

## Rights Enhancing Safeguards

Submission to the Senate Committee on Legal and Constitutional Affairs and to the House of Commons  
Standing Committee on Justice: Bill C-14 Medical Assistance in Dying

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I am grateful to the Committee for extending an invitation to appear before it to discuss legislation of deep concern to all Canadians. My background is as a lawyer, at the national disability law centre ARCH and more recently in private practice, acting as counsel to persons with disabilities, including the national disability organizations for more than 35 years, including more than 20 appearances before the Supreme Court of Canada. In the courts and in submissions to government over that time it has been my honour and duty to advocate for the rights, autonomy, protection and advancement of persons with disabilities.

As some members of the Committee may be aware, together with health lawyer Gilbert Sharpe, I drafted a Bill which can be found with explanatory notes in the February 2016 edition of *Health Law in Canada*. The eligibility criteria in that Bill are comparable to those in Bill C-14, but the safeguards we proposed, while in no way hindering access to the right being conferred, are more rights enhancing and robust in addressing vulnerability. The criteria in the government's Bill, as is indicated in the Bill's preamble, represent an important safeguard, however the absence of any reference to vulnerability factors in the medical assessments prescribed by the Bill indicates insufficient value being ascribed to the autonomous choices and lives of persons with disabilities.

I wish to endorse without repeating the submissions to this Committee of both Professors Lemmens and Pothier. The government is commended for clarifying the definition of "grievous and irremediable". Its criteria are both *Charter* compliant and essential to the Bill's effective and consistent enforcement. The government is commended for recognizing the need for further study of a number of issues not addressed by the Court in *Carter*.

I will speak briefly about the issue of **safeguards**.

**Motivation** Suicide is a major issue across Canada. While we are here to address the issue of medical assistance in dying, there are communities across Canada working to stem a tide of premature and preventable deaths amongst those who do not have a disability. It will remain a criminal offence to help such persons to commit suicide. Suicide prevention protocols exist within hospitals and in the wider community to prevent people from taking their own lives. As a humane and compassionate society we intervene to support those who are in such dire circumstances. Persons with disabilities are not immune to the taking of their own lives for reasons that are comparable those motivating non-disabled persons to do so. Marital breakdown, loss of employment and feelings of loneliness and isolation are just as prevalent amongst persons with disabilities, including those with grievous and irremediable conditions.

MAD is not the cure for all "suffering" experienced by persons with disabilities. Unlike consent to the giving and withholding of treatment, MAD differs because there are criteria that must additionally be met before giving effect to a person's choice to die [see s. 241.2(2)(c) of the Bill]. It would be

discriminatory to treat persons with disabilities differently from persons who are not disabled in comparable circumstances. In *Carter* it is clear that an individual's motivation is important and when the motivation is not based on suffering caused by a grievous and irremediable condition it was not intended that MAD would be legalized. Motivation will not be apparent unless inquiries are made. What is clear is that where there is comparable motivation underlying the psychological suffering of two persons, it is the responsibility of Parliament to develop safeguards that ensures they are treated equally. This would require that assessors go beyond being required to confirm informed and voluntary consent to the receipt of medical assistance in dying ["MAD"] and inquire further into the source of the person's suffering.

Neither the Court in *Carter* nor the Bill provides direction about how this task is to be performed. Parliament was charged with creating safeguards that would ensure that vulnerable persons with disabilities are treated comparably to comparably motivated persons who are not disabled. Vulnerability involves motivation, and the statutory safeguards should expressly ensure assessors examine what is causing a person's suffering. Palliative care assessors are the health care providers with skills and experience in the identification and relief of suffering.

