Dying With Dignity Canada
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Brief: Stakeholder Consultation on Bill 84, Medical Assistance in Dying Statute Law Amendment Act

Submitted to:

Standing Committee on Finance and Economic Affairs,
Legislative Assembly of Ontario
99 Wellesley Street West
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March 30, 2017

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Preface

Thank you for this valuable opportunity to provide a written brief on Bill 84, the *Medical Assistance in Dying Statute Law Amendment Act, 2017* ("Bill 84"). Dying With Dignity Canada (DWDC) submits the following recommendations and conclusions to the Standing Committee on Finance and Economic Affairs at the Legislative Assembly of Ontario:

Recommendations

1. There has been significant debate in the Ontario legislature during the second reading of Bill 84 on the issue of conscience rights. Conscience rights are not currently mentioned in the draft legislation. If this Committee decides to write into Bill 84 a clause on conscientious rights, DWDC recommends that such a clause **should** reflect a fair balance between a patient's right to compassionate care and a physician's right to conscientious refusal. DWDC submits that the committee should look to the College of Physicians and Surgeons of Ontario's (CPSO) policy on effective referral for guidance on this issue. The CPSO's policy on medical assistance in dying is an appropriate reconciliation between the rights of the healthcare provider who conscientiously objects to MAID and the rights of the patient — the dying person — to information about all of their end-of-life options, including MAID; to an assessment for MAID; and if the individual is eligible, to an assisted death.

2. With respect to sections 3(12) and 4(6) of Bill 84, pertaining to the *Freedom of Information and Protection of Privacy Act* and the *Municipal Freedom of Information and Protection of Privacy Act*, DWDC recommends that facilities **should not** be included in the definition of "identifying information" and **should not** be immune to freedom-of-information (FOI) requests in relation to medical assistance in dying. However, we do support the provisions that shield the identities of individual patients who have requested MAID and their clinicians.

3. With respect to section 5 of Bill 84, pertaining to the *Vital Statistics Act*, DWDC recommends that it **should not** be compulsory for physicians and nurse practitioners to

report each and every MAID death to the coroner. Instead, the Ontario government **should** create a regional reporting system that is external to the coroner's office and that is coordinated with Health Canada.

We also recommend the creation of a new classification on official death certificates that records MAID as the manner of death and the patient's underlying condition as the cause of death.

4. DWDC recommends that section 6 of *Bill 84,* pertaining to the *Workplace Safety and Insurance Act, 1997*, **should** remain unchanged; and

5. DWDC recommends that section 2 of Bill 84, pertaining to the *Excellent Care for All Act, 2010*, **should** remain unchanged.

Other Comments

1. The "effective referral" practice policy outlined in the *CPSO's Professional Obligations and Human Rights Guidelines* strikes the appropriate balance between a patient's right to compassionate care and a physician's right to conscientious refusal;

2. Certain proposed amendments to the *Freedom of Information and Protection of Privacy Act* and the *Municipal Freedom of Information and Protection of Privacy Act* create unreasonable barriers to accessing information and do not hold public healthcare facilities accountable to patients and their communities;

3. Requiring physicians and nurse practitioners to give notice of death and related information to the coroner's office in all MAID cases stigmatizes assisted dying, the patient who has been approved for MAID, and the clinicians who choose to provide it. In addition, it adds further complexity to the already onerous MAID process;

4. Amending the *Excellent Care for All Act, 2010,* and the *Workplace Safety and Insurance Act, 1997,* improves the MAID process in Ontario by ensuring that patients and their beneficiaries are not unfairly denied insurance benefits or other entitlements; and

5. Amending the *Excellent Care for All Act, 2010,* improves the MAID process by ensuring that healthcare professionals are immune from civil liability for their participation or intended participation in MAID, unless they are found to have been negligent.

Brief

DWDC is the national not-for-profit organization committed to improving quality of dying, protecting end-of-life rights, and helping Canadians avoid unwanted suffering. We defend human rights by advocating for compassionate end-of-life choices and by providing personal support to adults suffering greatly from a grievous and irremediable medical condition who wish to die on their own terms. We educate Canadians about all of their legal end-of-life options, including the constitutional right to medical assistance in dying (MAID), and the importance of advance care planning. Finally, we support healthcare practitioners who assess for or provide MAID.

