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The Honourable Dr. Marc Garneau, P.C., M.P. marc.garneau@parl.gc.ca

Joint Chairs, Special Joint Committee on Medical Assistance in Dying Parliament of Canada Ottawa, Ontario

Dear Senator Martin and Dr. Garneau:

As you know, under the current medical assistance in dying (MAID) law, eligibility for MAID will be extended to persons whose sole medical condition is a mental illness as of March 17, 2023. However, on December 15, 2022, the Honourable David Lametti, Minister of Justice and Attorney General, the Honourable Jean-Yves Duclos, Minister of Health, and the Honourable Carolyn Bennett, Minister of Mental Health and Addictions and Associate Minister of Health, issued a statement indicating the Government of Canada's intention to seek an extension to this date. The purpose of the extension is to provide additional time for important initiatives that will ensure MAID clinicians and health care systems across the country are ready to respond to requests for MAID in these circumstances in a safe and appropriate manner and to give the Government more time to properly consider the final report of the Special Joint Committee on Medical Assistance in Dying (AMAD).

I would like to take this opportunity to provide members of AMAD with an update on some key areas of progress since the Government's response on October 20, 2022, to AMAD's interim report. I trust this information will be timely for your Committee, as members work toward completing the Committee's final report.

As noted in the Government's response in October 2022, the systems and mechanisms supporting the safe application of MAID in Canada have matured significantly over the past six years since the legalization of medical assistance in dying came into force. These achievements are primarily due to the individual and collaborative efforts of health system partners, including provincial and territorial (PT) governments, health professional organizations, regulatory bodies, clinicians, and pan-Canadian organizations such as the Canadian Association of MAID Assessors and Providers (CAMAP). The Government has played and continues to play significant lead and coordinating roles by working with the provinces and territories, both at the Ministerial level with PT colleagues, and at the officials' level through a federal, provincial and



territorial (FPT) working group on MAID which has been meeting regularly since 2015 to share experiences and expertize and address challenges of mutual interest.

In keeping with this collaborative approach, significant progress has been made in anticipation of extending MAID eligibility to persons whose sole underlying medical condition is a mental illness. Despite this progress, the Government believes a delay of the March 2023 eligibility date is warranted to allow more time to enhance capacity and build confidence in a system that provides safe and consistent delivery of MAID.

You will recall that in its final report (http://bitly.ws/znQ6), the Expert Panel on MAID and Mental Illness concluded that challenges in establishing irremediably or incurability, assessing decision-making capacity of a requester, distinguishing patients who are suicidal from those making a rational and sustained request for MAID, and addressing the impact of structural vulnerabilities, are not unique to MAID requests from persons with a mental disorder, nor applicable to every requester who has a mental disorder. For this reason, the Panel emphasized that its recommendations should apply to any MAID request where similar concerns may arise, irrespective of the requester's diagnosis. We have heard from clinicians that assessing MAID requests where natural death is not reasonably foreseeable are generally more complex and require more time and attention to collect the necessary medical and treatment history, including opinions from other health professionals with expertise in the individuals' condition and potential available alternatives to relieve the person's suffering. To address these challenges and in keeping with the Expert Panel's approach, the Government is focusing on supporting a system to address complex MAID cases broadly, and not exclusively those where a mental illness is the sole underlying medical condition.

Activities to support the safe and consistent application of MAID across Canada to address expanded access in accordance with the March 2021 legislation primarily focuses on the development of guidance and support for regulators of health professionals and practitioners, enhancing transparency and accountability and meaningful engagement with Indigenous peoples.

### **MAID Practice Standards**

The Expert Panel on MAID and Mental Illness concluded that the existing MAID eligibility criteria and safeguards in the legislation provide an adequate structure for MAID where a mental disorder is the sole underlying medical condition, so long as they are interpreted and applied appropriately. Its first and most significant recommendation was for federal, provincial and territorial governments to facilitate collaboration among regulatory bodies on the development of MAID practice standards and the majority of the remaining recommendations provide guidance on interpreting the MAID eligibility criteria, applying the legislative safeguards and the assessment process.

In the Government's October 2022 response to AMAD's interim report, we indicated that Health Canada was creating a Task Group to develop practice standards as an extension to the evidence and recommendations in the Expert Panel's report.

