



Dying With Dignity Canada
It's your life. It's your choice.

**DYING WITH DIGNITY CANADA SUBMISSION TO THE
STANDING COMMITTEE ON
JUSTICE AND HUMAN RIGHTS**

**BILL C-7: AN ACT TO AMEND THE CRIMINAL CODE
(MEDICAL ASSISTANCE IN DYING)**

NOVEMBER 6, 2020

Executive Summary

Dying With Dignity Canada (DWDC) is the national human-rights charity committed to improving quality of dying, protecting end-of-life rights, and helping Canadians avoid unwanted suffering.

- We defend human rights by advocating for assisted dying rules that respect the Canadian Constitution and the Charter of Rights and Freedoms.
- We provide 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.
- We support healthcare practitioners who assess for and provide MAID.

For 40 years, DWDC has been committed to advancing end-of-life rights and helping Canadians avoid unwanted suffering. We represent the 86% of Canadians who support the 2015 Supreme Court decision in *Carter v. Canada* that struck down the prohibition on physician assisted dying.

DWDC is pleased to be able to share our thoughts, as well as those of thousands of Canadians across the country, on the legislative amendments put forward in Bill C-7. We support the legislative amendments put forward in Bill C-7, although we also have some concerns which we will address in this submission.

We are pleased to see the removal of the reasonably foreseeable natural death eligibility requirement which, in the words of Justice Christine Baudouin in *Truchon*, “infringes life, liberty and the security of the person guaranteed by Section 7 of the Charter”. Removing this eligibility criterion ensures the autonomy of the individual and their choice to end their lives at the time they chose.

We commend the government on the inclusion of Audrey’s Amendment, allowing waiver of the requirement for final consent for those individuals who are assessed and approved for MAID but who may lose capacity in advance of their scheduled date. This is something that 85% of Canadians support. It is our view that this waiver of final consent should also be extended to those whose death is not reasonably foreseeable.

DWDC is concerned with the express exclusion of those with mental illness in Bill C-7 and believes this to be stigmatizing, discriminatory and likely unconstitutional. Having a severe mental illness does not necessarily mean that a person is incapable of making free and informed decisions about their care, and suffering by severe mental illness is no less ‘real’ than suffering caused by a physical injury or disability.

We do not believe that an individual should be excluded from accessing MAID simply because their suffering is caused by a mental rather than a physical affliction.

DWDC hopes and expects that the five-year parliamentary review of the MAID legislation and the state of palliative care, previously planned to begin in June 2020, will commence as quickly as possible following the passage of Bill C-7. And more specifically, that the three areas addressed in the Canadian Council of Academies reports: advance requests, mental illness, and mature minors, be fully considered.

DWDC Position on Bill C-7

DWDC is pleased to share our thoughts on Bill C-7, an act to amend the Criminal Code, as it relates to medical assistance in dying (MAID). Our position on the proposed legislation has been informed by the lived experiences of Canadians across the country who have personally had to consider end-of-life choices either for themselves or watched as a family member considered or experienced their end-of-life choices. It is also informed by the thousands of Canadians who shared their personal stories during the federal government's consultations on MAID. DWDC has polled Canadians over the years and those results are largely consistent with the result of the extensive government consultation earlier this year. Simply put, access to personal end-of-life choices is what Canadians across the country want. In fact, 86% of Canadians support the right to MAID, according to a 2020 poll commissioned by DWDC and conducted by Ipsos.

DWDC Support for Bill C-7

Reasonably Foreseeable

DWDC supports removing the clause that 'natural death has become reasonably foreseeable' as an eligibility requirement, which was found to be unconstitutional in 2019 (Truchon and Gladu v. Canada (Attorney General) and Quebec (Attorney General)). Removal of this clause respects Canadians' rights to life, liberty and security and the right to end their lives in a way that acknowledges individual rights and autonomy.

Jean Truchon and Nicole Gladu spoke for hundreds of Canadians who have been excluded from accessing MAID, because they were not imminently dying; hundreds of individuals who experience constant physical pain and suffering that is intolerable to them, and who have carefully considered their decision.

Individuals like 75-year old Susan, who has suffered for thirty years with continuous pain and who, despite her compromised mobility and worsening condition has not been able to access MAID because her death is not reasonably foreseeable. We know that over 70% of Canadians support the removal of this eligibility requirement.

Susan shared with us, "Last time I counted, there were 20 things wrong with my body. I take 12 prescription medications, but many of my conditions are not curable or even treatable, and for some, there are no known causes. I am in some kind of pain continuously.

