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RE: REGULATIONS FOR MONITORING OF MEDICAL ASSISTANCE IN DYING

Thank you for the opportunity to review and comment on the government's proposed draft regulations for monitoring Medical Assistance in Dying (MAiD). As an Advisor to the Vulnerable Persons Standard and an active member of Canada's disability rights community, I have been deeply concerned for some time about the absence of a consistent and comprehensive system for monitoring the practice and impacts of Canada's MAiD regime. While the proposed regulations are a step forward in that regard, the drafters still have some distance to go if we are to achieve a truly transparent and accountable system that can earn the confidence and trust of all Canadians.

It is not my intention to offer a detailed technical response to the draft regulations. In my opinion, that task has been fulfilled impressively both by the Vulnerable Persons Standard Secretariat, and by the disability rights organization, Not Dead Yet. I have carefully read and fully support both of these submissions, and would urge adoption of their important recommendations.

My contribution to this process will be guided by two overriding objectives: to ensure robust safeguards to protect persons from choosing an assisted death because of inducement, coercion or external pressure; and to guard against the perpetuation of prejudice and stigma both in the MAiD ecology and in our broader social ethos. In this context, I understand that the reporting of MAiD practices by practitioners is not merely a technical exercise. Rather, a carefully crafted system for MAiD monitoring can provide crucial insights as we endeavour to understand the sources of suffering that lead individuals to seek MAiD, and to ensure that the law's protections against inducement and external pressure are working effectively.

TWO FUNDAMENTAL FAILINGS IN THE PROPOSED REGULATIONS

a) THE PROPOSAL EXCLUDES THE PERSPECTIVE OF PEOPLE MOST IMPACTED BY MAiD PRACTICE – PATIENTS.

The monitoring system proposed by the federal government sets out detailed requirements for medical practitioners who participate in the assessment and provision of MAiD services. Over time, the information compiled as a result of this reporting process will provide Canadian citizens and lawmakers with important insights about how MAiD is administered across the country, who it serves, and whether the current law strikes an equitable balance between respecting individual autonomy and protecting people from harm.

However important the perspective of physicians, nurse practitioners and pharmacists, a picture of MAiD practice that relies solely on these constituencies will be at best an incomplete picture and at worst, a gross distortion of the MAiD landscape. Only by permitting patients, patient

representatives and other third-party actors the opportunity to record their experience and report their assessments of the MAiD process, will our MAiD regime earn the confidence and trust of all Canadians.

For this reason, I extend my support in the strongest possible terms, to the recommendation that the monitoring system for MAiD be designed to accord equal value to the reported experience of patients and their designated representatives. I can assure you that within disability rights communities and among supporters of the Vulnerable Person Standard, there is both expertise and goodwill sufficient to assist the government in designing a fully accessible and inclusive process that would permit patients like [Archie Rolland](#)¹, the opportunity to be heard, and to have their reasons for pursuing MAiD fully understood. I would add to this assurance my own anecdotal observation that among physicians and other health practitioners who for reasons of conscience will not participate in MAiD, there may be willingness to conduct short interviews at a patient's request, or to otherwise facilitate a process of patient reporting that need be neither cumbersome nor intrusive.

In short, engaging meaningfully with persons who have requested MAiD, as well as persons who feel themselves to have been coaxed toward MAiD, is within our capacity, if there is the will to do so.

b) THE PROPOSAL APPEARS TO PRIORITIZE COST-EFFECTIVENESS OVER PUBLIC ACCOUNTABILITY

I applaud and support the explicit policy objectives set out in the introductory text to the proposed Regulations, and note in particular their explicit affirmation that monitoring should help to determine whether our MAiD law is meeting its legislative objectives. However, my analysis of the regulations suggests that these objectives are not “front and centre” in the proposal, and further, that the regulations depart in some notable ways from the preambular commitments of the current law.

The “Regulatory Impact Analysis Statement” published along with the draft regulations devotes considerable attention to measuring the “administrative burden” upon health practitioners required to report MAiD-related activity. Very specific cost valuations estimate that most reporting would require no more than 10 minutes of a practitioner's time, resulting in an “annualized average increase in total administration costs” of \$5.00.