The MAID Practice Standards Task Group was convened in September 2022 and is comprised of individuals with clinical, regulatory and legal expertise. The Task Group worked diligently over the fall to develop a series of documents including:

- A comprehensive illustrative practice standard;
- 2. A series of points drawn from the comprehensive standard that could be incorporated into existing standards (in cases where the regulatory body prefers to build on its own pre-existing standard); and
- 3. A set of frequently asked questions addressing topics relevant to the assessment of complex track 2 (persons receiving MAID whose natural deaths were not reasonably foreseeable [non-RFND]) MAID requests.

Provincial-Territorial Ministries of Health, other federal departments, PT medical and nursing regulatory bodies, national health professional organizations, Indigenous health organizations, MAID practitioners and consumer groups were invited to review the documents. In early December, the Task Group shared drafts of the documents and hosted briefing sessions with invitees. Analysis of feedback and revisions is underway and will be completed in February 2023. A comprehensive dissemination and education process will begin in March 2023. The response of participants in the rapid review briefing sessions was very positive and constructive. Regulatory bodies in particular are keen to incorporate the new material. To this point, there is widespread agreement on the desirability of a harmonized, rules-based approach. Health Canada will work with its PT counterparts to support uptake of the practice standards by medical and nursing regulatory bodies.

#### Canadian MAID Curriculum

In its final report, the Expert Panel recommended training of MAID assessors and providers, to support the safe and consistent application of the MAID law. In the Government's October 2022 response to AMAD, we noted that Health Canada was providing \$3.3 million to the Canadian Association of MAID Assessors and Providers (CAMAP) for the development of an accredited Canadian MAID curriculum to support practitioners.

Development of the MAID curriculum began October 2021, and it consists of seven training modules addressing various topics related to the assessment and provision of MAID. The modules include:

- 1. Foundations of MAID in Canada—provides a history of MAID evolution in Canada and an introductory primer for health professionals who wish to know more about MAID eligibility criteria and procedural safeguards, reporting guidelines, and the ethical issues to be considered in clinical practice. Available entirely online, this module will be public facing but primarily helpful to health professionals who are considering participating in MAID assessments and provision;
- Clinical Conversations—assists a variety of health care professionals in navigating appropriate timing and language for discussions about MAID. It also identifies resources for individuals and families considering MAID;
- 3. How to do a MAID Assessment—provides a foundation for the preparation and completion of a MAID assessment against the eligibility criteria, including assessing a reasonably foreseeable natural death, identifying necessary skills and strategies in addressing challenges. Delivery is a combination of online resource material and an in-person, facilitator-led workshop;
- 4. Assessing Capacity and Vulnerability—primarily meant as an advanced course, this module will help identify common indicators of complexity or areas of concern with respect to capacity and identify tools to assist in capacity assessment. It will also help assess and identify vulnerabilities through a biopsychosocial lens in the context of MAID, and help clinicians address whether these vulnerabilities may affect capacity, suffering or the voluntary nature of a MAID request. This module will also include information to help understand implicit bias and cultural safety and humility in relation to MAID. Delivery is a combination of online resource material and an in-person, facilitator-led workshop;
- 5. MAID Provisions—provides guidance on how to plan for and manage the practical and emotional aspects of a MAID provision. This includes preparation and support for the MAID team, the patient, the family and friends before, during and after the provision, and includes contingency planning. Special topics such as how to prepare and implement a waiver of final consent, MAID reporting requirements and identifying resilience strategies that can support a sustainable MAID practice are included. Delivery is a combination of online resource material and an in-person, facilitator-led workshop;
- 6. Managing Complex and Chronic Situations—envisioned as an advanced course, this module will identify and address many of the factors that make a MAID assessment or provision clinically or logistically complex while recognizing and respecting professional, clinical, and/or program boundaries. Delivery is a combination of online resource material and in-person simulation of challenging case scenarios; and

7. MAID and Mental Disorders—will allow practitioners to develop an approach to assessing MAID requests by persons with a mental disorder and to practise strategies to ensure that the assessment process is safe and thorough. Delivery is a combination of online resource material and an in-person facilitator-led workshop which will consist of an in-depth discussion of two or three case scenarios illustrating the importance of a multi-perspective approach as a key process component.