For 30 years, I have had fibromyalgia which causes fatigue and almost non-stop physical discomfort. Even though I am always tired, I cannot sleep or rest because of my Restless Leg Syndrome and the uncontrollable twitching and jerking of my whole body. I have various joint problems (which have compromised my mobility), worsening COPD, and worsening Macular Degeneration (an eye disease that can cause severe and permanent loss of vision).

I had applied and been accepted for voluntary assisted death at a Swiss clinic. COVID made it impossible to travel — and of course I would much rather die at home — so earlier this year, I was surprised, relieved and pleased to learn that I will qualify for medical assistance in dying once the changes proposed in Bill C-7 come into effect.

I do not qualify under Bill C-14 because of the reasonably foreseeable death requirement — something that was declared unconstitutional almost a year ago. Once Bill C-7 is passed, I plan to access MAID almost

immediately. My forms are in place and my doctors are on side. Waiting for the new legislation and the uncertainty about when it will pass in parliament is very difficult and very stressful.”

There is also Justine from Ontario, who lives with chronic pain but was formally denied a medically assisted death because her natural death is not reasonably foreseeable. In her own words: “Chronic pain from fibromyalgia has left me in a prison of my own existence, unable to escape. I spend nearly 24 hours a day on my back between the bed and the couch as I struggle to even sit upright. I struggle to get down our stairs and my body aches constantly. My muscles sometimes give out on me in the middle of an activity as simple as holding up my phone or bringing a glass of water to my lips. I have had a headache ever since I can remember. I can’t make very many meals for myself anymore, and my quality of life has decreased to barely anything. At times, it hurts even to take a breath”.

Although Justine and her healthcare team have established that she meets most of the requirements to access MAID – living with a serious illness and/or disability, in an advanced state of irreversible decline, and she experiences unbearable physical and mental suffering that cannot be relived under conditions acceptable to her – clinicians do not believe her natural death is reasonably foreseeable, and she is therefore ineligible for MAID. Today, Justine is housebound, unable to live independently and is in constant pain “every single moment of every day”.

Justine, closes by saying “I am not sure how much time I have left; however, I want to communicate to anyone listening that this is not right. No Canadian should be denied their right to a medically assisted death. The irresponsible, vague criteria that has excluded people like me has not been done to “protect the vulnerable” as has been repeatedly stated. Let me be clear — I am the vulnerable. I can say with the utmost certainty that I do not need any protection from myself. I need support and I do not have years to wait for the assisted dying legislation to be potentially amended. Whether it says so on paper or not, I am slowly dying. If I am ever to qualify for medical assistance in dying, I would be provided the safe death I desperately want”.

Waiver of Final Consent - Audrey’s Amendment

DWDC is also supportive of the proposal to allow for waiver of final consent, also known as Audrey’s Amendment. Waiving this requirement for those patients who are eligible, but who may lose capacity in advance of their scheduled date, means that no one who has been assessed and approved for MAID will have to choose to end their life early because they fear they will not have capacity to consent at the time of the MAID procedure. This was the case of Ms. Parker, whose last wish was to spend one last Christmas with her family but was forced to reschedule her MAID procedure to an earlier date in fear of losing capacity.

As she said at the time, “...the law has forced me to play a cruel game of chicken. I would like nothing more than to make it to Christmas, but if I become incompetent along the way, I will lose out on my choice of a beautiful, peaceful and, best of all, pain-free death.”

There is also the story shared by Johanna of her husband Neil, who accessed his wish of a medically assisted death in May 2018, with the heartbreaking knowledge that he could have lived for longer, had it not been for his fear of losing capacity to consent. As Johanna puts it, “the Canadian government needs to amend its legislation so that people like my husband and Halifax’s Audrey Parker could have lived a longer life, knowing that their wishes for an assisted death would be met in a more humane way . It takes an unspeakable act of bravery to deliberately go through with ending your life at a specific time with full clarity of mind”.

Sadly, stories such as Audrey and Neil's are ones we hear every day. We will be forever grateful to Audrey Parker for her advocacy and appreciate the acknowledgement that this amendment provides of the unnecessary pain caused to individuals like her and Neil.

Witnessing Requirements

Bill C-7 also proposes other changes, including allowing for persons who are paid to provide health care services or personal care and who are not involved in the assessment of the person's eligibility for MAID, to act as an independent witness. DWDC supports this change as many patients have established relationships with their personal support workers and other caregivers. DWDC also supports changing the witnessing requirement from two to one, as the requirement for two often serves as a barrier to accessing MAID for patients in remote communities.