Our first priority when reviewing and considering legislative or regulatory frameworks for MAID is putting the patient — the *person* — first. Our patient-centred perspective is what informs our concerns about some of the proposals in Bill 84.

It is critical to note that Ontarians who request assistance in dying are among the most vulnerable patients in our healthcare system. They are often physically frail and unable to advocate for themselves due to the severity of their medical condition(s). Due to parameters in the federal government's legislation in Bill C-14, many patients who will be eligible for assisted dying will be terminally ill and imminently dying.

Factual Information Substantiating Our Recommendations

1. Effective Referral

Physicians in Ontario have a fiduciary duty to their patients.[1] The CPSO allows physicians who conscientiously object to certain procedures to limit their services in a manner that (i)

[1] "The Practice Guide, Medical Professionalism and College Policies" *College of Physicians and Surgeons of Ontario* (September 2007) at pp. 5 < http://www.cpso.on.ca/CPSO/media/documents/Policies/Policy-Items/PracticeGuideSept07_nolinks.pdf>.

respects patient dignity; (ii) ensures access to care; and (iii) protects patient safety.[2] The objecting physician is required to inform the patient of his/her objection directly, with sensitivity, without promoting his/her religion or expressing personal judgment. The objecting physician must provide information about all appropriate clinical options and, if the patient wishes to proceed with his/her request, provide an effective referral. The effective referral must be made in good faith, to a non-objecting, available and accessible physician, other healthcare professional or agency. As a result, the CPSO's existing effective referral policy strikes an appropriate balance by respecting conscience rights while ensuring compassionate care.

Even with the effective referral policy in place, patients continue to report that some doctors are refusing to discuss, let alone provide a referral for, MAID. Other doctors are instructing patients to find providers on their own. This form of patient abandonment imposes a burden of undue hardship on vulnerable Ontarians who do not have the wherewithal to find a provider on their own. Providing them with only a website or a phone number is an unacceptable standard of care and it represents a violation of a physician's fiduciary duty to his/her patients. To suggest otherwise is to allow clinicians to abandon individuals in their care at what is often the most vulnerable time in the patients' lives.

2. Accountability and Transparency of Public Healthcare Institutions

DWDC supports protecting the privacy of individuals who access MAID and the healthcare professionals who assess and provide this profound medical treatment. However, public healthcare facilities have no right to hide their policies for MAID.

Public healthcare institutions have an obligation to be accountable to the patients and communities they serve. Allowing these institutions — which receive public funds and are charged with providing public healthcare — to opt out of providing policies and information related to medical assistance in dying creates barriers to access. Individuals

[2] "Professional Obligations and Human Rights" The College of Physicians and Surgeons of Ontario (March 2015) < http://www.cpso.on.ca/policies-publications/policy/professional-obligations-and-human-rights#Endnote17>.

and their families have a right to know which healthcare facilities in their communities will provide assisted dying; this includes hospitals, hospices and long-term care residences.

In addition, in democratic societies, freedom-of-information requests are a critical tool civil-society organizations can use to hold government and public agencies accountable to citizens and residents, and in turn, protect the public interest. For instance, a freedom-of-information request that our organization filed to the Erie St. Clair Local Health Integration Network eventually revealed that a terminally ill patient was refused MAID at Hotel-Dieu Grace Healthcare and could not be transferred to Windsor Regional Hospital because the latter hospital refused to accept the patient.[3] The *Windsor Star* published a story on this case, and the attention it generated led the Erie St. Clair Community Care Access Centre to strike a committee that will, with the help of other local stakeholders, develop protocols for coordinating the care of patients who request MAID.[4] If we hadn't had the ability to obtain information about these institutions' decisions related to MAID, then this positive development might never have come to be.

In Bill 41, the Ontario government has already prioritized institutions' rights over patients' rights by allowing religiously affiliated hospitals to opt-out of following directives from the Health Minister related to policies and procedures that are contrary to the facilities' religious beliefs. If the Ontario government and the members of this committee are serious about putting patients first, then they should start by striking the proposed amendments in Bill 84 that would limit Ontarians' access to vital information about which of their healthcare institutions will respect their *Charter* right to an assisted death.

