Written evidence submitted by James Downar, MDCM, MHSc (Bioethics), FRCPC (ADY0161)

To the members of the Health and Care Select Committee,
I am writing this submission to your committee as part of your inquiry into Assisted Dying. As a **Canadian Palliative Care Physician and Researcher**, I will not be affected by any change in the UK's laws, and I have no wish to push my own view of Assisted Dying (or Medical Assistance in Dying- MAiD, as we call it) on UK citizens. However, as the prospect of legislation in the UK comes nearer, I am concerned that Britons and Canadians alike have been subjected to a number of **misleading or false public claims** about what is happening in my country. My only purpose in making this submission is to set the record straight about **who is actually receiving Assisted Death in Canada**, and what this says about the drivers of Assisted Death. I respect those who disagree with MAiD on a principled basis, as a number of my friends do, but this does not entitle anyone to make false claims.

Key Points – Focused on the state of Palliative Care in Canada

1. Many Canadians have poor access to Palliative Care, as do many in the UK, but funding/support for clinical palliative care has increased dramatically in much of the country since MAiD became legal, including:

- A large growth in funding and salaried positions for Palliative Care physicians. For example, in the past 4 years, the division I lead in Ottawa has almost doubled in size (~40 physicians).
- $3 billion invested in home care in 2016, much of which went to palliative care services.
- Millions of dollars invested in research at the federal and provincial levels, providing funding for the Pan-Canadian Palliative Care Research Collaborative in Ottawa, and the Palliative Care Institute in Alberta, and announcing dedicated research funding for palliative therapies including psilocybin.
- There has been a large growth in the number of funded community hospice beds in Canada in particular over the past 5 years, mirroring the rapid growth seen in the Benelux countries following MAiD legalization there.[1] Some palliative care services have been transiently reduced as a result of staffing challenges during the pandemic, which has caused similar problems around the world. This is unrelated to MAiD and is already recovering.

2. There is no data suggesting that the practice of MAID in Canada is driven to any degree by poor access to Palliative Care, socioeconomic deprivation or isolation. On the contrary, multiple reports have shown that MAiD is extremely rare in "vulnerable" demographics, indicating that vulnerability is not a driver of MAiD. We do expect people requesting MAiD from every demographic, as suffering is not limited to the privileged. But if vulnerability was driving MAiD requests, MAiD would be more common in structurally vulnerable groups; in reality, MAiD is substantially less common in these groups.

- The second annual report on MAID in Canada (covering 2020)[2] indicated that even during the pandemic, only 126 of 7394 people (1.7%) who received MAID were unable to access palliative care services that they needed. Similarly, only 3.8% of those receiving MAiD were unable to access disability services that were needed.

- This claim is not based on "self-reported data", as is sometimes reported. In Ontario, the Coroner's office reviews every MAID case and their own assessments of Palliative Care involvement concur with the findings of the Health Canada report[3].
- Canadians who receive MAID are much wealthier, more likely to be married and less likely to be widowed, and far less likely to be institutionalized[3] than those who do not receive MAiD.
- In Ontario, the poorest fifth of the population are 40% less likely to receive MAID than the richest fifth[4], even though the prevalence of chronic illness is much higher.
- Bottom line, **there are people who struggle to access palliative care[5,6] and disability services in Canada, but they're rarely if ever receiving MAiD**. We need to improve access to palliative care and disability services, not because it will have any effect on MAiD, but to meet the needs of the 97% of Canadians who do not request MAiD.

3. The interaction between MAiD and Palliative Care doesn't need to be a conflict. MAID is a point of friction in our community- many prominent palliative care providers are opposed to MAID. But **in much of the country a respectful coexistence has evolved, as it has in most of Europe.** Palliative care and MAID have been integrated in many palliative care units and hospices in Canada, and ~20% of Canadian MAiD procedures now take place in a palliative care facility[2]. They are not fully integrated everywhere, but it is incorrect to say that they are incompatible.