A DWDC volunteer shared the challenges that may be faced in finding witnesses: "Three years ago, another loved one, in her 90s suffering from congestive heart failure, early stage renal failure, difficulty breathing and general frailty asked me why she couldn't have an assisted death. I told her, 'You must ask your doctor for MAID if this is what you want.' She did, and her palliative care physician referred her to a MAID assessor. Given her age and limited social circle, it was difficult to find witnesses for her formal request – fortunately DWDC volunteers came through, but if the proposed change to allow one witness who can be a healthcare or personal care worker had been in place, she would not have faced this barrier."

Mandatory 10-day Reflection Period

For those whose death is reasonably foreseeable, Bill C-7 proposes the removal of the mandatory 10-day reflection period after the written request for MAID is signed. Although we understand that the original intent of this requirement was to provide patients enough time to (re)consider their request and allow health practitioners to feel confident about the individual's commitment to their decision, DWDC has heard from countless number of individuals that this requirement will only serve to prolong suffering for individuals who have already been assessed and approved.

In the words of an individual whose family member had been assessed and approved for MAID, "Once she was assessed and approved, she had a great sense of relief, but was frustrated and anxious that she had to go through the 10-day wait period. She said to me, 'I've been talking to you about this for years. I'm ready, why do I have to wait?' I explained this is what the law requires. She was on medications and was very anxious about losing capacity to consent prior to the date. In fact, her medication was reduced and her condition did deteriorate quite significantly but, fortunately, on the scheduled date she was still able to respond to the clinician's question – Do you understand what is happening? 'Yes', she said, 'I am going to die, and let's get on with it.'"

We have learned over the last four years that individuals who decide to seek MAID are highly committed to their choice. Removing the 10-day reflection period will ensure that others, like her, very clear and committed to their choice, will not have to endure further suffering and anxiety with respect to their ability to confirm their consent at the last moment of their lives. DWDC supports the removal of the mandatory 10-day reflection period.

DWDC Concerns with Bill C-7

Waiver of Final Consent – Audrey's Amendment

DWDC agrees with the Canadian Bar Association that the waiver of final consent be permitted, whether natural death is reasonably foreseeable or not. As stated by Justice Baudouin in the Truchon decision, *“What the plaintiffs are looking for is that the law recognizes equally the suffering, the dignity and, ultimately, the autonomy of people who, like them, are affected by serious and irremediable health problems, without hierarchy and regardless of whether or not death is imminent.”* DWDC proposes that the process of documenting the waiver of final consent be permitted regardless of whether the person is recognized to be at risk of loss of capacity, since the person could lose capacity due to an unexpected event (e.g., coma, loss of consciousness due to medication, sudden brain seizure, etc.) and then be denied MAID.

Assessor Must Have Expertise in the Condition Causing Suffering

Bill C-7 also proposes specific measures for individuals whose death is **not** reasonably foreseeable, including the requirement (safeguard) that one assessor have expertise in the condition causing the patient's suffering. DWDC is opposed to such a measure as it poses a barrier for patients in rural and remote areas, and it will simply be unlikely to find an assessor with expertise. We therefore call on the government to change this requirement so that documentation of appropriate consultation with a healthcare provider who does have expertise will be accepted. Practitioner members of DWDC's Clinician Advisory Council have indicated that this type of consultation is already common practice in more complex MAID cases.

90-Day Waiting Period

DWDC is also concerned with Bill C-7's proposal for a minimum 90-day waiting period between the first MAID assessment and the MAID date for people whose death is not reasonably foreseeable as it will serve only to unnecessarily extend suffering. We encourage the government to revise this clause to provide an assessment period of 30-days allowing for full assessment, consideration of the enduring nature of the request and review of possible interventions and supports.

Requirements Regarding Treatment

DWDC calls on the government to revise the clause which requires that *“the person has been informed of the means available to relieve their suffering, including, where appropriate, counselling services, mental health and disability support services, community services and palliative care and has been offered consultations with relevant professionals who provide those services or that care;”*

Jean Truchon and Nicole Gladu, plaintiffs in Truchon, are representative of those who do not have reasonably foreseeable deaths seeking MAID. Specifically, those with debilitating conditions, chronic pain, degenerative diseases etc., who have exhausted treatment options, counselling, mental health and support services, community services and have considered the option of palliative care. It is for precisely this reason they would be seeking approval for MAID, and they should not be burdened with further requirements.