Content for each of the modules was developed by working groups comprised of experts from a variety of disciplines including clinical expertise and lived experience. Content for each module undergoes an extensive multi-stage review process, including various health professional organizations and an accreditation review, prior to its release. To support broad distribution and access, especially to areas which are typically hard to reach, toolkits are being developed that will assist organizations/provinces to adapt material specific to their needs and train-the-trainer workshops will be offered to leaders within these areas.

Content for all seven modules has been prepared and is in various stages of review and transition to online and in-person course material. Curriculum development is on track for a phased soft launch (i.e., pilot testing) of modules as well as train-the-trainer workshops to begin spring/summer 2023. A rolling launch of final modules available for practitioner registration will begin in the fall 2023, including the module on MAID and Mental Disorders, with the aim for all modules to be available by the end of 2023.

Following the launch of the modules, CAMAP will be evaluating course material and updating it based on participant feedback and aligning it with evolving legislative and/or regulatory changes to the MAID framework.

## Indigenous Engagement

As indicated in the Government's October 2022 response to AMAD's interim report, Health Canada recognizes the importance of meaningful engagement and ongoing dialogue with Indigenous peoples to support culturally safe implementation of MAID. The need for consultations with First Nations, Inuit and Métis peoples was also highlighted in the Expert Panel report.

Health Canada has developed an extensive plan for engagement after preliminary discussions with Indigenous partners, using a distinctions-based approach to better understand the unique perspectives around end-of-life held by Indigenous peoples, which need to be considered in the context of ensuring safe access to MAID.

An engagement process will serve to foster understanding of differing Indigenous views and perspectives on MAID and inform federal policy to support distinctions-based and culturally safe MAID assessment and delivery.

A pre-engagement phase is underway which includes establishing relationships and opening a dialogue with a variety of Indigenous partners. Health Canada has met with a number of key Indigenous organizations, including national organizations representing all distinctions, as well as Indigenous women's organizations.

Based on activities to date, Indigenous partners have stressed that engagement should be undertaken at the pace and timing determined by communities, and using a grassroots, ground-up approach. This approach is critical due to engagement fatigue and the myriad of pressing priorities related to equal access to the basic necessities of life, access to health care, and the suicide crisis due to trauma from colonialism, residential schools, forced relocation and other atrocities, as a result of past and present federal policies.

Health Canada will determine the timing and details of the engagement in close collaboration with Indigenous partners. This will include web-based engagement, knowledge exchange roundtables, and Indigenous-led engagement sessions. Work is underway to prepare for the first Roundtable with Indigenous health care providers in Spring 2023.

## Monitoring and Reporting on MAID

The original MAID legislation passed in 2016, required the federal Minister of Health to develop regulations for the collection of data and annual public reporting on MAID in Canada. Regulations for the Monitoring of Medical Assistance in Dying came into force in November 2018, and have been the primary source of information published in Health Canada's annual reports on MAID. Legislative changes resulting from the passage of former Bill C-7 in March 2021 required amendments to the 2018 MAID regulations to align with the revised legislation. Amended Regulations for the Monitoring of MAID came into force on January 1, 2023.

As of this date, clinicians are required to report additional details related to the assessment of persons whose death is not reasonably foreseeable, in keeping with the procedural requirements in the law. As just one example, an assessing clinician will report on the type of services that may alleviate suffering that are offered to an individual requesting MAID, and the reasons why the clinician was of the opinion that the individual gave serious consideration to these services. Data will also be collected on gender identity, race, Indigenous identity and disability for the purposes of determining the presence of any inequality—including systemic inequality—in MAID (if the requester consents to this information being collected).

Reporting is now expanded beyond physicians, nurse practitioners and pharmacists to include other health care professionals and pharmacy technicians, thereby obtaining information on all assessments following a person's request (verbal and written) for

MAID. Additional data is also being collected on disability support and palliative care services, such as the type of and location where disability support services were received and the place where palliative care was received.

The Third Annual Report on MAID (http://bitly.ws/znQ9), providing an overview of all MAID activity in Canada during 2021, includes a profile of persons receiving MAID whose natural deaths were not reasonably foreseeable (non-RFND). In 2021, the total number of MAID deaths for individuals whose natural deaths were not reasonably foreseeable was 219, or 2.2 percent of the total number of MAID deaths in that year.

