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DYING WITH DIGNITY CANADA

Dying With Dignity Canada
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June 21, 2022

Lindy VanAmburg
Director of Policy Health Care Programs and Policy Directorate
Strategic Policy Branch Health Canada
200 Eglantine Driveway, 4th Floor, Room 411A
Tunney's Pasture
Ottawa, Ontario K1A 0K9

Sent by e-mail: maid.report-rapport.amm@hc-sc.gc.ca

RE: Proposed amendments to the *Regulations for the Monitoring of Medical Assistance in Dying*

Dear Ms. VanAmburg:

Dying With Dignity Canada (DWDC) is pleased to provide comments on Health Canada's proposed amendments to the *Regulations for the Monitoring of Medical Assistance in Dying (MAID).*

DWDC welcomes the consultation's goal to ensure a robust monitoring regime is implemented for the assessment and provision of MAID in Canada. When this consultation process concludes, it is our hope that public accountability and transparency will be maintained for people across Canada, including those that are accessing or trying to access MAID services.

Most importantly, and to ensure that the voices of patients and their loved ones who have accessed or are currently accessing MAID are represented, we have drawn upon our extensive experience supporting those navigating MAID. We have also consulted with our Clinicians Advisory Council (CAC). Comprised of nurse practitioners and physicians who are MAID assessors and/or providers, the CAC provides advice on matters related to MAID. DWDC has also consulted with the Nurse Practitioner Association of Ontario (NPAO). We would support the perspective of the Canadian Association of MAID Assessors and Providers (CAMAP) as relates to clinician feedback of these changes.

We are pleased to provide comments and recommendations that Health Canada can consider and act upon prior to the publication of the final *Regulations* in *Part II of the Canada Gazette* in October 2022.

Interpretation

Definitions

DWDC is concerned with the definition and use of the term ***preliminary assessor***. This term remains confusing and is not clearly defined. We have heard from two groups of people: those who may initially appear to qualify, but then do not after assessment; and those who may not appear to qualify, but once

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an assessment is complete, do qualify. The inability to be formally assessed because of a preliminary assessment is a significant concern and may create a barrier to access. The use of a term such as ***triage*** may be more appropriate. In some areas, we understand that assessments are not available to all requesting them due to a lack of clinicians prepared to see track 2 patients, for example. This is not a result of ineligibility but an inability to locate an assessor or provider.

Recommendations:

1) **Further define the term "preliminary assessor" and consider using the term "triage" to ensure that access to a MAID assessment is maintained for those who request it.**

Provision of Information

Practitioners and Other Persons

Section 4 of the Regulations has been repealed
The rights of clinicians who conscientiously object to assessing for or providing MAID are well protected in Canada. We continue to hear from individuals who do not receive information about end-of-life options or transfer of care on a timely basis. Removing the requirement for clinicians to report on their referral or transfer of care removes the requirement that they act in a timely manner. This does *not* protect or ensure timely information or access for people who are trying to understand their end-of-life choices.

Ineligibility

As noted above, we are concerned about the potential for preliminary assessments to disqualify people who may be eligible for MAID if assessed.

Recommendations:

1) **Do not repeal Section 4 of the Regulations or alternatively, require that the data currently in Schedule 2 be otherwise collected.**

Collection of Information

Information respecting the race or indigenous identity of persons who have made a request, and any disability of those persons, if they consent to providing that information, and sex at birth and gender identity.

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DWDC's primary concern with the proposed regulatory changes is around how the new requirement to collect data related to gender identity, race, indigenous identity, and disability of persons requesting MAID will be fulfilled. We share Health Canada's view that it will help determine whether the presence of individual or systemic inequality exists within the context of how MAID is delivered and believe this sensitive and personal information needs to be provided by the person (the patient), not the clinician.

Clinicians have expressed concerns around assigning answers for personal questions on the form. For example, they noted that they would feel uncomfortable trying to retrieve such information during the preliminary phase – the most sensitive part – of the MAID process. It must be the individual – not the clinician – that provides these personal details. The clinician cannot and should not be responsible to assign these types of answers.

Further, people should be able to answer these sensitive and personal questions themselves through an electronic survey. As this data is not collected in all areas of health care, the person who is being assessed for MAID should have the ability to say on the form "choose not to answer."

The additional questions considered about disability and disability supports may be problematic. One clinician noted that it is already an ambiguous question to answer and without good data, is difficult to use well in research. In addition, people with disabilities may not consider themselves to be part of the "disability community."