While I appreciate the necessity to manage a pan-Canadian monitoring system responsibly, I am deeply concerned that an emphasis on efficiency and cost-effectiveness has undermined the process of careful balancing mandated by the Supreme Court in Carter. This critical balance, between respecting the autonomy of persons who seek MAiD, protecting persons who may be vulnerable to harm or abuse, and preserving a social fabric that accords dignity and respect to all persons, is the cornerstone of Canada's system for medical assistance in dying.

It is with this in mind that the VPS submission proposes a series of amendments aimed to bring the proposed regulations back in line with the fundamental legislative objectives that must frame Canada's

¹ For a compelling account of Mr. Rolland's MAiD experience – an experience that would not be captured in the proposed monitoring Regulations – please see <http://montrealgazette.com/news/local-news/life-in-long-term-hospital-unbearable-montreal-man-with-als>

MAiD monitoring regime. Again, I urge you to adopt the recommendations articulated by the VPS, which in my opinion are strongly aligned with what the Court in Carter intended by its assurances about “a stringently limited, carefully monitored system of exceptions”.

In addition to these two overriding concerns, I wish to underscore three recommendations that are key if our monitoring system is to accurately track the impact and implications of MAiD.

1. WE MUST KNOW WHO IS REQUESTING MAiD, AND WHY

I am sure you are well aware that data from Oregon suggests that the vast majority of MAiD recipients are privileged by race, education and social class, and accustomed to lives unfettered by adversity or external authority. While these characterizations would accurately describe individuals like Dr. Donald Low, who is often regarded as the paradigm example for whom MAiD is designed, we have no evidence about whether indeed this is the case for MAiD in Canada. It should go without saying that Canada’s demographic profile differs dramatically from that of the state of Oregon, and further that issues of diversity and substantive equality resonate differently for Canadians than for our American neighbours.

My point is that we cannot assume that MAiD is not creating disparities in Canadian society, and we cannot say with confidence that it has no adverse impacts upon minority and disadvantaged populations and communities. In order to know this, we must have detailed demographic data about who requests MAiD, and what their motivations are for making such requests

2. WE MUST BE VIGILANT IN PURSUING A DEEPER UNDERSTANDING OF INDUCEMENT

A growing body of social science research and jurisprudence demonstrate that the dynamics of inducement are both highly variable and subtle, and that even outright coercion can be latent or unspoken. Practitioners, who are themselves positioned within asymmetrical relations of power vis-à-vis their patients, may not be well equipped to detect external pressure in the context of MAiD.

The complex dynamics of inducement require study, and study requires data. For this reason, I would caution against supplying a “drop-down” menu which offers physicians a list of acceptable reasons for concluding that there was no external pressure. Rather, practitioners should be required to provide a free-form and detailed reporting of the reasoning that supports their conclusions about external pressure. If this recommendation is unacceptable for any reason, at a minimum, experts in both psychology and disability studies should be directly involved in the development of those menus or lists.

3. WE MUST ENSURE THAT NOTHING ABOUT MAiD COMPROMISES OUR NATIONAL COMMITMENT TO SUICIDE PREVENTION

An extensive body of medical and social science research points to heightened risk factors of suicidal behaviour among persons experiencing a wide range of social and medical stressors, including PTSD, chronic pain, substance abuse, unemployment, depression, bereavement and loneliness. In this context, and given the recognition in Canada’s MAiD law that “suicide is a

significant public health issue that can have lasting and harmful effects on individuals, families and communities”, it is crucial that our monitoring regime permits ongoing scrutiny for any patterns or trends that would link MAiD with known suicidal risk factors.

For this reason, I recommend that practitioners be required to report on all factors in a patient’s profile that would point to suicidal risk and all history of suicidal behaviour, for every patient who requests MAiD.

I thank you again for this opportunity to highlight the issues of greatest concern for me as I consider these draft Regulations. Please do not hesitate to call upon me if I can be of any assistance in elaborating further on any of these submissions or in supporting your efforts to succeed with these regulations.

Respectfully,



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