hard to bear as the disease itself (and which can be permanent even after cessation of treatment). It would therefore be both cruel and discriminatory to deny or restrict access to PAD for competent individuals enduring persistent illness of this sort.

I also would like to comment on the fact that the SCC purposely did not define the term 'adult' in their ruling, allowing for the possibility of mature minors, who are often involved in other decisions about their health care, to have access to PAD if they are judged competent to do so. While our society does use arbitrary age limits to determine less important rights (like the right to purchase alcohol, for instance), such an approach is obviously not appropriate when it comes to PAD.

We could not possibly seek to determine when exactly each Canadian youth is mature enough to drink alcohol. It would be entirely impractical, even though we understand that setting arbitrary age limits will always strand certain individuals on the wrong side of the line. I think, for example, that we can all conjure up the image of a sixteen year old boy who should never be given the keys to an automobile, drivers license notwithstanding.

However, for the very few youth who meet all other criteria for PAD, I submit that we have a responsibility to look at each case individually and make use of the competence assessment procedures already well defined within the practice of medicine. I am not any more enthusiastic about torturing children to death against their will than I am about doing the same thing to adults. It is unconscionable.

Another worry regarding the new legislation is that it will fail to provide a level of access that truly respects the SCC ruling. Therefore, not only do I beseech you to refuse to treat certain identifiable groups within our society differently in respect to the requirements they must fulfil to choose PAD, I am also concerned about more practical matters of provision.

Many Canadians cannot get a family doctor at all, and yet some expect that a candidate for PAD not only find a GP willing to grant them their rights, but then find a *second* willing physician. This is not necessary for other patient decisions (i.e. choosing palliative sedation, electing to stop chemotherapy, etc.), so why should it be different when somebody chooses PAD? Based on the availability of physicians, and the significant number who will refuse to put their patient's wishes before their own, I feel it is likely that requiring a second doctor to agree to the patient's request will constitute an

insurmountable barrier for some individuals, denying them what is now a basic human right. Concerns about lack of access could also be partly alleviated by ensuring that all publicly funded medical institutions must provide the service when asked, and that other health care professionals, like practical nurses, pharmacists, medics and so on, be permitted to assist with dying. Of course, these individuals must be properly trained, and held to the same standards regarding proof of informed consent, proper record keeping, and reporting appropriately to the authorities as would physicians.

Finally, I would like to stress the importance of allowing those who wish it to make an advance directive while competent which must be adhered to should their illness render them incompetent over time. I know of so many people who would take the greatest comfort from being able to precisely state their wishes about end of life choice before an unexpected health crisis arises. Why should every competent person not be able to document their wishes ahead of time, so that it is their deeply held values and beliefs which are respected at the end of life instead of those of others?

To summarize, I respectfully submit that the following points might inform your deliberations:

- ⑩ any person who has a grievous and irremediable condition, and who wishes access PAD due to their suffering, should be given access without discrimination, based on their ability to provide fully informed consent (using the well developed practices for assessing competency already in place)
- ⑩ the largest practical difficulty for the government in upholding the SCC's ruling will be lack of access to PAD for those patients who qualify, and the Joint Committee should take all reasonable steps to promote timely access
- ⑩ it is essential that those who wish it be allowed to set out in detail, at a time when they are competent and fully themselves, what their true wishes are regarding PAD in the event that they become incompetent while concurrently grievously and irremediably ill

The horrible choice that the majority of Canadians wishing to end their lives have had up until now is between using a firearm and hanging. These are terrible options for both the patient, and those who find their remains. Hanging in particular can result in much agony before death, and also in dreadful permanent injury if the desired release from life is not achieved. Let us move forward and ensure that no one is ever forced into this kind of unspeakable choice again. Let us focus on liberty, compassion, and the freedom to choose, unencumbered by the religious prejudices of the past.

Thank you for the consideration of my submission.

Sincerely,
Lena Lindstrom

- 1) Pigott, H.E., Leventhal, A.M., Alter, G.S., Boren, J.J.: Efficacy and effectiveness of antidepressants: current status of research. *Psychotherapy and Psychosomatics* 2010; 79: 267-279.
- 2) Turner, E.H., Matthews, A.M., Linardatos, E., Tell, R.A., Rosenthal, R.: Selective publication of antidepressant trials and its influence on apparent efficacy. *New England Journal of Medicine* 2008; 385: 252-260.