The average age of these individuals was approximately 70 years, which was six years younger than the average age of MAID deaths in the 2021 MAID population. The main underlying medical condition reported in the non-RFND population was neurological (45.7 percent), with Parkinson's disease, Multiple Sclerosis, and chronic pain frequently cited conditions. Although the number of MAID deaths for non-RFND persons will likely increase over the next few years, it is expected to remain a relatively small proportion of total MAID deaths. The vast majority of MAID deaths continues to be attributed to individuals whose deaths are reasonably foreseeable, and of these, primarily related to a cancer diagnosis. This is all to say that the steady increase in the number of MAID deaths as a proportion of total deaths in Canada is overwhelmingly related to persons whose natural deaths were reasonably foreseeable.

The Fourth Annual Report on MAID that will provide an overview of MAID activity in 2022 is expected to be released this summer and will provide information on similar data elements as noted above. This will permit the first year-over-year comparison for the non-RFND population. The subsequent annual report to be released in 2024 will reflect enhanced data collected in 2023 based on the *MAID Monitoring Regulations* that came into force January 1, 2023, and will provide an even broader picture of who is requesting MAID, how many requests result in MAID provisions and why.

# **Oversight**

The responsibility for oversight—ensuring that medical practitioners adhere to the eligibility criteria and procedural safeguards outlined in the *Criminal Code*, and in some instances, alignment with college standards and clinical practice—is the responsibility of the provinces and territories and their medical/nursing regulators. The federal government is responsible for monitoring MAID through data collection and reporting as outlined in the previous section.

In light of this division of responsibility, the Expert Panel on MAID and Mental Illness recommended that the federal government support the development of a model of prospective oversight for all or some non-RFND cases that could be adapted by the

provinces and territories. Its report specified that the purpose of this prospective oversight model would not be to make judgments about the eligibility of individuals requesting MAID, but to review documentation to determine whether the MAID clinician has completed their assessment in full compliance with the legal requirements. If this is not the case, the assessor will be informed so that they can complete the assessment fully.

A number of PTs currently have oversight systems and are establishing new mechanisms. In those provinces, which represent approximately 70 to 80 percent of the country's MAID provisions, formal provincial-level mechanisms exist for MAID oversight. For example, in Ontario, the Chief Coroner reviews every MAID provision, as does Québec's Commission sur les soins de fin de vie (End-of-Life Commission).

Both these bodies have strict policies regarding the timing and type of information to be reported by clinicians. The Québec Commission issues annual reports that include information about instances of non-compliance with its *End-of-Life Act*. Alberta and Saskatchewan each have MAID review committees. Health authorities in Manitoba and Nova Scotia each have protocols in place for the coordination, review and debrief of MAID requests in their respective provinces. Most health professional regulatory bodies in the PTs have policies and guidelines in place for MAID.

In addition to individual PT mechanisms, a pan-Canadian community of practice has been established by the Canadian Association of MAID Assessors and Providers that is used by MAID clinicians to obtain advice and guidance in addition to mechanisms available through their provincial/territorial regulatory colleges.

Health Canada will continue to work with the provinces and territories to support improvements in the oversight and delivery of MAID assessment and provision, including engaging in preliminary discussions on additional oversight and quality assurance processes.

I trust this letter has conveyed the key milestones that have been achieved so far, and the significant amount of work underway to further support a Canadian MAID framework that permits an individual's request for MAID to be assessed consistent with, and in full compliance with the stringent eligibility criteria and safeguards in the law, while at the same time, supporting the safety and security of persons who may be vulnerable. In the AMAD's interim report, you encouraged the federal government to work with the provinces and territories, and other health partners to swiftly implement the recommendations of the Expert Panel on Mental Illness. Health Canada acknowledges the important recommendations arising from the work of the Expert Panel and, as outlined in this letter, is acting on those recommendations.

Members of AMAD can be assured that the necessary elements will be in place to address MAID requests involving complex conditions where assessments pose particular challenges, including conditions involving mental illness.

Canadians can be confident in the MAID system that has evolved since the passage of the original legal framework for MAID in 2016.

The Government looks forward to reviewing your Committee's final report in the near future.

Please accept my best wishes.

Yours sincerely,

Stephen Lucas, Ph.D.