Further, the Carter decision made clear that individuals seeking MAID are not required to pursue treatment that is unacceptable to them. DWDC proposes that the government change the wording to reflect that it is sufficient that the medical file indicates the patient has seriously considered or has experienced a range of interventions designed to address their suffering, has been offered and considered additional consultations, and has found none of them effective or acceptable to them.

DWDC also calls on the government to change the clause which requires that the patient *“and the medical practitioner or nurse practitioner referred to in paragraph (e) have discussed with the person the reasonable and available means to relieve the person’s suffering and they and the medical practitioner or nurse practitioner referred to in paragraph (e) agree with the person that the person has given serious consideration to those means;*

Specifically, DWDC agrees with the Canadian Bar Association’s recommendation for removal of the requirement that the medical or nurse practitioner **agree with the person** that they have given serious consideration to the means to relieve their suffering. Members of DWDC’s Clinician Advisory Council affirm that the assessment process itself would require that the individual receive all possible information about potential treatments and resources so that they could provide informed consent; further, an assessor would be unlikely to find the person eligible prior to their having this information. Once again citing the Carter decision, it is the right of the individual to request MAID, and they are not required to pursue treatments unacceptable to them.

Conscience Rights

While conscience rights are not referenced in Bill C-7, it is important to note that DWDC agrees that conscience rights of healthcare professionals who oppose MAID must be balanced with the rights of patients and individuals. Conscience rights are protected in the preamble of Bill C-14, in the text of Bill C-14, in section 2 of the Canadian Charter and even in the Carter decision. The Carter decision states, in paragraph 132, that, “In our view, nothing in the declaration of invalidity which we propose to issue would compel physicians to provide assistance in dying.” Provision of MAID is regulated provincially. DWDC believes that clinicians should be required to provide an effective referral. This has already been litigated and incorporated into practice in provinces such as Ontario.

Parliamentary Review

DWDC strongly believes that the five-year parliamentary review of the MAID legislation and the state of palliative care, planned to begin in June 2020, should commence as quickly as possible following the passage of Bill C-7. More specifically, we expect that the three areas identified for further study in C-14 and addressed in the Canadian Council of Academies reports: advance requests, mental illness, and mature minors, will be fully considered.

Advance Requests

From our perspective, the concern that we hear most frequently from Canadians is that of advance requests, something that 85% of Canadians support, as confirmed by both our own research and the government’s consultation this year. People like Ron, an 80-year old man with dementia who wants to decide today to access MAID when his request specifies, regardless of his capacity at that time. As the law now stands, Ron and others like him, cannot ask for an assisted death in advance and may not be competent to ask for it later. Today over half a million Canadians live with dementia – there is no place for them in our current legislation.

Overwhelming public support for advance requests has been demonstrated through recent surveys and public consultations. In the recent Ipsos survey (2020) commissioned by DWDC, 82% of Canadians believe people diagnosed with a grievous and irremediable medical condition which may lead to a loss of capacity, including those with dementia, should be able to have an advance request for MAID to be respected at a

later date. The government consultation in 2020, which asked which asked which asked which asked a similar question demonstrated support by 80% of the 300,000 Canadians who responded to the survey.

Our research also indicates that 75% would also support allowing a patient without a diagnosis of a grievous and irremediable illness to make an advance request for physician-assisted dying that would be honoured if certain pre-stated conditions were met. And that 73% of respondents are in favour of changing the current legislation to make medical assistance in dying available in cases where patients are competent at the time of request but lose competency before said request can be carried out.

In the words of Marion, who lost both her parents to dementia, “At the age of 55 years old, I would like to put a plan in place to come into effect if I am diagnosed with dementia or Alzheimer’s disease. I would like to form a committee of five people: my two sons, a medical and legal advocate, and a family friend. I would clearly spell out that if there is no prognosis for improvement and I can no longer care for myself, am in a diaper, or do not know who my children are, I want them to unanimously decide to throw me a farewell party and assist me in my death. I do not want to commit suicide; I want medical assistance with my death.

The Canadian government has come a long way with granting the wishes of those who choose assisted dying due to grievous and irremediable illness, but by prohibiting advance requests for assisted dying, far too many people with conditions like Alzheimer’s will be denied a dignified death.”

Mental Illness as the Sole Underlying Medical Condition

DWDC is concerned with the express exclusion of those with mental illness from the Bill. It’s worth highlighting the words of Justice Baudouin in Truchon that “the vulnerability of a person requesting medical assistance in dying must be assessed on a case-by-case basis, according to the characteristics of the person and not based on a reference group of so-called ‘vulnerable persons’”. And that “the patient’s ability to understand and to consent is ultimately the decisive factor, in addition to the other legal criteria.”