**Error Influence and Choice** Here is evidence accepted by Justice Smith [para. 400] in *Carter* of disability-related motivational factors identified by the persons who were subsequently determined to be eligible for MAD in Oregon, where the statutory criteria requires that death be imminent [within 6 months].:

- a) Loss of autonomy;
- b) Ability to engage in activities to make life enjoyable;
- c) Loss of dignity;
- d) Loss of control of bodily functions;
- e) Perceptions that care requirements represent a burden for family, friends or caregivers;
- f) Pain control, including access to proportionate palliative care and/or hospice care; and
- g) Concerns about the financial implications of care that is not an "insured service".

In order to give an informed consent to MAD it would be necessary for the person to be aware of what choices exist to be made concerning these factors. We are all aware that many people who want and need palliative care in this country are unable to get it. Similarly many people seek a "good death" in their own home surrounded by friends and family. Making this choice, without becoming burdensome for family or friends, may be impossible for some without home care. Social workers address financial matters and nurses or case managers enable personal care.

Parliament may not go as far as did Quebec and guarantee a coincident right to palliative care, but surely it can ensure that people are aware of the choices open to them. This could be accomplished by adding or substituting a palliative care assessment for the opinion of the second physician in s. 241.2(3)(e). A palliative care assessment would in practice be multidisciplinary and would inform people about the choices open to them on the issues that would be uppermost in the minds of those contemplating MAD. Palliative assessments are also intended to identify and alleviate pressures, including pressure created by those close to the person, whether or not intended, that could otherwise amount to undue influence. It is intended to assist people to come to grips with a difficult prognosis, which may initially trigger anxiety, depression and despair and cause people to make a decision to

request MAD in error [ie. Which, given the opportunity, they would later regret]. S. 241.2(7) contains the assurance that MAD is to be performed with “reasonable knowledge, care and skill”. Most physicians would claim to have the requisite knowledge or skill to adequately inform a person about the “quality of life” issues that cause disability-related suffering, which are precisely the issues that must be identified and addressed with the person before it can be said that a consent to MAD is voluntary, informed and meets the statutory eligibility criteria. Canada may not yet be willing or able to confer a right to palliative care, but a palliative assessment should be a requisite element in the safeguards contained in this legislation.

**Conclusion** MAD is becoming an “insured service” under the *Canada Health Act*. Basic safeguards can be readily implemented to enhance the rights and protect the vulnerable without impeding access to the right to MAD being conferred by this legislation. These safeguards are proportionate and consistent with demonstrating due regard to the autonomy, dignity and safety of persons with disabilities.

It is specifically recommended that ss. (g) be added to s. 241.2(3) or alternatively substituted for ss. (e):

Before a medical practitioner or nurse practitioner provides a person with medical assistance in dying, the medical practitioner or nurse practitioner must...

(g) confirm that a qualified clinician, without any other role in considering or administering medical assistance in dying for that person, has:

(i) provided the person with a palliative care consultation outlining the full range of treatment, technology and support options that might alleviate suffering and any vulnerability to inducement to commit suicide, and has attested that the person understands information relevant to using those options and appreciates the reasonably foreseeable consequences of a decision or lack of decision to use those options, thus establishing that the person has made an informed decision in this regard; and

(ii) provided the medical practitioner / nurse practitioner with a written palliative consultation report identifying the person's sources of suffering and any vulnerability to being induced to commit suicide; the options considered through the consultation; the clinician's assessment of the person's capacity to provide informed consent to use the options; and the reasons why the person chose not to use the options in the circumstances.

In the event the Committee is looking for a prior review mechanism, which ensures transparent and consistent application of the criteria coast to coast, while conferring a provincial right to appoint members, and which has passed constitutional muster on numerous occasions it may wish to consider s. 241.1(10) and related sections in the Baker-Sharpe Bill found in the February number of [2016] 36 *Health Law in Canada* at p. 169-70.

Either or both of the palliative assessment or prior review mechanism would produce data upon which a meaning functional assessment of MAD could be conducted that would guide governments in ways to further enhance the rights and offer relief from the suffering of persons with grievous and irremediable conditions.

All of which is respectfully submitted.