3. Referring all MAID deaths to the coroner

The proposed requirement to report all MAID death to the coroner is inappropriate. Assisted deaths are neither sudden nor suspicious. Involving the coroner in MAID

[3] Anne Jarvis, "Jarvis: Searing 'along the 201' for a place to die" Windsor Star, February 17, 2017 <http://windsorstar.com/opinion/columnists/jarvis-searching-along-the-401-for-a-place-to-die>.

[4] Brian Cross, "LHIN looks to improve how physician-assisted death handled locally" Windsor Star, February 28, 2017, <http://windsorstar.com/news/local-news/lhin-looks-to-improve-how-physician-assisted-death-handled-locally>.

stigmatizes the process, the patient and the clinicians involved, and adds an unnecessary layer of complexity to the MAID process that can be harmful for patients, families and clinicians.

The involvement of the coroner may cause additional burdens for the families of patients, since they will not know until after the assisted death has been reported to the coroner whether an investigation will be triggered. This is unnecessary and it can foist added stress upon families who are already grieving.

From a clinician's perspective, referring every MAID death to the coroner imposes barriers to participation. Referring each MAID death to the coroner creates a degree of insecurity, since a clinician cannot predict when an investigation will be triggered. This insecurity is exacerbated by the additional time and work commitments required of the clinician by the coroner (i.e. paperwork, consultations, etc.). These barriers represent a disincentive for the already small number of clinicians involved in MAID to continue assessing and providing this health service, exacerbating a major existing barrier to patient access.

There are numerous safeguards built into the federal legislation, while provincial regulations and institution-level policies and protocols provide additional security. Other end-of-life interventions such as palliative or terminal sedation — which have very few safeguards — are not referred to the coroner, and thus, it should not be required for MAID. Other jurisdictions such as New Brunswick, Nova Scotia and Quebec have set up alternative review mechanisms.

Additionally, the coroner's office is simply not equipped to collect meaningful and informative data related to the practise of MAID in Ontario. While they will collect information related to MAID requests and provision of those requests, they will not capture enough data to help the Ontario government assess how effective or not, the federal legislation in Bill C-14 is for residents in this province, or where the gaps are in the implementation process. For example, they will not collect data on the number of requests received that were denied and what the underlying conditions are. They will not collect the

number of requests that were approved but MAID was not carried out; and were those deaths not assisted because: the patient changed their mind, the patient died unexpectedly, the patient lost capacity during the waiting period, OR because there was a delay in finding help for the patient. The coroner will not track if the patient who has had MAID was already in hospice or palliative care, or the options for care and treatment for people who are denied access to MAID.

Under Bill C-14, the federal government is required to collect and coordinate MAID related data. The plan for this data collection has not materialized and Dying With Dignity Canada has been informed that national MAID data may not be available for another 15 months. We also note that this provision in Bill 84 is slated for review in two years. We urge the Ontario government to work proactively with the federal government to set up a reporting mechanism external to the coroner's office and one that focuses on post review and collection of key MAID data as opposed to the coroner's investigative mandate.

And lastly on the issue of the coroner's office, Bill 84 does not make specific mention of new regulations related to official death certificates. As it currently stands, a MAID death is recorded as a "suicide," which is factually inaccurate and may cause distress to families when they obtain the death certificate. We urge the Minister of Health to work with the coroner's office to create a new classification for the death certificates, one that records the patient's underlying condition as the official cause of death and MAID as the manner of death. This practice is consistent with how MAID deaths are already recorded in many jurisdictions across Canada, and it would help ensure that assisted dying is administered safely and accountably.

4. Life Insurance

DWDC supports the proposed amendment to section 13.9(1) of the *Excellent Care for All Act, 2010,* as it would ensure MAID recipients and their beneficiaries are not unfairly denied insurance benefits or other entitlements.

5. **Legal Protection for Healthcare Professionals**

   Protecting the healthcare team that participates in the MAID process from civil liability (except in cases of negligence) is crucial to involving the medical community in the process. DWDC supports this part of Bill 84, as it ensures that the full healthcare team is protected, giving providers of MAID additional support.

Conclusion

The rights, the choices and the interests of the person — the patient — must come first in all policy decisions about end-of-life care, especially MAID. We urge you to adopt this person-centred approach as you consider possible amendments to Bill 84. We thank you for your time and consideration.