- One key concept is that although Palliative Care can be effective for providing comfort, no field of medicine can claim to fix every problem it sees. Even in the best Palliative Care Units in the world, suffering can be substantial and symptoms increase as patients approach death[7]. This does not mean that anyone should request MAiD, but it explains why so many MAiD recipient chose to end their lives despite having good access to PC.
- Palliative Care is generally more effective for addressing quality of life and physical symptoms, and less effective (or even ineffective) for treating **psychological or existential distress**[8]. Our Health Canada reports have clearly shown that this latter type of distress is the main driver of MAiD requests[2].
- **Existential Distress** is not simply a concern about "being a burden" on others, but rather a sense of distress about their inability to do things that they enjoy, the things that define us as people. Existential distress is not caused by a lack of social or emotional support- these individuals often have very good emotional support available, and people to help with their physical needs. The distress is caused by the fact that they need those supports in the first place. We currently have no proven, scalable, effective treatments for relieving existential distress. **We should not trivialize existential suffering** by claiming that it doesn't exist, or that it is an irrational fear, or that we can easily treat it.
- **Admitting that there are limits to what Palliative Care can achieve is not a sign of failure, but a call for more innovation and research into treating all types of suffering.** The benefits of such research would be felt far beyond any impact on MAiD statistics, because suffering is much more common than MAiD among the dying.
- Ultimately, **the purpose of Palliative Care is not to prevent MAID, and MAID should not be considered a failure of Palliative Care or of the healthcare system**. Legalization of MAiD in Canada has allowed for more open, honest communication about end-of-life

options. There are many people who have obtained better palliative care as a result of an honest conversation about MAiD.

4. MAID does not siphon resources from Palliative Care, or pull Palliative Care providers away from patients who are more appropriate. The vast majority of MAID requests in Canada arise in patients who are already followed by Palliative Care providers at the time of the request (75-80%)[3], and most were followed by Palliative Care for months before they received MAID. For the remainder- they are almost always people with end-stage or terminal illnesses, who have intolerable suffering. These are absolutely appropriate referrals for Palliative services, and should not be seen as a burden or a distraction from the mission of Palliative Care. If we make them feel more comfortable even for a short time, and they still request MAID, then that was definitely not a waste of our time or resources. To address some common misconceptions:

- **MAID providers do not receive resources that were intended for PC**. MAID providers use palliative care fee codes in Ontario to be paid, but this doesn't reduce payments to Palliative Care providers in any way.
- Some MAID assessments are performed by salaried Palliative Care providers, but they will usually do MAID assessments for their own patients (which is a minimal additional workload for a provider who already knows the patient), or provisions during their non-clinical time. **It would be false to state that MAID is pulling providers away from their PC duties.**
- **There is no "right" to MAiD in Canada** any more than there is a right to any healthcare service, including Palliative Care. This comment is usually raised during a discussion of access. Access to Palliative Care is a substantial issue for many Canadians, but Canadian data clearly show that the people who struggle to access palliative care and disability services in Canada don't seem to access MAID either.

5. There are many misconceptions about "Track 2" cases, or MAID for people who meet eligibility criteria but do not have a reasonably foreseeable death. To be sure, there are people with chronic, advanced conditions who want to receive MAID and meet eligibility criteria. On the other hand, there are also people who are not eligible but are requesting MAID as a signal for help obtaining social supports. These cases cause distress among caregivers and are challenging to address, as it may not be apparent how much of the suffering would truly be reversible given improved supports. Some key points here are:

- **Nobody is eligible for MAID based on social deprivation**; the eligibility criteria (e.g. serious and incurable condition, advanced state of irreversible decline in capability) are only met by a small proportion of the population and many "track 2" requests are found to be ineligible. There may be eligible individuals living in poverty who request MAID, but financial distress would be only one of a long list of causes of suffering. These cases, and suffering in general, can be highly complicated. It should never be described in the unidimensional, black-and-white way that it has been presented in some media stories.
- **"Track 2" cases are a very small proportion of all MAID cases, and extremely rare overall-** 219 according to Health Canada's report for 2021 (2% of all MAID cases). For comparison, ~150-200 Canadians are struck by lightning every year[9].
- Track 2 is definitely not an easy option to avoid more difficult questions about how we support the disabled and the vulnerable. Clinicians are generally hesitant to take these

cases on because of the emotional burden and workload involved, which is why they are so rare.

- We should definitely increase supports that address key social determinants of health, particularly for the vulnerable. We should do this not because of the effect on MAID requests, but because it is the right thing to do as a society. The impacts of social deprivation on health are well-established in Canada, as they are in the UK:
    - More than 4000 people die by suicide in Canada every year (20x the total number of track 2 cases) and much of this is driven by social deprivation.
    - Income inequality is associated with as many as 40,000 deaths per year in Canada (200x the total number of track 2 cases)[10].
- **The legalization of MAiD did not create a link between social deprivation and death. This link was already there and very impactful.** Trying to blame MAiD legislation for mortality among the poor is a cynical and inappropriate distraction from the real issues that drive this problem. Anyone concerned with supporting the vulnerable should focus on things that we know will help improve the lives and survival of the vulnerable, such as better pharmaceutical coverage, increased social assistance, affordable housing, etc.