DWDC was disappointed not to see a requirement to report on persons forced to transfer from a non-supporting institution. This potential infringement on a person's right to have an assisted death if they are eligible causes very real and increased suffering and is something which should be closely monitored.

Recommendations:

1) **Ensure that the person requesting MAID – not the clinician – answers questions related to gender identity, race, Indigenous identity, and disability.**

2) **Require the collection of data that identifies people who are forced to transfer from a non-supporting institution in order to received MAID.**

Administrative Burden

At the outset, it is important to note that training, support materials, and individual support will help to ease the transition and ensure that clinicians feel equipped to meet the new requirements. While clinicians would welcome these tools, this will not resolve the adverse impact and administrative burden caused by increased time and costs of proposed regulatory changes.

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We know that many clinicians are already overwhelmed. DWDC has been informed that the new administrative burden may dissuade some assessors from continuing to assess for or provide MAID. Reporting is already a barrier to participation in MAID – with the increased requirements and the risk of prosecution, it will be challenging to maintain and recruit clinicians. This will negatively impact access for people across Canada seeking MAID services. Therefore, DWDC recommends that Health Canada consider additional steps to reduce the amount of time it takes to complete the reporting process., ensuring that person-centred care is maintained.

This problem is particularly critical for Nurse Practitioners (NPs), many of whom are already challenged by the inability to be paid for their assessments and MAID provisions. The new reporting requirements will increase the financial burden on those clinicians.

The requirement that clinicians follow a track 2 patient for two years may be difficult. The MAID assessor or provider may not be the clinician who is most responsible for a patient – the additional burden of attempting to follow these patients may again impact the ability of clinicians to assess or provide MAID and may further discourage recruiting efforts, particularly for clinicians to support track 2 patients.

Recommendations:

1. **That Health Canada consider additional steps to reduce the amount of time it takes to complete the reporting process.**

2. **That the federal government work with its provincial and territorial partners to find ways to lessen these costs on MAID practitioners and assessors, especially NPs, by providing reasonable administrative support through targeted funding.**

Remuneration for Nurse Practitioners

While not directly related to Health Canada's proposed amendments to the *Regulations for the Monitoring of Medical Assistance in Dying (MAID)*, the lack of fair and equitable remuneration is an issue that is facing NPs across Canada and is increasingly impacting accessibility and care for people seeking MAID. The increased reporting demands will further exasperate this significant issue and the continued lack of remuneration means that NPs, who could provide more care in this area, are unable to do so. This creates a domino effect, placing the burden on those clinicians that can be remunerated for their work, and does not take advantage of or allow the participation of the many willing and able NPs who could step forward.

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For example, one NP told us that NPs are "squeezing in an assessment or two but that is not enough to gather the experience one would need to grow into seeing more complex track 2 patients." This means that NPs and salaried physicians will not be able to see as many people as they would be able to if there was no additional reporting required under the proposed regulatory changes.

The Nurse Practitioners' Association of Ontario (NPAO) has outlined the challenges facing NPs in Ontario. One of the obstacles for NPs in Ontario is that they are often providing MAID services without compensation. They are providing this health care service out of professional obligation and compassion. While many are providing MAID services to address the geographic gaps in Ontario, the lack of a compensation mechanism is a critical barrier.

NPAO suggests that NPs can play a key role in meeting the increased demand for MAID services, but without a compensation mechanism in place, the gaps will continue to grow. To resolve this issue, DWDC supports NPAO's call for the Government of Ontario to establish a province-wide funding mechanism for NPs to deliver MAID services. While we have highlighted concerns specific to Ontario as an example, this problem exists in many areas of Canada. Increased administrative burden caused by changes to reporting will only serve to widen the gap.

Recommendations:

1. **The federal government work with the provinces and territories on the development of a model for the fair and equitable remuneration to NPs who provide – or are prepared to provide – MAID services.**

DWDC recognizes that the responsibilities for medical assistance in dying at the federal and provincial and territorial levels, vary greatly. However, those responsibilities greatly impact one another and the delivery of MAID across the country. For those in Canada who are eligible, and who wish to access an assisted death, it is critical that the process be patient-centric, compassionate, and considerate of the intolerable suffering of that person. Working to ensure equitable remuneration and reducing the burden on clinicians whenever possible will support that process.

Thank you for providing us with an opportunity to take part in this important phase of the consultation process. If you have any questions or concerns, please contact David Granovsky, Director of Government and Stakeholder Relations at david.granovsky@dyingwithdignity.ca or 647-956-4127.

Sincerely,

Helen Long, CEO