Regrettably, we continue to hear from individuals with mental illness such as Cody, who shared, “I, like anyone else who has suffered from a debilitating illness and addiction, can only try to find the path that is right for me. There comes a time when the fight has gone on to the point of total exhaustion, and after the over twenty years of battle it should be my own moral and ethical choice to escape my unbearable suffering by the way of medical assistance in dying (MAID). The struggle with the current laws is putting MAID assessors and practitioners in a situation where they have to deny suffering people the right to manage their own end-of-life choices.”

Canadian law presumes an individual has the capacity to provide informed consent unless they are determined not to have this capacity. DWDC urges the federal government to respect this standard and to avoid any provision which might assume lack of capacity or establish additional barriers to access by requiring a mandatory psychiatric, psychological or other specialist review to qualify an individual for MAID. We recognize that in cases where an individual has already been diagnosed with a severe mental disorder, their treating psychiatrist, or in the case of conscientious objection, an alternate practitioner to whom they were referred, may need to be engaged in the process of assessment. In some cases, an assessor might wish to request a consult with a psychiatrist or other specialist familiar with the patient’s condition.

Finally, DWDC points out a 2016 Alberta appeal court ruling (*Canada (Attorney General) v E.F.*, 2016 ABCA 155) that the Supreme Court’s ruling one year earlier did not expressly limit MAID to those with terminal illnesses or expressly preclude those with psychiatric conditions from accessing MAID.

Mature Minors

In many jurisdictions across Canada, mature minors (minors who have the capacity to understand and appreciate the nature and consequences of a decision) already have the right to make important decisions regarding their care. This includes the right to consent to, or refuse, life-saving medical treatment. DWDC has long maintained that it is unfair to allow a 70-year-old with terminal cancer the choice of a peaceful death but deny a 17-year-old who has been given the same prognosis and demonstrates a clear capacity to make the decision as an adult.

Recognizing that special eligibility criteria and safeguards may be required, the allowance of MAID for mature minors who are otherwise eligible, should be considered during the parliamentary review.

Conclusion

DWDC appreciated the opportunity to appear before the Standing Committee on Justice & Human Rights as it studies Bill C-7.

The positions, arguments, and stories contained in our remarks before the committee and in this submission are only a few of the accounts of the thousands of Canadians and their families and caregivers who have shared their connection to the issue of medically assisted death with us over the years. They are the stories of individuals who continue to suffer in pain every day because the law currently denies them access to a constitutional and human right to MAID because their natural death is not reasonably foreseeable; of individuals who have been assessed and approved for MAID but are forced to continue to wait in pain; and of Canadians like Audrey Parker who are forced to die earlier than they would like because they fear losing capacity to consent.

We hear other stories of lived experiences, too. Like the ones that share the beauty of peaceful and pain-free experiences with MAID; and stories of the power of the freedom to exercise a constitutional and human right to each choose our own end-of-life experience. The people behind these experiences are Canadians from coast-to-coast-to coast. And they come from various religions, ages, and political leanings. We hear from many of these Canadians through the mail, email, and social media. In January 2020, it was through a poll conducted by Ipsos on our behalf, which found that Canadians are clear when it comes to their thoughts on MAID. The results of the polling are fairly consistent regardless of the demographic of the respondent:

- A large majority (86%) support the Supreme Court of Canada’s decision in *Carter v Canada* that recognizes medical assistance in dying as a right protected by the constitution, and they support it with more vigor than they oppose it. Half (50%) say they “strongly support” the decision, and only 5% say they “strongly oppose” it;
- 7 in 10 (71%) support in some way removing the “reasonably foreseeable” requirement. Roughly one-third (32%) say they strongly support removing this requirement (and only 8% say they strongly oppose it);
- 73% agree that MAID should be available for patients who are competent at the time of the request but lose competency before the request can be carried out.

As parliament studies Bill C-7, DWDC continues to hear daily from Canadians. We know that these individuals have sent over 150,000 letters to parliamentarians. And they are telling us they want Bill C-7 passed as soon as possible and that government must act quickly to initiate the mandated parliamentary

review of the MAID legislation and the state of palliative care that was to start in June 2020. This review should consider the three areas identified for further study in C-14 and addressed in the Canadian Council of Academies: advance requests, mental illness, and mature minors. DWDC looks forward to that review and to being called upon to share our recommendations and the lived experiences of Canadians.