6. Media reports of "abuses" should be treated with skepticism. As the UK and other jurisdictions have moved closer to legalizing MAID, there has been intense speculation about what is happening in Canada. Broadly speaking these stories fit into one of several categories:

- Claims that people have received MAiD despite being ineligible or incapable of making decisions. These claims are usually made by family members who were estranged, or who are morally opposed to MAiD. In Canada, eligibility is assessed by at least two assessors in every case, and each case is reviewed by a coroner or delegate to confirm eligibility. Some cases reported in the media were even reviewed by the police or the medical regulator. Despite such scrutiny, **I am not aware of any case where these claims were substantiated**.
- Claims that people are seeking MAID due to trivial medical conditions. These claims often derive from the fact that people are asked to indicate a single diagnosis or problem prompting a MAiD request. This may be appropriate for some conditions (e.g. lung cancer) but not for others (e.g. multimorbid frailty- which can be debilitating but is not caused by a single diagnosis). In one well-known case ("AB"), a person requested MAiD due to severe osteoarthritis that had required multiple operations and left her completely bedbound, unable to sit upright, and in nearly constant pain, with no further treatment options[11]. This case was reported by some in the media as "simply arthritis". Of course, not everyone in AB's condition would request MAiD, but **it is wrong to trivialize or misrepresent the suffering of others**.
- Claims that hospital staff members are pressuring patients to receive MAID. This claim stems from a story of a patient in London, Ontario, who was in a dispute with their hospital about the home care that would be provided on discharge. He recorded one of his interactions with an ethicist, and then sent the recording to a reporter who published a story entitled "*Chronically ill man releases audio of hospital staff offering assisted death*"[12]. In fact, the recording indicated the opposite- that **the ethicist was quite clearly discouraging him from pursuing MAID but this was not picked up by the media outlets**:

- "Oh, no, no, no," the man is heard saying. "…Don't get me wrong. I'm saying I don't want you to be in here and wanting to take your life."

Needless to say, privacy rules prevent many MAID assessors and providers from coming forward to discuss these cases and provide the missing information. In such a context, it is easy for misinformation to persist and get amplified by those with an agenda.

7. Changes in MAiD eligibility criteria in Canada do not represent a "Slippery Slope". Canada's Supreme Court was very clear and unanimous in the initial *Carter* ruling about who should be eligible to request and receive MAiD. Following this ruling, **Canada's Parliament initially attempted to restrict eligibility more than the court intended**, passing a MAiD Bill (C14) in 2016 that specifically excluded:

- …those with a reasonably foreseeable death- this part of the law was struck down by a Quebec Superior Court decision (*Truchon*), which simply reflected the original *Carter* decision.
- …those with mental illness as an incurable condition- this part of the law was removed by a subsequent Bill (C7) passed in 2021, which takes effect in March 2023.

Of course, every country that has legalized MAiD has chosen a slightly different set of eligibility criteria. But in Canada, the criteria set out in the Carter decision have never been changed, and the Quebec superior court has simply upheld the precedent set in the *Carter* decision. This is evidence of a Constitutional Democracy, not a slippery slope.

My Brief CV (Relevant to Palliative Care)

- Professor and Head, Division of Palliative Care, University of Ottawa
- Clinical Research Chair (Tier 2), Palliative and End of Life Care, University of Ottawa
    - Founder, co-chair of the Pan-Canadian Palliative Care Research Collaborative
    - Authored or co-authored >115 scientific publications
        - International guidelines on end-of-life care in the ICU
        - Communication and decision-making for people with serious illness
    - $24 million in peer-reviewed grant funding
- Lead, Hospital-Based Models of Care (Adult) working group in the Ontario Palliative Care Network (part of Ontario Health).
- Former Member, Palliative Medicine Subspecialty Working Group at the Royal College of Physicians and Surgeons of Canada (established the standards of subspecialty training in Palliative Care in Canada).
- Former Chair, Postgraduate education committee of the Canadian Society of Palliative Care Physicians and the Education Committee of the Ontario Palliative Care Network.
- Founder, former director of the first accredited subspecialty palliative care residency training program in Canada at the University of Toronto (2016).

Specific Relevance to MAID

- Former Co-Chair of Physician Advisory Committee, Dying with Dignity Canada
- Expert witness for prosecution in *Truchon* case, also called as a witness in *Lamb*

- Developed Canadian Medical Association educational material to train MAID assessors and providers in Canada, also used in educational material in Australia
- Advised on legislation developed in Australia and New Zealand

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